

‘It has taken me into a whole new life and world, a turning point’: Fathers’ Experiences of the Diagnosis of Autism

Dr. Vijaya Jagan^{1*}, Dr. Anuradha Sathiyaseelan²

ABSTRACT

This manuscript focusses on the experiences of fathers before and after the diagnosis of autism. Using a qualitative approach, the study mapped the passage of twelve fathers of children with autism. Though the diagnosis was perceived as being devastating and shocking it opened the pathways for treatment and interventions. The new situation led to confidence, cognitive valuation as well as a sense of empowerment for the fathers. The major challenges were their child’s uncertain future, social survival, and the child’s potential for future independence. This study makes a significant contribution to the existing literature as few studies focus on the personal experiences of fathers. The extent of involvement and the intense desire to work with their child clearly shows the evolving role of fathers in our society. There is a need to encourage, value their contribution, and engage them in the child’s special education process and intervention activities.

Keywords: *autism, autism spectrum disorder, fathers, diagnosis, qualitative*

“It was like really... I would say really sad and low. That is the lowest point. Personally, for me, it was the lowest point I would say. For almost six months I just... I just I couldn’t believe it... I said all the psychiatrists... all are lying...(P:6)

The birth of a child is often awaited with a sense of joy and incomplete grasping of parental responsibility. But nothing can equal the unanticipated arrival of a child with special needs. Autism a neurodevelopmental disorder is characterised by lifelong and pervasive impediments in communication, reciprocal social interactions, and the presence of repetitive, restricted, and stereotypical patterns of behaviour ([APA], 2000). Receiving the diagnosis of autism could mean the loss of a ‘normal child’, lost hopes and dreams, an insecure future, and is linked to bereavement and grief (Ariel & Naseef, 2005). Many parents find it hard to alter their expectations and realign their dreams to match the challenges presented by the special needs of their child (Hanson & Lynch, 2013). As parents try to cope with the unknown fears of what lies ahead, they are faced with the struggles of dealing with the responses of the family, friends, and sometimes the medical professionals. This stress may interfere in parents reaching out for special intervention services for the child.

¹Department of Psychology, CHRIST (Deemed to be University), Bengaluru, India

²Professor, Department of Psychology, CHRIST (Deemed to be University), Bengaluru, India

*Responding Author

Received: June 5, 2020; Revision Received: June 21, 2020; Accepted: June 25, 2020

'It has taken me into a whole new life and world, a turning point': Fathers' Experiences of the Diagnosis of Autism

Though numerous studies focus on the stress of parents on receiving the diagnosis only a few provide qualitative data through interviews (Glynne Owen, 2016) and rarely studies that target the personal experiences of fathers. Being a significant contributor to the child's welfare, the societal interest in the father's role has advanced tremendously over the years (Tamis-Lemonda, 2004). Father's thoughts, attitudes, and caring towards his children have a more beneficial effect on the child's socio-emotional development than does the amount of time spent in engaging and interacting with the child (Easterbrooks & Goldberg, 1984). Gray (2003) states that fathers respond differently to the unique needs of the child with autism than mothers. Hence studying and exploring the experiences of fathers in the life of a child with autism especially in the Indian context is important as the research in the domestic context is limited. Local descriptions in the cultural context will help in enhancing and empowering community-based care as parent perspectives may differ across countries (Divan et al., 2012).

This manuscript examines two themes that developed from one objective which emerged from a larger interpretative phenomenological study on the experiences of fathers of children with autism. The specific objective was:

What are the experiences of the fathers before and after the diagnosis of autism?

Research design

Using the Interpretative phenomenological framework (Smith, Flowers, & Larkin, 2009) this study has tried to understand the experiences of fathers around the diagnosis of autism. Qualitative methods help to expand our understanding of the social phenomena including the growth and changes (Attride-Stirling, 2001), and are relevant for exploring areas where studies are limited and little is known from the "inside" perspective. (Padgett, 2009).

Sampling and recruitment

Participants were recruited from special schools based in three cities from the Southern part of India. Convenience sampling for schools and purposive sampling for participants has been used. The inclusion criteria were fathers of boys with a formal diagnosis of autism aged between six to 11 years. Additional criteria were fathers who have no mental health issues or alcoholism, aged between 30 to 45 years, fluent in English, married and living with the spouse, employed, from the middle socioeconomic status, part of a nuclear family and with or without a neurotypical child (additional children). All the boys were part of special schools. Two screening tools the General Health Questionnaire (12 items) and Kuppuswamy's Socio-Economic Status Scale 2015 were administered. The participants were referred by the Head of the Institutions. Once referred the initial screening was done by the researcher and the participants who fit into the inclusion criteria were contacted over the telephone. The researcher contacted 41 fathers. Most of them cited work as a barrier to meet. A few felt they wouldn't be comfortable to speak. Possibly due to this literature has consistently indicated the need for more studies with fathers (Flippin & Crais, 2011; Hunt-Jackson, 2007; Dollahite, 2003). 12 fathers agreed to participate in this study. The average age of the fathers was 41 years, and the child with autism was 8.5 years. All the participants were given details about the study, their doubts clarified and a convenient date and time for the interview were fixed.

The sampling procedure is focussed in contextualising the study within this specific setting and the intention is not to generalise the results to all families with autism.

