

THE PARENTS OF THE CHILD WITH AUTISM

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Abstract

Autism has been at the centre of attention for clinicians and researchers since Kanner described the syndrome in 1943. No evidence has been emerged for the suggested psychogenic etiology of autism. Evidence has shown that autism is a neurodevelopmental disorder with a strong genetic component. Having a child with autism is felt as a catastrophic event by many parents. The parents trying to cope with the special needs and problems of the child frequently experience high levels of stress and may get into a chronic state of depression and need psychological support and guidance on how to manage the child. Trying to find resources in the community for an adequate therapeutic program may be a frustrating experience.

Review of past concepts on autism and parents

Since Kanner (1943) [14] described autism on 11 children, this syndrome has been at the centre of attention for clinicians and researchers. Impetus for the research was initially given by Kanner's assertion that an important factor for the pathogenesis of autism was the handling of the child by his parents. The parents were considered professional, obsessive – compulsive, cold and unemotional. Subsequent research showed that the parents of children with autism were not different from parents of children with other organic brain disorders, in terms of occupation, personality characteristics and attitude towards their infant child. Kanner's initial finding was probably related to a sampling error. Kanner was the most distin-

guished child psychiatrist in USA in the 1930s and 1940s and his clients were probably from the upper socio-economic classes. Views similar to those of Kanner were also expressed by Bettelheim in the 1960s.

In recent years there have been clinicians who claim that some infants at 'risk for autism' have failed to develop important emotional synchrony with the caring parent. Result of the lack of synchrony is deep sorrow and 'autistic' withdrawal of the child. Proof of the child's withdrawal was considered the avoidance of eye contact with the maternal person which was subsequently generalized towards others people (Delion, 2000) [5]. Evidence, however, has not been available to the effect that avoidance of eye contact is due to initial lack of synchrony between the baby and mothering person.

If the child with autism had suffered 'autistic withdrawal' he would be expected to present with deficient attachment with the maternal person. Evidence however indicates that children with autism develop attachment relationships similar to those with typically developing children. Meta-analysis of studies on attachment has shown that children with autism present typical responses to the 'strange situation procedure' which assesses attachment. A child deviated in his response only if he also presented with mental retardation (Rutgers et al, 2004) [34].

Contrary to theories of psychogenic origin of autism evidence indicates that absence of eye contact with the maternal person is part of the child's inability to communicate and interact with the environment due to a developmental brain dysfunction which began very early in life.

The psychological burden on parents as a result of their supposed noxious effect on the child was great. Parents were expected to undergo psychotherapy at the same time with their child. Freeing the parents from the burden of responsi-

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bility for the child's misfortune was not easy since blaming them had become part of many therapists' philosophy. Activists such as Schopler (1971) [36] defended the parents vigorously who had unjustly been victimized.

Recent views on the parents

Research in recent years has examined genetics in the family, the psychological effect on the parents of having a child with autism, their response and secondary effect on the child, and measures to assist them cope with the special needs of their child.

Genetic studies indicate that autism has a genetic basis with an effect of more than 90% (Rutter, 2000) [35]. The autistic trait is transmitted according to non-Mendelian rules. It is the effect of multiple genes interacting. Research on genetics is currently extensive. Within a family with one child with autism spectrum disorder the chances of having another one with the same condition according to new evidence goes up to 18,7% (Ozonoff et al. 2010) [28]. Evidence from twin studies has shown that there is high concordance for autism spectrum disorders among monozygotic twins (82-92%) while in dygozygotic twins concordance is lower (10%) but much higher than the prevalence (about 1%) in the general population (De Sousa et al, 2011) [6].

With regard to the question whether the parents of the child with autism present with specific psychiatric problems, studies compared these parents with samples of parents with children with a variety of other problems and with parents with typically developing children. The parents of children with autism presented with depression related to the condition of the child with autism and the stress experienced while taking care of him/her Yirmiya & Shaked (2005) [43]. Higher level of stress was experienced by the mothers whose child was irritable, older in age and inflicted self-injuries. These mothers wished that they received more assistance by their husbands (Konstantareas and Homatidis, 1989) [17]. A study of 48 mothers and 41 fathers of children with autism of preschool age showed high levels of stress for both parents but the mothers suffered more with depression. Mother's problems were explained by their higher involvement in the care of the child. It was also observed that the level of stress experienced by

the mother was higher if the father also suffered of depression (Hastings et al, 2005) [9]. The functioning of the family and adjustment strategies were investigated in 53 families with a child with autism from a rural area in Australia. The study showed lower levels of conjugal satisfaction, family cohesion and social adaptability compared to controls. However despite the difficulties the parents presented with good levels of self-satisfaction (Higgins et al. 2005) [11].

