

Challenges, Coping Strategies, and Unmet Needs of Families with a Child with Autism Spectrum Disorder in Goa, India

Gauri Divan, Vivek Vajaratkar, Miraj U. Desai, Luisa Strik-Lievers, and Vikram Patel

Autism Spectrum Disorders (ASD) are increasingly recognized in developing countries like India. However, little is known about the experiences of parents raising a child with ASD. This study aimed to describe the experiences of families in Goa, India with a view to understanding the unmet needs of families raising a child with ASD. Twenty in-depth interviews and nine focus group discussions were carried out with families of children with ASD and key community stakeholders such as special educators, teachers, and parents of typically developing children. This qualitative data was triangulated to explore the experiences, life impact, and unmet needs of raising a child with ASD. Key findings suggest that raising a child with ASD puts a tremendous strain on families due to competing commitments, often leading to initial social withdrawal with later reintegration into social networks. Second, the impact is multidimensional, involving the personal sphere but also extending into the wider community with negative experiences of discrimination. Third, parents actively respond to these challenges through a range of approaches with help from existing and new social support networks and health care providers. Fourth, professionals from the health, education, and religious sectors have a low awareness of the unique needs of families living with ASD which leads to a considerable economic and emotional burden on families. Finally, as a consequence of these experiences, several unmet needs can be identified, notably for supporting increasingly isolated families and the limited access to multidisciplinary evidence-based services for ASD. *Autism Res* 2012, 5: 190–200. © 2012 International Society for Autism Research, Wiley Periodicals, Inc.

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Introduction

The Autism Spectrum Disorders (ASD) once considered rare [Gillberg, Steffenburg, & Schaumann, 1991] are now increasingly recognized throughout the world [Fombonne, 2009]. There have been a number of attempts to examine the experiences of parenting a child with ASD in developed countries [Altieri & von Kluge, 2009; Gray, 1994, 2001, 2006; Luong, Yoder, & Canham, 2009; Myers, 2009; Shaked, 2005; Tzoy, Connolly, & Novak, 2007; Woodgate, Ateah, & Secco, 2008]. Parents experience challenges at a personal and social level across various contexts. These include an increase in personal stress, effects on interpersonal relationships, as well as increasing isolation [Altieri & von Kluge, 2009; Wang et al., 2011].

These studies have shown that while the disruptive behavioral problems associated with ASD increase parental stress, parents harness a range of strategies that help them come to terms with the parenting experience. Examples of such strategies include acceptance of the biological basis for ASD (“accommodation”), “resistance,” to the biological basis, and “transcendence” of them (e.g.,

using a spiritual pathway to understanding their situation) [Gray, 2001]. Parental approaches across the studies have included empowering themselves with information, withdrawing from social interactions, redirecting their energies into areas beyond the child, changing their expectations, and working toward inclusion and greater acceptance [Gray, 2006; Luong et al., 2009]. However, unmet needs remain in both high and lower resource settings and primarily relate to the access to appropriate services. [Brown et al., 2010]

Contemporary literature on ASD in India has predominantly focused on reporting symptoms and profiles of small samples of patients from specialist centers or special schools [Juneja, Sharma, & Mukherjee, 2010; Kalra, Seth, & Sapra, 2005; Thomas, 2011]. While there is a growing body of literature which has explored the impact of other developmental disabilities on Indian families and the accompanying social ostracism and stigma that they face [Dhar, 2009; Edwardraj, et al., 2010; Gupta A, 2004; Kembhavi, 2009], there is comparatively little work which has explored the impact of ASD. A notable exception is the work of Daley in the 1990s [Daley, 2004; Daley & Sigman, 2002] who observed that whereas the Indian

From the Sangath, 841/1 Alto Porvorim, Goa, India (G.D., V.V., M.U.D., V.P.); Department of Psychology, Fordham University, Bronx, New York (M.U.D.); Neuropsychiatry Infantile Ospedale San Paolo, Università degli Studi di Milano, Milano, Italy (L.S.-L.); Faculty of Epidemiology & Population Health, London School of Hygiene & Tropical Medicine, London, UK (V.P.)

