## **Original Article**

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# Pathway to care and clinical profile of children with attention-deficit hyperactivity disorder in New Delhi, India

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#### Abstract:

**BACKGROUND:** Attention-deficit hyperactivity disorder (ADHD) is a common childhood neurobehavioral disorder, which may cause impairment in multiple domains. Understanding the pathway to care helps in planning effective early interventions. The study aims to provide a quantitative description of the factors affecting the help-seeking pathway.

**MATERIALS AND METHODS:** The study was conducted at an outpatients department of a tertiary care multispecialty hospital. Fifty consecutive consenting children aged 5–15 years were screened and diagnosed for ADHD using Conners' Parent Rating Scale-Revised: Short Form, Diagnostic and Statistical Manual of Mental Disorders fourth edition text revision criteria, and Kiddie Schedule for affective disorders and schizophrenia. A semi-structured questionnaire was used to study the pathway of care, using the WHO template. The data were analyzed using appropriate parametric and nonparametric tests in SPSS software.

**RESULTS:** The average delay from the onset of the illness to first consultation with a qualified health professional was  $2.32 \pm 1.9$  years. Children with an urban background, from a nuclear family, with literate mothers, with a family income of more than Rs. 30,000/month, having hyperactive and combined type of ADHD, and who were referred by school teachers presented significantly earlier. The main source of referrals were school teachers and general medical practitioners. The most common parental beliefs for delay were the views that the "child is naughty" and that "hyperactivity is part of normal growth."

**CONCLUSION:** Parents' help-seeking behavior is affected by different sociocultural beliefs. Such factors as the lack of recognition and awareness of ADHD, resulting in the delay in seeking treatment should be addressed through health promotion programs.

#### **Keywords:**

Attention-deficit hyperactivity disorder, children, Diagnostic and Statistical Manual of Mental Disorders-fourth edition text revision, India, pathway to care

### Introduction

Attention-deficit hyperactivity disorder (ADHD) is a complex childhood neurobehavioral disorder, affecting approximately 5% of children of school-going age. ADHD manifests with features of hyperactivity, inattention and impulsivity in various combinations, with

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onset before 7 years of age.<sup>[1]</sup> ADHD, which may persist into adulthood, affects an estimated 1% to 4% of adults worldwide.<sup>[2]</sup> It has an impact on multiple domains of life, including academic functioning with possible long-term consequences on the quality of life in adulthood.<sup>[3-6]</sup>

The long delay between the initial onset of the symptoms and formal diagnosis of ADHD has raised concerns in that it can

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result in increased functional impairment (e.g. poorer educational and psychosocial outcomes)<sup>[4,7]</sup> and financial burden.<sup>[8,9]</sup> Furthermore, despite available unequivocal role of evidence-based treatments, ADHD is underdiagnosed and specialist services are still underutilized.<sup>[10]</sup>

This is of particular concern considering the available extensive scientific evidence indicating that children with ADHD may benefit immensely from a range of interventions, including medications and nonpharmacological therapy.<sup>[11,12]</sup> Recent international guidelines emphasize the need for a better understanding of access to health-care services available to these children and their families and identify possibilities for improvement.<sup>[12]</sup>

The first care provider is considered the most important link, as he/she provides a valuable pointer toward further help. Failure to identify and diagnose at this level is one of the main impediments in the pathway to care.<sup>[13]</sup> Parents have been considered the primary gatekeepers of access to specialist services.<sup>[13]</sup> They usually seek help when children with ADHD have difficulties at school,<sup>[14]</sup> and teachers are often the primary referral points for specialist services. Factors such as societal belief systems, ignorance, and stigma for psychiatric disorders determine the initial pathway to treatment.<sup>[15,16]</sup>

There are very few studies which have assessed the pathway of care in childhood psychiatric illness in India, and the data are limited if present. Understanding the pathway to care for any illness helps in the planning of effective early interventions. We could not find any Indian study conducted on a similar topic in a pediatric setup, in spite of the fact that many patients with ADHD are initially brought to the pediatric unit. Moreover, the social, cultural, and individual factors involved in access to specialist services in India are so diverse that assessment is complicated and can only be done in a series of studies. The exploration of underlying hidden factors which impact the help-seeking behavior need detailed research. Hence, the study was planned on a sample of ADHD patients in a tertiary care center in North India to provide a quantitative description of the factors affecting the help-seeking pathway and investigate the relative contributions of illness and patient-related factors in determining the use of the service.

