ORIGINAL ARTICLE

Quality of Life, Treatment Seeking Pathways and Out of Pocket Expenditure of parents with children with Autism Spectrum Disorder (ASD) in South Delhi

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CITATION
Islam F, Salam ASA, Gautam R, Roy S, Kashyap V. Quality of Life, Treatment Seeking Pathways and Out of Pocket Expenditure of parents with children with Autism Spectrum Disorder (ASD) in South Delhi. Indian J Comm Health. 2024;36(3):428-437. https://doi.org/10.47203/IJCH.2024.v36i03.015

ARTICLE CYCLE
Received: 25/01/2024; Accepted: 16/05/2024; Published: 30/06/2024

ABSTRACT

Background: Autism is a neurodevelopment disorder requiring continuous preventive, curative and rehabilitative management of child. Taking care of these children leads to parents face various challenges. Lack of awareness, associated stigma, misdiagnosis, inappropriate management impacts parents' lives in various aspects. **Objectives**: To assess quality of life of the parents of ASD children, find out various treatment-seeking pathways adopted by them, and estimate out-of-pocket expenditure for childcare. **Methodology**: Cross-sectional mixed method study was conducted for assessment of quality of life of parents (WHO-QOL BREF), out-of-pocket expenditure, treatment-seeking pathways opted by parents for ASD management. **Results**: Quality of life of parents were found to be affected in various domains, however psychological domain was most influenced. Age of parents had an impact on social domain. Delays in the identification of symptoms, confirmation of diagnosis, Lack of availability of treatment services, and non-integration of rehabilitative services were major loopholes in the treatment seeking. The median out-of-pocket expenditure was 16% of monthly family income. **Conclusion**: Community awareness, medical fraternity sensitization, integration of all services for management and rehabilitation are keys towards better quality of life for parents. Financial support through health programs, NGOs, or insurance is a much-needed reform to reduce catastrophic health expenditure.

KEYWORDS

Autism Spectrum Disorder, Quality of Life, Out-of-Pocket Expenditure.

INTRODUCTION

Parenthood is a blessing to the individual's life, parents play the crucial role in the development of the child be it personality, social, values, or academic.

Autism is a neurodevelopmental disability characterized by a spectrum of disorders mainly affecting verbal and non-verbal communication, social interaction, behavior, and imagination of the individual. The conceptualization of this process has been based on an assessment of Kanner in 1943.(1) It is mostly manifested in childhood near about 3- 4 years of age. One child per 100 children is found to have this disability globally. (2) According to a systematic review conducted by Elsabbagh et al., the median prevalence estimate of autism spectrum disorder is 62/10 000.(3) Overall prevalence in Asia has been reported to be 14.8 per 10,000 In India, it is estimated that there are approximately 1.7–2 million children with ASD in India.(4) The ability needs of autism disorder have a vast variation which keeps on evolving with age and it impacts the life of the majority of affected children for the long term. It has a wide spectrum of manifestations ranging from Autistic disorder i.e. classical autism to Asperger's syndrome, pervasive developmental disorder, Rett's syndrome and childhood disintegrative disorder.(5,6).

Raising an autistic child i.e. taking care of and managing all his needs requires a lot of efforts at various grounds which impacts the quality of life of the parents per say. It is very challenging to balance the work life, household chores and meeting the special needs of their child which impacts on their own health. Moreover, the prevalent stigma, discrimination and rights violation due to disease makes the lives of parents or caretaker miserable.(7,8,9,10)

This increases the stress of the caregivers and compromise their quality of life. Mugno et al. assessed that the QoL scores of the parents in the ASD were significantly lower than the healthy group in many fields.(11)

Add on to that the economic burden associated with ASD is substantial. Apart from direct costs of treatment and therapy, the other indirect costs are immense.(12,13)

This study is an attempt to fulfil the lacunae of knowledge in this aspect

Objectives:

1. To assess the quality of life of parents with children with Autism -Spectrum Disorder (ASD).
2. To assess various treatment seeking pathways in management of ASD
3. To estimate the out-of-pocket expenditure incurred by the parents for various therapies and other related expenses in rearing a child with ASD.

