Role of the Family in the Rehabilitation of Autistic Children

Essay

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Introduction

Autism is a lifelong complex neurological developmental disorder, characterized by core deficits in three domains: significant impairment in social interaction, communication, and by unusual restricted and repetitive stereotyped behaviors. It typically develops during the first 3 years of life ***(Tsuchiya et al., 2011).***

A neurodevelopmental disorder, or disorder of neural development, is an impairment of the growth and development of the brain or central nervous system. A narrower use of the term refers to a disorder of brain function that affects emotion, learning ability and memory and that unfolds as the individual grows. The term is sometimes erroneously used as an exclusive synonym for autism and autism spectrum disorders. Autism affects information processing in the brain by altering how nerve cells and their synapses connect and organize; how this occurs is not well understood ***(Levy et al., 2009).***

Disorders considered to be neurodevelopmental in origin or to have neurodevelopmental consequences when they occur in infancy and childhood include autism and autism spectrum disorders such as Asperger syndrome, Fetal alcohol spectrum disorder, traumatic brain injury (including congenital injuries such as those that cause brain damage motor handicapped), communication, speech and language disorders, genetic disorders such as fragile-X syndrome, and Down syndrome. Neurodevelopmental disorders are associated with widely varying degrees of mental, emotional, physical and economic burden to individuals, families and society in general ***(Levy et al., 2009).***

In recent years, the definition and criteria for diagnosing autism has been revised and broadened to include milder and more common forms of the disorder. Autistic disorder (AD) is classified in the Diagnostic and Statistical Manual of Mental

Disorders 4th edition (DSM-IV) as one of five related pervasive developmental disorders (PDDs). The remaining four PDDs are pervasive developmental disorder not otherwise specified (PDD-NOS), Asperger syndrome, childhood disintegrative disorder and Rett disorder ***(Johnson and Myers 2007).***

Parents usually notice signs in the first two years of their child's life ***(Landa, 2008).*** The signs usually develop gradually, but some autistic children first develop more normally and then regress. Diagnosis is made subjectively and based on a cluster of behaviors observed clinically as there is currently no laboratory test to diagnose autism. The DSM-IV outlines criteria for the diagnosis of AD and related PDDs. Autism is defined in the DSM-IV-TR as exhibiting at least six symptoms total, including at least two symptoms of qualitative impairment in social interaction, at least one symptom of qualitative impairment in communication, and at least one symptom of restricted and repetitive behavior ***(Ratajczak, 2011).***

The features of ASDs are different from those of other psychiatric disorders that typically begin in childhood, and there is tremendous variability in the child's or adolescent's ability to function. This variability means that a comprehensive assessment is critical to the accurate diagnosis and treatment of ASDs. Furthermore, the degree to which the deficits associated with an ASD affect and are affected by other areas of development may be greater than that found in other childhood disorders, necessitating input from various professionals to provide comprehensive care ***(Deokar et al., 2008).***

A review of epidemiological studies estimate a prevalence of 1–2 per 1, 000 for autism and close to 6 per 1, 000 for autism spectrum disorder (ASD) because of inadequate data, these numbers may underestimate ASD's true prevalence.

The number of reported cases of autism increased dramatically in the 1990s and early 2000s. However the apparent increase in prevalence may simply reflect a broadening of the concept of ASD, an increase in public awareness and more inclusive diagnostic criteria ***(Szpir, 2006).*** Autistic disorder is about four times more prevalent in boys ***(Newschaffer et al., 2007)*** and does not seem influenced by racial or ethnic status and occurs across the socioeconomic spectrum with similar frequencies ***(Bertoglio and Hendren, 2009).***

Many causes of autism have been proposed, but understanding of the theory of causation of autism and the other autism spectrum disorders is incomplete ***(Trottier et al., 1999).*** It appears that genetic predisposition plays a key role in the aetiology of autism although environmental influences are also implicated. Heritability contributes about 90% of the risk of a child developing autism, but the heritability of autism is complex and typically it is unclear which genes are responsible ***(Freitag, 2007).***

In rare cases, autism is strongly associated with agents that cause birth defects ***(Arndt et al., 2005).*** The risk of autism is associated with several prenatal risk factors, including advanced age in either parent, and diabetes, bleeding, and the mother use of psychiatric drugs during pregnancy ***(Gardener et al., 2009).*** Autism has been linked to birth defect agents acting during the first eight weeks from conception, though these cases are rare ***(Szpir, 2006).*** Prenatal viral infection has been called the principal non-genetic cause of autism. Prenatal exposure to rubella or cytomegalovirus activates the mother's immune response and greatly increases the risk for autism ***(Patterson, 2008).***