'It has taken me into a whole new life and world, a turning point': Fathers' Experiences of the Diagnosis of Autism

Data collection process

All interviews were face to face, conducted in the respective schools, and were completed in five and a half months. One pilot interview was conducted. Before the interview, participants filled the demographic details and the informed consent form was signed. Aspects of confidentiality were explained. Data were collected through a semi-structured interview guide consisting of a set of open-ended questions. This allowed the researcher to get deeper insights into their psychological world, explore and inquire about the participants' realm, their close experiences, and subjective meaning attached to these experiences (Todorova & Kotzeva, 2006). All Interviews began with the question 'What were some of the earliest behaviours you observed and led you to be concerned about your child?' The flow of questions facilitated in expressing their entire range of thoughts, feelings, and experiences. This involved the researcher to listen and be where the participant is, engage meaningfully with them in consistence with their nature, and use appropriate "probes" to encourage and build upon their answers. Each interview lasted between two to two and a half hours.

Establishing validity is an important step in Qualitative research and can be condensed as to whether the researchers see what they think they see and is about being truthful and accurate at all stages. Keeping this in mind the researcher in the present study has clearly stated and maintained reflexivity involving self-disclosure that underlies the researcher's beliefs, values, prejudices, and biases that possibly affect the process of inquiry. The researcher has been mindful of the thoughts and feelings and has 'bracketed out' the self-experiences and deliberately put aside the knowledge about the topic to be researched (Speziale & Carpenter, 2007). Additionally, member checking which is participant validation, a thick description which means a rich and detailed sketch of the participants, their settings, the situation, the interactions with finer points, and the themes that have emerged have been presented. An external coder who performed the analysis independently was also involved in validating the developing themes. During the entire process of analysis starting from the fixing of the interview, the researcher kept a reflective diary that was maintained throughout the study thus providing an audit trail. After each interview, the researcher noted the nonverbal behavioural responses of the participants, the researcher's subjective feelings, any unique responses of the father, and other general reflections about the entire interview process. The study has secured the approval of the Institutional Review Board (IRB) from the University. The content being emotional it was possible that participants might experience psychological stress and hence a list of contact services e.g. counselling services was kept in hand by the researcher. The participants had the right to withdraw from the study at any point in time

Data analysis

The individual recordings were transcribed and the participants have been referred to as P:1, P:2..... P:12. After each transcription, the narrative was read listening to the audiotape and any missing words, gaps, or identifiable information were added or deleted. The reading and rereading of the transcript helped to develop familiarity with the narrative, leading to the participant becoming the focus (Smith, Flowers, & Larkin, 2009). The transcript was divided into three columns. The mid-section consisted of the original transcript. On the right-hand margin, the initial notings and exploratory comments were written. The comments included annotations, important observations, summaries, the language used by the participant, and interpretations of the data. The left-hand margin consisted of the emergent themes which were 'concise phrases' (Smith, Flowers, & Larkin, 2009) and a

'It has taken me into a whole new life and world, a turning point': Fathers' Experiences of the Diagnosis of Autism

further level of abstraction based on the researcher's interpretations. At all times, the themes were rooted and remained connected to the participant's narratives. All the themes were then listed in the order they appeared in the transcript. Connections were found between some of the themes, and they were clustered together forming the superordinate themes. Some themes were dropped at this juncture as they did not fit well or were not very descriptive. A table of all the superordinate themes and the themes that comprises it with the verbatim of the participant was generated along with the page number. A summary of the results was developed for each participant. The above steps were followed for each transcript. Once all the 12 transcripts were analysed, a cross-case connection was established by examining the patterns across the narratives. The list of themes and superordinate themes for each participant was printed and cut out. They were then pasted on a larger chart and moved around looking for commonalities and differences. Sometimes similar themes were merged. Some themes were specific to a particular participant but not to others, and they were also chosen to give voice to all the participants equally. In the larger picture, this was required to understand the fathers' experience as a whole. Since the same superordinate themes presented itself differently across different narratives, a broader look at commonality was considered. This led to the master themes on the fathers' experiences around the diagnosis of autism and are presented below.

RESULTS AND DISCUSSION

While each participant had an individual storyline, the commonalities in their journey have been strung together. Two key themes and subthemes focussing on the fathers' experiences around the diagnosis of autism are presented below forming the basis of the discussion (1) Making sense of the early warning signs and (2) Impact of the diagnosis. Within each theme, a few subthemes and experiences were unique to a group of participants, and these have been included.

1. MAKING SENSE OF THE EARLY WARNING SIGNS

With fathers becoming cognizant of the child's problems and their delayed milestones the prediagnosis period was replete with confusion and unease. The sub-themes with a few verbatims describe the journey as the fathers' orient towards autism.

Understanding the atypical behaviours. Parents often become aware of the child's delayed milestones by 18 months (Lutz, 2008; Daley, 2004) and in the present study, the fathers became aware by the time the child was one and a half to two and a half years of age. Though they were not thinking of the actual developmental milestones, all fathers were highly perceptive of the differences in their child. They recognised and expressed symptoms that looked markedly distinct like 'no eye contact,' 'not noticing much,' 'no gestures' 'not listening.' 'being in his own world' 'non-responsive'. These words show that they were puzzled and were unable to make sense of the unknown and unexplained behaviours. Feelings of confusion and frustration during this prediagnosis period have been reported in other studies (Chilton, 2012; Keenan et al., 2010).