MATERIAL & METHODS

Study Type & Study Design: Cross sectional Mixed method study.

Study Setting: A facility- based study was conducted to assess quality of life of the parents of ASD children attending neuropsychiatric hospitals, clinics or specials in south Delhi.

Study Population: Study population comprise of Parents of children with Autism Spectrum Disorder attending facility for child treatment and management

Study Duration: 4 months

Sample size Calculation: As per convenient sampling a total of 75 participants were taken for quality of life assessment(15 participants from 5 facilities respectively) and 5 participants were selected for in-depth interview (1 from each facility). (Figure 1)

Inclusion Criteria:

1. The parents whose children were already diagnosed with ASD and undergoing therapy since at least one year.
2. The parents who gave consent for interview and were willing to participate were included in the study.

Exclusion Criteria:

1. The parents whose children were diagnosed with any other conditions other than ASD were not included in the study.
2. The parents whose children were diagnosed with any other chronic conditions excluded from study.

Strategy for Data Collection: A list of various neuro-psychiatric hospitals/ clinics/ special as well as inclusive schools/private therapists who were providing therapies in South Delhi was compiled. 5 centres were chosen via Convenient sampling. Necessary permission from head of the institutes was obtained, and 15 parents from each centre, either mother or father were contacted randomly and after written informed consent they were interviewed for quantitative part whereas for qualitative part 1 parent from each facility was interviewed randomly.

Study Tool: Data was collected using pre-designed, pre-tested questionnaire in four parts. In the first part, the sociodemographic details of parents along with the child's diagnosis and therapy details in brief were taken. The second part consisted of WHO Quality of Life BREF (WHO-QOLBREF) questionnaire (English version). (14) Third part consisted of qualitative component, from each facility one study participant was selected for in depth key informant interview and a total 5 such interviews were conducted to find out treatment seeking pathways opted by the parents.

Fourth part consisted of out-of-pocket expenditure incurred during disease management.

Due to Covid-19 situation the data collection for quantitative part was both offline as well as online as per the feasibility of the study subjects.

Ethical consideration, Data Confidentiality & Consent: Before the start of the study, ethical approval was taken from the Institute's Ethical Committee of Jamia Hamdard University.

The parents participating in the study were ensured of confidentiality of data. A written informed consent was obtained from all participants before filling the questionnaire. Also, a prior consent was obtained from Institutional Head for approaching parents.

Analysis & Statistical Tools: Data collected by above method was first entered and cleaned in MS excel and further analysed using SPSS 26.0. Re-categorization of QOL questionnaire was done as per the prescribed guidelines and mean scores were calculated among various domains of quality of life. The raw scores thus obtained were converted into transformed score as per the guidelines which were further converted into WHO 100 comparable score as per the table provided in guidelines.

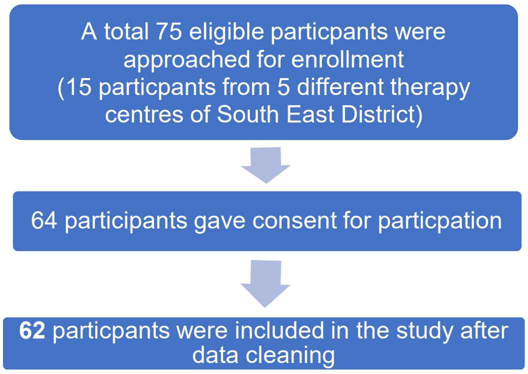
There after association with various sociodemographic factors and the quality-of life score in various domains were analysed to find the significance.

Transformed score= Actual raw score- lowest possible score * 100

Possible raw score range

In the qualitative domain all the 5 interviews recorded were transcribed and converted into verbatim's and thereafter sub themes and major themes were identified.

