

Original Research Article

## Perceptions Regarding Precipitating Factors of Autism among Caregivers of Autistic Children and Adolescents Visiting Health Facilities in Lucknow City

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### ABSTRACT

**Introduction:** The cause of autism is largely unknown. Genetics has a proven role in autism but many studies suggest the role of various environmental factors. This has led parents to create their own perceptions regarding the causal factors of autism in their children. The present study was conducted to determine the Perceptions regarding precipitating factors of Autism among Caregivers of Autistic Children and Adolescents visiting Health Facilities in Lucknow City.

**Methodology:** It was a cross sectional study conducted on 90 principal caregivers of diagnosed autistic children and adolescents visiting government and private care centres for autism in Lucknow city.

**Result:** The age at which the caregivers perceived the autistic symptoms in their child ranged from 6 months to 84 months. While, the age at which diagnosis of autism was made ranged from 6 months to 191 months. Majority (54.4%) of the caregivers didn't know what could be the probable cause of Autism in their children. Caregivers of 14.4% children perceived that the health issues which preceded the autistic symptoms and complications in the neonatal period like poor cry, birth asphyxia, meconium aspiration etc. were perceived to be the cause of autism by 13.3% caregivers in their children.

**Conclusion:** The knowledge of Autism problem per se is at its infancy in India especially among the parents. The absence of clear explanation about the causative factors for autism, has led to the development of many theories among caregivers regarding the causative factors of autism. This study showed lack of understanding about autism among the parents of autistic children and adolescents. This lack of understanding could be the root cause of delay in the diagnosis of autism of their children.

**Keywords:** Perceptions, Principal Caregivers, Precipitating factors of Autism

### INTRODUCTION

Autism is a neuro developmental disorder, with core features of impaired social interaction, impaired communication, and restricted and repetitive interests and activities. <sup>[1]</sup> The cause of autism is largely unknown. <sup>[2]</sup>

A genetic basis for Autism was suggested in the original paper, by Leo Kanner in 1943. <sup>[3]</sup> But findings suggest that the genetic factors must be influenced by the presence of nonheritable, prenatal, and perinatal risk factors for autism. <sup>[4,5]</sup> and "autism most probably is the result of complex interactions between genetic and

non-genetic risk factors.” [6] These non-genetic factors include perinatal factors, infections during early childhood, heavy metals exposure etc.

Several studies suggest the role of maternal and foetal perinatal factors as the causal factors of autism. The maternal factors that may cause autism in children includes previous foetal loss, maternal hypertension, proteinuria, pre-eclampsia and swelling, [7] hyperbilirubinemia, [8,9] advanced maternal age, advanced paternal age, [5,10] greater frequencies of threatened abortion, epidural caudal anaesthesia use, labour induction, and a labour duration of less than 1 hour. [10] The foetal factors that may cause autism includes preterm birth, breech presentation, planned caesarean section, low Apgar scores, birth defect, a birth weight small for gestational age, [8] foetal distress, been delivered by an elective or emergency caesarean section, and had an Apgar score of less than 6 at 1 minute, [10] birth weight and duration of gestation and intrapartum hypoxia. [5] But there was an insufficiency of evidence to implicate any one prenatal factor in autism aetiology, although there some evidence suggests that exposure to pregnancy complications may increase the risk. [7] Further, it remains unclear whether these risks are causal or play a secondary role in shaping clinical expression in individuals with genetic vulnerability. [8]

The environmental factors cited as allegedly causing or exacerbating autism include certain foods, infectious disease, heavy metals, solvents, diesel exhaust, PCBs’ phthalates and phenols used in plastic products, pesticides, alcohol, smoking, illicit drugs, vaccines and prenatal stress. [11] Dietert R R *et. al.* (2011), [12] in their study suggested the role of environmental factors like exposure to chemicals (like arsenic, lead, manganese, mercury, pesticides, polybrominated diphenyl ethers (PBDEs), polychlorinated biphenyls (PCBs), polycyclic aromatic hydrocarbons (PAHs), and solvents) and certain drugs during pregnancy and

infectious causes like infections in early ages of the child, infection during pregnancy etc. in causing autism.

