



## ATTENTION DEFICIT AND HYPERACTIVITY DISORDER & OCCUPATIONAL THERAPY WITH AYRES SENSORY INTEGRATION®: CARETAKER VIEWPOINT

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### ABSTRACT

Occupational Therapy given with Sensory Integration Frame of reference is individualized and unstructured and the response may not be dose dependent. Pre-determined parameters may not give adequate information about the wide impact the Occupational Therapy has on the child and its family.

**Study Design:** Phenomenology

According to caretaker Occupational Therapy with Ayres Sensory Integration has brought a notable change in kids and parents life but cognizance is something that is still needed. Most of the caretakers were ready for new boundaries in their daily family occupations. Though some goals are met after the intervention, the list of apprehensions is unending. Many parents were less worrying after Occupational Therapy intervention, whereas the few were still doubtful about future of their kids. We would have overlooked this ironic data, if we should have given verdict about effect of the intervention though quantitative measure.

**KEYWORDS :** Phenomenology, Attention Deficit and Hyperactive Disorder, Care taker Viewpoint, Family Occupation

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder characterised by a combination of inattentiveness, distractibility, hyperactivity and impulsivity. Children with ADHD have difficulties in play, executive functioning, to perform their occupational role as a student and to maintain healthy relationship with family members, relatives and peer group. The presence of a child with ADHD results in increased likelihood of disturbances to family and marital, parent-child relationships, reduced parental efficacy and increased level of parent stress.

In case of ADHD children, occupational roles and occupational performances of both the children and their parents are seen to be affected. Occupational Therapists involved in the treatment and management of children with ADHD provide therapy programmes to address their difficulties which can be applied for home environment and other surroundings.

It is well studied that sensory processing problem in children with ADHD is more common than in typically developing children (Phoebe P.P.Cheung, 2009)(Ghanizadeh, 2011). Use of Ayres Sensory Integration® in children with ADHD has been justified (Nandgaonkar Hemant P., 2016). Dr. Miller studied quantitatively the effectiveness of Occupational Therapy in children with sensory modulation disorder (Lucy Jane Miller, 2007). Most of the studies evaluate outcome on standardized scales using quantitative methods. But, it is equally important to take into consideration the family perspective, the impact on family occupation along with the child's participation in different life situations.

Ruth (Segal, 1998) found out that adapting particular occupations of children with ADHD affect the routines and occupations of other family members. According to Ruth, this concept should be used by occupational therapists working with children who have special needs and their families.

Hence a study is performed to gain insight into how parents perceive the effects of an Occupational Therapy intervention with Ayres Sensory Integration. According to Spitzer & Smith Roley (Spitzer, 2001), "Intervention emphasizing a sensory integration approach addresses the sensory needs of the child in order for the child to make adaptive and organized responses to a variety of circumstances and environments". It is best distinguished by the active engagement of the child who is allowed to move, jump, swing, and crash. Additionally the child is encouraged to move and change the environment to create higher and more challenging demands for perceptual-motor integration. The hallmark of sensory integration is that it is done in the context of play, the children love the activities, and the activities are their own reward. Ayres structured her intervention approach using sensory integration theory around principles of motor learning, the adaptive response, and purposeful activity.

As Occupational Therapy given with Sensory Integration Frame of reference is individualised and unstructured and the response may not be dose dependent. Predetermined parameters may not give adequate information about the wider impact the Occupational Therapy has on the child and its family. For the purpose of realizing viewpoint about the influence of the intervention, qualitative approaches assumed to be better as Quantitative Research has its own limitations. Qualitative research methods are the best approach for describing and understanding participants, life experiences.

### Aim of the Study:

The purpose of the study was to examine the perspective of Caretakers of children with a diagnosis of ADHD on effects of Occupational therapy with Ayres Sensory Integration on Occupational performance of children and family occupation.