Figure 1. Flow diagram of Study Participants inclusion



Results

Socio-Demographic Profile

A total 62 study subjects were enrolled in study among which 35 respondents were female and 27 were male Table 1 depicts the age and gender composition of the study participants in the study. Age of the enrolled participants ranged from 21 to 52 years with mean age being 39.48±7.5 years. All the participants belonged to the productive age group, Among the gender wise composition majority of males were above 40 years whereas most of females were below 40 years. All the participants were literate and 50% had completed their post graduation. Considering the marital status majority of the participants were married whereas 6% were separated and 2% were widow. All of them belonged upper class as per BG Prasad socioeconomic scale.

Table 1 Age and Gender Composition of the study Participants (n=62)

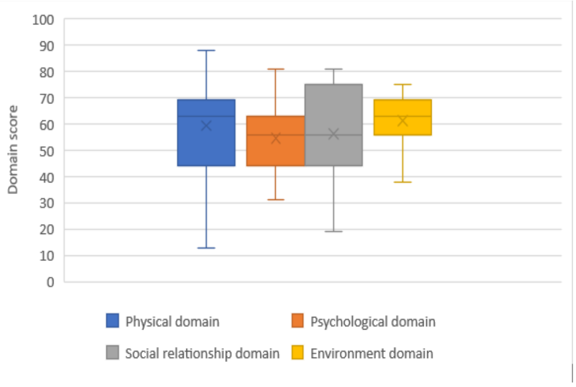
Age group (in Years)	Male (%)	Female (%)
21-30	3 (11%)	4(11.4%)
31-40	6(22%)	17(48.6%)
≥41	18(67%)	14(40%)
Total	27(100%)	35(100%)

Effect on Quality of life of the parents of autistic child

Quality of life was assessed using WHO QOL-BREF questionnaire in all the participants, the mean scores in physical, psychological, social and environmental domains ranging from 13 to 88. As per the means Psychological (54.61± 12.56) and social (56.31± 18.92) domains were the most affected whereas environmental domain (61.35± 9.57) was least affected.

Among the four domains of quality of life 29% of the participants had poor quality of in physical domain, 25% in psychological domain, 25.8% in social domain and 5% in environmental domain as depicted in Figure 2.

Figure 2 Quality of life of the parents of ASD children



On evaluation for gender wise difference among male and female parents no significant difference was found in their quality of life.

The association of age groups with various quality of life domains was assessed using Kruskal-Wallis H Test and it was found that there was a statistically significant difference in social domain score between the different age group, χ2(2) = 7.45, p = 0.024, with a mean rank score of 46.29 for Age 21-30, 33.52 for Age 31-40 and 26.81 for Age >41. While we also observe that in Physical, Psychological and Environmental domains had no significant statistical roll in Age distribution as depicted in Table 2.

Similarly, mean rank of the four domains quality of life (physical, psychological, social and environmental domains) was compared for the association with Education status using Kruskal-Wallis H Test which was not significant as depicted in Table 3.

Table 2 Association of age groups with various quality of life domains Kruskal-Wallis Test

	Age group	N	Mean Rank	Chi-square	p-value
physical domain	21-30	7	35.79	1.11	0.572
	31-40	23	28.65		
	>41	32	32.61		
psychosocial domain	21-30	7	38.14	5.12	0.077
	31-40	23	36.35		
	>41	32	26.56		
social domain	21-30	7	46.29	7.45	**0.024**
	31-40	23	33.52		
	>41	32	26.81		
environment domain	21-30	7	38.29	2.39	0.301
	31-40	23	33.76		
	>41	32	28.39		

Table 3 Association of Education status with various domains of quality of life Kruskal-Wallis Test

	Education	N	Mean Rank	Chi-square	p-value
physical domain	postgraduate	32	32.55	1.835	0.400
	Graduate	16	26.53		
	not graduate	14	34.79		
psychosocial domain	postgraduate	32	31.59	0.236	0.889
	Graduate	16	32.88		
	not graduate	14	29.71		
social domain	postgraduate	32	34.55	2.379	0.304
	Graduate	16	26.31		
	not graduate	14	30.46		
environment domain	postgraduate	32	33.13	1.290	0.525
	Graduate	16	27.19		
	not graduate	14	32.71		

Treatment seeking pathways: In order to know experience of parents during the years of management of their child, interview of 5 parents were conducted using open ended questions. This qualitative interview revealed following 6 major themes which are shown in Table 4.