Many published reports, stating the role of MMR vaccine in causing Autism, have created a doubt among parents who are searching for an answer for the cause of autism in their child. Till date many parents show their concern regarding the vaccine as the causative factor for autistic features in their child. [13]

As the cause of autism is largely unknown, parents of autistic children formulate their own theory about the causative factors for autism. [14] In a study by Sarrett J C (2015) [14] the author argued that the reliance on biological, but not genetic, causal models is reflective of the state’s high access to biomedical health care.

These theories are also affected by the sociodemographic factors of the parents, their knowledge regarding autism, the culture [15] etc. These theories also suggest false perceptions of parents regarding causative factors of autism. The false perceptions affect the way parents’ deals with the child’s problem. Also, the perceptions prevailing in a particular setup highly represents the clarity about autism among the caregivers as well as the facilities available to them.

The present study was conducted to determine the perceptions regarding the cause of autism of principal caregivers of autistic children and adolescents visiting health facilities in Lucknow city.

## METHODOLOGY

It was a cross sectional study conducted at the Child and Adolescent Psychiatry OPD at a tertiary care government centre and four private centres for Autism in Lucknow. The study participants were principal caregivers (< 60 years of age) of diagnosed children / adolescents with Autism Spectrum Disorder, aged 3-19 years. Non-random (Purposive) sampling technique was used in this study. This study was primarily done to determine the quality of life of principal

caregivers of autistic children and adolescents. Thus, taking the standard deviation of the mean of quality of life 0.96<sup>16</sup> and the acceptable deviation from the mean 0.2, and using the formula:  $n = (Z_{1-\alpha/2})^2 * (SD)^2 / d^2$ , the sample size calculated was 88. Thus, a total of 90 principal caregivers of the autistic children and adolescents were included in the study.

Owing to ethical considerations, permission was obtained from the institutional Ethical Committee of the King George's Medical University UP, Lucknow before commencing the study. Written permission (duly signed by the head of the department) was taken from the private centres included in the study. Written informed consent was taken from each selected participant to confirm willingness after explaining the survey purpose. Also, affirmation that they are free to withdraw consent and to discontinue participation at any point of time during the study. Privacy and confidentiality of collected information was ensured throughout the process. Children with presence of other behavioural disorders/medical co-morbidities requiring priority management, and children in whose family there were any other patient with severe physical or mental disability requiring constant nursing and care were excluded. Also, the caregivers with any significant medical disorder or disability which may interfere with care-giving were excluded from the study.

#### **Tools Used - A predesigned and pretested semi structured questionnaire to determine,**

Sociodemographic characteristics of the caregivers of autistic children and adolescents and child characteristics including Age, Sex, Number of siblings, age at which symptoms first appeared, age at which diagnosis was made etc.

In the present study, the caregivers were assessed for their knowledge regarding Autism. When the caregivers were asked, "With what problem is your child

suffering", a reply of "Autism" was considered enough for determining that the caregiver knew about the problem the child was suffering. Similarly, for determining the knowledge regarding Autism, the caregivers were asked "What do you understand about Autism" or "What is Autism". If a caregiver knew about any of the core features of Autism, it was considered that the respondent knew about Autism. The caregivers were further assessed about the knowledge about the treatment for autism. Although autism is rooted in biology, most effective interventions so far are behavioural and educational therapies; drugs have had only a minor role so far. [11] Thus, caregivers who knew that therapies are more effective (in some cases equally effective) than medicines were considered as having knowledge about the treatment for autism.

#### **Statistical Analysis:**

Data was tabulated and analysed by using the software SPSS version 16. The categorical variables were represented in the form of frequency tables. Mean was used as the measure of central tendency for the continuous variables like age at which autistic symptoms first perceived and age at which diagnosis was made.