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Address for correspondence and reprints: Gauri Divan, Sangath, 841/1 Alto Porvorim, Goa 403521, India. E-mail: gauridivan@gmail.com

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specialist biomedical professional had a similar understanding of ASD as in the West, Indian parents sought help later, possibly due to varying cultural perceptions. Having a child is a personal as well as a social experience; when problems are experienced in the parenting process, the perceptions, understandings, and attitudes of community stakeholders, such as educators and professionals, also influence parents' patterns of seeking care [Mandell & Novak, 2005].

The state of Goa, in Western India, with a population of 1.4 million, is a "transitional" state with blurring of urban-rural distinction and better economic and health indicators compared to the national average; for example, female literacy is 75%, and the rate of institutional deliveries is 94% compared with the national average of 54% and 40%, respectively [Census of India, 2001; National Family Health Survey 3 (NFHS-3) 2005–2006 India, 2007]. In this context, survival is not a significant child health concern, and developmental disabilities are emerging as a child health priority. As in other states in India, the delivery of health care is conducted both through a publicly financed government health system and a fee levying private health sector [Reddy et al., 2011]. The health care system is pluralistic with people accessing western allopathic medicine along with a variety of other systems of medicine (such as Ayurveda and Homeopathy) [Pal, Das, Sengupta, & Chaudhury, 2002]. While there is no universal health coverage in India, a range of state and central welfare schemes address issues of disability and chronic diseases.

Building on the sparse evidence base, this paper aims to explore the life impact of raising a child with ASD, how families respond to the challenges they face, and their unmet needs for care, in Goa, India. Knowledge of the impact on families with a child with ASD could help identify unmet needs. In addition, a more contextual understanding of life impact would add to the growing research on special needs which focuses on more than just the extra burdens on families and instead describes the complex experiences and practical actions of families [Gray, 1993; Green, 2007].

Methodology

Setting

The present study was part of the Autism Research and Training Initiative (ARTI), funded by Autism Speaks, USA and implemented by a community-based nonprofit organization providing services for and researching developmental disabilities and mental disorders in Goa, India.

Participants

Two kinds of participants were recruited: parents of a child diagnosed with ASD and stakeholders concerned with child health in the community. Twenty in-depth

interviews (IDIs) (Table 1) and nine focus group discussions (FGDs) involving a total of 98 participants were conducted. The participants were purposefully selected to ensure representation of diverse subgroups of the population in Goa. Ten families (seven mothers, one father, and two couples) were recruited via key informants at special schools and child development centers. Children had been diagnosed by qualified clinicians against standard diagnostic criterion for ASD. Parent participants were purposively sampled for their ability and openness to share personal experiences; as a result, families that were recruited unevenly represented a higher educational and socioeconomic group background. IDIs were also conducted with a range of stakeholders who were actively involved in the care of children with disability either at a personal level (such as general practitioners [GP]) or at the level of policy (such as senior administrators in social welfare and education). Focus group discussions were conducted with teachers from varied educational settings in urban and rural locations. They included those working with mainstream children at a preschool and primary level as well as special educators directly involved with children with ASD. The special educators who participated were familiar with four of the children whose parents were interviewed. Community perceptions were elicited by conducting FGDs with parents of children in mainstream schools.

Interview Design and Format

The in-depth semi-structured interviews with families explored themes which covered early experiences of their child, the recognition of a difference in the child's behaviors, pathways to and patterns of help-seeking, experiences with health care providers, and unmet needs. The questions were open ended, and researchers explored the parent experience to get rich details of the lived experience. The full interview guide has been published elsewhere [Desai, Divan, Wertz, & Patel, In Press]. Each interview was conducted by two researchers, one as a lead interviewer and the other as a note taker in a single sitting lasting 1 to 3 hr with additional follow-up via telephone as needed. The language used was of the participants' preference (viz., Konkani, Marathi, English, or Hindi).

The themes for the focus group discussions covered the understanding of child development, the awareness and knowledge of disabilities including its causes, the experiences of stigma and discrimination observed in the community toward families and persons with disability, and community perceptions of inclusion.

