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Original Research Article

Prevalence of Knowledge and Misconceptions Regarding ADHD Among Parents, Teachers and Anganwadi Workers and Impact of Missed Diagnosis on Quality of Life of Late Diagnosed ADHD Patients-A Mixed Method Study

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ABSTRACT

Background- ADHD causes high rates of co morbidities such as mood and anxiety disorders, substance use disorders etc. This study aims to assess the prevalence of knowledge and misconceptions in people who are in close contact with young children and to understand the impact of ADHD on quality of life among late diagnosed ADHD individuals.

Material and Methods-This is a community based cross sectional study done on 419 study subjects (parents -197, teachers -175, Anganwadi workers–47) in the urban field practice area of a tertiary care medical college during November and December 2023. For assessing the quality of life of the 30 late diagnosed ADHD individuals, were identified and in-depth interviews were conducted.

Results- None of the Anganwadi workers had adequate knowledge about ADHD. Majority of the parents (58.8%) and teachers (52%) had no knowledge about ADHD. Majority of the study subjects felt that symptoms of ADHD could be overcome by “willpower”. Most common attitudinal problem among anganwadi workers was that it’s not a real medical problem. Most common themes to emerge in the in-depth interviews was the problem in maintaining a career and lack of societal understanding.

Conclusions- Training of care givers in early identification of ADHD symptoms is essential.

Keywords- ADHD, qualitative research, mental health

INTRODUCTION

ADHD is among the most prevalent neurobehavioral disorders in children [1, 2] carrying risk of oppositional defiant disorder, mood disorders, and substance use disorders [3]. Costs of untreated ADHD are significant, including academic and occupational underachievement, delinquency etc [3-5,6,7].

A study done in Coimbatore, India found ADHD prevalence in children to be 11.32%[8]. Recognition of ADHD in adults has also been increasing recently [9,10].

This study aims to assess the prevalence of knowledge and misconceptions among parents, teachers and Anganwadi workers and to understand the impact of

ADHD on quality of life among late diagnosed ADHD individuals.

MATERIAL AND METHODS

This is an observational cross-sectional study done among two groups of individuals. One group included parents, teachers and Anganwadi workers working in urban field practice area of a tertiary care medical college in south India. After taking approval from institutional ethics committee, a pilot study was done to check the feasibility of the study and to assess the content validity of the questionnaire. Based on findings of pilot study, necessary modifications were made to the final Questionnaire. The prevalence of knowledge in pilot study was found to be 10 % in Parents, 12.5% in Teachers and 3 % in Anganwadi Workers. These prevalence percentages were used in the formula 4pq/l^2 to obtain an estimated sample sizes of 144, 175 and 46 for Parents, Teachers and Anganwadi Workers respectively. The study was conducted among 197 Parents, 175 Teachers and 47 Anganwadi Workers. Participants of pilot study were excluded from final sample size. Informed verbal consent was obtained from all participants.

Another group included subjects (30 individuals) from the same study setting who were diagnosed with ADHD at or above the age of 18. Adult ADHD Quality of Life Questionnaire (AAQoL)[11] was administered to gather data regarding quality of life.

The AAQoL fetches a total score and four subscale scores: Life Productivity, Psychological Health, Life Outlook, and Relationships. Total and subscale scores are obtained by reversing item scores for negatively worded items, then transforming all item scores to a 0–100 point scale.

For the purpose of statistical analysis, participants with AAQoL score greater than 60 were taken to have good quality of life, participants with scores between 50-60 were taken to have moderately poor quality of life and those with score less than 50 were taken to have extremely poor quality of life. This was decided based on the finding of a study done by Meryl Brod et al [12] on over 1800 individuals wherein participants with no symptoms and borderline symptoms had AAQoLI of 60 and were seen to be having a good quality of life.

In depth interviews were also carried out in this population to gather data regarding personal life experiences. Their responses were recorded and answers were translated verbatim by the investigators.

Analysis

The data was analyzed using SPSS and MS Excel softwares. Participants who answered “Yes” to Q1 (have you heard of ADHD?) were further interviewed to assess the level of knowledge.

Q2 to Q 10 were considered for assessing Knowledge. The scoring procedure was standardized as zero for the wrong answer and one for the correct answer. Knowledge score was divided into three-part 0 to 50 inadequate level, 51 to 75 moderate level, and 76 to 100 adequate level.

Participants who answered “No” to Q1 were also interviewed to assess their understanding of common behavioral issues among children.

Misconceptions were identified depending on their answers to the questions accordingly.

For the second group of study subjects, data collected was analyzed using the AAQoLI questionnaire. In depth interviews were recorded and answers were translated verbatim. Themes and subthemes were identified, categorized and tabulated.

Statistics- The data is presented as numbers and percentages. Mean and standard deviations were used where needed. Verbatim responses were used for qualitative study.

