

## FAMILY PERCEPTION AND DELAY IN TREATMENT OF ATTENTION DEFICIT HYPERACTIVITY DISORDER: AN IRANIAN EXPERIENCE

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*SUMMARY: Attention deficit hyperactivity disorder (ADHD) is one of the most common psychiatric disorders among school age children. This syndrome is a combination of different symptoms, manifested in the form of attention deficit and the psychomotor hyperactivity. Families' knowledge about ADHD and attitude towards it varies. This study explored the manner in which Iranian families dealt with ADHD. The sample study comprised of 284 children aged 6 to 14 years old, with DSM-IV diagnosis of ADHD, treated in a university clinic during the first semester of 2002. Data were analyzed using SPSS and running descriptive tests combined with focus group interview method. An overwhelming majority of children (80%) did not receive psychiatric help except two years after symptom formation. Most families (90%) considered these symptoms as "mischievous acts" or natural behavioural stage of childhood development. The variations observed in families' attitude toward ADHD have been explained in the context of socio-economic and cultural differences existing among the families. In view of these observations, it is imperative to familiarize families with symptoms of ADHD so a timely utilization of mental health services can be attained.*

*Key Words: Family, school age, ADHD, help seeking.*

### INTRODUCTION

Attention deficit hyperactivity disorder (ADHD) is the most common psychiatric disorder of school age children. In its comprehensive form, ADHD is comprised of wide range of symptoms in DSM-IV and its prevalence is considered higher compared to ICD-10 (1). Occurrence of ADHD in male is 3 times higher than female. ADHD is

one of the most common psychiatric disorders of childhood and adolescence and it counts for as much as 50% of child psychiatric diagnoses (1-3). Etiologically, neurochemical, genetic and learned factors play key role in the occurrence of ADHD. Disorders of dopamine neurotransmitters, positive family history, complications of pregnancy and delivery, low birth weight, brain trauma, consumption of alcohol and nicotine by mothers during pregnancy are some of the risk factors of ADHD (1).

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ADHD is a persistent problem that manifests its core symptoms throughout the life cycle from preschool years through adult life. It interferes with a child's family life, academic performance, social adjustment and its impairment can be seen extending into adulthood. Undiagnosed and untreated, ADHD predisposes a child to psychiatric and social pathology in later life. By far, ADHD is the most highly studied child psychiatric disorder. The DSM-IV estimates the prevalence of ADHD in school-age children to be 3% to 5% (3). Reported prevalence rate varies in different studies and range from as low as 2% and as high as 6.3%, with most falling in the range of 4.2% to 6.3% (4).

Peers often quickly reject children with ADHD because of their aggression, impulsivity, and non compliance with roles (5). Children with ADHD may be unpopular with their peers and may have difficulties with parents, siblings and teachers. These children may have few best friends and few enduring friendship relations and this unpopularity and inability to establish and maintain friendships may be replaced in life by social isolation (6). In the school, these children are characterized by underachievement (7), low self-esteem and low impulse control (6-7).

ADHD is characterized by two major features: inattention and hyperactivity-impulsivity. Inattention can manifest itself in various forms including: failure in paying attention, repeated mistakes in homework, easy-distractibility, and forgetfulness. Hyperactivity-impulsivity relates to situations like leaving seat when expected to sit, restlessness, over talkativeness, lack of patience, low impulse-control and defiant behaviour. ADHD is divided into three types: inattentive type, hyperactivity-impulsivity and combined type. The latter one is the most common (1-2). Average age for hyperactivity-impulsivity is 7 to 9 years, however, defiant and aggressive behaviour can be seen earlier (2,8). Unfortunately, inattention can result, or be accompanied by poor academic performance which sometimes is mistaken with mental retardation and school drop-out (8). It is also observed that clinical symptoms such as aggression result in future psychiatric disorders and antisocial behaviours, especially drug abuse (5). Family reaction to child's

behaviour can result in intensification of the behavioural disorder and may cause depression making the situation more complicated (2,6). In view of prevailing circumstances, this study was designed to explore the attitude of Iranian families towards ADHD and their help-seeking behaviour.

## MATERIALS AND METHODS

This cross sectional study was conducted between January to April 2002 in Isfahan-Iran. The sample study comprised of 284 children aged 6 to 10 years with DSM-IV diagnosis of ADHD, treated in Isfahan Child Guidance Clinic (ICGC). Children were clinically examined by two senior psychiatrists. Demographic data, the information about prenatal, antenatal, and postnatal care as well as infancy, and childhood history were recorded by means of an open ended questionnaire. We used focus group interview method to explore family's reaction to the child and the coping strategies adopted to deal with the situation. Families were encouraged to share their feelings and experiences of living with ADHD children and the paths they followed in seeking treatment. Data were analyzed using SPSS program and running descriptive tests.