For IDIs and FGDs with stakeholders unfamiliar with the diagnostic category of ASD, we presented a case vignette of ASD based on the Diagnostic and Statistical Manual of Mental Disorders (DSM IV) criteria to elicit

Table 1. Participant group for in-depth interviews and focus group discussions

In depth interviews with families of children with ASD		<i>n</i> = 10*
Family structure	Joint/extended	8
	Nuclear	2
Religion	Hindu	7
	Christian	3
Age of child with ASD (in years)	<5	1
	5–10	5
	10–20	3
	>20	1
Highest educational qualification of either parent	School	1
	High school	2
	Graduate	7
Gender of ASD child	Male	9
	Female	1
Occupation of the head of family	Agricultural laborer	1
	Government employee	2
	Private employment	7
In-depth interviews with stakeholder involved in the care of children with disability		<i>n</i> = 10
Government officials in Departments of Social Welfare and Education		4
General practitioners [GP]		6
Focus group discussions with stakeholder groups		<i>n</i> = 74
Teachers in mainstream schools [urban]/[rural]		6/10
Teachers in inclusive resource room in a mainstream schools working with children with ASD		6
Teachers in special schools working exclusively with children with disability [urban]/[rural]		7/8
Community preschool teachers [urban]/[rural]		7/14
Parents of typically growing children [urban]/[rural]		8/10

*Ten families which included seven mothers, one father, and two couples.

explanatory models about the condition. This case vignette represented a 6-year old with all the characteristic features of ASD. Case vignettes have been used to introduce community stakeholders to unfamiliar health conditions without using biomedical labels by creating a vivid, simple-to-understand “picture” of the disorder. The use of such vignettes to elicit views on mental disorders is a well-established methodology [Patel et al., 2007; Wig et al., 1980; Ying, 1990]. In addition to vignette-based responses, interviewees were also asked to think of specific children they may know within the community with behaviors similar to the child described in the case vignette.

Data Collection

The setting for data collection ranged from homes, the school, or the workplace. IDIs and FGDs were conducted by six qualitative researchers fluent in Konkani, Marathi, Hindi, and English. They were all bachelor degree holders with two having masters equivalent degrees and one at a doctoral level. All researchers received qualitative research training from local and national level resource persons. Each IDI and FGD was conducted by two researchers, one as a lead interviewer and the other as a note taker in a single setting lasting 1 to 3 hr. All interviews were simultaneously recorded.

Analysis

The analytic process is shown in Figure 1. The tape-recorded English, Konkani, Hindi, and Marathi interviews were transcribed verbatim into English by bilingual researchers. Local language interviews were translated into English by research members with fluency of each respective language. Before undertaking analysis, the audiotapes and transcripts were compared for accuracy by Vivek Vajaratkar and Gauri Divan. Meaningless or redundant utterances (“you know” or “this thing”) were eliminated to aid in clarification of analysis and readability. Any added language was placed in brackets and were intended to clarify particular sentences. The interview themes were developed iteratively, starting with the set of research questions by the authors. ATLAS-ti software (Berlin, Germany Scientific Software Development, 1999) was used for organizing and coding data. Codes from the data were identified and defined in an iterative manner. First, two interviews were coded by the three senior staff to generate a preliminary coding system until a consensus coding system evolved. This coding system was then tested by senior staff to achieve reliability by carrying out blinded double coding of two interviews. Analysis aimed at understanding the recognition of difference in the child’s behaviors, the pathways to and patterns of help seeking, the impact, the coping strategies, and the unmet