## **Materials and Methods**

The study was conducted at a tertiary care multispecialty hospital at New Delhi, India. Departments of Pediatrics and Psychiatry of the medical college associated with the hospital were involved in the study conducted in a year, from March 2010 to March 2011. The study was approved by the Institutional Ethics Committee and Thesis Review committee. The participants were assured of the confidentiality of the collected data, and it use for research purposes only. A written informed consent was obtained from the parents of the children before the study.

Children aged 5-15 years presenting at the Pediatrics Outpatient Department (OPD) of the hospital were screened for symptoms of ADHD using Conners' Parent Rating Scale-Revised: Short Form (CPRS-R: S) and behavioral observation. CPRS-R: S is a 27-item, 4-point Likert scale with proven validity and reliability.<sup>[17]</sup> Those screened positive were examined by a psychiatrist and diagnosed as ADHD using the Diagnostic and Statistical Manual of Mental Disorders fourth edition text revision criteria and Kiddie-Schedule for Affective Disorders and Schizophrenia-Present and lifetime version (KSADS-PL). The K-SADS-PL is a semi-structured diagnostic interview designed to assess current and past episodes of psychopathology in children and adolescents.<sup>[18]</sup> K-SADS-PL helped to confirm the diagnosis of ADHD and exclude other significant childhood psychiatric disorders.

Detailed histories were taken and thorough physical examinations were done to rule out any acute physical illness, hearing or visual defect, gross brain damage, epilepsy, and autism. The assessment was done by the first and second authors. Intelligence quotient assessment was done in suspected or borderline cases to rule out mental retardation. The exclusion criteria were any acute physical illness that required hospital admission as well as autism, mental retardation, chronic physical disability such as hearing or visual impairment, epilepsy, and psychosis. Children of either sex, aged from 5 to 15 years, accompanied by at least one parent (living with the children since birth), and willing to give written informed consent were included in the study. All patients who fulfilled the selection criteria were selected for the detailed assessment.

A semi-structured questionnaire was used to obtain information on personal characteristics, sociodemographic, and illness-related variables. To assess the pathway of care, the basic WHO encounter form available on the WHO website<sup>[19]</sup> was used to generate a semi-structured questionnaire. It included information on help/treatment-seeking behavior such as reasons for delay in seeking help, duration of the delay, first qualified caregiver contacted, and the final source of referral to the tertiary care pediatric clinic. The questionnaire was administered on the 1<sup>st</sup> day of contact with the parents.

The data were carefully analyzed using SPSS Inc. Released 2008. SPSS Statistics for Windows, Version 17.0. (SPSS Inc., Chicago, Ill, USA), with the help of a statistician. The data collected for cases and controls were entered in the Excel program. Confidence interval of 95% was used. For descriptive data, a simple table was prepared. Sociodemographic variables and clinical parameters were correlated with the delay in the help-seeking pathway (in years) using the unpaired *t*-test and ANOVA, depending on the number of variables to be assessed. For all analyses, probability of 5% or less represented as statistical significance.

### Results

A total of 62 children were screened for inclusion in the study. However, 7 of the screened children were excluded after psychiatric examination as they did not fulfill the criteria for ADHD after KSADS-PL assessment and clinical examination. Three of the parents did not consent to the study and follow-up. Two children had comorbid disorders (epilepsy and severe mental retardation) and had to be excluded. Thus, a total of 50 children were enrolled and completed the study.

The majority of patients were aged 5–10 years (n = 44, 88%). Only 6 were aged 10–15 years. There were more male children (n = 35, 70%) than females (n = 15). Most of these children came from urban areas (n = 42, 84%). Children living in nuclear families formed the major subgroup (n = 35, 70%). A majority of the children were classified as ADHD-combined type (n = 33, 66%) followed by ADHD-hyperactive type (n = 12, 24%) [Table 1].

