

A Study on the Socio-Demographic Characteristics of Parents with Children on the Autism Spectrum Disorders in Bangalore, India

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Abstract

To study the socio-demographic characteristics of the parents who have children diagnosed with Autism Spectrum Disorder (ASD) in Bangalore, Karnataka. Method: A self-prepared questionnaire was used for collecting data. The sample size $n=41$ who were mothers/care givers of children with ASD (<8 years) and willing to participate in the study between period 2018 and 2020. Results: The results in this study show that majority of the children with ASD do not go to a mainstream school. Nearly half of the families who have children with ASD are living physically separated due to interventions pocketed around the city, Bangalore, in addition, it is observed that the socio-economic factors play a major role in determining the access to treatment for ASD.

Keywords: Autism Spectrum Disorder (ASD), Diagnosis, Treatment, Sociodemographic Status

Introduction

Autism is defined as a neurological disorder characterized by Qualitative impairment in social interaction, Qualitative impairments in communication and Restricted repetitive and stereotyped patterns of behaviour, interests, and activities (ICD-10). Though there have been great movements and achievements in the study of Autism Spectrum Disorders in the world, India remains at a nascent stage (RCI, 2017). A pioneer in ASD studies in India has stated in her book that ASD is still in an "unfamiliar category" in India and most often undiagnosed or misdiagnosed as Intellectual Disability or Mental Retardation (Vaidya, 2016). The sixty-seventh World Health Assembly resolution states that to address Autism Spectrum Disorder we need to have comprehensive and coordinated efforts for the management of Autism Spectrum Disorder (WHO, 2014). As the cases of ASD is growing in India, (Vaidya, 2016) calls for urgent need in services and research. The socio-demographical condition of parents and the health care system for children with ASD, including their literacy levels and geographical locations, affects the early intervention of children with ASD. It is important for families with Autism Spectrum Disorder to have a timely diagnosis and intervention in the early stages (Stahmer et al. 2019). The quality

and effect of the intervention services will greatly improve if children are diagnosed early & intervened, which in turn improves the family’s quality of life.

Review of Literature

In the present study, the focus is to consider the socio-demographic factors of parents of children with ASD. Consolidating the reviews on the socio-economic factors of children with ASD the relevant findings are stated as under: ASD prevalence was high in areas of deprivation, unemployed adults, immigrants and single parent families (Nashwa, et al. 2020). Low income households have been associated with low therapy needs for a child with ASD, low engagement of services and faulty belief system. The same way maintaining a home schedule or a treatment schedule for a child with ASD is extremely challenging for families with low income who struggle to meet their basic needs where the stresses of poverty, multiple siblings & low education (Aubyn et al. 2019) weigh them down. Parents from low social economic background have difficulty accessing resources (Robert et al. 2017). The waiting period for diagnosis of a child with ASD is longer (more than 13 months) in the rural environments and underserved areas with lower socio-economic status. Similarly, individuals without access to diagnostic centres for socio economic or geographic reasons are not reported resulting in under-represented statistics (Yahy & Marwan, 2012). Higher income caregivers were more likely to get access to educational psychologist, speech therapist, occupational therapist & special educators (Malika, et al., 2015). Parents from USA who have children with autism more likely recognise problems related to their child’s lack of expressive language development as one of first pointer of the developmental deviance in the child’s milestone. But on the group contrary Indian parents who have children with ASD are more likely to first understand their child’s social interaction needs. There are various factors that contribute to an individual with ASD and their family’s marginalisation such as educational qualification, economic status, geographic where they stay, religious beliefs and cultural traditions in India (Nowell et al. 2015). Educated mothers had twice the rate of autism diagnosis. There is under

diagnosis for children of lower education status mothers. No significant relationship has been found between income status and ASD diagnosis(Kendall, 2014). Families who are socially vulnerable or live in rural areas have challenges accessing ASD related services and resources (Cheryl et al. 2014). From the cursory view of the review of literature, it is seen that most of the studies were conducted in developed countries context. It is seen that there are limited studies carried out in socio-economic factors of children with ASD in Indian context. In view of the research gaps, an attempt has been made to focus on the socio-economic factors of children with ASD in the present study.

Methodology

Objective: The study examines the socio-demographic factors of the parents of children with Autism Spectrum Disorder in Bangalore, Karnataka.

