

Parents of children with autism – review of current research

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Summary: *The parents of children with autism have become objects of many controversial studies and theories. This is a review of the studies that have been conducted in the nineties with this group of parents. The studies are combined into three categories: works on the broader phenotype, studies on the parental stress and the perception of the child, and finally, parents as therapists of their children.*

Although the idea of genetic determination of the cognitive, social and communication deficits has been widely spread, it still has not been sufficiently proved. The research shows that parents of children with autism experience profound stress. This stress response has a specific profile - the most difficult for parents are handicaps related with atypical child behaviors, and the lack of knowledge about real development limitation and child problems. But even though, the parents supported by professionals may become good teachers and therapists for their children. The partnership between parents and professionals is one of the conditions of the parent's success in these roles.

Key words: autism, parental stress, broader phenotype, parents as therapists

Infantile autism (according to ICD-10 [1]) or autistic disorder (according to DSM-IV [2]) is one of the most common developmental disorders. Its modern definitions pertain to behavioural indices and consider the coexistence of dysfunctions in three areas: (1) social development – especially social interactions and co-operation with others; (2) communication – verbal as well as non-verbal and (3) stiff set of rules of behaving, activity and interests.

Dysfunction appears in at least one of those areas before the child is 36 months old. Such early problems have an effect on the whole development. In about 70-75% of children with autism mental retardation can be noted [3, 4]. The causes of autism are unknown. Genetic concepts are very popular [amongst others 5, 6, 7]. Neuroanatomical and neurophysiological defects have been found [compare 8, 9, 10] as well as biochemical ones [comp. 11, 12]. A lot of data suggest that the causes of autism are multifactorial and differentiated in given persons.

Lacking effectivity of therapy and education go along with no adequate knowledge on etiology. Today we know that there is not one single effective treatment for all types

of autism. Due to the multi-etiological character of autism, the treatment too must be varied. Until now no given method or mode of treatment has been proved to be more effective than the rest, although there are many positive informations on behavioural techniques [13].

Statistical studies show that autism is a disorder with the worst prognostics. About 2/3rds of the patients have negative or highly negative prognoses [14]. Those remaining may live fairly independently, with a limited aid of other people. Complete recovery, as declared in some cases is rather rare. Due to the difficulty in diagnosing the disorder and finding appropriate specialists for therapy and education, parents of children with autism are in a specific situation. The specifics of autism, caused amongst others by a lack of visible, typical signs of the child's attachment to closest relatives, makes the raising of a child with autism very difficult. The child's behaviour, which is untypical and not understandable for others (stereotypies, self injurious behaviour, various self-stimulation, etc.) and is the dominating activity, make the situation worse [15]. Conflicting signals are another stress factor: no external signs of impairment (even a 'prince/princess-like' looks) and evidently hindered development, large disharmony of development – the coexistence of extraordinary talents along with significantly impaired functions [16, 17, 18, 19]. This makes it difficult for the parents to have a clear picture of their child – its traits, abilities and difficulties and to have a set role for themselves in supporting the child. If the specialist help is insufficient (which is the rule rather than exception), the parents have to rely on themselves only and find themselves in difficult situations. They are tired, feel dejected, may have low self-esteem and faith in themselves and in believing anything may be changed for the better.

In characterising the situation of this group of people, we must mention the controversial views about their possible role in the disorder's development in their child. Leo Kanner, who was the first to describe infantile autism [20], initially considered genetic and biological aetiology of the disorder. Later on, probably due to the dominating psychoanalytic theories in that time in psychiatry, he wrote: "it should not be forgotten that the emotional reification which children experienced from such parents cannot but be a highly pathogenic element in the patient's early personality development" (Kanner, 1954, after: Howlin i Rutter, 1991, p. 10). This view became extremely popular in the 1950-ies. Bruno Bettelheim was the one who most directly pointed to the role of the parents, mainly the mother in the child's inadequate development [22]. He described the functioning of psychotic children, amongst these were children with autism, as normal, but at times extreme reaction to the experience of enormous danger. It was to be connected with extreme emotional rejection experienced by the child from the mother and her wish that the child had never come into existence. The effect of such reasoning was a proposition of a therapy in which the children were separated from the parents and placed in a special centre (Orthogenic School in Chicago). It is worth mentioning that in the orthogenic school, the children with autism never made up more than 5–10% of the patients [23]. Bettelheim worked mainly with children who were maltreated, drastically abused and un-cared for mainly by their own parents. This probably influenced his concepts of the etiology of autism, although the life-experiences of these children were different.