### Research team and reflexivity:

**Personal Characteristics:** Interview was conducted by Principal Investigator and interns of Occupational Therapy Training school & Center, Seth GS Medical College, KEM Hospital, Mumbai. Principal investigator is assistant professor and had training in qualitative research. Also conducted some studies with in depth interview and published. Though PI is male gender but interns consist of either gender (1 Male and 4 female)

**Relationship with participants:** Participants of the study were regular clients of the institute and were recruited for the study for more than 6 weeks prior to the interview. During initial history taking and evaluation interviewer was accustomed to the care taker. During an interview, objective of the study was recalled and asked questions as per interview protocol after taking verbal consent. Interview was taken under the pretext that their identity would be safeguarded against any kind of exploitation. None of the interviewer was involved in giving treatment to reduce bias.

**Study design:** Phenomenology - underlying assumption was that we can holistically focus in on other parents' perspectives and feelings. This method will help uncover the meaning of humanly lived phenomena through the analysis of caretaker's descriptions. With this inductive, descriptive research method we wish to investigate and describe all phenomena, including human experience, in the way these phenomena appear.

After preparation of the protocol "Ayres Sensory Integration® for the Children with ADHD: A mixed method study", it was submitted to Institutional Ethics Committee, Seth GS Medical College, King Edward Memorial Hospital, Mumbai and got approval from the ethics committee.

**Participant selection:** The block randomized sampling method was

used. The participants were approached face-to-face while the child was receiving intervention in the other room.

**Sample size:** Total of forty participants was part of the study.

**Non-participation:** Three care takers refused to audio recording of the interview as they did not feel comfortable about the same.

**Setting:** The interview was conducted in the Occupational Therapy departmental library near sensory integration clinic to avoid interruption. Sometimes there was interruption from the library users or the other staff & students. We continued audio recording despite this as to continue flow of the interview.

**Recruitment criteria:** Caretakers of patients visiting Sensory Integration Therapy Clinic of Occupational therapy department were approached. The term caretaker is used as the children visiting for therapy were accompanied by parents, grandparents, uncle, aunt or the other relatives. **Inclusion Criteria** was Caretakers of children of either gender (with a diagnosis ADHD between age group of 5-12 years) who were receiving Occupational Therapy services for at least 6 weeks. **Exclusion Criteria** was Children with ADHD who are on medications to reduce hyperactivity, Caretakers who were unwilling to participate in the study and Children with other Diagnosis like Intellectual Disability, Down's syndrome, and Autism Spectrum Disorder.

**Data collection**

**Interview guide:** Following were questions, prompts, guides provided.

- According to you, what is the effect of intervention on your child?
- What's the effect of intervention on the family life?
- What were your initial complaints before Occupational Therapy intervention?
- What new things have you learnt from Occupational Therapy about your child and how do you deal with it?
- How has Occupational Therapy helped you with your occupational roles, family occupation and social life?
- What changes have you noticed in your child's Activities of Daily Living, play, schooling and social interaction?
- Are you able to inculcate the home programme suggested by an Occupational Therapist? Is it feasible to follow?
- What is child's response or reaction when child is brought to Occupational Therapy department? Does the child like the setup and enjoy coming to the department?
- Following Probes were used
- Parents were given examples of sample change in behavior, which might occur.
- Thank you statement for acknowledging the time the interviewee spent during the interview.

The format of the interviews encouraged the participants about any issue that they thought was relevant to the question asked. The questions were pilot tested before to use it during interview.

**Repeat interviews:** We carried out ten repeat interviews. That was during initial period of study. Others we did not feel the need of repeating. We used Sony Voice recorder for audio taping the interaction. Field notes were made during the interview on the notepad. Each interview lasted for about 45 minutes at the maximum. On an average 20 – 25 min interview was common practice. We did not make transcript as we stored data on the computer and repeatedly listened to it for deriving the codes. Considering the educational level of the participants we did not made transcript and returned to the participants. Data collection was stopped when saturation point was attained.

**Analysis and findings**

**Data analysis:** The coding was done by four coders including principal investigators. Total numbers of participants were 40 (33 boys + 7 girls). We derived 175 codes. We prepared theme after coding. Themes were derived from the data and were not identified in advance. Themes comprise of codes consisting of similar message. We used chart paper and markers for analysis. We did not involve participants to provide feedback on the findings though we shared the finding with them.

