Asian Journal of Psychiatry 17 (2015) 10–15

Contents lists available at ScienceDirect

Asian Journal of Psychiatry

journal homepage: www.elsevier.com/locate/ajp

A study of pathway of care in children and adolescents with attention deficit hyperactivity disorder

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ARTICLE INFO

Article history:
Received 27 November 2014
Received in revised form 16 July 2015
Accepted 25 July 2015

Keywords:
Pathway of care
Attention deficit hyperactivity disorder (ADHD)
Children and adolescents

ABSTRACT

Objective: Attention deficit hyperactivity disorder (ADHD) is associated with impairment in all aspects of the patient's life. Despite availability of effective treatments for ADHD, a majority of the patient lack access to or have a significant delay in seeking help. This study aimed to assess the pathway of care in ADHD among patients attending the outpatient psychiatric services of a tertiary care centre in India.
Methods: 57 newly registered cases of the age group 6–16 years with the diagnosis of ADHD as per DSM-IV-TR criteria were included in the study. Pathway of care was assessed on the semi structured proforma.
Results: The mean duration of delay in seeking help for ADHD symptoms was 3.96 Years (SD = 1.96). Only 50% of the subjects consulted psychiatrists as first contact. Majority of the patients (45.61%) were referred by school teachers. Major reason given by the family members was that the patient was naughty rather than having any disorder for not seeking treatment in (89.47%).
Conclusion: Our study showed that there was lack of recognition of ADHD at the level of other qualified practitioners and subsequent delay in referral to CAMHS. Sociocultural beliefs affected the help seeking by the parents.

1. Introduction

Attention deficit hyperactivity disorder (ADHD) is one of the most common childhood neuropsychiatric disorders, affecting 3–7% of school-age children (Clinical practice guideline, American Academy of Pediatrics, 2000). ADHD is characterized by a persistent pattern of hyperactivity, inattention and impulsivity that is pervasive across situations (National Institutes of Health, 1998). ADHD is associated with impairment in daily activities, academic performance, peer relations and family functioning (Sawyer et al., 2002; Bastiaansen et al., 2004; Danckaerts et al., 2010).

Because of the impact of ADHD on patient and their family, the disorder is likely to have significant economic implications for the patient, family and society as a whole (Coghill et al., 2008; Hakkaart-van Roijen et al., 2007; Pelham et al., 2007; Harpin, 2005; Klassen et al., 2004).

It has been seen that despite the availability of evidence-based treatments of psychiatric disorders in general and ADHD in particular, there is low use of specialist services and only a minority of children with mental health problems access specialist mental health services (Ford, 2008; Canino et al., 2004; Sayal and Taylor, 2004; Garralda, 2001).

Early identification and interventions are more important in child psychiatric disorders like attention deficit hyperactivity disorder, because delay in initiation of appropriate treatment, due to any reason, often leads to poor outcome. Contrary to the previous belief that children eventually outgrow ADHD, recent studies suggest that 30–60% of affected individuals continue to show significant symptoms and cause impairments during adolescence and adulthood (Turgay et al., 2012; Kim-Cohen et al., 2003; Mannuzza et al., 1993). These findings further highlight the importance of early identification and intervention in ADHD.

Help seeking behaviour of an individual depends upon many overt and covert factors which play an important role at various steps. Factors causing delay in initiation of adequate treatment vary from one region to another depending upon the sociocultural

Abbreviations: ADHD, attention deficit hyperactivity disorder; GMP, general medical practitioner; LP, local practitioner; ODD, oppositional defiant disorder; CAMHS, child and adolescent mental health services; DOP, Department of Psychiatry; KGMU, King George's Medical university.

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http://dx.doi.org/10.1016/j.ajp.2015.07.013
1876-2018/

belief system, awareness and attitude of family towards the illness, availability/accessibility of psychiatric services, myths, misconception and stigma (Razali and Najib, 2000; Patel et al., 1997; Gureje et al., 1995; Kiliç et al., 1994). These factors also differ in their strength of impact in deciding the pathway of care in different geographical regions of world. There is also significant role of care providers along the pathway, the first care provider being the most important, who gives a direction to the pathway of care to seek further help (Vazquez-Barquero et al., 1993; Gater and Goldberg, 1991; Amaddeo et al., 2001).

Woodward et al. (1997) reported that both child and parenting factors play an important role in determining whether a child with hyperactivity will be referred for child guidance services or not. The best predictors of clinical referral were the parent's ability to cope with child behaviour, child emotional disturbance, school problems, and parental disciplinary indulgence.

In a study conducted by Sayal et al. (2002) it was found that parents could be regarded as the main gatekeepers for access to specialist services and most of the high-risk children attend primary care for help. There is an opportunity for early identification by primary care physician and non-recognition at this level was seen as the main barrier in the pathway to care. Appropriate primary care physician/GP recognition of the disorder and referral to specialist care are important elements of the pathway.