There is also evidence to suggest the immune system plays a role in the aetiology of autism ***(Kidd, 2002)*** and that autistic symptoms may be due to immune deficiency,

autoimmunity or abnormal immunologic response to infections ***(Ashwood and Van de Water, 2004; Levy and Hyman, 2005).***

There are many theories linking autism and immunization; however there is no scientific evidence to support causality. Numerous epidemiological studies conducted around the world have discounted a connection between immunization and the development of autism (***Lim et al., 2006).***

Rehabilitation has been defined by the World Health Organization as the application of measures aimed at reducing the impact of disabling and handicapping conditions and enabling disabled people to achieve social integration ***(World Health Organization, 1980).*** Implicit in this definition are two components. First, an active process through which a person adapts or acquires the skills needed to reduce the constraints of disease, and second, an acknowledgement that there may also need to be changes in the environment, including the attitudes of non-disabled people, if optimal social integration is to be achieved.

Autism therapies attempt to lessen the deficits and family distress associated with autism and to increase the quality of life and functional independence of autistic individuals, especially children. No single treatment is best, and treatment is typically tailored to the child's needs. Treatments fall into two major categories: educational interventions and medical management. Training and support are also given to families of those with autism ***(Myers and Johnson, 2007).***

The degree of impairment among individuals with ASD is variable, but the impact on affected individuals and their families is universally life-altering ***(Newschaffer et al., 2007).***

Parents of children with developmental disabilities face challenges placing them at risk for high levels of stress and other negative psychological outcomes. Parents of a child with autism may pose additional stressors related to the child's challenges in communicating, difficult behaviors, social isolation, difficulties in self-care, and lack of community understanding ***(Schieve et al., 2007).***

Several studies reported increased psychological distress, including depression, anxiety, and components of stress, such as decreased family cohesion and increased somatic complaints, among parents of children with autism and related autism spectrum disorders (ASDs) in comparison to parents of typically developing children ***(Higgins et al., 2005; Sivberg, 2006)*** or parents of non-autistic children with mental retardation or other developmental disabilities ***(Weiss, 2002; Yirmiya and Shaked, 2005).***

In addition, in several studies of parents of children with ASDs, the child's behavior and conduct problems were most strongly related to parent stress, rather than other autism symptoms, severity of developmental delay, or adaptive skills ***(Bromley et al., 2004; Hastings et al., 2005; Lecavalier et al., 2006).***

A growing body of literature has demonstrated the effectiveness of teaching parents to provide intervention to their children with autism. Parent training offers several important benefits for the child and family. First, researchers have found that parent-implemented intervention leads to better generalization and maintenance of skills than therapist-implemented intervention and may lead to more child gains in overall. Second, parent training has been shown to improve the quality of life for the family by decreasing parental stress and increasing leisure and recreation time. Third, parent training can increase parents' optimism about their ability to influence their child's development, which may help them sustain their

efforts with their child over time. Finally, parent training can be very cost effective because it requires fewer hours of direct service. Indeed, parent training is now considered to be an essential component of quality early intervention programs for young children with autism ***(Ingersoll and Gergans, 2008).***

The majority of research on parent training for children with autism has focused on interventions which teach verbal language skills. Recently, there has been an interest in training parents to teach earlier emerging, non-verbal social-communication skills to their children. This interest has been driven by developmental research indicating a relationship between non-verbal social-communication skills, particularly joint attention, and later language development. Many researchers have suggested that targeting imitation in young children with autism may assist in the development of social communication more broadly ***(Ingersoll and Gergans, 2008).***

Although many psychosocial interventions have some positive evidence, suggesting that some form of treatment is preferable to no medication ***(Krebs Seida et al., 2009).***

Intensive, sustained special education programs and behavior therapy early in life can help children with autism acquire self-care, social, and job skills ***(Myers and Johnson, 2007),*** and often can improve functioning, and decrease symptom severity and maladaptive behaviors ***(Rogers and Vismara, 2008).*** Available approaches include applied behavior analysis (ABA), developmental models, structured teaching, speech and language therapy, social skills therapy, and occupational therapy ***(Myers and Johnson, 2007).***

Educational interventions have some effectiveness in children: intensive ABA treatment has demonstrated effectiveness in enhancing global functioning in preschool children ***(Eikeseth, 2009)*** and is well-established for

improving intellectual performance of young children ***(Myers and Johnson, 2007).***

The evaluation and treatment of autism and associated disorders is a complex and often long-term relationship between the medical or mental health provider, the child or adolescent, the family, and various professional program staff. Although many effective interventions focus on behavior, the careful administration of medication may be helpful for children who are experiencing dramatic physical, hormonal, and behavioral changes. Specific recommendations can be made to medical and mental health professionals about the clinical management of children with an ASD ***(Deokar et al., 2008).***

Aim of The Work

The aim of this study is to present a comprehensive review about the recent approaches for rehabilitation of autistic children with stress on the role of the family in rehabilitation, in order to help those children.

