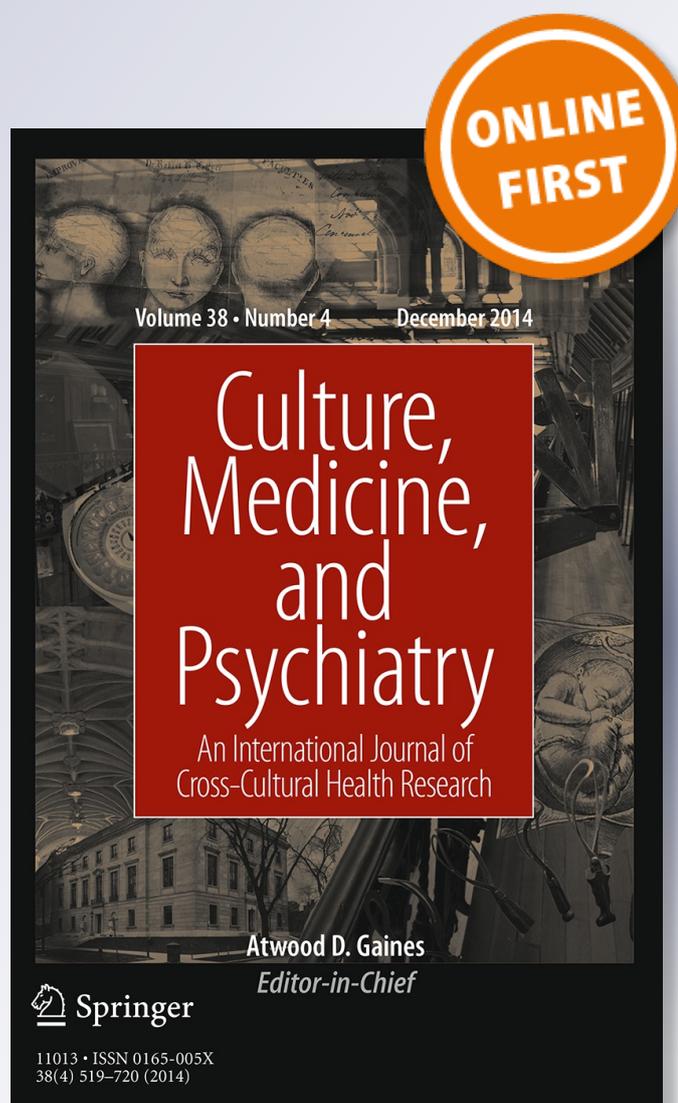# Parenting a Child with Autism in India: Narratives Before and After a Parent–Child Intervention Program

Rachel S. Brezis, Thomas S. Weisner, Tamara C. Daley, Nidhi Singhal, Merry Barua & Shreya P. Chollera

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Parenting a Child with Autism in India: Narratives Before and After a Parent–Child Intervention Program

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Abstract In many low and middle income countries where autism-related resources are scarce, interventions must rely on family and parents. A 3-month Parent–Child Training Program (PCTP) at Action For Autism, New Delhi, India is aimed at empowering and educating parents, encouraging acceptance of their child, and decreasing parent stress. Forty couples were asked to describe their child with autism using the Five Minute Speech Sample (FMSS), an open-ended narrative method, before and after the program. Parents described a wide range of child behaviors, primarily social and cognitive skills. While all families were of a relatively affluent strata compared to the general Indian population, there were nonetheless significant differences in parents' narratives based on their income levels. Coming into the program, parents with relatively less income focused on their child's immediate and material needs, while higher income parents discussed their parental roles and vision for society. After the PCTP, parents were more likely to reflect on their child beyond comparisons to 'normality,' and beyond the here-and-now. Mothers were more likely than fathers to reflect on themselves and their

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relationships with their child. Understanding parents' experiences and narratives is essential for the evaluation of interventions such as the PCTP, as Indian parents are incorporated into a growing global network of 'parents of children with autism.'

Keywords Autism · India · Parents · Intervention · Five Minute Speech Sample · Socioeconomic status (SES)

Introduction

As the anthropological study of Autism Spectrum Disorders (ASD) around the world is growing (Brezis 2012; Cascio 2015; Daley 2002; Grinker 2007; Solomon and Bagatell 2010), so is autism awareness spreading, with more and more communities seeking out the diagnostic systems and treatments for autism developed in the West, and then adapting them (Elsabbagh et al. 2012; Grinker et al. 2011; Malcolm-Smith et al. 2013; Rios and Costa 2015; Sarrett 2015). This study examines a parent-training program at Action For Autism (AFA), New Delhi, adapted from Western treatment programs, that caters to Indian parents and their children with autism. We compare parents' narratives before and after the program, and report shifts in their perspectives, as they are brought into a growing, global community of 'parents of children with ASD.' Further, we examine the ways in which parents' gender roles and socioeconomic and educational backgrounds shape their views of their child, their relationships with their child, and their abilities to voice a desire for change in society at large. Finally, this study is conceived at its core as a cross-cultural collaboration, providing important practical information to our Indian collaborators, including qualitative information that complements a larger mixed-method evaluation of the Parent–Child Training Program (PCTP) (Daley et al., in preparation).