Table 4 Depicting Major themes and subordinate themes under treatment seeking pathways opted by parents in care of ASD child

Superordinate Themes	Subordinate Themes
Symptom recognition and initial diagnosis	Social difficulties Delayed language Poor eye contact Abnormal behavior
Initial contact professional, Final diagnosis by the professional	Diagnosis, medical management Rehabilitation services
Diagnosis and Treatment Pathways	Direct medical care Special therapies Approach towards different system of medicine in India
Parents take on the Treatment Pathways	Access to medical facility Access to special therapy centres Access to educational services
Current status	Childs current health

Symptom recognition and initial diagnosis: Most of the patients stated that all of them recognized something unusual in children, mostly at the age of second or third year of life. One of the parents said "*He was 3 and hadn't started speaking yet, unresponsive and absent minded. he had very low interest for interaction with anyone, he didn't achieve his developmental milestones at the same time as other children of his age either, it was comparatively quite delayed*." In order to analyse the behaviors of concern, responses from the interview were categorized into following subthemes: social difficulties, delayed language, poor eye contact, and abnormal behavior. Social difficulty was the major initial symptom noticed, where their child wouldn't respond to calls or reply in the appropriate way. All parents reported inability of the child to maintain eye contact, mentioning they preferred to be doing something else as they maintained conversation. Parents stated that their child adopted interests and hobbies to keep them centered and feel a sense of control, and they had repetitive behavior, being highly depended on a structured schedule for the day, deviating from the normal highly upset the child. Parents also showed concern regarding emotional and social neglect and presence of negativity. It was also observed by parents that the child tends to remain occupied with own self, playing alone, avoiding any social interactions. Early autistic signs went unnoticed among all parents interviewed until as some of the children developed aggressive behavior, posing as a great problem for others to interact with them. They imposed difficulty to control at home and in public as they got more restless, anxious and hyperactive. Most parents complained of odd appetites, some would have aversions to certain food and would only prefer to eat food they like and accept nothing else. Majority of the parents approached paediatric psychiatrists only after such behavior was witnessed first. The initial symptoms noticed were delayed milestones, unresponsiveness, eye contact avoiding, reduced interaction etc.

Initial contact with professional, Final diagnosis by the professional: Initial symptom recognition by family members was often followed by reaching out to professionals such as paediatrician, child psychiatrist, general practitioner, speech therapist, etc. Interviews with parents revealed that after recognizing the first symptoms, maximum parents consulted a paediatrician. However, after consultation, the paediatrician often referred the child to a psychiatrist, following which most of them consulted private institutions for further diagnosis and consultation. After recognition of initial symptoms, some parents chose to stay at home, and hire personal tutors for their child, while some consulted doctors, discussion among friends, colleagues and relatives, or searching the internet for more information. Consultation with the doctor was followed by reference to a healthcare facility where ASD in the patient was confirmed by the psychiatrist/child psychologist. The final diagnosis of ASD in the child was found to be given by different healthcare professionals as one of the participants stated that "*Around the age of three years he was diagnosed as a*

Borderline case of ASD by his paediatrician, whom we approached after having multiple discussions among family, relatives and colleagues at work". Parents also commented on poor diagnosis of their children, as it took them multiple visits to come for a conclusion to their child's diagnosis, they also showed concern toward lack of awareness, and services towards ASD and specialist access as stated" *I'm still not very sure if he is diagnosed right yet, as it was very improper and to my opinion there is extremely limited knowledge in this field and very few centres that provide proper definitive care. I hope to see some improvement of these two soon enough, a lot of children have ASD and various other neurodevelopmental disorders*", other parent stated that it's time that we acknowledge them and have more research conducted on them to spread awareness and provide better treatment. " "I had to consult a paediatrician after which I got referred to a child psychiatrist to get a diagnosis and visited three other centres to receive therapy for my child, during which I had also consulted a Homeopathy doctor for only 3 months only and discontinued as I wasn't satisfied with the progress of the homeopathic treatment."