Speech delay and social difficulties. One of the earliest behaviours that the fathers in this study discerned was the delay in speech and this been shown to be one of the most commonly noted difficulties in children with autism (McConkey, Truesdale-Kennedy, & Cassidy, 2009; Chawarska et al., 2007). Some fathers linked it to hearing problems as the child did not respond to name-calling. Due to sensory issues children with autism may be less sensitive, oversensitive, or not be sensitive to auditory inputs. It is in environs where the

'It has taken me into a whole new life and world, a turning point': Fathers' Experiences of the Diagnosis of Autism

child has to build or move with peers that the social difficulties become more visible and this happened in the case of three fathers (P:5, P:11, P:12) when they received feedback from the playschool about the child's suspected hearing and social interaction problems. In the Indian context, the study by Daley (2004) done in the region of Goa found that a greater proportion of parents identified the social difficulties first rather than the communication difficulties which she speculated was possibly due to the higher values of social conformity placed in Indian culture. Daley (2004) notes that the belief systems can cause confusion and the parents may wait before they meet a professional. A psychologist in the same study by Daley (2004) explained how due to the cultural influences a quiet child, who is devoid of emotions and keeps to oneself can be interpreted as a good child. This was found in the present study too. The standards for the child development are defined by the cultural background wherein a lower level of activity or unusual behaviour is acceptable and thus may affect the way a symptom is interpreted as being problematic (Kumar, 2005). Additionally, this can be explained through the adult distress threshold model (Weisz et al., 1992) which looks at the cultural influences in the acceptance of a child's undesirable behaviours. According to this model, the cultural effects set the adult threshold for the distress experienced in response to children's problems which decides whether the problems are salient enough and warrant action. Though children with autism have difficulty in forming social relationships, fathers in the present study considered it a behaviour that probably could have other reasons and hence they interpreted it as being 'pampered', 'naughty', or 'childishness'. They saw these behaviours as part of growing up and there is a possibility that it is preferable to call the child naughty or pampered than being tagged with the label of autism.

Identifying similarity between child and self. As fathers described the child's speech and social difficulties eight fathers observed similarities in the behaviours between themselves and their child especially in the areas of speech and social interaction.

"many of my son's features I feel resembles myself. I mean on the speech front. Any new person I am always not comfortable. If it is a new person, I am reserved. I take some time. I can't sit in a place for more than an hour. But if needed I can sit for the whole day also. I was very poor in studies. I am doing well for myself in spite of it (laughs)." (P:4)

Fathers saw these behaviours in themselves perhaps as their extension and hence did not see their child as 'only having deficits'. On the other hand, there was a fear if they were the cause as the etiology of autism is not clear, and one of the causal models includes the genetic linkage model (Sarrett, 2015).

"Yes, sometimes I felt responsible. Doctors say it is genetic and it is inherited from the father's side that's what the Doctors say. Sometimes we feel we shouldn't have planned a child...I felt very affected because I thought I was the cause. It has affected me my work a lot...I used to make silly mistakes at work... and it used to run in my mind that am I the cause.... (P:9)

Identifying similarities could either make the fathers feel guilty by targeting themselves as the cause of autism or could minimise the effects of the disability. This comparison reflects their strong inclination towards normalcy so the child can break away from the 'special needs' tag. Psychologically it provided an opportunity to express the traits they probably had repressed within themselves (Axup, 2012). Surprisingly fathers in the present study

'It has taken me into a whole new life and world, a turning point': Fathers' Experiences of the Diagnosis of Autism

identified the area of weakness, but no one spoke of the positive traits in themselves that the child carried.

Relying on professionals-contentment vs. discontentment. All fathers sought the allopathic doctors when they suspected the disparity in their child's behaviours which shows their belief in the biomedical perspective. The socio-economic status does not determine whether a child has autism, but it may play a part in determining whether or not a physician screens for autism (Gibson, 2014). Most families visited their pediatrician followed by other specialists like ENT, neurologist, and psychiatrist. The quest for the diagnosis was a common thread running across the narratives. Many families sought multiple opinions from different medical professionals. Father (P:1) said they visited almost 9 different psychiatrists just to get multiple opinions. The reason for seeking this kind of multiple viewpoints was described by one father (P:6) as 'collective wisdom' and expectations of some positive feedback.

Pediatricians initially tried to bring down or discount the worry and anxiety of the parents by maintaining that the child will grow out of it, or it could just be a mild delay, and to come back if the problems persist. Fathers in this study relied heavily on the professionals. Daley (2004) says that in India, doctors are often viewed as 'next to god', and parents very earnestly seek out the best of the doctors in their area. In the present study, the experiences of the fathers with the medical and other intervention professionals moved between being content to discontent depending on the information being sought. Some were frustrated because they did not get enough information and understanding about autism and yet others because of the constant suggestions of occupational therapy. P:10 felt upset because the 'child specialist' had not informed him appropriately and at the right time though they had taken the child with observable delays. His anguish being early recognition would have given them early access to intervention. He further felt that professionals ignore the child's uniqueness and are non-inclusive. Another father received an initial diagnosis of 'developmental delay.' One father (P:11) was upset as the doctors didn't want to give the parents any hearing or lend an ear to their experiences and would just shut them off. Similar discontent and unhappiness with medical professionals have been described in various studies (Kalash & Olson, 2012; Phelps et al., 2009; Burrell, Ives, & Unwin, 2017). In the absence of specific biomarkers or blood tests to identify autism, professionals find it difficult to give an accurate diagnosis. They depend on their observations, parents' inputs through interviews, and interpret the feedbacks in the backdrop of their medical experience. Thus, the severity of autism may depend on how "abnormal" a particular behaviour is considered by the professional which may differ from one to another (Chi, 2014). It becomes all the more important that the practitioner spends quality time with the parents, explaining the causes, the treatment options, and the long-term prognosis. This is important because all parents are not aware of the developmental milestones and the fact that such delays could be part of a larger problem like autism. A few fathers believed professionals are practical, balanced, present the real picture, and gave hope for improvement. The acceptance depends on the state of mind, as P:8 stated

"Maybe as parents, we want to hear something we want to hear. Maybe as parents, we may not be in a state of mind to accept what they are saying. Maybe what they are saying is true. So, can't blame them".