Method and Materials

The researcher used Quasi-experimental research design in this study. The researcher developed a questionnaire for collecting the socio-demographic data and approached inclusive schools, special schools, hospitals, therapy centres and special needs institutions all over Bangalore which was listed online in just dial. The study used convenience sampling as it was drawn from the centre/school having ASD children and consented to give parents information to the researcher. Another criterion was to select parents of children with ASD between (0-8) years and who agreed to participate in the Comprehensive Intervention Model Training for a period of one year.

Results and Discussions

Table 1 Demographic Profile of Children with ASD

Profile of Children with ASD	No. of Respondents (n)	(%)
Age (Years)		
2-5	36	87.8
6-10	5	12.2
Total	41	100
Gender		
Male	27	65.9
Female	14	34.1
Total	41	100

Attending Mainstream School		
Yes	12	29.3
No	29	70.7
Total	41	100

- Age:** The study shows that majority (87.8%) of the children with ASD are between the age of 6-10 years whereas the remaining (12.2%) are between the age of 2-5 years. The above result is in consonance with the study conducted by Shigeki Kurasawa, 2018 wherein it was reported that the mean age at ASD diagnosis was 7.2 ± 4.2 years and the mode age was 3 years.
- Gender:** The results shows that majority (65.9%) of the children whose parents constitute the study are male and the remaining are female (34.1%). However, (Shigeki Kurasawa, 2018) had reported that there is no sex difference noticed for age at which ASD has been diagnosed among children.
- Attending School:** The results show that majority (70.7%) of the children with ASD are not attending a mainstream school. This finding corresponds to the study by (Mukkiri, Kandasamy, Subramaniyan, Chandrasekaran, & Kattimani, 2021) that out of the 3967 children from 60 schools in Puducherry, India both private and government, only 2 children with ASD were found to be enrolled in mainstream schools. While 29.3% of the samples attend school. It is proven that mainstream schools, both government and private, are not equipped or structured to deal with the needs of children with ASD. (Harman, 2014)

Table 2 Demographic Profile of Parents with ASD Children

Parents Profile with ASD Children	No. of Respondents (n)	%
Mother's Age (Years)		
21-30	6	14.6
31-40	26	63.4
41-50	9	22.0
Total	41	100
Mother's Education		
Below High School	2	4.9
High School	2	4.9

Higher Secondary	11	26.8
Graduate and Above	26	63.4
Total	41	100
Mother's Occupation		
Home maker	21	51.2
Doctors	2	4.9
Engineers	2	4.9
Special needs Therapist	3	7.3
Managerial	3	7.3
Teachers	7	17.1
Other Professionals	3	7.3
Total	41	100
Mother's Income per Month		
No income	21	51.2
5000 - 10000	8	19.5
10001-20000	9	22.0
> 20001	3	7.3
Total	41	100
Father's Age (Years)		
21-30	1	2.44
31-40	19	46.34
41-50	21	51.22
Total	41	100
Father's Profession		
Doctors	2	4.9
Managerial	8	19.5
Engineers	10	24.4
Entrepreneurs	5	12.2
Daily wage labour	4	9.8
Semi-skilled workers	6	14.6
Other Professionals	6	14.6
Total	41	100
Father's Income per Month		
No income	1	2.44
5001-10000	3	7.32
10000-20000	6	14.63
20001-30000	3	7.32
> 30001	28	68.29
Total	41	100
Family Type		
Nuclear	25	61.0
Joint	14	34.1

Institution/Care home	2	4.9
Total	41	100
Family Structure		
Parents living with children	24	58.5
Living Separately due to child's intervention / occupation	13	31.7
Separated	3	7.3
Divorced	1	2.4
Total	41	100

The following are the observations derived from the demographic profile of the parents of children with ASD:

- Mother's Age:** The majority (63.4 %) of the mothers are aged between 31-40 years, followed by those who are between the ages of 41-50 years (22.0 %) and those between the ages of 21-30 years (14.6 years). The age of a mother can have multiple implications on her own health and in turn her ability to provide the required care for her child with special needs. However, it is a common aspect in collaboration with maternal instinct, for a mother to prioritize her child's care over her own, irrespective of her age.
- Mother's Education:** Majority (63.4%) of mothers are graduates and above. In another study (Brian et al. 2017) educated mothers had twice the rate of autism diagnosis and there is under diagnosis for children of lower education status mothers.
- Mother's Occupation:** In the present study, more than half (51.2 %) of the mothers are homemakers. While comparing to the mother's educational levels, it is inferred that most of the mothers gave up their careers to stay at home to nurture their child with ASD. However, it is worth to explore the relationship between the resilience of the parents with some of these demographic characteristics.
- Mother's Income:** The result of the mothers' income reveals that more than half (51.2 %) of the mothers have no income of their own. Similar findings was observed where the majority of the mother do not have income to cater to the needs of their special child. The financial load is majorly

managed on the father's income, while the care is predominantly from the mother (Malika Delobel-Ayoub, 2015).