Diagnosis and Treatment Pathways Following diagnosis, different kinds of therapy were given to the children, which were either home based rehabilitation therapy. The therapies with respect to rehabilitation services are classified into behavioural therapy, sensory integration therapy (colour puncture), speech therapy, occupational therapy or following other systems of medicine, like consulting with ayurvedic and homeopathic specialists. Parents felt helpless and challenging while taking care of their child due to add on needs, which per say led to deviation from other roles. 16 Home based therapies included appointing personal tutors/special educators to aid in personal and educational development of the child, and these tutors were continuing to help children till later ages. Majority of parents consulted speech therapists out of the other therapies listed, commonly attending three times a week.

Parents take on the Treatment Pathways: According to many parents, diagnosis of autism or ASD is itself is challenging for them. Initially, it difficult to understand whether there is some problem with their children or not. Many think that these symptoms of lack of eye contact, or not socializing, will resolve with increasing age. Then finally, when they are convinced that some help has to be sought, it takes another few months to years to reach out to specific treatment or therapy. Once diagnosed correctly for autism spectrum disorder (ASD) further challenge was the provision of adequate therapies on time. Due to scarce facilities providing services there were often delays in seeking care owing to huge list of patients prior to them. As the centres of different kind of services 17 were at different places and distance reaching to multiple facilities in a day was also tedious time consuming as well as the add on financial burden. As one of the parents said: "*First of all it was quite difficult to find him a suitable place to receive treatment from, and there was always a long list of people before, sometimes we would receive appointments for his speech therapy delayed by 2 to 3 weeks*." "*There's not enough centres providing speech therapy and occupational therapy, much less providing both together at the same time, I find myself having to reschedule meetings and other office related matters and busy on off days too just to take my daughter to her appointments which are very far away from home, and travelling around in Delhi is not easy, its immensely time consuming and tiring, not to mention expensive too*." Parents have faced difficulty in enrolling their children into regular schools of their choice too, as most schools did not have personal tutors or assistants to guide their children with ASD. So very often they were denied for enrolment into schools they preferred. Satisfaction Although most parents are satisfied with their child's improvement after receiving therapy, they still believe it can be done better and their journey could've been made much simpler.

Out of pocket Expenditure incurred during the care of child

All the study participants belong to upper class socioeconomic status. There was a wide range of variation in the monthly income ranging from 1000000 to 35000. The out- of pocket expenditure also varied as per the current age and needs of the child, it was found that the median out of pocket expenditure per month for the disease management was 20000 (16% of the total income) while the minimum expenditure was 2000 and the maximum was 1 lakh as depicted in Figure 3 & Figure 4

Figure 3 Treatment seeking pathways adopted by parents of ASD child.

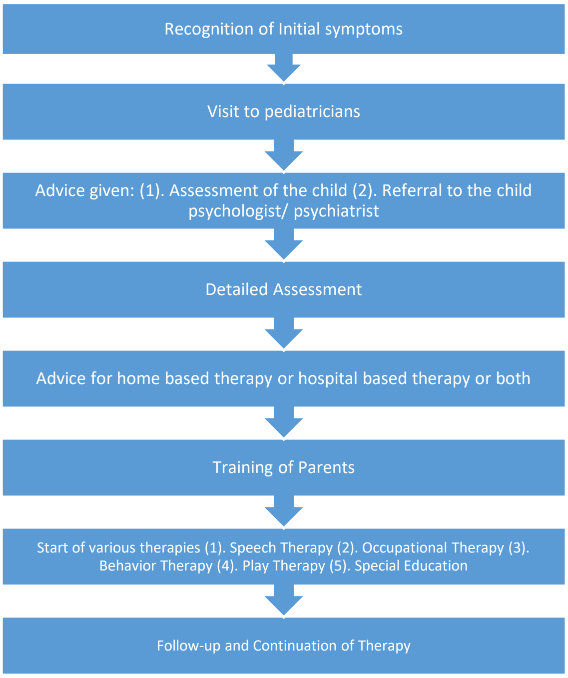
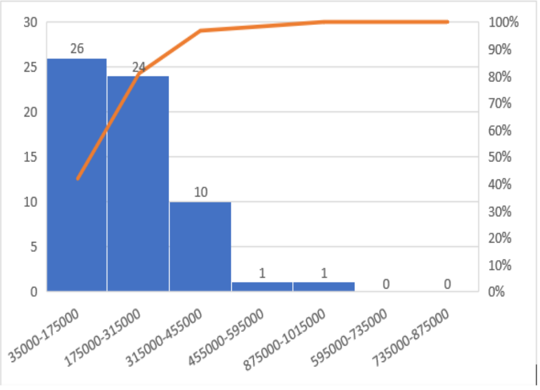


