INTRODUCTION

Attention Deficit Hyperactivity Disorder (ADHD) has worldwide prevalence of 5.29% (Polanczyk et al, 2007). Two prevalence studies in India done in schools in Bengaluru and New Delhi found the prevalence of ADHD to be 1.3% (Ramya et al, 2002) to 6.4% (Yewatkar et al, 2017) respectively. Symptoms of ADHD may persist into late adolescence and adulthood in up to 60% cases (Wilens et al, 2002) thus it has long term impact on quality of life of the patient. Approaches for the treatment of ADHD include behavioural, psychopharmacological and psychosocial therapies which are usually used in combination to best suit the needs of the patient and their family members (Brown et al, 2005).

During the assessment of the effect of treatment, view points of the healthcare professionals may differ from those of patient and the family members. Accurate assessment of the improvement from the view point of patient or the family members may help in better convergence, better compliance, a sense of involvement of patient and family members and a better rapport with the treating team. Although a lot of studies have been conducted on the effect of treatment on quality of life but studies on areas which are perceived more important by the patient and the family members are lacking.

OBJECTIVE

To study treatment goals and expectations of children having ADHD and their parents and preferred mode of treatment.

METHOD

Sample:

Ten children diagnosed with ADHD (6-13 yrs), boys n=8, girls n=2, mean age 8.7 years, attending regular school (from KG to class 8th) who came to Child guidance clinic in psychiatry OPD in GMCH 32 were enrolled in the study after taking consent from the guardians and assent from children older than 7 years. Six children were younger than 9 years and four children were aged 9 years or more.
Design:
The participants were taken serially and no randomization was done. Their parents (mothers n=6 fathers n=4) were interviewed regarding their expectations from the treatment of ADHD and the preferred mode of treatment (pharmacological versus non pharmacological).

Tool:
The tool used for the same was ADHD Preference and Goal Instrument (ADHD PGI) developed by Fikset al (2012) which was administered by the researcher (attached as appendix 1). The test was found to have good test retest reliability in all 3 domains namely medication preference domain, behavior therapy acceptance domain and goals domain (.86, .9, .9 respectively). The test also had good concurrent validity (r=0.3–0.6 compared with the Treatment Acceptability Questionnaire and Impairment Rating Scale).

This instrument has 3 scales to elicit parents’ preferences regarding medicines, behavior therapy, and goals for ADHD treatment. The scale has a total of 46 items with medication, behavior therapy and goal domain having 16, 14 and 16 items respectively. Maximum score in medication, behavior therapy and goal domain is 64, 56 and 64 respectively and minimum score being 0 in all domains (The score is calculated domain wise and not as a total). In medication preference scale there are 4 sub domains - acceptability, feasibility, stigma, adverse effects. Behavior therapy preference scale has 3 sub domains - acceptability, feasibility, adverse effects. Goal scale has 3 sub domains – Academic achievement, behavioral compliance and interpersonal relationships.

Items in the scale are scored from 0 to 4 according to how much the subject agrees: 0, not at all; 1, a little; 2, somewhat; 3, very much; and 4, completely. The average item score (0–4) is calculated for each scale and sub domain. Maximum obtainable score 18 Items of this scale considered relevant from point of view of the child were taken and appropriately modified (3 from medication domain 1 from behavior therapy domain and 14 from goals domain) to study the preference of children themselves (attached as appendix 2).

RESULTS
The score on the scales were analysed domain wise and sub domain wise. Responses with regard to children younger than 9 years and children 9 years and older were compared. The results were as under-
Assessment of parents responses indicated that acceptability of behavior therapy was slightly more than medications. Parents expressed slightly greater concern about feasibility of medicines compared to behavior therapy. Mean score on the stigma sub domain under medication (from parents perspective) was 42.5% and greater in sub group of parents with children aged less than 9 years (50%) compared to parents with children older than 9 years (31%). Among goal scale sub domains academic performance was given stronger preference by parents, (78%) followed by goal of behavioural compliance (68%) and Interpersonal relations (48%) respectively.

Among children (as per the scale applied to children directly), the goal scale sub domains academic performance was found to be stronger goal (74%) followed by behavioural compliance (57%) and interpersonal relations (40%). Among all 3 sub domains children 9 years and older had stronger goals (81%, 62.5%, 45% respectively) compared to children younger than 9 years (69%, 53%, 37% respectively).

