

Parental Attitude and Expectations in Raising a Child with Autism Spectrum Disorder in India

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Abstract:The current study aims to understand the attitude of parents of 28 children with Autism Spectrum Disorder in India. This study was conducted in Chennai, an urban metropolitan setting in South India, and most of the respondents were middle and upper middle-class parents. In a country like India with a vast number of languages, cultures, socio-economic disparities, and varying education levels, the challenge lies in finding a standardized understanding of Autism, and an optimal intervention package. Social norms and expectations play a significant role in shaping parental acceptance of ASD and their choice of intervention. Findings show that parents of children with ASD have the same expectations of their child as they do of their typically developing children, giving a leverage of a few years. There was also a mismatch between what was vocalized as being the ideal outcomes for their child and the steps taken to achieve them. This descriptive study illustrates the urgent need to provide parents with a uniform understanding of the condition, the availability of scientific intervention services and additionally, the need for a uniform policy on processes and educational and therapeutic intervention that will meet the needs of the child and that of the family.

Key Words:Autism, India, Parenting, Culture and attitude, Qualitative Research, Social Expectations, Education, Pedagogy

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I. BACKGROUND

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013), the core symptoms of Autism Spectrum Disorder (ASD) include deficits in social communication and social interaction across multiple contexts and in restricted, repetitive patterns of behavior, interests, or activities, which lead to clinically significant impairment in social, occupational or other important areas of functioning. With variations across children, a diagnosis of ASD impacts every facet of functioning from academic engagement and development to peer relationships, the family system and narrows potential options of occupation and growth into adulthood. Many individuals on the spectrum have severely impaired communication resulting in poor social skills and isolation from community based activities and interactions. ASD knows no barriers and impacts individuals across social and geographical boundaries and is termed as a lifelong disorder, that affects the individual into adulthood (Minhas et al., 2015)

According to Autism Speaks, the signs of ASD to look for at any age include loss of previously acquired speech, babbling or social skills, avoidance of eye contact, persistent preference for solitude, difficulty understanding other people's feelings, delayed and impaired language development, presence of persistent repetition of words or phrases, resistance to minor changes in routines or surroundings, restricted interests and repetitive behaviors such as flapping, rocking and spinning. Autism Spectrum Disorder has a current incidence of 1 in 54 according to the Center for Disease Control and Prevention (CDC), up from 1 in 150 in the year 2000. India has about 472 million children under the age of 18 and an extrapolation of the prevalence rates of ASD as indicated by the CDC would mean India may have around 2 million children on the spectrum. This would mean that 2 million parents in India are impacted by the repercussions of this diagnosis and are primary stakeholders, making their beliefs and attitude instrumental to the child's developmental trajectory. Parenting a child, regardless of the diagnosis is influenced by the immediate social and cultural context. The interpretation and understanding of the condition is similarly influenced by the cultural context and social expectations (Zechella & Raval, 2015). Majority of interventions that are based on significant scientific evidence such as Applied Behavior Analysis (ABA) and Early Start Denver Model (ESDM) originate from the West which has a very different culture from that of India (Minhas et al., 2015). It is recognized that the view from the lens of the parent often differs from that of the scientific community, and when posed with a parenting problem, they instinctively look for answers within their religion, family or local community and explore alternative treatments

that are aligned with their community and culture. The parent plays a central role in the intervention process, making it imperative that services are culturally sensitive and acceptable to them. Parental beliefs are reflected in everyday routines and activities, influencing the development of the child (Tuli, 2012)

Only this can ensure that the parent remains invested in their child's intervention and development, using best practices, and positive approaches (Minhas et al., 2015). Given this scenario, there is a pressing need for culturally relevant and inclusive research that will give the Indian parent the appropriate interpretation of autism, its impact on the child, and assist in choosing and implementing scientifically adapted interventions. The authors attempted to understand parental perspective by investigating 3 key questions; Navigating social expectations in the context of their child with Autism, Educational expectations for their child with Autism and Expected outcomes in adulthood.

II. METHOD

Setting

The study was conducted in the city of Chennai, in South India. It is the fourth largest metropolitan city in India, and Tamil and English are the primary languages spoken. The study summarizes the experience of parents raising children with ASD in the city.

Participants

The participants were parents of children who received intervention at an ABA center in the city. Parents whose children met the diagnostic criteria for ASD based on the DSM, Childhood Autism Rating Scale (CARS) or Autism Diagnostic Observation Schedule – 2 (ADOS-2) and medical reports from developmental pediatricians, were eligible to be a part of this study. The study had parents of 28 children with ASD. All the fathers were college educated professionals and of the mothers 5 were employed and the rest were homemakers. The age of the children ranged between 1.5 years and 17 years. Participation in the study was voluntary and not compensated. Informed consent was obtained for analyzing the data submitted by the participants and they were assured of anonymity in the research study.