Our study comes at a time in autism research and treatment when parents and families are receiving a renewed focus, after a long period of parental blaming and exclusion (Karst and Van Hecke, 2012). While parents have been involved in interventions with their children to varying degrees at least since the 1970s, and parent advocates have certainly shaped autism research and treatment in unprecedented ways (Grinker 2007), it is still the case that evaluations of treatments for children with ASD focus primarily on child outcomes, without evaluating the effects of the treatment on the family. Although the sociocultural, interactional, and family environment is widely appreciated as an important component in understanding family adaptation to children with disabilities (Ochs and Solomon 2010; Skinner and Weisner 2007), parents' views have only recently been incorporated in evaluations of autism treatments. As stated by Karst and Van Hecke (2012) in their review of autism treatment evaluations, "most interventions for ASD are evaluated only in terms of child outcomes, ignoring parent and family factors that may have an influence on both the immediate and long-term effects of therapy." In this paper, we apply a brief qualitative tool, the Five Minute Speech Sample (Magaña et al. 1986), which encourages participants to describe their experiences in their own words, alongside a wide battery of quantitative measures (Daley et al., in preparation).

In contrast to professional support available to many parents in the West, in India, as in many low and middle income countries, professional services for autism are so scarce that parents who wish to provide services for their child often have no choice but to take on an active role in either aggressively seeking help or providing the intervention themselves. Though many persons with mental illness and disabilities in India have historically been kept hidden in the home, in what have been called "zones of social abandonment" (Dhar 2009; Marrow and Luhrmann 2012), parents who come to AFA are being trained in a new model of parenthood and a new vision for disability (http://www.autism-india.org). AFA was founded by Merry Barua, an advocate and mother of a child with autism, in 1991; and in 2001, the PCTP was initiated to train parents and empower them to train others. The immediate goals of the PCTP are to increase parents' empowerment, acceptance, understanding of autism, and ability to teach; to decrease their stress; and increase their child's level of functioning. The long-term goals are to improve family functioning and to empower parents to spread the knowledge they have gained to other parents of children with autism and their communities at large (see Adams 2014, for a detailed description of the program and its goals. Additional program detail is available at the AFA website, http://www.autism-india.org/parent–child-training-programme).

As India's National Centre for Autism and the first organization of its kind in South Asia, AFA stands at the crux of the societal change regarding autism: increasing awareness of autism, training parents and professionals, and advocating for disability laws that will change the way persons with autism are viewed and treated in India in the future. Rooted in the particular challenges of Indian families and societies, AFA's visions are closely informed by global autism movements, including parental advocacy groups and the neurodiversity movements (Feinstein 2010; Grinker 2007). Thus, our study of parents who come to the PCTP serves to both illuminate this unique transitional moment regarding autism in India, while at the same time inform the evaluations of parent-training for autism in a changing world.

The study of autism in India has had a long and rich history, with over 170 studies, conducted by both Indian and international researchers, from various disciplinary perspectives between 1944 and 2010 (Daley et al. 2012). Several previous studies have examined the views of parents of children with autism, focusing mostly on parents' experiences with diagnosis and search for treatment (Daley 2004; Desai et al. 2012; Divan et al. 2012; Gupta and Singhal 2005). They identified the many challenges Indian parents face in determining their child's diagnosis and finding appropriate treatment, and the wide impact the diagnosis has on families and their relation with their communities. Our study examines a cohort of parents who have already received a diagnosis, and are taking a step further, viz., learning to become teachers and advocates for their child (and in some cases, teachers and advocates for others' children as well). In Desai et al.'s 4-stage categorization of parents' trajectories of grappling with their child's diagnosis, our parents lie somewhere between the 3rd and 4th stages: they have acknowledged their child's atypical behaviors, and are now searching for solutions; or, recognizing that most of their child's behaviors will be persistent, they are preparing for a future life of care. While the parents in our sample came from educated, high socioeconomic status (SES), our sample of 40 families nonetheless encompassed a range of socioeconomic and educational backgrounds,

enabling us to compare the views expressed by parents with different economic and cultural backgrounds, as they undergo intensive parenting training.

The Five Minute Speech Sample (FMSS)

To examine the changing views of parents participating in the PCTP, we employed the "Five Minute Speech Sample" (Magaña et al. 1986), a narrative interview method in which parents are prompted to speak about their child and their relationships with their child for five uninterrupted minutes. The FMSS is an abbreviated version of the Camberwell Family Interview (CFI; Leff and Vaughn 1985), which was originally developed to examine the impact of family environment on the rate of relapse among adults with schizophrenia. The CFI and its abbreviated form, the FMSS, have been used to determine rates of family "expressed emotion" (EE): criticism, hostility, and emotional over-involvement. The construct of EE has been examined extensively in wide-ranging cultural contexts, including India (Leff et al. 1990; Wig et al. 1987). The CFI has generated much debate about, and efforts to improve, its cultural validity (Bhugra and McKenzie 2003; Cheng 2002; Jenkins and Karno 1992; Subandi 2011; Kleinman 1988; Nunley 1998). Better relapse rates for patients with schizophrenia have been associated with reduced EE and better family support in developing countries such as India, yet critics argue that the EE construct has been over-simplified, and should be measured against local standards for 'over-involvement,' for example (Jenkins and Karno 1992; Nunley 1998). Given the wide-ranging controversy over the validity of EE in various cultural contexts, and its potential limitations for use with parents of children with autism (see below), we used the FMSS procedure to examine emergent themes in parents' descriptions of their child, rather than applying the EE coding scheme to the narratives.

While the FMSS has been widely used in the study of families of persons with various mental illnesses, it has only recently been extended to the study of families with children and adults with intellectual disabilities (Laghezza et al. 2010), and only a handful of studies have used the FMSS with families of persons with autism (Wasserman et al. 2010; Baker et al. 2011). Extending the FMSS to parents of children with ASD for the first time, Benson et al. (2011) noted that several parenting behaviors, such as affection and 'overprotectiveness,' are common and probably necessary in the case of children with ASD. These criticisms echo the limitations pointed at by cross-cultural researchers, and strongly suggest that the FMSS scored for EE should be used with care, as family values and expectations vary widely across cultural contexts and clinical conditions. Thus, given that, to our knowledge, our study is the first to use the FMSS with parents of children of autism in any culture outside Euro-America, we chose to begin our examination by identifying themes in parents' narratives, rather than using the EE scoring.