In an Indian study by Wilcox et al. (2007) about parental explanatory models for seeking help for attention deficit hyperactivity disorder it was observed that the most frequent reasons for consulting the community based child development centre were educational difficulties and the teachers were the primary referral points for the specialist services.

In a recent study of parental help-seeking behaviour in primary care for child and adolescent mental health problems by Sayal et al. (2010), it was found that parent's ability to cope with their child's difficulties and their awareness and knowledge about services were identified as important reason in seeking help. Barriers to seeking help included embarrassment, stigma of mental health problems, and concerns about being labelled or receiving a diagnosis. Some parents were concerned about being judged a poor parent. Other parents felt that it was difficult to discuss emotional or behavioural issues with healthcare professionals because of embarrassment or cultural factors influencing whether this was perceived as being appropriate. The receipt of delayed, ineffective or inappropriate help also contributed to parents saying that they had given up seeking help (Sayal et al., 2010).

The above facts reflect the need for further exploration of the underlying hidden factors that play a vital role in the help seeking behaviour of patients and their family members which determine the pathway of care. The data regarding an understanding of the way people seek care in childhood psychiatric illness like ADHD is limited especially from India. Pathway studies have been used to investigate the roles of previous care providers, the time spent on the pathway and to monitor the effects of service developments over time (Harrison et al., 1997; Lahariya et al., 2010). Thus, understanding of pathways of care is a prerequisite for early detection and effective treatment of illness. So this study was conducted to assess the pathway of care in ADHD among patients attending the child and adolescent mental health service (CAMHS) of a tertiary care centre in India.

2. Materials and method

This was a cross-sectional study conducted at Department of Psychiatry, King George's Medical University, Lucknow from August 2011 to July 2012. The study was approved by the Institutional Ethics Committee. The study sample consisted of newly registered subjects attending Child and Adolescent OPD between the age group of 6–16 years who fulfilled the DSM-IV-TR (American Psychiatric Association, 2000) criteria for attention deficit hyperactivity disorder (ADHD). Patients with mental retardation, major sensory-motor handicaps (blindness, hearing problem, paralysis), with physical disorder requiring priority medical management and parents not willing to give consent were excluded from the study.

All patients with the diagnosis of ADHD were assessed on selection criteria and those who fulfil the criteria were included for the detailed assessment. Information regarding identification data, demographic profile, history of present illness and past history along with treatment history (detailed time-line), family history, personal history, physical examination was obtained on the semi-structured proforma. Detailed evaluation on Kiddie-Schedule for affective disorders and schizophrenia-present and lifetime version (K-SADS-PL; Vazquez-Barquero et al., 1993; Kaufman et al., 1997) was done for ADHD and comorbid psychiatric disorders. Disorders (dissociative, somatoform disorders) not covered in K-SADS-PL were evaluated clinically. Diagnosis was established by applying DSM-IV-TR criteria (APA, 2000; Wilcox et al., 2007). Semi structured proforma for assessing the pathway of care was used on which Information regarding socio-demographic, help seeking behaviour, reasons for not seeking help, delay in seeking help, number of care providers contacted before coming to this centre and clinical detail were taken. In developing the semi-structure proforma for pathway of care, the basic idea was taken from the encounter form developed by the WHO (Gater and Goldberg, 1991). The pathway of care proforma was administered by the investigator either on the same day or on a mutually convenient day. Parents were also inquired in detail that how ADHD of the child affected family functioning, relationships and if they faced any problem due to the child's behaviour. All the assessments were done by third author and then the case was jointly seen with second author and/or first author and/or fourth author and a consensus diagnosis was made. Descriptive statistical analysis of data was done. Sociodemographic variables with nominal data analysed with the delay in pathway (in years) using the Mann Whitney *U* test (as all the data did not satisfy the normality test) and those with >2 categorical variables analysed with the Kruskal Wallis tests. The ADHD RS scores correlated with no of years in delay using Spearman's correlation analysis.

3. Results

A total of 62 patients were screened during the study period, 5 patients were excluded from the study (reason of exclusion being non availability of reliable informant among 2 patients and presence of physical illness among 03 patients). Majority of the subjects were of age 6–12 years 49 (85.9%), male 40 (70.2%), urban 46 (80.7%), belonging to the lower socio economic status (family monthly income less than Rupees 10,000) 28 (49.1%). Majority of subjects were students of junior high school 31 (54.4%). Most of the subjects were diagnosed as ADHD-combine type 39 (68.4%) and the commonest comorbidity among the subjects was oppositional defiant disorder (ODD) 13 (22.8%, Table 1).

3.1. The first care provider for the patients with ADHD in the pathway of care

Of the first care providers visited by the family members, 29 (50.9%) visited qualified psychiatrists (26 came to child and adolescent mental health service (CAMHS) directly while 3 consulted private psychiatrists), 8 (14.0%) consulted neurologists, 8 (14.0%) consulted general medical practitioners (GMPs), 7 (12.3%) consulted local practitioners (ayurvedic, homoeopathic or unani) and 5 (8.8%) consulted paediatricians.