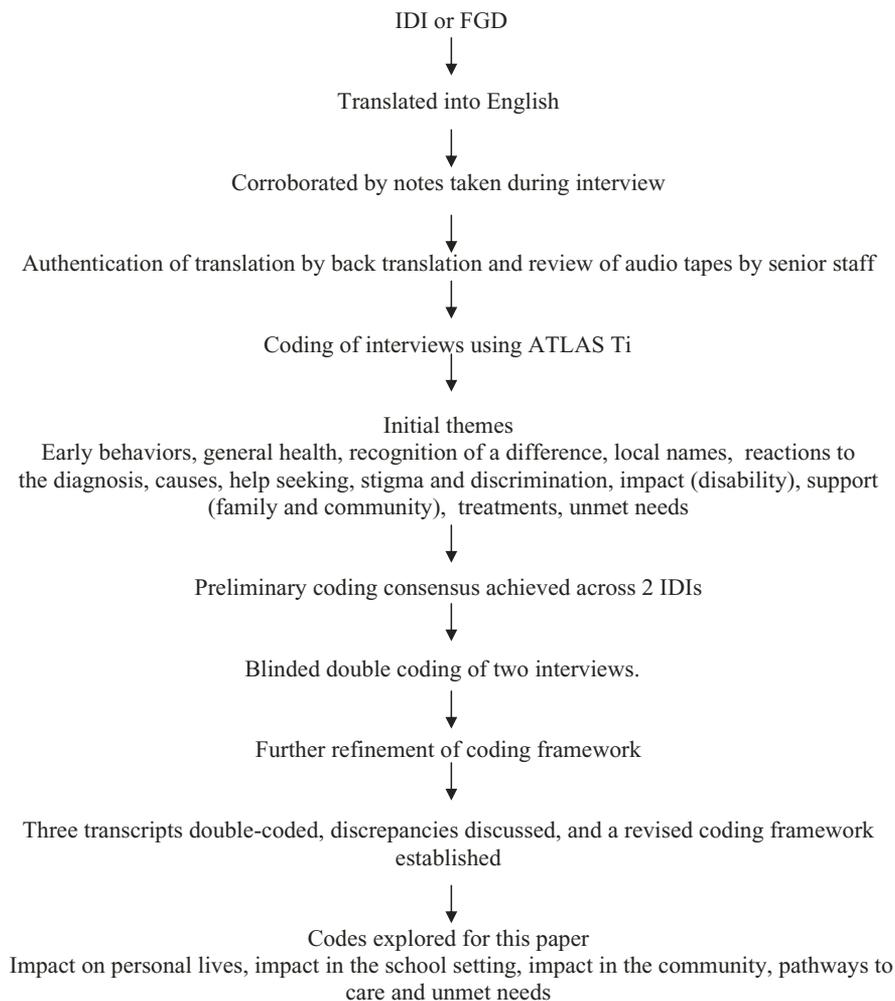


Figure 1. The analytic process.

needs of families with children with ASD. This resulted in a refinement of the coding framework. Three transcripts were then double coded, discrepancies discussed, and a final coding framework evolved. The remaining transcripts were coded using this framework.

Ethical Issues

Participation was voluntary and informed written consent was required. Ethical approval was obtained from institutional review board of Sangath. All results are presented in an anonymous fashion with the least possible identifying information.

Results

This paper describes the impact and changes to the parents' lives as they navigate the world around them with a child with ASD, the challenges parents face in their personal lives within the community and while negoti-

ating the health care and education system. Integrated into these narratives are the coping strategies and practical actions parents engaged in during this process. The phenomenology of the parents' experience of raising a child with ASD has been described in a concurrent paper [Desai et al., In Press].

Impact on Personal Lives: Competing Commitments

Most parents, especially mothers, have a strong commitment toward their children, spouse, and other family members. This section describes how these commitments compete at a personal level and affect relationships while caring for a child with ASD.

Parents' emotions and health. Most parents when they perceived their child was "different," sought understanding and assistance. Obtaining a diagnosis was a complex process, which is described later; however after an initial indifference to the diagnosis, reactions ranged from shock, disbelief, or rejection of the label. Initially,

most parents had yet to consider the concrete, long-range implication that was implied when professionals diagnosed “autism.” Almost all parents had never or only vaguely heard of ASD prior to receiving the diagnosis. A few parents immediately sensed the gravity of the situation on hearing the diagnosis.

I felt shaky . . . that something is wrong with my daughter . . . the reaction . . . Lost . . . Lost; I thought what is going to happen? At that time my husband was very focused on putting her in a renowned school. That dream was shattered for me.

One mother related her distress when she realized the implications of what having a child with ASD would mean for her family.

When I came to know about Autism, it was shock to me, my husband totally went mad. I was so frustrated that I felt like the three of us will go and commit suicide.

Sharing worries with the spouse was the predominant strategy between parents. Extended family members, especially grandparents, helped parents manage schedules and were often the first line of support. A general practitioner described the difference it makes to a child with disability when there are other family members in the house.