It need not be added how painful these concepts were for the parents. Owing to the fact that this problem was many a times analysed (this review may be found in another paper - Pisula, 1993a), it will not be brought up here in more detail. It may be only stated that data obtained from research does not allow to formulate a hypothesis for the parents involvement in the disorder's development.

In this paper I will present a review of studies on the parents of children with autism (mainly studies done in the 1990-ies). Many of them were probably inspired by the hypothesis of a psychogenic etiology of the disorder – e.g. studies on personality traits of parents or the course of interactions in these families. The described studies were arranged according to three leading issues into the following groups:

1. Studies on the genetic determination of the predisposition to autism;
2. Studies on parental stress and the parents' experiences connected with raising the child with autism;
3. Studies on the parents' involvement in the child's therapy and education.

Genetic predisposition towards autism

Amongst the views on the genetic bases of autism, there is a hypothesis on a genetically determined predisposition towards given deficits, mainly cognitive and linguistic [25, 26]. These congenital deficits along with brain damage could lead to autism. This concept would mean that similar disorders like those found in children with autism, would be found in their closest relatives – parents, siblings. Key symptoms of autism appear as much less intensified, but present in three domains: disordered social functioning, communication and limited schemas of repetitious interests and activities.

Many studies were conducted to verify the thesis on the appearance of these dysfunctions amongst the parents and they partly did verify this view. Ghaziuddin [27] analysed three autistic cases and noted that the parents showed disordered social functioning. They were close to the autistic symptoms: "The father of SK (an autistic person with Down syndrome) was always rather obsessive and socially 'awkward'. According to his wife (the patient's mother), he was stiff, isolating and a perfectionist. He insisted everything be systematically planned and was angered at the slightest changes in the surroundings (...) He was very punctual and obsessive on cleanliness. He was rather introvert and did not have many friends. His wife was responsible for initiating and sustaining social contacts" (Ghaziuddin, 1997, p.88). Another fragment on a different parent: "The mother of R.G. (...) described herself as a perfectionist (...) She had a tendency to follow certain routines and rituals excessively. For example, she would wake up at 5 a.m. and tried to fill out her daily plan, which was full of household duties. She would dust out the house, at times 12 times daily. She denied ever having any social or communicative problems" (Ghaziuddin, 1997, p.90). These examples draw attention towards stiffness and obsessiveness in the parents' behaviour.

Piven et al. [28] compared the personalities of autistic children's parents with those of the parents of children with Down syndrome. This comparison was made in 18 categories. In 3 of these, the parents of children with autism varied from the other group. These were restraint (reserve in social contacts – no interest or pleasure in being with other people), no tact (behaving in a manner that makes others suffer or

does not correspond with others) and no exuberance (limited emotional expression). No differences were noted in other categories, i.e. amongst others anxiety, hypersensitivity, scrupulosity-perfectionism, stiffness, impulsiveness, shyness, insensitivity to signals given by others, suspiciousness, aggressiveness, magical thinking, eccentricity, submissiveness, hypochondria.

In another study, done by Piven et al. [29], they found that relatives of children with autism had slight autistic traits. They were present amongst the parents, grandparents, aunts and uncles. Social deficits were noted in 57% of the fathers of children with autism and only in 13% of the fathers of Down syndrome children. Wolff, Narayan and Moyes [30] noted that the parents of children with autism lack emotional sensitivity and empathy and that they have specific interests. Landa et al. [31] found that this group of parents had disordered abilities to communicate.

Cognitive deficits are more common in relatives of children with lower IQ (less than 50 points) [32]. These deficits are also more common amongst the relatives of female autistic persons than the male. This may be so due to the fact that in the group of persons with autism whose functioning is worse there are more women than men.

The disordered executive functions are those mentioned amongst the cognitive deficits present in children with autism. Hughes, Leboyer and Bouvard [33] compared parents of those children with the parents of children with learning difficulties and normally developing children. Parents of children with autism (especially the fathers) did worse in performing tasks needing planning, attention shifting and operative memory than the other two groups. In other tasks (where the autism-specific cognitive difficulties were not taken into account), the groups had similar results. It must be stressed that these difficulties were shown only by 25% of parents of children with autism. They were also present in the parents of the other two groups, but in the autistic children's parent group they were 5-10 times more frequent. It was found that the cause of these worse results was a different strategy applied by parents of children with autism in dealing with the tasks.