Beyond extending the FMSS to parents of children with autism in India, our study presents several additional contributions. To our knowledge, this is the first study of parents of children with autism in any culture that uses the FMSS to assess changes in parents' views before and after an intervention program, to compare mothers' and fathers' views, and to examine the differences in FMSS themes across parents' SES backgrounds. Our study thus serves as a window to understanding the different views

held by parents of different gender and SES backgrounds, in a rapidly changing Indian cultural climate, before and after they undertake training in parenting their child.

Methods

Setting

The PCTP is a 3-month training program in New Delhi for parents of children with autism. The program is currently run by a trainer who is herself a mother of an adult with autism, and incorporates Western autism-training methods (such as TEACCH, Applied Behavioral Analysis, and Floortime) with cultural adaptations (see http://www.autism-india.org/parent–child-training-programme for a detailed description of the program). Except for families who live in Delhi, mothers leave their families and home towns and come to Delhi with their child for the 3-month training. Some fathers also come at initial and final periods, but virtually none participate in daily activities. The training includes daily group and one-on-one activities with the children (led by the parents), and group discussions for the parents. Parents are admitted into the program from a waiting list, and financial aid is available to support families who cannot afford the program cost. The study drew on three consecutive cohorts of participants ($N = 40$), who came in in January ($n = 16$), July ($n = 12$), and September ($n = 12$), 2012.

Participants

Forty pairs of parents—80 mothers and fathers—were interviewed prior to the intervention (pre-test), and 78 parents were interviewed after the intervention (post-test). In 39 families, the mother participated as the primary caregiver, while in one family, the father came in. Data from this latter family were coded and analyzed qualitatively, but excluded in quantitative analyses.

Family Characteristics

Most parents were Hindu couples from Northern India, and 15 families were from Delhi (Table 1). The average monthly income ranged from less than 10,000 Rs/month (185 USD) to more than 75,000 Rs/month (1389 USD), and the median income was 25–50,000 Rs/month. Relative to the Indian population, all these families were above the 90th percentile in income (Desai et al. 2010). Families were equally split between joint and nuclear households, with an average of 4.8 persons per household (range of 3–12). We found significant associations between our participants' income and household size (smaller families had greater income, $r = -0.339$, $p = 0.002$), and interview language (English speakers had higher income; $U = 1030$, $p = 0.001$); and between parents' level of education and interview language (English speakers had higher education, $U = 3410$, $p = 0.006$). These associations are consistent with demographic trends in the general Indian population.

Table 1 Family characteristics

Characteristics	Sample percent (N = 40)
Geographic origin in India	
North	65.0
South	12.5
East	7.5
Northeast	5.0
West	5.0
Central	2.5
Islands	2.5
Household composition	
Nuclear	50
Extended or joint	50
Household income (Rs/month)	
Less than 10 k (less than $185)	15
10–25 k ($185–$463)	22.5
25–50 k ($463–$926)	15
50–75 k ($926–$1389)	22.5
75 k & above ($1389 & above)	10
Religion	
Hindu	90
Muslim	5
Buddhist	2.5
Sikh	2.5

Parent Characteristics

Parents age ranged from 24 to 50 years, and a majority had a graduate degree or higher (equivalent to college-level training or higher in the US, Table 2). Mothers were significantly younger than their husbands ($t(77) = 8.45$, $p < 0.001$), and more likely to speak in Hindi during the FMSS ($\chi^2(2) = 26.17$, $p < 0.001$). Mothers on the whole were more educated than their spouses ($Z = 4.34$, $p < 0.001$), yet they were employed in significantly fewer numbers ($\chi^2(1) = 104.1$, $p < 0.001$), a common pattern seen much in India. 56 % of participants were native Hindi speakers, although families in this sample spoke 10 additional Indian languages as their native languages.

Child Characteristics

73 % of the children who were brought in to participate in the PCTP were male, with a mean age of 5.1 years (Table 3). Children ranged in age from 2.3 to 10.6; this range was purposeful, serving to expose parents in each PCTP cohort to a variety of

Table 2 Parent characteristics

Characteristic	Mothers ($n = 40$)	Fathers ($n = 40$)
Age [mean (SD)]	32.8 (4.3)	36.6 (4.1)
Range	24–42	30–50
Employed outside the home	12.5 %	92.5 %
Interview language	75 % Hindi	60 % Hindi
Education		
Class X pass	0 %	5 %
Class XII pass or professional course	7.5 %	17.5 %
Graduate	42.5 %	47.5 %
Post-graduate	45 %	27.5 %
Above post-graduate	2 %	2.5 %

Table 3 Child characteristics

Characteristic at entry	Mean (sd)	Range
Child's age (years)	5.1 (1.9)	2.3–10.6
Gender	73 % male	
VABS (Adaptive Behavior Composite)	60.0 (10.8)	40–89
SCQ	23.4 (4.9)	14–37
Child's age at diagnosis (months)	35.6 (15.2)	18–84
Time since child's diagnosis (months)	25.2 (16.2)	3–62

Child's level of language at entry	Percent
Fewer than five words	57.5
Recognizable single words only	22.5
Occasional phrases only, mostly single words	20.0

developmental stages. All children met autism diagnostic criteria on the ADOS, a clinical observation measure (Lord et al. 1999); autism symptoms and adaptive level were further ascertained through parental report using the SCQ and VABS (Rutter et al. 2003, Sparrow et al. 2005). Children's verbal and adaptive abilities were relatively low, with more than half speaking fewer than five words.

