

LATE DIAGNOSIS OF ASPERGER SYNDROME IN CROATIA - A LOW-INCOME COUNTRY

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INTRODUCTION

Asperger's syndrome (AS) is a pervasive developmental disorder that involves qualitative disorders in social relationship, atypical understanding of and use of pragmatic language, restricted and repetitive interests and activities, and high WAIS verbal/performance score ratio (Woodbury-Smith & Volkmar 2009). Although AS is an illness that begins in childhood, its diagnosis may frequently not be done until later stages (Toth & King 2008). The diagnosis of AS requires time, resources, and clinical experience. A clinical diagnosis is considered the "gold standard", although several structured clinical interviews help clinicians reach the diagnosis (Toth & King 2008, Volkmar et al. 2014). The child's total developmental profile as well as coexisting psychiatric and medical disorders needs to be considered. Whenever a definitive diagnosis of AS is made, the patient should be given comprehensive psychosocial counseling and offered the appropriate treatment (Volkmar et al. 2014).

While knowledge among health workers on childhood ASD and the prevalence are on the increase in developed parts of the world (Fombonne 2003), expertise and professional support services are limited in most of the developing world (Bakare et al. 2008, Samadi & McConkey 2011). Early identification and intervention which have been shown to improve the prognosis of AS may be compromised in low-income countries (Volkmar et al. 2014).

In Croatia, there is a serious shortage of specialists in child and adolescent psychiatry. Currently there are around 35 child psychiatrist in the country with the population of about 4,5 million inhabitants. Children with AS and ASD are diagnosed by child and adolescent psychiatrists through public child and adolescent psychiatry clinics which are only available in larger cities. Only few child psychiatrists are experienced in the diagnosis and treatment of patients with ASD. There is only one inpatient facility for children with ASD. State-funded special schools and day centre placements for children more severely affected or with other conditions such as intellectual disability are provided, but also only in larger cities. On a positive note, non-government organizations for children and families with autism have been founded recently in Croatia and have started with activities aimed at increasing the level of awareness on ASD among the general public and among various categories of health care workers.

The following case describes a male patient with AS diagnosed in adolescent age. This case illustrates a large delay between the age at which parents first report first symptoms and age at diagnosis. This paper also reflects the unsatisfactory situation of the knowledge of diagnosis and intervention in AS in Croatia, and in fact even many other low-income countries throughout Europe and the world, which will be discussed.

CASE REPORT

MM was a 17 years old young man who was born following a normal pregnancy and birth, and lived with his parents and older sister. Family history of psychiatric disorders was negative, and his sister was healthy. His early motor development was normal. However, in pre-school age he had unstable social relations, behavioral problems with a low frustration threshold and temper tantrums, and excessive isolated interests (he played with ants and bugs, and tore books into strips of paper). These behaviors did not seem prominent enough for his parents to seek professional help. At the age of 6, the boy was referred to the multidisciplinary assessment for enrollment in school. Child psychiatrist described him as „stereotypical, rigid in thoughts, does not look in the eyes, does not tolerate physical contact“. Until the age of 6 he suffered from constipation and encopresis. Psychologist noted that the boy was „tense, anxious, has obsessive preoccupation with restricted thought contents and difficulty accepting directed activity with occasional negativism“. His cognitive skills were at low average level, but he had difficulties with social reasoning, numerical reasoning, short-term memory and graphomotoric ability. MM was diagnosed with cerebral dysfunction, emotional inhibition and communication problems, dyslexia, and cluttering. Enrollment into elementary school was deferred, and psychotherapy and speech therapy were recommended but never realized. The boy started regular school a year later. He was an excellent student through the elementary school, but with his mother continuous support and assistance. He had difficulties integrating with peers and had no friends. He was often a victim of peer bullying. He exhibited obsessive preoccupation with restricted interests (history) and a series of compulsive behaviors which interfered with his homework. Due to

severe motoric clumsiness and deficient coordination, his performance during gym class was very poor. Social impairment increased when he entered high school. He showed no interest in social interactions and a lack of ability to empathize. He displayed a high level of preoccupation with routines and purposeless procedures. At the age of 15 years, he was still completely dependent on his mother in homework and personal hygiene (his mother shaved him and this has continued till present). His mother requested another psychiatric/psychological evaluation because of a lack of independence and adaptive psychosocial functioning appropriate for his age. Again, the diagnosis of AS was not reached. During the second year in high school, he began to fall behind with school work at an alarming rate. He was unable to keep up with regular high school. He was enrolled in high school education for adults which did not require every day attendance. Throughout elementary and high school, school personnel did not notice any behavior problems or referred the boy for assessment of mental health.

At the age of 17, MM was referred to a child psychiatrist due to panic attacks, derealization and depersonalization which unabled him to attend school. Accidentally, he was evaluated by a child and adolescent psychiatrist experienced in the diagnosis and treatment of patients with ASD. The patient was diagnosed with AS and comorbid panic disorder. The EEG examination and the brain MRI scan showed normal results. Fluvoxamine 100 mg/day and alprazolam 0.5mg as-needed up to 1 mg/day were prescribed. He responded well to these medications and is still taking fluvoxamine.

