

Research Article

Perception about Autism: An International Study

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Abstract

The prevalence of Autism Spectrum Disorder (ASD) in the United States is approximately 1 in 66 children. Many providers in the community are unaware of parental beliefs about their child's developmental concerns and available resources for ASD. Understanding these beliefs can help provide better comprehensive care while building awareness and treatment options for ASD. A Health Questionnaire with 15 questions was developed and sent out to parents who had children with ASD attending a developmental resource program locally in USA and receiving services at a community hospital in India. Our results indicate that parents of ASD children in India report developmental concerns including social, language, behavior at a much later age in their children as compared to the parents of these children in USA. Moreover, the perception of available resources in their schools, community including options for Living situation (besides themselves), seems much limited in India compared to USA for these children. One interesting finding was that parents exhibited a much higher satisfaction with treatment and doctors for their ASD children in USA compared to India. However, these findings need to be replicated with a much larger sample, specifically by comparing it with the normally developing children in both countries.

Introduction

The Centers for Disease Control and Prevention (CDC) estimates that 1 in 68 children (or 14.7 per 1,000 eight-year-olds) in multiple communities in the United States has been identified with Autism Spectrum Disorder (ASD). There have been numerous studies on developmental profile of children with Autism Spectrum Disorder (ASD). Clinically, there have been different strategies used to define these developmental milestones in children. Conventional developmental language milestones for infants are usually based on normative data from numerous standardized language instruments [1,2]Based on these norms, the lack of acquisition of the following milestones within known accepted and established ranges is considered abnormal: no babbling by 12 months; no gesturing (e.g., pointing, waving bye-bye) by 12 months; no single words by 16 months; no 2-word spontaneous (not just echolalic) phrases by 24 months; and any loss of any language or social skills at any age. Failure to meet these milestones is typically associated with a high probability of a developmental disability. An important aspect of this has been if parents provide reliable information regarding their child's development.

One study with 737 children showed that parental concerns about speech and language development, behavior, or other developmental issues were highly sensitive (i.e., 75% to 83%) and specific (79% to 81%) in detecting overall developmental deficits[3]. An additional study that used both parental concern and a standardized parental report found it effective as early developmental screening tools in the primary care settings. Specifically, parents' concerns and good-quality standardized parent report measures such as the Child Development Inventories capitalize best on parents' observations and insights into their children. In combination, these two types of parental information offer an effective method for the early detection of behavioral and developmental problems in primary-care settings[4]. Another study considered resilience in families where 175 parents and other primary caregivers of a child with autism - ages between 2 and 18 years showed that a considerable number of families of children with autism display factors of resilience - reporting having become stronger as a result of disability in the family [5].

One other area of concern has been the parental stigma or feeling socially isolated. Qualitative study of courtesy stigma

among 32 parents of autistic children indicated that autism has uniquely stigmatizing aspects because of the extremely disruptive nature of autistic symptoms, the normal physical appearance of autistic children, and the lack of public knowledge and understanding regarding the nature of autism. Most parents perceived this stigma due to their child's disorder with a stronger tendency for mothers to feel stigmatized than fathers. Parents with more severely disabled children and with children under the age of twelve were more likely to perceive themselves to be stigmatized[6].

While studying perception of 77 parents who had ASD children, it was found that most children were diagnosed by a neurologist and/or developmental pediatrician (54% and 47%, respectively). Average perceived delay in diagnosis of ASD was 18 months. Parents most frequently cited immunizations (54%), genetic predisposition (53%), and environmental exposure (38%) as a cause of their child's autism. Almost all parents (95%) indicated some use of Complementary and Alternative Medicine (CAM) therapies, with most of the self-reported referrals generated from a physician or nurse (44%) [7].

Parents of children with autism and behavior disorders experienced statistically and clinically higher levels of parenting stress and dysphoria than parents in the other two groups of normal development and Down syndrome in another study [8]. Another study compared child age at parent's first developmental concern with age at first discussion of concerns with a provider among 1420 children with ASD. This study found that although parents of children with ASD have early concerns, delays in diagnosis are common, particularly when providers' responses are reassuring or passive, highlighting the need for targeted improvements in primary care [9].

Many health care providers are unaware of parental beliefs about treatments and resources that parents use for their child with ASD. Understanding these beliefs and practices concerning development and availability of resources may help physicians provide better comprehensive care. Considering the lack of data in studies comparing parental perception of their child's development and of availability of school and community resources for ASD, this study was designed to be conducted in both India and USA. The purpose was three-fold:

- To compare the perception of parents about their child's developmental delays and its relationship with their diagnosis of ASD.

- The perception about the child's treatment and resources in the community and school.
- How a developed country like USA compared to a developing country like India in parent's attitudes towards their children with ASD.