**Codes for Different Themes**

Themes	Codes
<b>Outlook</b>	Interested, guarded, occupied, cooperative, reluctant.
<b>Response to intervention</b>	Positive: Improvement in: educational performance, cognitive and perceptual skills. Decrease in toe walking, Family occupation, coping strategies, Progress in Daily activities performance, likes to come to the session, fun Negative: intervention should have been for longer duration
<b>Vicissitudes of Behaviour</b>	Positive: Hard worker, loving, caring, intelligent, innocent, submissive, does not know how to defend himself Negative: Sensory processing issues, aggression, mischievous and stubborn behaviour, procrastination, Intolerance of boredom
<b>New Confines</b>	Job sacrifice, avoidance of social gatherings and meeting relatives, Adjusting daily Schedule
<b>Coping With Diagnosis</b>	Positive versus Negative: Denial, acceptance, optimism, stressful situations, insecurity and pessimism
<b>Cognizance</b>	Awareness about diagnosis, occupational therapy, appropriate guidance, Sensory Integration, parent education, counselling, home programme, reference to other professionals.
<b>Value of Services</b>	Cost effective, feasibility of therapy, economical, beneficial, suitable, workload, time barrier.

In some instances we used participant quotations presented to illustrate the findings without identification.

**Outlook/ Attitude:**

This theme describes the outlook of the interviewee's towards the approach of the interviewer. Attitude is defined as, "A predisposition or a tendency to respond to positively or negatively towards a certain idea, object, person or situation." There was a mixed reaction from the participants. Most of them were open, elaborative and intent in sharing their experiences. The willing close relative gave detailed description about their experiences. Whereas some parents came across as occupied, guarded and apprehensive about sharing their experience and hence did not agree for audio-taping. At the same we were disturbed by the mobile phones during the interview. Sometimes we could interpret it as not interested in the interview process. But we need to appreciate their priorities, circumstances and other contextual factors before concluding with our own bias.

**Vicissitudes of Behaviour:**

This theme describes about various behaviours coded during data analysis. We have categorized them into positive and negative behaviours. These per se are not the outcome of the intervention, but still is the part of child's repertoire.

Vicissitudes: a change or variation occurring in the course of something

: Unpredictable changes or variations that keep occurring in life, fortune, etc.; shifting circumstances; ups and downs

Behaviour is defined as, "the way in which a person behaves and responds to a particular situation or stimulus."

The various negative descriptions coded were aggression, mischievous, stubborn behaviour, jumping, talking excessively, interrupting during conversation, attention seeking behaviour, distractible, keeping tasks halfway, not able to complete activity, needs assistance all the time, being lazy, getting up many times while doing homework, keeping parents involved in conversation to avoid working, roaming around, hitting other kids and objects, running, hitting on head, irritable, lazy in daily work, makes a lot of excuses, has fear of darkness, distracts other students, quarrels with other children, irrational fears, hates to write, classwork remains incomplete, laid back attitude, weak in phonetics, if he has problems does not discuss, etc.

The various positive descriptions coded were: Hard worker, loving, caring, intelligent, innocent, submissive, does not know how to defend himself, lost into his own thoughts, energetic always alert, shy, quiet,

sensitive, caring person, very sweet, very social, open at heart, does not hold (grudges) against anybody, very happy child, very playful, good memory, good in languages, good grasping of concepts – no need to by heart, not afraid of anything, wants friends every time, smart, impulsive, loves big family culture, take care of other classmates, very helpful, very creative, has strong like and dislikes, loves to read, good natured, obedient, fun loving

*“Remembering things with visual presentation much more than verbal explanations”*

“A child will do anything for happiness of the people who loves him & whom he loves”

Concerns of the caretaker were, “my child would not sit at one place and study, constantly would shift from one task to another, hit and bite other children and would not play with children of his age.”

#### **New Confines:**

During the data analysis it was found that parents of children with ADHD have quite a few limits with regards to their occupational roles, social life and leisure, which is described in this theme.