- Father's Age:** Based on the results, it can be stated that the majority (51.2 %) of the fathers are aged between 41-50 years. This is followed by those who are between the ages of 31-40 years (46.34 %) and those between the ages of 21-30 years (2.44%).
- Father's Occupation:** It can be noted that the single largest (24.4 %) occupation of the fathers are engineers. This is followed by those who are engaged in managerial cadre (19.5 %), Doctors (4.9 %), and daily wage labourers (9.8%).
- Father's Income:** Based on the results, it can be stated that majority (68.29 %) of the fathers were earning more than Rs. 30,000 per month at the time of data collection. This was followed by those with a monthly income that ranges from Rs. 10,000 to Rs. 20,000 (14.63 %).
- Family Type:** Majority (61.0 %) of the respondents are living in nuclear families whereas the remaining (34.1 %) are living in joint families. Joint families have the option of extended family members like grandparents, aunts and uncles to provide additional care that children from nuclear families may not have immediately available. 54% of the respondents have stated that they do in fact receive extended family support. Extended family support could be extremely helpful for children with ASD and their families. Some parents have reported that extended family can go both ways, as some of them can be supportive while others do not react positively and were "embarrassed". The parents repeatedly expressed frustration towards extended family who could not accept that their special needs child (Kendall, 2014). In this study two children (4.9%) were found in an institution due to the family disintegration. One parent legally separated and the other parents have filed a divorce. This has left the young children with ASD within the age range of 2-8 years in an institution in Bangalore, Karnataka.
- Family Structure:** It is seen that majority (58.54 %) of the respondents live in a family unit where the parents live together with the child and other siblings in the same physical location, followed are those living separately/away from

their family due to their occupation (31.70 %). Living separately is predominantly due to child’s intervention and father’s occupation being in different states. A GapMap study in the USA on understanding the geographical gap in the intervention of ASD in US states that “there is a growing imbalance between the number of people who need autism care and the number of places that can provide care, it’s a geography distance problem. We need to quantify in real numbers the geography disconnect between people and treatment options so that we can see where the gaps are. We really need to see where the imbalances are and how big they are as the first step to creating change in the health care system.” (Thomas, 2017). We, in India also see many parents move to cities where ASD intervention is largely present. In this process the efficient functioning of a family is disintegrated. In this current study 31.7% have relocated from their geographic locations for intervention in Bangalore. The remaining are either separated (7.3 %) or are divorced (2.4%). Separated and single-parent families show a higher level of deprivation and prevalence of ASD, that those from regular family units.(Malika Delobel-Ayoub, 2015).

Table 3 Treatment related factors of Children with ASD

Treatment Related Factors of children with ASD	Frequency	%
Age of the Child with ASD (Years)		
2-5	5	12.2
6-10	36	87.8
Total	41	100
Age at which ASD was Diagnosed (Years)		
2-5	39	95.1
6-10	2	4.9
Total	41	100
Gender of the child with ASD		
Male	27	65.9
Female	14	34.1
Total	41	100
Place of Diagnosis		
Private Hospital	27	65.8

NGO	9	22.0
Therapy Center	5	12.2
Government Hospital	0	0
Total	41	100
Diagnosed Practitioner		
Doctor	20	48.8
Psychologist	21	51.2
Total	41	100
Therapies administered		
Yes	26	63.4
No	15	36.6
Total	40	100
Place of Interventions		
Private Centre	26	63.4
Government Centre	0	0
No Intervention	15	36.6
Total	41	100
Frequency of Private Therapy		
< 15 hrs/month	19	46.3
1-2 hrs/day	2	4.9
3-4 hrs/day	5	12.2
No Intervention	15	36.6
Total	41	100
Structured Home Schedule Followed		
Yes	14	34.1
No	27	65.9
Total	41	100

From Table 3, the following findings are as follows:

- Age of the Child with ASD:** From the findings, it can be inferred that majority (87.8%) of the children in the present study are between the ages of 6-10 years. The remaining (12.2 %) are between the ages of 2-5 years. Majority of studies that have been conducted in India and abroad are consistent with a mean age presentation of 3.5 to 4.5 years (Bilal Ahmad Bhat, 2019)
- Age at which ASD was diagnosed:** The vast majority (95.1%) of the children in the present study were diagnosed with ASD when they were between the ages of 2-5 years whereas the remaining (4.9%) were diagnosed when they were between the ages of 6-10 years. Based on research conducted for the diagnoses of ASD in children it is widely reported that the median age

was 6 years for both males and females, while the modal age was 3. (Shigeki Kurasawa, 2018)

3. **Gender of the Child:** The study results indicate that majority (65.9%) of the children in the present study are male whereas the remaining are female (34.1%).
4. **Place of Diagnosis:** Majority (65.8%) of the children were diagnosed in a hospital, followed by those who were diagnosed in an NGO (22.0%), and those who were diagnosed through Therapy centres were only 12.2 %. This findings is in line with (Bilal Ahmad Bhat, 2019) who found in his study that the situation of diagnosis in India has been consistent with other research to prove that ASD diagnoses in India has been largely confined to hospital settings.
5. **The Diagnosed Practitioner:** It was a psychologist who diagnosed the child (51.2%), whereas the other children in the present study were diagnosed by a doctor (48.8 %). In India, the lack of awareness among medical and therapeutic sectors negatively influence the available resources and quality of ASD diagnosis. (Harman, 2014)
6. **Therapies Administered:** The majority (63.4 %) of the children in the present study have received private therapy sessions, whereas the remaining (36.6%) have not. Studies conducted in Oman, have shown that 10% of low-income families are able to seek private therapy compared to 24% of middle-income families.(Yahy & Marwan, 2012) The affordability of private therapy is heavily based on socio-economic status. However it should be noted that only 19.2% of children received 3 – 4 hours of intervention per day. (Bhat, Hussain, Qadir, & Ahmad Dar, 2019). In a study in Kashmir India, (Bhat, Hussain, Qadir, & Ahmad Dar, 2019), majority of the children with ASD from rural areas (70%) of the children with ASD stayed at home with no intervention and no schools.
7. **Place of Interventions:** It may also be noted that all of the children who received therapy, received therapy in private clinics (63.4%) and the rest (36.6%) did not receive any intervention after a diagnosis. Government health care in India for ASD is in the nascent stage and do not have holistic and individualized therapeutic

intervention in government aided centers. Even if they are available its primary focus is on diagnosis, training and research and not intervention.

8. **Frequency of Private Therapy:** The majority of the children (46.3%) did not receive therapy every day, and received less than 15 hours of therapy per month. 4.9% of the children with ASD were able to access therapeutic interventions 1-2 hours per day. Only 12.2 % of them were able to afford 3-4 hours per day. Private therapy is easily accessible only to the rich and affluent and in the Indian context, is neither widely seen nor used. The high income families in Bangalore are able to afford private therapies more.
9. **Structured Home Schedule Followed:** From the results, it can be inferred that majority of the respondents do follow a structured schedule (65.9 %), whereas the remaining (34.1%) do not. A structured schedule can bring a sense of routine to a child with ASD, making their daily lives easier to manage and for therapy to be more effective.

Conclusion

The present study reveals that majority (70.7%) of children with ASD are not attending mainstream school in spite of the government initiatives and provisions for special needs children as per the Right to Education (RTE) in India. The schools should be made accountable to declare the percentage of children with ASD in their institutions to the education department. Majority of the mothers (63.4%) are educated indicating that educated mothers are more aware and open to the diagnosis. Mothers are predominantly (53.8%) homemakers and do not have an income showing that caregiving of a child with ASD lies majorly with mothers except two fathers who participated in the research. Extended family support in India plays a significant role and in this study showing 54% have the support of the grandparents. 31.7% of the families are living physically separated due to lack of available resources. A vast majority within (95.1%) of them are diagnosed in the age range showing better diagnosis services in Bangalore, Karnataka. Only 19.2% of children with ASD received 3 to 4 hours of maximum private therapies every day showing the economic disparity in the access to treatment for

ASD in Bangalore. Although majority of children are diagnosed as ASD in hospitals but they are undergoing treatment and therapy only at private settings. It is evident from the review of literature, there are few studies focusing on socio-economic factors of children diagnosed with ASD and almost very few studies have been carried out in Indian context. Thus, more studies should be carried out focussing on the socio-economic factors in order to identify various problems of children with ASD for proper intervention at appropriate stage for better prognosis.

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