'It has taken me into a whole new life and world, a turning point': Fathers' Experiences of the Diagnosis of Autism

Orienting towards autism. With the inputs from the professionals, fathers started moving and aligning themselves with the new knowledge. They became more vigilant and started observing the child more intently and every observation which was against the diagnosis gave them hope. It was self-assuring and a father described it as an 'expectation belief' that autism won't be true.

"things were not okay.' "We were praying inside that he should not fall under autism. that's all... he will still be okay... he will be okay...even now I feel he will be okay. So, we had a thin hope that he will be okay as an expectation belief...at the same time he is showing the behaviours of an autistic kid." (P:1)

These experiences reflect the dilemma and confusion that prevailed and were seen throughout the journey at different junctures and various stages of development. The uncertainty stemmed from what they were observing in their child versus the information given, and further the inconsistencies in the child's behaviours itself. The diagnosis eventually gave fathers an understanding of the child's behaviours by giving it a context.

2. IMPACT OF THE DIAGNOSIS

The diagnosis of autism was distressing and indeed a defining moment for the fathers. Looking back, they were able to recollect and revive the painful feelings experienced then. The diagnosis meant losing a sense of normality and adapting to the new status was indeed sorrowful for the fathers. But in the same breath fathers also spoke about the benefits of diagnosis as it meant looking for potential solutions and interventions. Bury (1991) describes this as a cognitive process wherein an individual learns to effectively come to terms with the effects of illness. The subthemes describe the recreated path of the fathers with newer understandings and learnings.

Devastated by the new understanding. All children had the diagnosis by the time they were four years of age. In consonance with the literature (Burrell, Ives, & Unwin, 2017; Ooi, Ong, Jacob, & Khan, 2016) the diagnosis of autism was perceived by the fathers as a setback and was described as devastating, confusing, saddening, and shocking. Even though the fathers had a clue and some were already exposed to this word and world of autism, the actual moment of the diagnosis of autism was articulated through strong emotions like 'went in without knowing anything... came out with a shock', 'helpless,' 'broke,' 'upset' 'setback' 'didn't sink in,' 'world came crashing down.' One father (P:1) was in denial and thought 'autism was a funny name and it doesn't mean anything.' The diagnosis carried personal meaning to the fathers. For one father it was a project to be completed successfully, for another a condition to be fixed and some blamed themselves for vaccinating the child which is in line with the vaccines as a causal theory of autism. But for all, autism was a continuing journey and that was disheartening. As one father said, "somehow deep within, I knew this is never going to end. It's not going to be easy. A long journey.... Something much more than I thought it was." (P:7).

Though there was a diagnosis of autism, some fathers avoided using the term. While they were not averse when the researcher used it during the interview, they often referred to autism using terms like 'this problem,' 'this condition,' 'it' or descriptive phrases like 'social connect problem' 'special needs.' Labelling the child could mean a state of permanency, a threat to their self-identity, and losing a sense of 'normalcy.' Labelling is based on the medical model and is executed by a physician and often results in an individual following or

'It has taken me into a whole new life and world, a turning point': Fathers' Experiences of the Diagnosis of Autism

producing the set role expectations (Scheff, 1984) and here it could be the child's deviant behaviour. It could lead to rejection, devaluing and discriminating both the child and the family (Link & Phelan, 2013).

Losing the golden period-delay in seeking a diagnosis. The diagnosis led some of them to map and look at the broader motor milestone and transitions like 'his changes of activities, or 'it was very clear as per the calendar prescribed by the doctor or by anyone,' 'looking at physical stages we never thought that he is different,' and so had no reason to suspect anything.

"So, we were trying to map it. Is it anything we missed? fortunately from zero to one we had videos. This is what he did when he was three months old, five months old, so we had observed what is happening. So, 11th month when we call him, he responds. He looks smiles, eye to eye contact. Everything was perfect or maybe not!!" (P:9)

Due to these new developments, some fathers felt like they had unknowingly ignored the 'behaviours of autism that were staring into their eyes.' One father (P:8) said, "We realised that there are some issues with speech but we didn't know that it is autism." According to Piaget's theory, the first stage of cognitive development or the 'zone of modifiability,' is from 0-2 years wherein appropriate intervention and skill-building lead to good developmental achievements. It was an agony for the fathers that they had wasted the 'golden period.' Early intervention is beneficial not only for the child but extends to the family too as it leads to a better acceptance and understanding of the child. This lag signified that the child could not be part of the mainstream classroom, had to go for therapies, or be in a special school. This loss of key period in the developmental stage is distressing for the parent. "I felt so sad. especially because I could see other children studying, enjoying the school activities, and here my child had no such opportunity." (P:7). The child had lost his age-related needs, his peer group, fun and enjoyment, the routines and activities.