**Confines:** keep or restrict someone or something within certain limits of (space, scope, or time).

Occupational roles of few parents were seen to be affected as they had to sacrifice their jobs for the betterment of their kids. Some parents limited their social gatherings and outings and avoided attending them due their insecurity and difficulty in handling their kids. Reason for avoiding social events or meeting relatives as stated by the parent was that the child is very mischievous and hence people may talk about us.

One of the parent mentioned during the interview, “I don't get time for myself, I like to go for an evening walk but I am not able to as I am engaged with my child's routine work.”

Frequently, heavy work such as jumping on a trampoline, jogging, running, heavy pressure, heavy bouncing on a therapy ball, swinging, or engaging in contact sports was opined. Caretakers were channeled to revisit as needed during the day as a sensory diet. One of the dads adapted his daily routine such that he could take the child to garden, so that child performs homework properly. It was one of the sensory strategies suggested to the parents. Some of the parents gave feedback that sensory diet improves child's performance and behaviour. These parents adapted sensory strategies as a new occupation for them.

#### **Response to intervention**

This theme describes about how Occupational Therapy Intervention has brought about change in Occupational roles of children with ADHD and their parents.

The codes for the following theme are  
Progress in involvement in activities of daily living,

Enhancement in educational performance pays attention in the school, legible handwriting, good performance in examination, sits while doing homework.

Other codes were Social behaviour, Peer interaction, communication skills, Everyday occupation, coping strategies.

Following are few positive statements spoken by parents when they were asked about effects of intervention

- “He likes to come for the session. He becomes upset if we are not able to come. Sometimes we use it as reward for the desired behavior.”
- “I could see 50% improvement in my child”, as said by one parent.
- (NBK) “if we are firm with him also playful at the same time he obeys commands”
- “My child stopped his excessive jumping after one month of therapy.”(VVR)
- “When we initially took admission in the school, teacher complained of my son not being attentive in class, not sitting at one place, not copy writing from the board and disturbing other kids and now, after Occupational Therapy treatment, I find considerable improvement in my child and presently there are no

complaints from the school.”

- Now he plays with other children. Previously other children did not use to take him for playing as he never used to follow rules.
- Family occupation were also influenced by the intervention
- “Occupational Therapy helped improve my child's attention and concentration and it also helped in daily activities due to which I got time for myself to do my activities.”
- Few parents did not notice any changes in their kids.
- He still is fidgets during the homework. He avoids it. Otherwise he is okay on other things.
- Still he finds math difficult. Does silly mistakes during examination.

#### **Coping With Diagnosis:**

This theme describes about different coping reactions observed in parents. Coping is defined as, “to deal successfully with difficult situations.” Two types of coping reactions were seen both positive and negative.

Positive reactions encountered were active participation, involvement, acceptance and optimism. Also caretakers' emphasized positive individualities of the child. The parents were proud about these features.

When asked the parents how do they deal with the diagnosis, one of the parent said, “I cannot ignore my child's problem as it can affect my child's future.”

Optimistic statement of a parent was, “if my child continues Occupational Therapy treatment there will be gradual improvement seen in my child.”

Negative reactions encountered were denial, stress and insecurity about the future.

Some of the parents were confused about the amount of time they devote in the management of the disorder and how long they have to go.

#### **Cognizance:**

This theme describes on what is parents understanding about the disorder of the child and intervention.

Awareness: knowledge that something exists, or understanding of a situation or subject at the present time based on information or experience.<sup>1</sup>

As seen through the interview process some parents were expecting to get more knowledge about the treatment given to their child in the Occupational Therapy sessions. “Occupational Therapy helped improve my child's attention and concentration and it also helped in daily activities due to which I got time for myself to do my activities.”

They were sure about the help they got it because of intervention but were interested in knowing about how it is helping and how far they have to seek help? Some of them were already using internet for gathering more information about the diagnosis, sensory processing disorder, and sensory integration therapy. But they found that, it's confusing and there is lot of mess. Additionally, they had concerns about the trustworthiness of the information. One of the constant queries was to take medication or not?