The presence of a grandparent makes a big difference. Because when the grandparents are not there, the child may not get enough attention as both parents may need to work.

Several parents stated that they had experienced significant health problems. These ranged from physical pains to disturbed sleep. For one mother, this physical exhaustion reached an unmanageable point.

Till he was 5 years I could not sleep in the night, I used to get black circles around my eyes, since he would run; not sitting in one place. I went through so many difficulties. At times I felt I don't want this child.

During the interview process, on an average of 7 years from diagnosis (range from 3 years to 21 years) most parents continued to express an underlying deep-seated worry for their child's future.

Withdrawing from life. The intensity of their child's needs meant that the professional lives of parents were affected—the mother, as the prime carer, adapted her aspirations and often became homebound. With fathers taking on the financial responsibility of the household, their working hours often increased, and one father relocated his work so as to supervise his son at home. A resource room teacher described one mother's increasing

social isolation and described the decrease in personal time for the mothers.

This mother says from the time he is born she cannot go out, because all the time she has to carry him, or he'll scream and shout. She has cut off all her friendships. It is basically a burden on the mother to take care of child. Since rarely the husbands cooperate.

Often parents dealt with the difficult situation by “locking the door” or closing themselves off from social interactions.

Life has really changed for me. I used to enjoy going out a lot before he was born; now I don't really socialize much. I normally don't go out with him and now I have to be with him even at night.

However over time, as parents became more involved with special schools and other parents, with a gradual re-integration into community life. Some mothers found rediscovering enjoyable activities a useful strategy. One described her initial 6 years of isolation which changed when she reentered the work place.

I used to put my heart and soul into work but then it was all the time for the Child, Child and Child. I used to get tense at home; thinking ‘what will happen to us? But now since I started working I am part of the outside world also.

Another mother adapted her work schedule.

I left my job and started to practice at home. I didn't leave my career. I used to work in the morning so I could spend time with him in the afternoon.

Disruption of family relationships. The time-intensive process of caring for a child with ASD influenced the quality of relationships with other family members, sometimes resulting in marital conflicts between spouses, increasing difficulties between parents and other children, and tense relationships between the usually supportive extended family networks. One mother in retrospect realized how she became consumed with caring for her son with ASD to the point of risking her marriage.

It has not been easy at all. I was kind of single-mindedly obsessed with bringing him up. I thought my marriage almost broke down because I neglected my husband.

The couple then explored religious sustenance resulting in a strengthening of their relationship and a reassessment of their future.

My husband used to be a social drinker and he used to get into lot of fights because of his horrible

temper. But because of this child today people say “What has happened to him? How has he become so tender?” Formerly religion was not so important but we turned to God.

Occasionally the conflict was due to a lack of understanding of the reason for the disorder which resulted in the “blame game” between the parents. A special educator described the accusations which parents often threw at each other.

I have heard husbands tell their wives “Because of you, this child is different”, and many mothers have cried in front of us.

Parents reported that other siblings were also affected. A mother reported her older daughter yearning attention that her sibling with ASD received with a plea.

Mamma you spend so much time with him and don't take me anywhere anymore.

A GP perceived that families faced difficult choices concerning the family's financial security and parenting duties.

In coastal belt, most of the people in the families are busy in the tourism business trying to earn a living. Often they hardly have any time to devote to the special child. In such cases, the child could turn into a burden for the family.

Impact in the School Setting

Typically, the child's differences came to parents' attention because of increasingly disruptive behaviors in school. Some educators were empathetic, but for one family the news that the child had difficulties was communicated via an accusation.

The teacher called me one day and said, “Why did you hide this from us?” I said honestly I didn't, I don't see a problem in her. She said, ‘Don't you know that she has some problem!’ while pointing to her head.

Although preschool teachers said that they had knowledge of child development, none of the participants of the FGDs were able to recognize the case vignette of a child with ASD as having a specific disorder. When the term Autism was introduced into the discussion, they stated familiarity with the term, attributing this to a recent television soap opera which had a protagonist named *Antara* with ASD¹.