RESULTS

A total of 419 respondents (parents -197, teachers -175, Anganwadi workers – 47) have participated in the survey.

Knowledge-

Table 1: Distribution of study subjects based on Knowledge about ADHD [n = 419]

Level of knowledge	Parents(n=197)	Teachers (n= 175)	Anganwadi workers(n=47)
Adequate knowledge	12 (6.09%)	21 (12%)	0 (0%)
Moderate knowledge	25 (12.6%)	21 (12%)	3 (6.3%)
Poor knowledge	44 (22.3%)	42 (24%)	18 (38.29%)
No knowledge	116 (58.8%)	91 (52%)	26 (55.3%)
	(100%)	(100%)	(100%)

None of the Anganwadi workers had adequate knowledge about ADHD. Majority of the parents (58.8%) and teachers (52%) had no knowledge about ADHD.

A total of 233 participants had never heard of a condition called ADHD.

Table 2: Distribution of study subjects based on level of knowledge about common behavior issues among children in those caregivers who had never heard of ADHD (n = 233)

Attitude	Parents (n=116)	Teachers (n=91)	Anganwadi workers (n=26)
Why do you think children as old as 8 years of age often forget how to do daily activities like bathing and brushing teeth.			
a. They are careless	30 (25.9%)	24 (26.4%)	10 (38.5%)
b. They are not interested	30 (25.9%)	21 (23.1%)	2 (7.7%)
c. It is normal for children to forget	34 (29.3%)	29 (31.9%)	10 (38.4%)
d. It is a neurodevelopmental disorder	22 (19%)	17 (18.7%)	4 (15.3%)

Why do you think some children (>5yrs of age) do not follow instructions.			
a. They are too young to understand	62 (53.4%)	33 (36.3%)	10 (38.5%)
b. There can be a genetic reason	13 (11.2%)	14 (15.4%)	7 (26.9%)
c. They are confused	22 (19.0%)	24 (26.4%)	5 (19.2%)
d. They are stubborn	19 (16.4%)	20 (22.0%)	4 (15.4%)
Why do you think some children have a poor academic performance and seem to make mistakes no matter how much you teach them.			
a. It is a disorder	9 (7.8%)	12 (13.2%)	5 (19.2%)
b. It is normal for children	31 (26.7%)	22 (24.2%)	4 (15.4%)
c. They are slow learners	58 (50.0%)	46 (50.5%)	11 (42.3%)
d. They do not want to learn	18 (15.5%)	11 (12.1%)	6 (23.07%)
In all above cases do you think child can overcome them with his or her will power.			
a. Yes	101 (87.1%)	67 (73.6%)	20 (76.9%)
b. No	15 (12.9%)	24 (26.4%)	6 (23.1%)
Would you advice to take an expert's help for the above situations.			
a. No, family help is sufficient	75 (64.7%)	52 (57.1%)	14 (53.8%)
b. Yes, medical help is needed	41 (35.3%)	39 (42.9%)	12 (46.2%)

A relatively higher percentage of population consider symptoms of forgetfulness (inattentiveness) and defiance (impulsivity) normal. Exercise of willpower by the child to was seen to be the solution to overcome these symptoms among the study group.

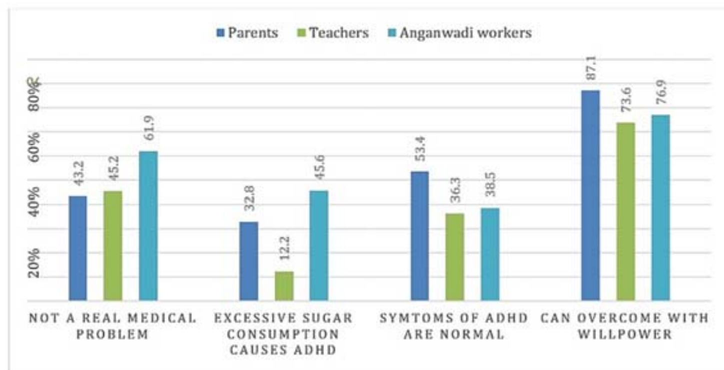
Table 3: Distribution of study subjects based on level of knowledge among those who had heard of ADHD before (n= 186)