History

A few examples of autistic symptoms and treatments were described long before autism was named. The *Table Talk* of Martin Luther in 1566, compiled by his notetaker, Mathesius, contains the story of a 12-year-old boy who may have been severely autistic ***(Wing, 1997).*** Luther reportedly thought the boy was a soulless mass of flesh possessed by the devil, and suggested that he be suffocated, although a later critic has cast doubt on the veracity of this report ***(Miles, 2008).***

The earliest well-documented case of autism is that of Hugh Blair of Borgue, as detailed in a 1747 court case in which his brother successfully petitioned to annul Blair's marriage to gain Blair's inheritance ***(Houston and Frith, 2000).*** The Wild Boy of Aveyron, a feral child caught in 1798, showed several signs of autism; the medical student Jean Itard treated him with a behavioral program designed to help him form social attachments and to induce speech via imitation ***(Wolff, 2004).***

The New Latin word *autismus* (English translation *autism*) was coined by the Swiss psychiatrist Eugen Bleuler in 1910 as he was defining symptoms of schizophrenia. He derived it from the Greek word *autós* (αὐτός, meaning *self*), and used it to mean morbid self-admiration, referring to "autistic withdrawal of the patient to his fantasies, against which any influence from outside becomes an intolerable disturbance" ***(Kuhn and Cahn, 2004).***

The word *autism* first took its modern sense in 1938 when Hans Asperger of the Vienna University Hospital adopted Bleuler's terminology *autistic psychopaths* in a lecture in German about child psychology**.** Asperger was investigating an ASD now known as Asperger syndrome, though for various reasons it was not widely recognized as a separate diagnosis until 1981 ***(Wolff, 2004).***

Leo Kanner of the Johns Hopkins Hospital first used *autism* in its modern sense in English when he introduced the label *early infantile autism* in a 1943 report of 11 children with striking behavioral similarities ***(Kanner, 1968).*** Almost all the characteristics described in Kanner's first paper on the subject, notably "autistic aloneness" and "insistence on sameness", are still regarded as typical of the autistic spectrum of disorders ***(Happé et al., 2006).*** It is not known whether Kanner derived the term independently of Asperger ***(Lyons et al., 2007).***

Kanner's reuse of autism led to decades of confused terminology like infantile schizophrenia, and child psychiatry's focus on maternal deprivation led to misconceptions of autism as an infant's response to "refrigerator mothers". Starting in the late 1960s autism was established as a separate syndrome by demonstrating that it is lifelong, distinguishing it from mental retardation and schizophrenia and from other developmental disorders, and demonstrating the benefits of involving parents in active programs of therapy ***(Szatmari et al., 2007).***

Although the rise of parent organizations and the destigmatization of childhood ASD have deeply affected how we view *ASD* ***(Kuhn and Cahn, 2004),*** parents continue to feel social stigma in situations where their autistic children's behaviors are perceived negatively by others ***(Heidgerken et al., 2005),*** and many primary care physicians and medical specialists still express some beliefs consistent with outdated autism research ***(Biever, 2007).***

The Internet has helped autistic individuals bypass nonverbal cues and emotional sharing that they find so hard to deal with, and has given them a way to form online communities and work remotely ***(Harmon, 2004).*** Sociological and cultural aspects of autism have developed: some in the community seek a cure, while others believe that autism is simply another way of being ***(Silverman, 2008).***

Characteristics

Autism is a highly *variable neurodevelopmental disorder* ***(Geschwind, 2008),*** that first appears during infancy or childhood, and generally follows a steady course without remission ***(World Health Organization, 2009).*** Overt symptoms gradually begin after the age of six months, become established by age two or three years **(*Rogers*, 2009),** and tend to continue through adulthood, although often in more muted form **(*Rapin and Tuchman, 2008).*** It is distinguished not by a single symptom, but by a characteristic triad of symptoms: impairments in social interaction; impairments in communication; and restricted interests and repetitive behavior. Other aspects, such as atypical eating, are also common but are not essential for diagnosis ***(Filipek et al., 1999).*** Autism's individual symptoms occur in the general population and appear not to associate highly, without a sharp line separating pathologically severe from common traits ***(London, 2007).***

Social development :

Social deficits distinguish autism and the related autism spectrum disorders from other developmental disorders **(*Rapin and Tuchman, 2008).*** People with autism have social impairments and often lack the intuition about others that many people take for granted. Noted autistic Temple Grandin described her inability to understand the social communication of neurotypicals, or people with normal neural development, as leaving her feeling "like an anthropologist on Mars" ***(Sacks, 1995).***