The theory of a genetic predisposition towards autism is strengthened by a higher frequency of affective disorders amongst the relatives of these children [34]. Piven and Palmer [35] have shown that the parents of children with autism suffer from severe depression and social phobia more frequently than parents of children with Down syndrome. As Lainhart rightfully points out [36], complex influences of genetic, neurological, cognitive and environmental factors should be taken into account when trying to explain these facts. It cannot be excluded that the majority of these depressive disorders of the parents and siblings are caused by the upbringing of a child with autism in the family.

All researchers do not confirm cognitive and social deficits in autistic children's relatives. Freeman et al. [37] noted, that in 1.6% of the parents and siblings there is mental impairment, which is similar as in the relatives of healthy children. Gillberg, Gillberg and Steffenburg [38] note that learning difficulties and impaired speech development are present in 13% of parents and siblings of children with autism and in 12% of normally developing children's relatives. Szatmari et al. [39] did not notice any differences in cognitive deficits amongst the closest relatives of children with

severe developmental disorders, Down syndrome or low birth weight. Boutin et al. [32] showed that cognitive deficits are present in 17% of autistic children's relatives and 16% of relatives of the children with mental retardation.

The comparison of personality traits of autistic children's parents and parents of children with mental retardation done by O'Handrahan, Fitzgerald and O'Regan [40] did not show any differences between the two groups.

In summing up of the results of studies on certain chosen deficits of autistic person's closest relatives, one should note the methodological drawbacks of many of these studies. Amongst these are no control groups, small groups, low representative character, selective criteria of diagnosing autism, retrospective gathering of data on the parents' development of speech and learning difficulties (these concern facts from the distant past and are extremely subjective). The criteria of social functioning evaluation are very doubtful – in some studies [e.g. 27] the source of the information is the opinion of someone who knows the parent or self-evaluation which is not re-evaluated by any objective means. In other studies it is based in the opinion of the person conducting the interview [e.g. 28, 33], and this also cannot be considered as fully objective. Our current state of knowledge does not allow an univocal conclusion that parents have any particular deficits characteristic for autism. The arguments are still too weak to consider that in fact there is a hereditary predisposition towards the development of this disorder. Notes on the specific cognitive functioning of the parents (abnormality of executive functions, central coherence) require further precise studies.

Perception of one's own child and parental stress in parents of children with autism

Studies on parental stress gave access to a lot of information on how the parents view their child and their own situation. It was concluded that parents of children with autism suffer the most stress as compared to parents of children with other disorders [41, 42, 43]. Bouma and Schweitzer [41] compared the mothers of autistic children with those having children with poorly prognostic chronic physical disability and mothers of healthy children. It was shown that autism caused more stress for the mothers than a chronic physical illness did. The most difficult for the mothers were problems in the cognitive development of the child, necessity of constant care and the perspective of a permanent dependency on others, as well as the child's difficult behaviour. They also felt a limitation in the family's functioning as a result of the child's upbringing. Fisman and Wolf [42] analysed stress in parents of children with autism, Down syndrome and those with normally developing children. Especially the influence of the child's autism on the well-being of the mother could be seen. They were more depressive than the other mothers and they worried about the child's difficulty in adapting to changes in the environment. They had also difficulties in accepting the child – they viewed it as a less attractive, intelligent and in general different than was wished for. The child's difficult behaviour requiring attention and constant care and presence was also a cause of the stress they experienced.

Parents of children with autism often feel themselves lost, as they do not know the potentialities of their child. They feel lacking in parental competencies [19, 44].

Olechnowicz [45] describes hopelessness and anxiety of these mothers in various situations.

Ryde-Brandt dealt with the problem of depression and anxiety in mothers of children with autism [46, 47]. These mothers showed a higher level of anxiety and depression than mothers of children with motoric disorders or mothers of Down disorder children.

Kruk-Lasocka, Skórczyńska and Malczewski [48] hypothesise that the problems connected with bringing up a child with autism can negatively influence the way in which the parents view themselves. Due to the child's impairment, they receive many signals that they do not perform their role well enough. Rodrigue, Morgan and Gefken [49] studied the psychosocial adaptation of the fathers of children with autism, children with Down syndrome and normally developing children. Fathers of children with impaired development had more difficulties in adapting than the fathers of children who were normally developing. They noticed a negative effect of the child on family plans and an increasing financial burden connected with its upbringing. At the same time they considered their paternal competencies, marital satisfaction and social support similarly to the fathers of normally developing children.