#### **RESULT**

(Table 1) Out of the total 90 caregivers, 56.7% first perceived the symptoms of Autism at 25-48 months of age. About 37.8% of caregivers perceived the symptoms of Autism as early as <24 months. Among the symptoms that appeared first, those "involved in self" and those with "slow speech development as compared to children of similar age" appeared in 60% and 61.1% of children respectively. While 33.3% children first presented with "loss of developed speech" as first symptom of autism. Among the children included in this study, 63.3% were diagnosed for autism at the age of 25-48 months while only 12.2% were diagnosed as early as <24 months.

**Table 1: Autistic symptoms that appeared first (Caregiver's Perception).**

Age at which symptoms of autism first appeared (as perceived by caregiver) (in months) (N = 90)	n	%
< 24	34	37.8
25 - 48	51	56.7
49 - 72	4	4.4
>73	1	1.1
Autistic Symptoms that appeared first*		
Loss of developed speech	30	33.3
Slow speech development as compared to children of similar age	55	61.1
Lack of emotional bonding with parents	8	8.9
Involved in self	54	60.0
Hyperactivity	20	22.2
No eye contact	14	15.6
Aggressive, irritable	8	8.9
Age at which diagnosis of Autism was made (in months) (N = 90)	n	%
<24	11	12.2
25 - 48	57	63.3
49 - 72	14	15.6
>73	8	8.9

\*Multiple Response

**Table 2: Mean age at which autistic symptoms first appeared and age at which diagnosis of autism was made (in months).**

Characteristics (in months)	Mean ± Standard Deviation	Range	
		Minimum	Maximum
Age at which symptoms first appeared (as perceived by caregiver)	29.79 ± 13.21	6	84
Age at which diagnosis of Autism was made	45.28 ± 26.24	6	191

(Table 2) The age at which the caregivers perceived the autistic symptoms in their child ranged from 6 months to 84 months [mean - 29.78 months (~ 2-year 6 months), SD - 13.21]. While, the age at which

diagnosis of autism was made ranged from 6 months to 191 months [mean - 45.28 months (~ 3.8 years)]. Thus, it took a mean lapse of 15.5 months in diagnosing children having autistic symptoms.

**Table 3 : Knowledge of principal caregivers regarding autism.**

Knowledge	Private sector (n = 66)	Government sector (n = 24)	Total (n = 90)
	n (%)	n (%)	n (%)
Knowledge about the disorder the child is suffering*	63 (95.5)	6 (25.0)	69 (76.7)
What is Autism*	63 (95.5)	6 (25.0)	69 (76.7)
Knowledge about the treatment of Autism*	63 (95.5)	5 (20.8)	68 (75.6)
Total	66 (100.0)	24 (100.0)	90 (100.0)
Source of knowledge about the treatment of Autism	(n = 63)	(n = 5)	(n = 68)
Doctors/ therapists	50 (79.3)	4 (80.0)	54 (79.4)
Other parents	3 (4.8)	0 (0)	3 (4.4)
Internet/ media	10 (15.9)	1 (20.0)	11 (16.2)
Total	63 (100)	5 (100)	68 (100)

[ ] – Column Percentage, ( ) – Row percentage, \*Multiple choice

(Table 3) Majority (95.5%) of the caregivers who were receiving treatment of autism from the private sector for their children, knew about the disorder the child was suffering and about “What is Autism” while only 25% of the caregivers who were receiving treatment of autism from the government sector for their children, knew

about these. Among the caregivers who were receiving treatment of autism for their children from the private sector 95.5% knew about the treatment modalities for autism (different therapies like speech Therapy, Occupational Therapy etc.) while only 20.8% of the caregivers who were receiving treatment of autism for their children from

the government sector knew about this. Among the caregivers interviewed, majority (79.4%) received information about the

different treatment modalities for autism from the Doctors or Therapists.