¹*Aapki Antara*. In this Hindi TV soap opera, a girl with ASD is abandoned by her mother. The storyline revolves around the father's initial denial and later acceptance of the diagnosis, with help from a special educator.

We have heard about it on TV. People used to call these children ‘ekhulo’ or ‘the person who likes to be alone,’ before this.

The need for greater awareness among teachers, given their central position in Goan children's lives, was emphasized by a GP.

What is needed is sensitization of school teachers who can identify or at least suspect cases of Autism. The teacher is in a very unique position; they can observe many of the children . . . so it is easier to spot that the child who maybe having some problem.

After a diagnosis, the school became an important support for parents. Resource room teachers reported the benefits of respite provided by the school setting.

They are just happy that their children are going to school. They are away from home for half a day. Some parents after the holiday say ‘Oh God! We were waiting for school to start.’

In contrast to a “special” school which identified their child as being “different,” going to an inclusive school with neighborhood children gave a semblance of “normality” to some families. Resource room teachers described this attitude.

Some parents said ‘No one should know that my child is going to a Special School.’ There is quite a social stigma that something is wrong with my child if he is going there, whereas here in the resource room it is in a normal school.

Impact in the Community

The surrounding community was a key influence on the overall experience in caring for a child with ASD. For some parents, concerns about their child's safety occasioned the search for safer neighborhoods. Three mothers had moved to Goa to be closer to their families. These parents identified the slower-paced, supportive environment in Goa as more comfortable than the fast-paced metropolitan areas of India or other parts of Asia.

When I came to know about my son's problem I left my job abroad and came back. The support system was not good enough there.

Parents made proactive choices of not sending their child out in the community to play, of not visiting certain places, and of curtailing celebrations such as birthdays in light of past or anticipated negative experiences.

Each episode ends with a short real life story of Indian parents sharing their experiences of raising a child with ASD. <http://apni.tv/serials/aapki-antara.html>

I can't go to church because he screams and shouts and that is the place where you have to be quiet and calm.

A mother, who had also stopped going out, managed her interactions in the community so as to allow her son with ASD to socialize in a limited way. She did this by organizing the way she and her husband visited a party in a staggered manner; this allowed her daughter to enjoy the event and allowed her son not to be overwhelmed by the social interaction.

We had completely cut down on socialization in the past few years. Then I devised another system, as we had two cars. I went earlier with my daughter, socialized for some time then my husband used to come with him. I used to serve him food and leave.

Siblings were also influenced by the comments made by neighbors. One sister stopped going out with her brother when he was labeled as being "different." This lack of awareness and insensitivity in the community was evidenced by children being labeled "pagal" (mad), a derogatory term. Preschool teachers described the tendency of society to blame parents for disorders where the cause is not understood. In a setting where arranged marriages are the norm, a special needs child would affect the marriage prospects of siblings and even cousins. A preschool teacher described a visit to the house of a child with special needs.

Once I had gone for a home visit to meet the parents. I asked some children in the neighbourhood for their address and they directly asked me 'Kunacha thia vedyanchia?' [Are you looking for that mad child's house]. People treat them very badly in the villages. They don't allow them to play and mix with other children.

Though negative experiences resulted in the parents isolating themselves and their child, positive experiences reassured and allowed parents to renegotiate these spaces. As one mother described the support found unexpectedly while on public transport.

Sometimes when I travel by bus, fisher folk say 'Na urun di dev boro kartolo' [Let it be. God will make him fine].

Another mother described the unpredictability of interactions within the community.

Some people understand his condition and behave properly with him. But some of them don't understand what is wrong with him . . . my child doesn't look different . . . he looks normal. At that time I have to tell them that this child is not okay.

The influence of the media in the local context was also reflected by a group of parents.

This awareness for autism has been done very well by Shah Rukh Khan [a film actor]. I didn't know the word autism. After watching the movie I came to know that there is something called autism. We don't know that there are special words for these problems. We thought that he is "Piso" [mad]. After watching that movie I came to know they need special training and with that they can improve.