Procedure

The FMSS was administered as part of a larger mixed-method study evaluating the PCTP (Daley et al., in preparation). Parents were interviewed at the start and end of the program. Since many fathers accompanied their wives and child to Delhi at the start of the program, both mothers and fathers were interviewed in person at pre-test. However, not all fathers joined their wives and children at the end of the program; thus, 17 fathers

were interviewed in person at post-test, and 21 were interviewed over the phone (two fathers could not be reached). For fathers who had spent less than 1 month with the mother and child during the 3 months of the intervention (that is, staying together in Delhi, not participating daily in the PCTP), the interviewers waited 2 weeks after the mother and child rejoined the father to call him—in order to allow the father to take time to perceive and adjust to any changes in the mother and child's behavior.

The interviews were conducted by a team of 5 local English- and Hindi-speaking research assistants, with MA training, who were overseen by a clinical psychologist (N.S.) who serves as the Director of Research and Training at AFA. After a brief background interview that was conducted jointly, mothers' and fathers' interviews proceeded separately, beginning with the FMSS. Parents were encouraged to speak in the language they were most comfortable with (Table 2).

During the FMSS, parents were asked: "I'd like to hear your thoughts and feelings about [CHILD'S NAME], in your own words and without my interrupting with any questions or comments. When I ask you to begin I'd like you to speak for 5 min, telling me what kind of a person [CHILD'S NAME] is and how the two of you get along together." If the parent paused before 5 min had elapsed, they were encouraged to continue by saying "go on" or "please continue." The audio data were professionally transcribed and translated into English in New Delhi, and a team of research assistants at AFA checked and cleaned the translations.

Coding

The coding scheme was developed thematically from the transcripts, and agreed upon by US and Indian research teams (see Table 4 for the resulting topics). Coding was conducted by four Hindi-speaking UCLA students, using Dedoose mixed-method software; the coding was performed on English transcripts, while coders listened to the original Hindi or English audio. Analysis and coding stopped at the 5-min audio time-point, regardless of whether the parent continued talking.

In order to establish inter-rater reliability, two coders coded a random set of 20 % of the transcripts for a particular set of topics, and inter-rater reliability was measured. If coders did not attain agreement using the reliability measure of kappa > 0.8 on a certain topic, coders discussed their disagreements and proceeded to code another 20 % of transcripts until agreement was reached. Once agreement was reached, these two coders continued to code the rest of the transcripts for these topics. All data in this report were coded reliably at kappa > 0.8.

Analysis

Data regarding the topic mentioned in each transcript (i.e., whether the topic was mentioned or not, regardless of the amount of times a parent may have mentioned it) were transferred to SPSS v. 22. This binary variable mentioned or not served as the dependent variable for quantitative analyses. Mother–father, and pre-post differences were determined using McNemar's paired-proportions test. Differences in the topic mentioned across background variables were determined using the

Table 4 (a) Topics mentioned by parents in the FMSS (including data from both mothers and fathers, before and after the training program) and (b) child behavior [expansion of first row of panel (a)]

(a)

Topic	Percent of parents that mention ($N = 158$)
Child's behavior [panel (b) expands this topic further]	100
Growth and change in parent or child	69
Parent (self-reflection)	63
The parent–child relationship	62
Other people and children	58
Spouse	54
Other treatments and diagnoses	54
PCTP	53
Autism terminology	53
Future	42
Family	36
Siblings	22
Religion	11
After parent's death	10
Society/community	8
Child as teacher	5
Parent display of emotion	4

(b)

Child behavior	Percent of parents that mention ($N = 158$)
Social relationships and play skills	77
Cognitive skills, academic skills, learning ability	65
Communication skills	61
Self-help, independent living skills	56
Challenging behaviors	44
Comparisons to normality	34
Attention and activity	34
Positive emotions	27
Following directions	26
Restricted interests and routinized behavior	12
Sensory interests or sensitivity	9

Mann–Whitney test for independent samples for continuous and ordinal variables, and the Chi-square test for nominal variables. Further qualitative and thematic analyses were conducted using Dedoose.

Preliminary Statistical Analyses: Cohort Effects and Narrative Length

The three cohorts did not differ on demographic characteristics, participation throughout the program, the lengths of their narratives, or the number of topics covered, so data from the three cohorts were combined. There were no significant differences in the length of narratives (measured by number of characters) between mothers and fathers, length of narratives before and after the program, or by any other background variable. Since narrative length did not differ across comparison groups (which could have skewed the probability of the topic mentioned), our analyses focused directly on the topic mentioned, without having to adjust for narrative length.

Results

Narrative Topics

In response to the prompt to speak about their child in the space of 5 min, parents chose to focus on a wide range of child behaviors, and elaborated on many topics in addition to their child and their relationships with their child (see Table 4 for a summary of topics used by both parents, at both time points). A majority of parents reflected on their relationships with their child, and their roles within the relationship, highlighting ways in which they, their child, and the relationship grew and changed over time. Many parents also spoke about the people that surround them—their spouses, family, and other people and children (we will return to these topics as we discuss the ways topics varied between mothers and fathers, across time and demographic backgrounds). A majority of parents spoke about their child's diagnostic process and other treatments they had tried before the PCTP; and more than half the parents used autism terminology (e.g., "autism," "repetitive behaviors," "hyperactive") in their narratives.