Diagnosis as a pathway to intervention and knowledge. Fathers acknowledged that the diagnosis gave a direction and helped them gain knowledge. It paved the way to move through the maze of autism and understand what will work for their child. These were active efforts at intervention expressed with words like 'fixing it,' 'defeat this' 'a project to be completed,' 'bailout.' Fathers moved from looking at 'why' to 'how,' and hence instead of looking at causes or reasons they looked at the various treatment options, interventions, alternative medicines, and biomedical treatments. Despite the lack of factual evidence, alternative treatments are often used by parents of children with autism (Hall & Riccio, 2012). This can be explained through the 'Biomedical model' as the cause of autism which implied that some fathers thought of autism as a disease and hence a search and a hope for a cure. If symptoms didn't get better, they may switch to additional treatments. Fathers conceded to the fact that they all thought and still think of 'fixing the problem.'

"I had a good share of desperate attempts to reach out to some freaks. Alternate medicines and stuff. In fact, I am still trying some. I am not going to go give up (laughs) I want to try..." (P:2)

Kleinman (1988) found that traditional healing and biomedical treatment can co-exist and are not seen as conflicting. Literature suggests that families in India hold multiple beliefs about disability, based on both medical and socio-cultural models of causation and treatment (Saravanan et al., 2004; Edwardraj et al., 2010). These can include religious beliefs about

'It has taken me into a whole new life and world, a turning point': Fathers' Experiences of the Diagnosis of Autism

causation (e.g., beliefs in karma, sin, punishment, black magic, evil spirits) as well as biological explanations (e.g., disease). As a result, families are likely to seek treatment from a range of sources available in the community both for relief from symptoms and a possible total cure. These beliefs may sometimes be resistant to change even when sufficient knowledge and information is provided (Das et al., 2006). The complex interaction between health and culture makes it important to understand local perceptions of disability and concepts in indigenous systems of medicine and healing to provide culturally sensitive health care to the community (Weiss et al., 2012). The professionals must accept this duality and support the alternative and cultural cures that parents pursue in the hope of their child improving. If the parents are encouraged to share their beliefs about the etiology as well as other alternative forms of treatment it builds an environment of trust and confidence. In the present study, the different treatment options included speech therapy, occupational therapy, sensory integration, play therapy, diet changes, and Indian traditional healing methods. These alternative therapies help parents to look for options other than medications, which often carry the fear of undesirable side effects.

For medical professionals, therapists, and counsellors it is important to understand the family's beliefs and their perspectives about the various treatments. This could guide them to integrate the allopathic and traditional healing practices for the benefit of the family and the child. These explanatory models of the disability that are prevalent in the native communities or a particular culture can help the health care providers to create educational programmes specific to the needs of the community. While families should be encouraged to consider the biomedical framework, they should not be taken away from their cultural beliefs as these beliefs can have an impact on one's mental health and hence the need to be sensitive (Edwardraj et al., 2010).

For fathers' interventions meant empowering self with knowledge and information about autism which is an important way of coping and shifts the locus of control to themselves. This strategy of gaining knowledge may improve self-efficacy, reduce stress, and derive strength and confidence in themselves (Kuhn & Carter, 2006). By default, the internet was found to be the main source of information but sometimes it confused them as many websites were not authentic or validated. As one father (P:2) puts it,

“So much information that you are perplexed and thrown into the world of unknown. And you cannot conclude anything based on that after so much of research and findings. You will be back to square one. Still puzzled and confused.”

Other than the internet books, videos, and meeting various health care professionals was followed by most of the fathers. Pursuing different professionals to seek multiple opinions and assessments especially in the Indian context has been reported in other studies too (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Vaidya, 2009; Daley, 2004). Fathers' also benefitted through social interaction with other parents of children with autism as they felt they were 'all in the same boat'. All this led to a better understanding and clarity on autism. Additionally, it served an important purpose in relieving them of the burden and guilt of being responsible for the child's condition. They were now assured that the condition emanated from clinical reasons and the child's internal, biological, and within-child causes and not due to parental inefficiency.

'It has taken me into a whole new life and world, a turning point': Fathers' Experiences of the Diagnosis of Autism

Reluctance for a second child. One of the backlashes of the diagnosis was the fear of having another child and those who did, had the constant worry if the other child too would be affected. The chances of 'autism being genetic and doctors giving 50-50 chance' created uneasiness in them that 'something will go wrong' nonetheless four fathers did have a second child. "But again, the fact is a second child is not... lucky if we have a good one. Unlucky if we have another.... I mean a child with special needs. That we don't want to take the risk with the other one." (P:7). Parents who firmly believe in the genetic basis for autism may be reluctant to have another child due to fears of recurrence (Hebert & Kouloughlioti, 2010). One father stopped the vaccination for the second child but developed fear later if they had done the right thing (P:3). Similar beliefs about parents having fears about vaccines being the cause have been shown in other studies (Singer & Davis, 2010; Goin-Kochel et al., 2015). Some fathers felt that they did not want to build expectations around the able sibling and had fears of 'sibling rejection.' But for one father having another child was building a support system for his child with autism.

"At least 'A' will have a support. After us instead of going to relatives it is better, he has his own brother or sister. Even if not very close at least who may care for him (P:8)

For some having another child meant losing their 'attention and focus on their child with autism.'