Unusual social development becomes apparent early in childhood. Autistic infants show less attention to social stimuli, smile and look at others less often, and respond less to their own name. Autistic toddlers differ more strikingly from

social norms; for example, they have less eye contact and turn taking, and do not have the ability to use simple movements to express themselves, such as the deficiency to point at things ***(Volkmar and Chawarska, 2008).***

Three- to five-year-old autistic children are less likely to exhibit social understanding, approach others spontaneously, imitate and respond to emotions, communicate nonverbally, and take turns with others. However, they do form attachments to their primary caregivers ***(Sigman et al., 2004).*** Most autistic children display moderately less attachment security than non-autistic children, although this difference disappears in children with higher mental development or less severe ASD ***(Rutgers et al., 2004).***

Children with high-functioning autism suffer from more intense and frequent loneliness compared to non-autistic peers, despite the common belief that children with autism prefer to be alone. Making and maintaining friendships often proves to be difficult for those with autism. For them, the quality of friendships, not the number of friends, predicts how lonely they feel. Functional friendships, such as those resulting in invitations to parties, may affect the quality of life more deeply ***(Burgess and Gutstein, 2007).***

There are many anecdotal reports, but few systematic studies, of aggression and violence in individuals with ASD. The limited data suggest that, in children with mental retardation, autism is associated with aggression, destruction of property, and tantrums. A 2007 study interviewed parents of 67 children with ASD and reported that about two-thirds of the children had periods of severe tantrums and about one-third had a history of aggression, with tantrums significantly more common than in non-autistic children with language impairments ***(Dominick et al., 2007).***

Swedish study in 2008 found that, of individuals aged 15 or older discharged from hospital with a diagnosis of ASD, those who committed violent crimes were significantly more likely to have other psychopathological conditions such as psychosis ***(Langstrom et al., 2008).***

Communication :

About a third to a half of individuals with autism do not develop enough natural speech to meet their daily communication needs ***(Noens et al., 2006).*** Differences in communication may be present from the first year of life, and may include delayed onset of babbling, unusual gestures, diminished responsiveness, and vocal patterns that are not synchronized with the caregiver. In the second and third years, autistic children have less frequent and less diverse babbling, consonants, words, and word combinations; their gestures are less often integrated with words. Autistic children are less likely to make requests or share experiences, and are more likely to simply repeat others' words (echolalia) or reverse pronouns ***(Landa, 2007).***

Joint attention seems to be necessary for functional speech, and deficits in joint attention seem to distinguish infants with ASD ***(Johnson and Myers, 2007).*** For example, they may look at a pointing hand instead of the pointed-at object ***(Volkmar and Chawarska, 2008),*** and they consistently fail to point at objects in order to comment on or share an experience ***(Johnson and Myers, 2007).*** Autistic children may have difficulty with imaginative play and with developing symbols into language ***(Volkmar and Chawarska, 2008).***

In a pair of studies, high-functioning autistic children aged 8–15 performed equally well as, and adults better than, individually matched controls at basic language tasks involving vocabulary and spelling. Both autistic groups performed worse than controls at complex language tasks such

as figurative language, comprehension and inference. As people are often sized up initially from their basic language skills, these studies suggest that people speaking to autistic individuals are more likely to overestimate what their audience comprehends ***(Williams et al., 2006).***

Repetitive behavior :

Autistic individuals display many forms of repetitive or restricted behavior, which the Repetitive Behavior Scale-Revised (RBS-R) ***(Lam and Aman, 2007),*** categorizes as follows:

- **Stereotypy** is repetitive movement, such as hand flapping, head rolling, or body rocking.
- **Compulsive behavior** is intended and appears to follow rules, such as arranging objects in stacks or lines. **Fig (1 & 2)**
- **Sameness** is resistance to change; for example, insisting that the furniture not be moved or refusing to be interrupted.
- **Ritualistic behavior** involves an unvarying pattern of daily activities, such as an unchanging menu or a dressing ritual. This is closely associated with sameness and an independent validation has suggested combining the two factors.
- **Restricted behavior** is limited in focus, interest, or activity, such as preoccupation with a single television program, toy, or game.
- **Self-injury** includes movements that injure or can injure the person, such as eye poking, skin picking, hand biting, and head banging **(Johnson and Myers, 2007).** A 2007 study reported that self-injury at some point affected about 30% of children with ASD **(*Dominick*et al., 2007).** No single repetitive or self-injurious behavior seems to be specific to autism, but only autism appears to have an elevated pattern of occurrence and severity of these behaviors **(*Bodfish et al., 2000).***