In speaking about their child, most parents focused on their child's social and cognitive skills, followed by their communication and self-help skills; other autism symptoms, such as repetitive behaviors and sensory interests and sensitivities, were noted more rarely (Table 4b). In describing their child's social and play skills, parents said, for example: "he doesn't like to play with other kids; he only plays with his toys"; "she doesn't notice if I'm present or not." In describing their child's cognitive and academic skills (the second most common topic), parents either described their child's difficulty or special skill ("even though he is autistic his memory is very good"); or voiced their hopes and expectations ("I want him to complete his education and do something in life."). Parents' observations of communication skills included: "He has no speech at all. Not even mummy, papa." "It's very difficult to [understand] what he is trying to say." Parents' mentions of self-help skills encompassed different aspects of daily life, including feeding ("he used to eat *roti* [bread], but never touched the vegetables"), clothing ("he can't put on his shoes by himself"), sleeping ("he never used to sleep till 2–3 at night"), and toileting ("he does not tell when he needs to use the toilet").

Differences in Parents' Narratives Before and After the Program

After participating in the PCTP, parents were significantly less likely to mention other people and children and the child's siblings, or compare their child to 'normal' standards; at the same time, they were more likely to reflect on the past and future. Before the PCTP, in describing other people and children, parents spoke of their child's difficulty in interacting with others ("he tries to play with other kids, but his playing is different"), or their own difficulties with others' reactions to their child ("it is very difficult taking her to the market because she displays disturbing behaviors… all the people watching gives us an inferiority complex"); though they might also mention other people in a positive context ("everyone loves her"). In speaking about siblings, the parents either described their autistic child's relationships with another sibling ("she loves her sister very much… she knows that her sister is scolding her"), compared their autistic child with a typical sibling ("whatever my elder son does he is not able to do"), or expressed their dilemmas about having another child. It is possible that parents' decreased mentions of other people and children, and children stemmed from the fact that the majority of parents were living away from their families during the training, and were thus spending more one-on-one time with their child. More broadly, however, it may reflect an increased acceptance of their child's condition, and less concern over what others are thinking.

There was no significant change in parents' mentions of any particular child behavior before and after the program; however, we found a significant decrease in parents' mentions of normality. Mentions of normality by parents before the program could be made in the context of positive or negative comparisons (example: "my child is normal, like all kids," or "we wish that our child could be normal"). Making comparisons to "normal children" is discouraged in the PCTP program. Parents are explicitly encouraged to accept their child's ASD, and focus on goals that would be realistic and useful for their child. Thus, parents' decrease in mentions of normality (in both positive and negative contexts), along with their decreased mention of other people and children, may be an indication of the parents' increased level of "acceptance" of the child's condition and focus on positive behavior management—both PCTP program goals. We are currently following up with these families to see whether this increased level of "acceptance" ultimately leads to positive changes in child outcomes and family functioning.

Two topics that increased in frequency of mention over time were parents' retrospective descriptions of growth and change, and their thoughts about the future. It is not surprising that more parents spoke of growth and change after 3 months in the PCTP, as they acknowledged the changes they, and their child, underwent. However, it is interesting to focus on the *types* of change parents mentioned. Most parents, such as this father, reflected on changes in their child: "she used to not give attention to me; now she comes to me, sits on my lap also, hugs me tightly as well." Other parents, such as Rachna (pseudonym), the mother of 5-year-old Paarth, tied the changes in their own perception and understanding of autism with changes in their child's behaviors:

> "My perception about autism has changed a lot… Paarth's behavior tantrums that were there 3 months ago, which used to occur 2-3 times a day.., now I

should say that it happens once or twice in a week…, this means I have been able to understand his behavior quite well. [Before the PCTP,] I didn't pay much attention to why [my child does certain things], now when I paid attention to why, I have been able to tackle this quite well, and the bonding between me and him has also strengthened, and I am feeling quite positive after this. And I feel that Paarth has also become more attached to me."

In Rachna's interpretation, her increased understanding decreased Paarth's tantrums, and thus their bond strengthened.[1]

As parents prepared to transition out of the PCTP program, and back into their family settings, a greater percent of parents mentioned the future. Their thoughts ranged from straightforward wishes ("I want him to be independent"), to concrete plans to change their child's educational setting ("I want to send him to school"), or their own behavior ("when we go home, I want to give him more of my time"; "I feel I am going to make autism my career"). Parents' increased mentions of the future might well be expected in the context of this final encounter with the study team, seeing the FMSS as an 'exit interview' of sorts. More broadly, however, along with their increased mentions of growth and change, it may also indicate a more subtle shift in parents' perspectives: rather than focusing on the here-and-now, they have begun to look up from their day-to-day concerns, and reflect more broadly about their and their child's lives.

Differences in Mothers' and Fathers' Topic Mentions

In order to understand the differences in mothers' and fathers' views, we compared the topics mentioned by mothers and fathers, pooled over time. Mother/father comparisons reflect not only gender but also differences in their PCTP experiences: mothers participated in the program day-to-day, while fathers' contact with the program was largely indirect, derived from what their wives say and do and what they see of changes in their child's behavior. We found that mothers were more likely than fathers to speak about their relationships with their child, and to reflect on their roles within the relationship, while fathers were more likely to speak about their spouses (Table 5). Further, mothers'—but not fathers'—self-reflections and reflections on their relationships with their child increased significantly with time (Self-reflection, McNemar's $p = 0.021$; parent–child relationship, $p = 0.019$). Mothers' reflections on their relationships with their child ranged from observations that the relationship is difficult to neutral or positive. Difficult relationships may include extreme dependency ("She cannot stay even for a second without me"), or a child's erratic behavior, that manifests against the mother ("He gets so angry at night… he nearly beats me."). Many mothers, however, described the positive

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[1] While this was not a direct focus of the FMSS, we have evidence that parents' increased in their theoretical and practical understanding of autism from quantitative and qualitative measures directly designed to assess their knowledge and skills (Daley et al., in preparation). These include increased knowledge about the symptoms and causes of autism (e.g., my child may have unusual sensory interests and a need for sameness in the environment), and strategies (e.g., using structure and visual cues, matching one's language to the child's level of understanding, using positive facial and body language to encourage one's child to engage with oneself etc.).