Future concerns. The diagnosis resulted in thoughts about the child's future which seemed unclear and inconclusive. Several studies have revealed that in families the diagnosis of autism is often accompanied by grief and a hard to perceive future (Banach, Iudice, Conway, & Couse, 2010; Lutz, 2008; Donaldson, Elder, Self, & Christie, 2011). In the present study, the fears were about the long-term prognosis of autism. "Suddenly you see a different world and think maybe your child will be like this when he grows up (as mentally challenged). What if he grows up to be 18 -20 and behaves like this and all that... that's the future I could see." (P:4). One father called it 'churns in the stomach.' The uncertainty and anxiety were expressed through phrases like 'will things be normal,' 'can they bring him out of it,' 'is it going to be lifelong?', 'no future security.' Father P:7 said, "My main fear is what will happen to him after us? Who will take care? He has no siblings also. I am trying to keep some savings for him. How will he manage in this society? Be independent? Have some work... I have no control over the future. God knows what will happen. I wish I could give him some academic input. Wish we had some governmental help in this."

Voices of fathers echoed with sentimental statements like 'we are not forever,' 'don't know what is going to happen after me' 'what happens to him if I don't finish my job' 'who will support him.' Similar sentiments of worry and concerns for the child's future when they are no longer around, child developing self-help skills and becoming independent has been shown in other studies (Desai, Divan, Wertz, & Patel, 2012; Maloni et al., 2010). Fathers started investing and building some long-term funds for the child. This was their way of providing social security for the child. The angst was not only about keeping the money but the thought if the 'child will be able to manage it.' The child's 'social survival', the level of independence, and the anxieties of the long journey ahead was pervasive through all the narratives in the present study.

Limitations

The sample of fathers was restricted by their diversity in age, religion, academic qualification, socioeconomic status and the gender of the child as alterations in these could open up newer understandings and experiences. The participant fathers were those who

'It has taken me into a whole new life and world, a turning point': Fathers' Experiences of the Diagnosis of Autism

agreed to be part of the study and were recommended by the school authorities. Fathers who did not choose to participate or were not part of this school system may have different experiences and hence should be considered in future studies. All the children in the present study were boys and it is important to know whether the diagnosis would have made a difference for a girl. All the children in this study had mild to moderate autism. The inclusion criteria though served the purpose of homogeneity could itself be a limitation in generalizability.

CONCLUSIONS

The findings in this study make a significant contribution to the literature as the number of studies on fathers of children with autism is restricted. Once they found that something was different in their child, they relentlessly pursued the reason for it. Fathers in this study went through the process of meeting different professionals and getting a diagnosis was not a challenge. Fathers saw some commonality in the child and their behaviours and this genetic linkage helped them to empathise with the child's difficulty, absolve themselves of the guilt and lessen the effects of the disability. The diagnosis led to self-education, knowledge, and learnings which empowered them and made them more confident to handle the new situation. The biggest challenge and stress were the unsettling and obscure thoughts about their child's future, their social survival, and gaining personal independence. Seeing the extent to which fathers seemed to be involved in their child's life, and the intense desire to work with their child clearly shows the evolving role of fathers in society.

REFERENCES

- Ariel, C. N., & Naseef, R.A. (Eds.). (2005). *Voices from the spectrum: Parents, grandparents, siblings, people with autism, and professionals share their wisdom*. Jessica Kingsley Publishers. doi: 10.1080/00981380902979292
- Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative research*, 1(3), 385-405. doi:10.1177/146879410100100307
- Axup, T. E. (2012). *Exploring the Experiences of Fathers Raising Sons with Asperger Syndrome: An Interpretative Phenomenological Analysis* (Doctoral dissertation, University of East London). doi:10.15123/PUB.1791
- Banach, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post autism diagnosis support group for parents. *Social work with groups*, 33(1), 69-83. doi.org/10.1080/01609510903437383
- Burrell, A., Ives, J., & Unwin, G. (2017). The experiences of fathers who have offspring with autism spectrum disorder. *Journal of autism and developmental disorders*, 47(4), 1135-1147. <https://doi.org/10.1007/s10803-017-3035-2>
- Bury, M. (1991). The sociology of chronic illness: a review of research and prospects. *Sociology of health & illness*, 13(4), 451-468. doi: 10.1111/j.1467-9566.1991.tb00522.x
- Chi, Z. (2014). *Making Sense of Autism: Parents' Experiences in the People's Republic of China*. ProQuest LLC.
- Chilton, I. (2012). *Autism Spectrum Disorder in Multiplex Families: A Qualitative Study of Diagnostic Experiences and Parental Perceptions* (Doctoral dissertation, Brandeis University).
- Chawarska, K., Klin, A., Paul, R., & Volkmar, F. (2007). Autism spectrum disorder in the second year: Stability and change in syndrome expression. *Journal of Child Psychology and Psychiatry*, 48(2), 128-138. <https://doi.org/10.1111/j.1469-7610.2006.01685.x>

'It has taken me into a whole new life and world, a turning point': Fathers' Experiences of the Diagnosis of Autism