DISCUSSION

Patient is the centre of every approach to treatment of all psychiatric disorders. Thus, personal needs and values of the patient should be adequately considered while treating these disorders. A review of studies on prevalent knowledge and attitudes of children suffering from ADHD, their parents, educators, healthcare professionals and general public regarding ADHD found that misconceptions about ADHD were prevalent. Though the studies reviewed showed both similarities and dissimilarities in views of parents and professionals about treatment effectiveness but information sharing and collaborative method of working was supported by all stakeholders (Moldavsky et al 2013).

Another study carried out with the objective of gaining insight into parents decision making process with regards to treatment for their children with ADHD observed that these decisions were made under stressful conditions and were frequently revisited due to various factors. This study warranted the need for developing support systems for parents decision making (Brinkman et al 2008).

Treatment is concerned with both change in clinical symptoms and improvement in the health status as perceived by the patient. Giving appropriate importance to both can help strengthen clinician patient relationship and improve treatment adherence. But it has been found that patient preferences and goals regarding treatment may be overlooked by the clinicians (Corkum et al 1999, Fiks et al 2010, Brinkman et al 2011). These considerations are important with regards to ADHD from point of view of the fact that ADHD has short, medium and long term consequences which are beyond the immediate concerns of healthcare system (Brown et al 2000, Brown et al 2005, Barkley et al 2006) which are mainly related to active symptomatology which brought the patient into contact with healthcare system. A number of studies have focused on improvement of quality of life with drug treatment (Wehmeier et al 2007, Mitt et al 2008) but which aspects are considered important by patients or parents is relatively less studied.

It has been found in clinical trials that families which participated in decision making have better knowledge and lesser indecisiveness about treatment (O’Connor et al 2003). In the study carried out by Fiks et al in 2012 (in which ADHD preference and goal instrument was validated) scores for acceptability and adverse effects in the medication domain were lowest; that is they were the important barriers. However, in the current study scores on stigma were lowest followed by adverse effects, thus they were the important barriers.

In the study by Fiks et al in behaviour therapy domain feasibility was found to be the important barrier whereas in current study it was given almost equal weightage as to the side effects. In comparative terms acceptability of behaviour therapy was found to be slightly higher than medications which can possibly be attributed to fear of side effects of medicines especially in the pediatric age group. Academic achievement was found to be the most indicated goal in the current study which is consistent with findings of the study carried out by Fiks et al.

In current study academic performance was found to be stronger goal followed by behavioural compliance and interpersonal relations among children. The study by Fiks et al (2012) did not study the goals of children directly.

In the study by Fiks et al importance of parents' goals in treatment selection was also discussed. For example, for stronger goal of academic achievement; organisational skill training, subject specific interventions and behaviour therapy on homework strategy may be useful (Power et al 2009). Similarly, for prioritizing behaviour compliance parent training and better family school collaboration maybe important (Pelham Jr et al 2008, Power et al 2009). Furthermore, studying multiple dimensions of preference may help in better understanding of barriers to treatment.

Fiks et al carried out another study in 2013 in which they applied ADHD preference and goal instrument to assess preferences and followed the sample for six months to study its relationship with the receipt of treatment. Clear preference for behaviour therapy or medication were found to be associated with eventual treatment receipt of either behavior therapy or
medication. It was also found that academic goals were associated with starting medication and behaviour compliance goal was associated with starting behaviour therapy (Fiks et al 2013). Another study by dosreis et al concluded that parents views on medication could predict initiation and continuation of treatment of ADHD (dosreis et al 2009).

A study on goals of parents of children with ADHD found that goals relating to inattention were most common. Although the goals were co-related with symptomatology, they were found to extend beyond symptoms of ADHD. Thus, the study pointed towards the need for multiple resources for addressing the parental goals (McGoron et al 2013)

This study has many limitations. The sample size of the study was very small leading to low external validity, but it was planned as a preliminary study with a view to analyse the results and plan a subsequent study with a larger sample. Also, the study included only those parents and patients who were actively seeking treatment for the condition and may not be representative of the general population. Randomisation of sample was not done which limits the external validity of the results. Longitudinal data was not collected to correlate preferences with actual treatment received.

CONCLUSION

In conclusion, as emphasis has increased on patient empowerment and shared decision making in management of the patient, subjective values and preferences of patients and caregivers need to be studied. But it is often seen that preferences and values of these critical stakeholders play a subordinate role in decision making during management. If participation of all stakeholders is increased it would lead to better management of the patient. Hence more research is needed to study these values especially in chronic disorders like ADHD for a more holistic and comprehensive management and better treatment outcomes.

REFERENCES


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