Table 5 Significant differences in the topics mentioned by parents before and after the PCTP

Topic	Percent of parents that mention before program ($n = 80$)	Percent of parents that mention after program ($n = 78$)	McNemar p value
Decrease after PCTP			
Other people and children	67	47	0.018
Comparison to normal	44	24	0.015
Siblings	31	14	0.002
Increase after PCTP			
Future	33	54	0.021
Growth and change	51	88	<0.001

aspects in their relationships with their child, despite their difficulties: "he still has some tantrums, but still he is ok to me… he follows all my instructions very clearly." Other mothers, such Rachna (cited above), described the increased understanding and bonding she has with her child.

Many mothers spontaneously commented on their parental role, though they differed greatly in their degrees of self-reflection. Some mothers reflected on their subtle shift of perspective: "Earlier I was so worried, because my son cannot even recognize me. But now [I understand that] he is slow, yet he will be able to learn later…" Other mothers described the changes in their behavior—and its effects on the child: "[Earlier] I didn't understand how I can handle [my child]. Then I came here, then I know all these [ways] how I can handle things. If I put things in a structure or schedule, life will be a lot easier." In a small minority of mothers, their self-reflections led them to a deeper understanding of their child and their relationships with their child—viewing their child as a teacher of the parent, and drawing lessons from their relationships that could be applied to society at large. We will return to these examples below, in discussing the patterns of the topics mentioned by high-income, English-speaking parents, since most such comments came from this group of parents.

While both partners were equally likely to speak about their family (McNemar's $p = 0.265$), or other people and children ($p = 0.108$), fathers were significantly more likely than mothers to mention their spouses. Fathers also showed an increase in their mention of their spouses after the PCTP—at the level of a statistical trend ($p = 0.092$). Most fathers who mentioned their spouses did so in passing (19/30); two mentioned they did not have enough time to spend with their child; and nine fathers spoke about how they split duties with their wives (e.g., "his mother takes care of his studies. I am not the right person for that… I generally prefer spending my time with my child on the fun part of it, playing, roaming around."). It is interesting to note in this regard that one father who participated in the program as a primary parent did not mention his relationship with his child, nor his parental role at the start of the program. Interestingly, by the end of the program, he spoke of both these topics at length, though he continued to speak of his spouse. Thus, it seems that he acquired many of the perspectives mothers acquired through participation in the program, though he maintained the tendency of fathers to speak more of their spouses than their wives (Table 6).

Table 6 Significant differences in the topics mentioned by mothers, who participated daily and directly in the PCTP with children, and fathers, who did not

Topic	Percent of mothers that mention ($n = 80$)	Percent of fathers that mention ($n = 78$)	McNemar p-value
Greater in mothers			
Parent–child relationship	73	50	0.012
Parent self-reflection	72	54	0.031
After parent's death	17	4	0.006
Greater in fathers			
Spouse	40	68	0.001

Demographic Differences and Unique Topics

In order to understand the effects of demographic variables on parents' narratives, we examined the distribution of the topics mentioned by parents as they varied in SES, household size, education, and language chosen for interview. We found that parents who spoke in Hindi, came from relatively lower income families, and who were living in larger, joint households, were significantly more likely to mention their child's independent skills; to speak about their concerns for what would happen to their child after their death; to make references to religion; and to cry during the 5-min narrative period (see Table 7). In contrast, parents who spoke in English, and who came from smaller, nuclear families, with a higher income, were more likely to reflect about their own role as a parent; to speak about the broader society and community; and to view their child as, at times, their teacher.

Although not all mentions of specific topics were associated in every case with the same set of background variables (Table 7), as noted above, we found a pattern of significant correlations within subjects' SES, education, and language of choice, which supports our division of parents into two broad demographic clusters.

An important finding regarding pre-post PCTP impacts is that the differences in the topic mentioned across demographic variables were almost all significant at pre-test, while almost none were at post-test. The one demographic difference in topic mention that emerged as significant at post-test was the greater focus of parents from nuclear families (vs. joint families) on their child's cognitive skills.

Case Examples of Lower Income, Hindi-Speaking Parents

To explore these statistical findings in depth, we re-examined the narrative excerpts from parents who mentioned the suite of topics characteristic of lower income, Hindi-speaking parents. Deepti holds a graduate certificate, and lives in a joint family of 6 in New Delhi; her husband is a public servant and their monthly family income is less than 10,000 Rs/month. She spoke in Hindi about her concerns for her 6-year-old son: "I just want him to… be able to do things for himself in life. Like peeing on the potty. [I want him to] be dependent on himself when we are not there for [him] tomorrow… (*crying*)." Here, Deepti's concerns for her child's

