BACKGROUND

Attention deficit hyperactivity disorder (ADHD) is a prevalent disorder of childhood. The worldwide prevalence of ADHD in all age groups is 5.29%. But in children and adolescents, it is about 6% to 13% and is more common in males. In Asia, the prevalence of ADHD is 3.7% and in India that involves some 10 to 15% of the children (Mukhopadhyay, Misra, Mitra, & Nyogi, 2003).

ADHD affects child’s participation in different life situations. It might be school, playground, family or any other community contexts. Most often times, the typical symptoms of impulsivity, inattention and hyperactivity, prevent the child from participating in many situations. Initial affectation because of this disorder might be low self-esteem, learning delay and poor social skills. However, later on it might lead to school exclusion, conduct disorder, substance abuse and criminal behavior. Also, it is well studied that sensory processing problem in children with ADHD is more usual than in typically developing youngsters (Davies & Tucker, 2010)(Dunn & Bennett, 2002)(Mangot et al., 2001).

Participation in activities at home, school and in the community is being a significant part of childhood. It will be useful to know what the parents’ are finding difficult to handle related to his/her successful participation in day-to-day activities. Most often, it is a basis for giving intervention. We wanted an outcome measure that quantifies the level of participation of the children with a diagnosis of ADHD after giving Ayres Sensory Integration’. From the literature review and clinical experience, we realized that there is need to design a tool to find out priorities in parents’ perceptions about the child’s participation in the day-to-day activities.

METHOD

After preparation of the protocol, it was submitted to Institutional Ethics Committee, Seth GS Medical College, King Edward Memorial Hospital, Mumbai and got approval from the ethics committee.

Trial design: psychometric design using cross section survey

Participants & recruitment: “Informed consent was obtained from all individual participants included in the study.” We conducted study at Occupational Therapy Training School and Centre, Seth G.S. Medical College, K. E. M. Hospital, Mumbai, India. We enrolled parents of typically developing children and parents of children with a diagnosis of ADHD between age of 5 years and 12 years from Mumbai and Thane district. We got referral of Children with a diagnosis of Attention Deficit and Hyperactivity Disorder (ADHD) from Child Guidance Clinic of Department of Psychiatry, Department of Pediatric and Pediatric Research Laboratory. The participants were with an average intelligence. We excluded clients with behavior defiance from the study.

For checking validity of the questionnaire, we recruited professionals from the diverse institutions in Mumbai. We selected the participants by universal sampling. To check the face validity of the questionnaire, we recruited 20 professionals (Occupational Therapist, Pediatrician, Psychiatrist, and Psychologist). For checking discriminant validity, we administered the questionnaire on the parents of typically developing children and parents of children with ADHD.

In addition to newly developed questionnaire (APP), we administered Sensory Processing Measure and ADHD rating scale IV: Home Form to screen the children before starting Occupational Therapy.

Instrument development: During questionnaire development, our emphasis was the purpose of the measurement. The purpose was “to measure the degree of the participation in real life situations from the parents’ standpoint”. Understanding the purpose, we identified it as “Participation Profile”. We considered following definitions,

- Participation: the action of taking part in something... life situations
- Profile: an outline of something.
- A graphical or other representation of information relating to particular characteristics of something, recorded in quantified form
- A record of a person’s psychological or behavioral characteristics, preferences, etc. to assess their capabilities in certain sphere or identify categories of the people.

During review of literature, we came across various outcome measures which measures Participation (Dunford, Bannigan, & Wales, 2013). They have various limitations like age range for administration, number of domains, specific diagnostic criterion. Other tools are Miller Function & Participation Scales (M-FUN), The Child, and Adolescent Scale of Participation (CASP) ©. Nevertheless, they too have fewer domains and items under consideration.

Conceptual Framework: Our concept was to determine the parents’ perception about the level of participation in children with a medical diagnosis of ADHD and having sensory processing disorder. We derived the questions for the initial draft of a questionnaire from the WHO International Classification of Function (Child and Young), literature related to Attention Deficit and Hyperactivity Disorder (ADHD), Sensory Processing, and clinical judgment from the experience.