The parents of children with autism are especially vulnerable to losing their strength [19]. They feel themselves as burdened by the constant care over the child, hopelessness of their attempts, exclusivity for the responsibility over the child's fate. They are often resigned, tired and frustrated with their contacts with professionals. The uncertainty as to the child's possibilities is a significant problem. It is similarly with the lacking knowledge and capability required in bringing up the child. Parents notice many abnormalities in their child's functioning [50, 51]. Schreck and Mulick [52] have shown that parents of children with autism in the age group 5-12 years noticed a lot more sleep disorders in their children than parents of children with mental retardation. Studies on the parental perception of emotional expression in children with autism show, that these parents notice negative emotions more frequently than parents of mentally retarded or normally developing children do [53]. Amongst the many problems characterising these children are sleep disorders. They happen to be very intense (especially in younger children) and they are a serious problem for their caretakers.

The way in which the child shows attachment to the caretakers is especially important from the point of view of parenthood. Hoppes and Harris [54] studied, how mothers having autistic and Down syndrome children in the age 4-10 years, view their attachment. Almost all of the autistic children's mothers wished their children would show them more emotions. Emotions were conveyed to the mothers by children with autism mainly through physical contact whereas mothers of children with Down syndrome reported more complex and complicated manners of expressing emotions e.g. verbalising feelings, helping them, complementing them, speaking with concern about their well-being, etc. Majority of autistic children's mothers felt they were treated as objects. Some mothers claimed that their children showed them feelings in a discrete and hidden manner that could not be observed by third parties. Here's an example: "He shows me feelings but he does it in a subtle way. He cuddles up to me when we

are sleeping together in bed. He cannot put what he feels into words. I can make him say: "... (boy's name) loves mummy", but I would feel as if I was forcing him to say that. I think he knows that he likes to be with us but he doesn't know what love is, love in a sense that other children understand" (Hoppes and Harris, 1990, p.368). The awareness that one is loved by one's own child has a key meaning for parental satisfaction. Henceforth, there is nothing strange, in the fact that parents of children with autism value their child's ability to form emotional ties much higher than the specialists do [55].

Comparing the stress profile of parents having children with autism and those with Down syndrome, cerebral palsy and mental retardation due to various causes, allows for the following notions: 1. Level of stress is highest amongst the parents of children with autism and 2. The stress profile in this group is very specific – the biggest stress is connected with the personality characteristics of the child and its behaviour [43, 56]. Dunlap et al. [15] collected information about the most difficult types of child's behaviour for the parents. Stereotypes, self-stimulation and destructive behaviour were the most common. The parents found help in using a system of reward and punishment (e.g. verbal reprimand) or in ignoring these behaviours. Teachers, other family members as well as publications on the topic were mentioned as the most valuable sources for support. Doctors, psychologists, friends, social workers and the church were amongst the least helpful.

In the process of diagnosing the child's developmental disorder an interesting analysis of parental observations and expectations, was done by Advi, Griffin and Brough [57, 58]. It seems that the parents believe themselves to be experts in matters of the child, and that they know the best how the child "really" is [57]. They feel frustrated with their contacts with professionals whom they view as not revealing them all the truth about their child (but at the same time they allow for a selection to be made by the professional as to what and how things are told them). This is viewed as a will to "protect" the parent, but at the same time it is connected with evaluating, controlling and judging. A precise analysis of the parental expressions may help to understand the processes taking place during the diagnosis of the child and passing on the information about the diagnosis to the parents. The interaction between parents and professionals leads to a common understanding of the situation and often has an element of the parents' negotiating the span of the abnormalities in the child's development and the prognoses on its future.

The perception of their own situation changes in the parents with time. At times exhaustion and loneliness in dealing with the difficulties have an effect on this perception. However, as Gray's longitudinal studies have shown [55, 59, 60], many parents adapt to the situation's requirements and find effective means of dealing with stress. The parents were studied twice, and 8-10 years from the first study they had improved in their general condition: they declared less problems with their physical health and the intensity of stress was reduced. They also felt that their healthy children were now functioning and felt better than before. The parents also felt that their relations with further members of the family had improved and that the stigmatising reactions on part of others (outside the family) were less in number. These optimistic findings were not

present in families where the children behaved aggressively. They still experienced immense stress and the parents felt lonely in trying to cope with the situation.

Undoubtedly, this is supported by the results of the studies presented in this part of the study – the parents really need support. Giving the child with autism specialist care is only a part of the things that need to be done in order to help the family of the child with autism.