The delay in seeking treatment for ADHD was assessed. The mean delay from the first onset of the illness to first consultation with a qualified health professional, in our subset of patients, was  $2.32 \pm 1.9$  years [Table 1]. The children in the age group 5–10 years presented with a mean delay of 2.3 years, while the mean delay in those aged 10–15 years was 2.7 years (P = 0.601). Similarly, there was no significant difference in the mean delay of male and female children (P = 0.253) and type of school they attended (government or private school) (P = 0.076).

Children from urban backgrounds presented significantly earlier than those from rural areas (P = 0.015). We found that higher maternal education, living in a nuclear family, and higher family income tended toward seeking earlier consultation for ADHD (P < 0.01). Children with combined and hyperactive type of ADHD presented significantly earlier than children with inattentive type of ADHD (P = 0.002). Children referred by the school teachers presented significantly earlier than the referrals from the health practitioners (1.8 years vs. 2.2 years).

Most of the children had pediatricians (n = 26, 52%) as the first level of contact with a qualified health professional, followed by general medical practitioners

(GMP) (n = 14,28%). Only 4 children had contacted a psychiatrist at the first level [Table 2].

The majority of the patients were referred by school teachers (n = 14, 28%) followed by GMP (n = 12, 24%). Six children were sent by relatives or family members, four from social workers and two by the faith healers. Pediatricians also referred six children to the tertiary center for management [Table 3].

Table 4 depicts the reasons given by the family members for the delay in seeking help. The most common reason for the delay was that they thought the children were "just naughty" not that they had any disorder (n = 42, 84%), followed by belief that "hyperactivity was part of normal growth" (n = 32, 64%) and that the children would improve with time (n = 28, 56%). Lack of awareness of treatment options and associated stigma also contributed significantly to the delay.

## Discussion

The study was conducted to evaluate the pathway of care for children with ADHD presenting at a pediatric clinic in India. The present study was significant in that it was the first to evaluate the pathway to care in ADHD children in pediatric clinic in India. Earlier studies were conducted in a psychiatric setup.<sup>[20]</sup>

In this study, 26 (52%) children had their first contact with a pediatrician, but only 4 (8%) saw a psychiatrist in the first instance. This is in contrast to a few previous studies which reported that 31% and 51% of children with ADHD initially saw a psychiatrist.<sup>[20,21]</sup> There is confusion in the minds of the general public as well as medical practitioners on the nature and treatment domains of ADHD (psychiatric disorder or pediatric disorder). There could be reporting bias also, as parents may not have revealed the entire truth, because of the stigma associated with a visit to a psychiatrist. This may also be the reason why many parents first consult a pediatrician. A study in adults showing a similar trend indicated that only 9.2% of the patients had psychiatrists as their first point of contact.<sup>[22]</sup> Furthermore, 40% of the children first saw GMP, neurologists, and AYUSH practitioners as the first level of contact. This underpins the importance of GMPs and allied health professionals, as people with deep roots in our society, able to provide guidance on appropriate treatment.

School teachers were the main source of referral to our center (28%). Arya *et al.* also reported high referrals from school teachers (45.6%),<sup>[20]</sup> so did Wilcox *et al.*, who also identified school teachers as the main source of referral.<sup>[14]</sup> ADHD children often perform poorly academically and have, difficulty concentrating on their work because of