**Table 4 : Precipitating Factors as Perceived by the Caregivers**

Precipitating Factor (N = 90)	n	%
Immunization related (MMR)	5	5.6
Watching movies, videos in early childhood	3	3.3
Was left alone in early childhood, working mother	2	2.2
Any health issues preceding symptoms	13	14.4
Allergy to milk at 1 year of age	1	1.1
h/o Diarrhoea	4	4.4
h/o seizures	2	2.2
h/o high grade fever	4	4.4
h/o Asthma, bronchitis	2	2.2
Pregnancy related (umbilical cord prolapse, TORCH infection during pregnancy)	2	2.2
Complications in the neonatal period	12	13.3
Poor cry, birth asphyxia, meconium aspiration	5	5.6
Jaundice	3	3.3
Prematurity	4	4.4
OTHERS	4	4.4
Father is suffering with some mental illness	1	1.1
Hydrocephalous with Meningomyelocele at birth	1	1.1
On blood pressure medicines during pregnancy	1	1.1
Vitamin D deficiency in child	1	1.1
Don't know	49	54.4

(Table 4) Majority (54.4%) of the caregivers didn't know what could be the probable cause of Autism in their children. Caregivers of 14.4% children perceived that the health issues which preceded the autistic symptoms (leading to hospitalization) could have caused autism in their child. Complications in the neonatal period like poor cry, birth asphyxia, meconium aspiration etc. were perceived to be the cause of autism by 13.3% caregivers in their children.

## DISCUSSION

By 24 months of age, approximately 80% of parents notice abnormalities in their child in the form of language impairment or social deficit. [17] In India, there is a perception among some professionals that Indian children speak single words by 1 to 1.5 years of age and on an average, Indian parents identify problematic behaviours approximately seven months later than those reported in the United States. [2,18,15] Thus, the perception of delayed normal speech in Indian children and late recognition of social deficits by Indian caregivers could be the reason that majority of the caregivers first observed abnormal autistic features in their child after 2 years of age. The age at

which the caregivers perceived the autistic symptoms in their child ranged from 6 months to 84 months [mean - 29.8 months (2-year 6 months), SD – 13.21]. The similar findings were observed in an Indian study in which the author reported that “the caregivers of autistic children first noticed something different when their child ranged in age from 3 months to 6 years 5 months of age (M=25.7 months, SD=12.8). It was in contrast to studies conducted in the West where autism recognition occurs between 14.9 and 19.1 months”. [19]

The mean age of diagnosis was found to be 45.28 months (3.8 years). A similar finding was observed in a study done by Mandell D S et al., in which the author found that the average age of diagnosis, was 3.1 years for children with autistic disorder. “There is an average lapse of 13 months between the average age at first evaluation and the initial diagnosis of autism or ASD”. [17] In the present study, lapse of 15.49 months between age of first perception of autistic symptoms and the age of diagnosis was noticed. “Factors implicated in exacerbating this delay includes, limited knowledge among many physicians regarding the presentation, prognosis, and treatment of ASD or other

developmental disorders with polymorphous phenotypes, education, and health system resources associated disparities in the proportion of children who receive a diagnosis of ASD and family-level factors. [20]

In the present study, when the caregivers were inquired about the abnormal symptoms that they noticed first in their child, the findings were similar to that of a study by Daley T C (2017). [19] It is worth noting that an equal number of children had abnormal speech-language development and social deficit in the present study as well as in the study done by Daley T C. Thus, abnormal speech-language development and social deficit were found to occur together among the autistic children and adolescents.

Among the caregivers who knew "What is Autism" (Table 3) 91.3% were taking treatments from the private centers while only 8.7 % were taking treatment from the government sector. In a study by Pathappillil J S J et. al. the mothers were asked to define autism; most mothers (72.7 %) vaguely indicated that autism was a disorder that resulted in emotional and/or social deficits, and a few of the mothers (18.0 %) were unsure or did not know, and even fewer mothers had another explanation such as autism being a disorder similar to Attention Deficit Hyperactivity Disorder. In the present study also, most caregivers who knew "What is Autism" replied that it was a disorder in which the child is involved in self, thus depicting social deficit. Among the caregivers who were receiving treatment from the government sector, only 25 % knew "What their child was suffering" and "What is Autism" in comparison to the caregivers who were receiving treatment from the private sector, among which 95.5 % knew about these. Thus, the caregivers who were receiving treatment from government sector severely lacked knowledge about Autism. The reason can be the differences in the sociodemographic characteristics and difficulty in accessibility of services as compared to that of the caregivers who were receiving treatment