- Chung, M. C., Vostanis, P, Cumella, S., Doran, J., Winchester, C., & Wun, W. L. (1999). Children with special needs: Use of health services, behaviour and ethnicity. *Children and Youth Services Review*, 21(5), 413-426. [https://doi.org/10.1016/S0190-7409\(99\)00029-8](https://doi.org/10.1016/S0190-7409(99)00029-8)
- Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, 20(2), 153-162. doi:10.1177/1362361315573636
- Daley, T. C. (2004). From symptom recognition to diagnosis: children with autism in urban India. *Social science & medicine*, 58(7), 1323-1335. *future. Autism*, 10(5), 463-479. doi:10.1016/S0277-9536(03)00330-7
- Das, S., Saravanan, B., Karunakaran, K. P., Manoranjitham, S., Ezhilarasu, P., & Jacob, K. S. (2006). Effect of a structured educational intervention on explanatory models of relatives of patients with schizophrenia: Randomised controlled trial. *The British Journal of Psychiatry*, 188(3), 286-287. <https://doi.org/10.1192/bjp.bp.104.007245>
- Desai, M. U., Divan, G., Wertz, F. J., & Patel, V. (2012). The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcultural psychiatry*, 49(3-4), 613-637. doi: 10.1177/1363461512447139
- Donaldson, S. O., Elder, J. H., Self, E. H., & Christie, M. B. (2011). Fathers' Perceptions of Their Roles During In-Home Training for Children with Autism. *Journal of Child and Adolescent Psychiatric Nursing*, 24(4), 200-207. doi: 10.1111/j.1744-6171.2011.00300.x
- Divan, G., Vajaratkar, V., Desai, M. U., Strik-Lievers, L., & Patel, V. (2012). Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India. *Autism Research*, 5(3), 190-200. doi: 10.1002/aur.1225.
- Dollahite D. C. (2003). Fathering for eternity: Generative spirituality in Latter-day Saint fathers of children with special needs. *Review of Religious Research*, 237-251. doi: 10.2307/3512385
- Easterbrooks, M. A., & Goldberg, W. A. (1984). Toddler development in the family: Impact of father involvement and parenting characteristics. *Child development*, 740-752. <https://doi.org/10.2307/1130126>
- Edwardraj, S., Mumtaj, K., Prasad, J. H., Kuruvilla, A., & Jacob, K. S. (2010). Perceptions about intellectual disability: a qualitative study from Vellore, South India. *Journal of Intellectual Disability Research*, 54(8), 736-748. doi: 10.1111/j.1365-2788.2010.01301.x.
- Flippin, M., & Crais, E. R. (2011). The need for more effective father involvement in early autism intervention: A systematic review and recommendations. *Journal of Early Intervention*, 33(1), 24-50. <https://doi.org/10.1177/1053815111400415>
- Freed, G. L., Clark, S. J., Butchart, A. T., Singer, D. C., & Davis, M. M. (2010). Parental vaccine safety concerns in 2009. *Pediatrics*, 125(4), 654-659. doi: 10.1542/peds.2009-1962.
- Gibson, K. A. (2014). Appreciating the world of autism through the lens of video interaction guidance: an exploration of a parent's perceptions, experiences and emerging narratives on autism. *Disability & Society*, 29(4), 568-582. doi:10.1080/09687599.2013.844096
- Glynne-Owen, R. E. (2016). "I want to have a path": an exploratory study of parent experience of early autism diagnosis in Massachusetts and Central Scotland.
- Goin-Kochel, R. P., Mire, S. S., & Dempsey, A. G. (2015). Emergence of autism spectrum disorder in children from simplex families: Relations to parental perceptions of etiology. *Journal of autism and developmental disorders*, 45(5), 1451-1463. doi: 10.1007/s10803-014-2310-8