Materials and Method

A Health Questionnaire with 15 questions was developed and sent out to parents who had children with ASD attending a developmental resource program locally in USA. This survey was completed over the course of six weeks. A similar survey over the course of six weeks was also sent out to parents who had children with ASD receiving treatment in community hospitals in India concurrently. Both population were selectively randomized and matched for age (0 to 15-year-old) and gender (19 males, 4 females for India; 17 males, 5 females for USA). There were 23 surveys filled by parents of ASD children in India with 22 surveys completed by parents of these children in USA. These surveys were then analyzed for the data gathered through them. There are two basic types of survey question, distinguished by the form of the response. One type utilizes four categories of ages: "0-2 Years Old", "3-5 Years Old", "6-8 Years Old", and "9 and Above Years Old". The other type of question utilizes a Likert-like scale with 1 representing the lowest, and 5 the highest.

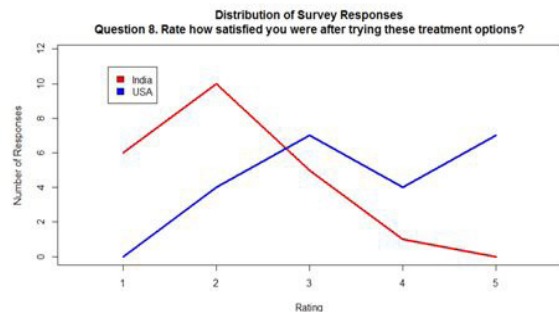
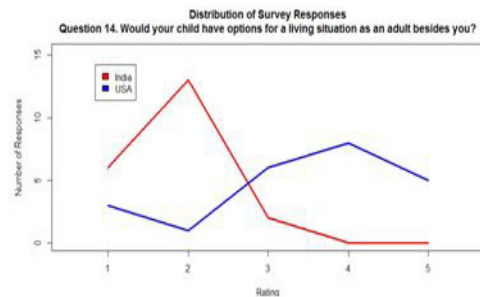
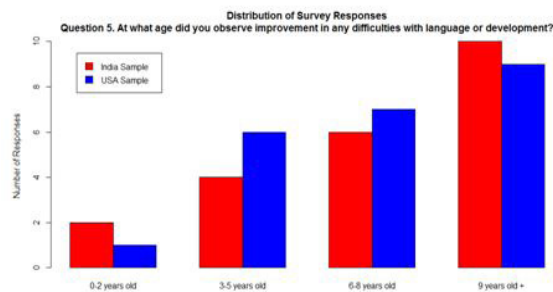
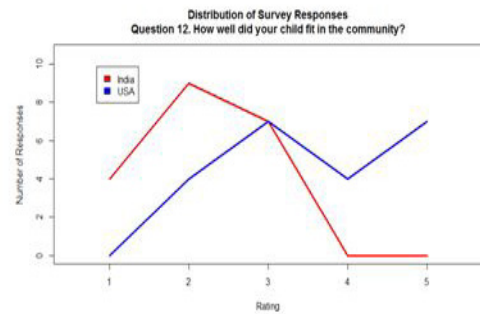
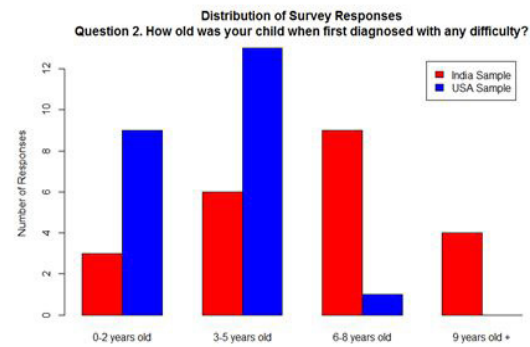
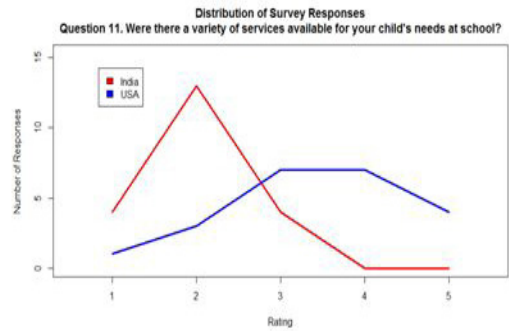
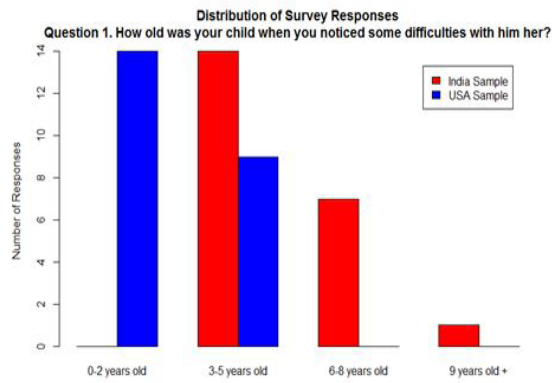
For analysis, the two types of questions are tested differently. The age category questions are tested using Fisher's exact test for count data. The Likert-type questions are tested by Welch's two sample t-tests. Because the responses may only take the values from 1 to 5, the data is not quite normally distributed, a condition for the t-test. Because of this, tests were double checked using both Wilcoxon rank sum tests and Fisher's exact test. Because of agreement between all these tests, only the t-test statistics and p-values are shown for those questions. Each survey question was tested individually, with the null hypothesis being no difference between the sample from India and the sample from the USA.