After formation of the draft questionnaire, we requested the professionals to evaluate each question. The criterion for evaluation were Applicability, Clarity, Comprehensiveness, Concreteness, Ease of use, Fairness, Parsimony, Pertinence. For each these criterions, we requested the experts to grade YES or NO. After this, we finalized the
questions, which fit the above-mentioned standard. The relevance of the question was the most important measure. The relevance mainly decided the inclusion of the question in the second version.

We examined Content validity to ascertain whether the content of the questionnaire was appropriate and relevant to the study purpose. Once the conceptual framework was established, we asked nine purposely chosen experts in the areas of Occupational Therapy, Pediatrics, Psychology, and Psychiatry to review the draft of 114-items Participation Profile to ensure it was consistent with the conceptual framework. Each reviewer independently rated the relevance of each item on the Participation Profile to the conceptual framework. The Content Validity Index (CVI) was used to estimate the validity of the items (Schilling et al., 2007). According to the CVI index, a rating of three or four indicates the content is valid and consistent with the conceptual framework. If seven of eight content experts rate an item as relevant (3 or 4) the CVI would be 7/8 = 0.87.

Also to elect the parent’s perceived level of difficulty of the child during participation, the grading are No Difficulty, Mild Difficulty, Moderate Difficulty, Severe Difficulty and Complete Difficulty.

**Face validity:** Face validity indicates the questionnaire appears to be appropriate to the study purpose and content area. It evaluates the appearance of the questionnaire in terms of feasibility, readability, consistency of style and formatting, and the clarity of the language used (Trockim, 2001). Thus, face validity is a form of usability rather than reliability. We developed an evaluation form to determine the face validity of the ADHD Participation Profile, to help respondents assess each question in terms

1. The clarity of the wording,
2. The likelihood the target audience would be able to answer the questions,
3. How is the layout and style?

Grading (5-point Likert scale: 4 = strongly agree 3 = Agree; 2 = Neither agree or disagree 1 = disagree; 0 = strongly disagree) given to the criteria helped for modifying the questions mainly layout, style and font size of the final version (**Face Validity**).

**Concurrent validity** is a measure of how well a particular test correlates with a previously validated measure. For checking criterion validity (**concurrent**), we correlated the newly formed ADHD Participation Profile with Social Participation domain of Sensory Processing Measure (Western Psychological Services).

**Internal Consistency Reliability:** To examine the internal consistency of the ADHD Part All the items were valid with CVIs ranging from 0.87 (7/8) to 0.100 (8/8) and were retained.

To examine the internal consistency of the ADHD Participation Profile (APP), we computed Cronbach’s alpha. Internal consistency examines the inter-item correlations within an instrument and indicates how well the items fit together conceptually (Devo et al., 2007). In addition, to estimate the consistency of the whole questionnaire, we computed the total score of all the items.

After the formation of the final version, we administered the questionnaire on parents of typically developing children and then on parents of children with a diagnosis of ADHD. All scores revealed differences between perception of parents of typically developing children and of parents of children with a diagnosis of ADHD (p < 0.001). Likewise, we checked discriminant validity with Mann Whitney U test.

**RESULTS**
Detailed characteristics of participants are in Table 1.

**Table 1: Characteristics of the Study Participants**

<table>
<thead>
<tr>
<th>Domain of APP</th>
<th>Other Domain</th>
<th>Correlation coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Score (PP)</td>
<td>Socialization domain score (SPM)</td>
<td>-0.35264</td>
</tr>
<tr>
<td>Total Score (PP)</td>
<td>Total score (SPM)</td>
<td>0.480598</td>
</tr>
<tr>
<td>Total score (PP)</td>
<td>Age</td>
<td>0.0145</td>
</tr>
<tr>
<td>Total score (PP)</td>
<td>IA</td>
<td>0.463554</td>
</tr>
<tr>
<td>Total score (PP)</td>
<td>HI</td>
<td>0.500994</td>
</tr>
<tr>
<td>Total score (PP)</td>
<td>Total (ARS IV–Home Version)</td>
<td>0.535334</td>
</tr>
</tbody>
</table>

**Reliability:** We computed Chronbach alpha for the final version of ADHD Participation Profile after construct validation and was 0.97.