Pathways to Care

The experience of seeking external help involved multiple consultations in which families did not receive satisfying answers and were confronted with the lack of accessible support and resources when a serious problem was perceived. The majority of families consulted practitioners outside Goa, often requiring long stays in metropolitan centers. Parents sought multiple opinions because the diagnosis itself did not make much sense to them, or because they were dissatisfied with the information or treatment that was offered. Most families had consulted initially with a general pediatrician and later a developmental pediatrician. Other health care professionals consulted included neurologists and ear, nose, and throat specialists.

GPs who are responsible for routine child care were not confident in describing diagnostic criteria for ASD. When introduced to case vignettes, though they recognized that the child had a "problem" requiring further referral, they were hesitant to use a specific diagnostic label. One of the GPs stated:

I won't say the diagnosis because I don't claim to be right. Autism is something that cannot be measured in easy terms. It requires a detailed analysis. So I tell the parents that at least you seek a senior opinion.

The interactions with biomedical doctors and complementary treatments resulted in many adverse experiences for parents, including dissatisfaction and financial strain; for example, one child was inappropriately prescribed an expensive hearing aid which was never used. A father spoke about the long journeys and the financial burden of multiple consultations.

We checked him at the government hospital. They checked his brain. They sent us to the Mental Health Institute; there they gave him medicine and called him every Monday. We took him there 10–12 times. But there we did not get much benefit. They gave us only sleeping tablets; they thought if he sleeps he will improve. Then we took him to a private doctor. He now needs Rupees 1500 for his tablets every month. I am now thinking of taking him to another doctor, I have heard he is giving some tonic for the brain.

The difficulty in accessing ASD specific interventions proved a challenge for parents.

When he was 6 years, he had this problem. At the centre they told us that there is no need of giving him tablets, he only requires to be given speech therapy. However it was not possible to go every day so we went for only a few days.

In contrast, some parents had positive experiences of mentorship from professionals. Special educators were the main advocates for most of the families providing educational inputs and emotional help. Parents characterized the respective educators as “inspiring,” “pillars of support,” and a “source of pride.”

Religious support was central for the majority of families. Most experienced healing retreats as transformative, calling it “divine”, “miraculous” or an “inner healing.” Other common practices included prayers and ceremonies to remove “bad spirits,” consuming blessed foods and holy water, making offerings, tying holy threads, and fasting. Some parents, however, felt that occasionally, religious practitioners took advantage of the families’ misfortunes. Special educators described the risks of informal help seeking from their perspective.

This family had a lot of faith in this place of worship. They used to take her there and they would tie a ‘dore’ [holy thread], then slowly they stopped her medication and left it completely to God. It has been told to them by someone who gets ‘Bhar Yeto’ [possessed by spirits] that there is no use sending her to school . . . and now the girl is ruined.

Traditional Indian systems of medicine, such as Ayurveda, were consulted by a majority of families. Besides educational inputs, these were the most consistent preferred treatment for many of the children. Practitioners were recommended by family and friends with positive results as described by a mother.

People don’t trust Ayurvedic doctors, but I got benefit from the treatment. My son was not giving eye contact, not understanding anything. I started him on Ayurvedic medicine, within a month he started giving eye contact and his progress started. He continues on that medicine.

Discussion

We aimed to describe the impact of living with a child with ASD in Goa, India through qualitative research with families and diverse stakeholders. We observed several key findings. First, raising a child with ASD puts a tremendous strain on families due to competing commitments, often leading to initial social withdrawal with subsequent reintegration into social networks. Second, the impact is multidimensional, involving the personal sphere but also extending into the wider community

with negative experiences of discrimination. Third, parents actively respond to these challenges through a range of approaches with help sought from existing and new social support networks and health care providers. Fourth, professionals from the health, education, and religious sectors have a low awareness for the unique needs of families living with ASD which leads to considerable economic and emotional burden on families. Finally, as a consequence of these experiences, several unmet needs can be identified, notably for supporting increasingly isolated families and the limited access to multidisciplinary services for ASD.

Our findings that emotional distress was a major impact on parents is consistent with other research on disability in general [Dhar, 2009; Green, 2007; Mirza, Tareen, Davidson, & Rahman, 2009] and families affected by ASD in particular [Gray, 1994; Gupta A, 2004; Mori, Ujiie, Smith, & Howlin, 2009]. Emotional stressors often related to interpersonal interactions. Parents struggled with managing various relationships with spouses, other children, and extended family members due to the increased attention required for their child. However, few external supports directly addressed parents’ emotional distress.