Data collection

Information was collected in the form of an initial survey questionnaire where the participants had to indicate yes/no to the questions, along with one question that required a descriptive answer. This was followed by qualitative telephonic/ telehealth interviews that were video/audio recorded with their consent and professionally transcribed. The follow up interviews were conducted in the language preferred by the participant in order to obtain further clarifications on the responses to the survey questionnaire and to elicit the parent's narrative, particularly of receiving a diagnosis for the child. Parents were asked about their experiences and the path they chose to follow thereafter. They provided valuable information that tackled both the positive aspects and the challenges that came with raising a child on the spectrum.

Table1: Participant Demographics

	Parental Age (M)other; (F)ather	Age of Child	Gender	Sibling (Y/N)	Family Type
1	47 F	18	Male	Y	Nuclear
2	34 F	4	Female	N	Nuclear
3	36 F, 27 M	4.5	Male	Y	Joint
4	48 F	13.5	Female	N	Nuclear
5	39 M	3	Male	Y	Joint
6	39 M	3	Male	Y	Joint
7	33 M	4.8	Male	N	Nuclear
8	35 M	8.5	Male	Y	Nuclear
9	45 M	11	Male	Y	Joint
10	42 F	12	Male	N	Nuclear
11	38 M	4.5	Male	Y	Nuclear
12	25 M	2.11	Male	N	Joint
13	35 M	3.8	Male	N	Joint
14	40 F, 39 M	7	Male	Y	Nuclear
15	36 M	6	Male	N	Joint
16	36 F	6	Male	Y	Joint
17	39 F, 35 M	5	Female	Y	Nuclear

18	43 F	8	Male	Y	Nuclear
19	34 F	8	Male	N	Nuclear
20	32 F, 32 M	5	Male	Y	Joint
21	30 M	9	Male	Y	Joint
22	30 M	1.5	Male	Y	Joint
23	28 M	4.7	Male	N	Nuclear
24	42 F	11	Male	N	Nuclear
25	50 M	17	Male	N	Joint
26	32 M	3.6	Male	N	Joint
27	34 M	8	Male	N	Nuclear
28	37 F	2 years 11 months	Male	N	Joint

Data analysis

The authors obtained data in the form of questionnaires filled by the parents, supplemented by video and telephonic interviews.

Video recorded interviews were replayed for data extraction and narratives. The responses on the survey form were tabulated for further analysis. Tabulated data included family type, presence of a sibling, gender and age of the child. Parental age was indicated with M for mother's age and F for father's age, in the table. Video interviews in languages other than English were translated by the author who was fluent in both languages.

III. RESULTS

The survey form was analyzed on the basis of the three research questions, relevant statements filled by the research participants were extracted for the study and supplemented with narratives from the participants. Out of the total participants, 46 % were of the opinion that their child with ASD must enroll in the mainstream educational system, and 32% wanted their child to pass class 10 and 12 Board exams. Four of the children whose parents indicated that their child should be in school by age 5, had zero to few vocals at the time of the interview. Almost all the participants insisted that their child must learn to read while 78% required for their child to learn to write. Typing was not an acceptable alternative for them and neither was assistance in the form of support staff. Of the parents who wanted their children to finish higher secondary education 42% expressed reluctance to use a scribe. Passing higher secondary exams through the National Institute of Open Schooling (NIOS) was not the preferred choice for 46% of them. Of all the participants, 85% believed that their child would benefit from being in an environment with neuro-typical children. When asked what they would do to help their child, 71% of the participants claimed they would do anything to make their child normal. A large segment of the participants (89%) have indicated that they told their extended families about their child having a diagnosis of ASD and had no problem taking their child out to public places. Adult outcomes were fairly consistent across the population, all the participants wanted their child to live independently as an adult.

IV. DISCUSSION

This study aims to explore in depth the experiences and attitudes of parents in India, raising a child with ASD, from coming to understand the implications of the diagnosis to navigating through social and educational expectations. This detailed account throws light on some of the challenges parents face, and the dilemma between recognizing and meeting the child's needs and that of what society thrusts on them.

Parenting in India:

In India, there is the need for adhering to social norms and social relatedness (Daley, 2004). Social approval is an important part of a collectivist society like India, resulting in parents expressing more concern about social difficulties and adherence to social norms, over other developmental criteria (Patra, Arun and Chavan, 2015). The literature just reviewed suggests that parenting is driven by collective cultural beliefs of the society or community, resulting in a set of constructs that are termed as parental beliefs.

From childbirth, parents are driven by a set of principles and rules on the child's upbringing, everything from what would be considered appropriate for the child to do and what would be deemed as inappropriate, the path his educational journey should follow, including what he should be doing as an adult. When there is a diagnosis of ASD there is a temporary disruption in this well-established set of rules. After a temporary phase of disruption, the parents attempt to fix this aberration or perceived anomaly in the child in order to go back to the well beaten path and established beliefs of child upbringing. The child on the spectrum is seen as the one who has to change and necessarily fit into the existing system.

