A preliminary study of factors affecting adherence to medication in clinic children with attention-deficit/hyperactivity disorder

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INTRODUCTION

Attention deficit/hyperactivity disorder (ADHD) is a common disorder of children and adolescents (hereafter referred to as children). The core symptoms of ADHD are inattention, impulsivity and hyperactivity. It causes serious impairment in academic performance and social functioning. It also adversely affects the family relationships and functioning. Both longitudinal studies in children with ADHD and retrospective studies in adults indicate that the disorder persists into adulthood, often with negative consequences. Children with ADHD may require long-term medication to control their symptoms. Effective medications like methylphenidate, atomoxetine or clonidine are available in India. However, the literature reveals that all children do not persist with the prescribed treatment. The studies have reported a wide range of stimulant adherence rates, ranging from 35% to 87%.

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nonadherence to medication in ADHD, like adolescence, male gender, low IQ in children, severe ADHD symptoms, oppositional-defiant symptoms, lower socioeconomic status, multiple doses of medication, parental opposition to use of medication, side-effects and lack of perceived benefit.[4-6]

The majority of the above studies have been carried out in the Western countries. As India is socioculturally and economically different from the Western countries, the factors affecting adherence to medication may also be different. Besides, India differs from the Western countries in the systems of medical care. This too may affect adherence to medication. A 1-year follow-up study of ADHD children was carried out by Seth[7] to study the phenomenology, comorbidity and global functioning of the children earlier diagnosed as having ADHD in a previous study by Bharti.[8] Only 11.3% of the original sample, at the follow-up, were adherent to the prescribed medication at 1 year. This rate (88.7%) of nonadherence was higher than the rates (13–65%) reported in other studies.[4] Thus, there is a need to identify the factors affecting adherence to medication in our settings. This study was planned to examine the factors that affect adherence to medication in clinic children with ADHD.

MATERIALS AND METHODS

All children newly registered in the child and adolescent psychiatric clinic who were diagnosed as suffering from ADHD (DSM IV TR)[9] and whose parents agreed for drug treatment and gave informed consent to participate in the study were included. The children with mental age <6 years, children with drug-induced hyperactivity and children on nonpharmacological management of ADHD were excluded.

Psychiatric assessment was carried out by applying the Kiddie schedule for affective disorders and schizophrenia – present and lifetime (K-SADS-PL).[10] The behavior of the child was rated on a Hillside Behavior Rating Scale (HBRS).[11] The Clinical Global Impression scale[12] (CGI) was applied to assess the severity of the illness. The above assessments were carried out by the third author; SC. Intelligence was routinely assessed by the clinical psychologist for all children attending the clinic, including the subjects of our study.

These children were then prescribed treatment by the consultant (PS or VA, the first and second authors) if their parents consented for it and were handled in the usual hospital practice. The medications prescribed were methylphenidate (MPH) immediate release or clonidine in divided doses. In our clinic, MPH is usually started at a dose of 2.5–5 mg/dose in the morning and afternoon per day for the first week and then increased to 5–10 mg/dose in the second week. The weekly dose is increased depending on the efficacy or adverse effects, with the aim to reach 0.3–1 mg/kg/day. Similarly, clonidine is started at a dose of 4 mcg/day in two to three divided doses and increased weekly up to a maximum of 8 mcg/kg/day. To purchase MPH, the parents had to go to a specific agency as there was no other source in the study area. Clonidine was available at most of the chemist shops. The hospital did not provide medications. The parents were asked to revisit the clinic with the child at follow-up, usually after 2 week of the prescription. SC did the follow-up assessment of the subjects after every 3 months from the date of inclusion in the study. The dates and number of the visits of the subjects in the clinic were recorded.

Follow-up assessments

The subjects who visited the clinic on the scheduled follow-up were assessed the same day. The parents of the subjects who had stopped coming were contacted through postal intimations, phone calls or home visits. On each follow-up, adherence was checked for the period since the last evaluation. A proforma developed by the authors was applied to assess the factors affecting adherence to drug treatment. The proforma was pretested on other in- and outpatient children and their parents and modifications were made. The proforma comprised of two parts. Each part had an initial unstructured interview and a subsequent semistructured interview. It consisted of questions to the parents about factors affecting adherence. In the initial unstructured part of the interview, the parents had to write their reasons for nonadherence to treatment. The latter semistructured part consisted of questions to be answered by the parents. These questions were about the disorder and treatment, e.g. benefits or adverse effects of medications, hospital procedure and behavior of doctors or hospital staff, reasons related to the family members, economic reasons and social stigma. Each question was rated in the following manner. “Effect on treatment of the child: (a) No effect/Some effect (b) Definite effect.”