The diagnosis of AS was based on previous medical reports and several interviews with the patient and with his family conducted by a psychiatrist experienced in ASD. During examinations he avoided eye contact and used a monotone voice. His thought process was inflexible, concrete and persevering. No evidence was found of a psychotic disorder. His mood seemed euthimic with limited affect. However, a total lack of understanding of social codes of behavior and an inability to interact with other people in an appropriate and socially acceptable manner were evident. He displayed rigid behavior patterns and occupation with order, discipline, organization, and rules. In a comprehensive psychological examination, he had higher verbal than performance IQ, a non-verbal learning disability and impairments in some aspects of executive function. Adaptive functioning was significantly deficient. Described results are concordant to already familiar difficulties in the cognitive development of children with AS (Klin et al. 2000). By generally accepted criteria, the combination of these findings correspond to the diagnosis of AS. To confirm the diagnosis we used the Adult Asperger Assessment (AAA) (Baron-Cohen et al. 2005). His AQ score was 36 (a score of 32 or more is needed to establish a diagnosis), while the EQ score was 12 (a score of 30 or less is required to establish a diagnosis). MM will soon complete high school education with excellent grades.

DISCUSSION

The case presented here demonstrates that although AS is evident in childhood, it may remain undiagnosed into adolescence. One possible reason for the delay in the diagnosis of AS, may be the relatively "mild" manifestations of autism in this disorder, with an absence of cognitive, developmental or language delay in childhood (Lehnhardt et al. 2012). Consequently, parents often have no concerns about their child's early development. In addition, AS tends to be more apparent in adolescence and early adulthood, due to the marked importance of social communication during this period of life. Up to 70% of the affected persons develop comorbid disturbances, mainly anxiety disorders and depression (Lugnegård et al. 2011). Despite average intellectual capacity, autistic traits may complicate performance in many everyday situations and failure in personal and vocational relationships, thus leading to stress. These problems in turn often lead to depression, anxiety and sometimes psychosis-like stress reactions. If they then seek medical help, the manifestations of secondary psychiatric disorders (anxiety disorders, depression) may be the reason for referral as in this case, but may also camouflage autistic experiences and behavior, leading to difficulties in both differential diagnosis and treatment (Cath et al. 2008, Roy et al. 2015).

Another underlying contributory factor for the late diagnosis of AS in our case may be a limited capacity for early identification and intervention of AS in Croatia which is a low-income country. The early recognition of AS among health workers in Croatia may just be inadequate because of low level of awareness and knowledge. Physician's knowledge or lack of knowledge about autism greatly influences the average age of diagnosis of ASD, which is important to ultimate prognosis (Rhoades et al. 2007). Case reports and studies from the developing countries report on late diagnosis of AS and other ASD because of the dearth of professional services, very low level of awareness on autism among the general public and various categories of health care workers, a cultural context in less affluent countries with a disability still seen as stigmatizing, religious explanations of the disorder and healing practices, different child-rearing practices, adult tolerance, and expectations around children's behaviors (Samadi & McConkey 2011, Divan et al. 2012).

The solution to providing total care for children with AS as well as ASD in Croatia and other developing countries is twofold. The imperative need is to provide infrastructure and staff trained to deliver specialised care using the best resources at their disposal. Care of individuals with AS and ASD needs to be integrated into the primary health care system and other vital sectors such as schools and welfare as they are well placed to provide initial advice and guidance to families. Since early diagnosis and intervention programs for AS significantly improve the patient's long-term outcome, this case also highlights the need to

increase awareness of AS among the general population that may lead to parents and family members suspecting such a disorder in young children. To achieve important improvements in the quantity and quality of services for individuals with AS and ASD in Croatia and other less affluent countries, training and development programme on a national level should be developed and implemented. A national project for creating guidelines for early diagnosis and intervention for ASD has been initiated in Croatia involving health care, education and social welfare systems, and non-government organizations, but consensus has not been reached yet. The more comprehensive project to facilitate the development of systematic and sustainable solutions for enhancing autism awareness, research, training and service delivery conducted in Romania provides a transferable model to achieve important improvements on a national level within a brief time frame (Pasco et al. 2014). This project included a number of strategies aimed at developing knowledge and skills among professionals and increasing awareness in political and public spheres such as training programme for professionals working in services providing care for children with autism spectrum disorders and their families, courses for general practitioners and psychiatrists, activities for social and professional integration of people with ASD, and media campaigns.

CONCLUSIONS

We report a case of a male patient with Asperger syndrome diagnosed in adolescence when referred for anxiety disorder, secondary psychiatric condition due to chronic stress in academic and social functioning as a result of specific AS symptoms. This case presents the large delay in the diagnosis of AS in Croatia and many other low-income countries throughout Europe and the world. Unlike countries in Western Europe and North America where infrastructure and capacity are available to meet the needs of individuals with ASD, little expertise or capacity exists in most of the developing world. To improve early detection and intervention of AS in developing countries throughout the world, systematic screening, training of professionals and increasing awareness among the general public should be implemented through inclusive collaboration with local and international stakeholders.

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