In Hinduism, the predominant religion in India, having children and their upbringing are an intrinsic part of marriage and a righteous duty of the parents. The Hindu scriptures (Brihadaranyaka Upanishad 1.5.17) state that a couple requires to procreate in order to live a fulfilling life, childbirth is seen as a celebrated means to an end and a natural progression of life.

However, when the child is seen to have a difficulty or disability, the Hindu belief of children as products of past deeds influences the parent to blame the child's problem on karma. The immediate course of action tends to be one of fixing the karmic debt, by means of prayers and invoking special rituals, consulting with astrologers and gurus. This extends to the parental attitude of attempting to fix the child. Often times the parent is seen to rectify these perceived errors in the child, instead of adopting an approach of embracing their neurodiversity. However, one participant who had an 8-year-old child stated "I just want him to be happy, why should I fix him? He is great as he is!"

For most others, former expectations have to be re-evaluated and room has to be made for newer ones. Letting go of those expectations is known to cause tremendous pain for the parents and amplifies their need to fix and at the same time protect their child, resulting in an internal state of conflict.

The child-rearing style of Indian mothers has been described as indulgent and protective (Saraswathi&Pai, 1997). Thus, mothers who demand social-emotional closeness may be alerted to the unusualness of an aloof child, while their need to protect the child may lead them to dismiss or deny signs of problematic behavior. One participant stated that she saw a problem with her child early on but dismissed it as a temporary phase until medical professionals reiterated her fears. Protective parenting results in a conflict between rescuing the child from any struggle and wanting them to be independent, inadvertently increasing their dependence on the parent and this results in the protective behavior of the parent increasing as opposed to an increase in the supportive behavior of the parent.

On a positive note, 86% of the participants had told family members that their child had a difficulty. The parents who had not yet conveyed this to extended family had children younger than 4 years of age. The difference between the typically developing child and the child with ASD starts becoming more pronounced ages 5 and upwards, making it no longer optional for the parents to conceal the presence of the condition from others.

The desire for normalcy was an aspiration for the parents, when asked what 'normal' meant to them, the answer was that the child should be like other children, which included being able to speak and go to school. There is a belief that the child with ASD would benefit from being with other typically developing peers. For some of the parents, it was hard to deal with the social repercussions of their child not responding to conversation with other people, though a large majority indicated that they were willing to take their child to public places regardless of his lack of interaction and integration. For some others, understanding of the condition itself and the long-term implications of the diagnosis appeared rudimentary.

A large majority of parents believed that their child with ASD had a hidden talent, which would place their child in a different league and took it upon themselves to discover that special talent. The father of a 3-year-old stated, "I will nurture his sporting talent because he is quick at running". One mother said, "The doctors were assessing my child to see if he had hearing loss or ASD, I did not know what ASD was, and so I was praying that he had ASD and not hearing loss". Emergence of vocal language in the child is met with the expectation from the parent that the ASD features will recede away and the child will begin meeting typically developing milestones. One parent stated that "In the beginning I was worried whether my son would be able to go to college and go to work, but now I am not worried about it at all, I am confident that he will come out of it".

All of the participants were clear that their children should be able to feed themselves independently, although during the follow up interview, more than half of the children were being fed their meals. The reason stated was that the time taken by the child to self-feed would be better spent in acquiring academic skills.

Educational Expectations in India:

The start of a formal education is seen as an important social and developmental transition for children. According to the 2011 National Census, 1.05% of school going children have a disability, approximately translating into 2.13 million children. Indian parents express a high regard for formal education and scholastic performance. The significance of education is beyond that of a route to employment and financial gains, it is seen as a social achievement, a means to accomplish something that the parent could not, and without which a family might be subjected to embarrassment and often times stigma attached to the fact that their child did not complete formal schooling.

There is also an assumption that formal education will be the natural progression for their child and parents grapple when confronted with a delay in that progression. For some parents of children with ASD, this assumption turns out to be a luxury, when the child is unsuccessful at integrating into the system. Parents of children in the age group 6 and under opt to send their children with ASD to play schools and kindergarten,

frequently having to facilitate their interactions themselves or if the school permits, appoint a shadow or facilitator to assist the child through the day.