Previous studies on ASD [Vaidya, 2009] and disability [Dhar, 2009; Edwardraj, Mumtaz, Prasad, Kuruvilla, & Jacob, 2010] have observed the social isolation and community intolerance experienced by parents and the problems of negotiating public encounters. Similar difficulties were experienced in our sample of parents. This included insensitivity in schools and negative comments made by community members which resulted in parents restricting their movements. Stakeholders confirmed the negative labeling and exclusion of families of children with disability by society. However, most parents, over time, developed allies within extended family and social networks. Inclusive resource rooms in mainstream schools were also creating an atmosphere of tolerance among unaffected students and parents.

Despite the various adverse situations, financial constraints and limited services, the majority of parents had innovated strategies for creating a secure, loving, and rewarding space for their child and families. These strategies included actively going out to work, selective disclosure to close family, seeking religious help, and situational and selective socialization with gradual reintegration into wider community networks; similar strategies have been described in other studies with families with children with ASD [Gray, 1994, Wang et al., 2011, Woodgate et al., 2008].

The pathways to care were a difficult journey for many parents even in the context of the relatively well-resourced setting of our study. The pattern of multiple consultations has been described more generally in India [Daley, 2004; Vaidya, 2009]; however in the absence of adequate universalized health coverage, multiple consul-

tations lead to great financial burden on parents due to out-of-pocket expenses. Families described having to take financial assistance from the extended family network to support these costs of care. Multiple consultations also reflected the unfamiliarity with the diagnosis of ASD in the wider community.

Resource room teachers reported that “sending a child to school” was a strategy which primarily served the function of respite. This is consistent with other authors’ descriptions of respite care serving as a fundamental support for parents whose children had severe behavioral problems [Gray, 2003]. The lack of any organized respite care for parents in Goa reflects the paucity of any ASD-specific services and services for disability in general in India.

We acknowledge the limitations of our study. The relatively small numbers in our sample and the specific context of the study was aimed at acquiring rich descriptive data; as a result our parent group is nonrepresentative of the general population and, therefore, generalization of our findings should be considered with caution. However, we note that our findings are consistent with other studies from India and other countries. Thus, even though our sample represented a relatively “informed” group of parents and stakeholders, our findings of low general awareness, unsatisfactory experiences of help seeking and unmet needs even for such a sample indicate the likely large gaps in access to care and size of unmet needs in the larger population in Goa and elsewhere in India.

Our findings indicate that having a child with ASD puts a tremendous strain on the personal and emotional resources of families. They suggest the need for two major strategies to address the unmet needs of families. First, there is a need to build awareness of ASD and its impact on families in order to facilitate early detection and help seeking and to combat stigma and discrimination. Parents and families need to be empowered; parent support networks have been successfully established in India for families of children with cerebral palsy [Goldbart & Mukherjee, 2000], and this model could be extended to ASD to strengthen family resilience and to challenge stigma and discrimination [Desai et al., In Press; Papageorgiou & Kalyva, 2010]. Second, there is a need to greatly expand the coverage of evidence-based services by the health, social, and educational sectors [Abelson, 1999]. Studies from developed countries suggest that early diagnosis and intervention improves outcome for children with ASD [Dawson, 2010]. However, these remain specialist-intensive high-cost programs [Jarbrink, 2007; Knapp, Romeo, & Beecham, 2009] with limited applicability to settings like ours where skilled human resources are few and unaffordable. There is a need to develop low-cost models emphasizing the shift of front-line interventions to more readily available,

less specialized, human resources. This approach of “task shifting” has a growing evidence base for other mental disorders. There is an urgent need to build on these diverse experiences to develop “packages of care” [Patel & Thornicroft, 2009] for ASD and other developmental disorders, which can be delivered through a collaboration between trained community health workers and parents.

In conclusion, this qualitative study observed a range of adverse impacts associated with living with a child with ASD in Goa, India. Most parents undertook diverse strategies to address the challenges they faced, in the context of a health and social welfare system which had very limited awareness of, and services for, ASD.

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