**Discriminant validity:** Table 3 shows discriminant validity of the participation profile. There was significant difference between scores of children with a diagnosis of ADHD and typically developing children. Mann Whitney U value is smaller than values from the table (95.01% CI of difference - Exact). This indicates that ADHD Participation Profile is able to differentiate between typically developing children and children with a diagnosis of ADHD.

**Table 3: Discriminant validity (Mann Whitney test) (p<0.001, CI=95%).**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Sum of ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Typically Developing</td>
<td>301.5</td>
</tr>
<tr>
<td>ADHD</td>
<td>779.5</td>
</tr>
</tbody>
</table>

**Factor Analysis:** Extraction Method used was Principal Component Analysis. Rotation Method applied was Varimax with Kaiser Normalization. Principle component analysis resulted in 13 factors
with eigenvalue >1. We applied Kaiser-Meyer-Olkin Measure of Sampling Adequacy. It was 0.736 (> 0.6). We used scree plot to select the factors. We selected the loading of > .7 and deleted remaining items from the questionnaire. (N=93) (Mean Age: 7.52 years SD: 2.3) (Male: 72; Female: 21). (Table 4)

Table 4: Factor Analysis

<table>
<thead>
<tr>
<th>Sr. No.</th>
<th>Questions</th>
<th>Factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Does your child have any problem learning to calculate, such as using mathematical signs for addition and subtraction and applying the correct mathematical operation to a problem?</td>
<td>0.741</td>
</tr>
<tr>
<td>2</td>
<td>Does your child have any problem performing activities involved in the comprehension of written language? (E.g. Books, instructions or newspapers in text)</td>
<td>0.828</td>
</tr>
<tr>
<td>3</td>
<td>Does your child have any problem executing a complex task, such as arranging the furniture in one's home or completing an assignment for school?</td>
<td>0.780</td>
</tr>
<tr>
<td>4</td>
<td>Does your child have any problem managing and executing a task on one's own and without the assistance of others?</td>
<td>0.733</td>
</tr>
<tr>
<td>5</td>
<td>Does your child have any problem conversing with one person, E.g. discussing weather with a friend?</td>
<td>0.751</td>
</tr>
<tr>
<td>6</td>
<td>Does your child have any problem carrying an object from one place to another using the hands, such as when carrying a drinking glass or a suitcase?</td>
<td>0.711</td>
</tr>
<tr>
<td>7</td>
<td>Does your child have any problem manipulating, such as when handling coins or other small objects?</td>
<td>0.838</td>
</tr>
<tr>
<td>8</td>
<td>Does your child have any problem catching using fingers, hands and arms to grasp a moving object in order to bring it to a stop and hold it, such as when catching a ball?</td>
<td>0.746</td>
</tr>
<tr>
<td>9</td>
<td>Does your child have any problem using public transportation, such as being a passenger on a bus, train, subway or aircraft?</td>
<td>0.717</td>
</tr>
<tr>
<td>10</td>
<td>Does your child have any problem washing body parts, such as hands, face, feet, hair or nails, in order to clean them?</td>
<td>0.785</td>
</tr>
<tr>
<td>11</td>
<td>Does your child have any problem putting on clothes?</td>
<td>0.844</td>
</tr>
<tr>
<td>12</td>
<td>Does your child have any problem taking off clothes?</td>
<td>0.855</td>
</tr>
<tr>
<td>13</td>
<td>Does your child have any problem putting on footwear?</td>
<td>0.809</td>
</tr>
<tr>
<td>14</td>
<td>Does your child have any problem taking off footwear?</td>
<td>0.849</td>
</tr>
<tr>
<td>15</td>
<td>Does your child have any problem cleaning living area?</td>
<td>0.746</td>
</tr>
<tr>
<td>16</td>
<td>Does your child have any problem regulating behaviours within interactions? (Regulating emotions &amp; impulses, verbal aggression &amp; physical aggression in interactions with others, in a contextually &amp; socially appropriate manner)</td>
<td>0.728</td>
</tr>
<tr>
<td>17</td>
<td>Does your child have any problem interacting according to social rules?</td>
<td>0.727</td>
</tr>
<tr>
<td>18</td>
<td>Does your child have any problem creating and maintaining relationships with one's parent, such as a young child obeying his or her parents?</td>
<td>0.710</td>
</tr>
<tr>
<td>19</td>
<td>Does your child have any problem creating and maintaining a sibling relationship?</td>
<td>0.843</td>
</tr>
<tr>
<td>20</td>
<td>Does your child have any problem creating and maintaining a family relationship with members of one's extended family, such as with cousins, aunts and uncles and grandparents?</td>
<td>0.702</td>
</tr>
</tbody>
</table>