Criteria for nonadherence

For this study, nonadherence was defined as taking <80% of the prescribed medication and/or not visiting the clinic within 2 weeks of the scheduled appointment.

Method for assessing adherence

The parent or child report was used for assessing adherence to medication. The child and adolescent psychiatric clinic records were used for assessing the subjects' adherence to appointments.

Statistical analysis

Pearson's correlation and regression analysis were applied.

RESULTS

Twenty-four subjects (21 males and three females; mean age 8.5±2.6 years) participated in the study. Twenty (83.3%)
of these were school going and belonged to urban areas, 18 (7%) belonged to middle socioeconomic status families while six (25%) belonged to low socioeconomic status families. Diagnosis of five children was ADHD-inattentive type, of seven was ADHD hyperactive-impulsive type and of 12 was ADHD combined type. The mean baseline scores on PSQ-HI were 10.4±4.0 and on HBR was 19.6±6.2. Severity of illness on CGI was 4.9±0.7. Twenty (83.3%) subjects had comorbidities. Common comorbidities were oppositional defiant disorder in 12 (50%), enuresis in seven (29.2%) and mental retardation in five (20.8%). The mean IQ was 85.6±20.9. Nineteen subjects were put on MPH-IR and five on clonidine.

It was possible to contact the parents/guardians of all the 24 subjects. Only four (16.7%) subjects were treatment adherent at the end of the study. Eleven (45.8%) subjects did not come for follow-up after inclusion in the study. Another nine (37.5%) subjects came only once for follow-up after the inclusion in the study. Thus, a majority, 20 (83.3%), of the subjects were nonadherent for the prescribed medication within the first month. The reasons for nonadherence in these 20 subjects were side-effects of medication in 13 (65%), lack of perceived effectiveness of medication in 10 (50%), problems in hospital, like long waiting time, in 10 (50%), fear that the child will become addicted to medication in nine (45%), problems in access to treatment in eight (40%), high cost of medicines in eight (40%), careless attitude of caregivers in eight (40%), child refusing to take the medication in six (30%), family members other than the parents opposing the medication in six (30%), long duration of treatment in six (30%), a notion that disorder will subside in its own in six (30%), fear of side-effects in four (20%), multiple doses of medication in three (15%), other medical practitioners opposing the use of medication in three (15%) and ADHD not being the primary parental concern for treatment in two (10%).

Presence of comorbid mental retardation was negatively correlated with adherence to medication ($r=-0.477$, $P<0.05$). On regression analysis, higher baseline severity of ADHD on HBR was the only subject variable predictive of follow-up and adherence (Beta=0.97, t=2.84, $P<0.01$).

**DISCUSSION**

A 83.3% rate of nonadherence in the first month in our study is very high and unexpected in comparison with the nonadherence found in the previous Western studies. Although side-effects and lack of improvement were the most common reasons for nonadherence as stated by the parents, we do not agree with these. As far as the side-effects are concerned, the medication was started at a low dosage and weekly titrated upwards to minimize the side-effects. Also, none of the parents reported any severe side-effect. Before starting the medications, the parents were also informed about the possible side-effects. Similarly, beneficial effects are seen usually after an optimum dose is reached, which usually takes 2–4 weeks. A majority of the parents stopped medication before this time despite being informed in this regard. Therefore, in our opinion, there were other factors that affected the adherence to treatment.

We found some sociocultural reasons like family members other than the parents opposing the medication, careless attitude of caregivers, other medical practitioners opposing the use of medication and ADHD not being the primary parental concern for treatment. Along with these, there were some local, situation-specific reasons for nonadherence, like long waiting time, problems in access to treatment and high cost of medicines. In our opinion, these factors significantly affected the adherence to treatment in our study.