Sociodemographic and clinical variable	N (%)	Mean delay in seeking treatment (years)±SD	<i>p</i> -Value
Age (years)			
5–10	44 (88)	2.3±1.8	0.601
10–15	6 (12)	2.7±1.2	
Gender			
Male	35 (70)	2.5±1.2	0.253
Female	15 (30)	2.0±1.8	
Domicile			
Rural	8 (16)	3.3±0.6	0.015
Urban	42 (84)	2.2±1.2	
Type of family			
Joint	15 (30)	2.8±1.6	0.002
Nuclear	35 (70)	2.1±0.5	
Mother's education			
Illiterate	5 (10)	3.5±0.5	<0.001
Below 10 <sup>th</sup> standard	30 (60)	2.8±0.8	
Above 10 <sup>th</sup> standard	15 (30)	1.6±1.5	
Family income (per month), in Indian Rupees			
<15,000	24 (48)	3.0±0.8	<0.001
15,000–30,000	15 (30)	2.5±1.2	
>30,000	11 (22)	1.9±1.6	
Diagnostic subtype			
ADHD-hyperactive	12 (24)	2.3±1.2	0.002
ADHD-inattentive	5 (10)	3.8±0.4	
ADHD-combined type	33 (66)	2.2±0.8	
Type of school			
Government	15 (30)	2.8±1.4	0.076
Private	32 (64)	2.1±1.1	
Not presently studying	3 (06)	3.3±0.8	
Source of referral			
School teacher	14 (28)	1.8±1.2	<0.001
Health practitioners*	24 (48)	2.2±1.6	
Others**	12 (24)	4.3±0.6	

\*Includes general medical practitioners, pediatricians, neurologists, and allied health practitioners such as Ayurveda and Yoga \*\*Includes relatives/family members, faith healers, and social workers. SD=Standard deviation, ADHD=Attention-deficit hyperactivity disorder

Table 2: First level of contact of attention-deficit
hyperactivity disorder children with qualified health
professional ( <i>n</i> =50)

1 <sup>st</sup> Contact	N (%)
Pediatricians	26 (52)
General medical practitioners	14 (28)
Psychiatrist	4 (8)
Neurologists	4 (8)
AYUSH practitioners	2 (4)
AVLISH: Avunveda, Voga, Unani, Siddha and Homeonathy	

AYUSH: Ayurveda, Yoga, Unani, Siddha and Homeopathy

hyperactivity and inattentiveness. Therefore, teachers, who are aware of the disorder, can easily identify them in the classrooms. This underpins the importance of school teachers in early recognition of ADHD. Various studies have reported that teachers' knowledge on ADHD is inadequate.<sup>[23-25]</sup> Considering the crucial role of teachers play in the pathway to the care of ADHD, there should be compulsory mental health education in the comprehensive health programme for teachers.

Health practitioners (GMP, pediatricians, and neurologists) referred a significant number of children (44%). In a previous study, GMPs referred around 9% of the children.<sup>[20]</sup> Sayal and Taylor indicated the prominent role of GMPs in the pathway to care and acknowledged that delay in referring these children was mainly due to nonrecognition by GMPs.<sup>[13,26]</sup> Adequate training (including periodic lectures and orientation sessions by qualified professionals) should be given to GMPs on ADHD so that they can refer these children in a timely manner.

Relatives/family members and social workers were also an important source of referral for these patients (20%). Parents sometimes think of the symptoms of ADHD as a part of normal child development, and therefore, a check by someone close in the extended family is essential. This is what makes public awareness and outreach programs important. More health workers should be trained to screen children for ADHD and encourage people to seek treatment as they easily identify with the cultural

## Table 3: Various sources of referral of the participants to pediatrics service (n=50)

Source of referral	N (%)	
School teachers	14 (28)	
General medical practitioners	12 (24)	
Pediatricians	6 (12)	
Neurologists	4 (8)	
AYUSH practitioners	2 (4)	
Relative/family	6 (12)	
Faith healers	2 (4)	
Social worker	4 (8)	

AYUSH=Ayurveda, Yoga, Unani, Siddha and Homeopathy

## Table 4: Reasons given by the family members for the delay in seeking treatment (n=50)

Reasons/beliefs for treatment delay	N (%)
1. Child is naughty	42 (84)
2. Hyperactivity is a part of normal growth	32 (64)
3. Child will improve with time	28 (56)
4. Lack of awareness of treatment options	26 (52)
5. Mental problems are stigmatizing	12 (24)
6. Poor availability of resources	8 (16)

and religious beliefs of the people. Two children were also referred by faith healers which indicate that our society still has trust in such forms of treatment. In an adult study, 68.5% psychiatric patients were referred by faith healers.<sup>[22]</sup> However, that study was conducted in an exclusive psychiatric hospital in Central India, where certain beliefs on the origin of mental illnesses are common.