Parental role in the process of therapy and education of the child

In the therapy of autism different methods are applied which have their roots in various concepts. Their effectiveness in a given specific case depends upon many factors, such as the characteristics of the child and its environment. Surely, appropriate therapy and education substantially influence the quality of life of the person. At the same time, because there is no universal – tested and effective method, many controversial and unconventional methods of treatment appear. Many parents try these as they cannot find any alternative. Smith and Antolovich [61] asked parents to evaluate 14 therapeutic methods, amongst which the majority may be considered as experimental. It may be added that the children were treated with behavioural therapy (Applied behavioural analysis – ABA), the parents were asked to evaluate the accessory methods. 121 persons took part in the study. Definitely, the worst results were obtained by psychotherapy (psychoanalytic, play therapy, Option Method and others). Biomedical therapies had different results – e.g. one third of the persons were positive on the eliminating diets, and one fifth judged this as negative. Large doses of vitamin B6 and Magnesium was viewed positively by 28 persons and negatively by 41 persons. These results show just how varied the effectiveness of these methods is in the eyes of the parents, with no single, given method of treating autism and the necessity of individual selection of the various methods.

In the 1960-ies the positive role in therapy and education that the parents could play was noted. This led initially to the formulation of one of the most popular and valued educational programmes concerning the children with autism and other communicative difficulties – TEACCH [comp. 62]. One of its aims was that the parents would be treated as partners by the specialists and allowed in participating in formulating and conducting of the educational programmes. Many studies were done on the effectiveness and consequences of the parental participation in the therapy and education of the child. The results encourage such an approach. Children taught at home make bigger progress than those working at special centres or schools [63, 64]. The biggest improvement can be seen in communicative skills, mainly language development [65]. Besides this, the parents' better handling of the child's behaviour brings positive results to family life. It was shown that in families where the parents were taught behavioural techniques, the interactions between the child and the parent were better, less stressing, the parents were more interested in having a contact with the child and the style of communicating was more positive. Naturally not all children and not all parents benefit from these programmes equally [66]. Amongst the factors influencing the final effects are the educational backgrounds of the parents and earlier abilities in

teaching children. Even though there is a differentiation, positive effects of preparing the parents for working with the child can be found in the majority of cases [65]. This may be easily justified. The parents who are quite lost, frequently paralysed with fear, hopeless – become equipped in concrete skills and learn the basic rules of what they can do with the child. Even though behavioural techniques are not a cure for every malady, the change in functioning of the parent, who becomes more stable, predictable and readable, brings about a big change for the child. The level of stress connected with the upbringing of a child with autism, is understandably lowered [67]. Besides this the better the effects of the therapy, the lower the stress [66]. Unfortunately it is usually only the mothers who participate in such training and work with the child. This is a common theme in different countries and cultures [68].

Owing to the fact that the wanted effects of the therapy are not achieved, many parents attempt a therapy that has unclear theoretical bases, but promises a lasting cure. This often means taking the workload on themselves and becoming the child's therapist. These alternative methods are e.g. holding therapy, which was once quite popular in Poland [69]. Due to its specifics, it brings about a lot of emotions and thus has a lot of supporters as well as opponents. Parents also evaluate this method and its effectiveness differently. Some notice an evidently positive effect on the child [70]. Many withdraw from this form of therapy because of the excessive emotional burden it brings for them and the child.

Parents should have the possibility to take part in key decisions on the child's therapy and education, even if they do not actively participate in the process itself (for various reasons not all parents are able to actively participate).

Conclusions

Many false myths and convictions have been formed about the parents of children with autism. Amongst these are theories that see the parents as responsible for the child's autism as well as those that point to an extremely good socio-economical status of the families. Children with autism may be found in different cultures, different countries and different social groups. Their parents are the same as the parents of other children, but such a serious disorder as autism, must leave its impression on them. Undoubtedly, the specific developmental needs of these children place big demands on the parents. These demands cannot be met without the support from the closest persons as well as professionals.

From the studies done in the 1990-ies on this group of parents, we can see them as living in extreme stress, often alone in their strivings, with a very little specialist help. As it turns out, parents can be excellent teachers for their children and can successfully participate in their therapy. However, in order to make this possible, they need to be accepted in this role by the professionals.

It still remains unclear for us to what extent hereditary cognitive, social and communicative deficits are essential factors in the etiology of autism. Studies done on the parents bring about unclear data. It is possible that genetic conditioning is responsible for some of the cases of autism, and in these families, the characteristic deficits are present in the closest relatives. Many questions in this domain remain unanswered.

They will surely be the subject of further studies.

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