In 10 (50%) nonadherent children, the parents expressed problems in hospital procedures, like long waiting time and long time taking assessments by the doctors. The average time taken in assessment by SC was 3–4 h per child. This time was arranged according to the convenience of the parents in one or more appointments. It was advantageous for the children to have a thorough assessment, which would necessarily require such a period of time. But, the parents viewed it as an inconvenience.

In eight (40%) children, the reason for nonadherence was high cost of MPH. Another eight (40%) nonadherent children had difficulty in obtaining medication because the hospital and drug stores were far away from their home. They had to travel more than 15 km to reach the hospital. But, this is the usual situation in India. Child psychiatric services are not available at all the places in India. People have to travel long distances to avail these services. Undoubtedly, this situation needs to be improved.

MPH is an expensive drug in India. Also, it is currently available at only one agency in the entire district in which our study was performed. Such problems assume greater importance in developing countries like India where the family resources are limited and the parents can spend only a limited amount of time and money on the treatment.

In eight (40%) children, the parents reported forgetfulness as one of the reasons for nonadherence. More frequent follow-up and reminders may resolve this problem.

In two (10%) children, ADHD was not the primary concern of parents for treatment. One child was primarily brought for the treatment of mental retardation and the other for the treatment of oppositional defiant disorder. It seems that the parents did not take ADHD of the child seriously, although they were explained about its potential adverse consequences and impact on mental retardation and oppositional defiant disorder and their management.
In six (30%) nonadherent children, the family members or relatives other than the parents opposed the use of medication. This may be a cultural difference between Indian and the Western cultures. In the Indian culture, especially in joint families, chances of opposition by relatives other than the parents are higher. This means that it would be better if more family members, whose opinion could influence treatment of the children, are educated about ADHD and are involved in taking the decision for treatment. Similarly, in three (15%) children, other practitioners opposed the use of medication. Medical practitioners of other disciplines do not understand the nuances of child psychiatry and advice the families against the use of medication. Therefore, more awareness also needs to be created in the medical fraternity in this regard.

In the present study, information provided about ADHD and the informed consent had no effect on adherence to treatment. Information was given regarding the symptoms and course of ADHD. Information about short-term and long-term adverse consequences of ADHD, rates of response to treatment, cost of therapy, possible side-effects of drugs and that the drugs had little addiction potential in children was discussed with the parents. They were also informed about the alternative medicines available for treatment. It was hoped that informed consent would elicit more cooperation and communication between the parents and the doctors, and also greater adherence to medication, but it did not. Even after the above information, the parents of nine (45%) children feared that the child will become addicted to medication. In six (30%) children, the parents thought that the illness would subside of its own, although the parents were explicitly told about the long course of the illness and that the illness can persist into adolescence and adulthood. In four (20%) children, fear of side-effects was given as the reason for nonadherence. Charach et al.,[6] reported that accepting the diagnosis of ADHD and decision to start medication was difficult for the parents. This and our results suggest that the parental knowledge about ADHD and its treatment needs to be updated from time to time.

In our study, six (30%) children refused to take the medication. In the present study, only the parental consent to start the treatment was taken into consideration and the children were not asked about their willingness to take medicine. Charach et al.,[6] reported that parents reconsider the use of medication specially when the child opposes the use of medication, and they may give in to the child’s wish. It implies that closer attention also needs to be given to the attitude of the children toward their disorder and the problems that the children feel in taking their medicines. The children also need to be educated about ADHD and need to be motivated for treatment.

In our study, we found that on regression analysis, higher severity of ADHD on HBRS was the only factor significantly predictive of adherence ($p<0.01$). This is understandable because the parents of children with severe ADHD are likely to have greater motivation for treatment, and any side-effect may be overlooked if the ADHD symptoms are improved.

The results of our study cannot be generalized due to its small sample size. The strength of our study is that it recruited clinic subjects and that they were managed in the usual hospital practice. They were not part of any clinical trial and were not treated in any special way. Therefore, the findings reflect the true picture of adherence to ADHD medication (MPH IR and clonidine) in our setting. However, the results require further validation in larger samples and at other centers also to look for India-specific reasons for nonadherence to treatment of ADHD.

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