We found that the mean delay in seeking the first consultation was approximately 2.35 years, in spite of the fact that the majority (90%) of children had hyperactive and combined type of ADHD, suggesting that there were gross ignorance and unawareness on the part of the parents and teachers. Arya *et al.* reported a mean delay of 3.9 years in seeking treatment.<sup>[20]</sup> The difference may be due to the hospital setup. Our study was conducted in a pediatric unit, while the study referred to above was done in a psychiatric unit. Significant stigma is associated with consulting a psychiatrist, and parents are always anxious to avoid having their child labeled with a disease.<sup>[27]</sup>

The long delay from the onset of the disorder to the first contact with a specialized professional is common to many psychiatric disorders and is attributed to one or more of three factors: stigma, ignorance, and lack of access to specialized care. Strategies such as the training of pediatricians, general practitioners (GPs), teachers, and social workers; and the education of families on the symptoms, nature, treatability, and appropriate guidance could shorten this delay and help to seek early intervention. Early treatment is crucial for ADHD children as delay in seeking treatment aggravates the impairment associated with their symptoms. When parents were asked the reasons for the delay in seeking treatment, the most common response was that patient was naughty (84%) and that hyperactivity was part of the normal process of development (64%). A previous study also reported a similar frequency of such common beliefs as being a naughty child (89.5%) and normal growth process (75.4%).<sup>[20]</sup> Wilcox *et al.* reported that parents do not accept the biomedical explanatory model as a cause of symptoms and attribute it to learning and memory difficulties.<sup>[14]</sup>

The variables of age and gender did not affect the mean delay in seeking treatment. All the same, females presented relatively earlier than boys, as such behavioral problems in boys are considered part of growing/normal childhood. Patients from urban areas presented significantly early (2.2 years) compared to those from rural areas (3.3 years). This may be due to easy accessibility of health-care facilities to the urban population. A study reported that adult psychiatric patients from rural areas traveled a mean distance of 249 km to seek treatment.<sup>[22]</sup> Children living in an extended family environment throughout the study presented late (2.8 years) compared to those in nuclear families (2.1 years). This was similar to the report by Arya et al.<sup>[20]</sup> A major reason is the opposition from other family members or relatives.<sup>[28]</sup> In most extended families of India, the head of the family takes the major decisions. Therefore, they should be taken into confidence to avoid opposition with regard to diagnosis and treatment.

The education of mothers also played a very crucial role as children whose mothers were educated (above 10th standard) presented earlier. This may be due to greater awareness and vigilance of literate mothers to behavioral changes in ADHD children. The role of maternal education has not been described before. Children with good socioeconomic status presented significantly earlier. This also might be due to better education and awareness of parents in this class. However, studies have also reported less delay in middle-income group families.<sup>[20]</sup> Children with hyperactive and combined type of ADHD presented earlier as compared to inattentive type. This was consistent with previous studies.<sup>[13,20]</sup> Children with the hyperactive type of ADHD are very disruptive, usually aggressive and easily identifiable by teachers and parents.

The main limitation of our study is its small sample size and therefore precludes any generalization. The results need to be further validated in large sample size and at other centers. Recall bias of parents cannot be ruled out among parents, since it is difficult to pinpoint the exact onset of illness. Because of the stigma associated with psychiatric illness, reporting bias has to be taken into account. Sociocultural variations in the pathway to care need to be assessed further since our catchment area was mostly urban. However, our study adds to the limited experience of the pathway of the care of ADHD children and emphasizes the need to generate public awareness and increase the knowledge of teachers and health-care professionals on ADHD so that these children can be identified early and the delay of treatment minimized.

We can conclude that the numerous impediments resulting in the delay in seeking help, such as ignorance and the lack of recognition of ADHD should be addressed through health promotion programs. Teachers and GPs form an important source of referral. Parents' help-seeking behavior is affected by various sociocultural beliefs. Understanding the pathway to the care of ADHD children can help in planning early effective interventions.

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#### **Conflicts of interest**

There are no conflicts of interest.

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