Figure 4 Out of Pocket expenditure incurred during care of ASD children



Discussion

Present study was the multiple facility based cross sectional study conducted for the duration of 2 and half months in South East District of Delhi India. Certain studies conducted in the international and Indian settings revealed the over burden among the parents or care givers of autistic children due to added responsibilities and challenges of parenting a special needs child which impacts their quality of life. The South East Delhi district is the residential area of 27.5 lakhs persons as per census 2011, along with this population the health facilities also cater to nearby cross border area the specific characteristic of this area is the migratory population which has its own hardship in leading their life.

In the study majority of the participants were females (56%) who visited the health facility for seeking treatment for their child as compared to 44% males. All the participants belong to the productive age group with mean age of 39.48±7.5 years. Almost 90% of them were married. These sociodemographic features were similar to other studies as well. Ahmed et al in their study reported that 58% were female and 42% were male participants and 60% of them belonged to 30-40 years of age group. Similarly, Eapen et al in their systematic review reported that mean age of the parents was 42.4 among male and 45.6 in female.(16) This is in concordance with age of disorder diagnosis and treatment seeking time period of the parents.

In the study the self-perception of the overall quality of life was found poor in 27.1% participants while 3% reported it as very poor. Similar to our finding Mugno et al reported in their comparative study that both mother and father of pervasive developmental disorders had significant difference in their quality-of life perception (p value= 0.0001). In their study they also reported that parent's perception towards their health was also significant (p value 0.005).(11) The level of satisfaction towards their health was found different among the different genders, 28% (10) of the females dissatisfied and5.7% (2) were very dissatisfied in comparison to this 18.5% (5) males were dissatisfied and only 3.7% (1) was very dissatisfied.

The overall quality of life and perception of health was also affected by the level of education (p value= 0.009) and Age group (P value = 0.009) respectively. Similar to our finding Ozgur et al also reported in their study that participants with low education level had lower quality of life.(17)

Among the four domains quality of life, we found that most affected domain was psychological domain followed by social, physical and environmental domains respectively, other studies also reported lower quality of life in various domains like Aparna et al reported that in their study parents had poor quality of life in physical domain followed by psychological and social domain. Eapen et al also reported in their study that physical domain followed by psychological and environmental and social domains were affected.(16) Alnazi et al reported that 63% of their participants had impaired quality of life.(8) This shows that impact on life due to stress of pertaining due to various factors such as stigma, societal acceptance, negative feelings, poor self-esteem, deprived social support and weak interpersonal relationships is hard. The perceived burden of disease, challenges in seeking required care and treatment also acts as an added factor to impair the quality of life of the parents.

In the study we found out that social domain was affected by the age group of the parents (p value 0.024). Whereas other factors like gender, education level did not show any impact on individual domains of quality of life. Whereas other studies conducted by Ali et al, Alnazi et al and Ozgur et al reported that gender, unemployment of mother, poor income, low educational level also affected quality of life domains. (8,17) This reflects that these factors play very important role. Good social support, better availability and accessibility to treatment facility, better employment, better work place conditions lead to improved quality of life of the parents.