	Parents (n=81)	Teachers (n=84)	Anganwadi workers (n=21)
Do you think ADHD is a real medical problem.			
a. Yes	46 (56.8%)	46 (54.8%)	8 (38.1%)
b. No	35 (43.2%)	38 (45.2%)	13 (61.9%)
Do you think ADHD students have low IQ or have difficulty in learning.			
a. Yes	45 (55.6%)	43 (51.2%)	10 (47.7%)
b. No	36 (44.4%)	41 (48.8%)	11 (52.3%)
Do you think early diagnosis can help with better management of ADHD.			
a. Yes	69 (85.2%)	62 (73.8%)	11 (54.5%)
b. No	12 (14.8%)	22 (26.2%)	10 (45.6%)
What do you think will happen if ADHD if left undiagnosed.			
a. Will not face any difficulties	13 (15.4%)	7 (8.4%)	2 (7.2%)
b. Academic and career difficulties	26 (32.1%)	27 (32.1%)	8 (35.7%)
c. Frustrated all the time	13 (16%)	7 (8.3%)	3 (12.5%)
d. Substance use	2 (2.5%)	8 (9.5%)	1 (7.1%)
e. Frustrated all the time + Academic and career difficulties	16 (19.7%)	14 (16.7%)	4 (19.6%)
f. Frustrated all the time + Academic and career difficulties + Substance use	15 (19.3%)	14 16.7%)	1 (7.1%)

About 50 % of the Anganwadi workers, 52.38 % of Teachers and 56.1% of Parents believe ADHD is a neurodevelopmental disorder. Most common attitudinal problem among anganwadi workers was that ADHD was not a real medical problem.

Misconceptions:

Figure 1 showing Misconceptions regarding ADHD (in %) among the study subjects



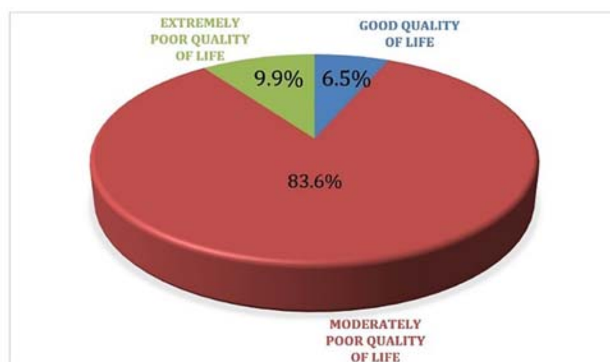
The most common misconception was that ADHD can be overcome with willpower. This was followed by 61.9% of Anganwadi workers, 45.2% of Teachers and 43.2% of parents believed that ADHD is not a real medical problem.

Qualitative study

A total of 30 participants from the same study setting who were diagnosed with ADHD at or above the age of 18 were chosen for the purpose of qualitative analysis. Mean age of ADHD diagnosis among these subjects was 25.53 +/- 1.24 years. Adult ADHD Quality of Life Questionnaire (AAQoL) was administered to gather data regarding their quality of life.

This is a 0-100 point scale.

Figure 2: Distribution of study subjects depending on Quality of life from AAoQLI scoring (n=30)



Most of the study subjects i.e 25 of them felt they has a moderately poor quality of life (83.6%). Where 3 individuals (9.9%) had extremely poor quality of life and only 2 (6.5%) individuals had scored corresponding to good quality of life.

The mean AAQoL score of the study group was 59.01 +/- 1.34. Mean and standard scores were also calculated for each of the subscales. The following are the values obtained.

Table 4- Mean and standard deviation values of each subtype of the AAQoL questionnaire

Subscale	Mean	Standard deviation
Life productivity	67.23	1.34
Psychological health	34.02	1.79
Life outlook	66.2	1.21
Relationships	65.46	2.19

Among the four subtypes, life productivity had the highest score i.e it was the worst affected quality of life indicator.

Table 5 showing the personal experiences of the adult ADHD study participants

Themes	Subthemes	Verbatims
Career choices	Inconsistent career	"I get burnt out and find it difficult to hold on to a job after a while." "I cannot do any job if I am not interested in it. If I force myself, I get burnt out and cannot function. I get bored of doing the same thing and need constant variety." "Dropped out of two courses and never completed"
	Unable to pay attention	"Wasn't able to concentrate on important things on right time and then regretting it later" "I'm unemployed from 10 years though I know I could be employed quickly if I pay more attention while working"
	Regret their career choice	"Extremely. Suffering because of my pre-diagnosis career choices, hoping to switch to a more ADHD friendly one" "Have seen my peers climbing corporate ladder and here I am doing job with very little salary and less potential for career growth even after more than four years of graduation." "My career ended before even starting off"
Societal perceptions	Not a medical problem	"Many do not know what ADHD means in the first place. When explained, sentences like "Oh, you have a label for everything;" "I also go through this, what is the big deal;" "Everyone has some ADHD in