**'It has taken me into a whole new life and world, a turning point': Fathers' Experiences of the
Diagnosis of Autism**

- Hall, S. E., & Riccio, C. A. (2012). Complementary and alternative treatment use for autism spectrum disorders. *Complementary Therapies in Clinical Practice*, 18(3), 159-163. doi: 10.1016/j.ctcp.2012.03.004
- Hanson, M. J., Lynch, E. W., & Poulsen, M. K. C. (2013). *Understanding families: Supportive approaches to diversity, disability, and risk*. Paul H Brookes Publishing.
- Hebert, E. B., & Koulouglioti, C. (2010). Parental beliefs about cause and course of their child's autism and outcomes of their beliefs: A review of the literature. *Issues in comprehensive pediatric nursing*, 33(3), 149-163. doi.org/10.3109/01460862.2010.498331
- Hoff, K., & Pandey, P: (2006). Discrimination, social identity, and durable inequalities. *American Economic Review*, 96(2), 206-211. doi: 10.1257/000282806777212611
- Hunt-Jackson, J. L. (2007). *Finding fathers' voices: Exploring life experiences of fathers of children with autistic spectrum disorders (Doctoral dissertation)*, Retrieved from: ProQuest dissertations and theses global. (304767555)
- Kalash, L. A., & Olson, M. R. (2012). Perspectives of Parents Who Have a Child Diagnosed with an Autism Spectrum Disorder. *Journal of the American Academy of Special Education Professionals*, 93, 121.
- Kapoor, S. (Ed.). (2000). *The Hindus: Encyclopedia of Hinduism (Vol. 2)*. Cosmo Publications
- Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The Experiences of Parents During Diagnosis and Forward Planning for Children with Autism Spectrum Disorder. [Article]. *Journal of Applied Research in Intellectual Disabilities*, 23(4), 390-397. https://doi.org/10.1111/j.1468-3148.2010.00555.x
- Kleinman A. *The Illness Narratives: Suffering Healing and Human Conditions*. New York: Basic Books. 1988. doi: 10.1177/136346158902600303
- Kuhn, J. C., & Carter, A. S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry*, 76(4), 564-575. https://doi.org/10.1037/0002-9432.76.4.564
- Kumar, K. (2005). *Disability in pervasive development disorder: A comparative study (Order No. 10165094)*. Available from ProQuest Dissertations & Theses Full Text. (1822511529).
- Lambert, M. C., Weisz, J. R., Knight, F., Desrosiers, M. F., Overly, K., & Thesiger, C. (1992). Jamaican and American adult perspectives on child psychopathology: Further exploration of the threshold model. *Journal of Consulting and Clinical Psychology*, 60(1), 146. doi: 10.1037//0022-006x.60.1.146
- Link, B. G., & Phelan, J. C. (2013). Labeling and stigma. In *Handbook of the sociology of mental health* (pp: 525-541). Springer, Dordrecht.
- Lutz, H. R. (2008). *Coping with autism during childhood and adulthood: Mothers' journeys towards adaptation*. Widener University School of Nursing.
- Maloni, P: K., Despres, E. R., Habbous, J., Primmer, A. R., Slatten, J. B., Gibson, B. E., & Landry, M. D. (2010). Perceptions of disability among mothers of children with disability in Bangladesh: Implications for rehabilitation service delivery. *Disability and rehabilitation*, 32(10), 845-854. doi: 10.3109/09638280903326063
- McConkey, R., Truesdale-Kennedy, M., & Cassidy, A. (2009). Mothers' recollections of early features of autism spectrum disorders. *Child and Adolescent Mental Health*, 14(1), 31-36. doi: 10.1111/j.1475-3588.2008.00495.x
- Navalkar, P: G. (2010). *Fathering a child with a disability in India: A perspective Mumbai*. *Childhood Education*, 86(6), 389-393. doi: 10.1080/00094056.2010.10523175

'It has taken me into a whole new life and world, a turning point': Fathers' Experiences of the Diagnosis of Autism

- Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric disease and treatment*, 12, 745. doi: 10.2147/NDT.S100634
- Padgett, D. K. (2009). Qualitative and mixed methods in social work knowledge development. *Social Work*, 54(2), 101. doi:10.1093/sw/54.2.101
- Phelps, K. W., McCammon, S. L., Wuensch, K. L., & Golden, J. A. (2009). Enrichment, stress, and growth from parenting an individual with an autism spectrum disorder. *Journal of Intellectual and Developmental Disability*, 34(2), 133-141. doi: 10.1080/13668250902845236.
- Roopnarine, J. L., & Suppal, P: (2000). Kakar's psychoanalytic interpretation of Indian childhood: The need to emphasize the father and multiple caregivers in the socialization equation. *International Journal of Group Tensions*, 29(3-4), 349-370. <https://doi.org/10.1023/A:1026529413613>
- Saraff, A., & Srivastava, H. C. (2008). Envisioning fatherhood: Indian fathers' perceptions of an ideal father. *Population Review*, 47(1).
- Saravanan, B., Jacob, K. S., Prince, M., Bhugra, D., & David, A. S. (2004). Culture and insight revisited. *The British Journal of Psychiatry*, 184(2), 107-109. DOI: <https://doi.org/10.1192/bjp.184.2.107>
- Sarrett, J. C. (2015). "Maybe at Birth There was an Injury": Drivers and Implications of Caretaker Explanatory Models of Autistic Characteristics in Kerala, India. *Culture, Medicine, and Psychiatry*, 39(1), 62-74. doi: 10.1007/s11013-015-9440-0.
- Scheff, T. (1984), *Being Mentally III: A Sociological Theory* (2nd ed.). New York: Aldine. <https://doi.org/10.1002/bs.3830120208>
- Smith, J. A., Flowers, P., & Larkin, M. (2009) *Interpretative phenomenological analysis: Theory, method, and research*. <https://doi.org/10.1080/14780880903340091>
- Streubert Speziale, H. J., & Rinaldi Carpenter, D. (2007). *Qualitative research in nursing: advancing the humanistic imperative.*, 4th edn. (Lippincott Williams & Wilkins: Philadelphia).
- Tamis-LeMonda, C. S. (2004). Conceptualizing fathers' roles: Playmates and more. *Human development*, 47(4), 220. <https://doi.org/10.1159/000078724>
- Todorova, I. L., & Kotzeva, T. (2006). Contextual shifts in Bulgarian women's identity in the face of infertility. *Psychology and Health*, 21(1), 123-141. doi.org/10.1080/14768320500143354
- Weiss, J. A., Cappadocia, M. C., MacMullin, J. A., Viecili, M., & Lunsy, Y. (2012). The impact of child problem behaviors of children with ASD on parent mental health: The mediating role of acceptance and empowerment. *Autism*, 16(3), 261-274. doi: 10.1177/1362361311422708

Acknowledgements

The author appreciates all those who participated in the study and helped to facilitate the research process.

Conflict of Interest

The author declared no conflict of interest.

How to cite this article: V Jagan & A Sathiyaseelan (2020). 'It has taken me into a whole new life and world, a turning point': Fathers' Experiences of the Diagnosis of Autism. *International Journal of Indian Psychology*, 8(2), 1102-1115. DIP:18.01.127/20200802, DOI:10.25215/0802.127