Autistic children have special needs and abilities once fulfilled they outstand in their life, but this takes great effort from the parents

In the study out of pocket expenditure was one of the identified concerns although the socioeconomic status of participants was upper class yet the total expense in the management was near about 20000 to 2000 depending upon the child's requirements, similar to this Liao et al in their study reported that presence of autistic child in the family imposes immense financial burden both in direct as well as indirect terms which further varied with the severity of disease. Families having insurance or aided financial assistance were less likely to face economic difficulties. They also reported that sustaining non reimbursement of expenses and low income were the factors affecting economic outcome negatively. Travel for seeking medical care and therapies was the add on huge cost over the families. In a national representative survey, they found that average annual income for the care of autistic child was around 14% of the household income which is similar to our study where we found it to be 16%. (13,15)

It is the need of hour to improve the service provision towards ASD sufferers in order to ease the life of both parents as well as children. India itself needs to identify Autism spectrum-disorder management in an integral way by strengthening the medical, educational services and social benefits. Also improving health of the parents or care takers should be visualized as an important aspect. Better job opportunities, bringing up new insurance plans and health policy towards ASD can be the way forward.(18,19,20)

CONCLUSION

To conclude results of the study postulated that the quality of life of the parents of autistic syndrome disorder child is deprived in various domains. It has more deterioration in psychological and social aspects. Females have poor perception towards their health and quality.(21) Also, age of the parents and education are the determinants of their quality of life. It was observed that parents face many challenges in the initial period for early diagnosis and in reaching to the correct diagnosis and start of early intervention therapy. Most of parents consulted first to a paediatrician and from there were further referred to psychiatrist or child psychologist where the final diagnosis was made. It took near about 2-3 doctors' consultation and more than six months in coming to final diagnosis. Delay and poor diagnosis were a matter of concern for them. About 16% out of pocket expenditure on the health which further varies on the child's requirement is a matter of concern. In the country like India, we need to focus on creating awareness regarding condition among general population in order to make them more receptive, Holistic approach towards managing the condition is required to reduce the emotional, social and financial burden over the parents.

RECOMMENDATION

- To bring up new public health policy and planning towards integral services for ASD at single platform.
- To bring up the health plans for parents in order to improve their life.
- For increasing the financial assistance through insurance schemes.
- To provide better job opportunities for the parents of ASD children accomplishing their child care needs and financial need.

LIMITATION OF THE STUDY

Generalizability of the study is limited due to small sample size and population characteristics.

- The COVID -19 pandemic situation and lock down which halted various services, might have further more impact on the health.
- Study was conducted in facility based private settings where possibility of severe cases is more leading to further deteriorated findings.
- All the participants belonged to upper class socioeconomic status hence the burden over the middle and lower socioeconomic class couldn't be assessed.

RELEVANCE OF THE STUDY

current study insights gap in the existing community awareness, diagnostic and rehabilitative services for autism spectrum disorder children which impacts quality of life of the parents.

The Determinants of poor quality of life needs to be addressed by policy and planning for betterment of the children as well as parents.

The study also highlights need for the financial and social assistance for the care of autism spectrum disorder children.

AUTHORS CONTRIBUTION

All the authors contribution has been described in the Contribution form attached as per the prescribed format of journal.

FINANCIAL SUPPORT AND SPONSORSHIP

STS – 2020, Indian Council of Medical Research Funded Project ID 2020-06394.

CONFLICT OF INTEREST

There was no conflict of interest.

ACKNOWLEDGEMENT

We acknowledge all the health facilities for permitting us for data collection from their respective health facilities, also we acknowledge Miss Prachi Srivastava Child and Adolescent Psychologist for her support in the patient's referral for rehabilitation. We are also thankful for institute ethics committee of Jamia Hamdard.

DECLARATION OF GENERATIVE AI AND AI ASSISTED TECHNOLOGIES IN THE WRITING PROCESS

The authors haven't used any generative AI/AI assisted technologies in the writing process.