Barriers to educational expectations:

Despite the optimism of inclusive practices and the availability of admission into formal schools, children with ASD are often faced with the challenge of being truly included in the classroom experience. Research has pointed out that merely physically integrating students with Special Education needs in regular schools is not enough (Pijl, Frostad, and Flem 2008). While there is no single definition of inclusion, the concept itself consists of social integration, academic integration and social participation. Teaching staff may have positive attitudes towards children with different needs, however the lack of specialized training on inclusion practices and special support makes it a challenge to effectively provide the required resources. Additionally, training on inclusion pedagogies are not part of most Indian teaching curriculums. The successful integration or even placement of the child with a disability continues to decrease after the completion of primary school. While social contact and building peer relationships are motivating reasons for the parents to enroll their child with different needs in a mainstream set up, the prolonged exposure in an environment that does not address their specific needs tends to isolate them further and this in turn works counterproductive to the very reason they were enrolled in the set up while also posing the risk of disrupting their emotional health. Parental attitudes indicated that schooling was a non-negotiable, however when the difference between their child and a neurotypical peer becomes potentially problematic is when they evaluate their choices.

A half of the participants continue to aspire to enroll their child in a formal education system, irrespective of the child's level of functioning. Interestingly, one of the parents who has answered this question in the affirmative, had withdrawn his child at age 10 from school, given that he was unable to comprehend the curriculum and had exhibited problem behavior at school. A majority of the parents expressed that literacy and the ability to write were critical skills to acquire. At the very minimum, the child's ability to write his own name was deemed necessary. "He should at least be able to sign off on a cheque or bank documents" said a few parents when asked why typing was not an acceptable alternate. More parents aspired for their child to receive a college education than getting through higher secondary school, indicating a significant gap between current skill levels and future aspirations, and a lack of clarity on the efforts needed to bridge the gap. What remains unexplained is why parents of children with ASD continue to emphasize on a formal education even if it means that their child will not only face academic failure but also have to cope with the stress of being unable to decipher social norms and subtle social cues. The emphasis on physically being present in mainstream school was more important than learning outcomes (Ivey, 2004). Additionally, this path of education fails to foster the required independence and facilitate skill acquisition for the child to meet the long-term objective of living as independently as possible.

Expected outcomes in Adulthood

Studies have shown that many individuals with ASD achieve limited independence in adulthood, are unemployed or underemployed with low hours and wages (Carter et al. 2012; Cimera and Cowan 2009; Roux et al. 2013). Little research has explored the actual outcome of various interventions influenced by parental attitudes in adulthood. Environmental demands grow at breakneck speed as the child grows and adult outcomes for children with ASD are of great concern for families and therapists. Planning for transition to adulthood is approached by every clinician and is a part of the educator's plan of action, but a majority of the stress of transition is borne by the parents themselves. Parents are thrust with the job of identifying activities that facilitate successful transition into adult life (Holmes et al. 2018). This combined with the lack of a formal system both financially and in terms of community assisted welfare by the government is seen as a major barrier to successful transition to adulthood. Adults with ASD often have to resort to continued dependence on the parents/ immediate caregiver for assistance with communication, self-help skills, vocational and financial support.

More than half of the parents were clear that their child cannot be engaged in routine tasks/jobs such as washing, cleaning, or waiting tables as adults, indicating that they would like for their child to grow up to be an adult working in an office environment or simply stay home. In contrast to the west, the Indian culture perceives white collar jobs to be the only acceptable occupation for their child with ASD. Every parent expressed that their child must be able to live independently, meaning that he must be responsible for his own needs, while continuing to physically live in the same space as the family. The cultural belief of living together as a unit continues once a child is an adult, the only differing aspect being that the child with ASD in a majority of the cases cannot look after himself, marking his future uncertain. Despite the stated long-term goal of independence, many of the participants admitted to physically assisting their child 8 years and above to complete self-help and personal hygiene tasks such as dressing, bathing, using the washroom and feeding. By

expressing reluctance to work on these goals, it is hypothesized that the parent often engages in protective behavior that overrides the behavior of supporting the child.

V. LIMITATIONS AND RECOMMENDATIONS

There are natural limitations to the study, in that the sample consisted of participants who were in an urban setting and had received Applied Behavior Analysis services (of varying time durations) and had established some contact with medical professionals and other autism interventionists (Occupational Therapists, Special Educators, Speech Therapists). The authors were unable to include families who had zero contact with interventionists or people situated in a rural setting.

Given the strategic role of the parent in the child's developmental trajectory, the aim of the current study was to understand their perspective on ASD, the implications of their attitudes on the child's education and adulthood. The current study was conducted in Chennai, a context where availability of evidence based behavior analytic services and evidence based parental counselling is very limited. The outcomes of this study coupled with an increasing trend in the number of children being diagnosed with ASD, reinforce the need for an ecological framework in India to guide further research into accessibility of evidence based inputs and programs that partner with and support parents of children with ASD with the primary objective of enabling and enhancing their abilities to clarify and align their actions with their aspirations for the child. A final consideration for future research would be broadening the scope to understand parental attitudes in rural settings to investigate broad approaches and outcomes for children with ASD raised by parents in non-urban settings.

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