Results

Many of the responses show a significant difference between the samples, as measured by a p-value less than 0.05. The (Table 1) below show how the questions compared to their p value.

Q ¹	Topic	Test	Statistic (df ¹)	p-value	sample means
1	Age when difficulties noticed	Fisher's Exact		1.81e-06***	
2	Age when diagnosed	Fisher's Exact		0.0007835***	
3	Accuracy of first diagnosis	t-test	-2.9219 (41)	0.005636**	India 2.70, US 3.74
4	Age improvement noticed	Fisher's Exact		0.7867	
5	Age language improvement	Fisher's Exact		0.67	
6	Age difficulties obvious	Fisher's Exact		0.0443*	
7	Availability of treatments	t-test	-4.379 (40.632)	8.156e-05***	India 2.36; US 3.68
8	Satisfaction with treatments	t-test	5.2736 (38.77)	5.346e-06***	India 2.05; US 3.64
9	Satisfaction with doctor	t-test	-2.3618 (41.536)	0.02295*	India 2.90; US 3.65
10	Child fitted at school	t-test	-3.3971 (29.555)	0.001963**	India 2.05; US 3.23
11	Services available at school	t-test	-5.3418 (33.789)	6.29e-06***	India 2.00; US 3.45
12	Child fit in community	t-test	-5.0567 (36.54)	1.219e-05***	India 2.15; US 3.64
13	Community accepting of child	t-test	-2.7519 (38.199)	0.009012**	India 2.55; US 3.57
14	Options for living situation	t-test	-5.6297 (31.953)	3.195e-06***	India 1.81; US 3.48
15	Future living options as adult	t-test	-5.1463 (31.367)	1.369e-05***	India 1.55; US 3.43
¹ Q=Question number; df=degrees of freedom in t-tests *significant at 0.05; **significant at 0.01; ***significant at 0.001					

Table 1: Show How the Questions Compared to Their P Value.



Age at which difficulties were first noticed showed 0-5-year range for USA sample while the range changed to 3-9-year-old; highest being 3-5-year-old. Whereas for age when child was first diagnosed with ASD was 3-5-year range for USA sample with a much higher age of 6-8 year for Indian sample. Language difficulties in both groups improved most at age 9 years and above. The sample from India showed much less satisfaction in treatment options with scores of 1, 2 whereas USA sample showed more satisfaction of 4-5. On the question of “How Well Does Your Child Fit in The Community”, highest number of Indian sample scored it a 2 with USA sample scoring a 3 and 4 showing a better fit in the community. Similarly, for both questions of availability of resources in the community and school, sample from India gave it a lower score of 2 mostly with sample from USA giving it a score of 3 and then

4. On the question of Living situation options besides the parents, sample from India gave it a lower score of 2 (less options); while sample from USA gave it a higher score of 4 and then 5 (showing several options besides parents).

Discussion and Conclusion

Our results indicate that parents of ASD children in India have found developmental concerns including social, language, behavior at a much later age in their children as compared to the parents of these children in USA. Moreover, the perception of available resources in their schools, community including options for Living situation besides them, seems much limited in India compared to USA for these children. One interesting finding was that parents are exhibiting a much higher satisfaction with treatment and doctors for their ASD children in USA compared to those in India. This study was very relevant in determining how the parent's own perception of child's developmental trajectory can lead to not only an early diagnosis but intervention for ASD. As many studies have shown that the early intervention is typically determined by parental concern about their child's development; which consequently leads to screening, diagnoses and treatment for ASD. Our study demonstrated the importance of parental awareness of their child's development helping improve the global care for their ASD diagnosis. Not only can this awareness be critical but also something that needs to be strengthened with education, training and support for parents struggling with children with ASD. This understanding can help build better and necessary resources in treatment settings, community and school for these children. In addition, a comparison of people in India who can read English with those who are cannot might shed additional light on some of the issues that were studied.

However, these findings need to be replicated with a much larger sample, specifically by comparing it with the normally developing children in each country. This would minimize some biases including perception about the availability of resources for treatment or in community and in school for each country. In general, one would expect that a developed country like USA would

have better resources for treatment and in the community for ASD children. And this study actually showed that parents in USA do agree with this perception compared to those in India. This study was one of the first attempts of its kind to compare how perception of parents with ASD children differs in countries like India and USA. It is possible that the socio-economic status of the sample in India might have been lower compared to the one from USA. This selection bias could have possibly contributed to less awareness and knowledge about the treatment options and resources for parents of ASD children in India.

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