Parents managing problem behaviours

The child and the adolescent with autism often presents with emotional and behaviour problems mainly aggression (Kane & Mazurek, 2011, Simonoff et al. 2008) [13, 38]. A large cross-sectional study from Belgium examined with the aid of questionnaires the management by the mothers of 552 children with autism and 437 with typical development. The study showed that children with autism presented more frequently with behaviour problems which appeared to show low positive statistical correlation with a particular maternal management practice such as for example strictness of discipline. The researchers suggested that these questions may be studied more reliably with longitudinal studies (Maljaars et al., 2014) [24].

The prevalence of aggressive behavior of children with autism and the risk factors was investigated by Kane and Mazurek (2011) [13]. The prevalence of aggression was high. Among the risk factors was the high the socio-economic level of the family contrary to the hypothesis of the study. This finding may be interpreted as evidence of heightened pressure by the parents on the child for higher achievement with consequent sense of failure-frustration and aggressiveness by the child. Other factors related to aggression were younger age of the child, exceeding difficulty in sociability, stereotyped behaviours if they were blocked and frustrated, self-inflicted injuries which was probably related to emotional dysregulation.

Family and therapeutic intervention

Parents, of whom the infant does not develop speech and does not communicate, enter a period of uncertainty and anxiety about the unexpected problem of their child.

The search for a reliable diagnosis and for advice

on the condition of the child and on what to do for him may become a painful and traumatic experience for one or both parents. The experience may become more painful in the absence of appropriate community resources available for diagnosis and therapeutic intervention for the child with autism.

Having a child with autism will cause to the parents frustration of the hope of having a normal child, with consequent sense of loss and grief without an end. Taking care of the special needs of the child with autism will also become a source of continuous stress for the family. This is a child who does not communicate and interact and is unable to become part and adjust to the network of family relationships. Instead the family will have to adjust and accommodate the special behaviour needs of the child particularly if this is particularly disruptive. In the family environment the stress may be high for parents and siblings. The physical and psychological endurance of the parents may crumble if there is no support and assistance from psychiatric and social services.

The limited presence of health and social services available for the child with autism and his family may lead to high levels of stress to parents who are left alone to cope and manage the difficult behaviours of their child. Some of these develop post-traumatic-stress disorder that becomes part of everyday life. In countries with limited social resources part of the parents' worries becomes what may happen to the child after their own death. In this context the parents try to build some property which will sustain the invalid child after their death.

The family as therapeutic environment

Parents perplexed about the problem of their child and under conditions of stress are in need for psychotherapeutic support, reliable information about the child's condition and advice where from to seek help. Modern therapeutic interventions also attempt to assign the parents role as co-therapists under the conditions of therapeutic schemes. Therapy programs require up to 1 or 2 hours a day of active treatment at home a day. Treatment at home may become an extension of a therapeutic program.

Major problems the parents will have to handle are difficulties in communication and interaction,

stereotypes and absence of motivation. Major obstacle to motivation is the sense of learned helplessness that the child has already developed. The child should be motivated within the family following the guideline of well founded programs such as Applied Behavior Analysis (Lovaas, 2003) [23], Pivotal Response Treatments for Autism (Koegel & Koegel, 2006) [18] and the Early Start Denver Model (Rogers & Dawson 2010) [32]. At the same time the child should be trained under continuous direction to participate in household chores and self-care. The parents should also have play time with their child on the floor or the table. Immediate rewards for the child must not be forgotten at all proper occasions. Therapeutic value has every cognitive and motor achievement and behavior which brings the child closer to that of typical development of younger age. The child with autism may also have good chances to improve socialization by attending kindergarten together with children of typical development. Therefore attendance to a regular kindergarten should not be missed.

Conclusions

The parents of the child with autism will need special attention and support by health and social services in order to maintain their endurance and ability to cope with the special needs of their child. Many parents experience stress and depression managing the child with special needs. The parents instead of becoming helpless and giving in under the burden of raising a difficult child, with assistance are called to become co-therapists of the child. In that role they may contribute substantially to the normalization of the child.

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