**DISCUSSION**

The aim of the study was to get a profile of the children with a diagnosis of ADHD. This profile was to quantify the parent’s perception regarding the level of difficulty the child is facing during the participation of the daily chores. We assembled the evidence for the final profile through newly developed questionnaire. The present study determined validity and reliability of newly drafted questionnaire viz. ADHD Participation Profile. This questionnaire assesses the level of participation in children with a diagnosis of ADHD from parent’s viewpoint.

For signifying primacies of the parents’ perception we did Factor analysis of the ADHD Participation Profile (APP). Factor analysis resulted in the identification of 13 factors. Out of 13, we selected five factors as they contained the majority of the items. In conclusion, we selected total 20 items.

Factor I represented behaviors from various domains. They are Mobility, Self-care and Domestic life. The items consisted of carrying items neatly, in hand manipulation, bilateral coordination during play, behaving appropriately as a passenger during travel, being independent in daily chores of washing body parts, dressing and wearing footwear. As the population consisted of the children between the age group of 5-12, according to parents, these items represents the participation level of the children with a diagnosis of ADHD.

Factor II represented a combination of Learning and applying knowledge & General Tasks and demands. It mainly represented educational tasks. It is the main reason for parents getting the children for intervention in the study population. Usually school raises the concern about the child’s behaviors and they refer the child for professional intervention. Moya Kinmealey attributed this to
"learning style differences". It is attributed to the discrepancies between visual/perceptual and auditory/language learning which will result into great inefficiency in learning.

Factor III was related to Interpersonal interactions and relationships. It consisted of the behaviors, which are required for healthy interaction with family members and significant others. These were important parent goals for children with a diagnosis of ADHD as designated by McGoron (McGoron et al., 2014). McGoron termed them as Family well-being. Family well-being comprises of goals related to relationship with siblings, relationship with parents, and family functioning; Relationships included goals related to relationships with siblings, relationships with peers, relationship with parents, and relationship with teachers. These are the key determinants of the child receiving acknowledgement in the real life situations. In some circumstances, based on it the people categorize the child as a good or bad.

Factor IV consisted of items related to the communication. Parents perceive the child's involvement in discussions and deliberations, as an important factor for improving the level of participation.

At home, parents anticipate the child to take part in cleaning living area. This relates to organization of behavior, keeping the things neatly and considered the sign of maturity. Thus, these 20 items represented the level of participation according to the parent's perspective in the study population. Alexander Fiks (2012)Fiks et al., 2012) found similar parent's preferences and goals for children with ADHD (children between 6 to 12 years of age) viz. academic achievement, behavior compliance, and interpersonal relationships. The factors like age, gender, culture, socio economic status and family expectation will have an impact on the perceived level of difficulty by the parents. Lucy Miller (2012) also elaborated on how ADHD and sensory processing issues impair social, academic and occupational functioning.

The Child and Adolescent Scale of Participation (CASP) © (Gary Bedell, 2011) has similar items for measuring participation. A few additional items are also included. Not all the items in the CASP are relevant for children with a diagnosis of ADHD. The items are: Family chores, Moving in and around home, Structures events in the community, & Shopping and managing money. These items appear to be important in a particular culture, for a particular diagnosis but may not be primacies for the parent's in the study population.

Miller Function and Participation Scales (M-FUN) (Lucy Miller, 2006) is designed for the children between the age of 2.6 years through 7.11. It has its items, which are important from developmental perspective. These items are Self-control, Computer key boarding, Eating & Toiletting. These items were part of the 74 items questionnaire of ADHD Participation Profile. However, according to parents, they were not the determining factor for level of participation in the study population. One needs to acknowledge the variation in perception of the families. This underscores the importance of measuring goals in order to match families with evidence-based treatments on a single tool.