from the private sector. Among the caregivers, the greatest doubt which came up during the interview was "Is this a kind of mental retardation/ Kya humarabachchaPagal Hai?". Caregivers who were receiving treatment from both government and private sector were seen struggling with this doubt. The caregivers who were receiving treatment at the private sector, due to better accessibility of internet/ media/ services, were able to find answers to their doubts but due to the need of lifelong treatment, each one showed spurts of loss of patience and emotional breakdown.

In the present study, the doctors and therapists were found to be the major knowledge providers for autism. In certain private centers, the doctors addressed the caregivers of the autistic children in a group. The caregivers can put forward their doubts and share their experiences with others. This two-way interaction helped the caregivers in coping with their constant stress and also helped them in formulating their own strategies (for handling their autistic child) through other parent's experiences and doctor's suggestions.

In the present study, a group of 5.6 % of caregivers perceived that after the MMR vaccination of their children, the autistic symptoms appeared. "Most recently, public anxiety about autism has been raised as a result of reports linking the measles, mumps, and rubella (MMR) vaccine with autism and a rise in the prevalence of autism, despite the epidemiological evidence of a lack of association." [13] "Several recent studies indicate that MMR vaccination does not increase the risk of autism. This includes a study where the MMR vaccine was administered for a 4-year period (1989\_1993) in Japan; the incidence of autism was not different across the interval before, during, and after this MMR vaccination window". [2]

There is a paucity of studies suggesting the importance of watching videos, movies in early childhood, leaving

children alone or working mother as causative factors for Autism.

The caregivers who gave history of infections preceding appearance of symptoms of autism in their children, also added that the infections were very severe and it needed hospitalization of their children. The doctors gave high doses of medicines and after a few days of discharge from the hospital, the autistic symptoms appeared in their children. Not many studies emphasize the role of preceding childhood illnesses as a causal factor for autism. A study found that chances of children to be diagnosed with autism were similar for those who were admitted to hospital for infectious diseases and for those who were admitted to hospital for non-infectious diseases. [21]

Among the caregivers interviewed, 13.3% perceived that birth and neonatal complications like poor cry, birth asphyxia, meconium aspiration, jaundice, and prematurity could have caused autism in their children. In a study the PDD-NOS group showed a higher incidence of hyperbilirubinemia when compared with the general population. [9] In another study by Glasson E J *et. al.*, the autism cases were more likely to have experienced fetal distress, been delivered by an elective or emergency cesarean section, and had an Apgar score of less than 6 at 1 minute. Similarly, in a study by Guinchat V *et. al.*, found that during the perinatal and neonatal periods, the risk factors for autism were preterm birth, breech presentation, planned caesarean section, low Apgar scores, hyperbilirubinemia, birth defect and birth weight small for gestational age. Further, they concluded that “despite evidence for the association of some pre, peri- and neonatal risk factors associated with autism, it remains unclear whether these risks are causal or play a secondary role in shaping clinical expression in individuals with genetic vulnerability. A plausible hypothesis is that improvements in obstetric and neonatal management have led to an

increased rate of survivors with pre-existing brain damage.”

The knowledge of Autism problem per se is at its infancy in India especially among the parents. The absence of clear explanation about the causative factors for autism, has led to the development of many theories among caregivers regarding the causative factors of autism. This study showed lack of understanding about autism among the parents of autistic children and adolescents. This lack of understanding is the root cause of delay in the diagnosis of autism of their children. Studies reveal that poor knowledge and understanding exist among the health professionals as well regarding autism. As the prevalence of autism is constantly increasing in developing countries, there is a need of increasing the understanding about autism among parents as well as health professionals. This could increase the early detection and thus early intervention for autism.

**Limitations** - Non-random sampling technique was used in this study thus the results cannot be generalized. Further, the causative factors for autism, asked by caregivers, could have recall bias.

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