REFERENCES

1. Baron-Cohen S. Leo Kanner, Hans Asperger, and the discovery of autism. The Lancet. 2015 Oct;386(10001):1329–30.
2. Autism spectrum disorders [Internet]. [cited 2024 June 29]. Available from: https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders.
3. Elsabbagh M, Divan G, Koh Y-J, Kim YS, Kauchali S, Marcín C, et al. Global prevalence of autism and other pervasive developmental disorders. Autism Res. 2012 Jun;5(3):160–79.
4. Mahapatra P, Pati S, Sinha R, Chauhan AS, Nanda RR, Nallala S. Parental care-seeking pathway and challenges for autistic spectrum disorders children: A mixed method study from Bhubaneswar, Odisha. Indian J Psychiatry. 2019;61(1):37–44.
5. Types of Autism - 5 Major Autism Spectrum Disorder Forms [Internet]. Autism 360TM. 2014 [cited 2021 Nov 27]. Available from: https://www.autism360.com/types-of-autism.
6. Baxter AJ, Brugha TS, Erskine HE, Scheurer RW, Vos T, Scott JG. The epidemiology and global burden of autism spectrum disorders. Psychol Med. 2015 Feb;45(3):601–13.
7. Fairfax A, Brehaut J, Colman I, Sikora L, Kazakova A, Chakraborty P, et al. A systematic review of the association between coping strategies and quality of life among caregivers of children with chronic illness and/or disability. BMC Pediatrics. 2019 Jul 1;19.

8. Alenazi DS, Hammad SM, Mohamed AE. Effect of autism on parental quality of life in Arar city, Saudi Arabia. J Family Community Med. 2020;27(1):15–22.
9. Kuru N, Piyal B. Perceived social support and quality of life of parents of children with Autism. Nigerian Journal of Clinical Practice. 2018 Sep 1;21(9):1182.
10. Milgram NA, Atzil M. Parenting stress in raising autistic children. J Autism Dev Disord. 1988 Sep;18(3):415–24.
11. Mugno D, Ruta L, D'Arrigo VG, Mazzone L. Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. Health Qual Life Outcomes. 2007 Apr 27;5:22.
12. Subjective Burden and Depression in Mothers of Children with Autism Spectrum Disorder in India: Moderating Effect of Social Support | SpringerLink [Internet]. [cited 2021 Nov 27]. Available from: https://link.springer.com/article/10.1007/s10803-017-3233-y.
13. Rogge N, Janssen J. The Economic Costs of Autism Spectrum Disorder: A Literature Review. J Autism Dev Disord. 2019 Jul 1;49(7):2873–900.
14. 76.pdf [Internet]. [cited 2021 Nov 27]. Available from: https://www.who.int/mental_health/media/en/76.pdf.
15. Liao X, Li Y. Economic burdens on parents of children with autism: a literature review. CNS Spectr. 2020 Aug;25(4):468–74.
16. Eapen V. Parental Quality of Life in Autism Spectrum Disorder: Current Status and Future Directions. Acta Psychopathologica [Internet]. 2016 Feb 1 [cited 2021 Nov 29];2(1). Available from: https://psychopathology.imedpub.com/abstract/parental-quality-of-life-in-autism-spectrum-disorder-current-status-and-future-directions-8501.html
17. Özgür BG, Aksu H, Eser E. Factors affecting quality of life of caregivers of children diagnosed with autism spectrum disorder. Indian J Psychiatry. 2018;60(3):278–85.
18. Divan G, Vajaratkar V, Desai M, strik lievers L, Patel V. Challenges, Coping Strategies, and Unmet Needs of Families with a Child with Autism Spectrum Disorder in Goa, India. Autism research : official journal of the International Society for Autism Research. 2012 Jun 1;5:190–200.
19. Subjective Burden and Depression in Mothers of Children with Autism Spectrum Disorder in India: Moderating Effect of Social Support | SpringerLink [Internet]. [cited 2021 Nov 27]. Available from: https://link.springer.com/article/10.1007/s10803-017-3233-y
20. Das S, Das B, Nath K, Dutta A, Bora P, Hazarika M. Impact of stress, coping, social support, and resilience of families having children with autism: A North East India-based study. Asian Journal of Psychiatry. 2017 Aug 1;28:133–9.
21. Abbeduto L, Seltzer MM, Shattuck P, Krauss MW, Orsmond G, Murphy MM. Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. Am J Ment Retard. 2004 May;109(3):237–54.