Adherence strongly predicts improvement for children on all ADHD treatments. The approach of measuring and targeting treatment toward families' goals may directly promote adherence since adherence depends upon families recognizing that their regimen is beneficial. In this context, it is important to use a measure the outcome of the intervention taking into consideration the family concerns and local cultural issues. One should remember that factors present in outcome measure should be consistent with family's priorities. Researcher should test the outcome measure on the local population. Alexander Fiks et al., 2012

We computed Cronbach's alpha for the final version of ADHD Participation Profile after examining the construct validity and was 0.97, which indicates a high correlation between the items and the questionnaire is consistently reliable. Opinions differ about the ideal alpha value. Some experts recommend the alpha should be at least 0.90 for instruments used in clinical settings. Others suggest an alpha of 0.70 is acceptable for a new instrument(DeVon et al., 2007). The internal reliability (alpha) reached the recommended level for clinical use. Therefore, clinicians can use the ADHD Participation Profile in routine client education and management, for example, clinicians could use it confidently in usual clinical practice to incorporate the level of participation in the care of their clients.

After item pool generation, the Content validity helped assess whether the content of the questionnaire represented the concept of participation defined in the study.

While face validity is the lowest kind of validity, it was useful in that provided important information close to the operationalization of the questionnaire by parents of youngsters with a diagnosis of ADHD. Face validity of 72% indicated that the appearance, clarity of wording and layout would be acceptable to the targeted audience.

We found a significant difference between scores derived from the parents of children with a diagnosis of ADHD and parents of typically developing children (p<0.001). This indicates that ADHD Participation Profile was able to discriminate parents' perception about typically developing children and children with a diagnosis of ADHD.

There is a negative correlation between ADHD Participation profile total score and socialization domain of SPM. This might be because of fewer items related to participation in daily life in Socialization Section of SPM. Our assumption that Socialization and level of Participation correlates positively might be incorrect. In ADHD Participation Profile, we collected data from several domains other than related to socialization. Though we did not prove, other domain might have better correlation like interpersonal interaction and relationship domain of Participation profile might have good association with Socialization Section of SPM. We cause to agree that Socialization and Participation are different concepts.

Amazingly, we found a positive correlation with Total score of SPM. This might be because of the many items from ADHD Participation Profile were also evaluated in SPM. In addition, we observed positive correlation with age, Inattention, Hyperactivity and Total score on ADHD Rating Scale-IV (Home Version).

However, to strengthen the rigor of the questionnaire for further research, the researchers recommend undertaking convergent and discriminant validity to examine the similarity and differences of the ADHD Participation Profile with other tools.

Clinical application: We recommend using APP to record the parent’s concerns about the child at the starting point before intervention. In addition, we can monitor the progress using ADHD Participation Profile. Various professionals like Occupational Therapist, Physical Therapist, Pediatrician, Child psychiatrist, remedial educators, and general physician can make use of this tool. The findings from the study will be helpful for the development of ICF core sets for ADHD(Bolte et al., 2014).

Limitations: There is a need of further Validation and Reliability studies. In addition, there is a need of getting norms of age wise variation in level of participation. We should have done the concurrent validity with outcome measures for ADHD.

Conclusion:

- Self-care, academics, interpersonal interactions and communication are important primacies for the parents of children with a diagnosis of ADHD.
- Priorities of the parents of children with a diagnosis of ADHD
change according to the culture they belong.

- Use culture congruent outcome measures in order to relate the treatments across different cultures.
- ADHD Participation Profile (APP) is a valid & reliable questionnaire to monitor progress of children with a diagnosis of ADHD.

**Ethical approval:** ‘All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.’

**Declaration of Interest:** The authors report no conflicts of interest.

**Acknowledgment**

We would like to thank Pratap Jadhav for helping us in statistical analysis.

1. **Applicability** of question in this questionnaire for intended assessment (purpose).
2. **Clarity** in question so that parents give an appropriate response.
3. **Comprehensiveness** of questions to get the intended information.
4. **Concreteness** (specific/ Particular) of question to get specific information.
5. **Ease of use** of question during administration of questionnaire.
6. **Fairness** (Impartial) of questions to get an unbiased response from the parents.
7. **Parsimony** (Economy of words) use of an adequate number of words to gather the information.
8. **Pertinence** (Relevance) of question to the meet purpose of the questionnaire.

**References**