## RESULTS

Children's age ranged between 6 to 14 years and (51.5%) were between 6 to 10 years, and 32.7% were below 6 years. The rest (16.2%) were 10 to 14 years. The majority of them were females and only 27.5 per cent were males. Positive family history of ADHD was reported by 7.4 per cent. About 2.4 per cent of mothers with affected children had complications and difficulties during pregnancy, whereas 4% experienced prenatal and postnatal problems. More than 9 per cent of the children with ADHD were underweight at the time of birth. More than 3% of children were born into families with physical trauma or psychological trauma. More than 37 per cent of children were sent to ICGC because of their defiant and aggressive behaviours. More than 31 per cent of the children were facing severe educational difficulties with poor school performance. However, no child received immediate attention for psychiatric evaluation. Only 5 per cent of the children with ADHD received psychiatric help within the first year of the symptoms onset, while 17 per cent sought the help between year one and

two after the onset or with exacerbation of symptoms. Interestingly, for the majority (77.5%), psychiatric treatment was delayed for two years or more.

We explored the reasons for overlooking the symptoms and the delaying the treatment and found that the fear of embarrassment with the stigma of mental illness was the reason in more than 23 per cent of the families. More than 10 per cent of parents did not have any faith in psychiatric treatment and more than 5 per cent of the grand parents objected to the children's' psychiatric treatment and interestingly, more than half of the parents (52 per cent) considered the child's behaviour as mischievous acts and attributed it to normal growth and development.

#### DISCUSSION

Findings of this study revealed that at only two third of the ADHD children received a psychiatric evaluation that was delayed two years after the onset of the illness or with its exacerbation. Poor educational performance and school maladjustment turned out to be the major trigger for the referral to psychiatric clinics. Families came out with various reasons for delaying the treatment process. As reported earlier an overwhelming majority of them considered these behaviours as mischievous acts that is part of natural childhood, specially in boys. This shows that in Iranian culture, families are unlikely to consider behaviour associated with ADHD in boys pathologic. Families tend to consider these behaviours natural unless and until the child's aggressive behaviour comes in the way of their school achievements. It is also possible that as noted by Hoza and associates, children have exceeded their parent's expectations and misled their families (9) In this context, Gadow and associates argue that mothers and teachers interpret symptoms in terms of behaviours that are most relevant for their daily concerns (10). Additionally, fear of stigma among families continued to play a role significant obstacle in seeking psychiatric help. Irrespective of educational status, most of the families in this study held negative attitude towards psychiatrists. As a general attitude, Karnik has specifically studied fostering families' attitude and the way they challenged the medical and child-welfare authorities dealing with ADHD children (6).

Implications and consequences of untimely treatment of ADHD is well documented. Faraone and associates believe that untreated or undiagnosed ADHD in childhood results in severe complications in adulthood (11). Thome-Souza *et al.*, have reinforced the importance of early treatment in epileptic children with ADHD and depression (12). A study by Kelly and associates has shown that children with ADHD are at a higher risk of committing suicide compared with normal children (13). It is feared that ADHD is a never ending disorder in life process. According to Hermens *et al.*, at least one half of the ADHD children continue to manifest these symptoms in adulthood (14). Some studies have estimated ADHD in adults between 0.3-5 per cent (15).

Under utilization of psychiatric services by families of children with ADHD may also be attributed to the family atmosphere. Scholars have shown that these families are characterized by high expressed emotion (EE) and poor functioning (16-17). Corelius *et al.* have specifically shown that parental psychopathology including the presence of conduct disorder and substance abuse as well as increased number of siblings act as barriers to having adequate mental health among adolescents (18). In this context, Sawyer and associates have argued that clinical and public health interventions must take into account the co-morbid problems experienced by children with ADHD (19). Dilsaver and Akiskal have observed a strong association between familial affective disorders and ADHD in offspring (20). Dunn and Austin have reinforced this view by relating ADHD to family pathology (21). Earlier, Faraone *et al.* studied the mechanisms of familial transmission of ADHD (22). Later, thier findings did not support the idea that parents of ADHD children are biased to report ADHD symptoms (23). In a similar study these authors once again showed that parental ADHD do not affect maternal reports of offspring ADHD (24).

Drop out and poor attendance in treatment of ADHD has been noted (25-26). Brook and colleagues have established an association between teacher's knowledge and attitude towards ADHD (27). Some scholars believe that ADHD children can begin to contribute to decisions about the diagnosis and treatment of

ADHD during medical visits from age 7 to 11 years (28). Hazell *et al.* believe that both parents and teachers should be involved in the process of early diagnosis of ADHD (29). Shaw *et al.* have emphasized on contribution of general practitioners in early detection of ADHD (30). At the same time Slowik and Noronha have highlighted the role of pediatricians in ADHD care (31). Biederman *et al.* and Bor emphasized on community based programme in screening and early treatment of ADHD (32-33). Kendall has shown great concern about

siblings of ADHD children (34). Keatinge *et al.* advocate family support in having access to health care advice, information, and support system (35). Brook and Geva suggest that information about ADHD should be added to the curriculum and be taught by qualified specialists (36). According to Wang and associates delays in initial treatment contact are an important component of the larger problem of unmet need for mental health care which need special attention and a holistic approach to the problem (37).

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