Table 7 Demographic differences in the topic mentioned

Topic	Demographic distribution at Time 1
Independent skills	Mentioned more frequently by lower income parents ($U = 589$, $p = 0.043$)
Religion	Mentioned more frequently by parents of larger households ($U = 528$, $p = .008$) of joint families ($\chi^2(1) = 4.114$, $p = .043$), with a lower income ($U = 196$, $p = 0.021$)
After parent's death	All mentions made by parents of lower income families ($U = 128$, $p = 0.026$)
Parent crying	Parents that cried came from larger households ($U = 371$, $p = 0.005$)
Parent self-reflection	More often mentioned by English-speaking parents ($\chi^2(1) = 6.689$, $p = 0.010$), with higher education ($U = 986$, $p = 0.037$)
Society/community	All mentions made by parents from smaller households ($U = 40$, $p = 0.009$), of nuclear families ($\chi^2(1) = 4.211$, $p = 0.040$)
Child as teacher	All mentions made by parents from smaller households ($U = 31$, $p = 0.028$), and English-speaking parents ($\chi^2(1) = 6.474$, $p = 0.011$)
Cognitive skills (post-test)	Mentioned more frequently by parents of nuclear families ($\chi^2(1) = 5.769$, $p = 0.016$)

Mann–Whitney (for ordinal and continuous variables) or Chi-square statistics (for nominal variables) noted where appropriate

independent daily skills are directly tied with her concern for the future—when "we are not there." Her developmental expectations are further framed by her religious beliefs: "other children do other activities that God has given everyone naturally. Like eating by himself, dresses up by himself… I just want for him to be self-dependent on himself." Further, while parents of nuclear families were concerned with their child's cognitive abilities and education, Deepti says that "with regard to his studies I do not have this [concern], that he does his studies or not, I just [want to see that he] gets well and can care for himself."

Chandni, a mother from Assam from a family of 4, with an income of 10–25,000 Rs/month, speaks in Hindi about her 8-year-old daughter: "And I want her to become independent so that after we are no more she can look after herself, she can carry on on her own if she does all this. Because, when we are no more, who will take care of Puja?" Having fewer economic resources and less domestic help, parents of lower income families such as Deepti and Rakhi, may feel more pressed for their child to gain independence. For similar reasons, they are more concerned for their child's future after their death: though they have more family members to share the burden, they also have fewer resources to provide for their child after they are gone.

Case Examples of Higher Income, English-Speaking Parents

In contrast with Hindi-speaking parents of lower income, joint families, English-speaking parents of higher income, nuclear families were more likely to focus on the child's cognitive skills, and to reflect about themselves and their vision for society. Further, all parents who viewed their child as a 'teacher' spoke English and came

from nuclear families (though mentioning this was relatively rare overall). Ajit, an advertising consultant earning 25–50,000 Rs/month, from a nuclear family of 3, clearly expresses his academic concerns for his 3-year-old son: "I only pray that he starts going to a good school." Similarly, Aanand, a software professional from Hyderabad, earning 50–75,000 Rs/month, worries that "there is a big gap between [my son's] other abilities and [his academics]." As with many members of the Indian middle class, Ajit and Aanand view their child's education as key to success, and apply their expectations even to their child with special needs.

Interestingly, Nandini, Aanand's wife, takes a different approach to their 6-year-old son (whom they raise in a nuclear family of 3). Nandini's narrative is deeply self-reflective, describing her own personal journey toward acceptance, and her shifting educational expectations: "I have no difference between normal and abnormal now, I have no sense of success now… These days I feel success is nothing but feeling the feelings and living for the moment, and being happy…"

Drawing from her experiences, Nandini reflects on society at large, viewing her son as a teacher in the process:

"And I think my son is a kind of instrument for me to evolve spiritually also. So … in fact I feel above people who are running on about their career or about [their] kid's grades and things like that. These things look very minute to me now. It's not… that parents should not give any kind of effort. But I think we miss the very core thing: that we are here to live our lives and to make the most of it. I see my son as kind of an eye opener…It's a different world and it's a different teaching and he is my teacher here."

Nandini's rejection of the educational expectations expressed by her husband, and her embracing of broader goals for her child's well-being, can be due to her own personal growth. At the same time, it may also be indicative of the shifting priorities among higher middle-class parents, especially in Hyderabad, who seek to augment a focus on grades with broader, more humanistic training for their children (Gilbertson 2014).

While Nandini's degree of self-reflection was exceptionally high, other parents (predominantly from nuclear, higher income, English-speaking backgrounds) also tied their own self-reflections to thoughts about society at large. For example, Rakhi, a 32-year-old mother with a post-graduate degree and a family income of 50–75,000 Rs/month speaks about her desire to draw from her experience to teach others:

"And I am even planning to do my diploma and train myself [in special education] so that along with my child, if I see an autistic child I can help him… As we got to know about our child's diagnosis very late, so I think if I can [gain this] knowledge, then I can help a child of another family, give them knowledge and awareness. So this will be helpful for everyone because in India, not everyone has knowledge about autism."

In contrast to relatively lower SES parents, higher SES parents such as Nandini and Rakhi, choose to move beyond their child's daily concerns to reflect on their roles vis à vis their child, and their situations in society at large. In expressing their

goals for their child, they focus on education and broader well-being, rather than independent living skills. Rather than viewing their child only as a burden—in the present and future—they choose to view their child as an opportunity to learn, as a 'teacher,' leading parents to re-think their own plans, such as attaining professional training, or re-thinking what is important for their own goals in life. These narratives are a stark reversal from traditional Indian family roles, and a form of 'cognitive luxury' in addition to socioeconomic advantage, which perhaps only parents of children whose basic needs are provided for are able to engage in. Further, their increased reflections on themselves and on society at large may stem from their more individualistic, English-based education, and their higher societal position.

Through these case examples, we begin to see how differences in parents' economic, educational, and family background may affect the views and expectations they hold regarding their child with autism—and how these subtle changes in parental views in turn affect their desires to change the views held by Indian society as a whole. It is important to reiterate, however, that while parents of different economic and educational backgrounds differed in the topics they mentioned at pretest, by the end of the 3-month programs, most topics—except for the focus on the child's cognitive skills—no longer differed significantly by demographic variables. Thus, the PCTP may have had an equalizing effect, suggesting that all parents move beyond their child's daily concerns to reflect more on themselves and on society at large—which indeed is a goal of the PCTP and AFA programs. Our follow-up studies of these families currently are examining whether parents of different SES strata maintain these views as they return to their families, and are faced with varying degrees of societal barriers and frustrations.