#### **Value of Services:**

This theme describes on the value of services provided by Occupational Therapy in K.E.M.Hospital and various codes under it. Service provision refers to the way inputs such as, money, staff; equipment is combined to allow the delivery of health intervention. Value: the regard that something is held to deserve; the importance, worth, or usefulness of something.

After interviewing many parents, we realised that, many parents prefer Occupational Therapy at KEM Hospital Occupational Therapy department as it is cost effective, feasible and positive outcome results are seen. As said by one of the parents, treatment in private setups is very costly so we prefer treatment in K.E.M.H. One of the parent also said “I prefer to come for OT treatment in K.E.M.Hospital as I get frequent sessions and the home program given is easy to follow.”

KEM Hospital has legacy of more than 90 years of patient care. Few parents emphasized that, "Whatever happens to anybody in the family we come to KEM (hospital). We know that everything happens good in KEM. So our child is also showing progress"

Negative factors which were referred to during the interview were workload, time of the appointment barrier, timeliness for scheduled appointment and frequent change of therapists.

#### Discussion:

We have conducted a qualitative research with an aim to study the perspective of Caretakers on effects of Occupational Therapy with Ayers Sensory Integration on children with a diagnosis of ADHD.

The descriptions given by caretakers portray the amount of engrossment the child is demanding and how it is affecting individual caretaker and family functioning. Harpin (VA, 2005) which stated the stresses parents have to go through in handling the kid in difficult situations and how does having ADHD adversely affects the equation within the family.

Another section of the interview included the effects of Occupational Therapy intervention for ADHD. The results found were typically positive and how Occupational Therapy intervention based on the Sensory Integration frame of reference has helped resolve the problems of children and family occupation. The results found by us were similar to (Sadako Vargas, 1999); (Sarah KN, 2017); (Kristie Koenig, 2015); But after reflecting on the lingering concerns of the parents, we realized that the effect was reassuring. Though short-term benefits are confirmed, it's not a permanent intervention. Hinshaw also concluded that Intervention for ADHD must be viewed as a lifelong enterprise (Hinshaw, 2015).

There were new confines in the family occupation in the form of sensory diet recommendations. But the need of the hour is suggestions for adapting everyday life situations to meet the needs of children with different patterns of sensory processing (Dunn Winnie, 2007). As determined by (Miao, 2017), family occupations are inherently manifold, evolving, and negotiated. Blending therapeutic interventions into daily life necessitates attention to the complexity of family doing. Families are culturally-specific groups and require customized supports and health interventions. Also families rarely have singular aims forms of action. It may not be enough to carve out a dedicated time of day or week in which to "fit" health interventions. Practitioners may also need to consider how these interventions can be overlapped, intersected, and distributed into the general milieu of activity.

The last theme was related to the cognizance. It included an understanding of diagnosis; intervention and other factors. Endowment related to all the aspects was indeed needed. Considering the complex nature of condition, multitude of interventions; parents were expecting more enlightenment in this domain. Rana (Ahmed, 2014) also found out at the end of qualitative enquiry that "There are gaps in parents' knowledge about ADHD and its treatment, and an expressed need for tailored and reliable information." As detected by Joshi (Joshi A., 2008), empowering parents of children with special needs would not only help them to understand their children better but would also provide an indirect boost to our therapy.

We conclude that that Occupational Therapy has brought a notable change in kids and parent's life, but cognizance is something that is still needed. Most of the caretakers were ready for new boundaries in their daily family occupations. As a professional, we just need to guide them to a child's performance or relate to the positive outcome. Though some goals are met after the intervention, the list of apprehensions is unending. Many parents less worried after Occupational Therapy intervention, whereas the few were still doubtful about future of their kids. We would have overlooked this ironic data, if we should have given a verdict about the effect of the intervention though quantitative measure. Mixing the methods was a suitable solution.

**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."

- <sup>1</sup>. <http://dictionary.cambridge.org/dictionary/english/awareness>
- <sup>2</sup>. <http://dictionary.cambridge.org/dictionary/english/value>
- <sup>1</sup>. <http://www.dictionary.com/browse/vicissitudes>

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