		them;" "Why are so sensitive & emotional;" "Why is it so hard for you to be consistent;" "You are not mentally challenged so do not worry, it will all be cured." These are the common lines I hear from people when mentioned about ADHD" "It's always like, "everyone has some ADHD!" Awareness about adult ADHD is quite limited even amongst professionals."
	Laziness	"Laziness, an excuse. They don't tend to think this as a disorder." "Dismiss it as a lack of motivation/will or just an excuse as a result of being lazy." "Adults don't apparently have it. ADHD adults are being lazy and they are apparently stubbornly not using their will that's all.
Interpersonal relationships	Lack of understanding	"Highly toxic relationships. Parents think as inattentive and lazy; spouse thinks as lazy and not serious about anything, friends think as loose character. Nobody understands you or your struggles." "My parents still do not believe that I have ADHD. It seems impossible to make my family understand that I am not lazy or unmotivated and that my brain genuinely makes it difficult for me to do even basic everyday tasks." "It's not taken seriously at all. The struggle is taught to be fake. My girlfriend always had troubles to understand me and finally gave up on me in the end. It's hard to maintain relationships when you have ADHD."
	Alienation / stigmatization	"In college, I was bullied as I could not study due to attention deficit. Classroom was my enemy." "I have been alienated from many spaces since I was a kid." "Relatives are toxic and stigmatize me."

Reflections upon missing the diagnosis at the right age and its impacts.	Better education and career	"Yes. I wouldn't have slept through my classes and gotten thrown out. Maybe my career path would have been different, maybe I wouldn't have lost all those internships and built better contacts because I had learned how to get tasks done." "I would have been able to study better if I would have had access to medication and therapy. I wouldn't have failed in 11th and 12th."
	Improved mental health	"I am just 28 years old, I have suffered 4 episodes of depression, many attacks of self-bullying, if I knew earlier, I would have been happier and healthier. " "I spent nearly 20 years of life in the shame and guilt of not being 'functional' enough. I think early diagnosis might really help getting rid of that shame, both from society and your own self."

The themes that emerged were regarding inconsistency in career, followed by societal lack of understanding and apathy and strained interpersonal relationships. Many felt that they might have had a normal life if interventions began early.

DISCUSSION

The present had a total of 419 respondents (parents -197, teachers -175, Anganwadi workers – 47). Majority of the parents and teachers had no knowledge about ADHD. These findings were in agreement with the results of study done by Nasrin Dodangi [13] in Tehran where it was found that most parents do not have enough information about the disorder.

In a study by Ghanizadeh et al, [14] over half of the parents believed that this disorder was associated with the risk of delinquency and two-third of the parents assumed ADHD as a serious problem. In addition, teachers of one-fifth of these children did not recognize their problem. This study also reported, Iranian teachers' awareness of ADHD to be low.

In a study by Koosha M et al [15] in Rasht, the majority of primary school teachers had moderate knowledge about ADHD.

In a study done by Lai-Chu See et at, [16] primary school teachers knew significantly more about ADHD than did parents of children with ADHD and the general public. This study also showed that housewives had significantly more knowledge of ADHD than did service workers and retired/unemployed respondents. This was in contradiction to our study where none of the Anganwadi teachers interviewed had adequate knowledge about ADHD. This discrepancy can be explained by the exam scope, in Taiwan where this study was conducted, of recruiting primary teachers with the exam containing ADHD questions. Such a recruitment process can be very helpful in early diagnosis of ADHD and subsequently improving their quality of life.

A study done by Stampoltzis Aglaia et al [17] in Greece found that special education teachers are more knowledgeable of issues related to ADHD compared to general education teachers. This finding supports the need for continuous training of teachers with regard to ADHD.

We found the most common misconception of ADHD was that it can be overcome with willpower, followed by the misconception that sugar intake is responsible for ADHD. A study by Neelkant R. Rajcumar et al [18] in South Africa found that a majority of the patients believed that reducing sugar or food additives were effective to reduce symptoms followed by the misconception that treatments focusing on punishment reduced the symptoms.

The misconceptions about sugar intake-associated symptoms of ADHD (most common misconception in this study), use of stimulant leading to addiction, reliance on punishment methods to bring behavioral change and outgrowing ADHD were common in other studies as well. [19,20,21,22,23,24]

The themes that emerged after the qualitative study on the personal experiences among the adult ADHD participants were regarding career choices, societal lack of understanding, apathy and strained interpersonal relationships. Many of the participants regretted not being diagnosed early.

Our study findings were consistent with other studies where the ADHD patients faced struggle with unemployment and underemployment and functional impairment at work. [25,26,27] The findings of these studies suggest that adults with ADHD may benefit from workplace accommodations and decreased stigma around adult ADHD.

Other study participants reported feeling different from others, most notably in childhood [26, 27, 28, 29]. This experience was described as feeling misunderstood, like a misfit. [28, 29, 30,31,32]

CONCLUSIONS

Recruitment of teachers and Anganwadi workers should include questions about ADHD. Currently there are no on-the-job ADHD centric trainings being offered to teachers. This should be done. Enhancing parents' knowledge and correcting their myths decrease treatment resistance, leading to early diagnosis of ADHD and prognosis improvement.

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