Discussion

Our study aimed to shed light on the processes which Indian parents of children with autism undergo as they learn new methods to socialize their child, while informing the field of autism treatment evaluations and providing practical knowledge for our collaborators at Action for Autism, New Delhi. The FMSS proved useful to elicit the narratives of parents who participated in the Parent–Child Training Program at AFA, before and after the program. One important difference between our coding procedure and the standard 'Expressed Emotion' coding (e.g., degree of criticism, or control) (Magaña et al. 1986) is that we did not ascribe any valence to parents' narratives, focusing instead on the range of topics raised by parents as they described their child. While this precludes any direct comparison of our findings with FMSS studies that scored EE, we instead examined the changing views of Indian mothers and fathers of children with autism, in their own words.

Our participants' descriptions of their children with autism—especially their focus on educational and daily-living skills—are similar to those expressed by other Indian parents of children with autism (Desai et al. 2012; Divan et al. 2012) and other disabilities (Edwardraj et al. 2010; Maloni et al. 2010), and are also comparable to descriptions by other parents of children with autism in other countries (Pituch et al. 2011). Although most parents mentioned social and

communication skills—two core symptoms of autism—few parents mentioned their child's repetitive behaviors and sensory interests, though these are common symptoms of autism as well. It is possible that parents simply do not find them as salient in everyday settings. Further cross-cultural studies of parents of children with autism can help understand which symptoms of ASD are more or less salient and troubling to parents of a child with autism.

After the PCTP intervention, parents were less likely to speak about other people and children, or to compare their child to 'normal' standards, which may be indicative of their increased acceptance of their child's diagnosis, and reduced concern over outside societal approval. Further, they were more likely to reflect on the growth and change they had witnessed, and discuss their thoughts for the future—a natural reaction to the end of their training program, and perhaps also a growing ability to think beyond the here-and-now. Of course it is not particularly surprising that some of the PCTP goals appear in parents' narratives right at the end of the program; the more significant finding would be to continue to find these themes a year or more after the program ends and parents are back in their homes and communities. This is what we are finding, for the most part, in our longitudinal follow-up thus far (Daley et al. in preparation).

We found that fathers were more likely to speak about their spouses, while mothers were more likely to speak about their relationships with their child and their roles within it, and the percent of mothers who mentioned these topics increased with time. Fathers' lesser degree of self-reflection and greater focus on their spouses is probably due to both the importance of the traditional role of mothers as primary caregivers in India, and the effects of mothers' direct participation in the PCTP. Though fathers are encouraged to participate in the PCTP, with 'father days' for fathers who live in Delhi, the fact that their wives have undergone intensive autism training may make husbands more, rather than less, reliant on their wives. The unequal participation of fathers in children's direct care and day-in-day-out upbringing is the norm across South Asia [e.g., (Edwardraj et al. 2010), and in the West (Karst and Van Hecke 2012)]. Nonetheless, fathers' ability to make meaning of their parenting experience and take on a problem-focused approach, rather than responding in blame and withdrawal, has been shown to improve family and child outcomes (Pakenham et al. 2006). Thus, if the goal for the families and for the PCTP intervention is to make fathers and mothers more coequal, it is important that parent-training programs, such as the PCTP continue to empower fathers to care for their child alongside their wives.

Though our sample comes from the top 10 % of the income distribution in India, demographic differences emerged even within this restricted range. Relatively less educated, Hindi-speaking parents from lower income, larger joint households were more likely to mention their child's independent skills and to speak about their concerns for their child after they die. In contrast, English-speaking, higher-educated parents from higher income, nuclear households were more likely to mention their child's cognitive skills, to reflect on their own role as a parent, and their child's role as a 'teacher,' and to assert their views on autism within society at large. Demographic and family differences within any community matter, and must be accounted for in any clinical and research encounter with families of children

with autism worldwide. Lower income parents' focus on independent skills, and higher income parents' focus on academic achievement—or rejection of such goals altogether—may be shaped by class differences in developmental expectations (Donner 2006; Gilbertson 2014). More striking, perhaps, is the tendency of higher income parents, especially mothers, to reflect on their roles regarding their relationships with their child, and to draw on these insights to voice their goals for societal change. Recall that these class differences in parents' narratives prior to PCTP were no longer significant after the program, suggesting that the PCTP had an equalizing effect on parents (at least right at the end of the program). As the PCTP family model scales more widely in India, and research with much broader, more diverse family samples becomes possible, the question of the effects of more nationally representative demographic and other family characteristics on (further adapted) PCTP interventions can be better understood.

At a time when parent and family outcomes in training programs for parents of children with autism are being given a renewed focus in autism research, a brief, open narrative method can provide useful information. The full PCTP study is using longitudinal mixed methods to track families eight and 15 months after the program, and the FMSS findings can be used to understand long-term changes in families, if changes are sustained after the intervention and do not wash out. Complementing quantitative evaluations, we can begin to identify the subtle shifts in parents' perspectives that may accompany PCTP-generated child and family outcomes: increased self-reflection, an increased ability to project beyond the here-and-now, and the sense of empowerment that stems from a better understanding of ASD along with better behavior management. More broadly, our study enabled us to examine how Indian parents of children with autism make sense of their child and their parental roles, and how they bring their local class and gender expectations into the growing global movement of individuals with autism and their families.

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