

Fathers as care givers of children with autism spectrum disorder: a review

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ABSTRACT

When we talk about challenges in parenting children with Autism spectrum disorder or any other disability, we automatically draw our attention towards the mothers. But it is very important to also study the father's perspective of parenting the same child. A number of reviews and researches have been conducted on the same. The present study has been done on the basis of reviewing A Review of Fathers' Accounts of Their Experiences of Parenting Children with Disabilities and Raising Children with Autism Spectrum Disorder: A Study on Parenting Styles and Techniques. Another article was also reviewed in the namely The Experiences of Fathers Who Have Offspring with Autism Spectrum Disorder. The conclusion drawn from the review gives us an idea of the challenges faced by the fathers when we try to implement the same in the Indian context. The limitations have also been discussed in the conclusion and research implication.

Keywords: *Autism, Fathers and Caregiver*

Autism spectrum disorder (ASD) is the name given to a group of developmental disorders. ASD includes a wide range, a spectrum to be precise of symptoms, skills, and levels of disability. Over the past few decades, prevalence rate of Autism has increased globally in Europe, the United States, China and Japan (Barnevik-Olsson et al. 2008). It is now estimated to affect 1% of the population in England (Brugha et al. 2011), whereas recent data from the United States Autism and Developmental Disabilities Monitoring Network observes a prevalence of 14.6 per 1000 in children aged 8 across their surveillance sites (Christensen et al. 2016).

The characteristic features of ASD are-

Restrictive and repetitive behaviour pattern

1. Certain behaviors are recitative and unusual.
2. Children/ adults with autism have focused interests, i.e. interest in moving objects or parts of a certain object.

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3. They have a lasting, intense interest in certain topics, such as numbers, details, or facts.

Social communication/ interactive behaviour patterns

1. They often get upset by a slight change in a routine or being placed in a new or overly stimulating setting.
2. Eye contact is usually very little or inconsistent.
3. The tendency to look at and listen to other people less often.
4. It is very difficult for the individuals with ASD to conversations back and forth.
5. Often talking at length about a favourite subject without noticing that others are not interested or without giving others a chance to respond.
6. Repetition of words or phrases that they hear, a behaviour called *echolalia*
7. Use of words that seem odd, out of place, or have a special meaning known only to those familiar with that person's way of communication.
8. Facial expressions, movements, and gestures do not match of what is being said.
9. The tone of voice is unusual that may sound sing-song or flat and robot-like.
10. They have difficulty understanding other person's point of view or being unable to predict or understand other people's action.

Causes of ASD

1. Genetic factors play a major role in the cause of autism which are fragile X syndrome, down syndrome etc.
2. Defects during delivery, i.e. Getting choked by the umbilical cord and getting oxygen, injury to the head by external tools etc.
3. Exposure of the child to various chemicals, infections or radiations.

Red Flags in Autism.

Impairment in Social Interaction:

1. Lack of appropriate eye gaze.
2. Lack of warm, joyful expressions.
3. Lack of sharing interest or enjoyment.
4. Lack of response to name.

Impairment in Communication:

1. Lack of showing gestures
2. Lack of coordination of nonverbal communication
3. Unusual prosody (little variation in pitch, odd intonation, irregular rhythm, unusual voice quality)

Caregivers

In India, the awareness on Autism and disability in general is really low. People are still ashamed of a family member who falls under the category because people still feel that it is their "Karma" of past or present doing that they have a child or a family member of disability. When we generally discuss about the role of caregivers in any childhood disorder be it Down syndrome, Intellectual disability, learning disability, cerebral palsy, Autism etc. we always tend to focus our attention on mothers primarily. But the father not being the primary caregiver undergoes a lot of difficulty, parenting a child with the above mentioned conditions. The role of fathers has been not studied properly but the ground reality is that they have to work twice as hard to avail specialized educational facilities, occupational therapy etc. for the child. In order to provide these facilities they might go through a lot of

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stress. They not only have to work hard but they get very little time to spend with their child. Since lack of social communication is an evident feature of autism fathers might feel rejected by the child and not know how to accept that. They might also be various other problems like depression, substance abuse etc. The fathers might not see a way to deal with these problems and end up feeling hopeless and helpless. In a country like most parents don't get the support of their family members or friends in raising a child with a certain condition. This is because of a lot of stigma attached to the problems of past lives and mostly due to lack awareness in these sensitive areas. With the society at large not accepting these issues even the parents might engage in a cycle of self-hatred. Because of religious or stereotypes created by the society child rearing practices are always limited to the mothers, India culture has always emphasized that mothers love, care, sacrifice etc. matters most to the child's upbringing.

The current study focuses on the father's perspective of parenting a child with autism on the basis of other studies conducted on the similar line of work in different childhood disorders or disability. The main aim is to review different literatures regarding parenting children with a disability with the primary focus on autism.

REVIEW OF LITERATURE

Parenting children with Autism Spectrum disorder is usually considered more stressful and a much more challenging task than parenting children with no disorders or normal development. Across various literatures, parents reported higher signs anxiety, higher levels of depression than usual and a host of health issues to top it off (Falk. Et al, 2014).

When a group comparison study was conducted it was found that parents whose children fall in the autism spectrum showed higher levels of stress and significantly low levels of wellbeing than parents of typically developing children or parents whose children have other developmental disabilities (Hayes & Estes, 2013).

The most common source of stress in patients of children with Autism generally include the child's inappropriate and unpredictable behavioural or emotional problems with the severity of the disorder; Financial worries are generally secondary, in terms of the need to spend on treatment intervention and educational services (Rivard & Thames, 2016). Various studies have also highlighted the role of social support in helping to successfully cope with the higher levels of stress, including the support and easy access to mental health professionals for their issues (Vohra. Et al, 2014)

The levels of stress on both the parents is considered different. In some studies it has been found that there is an increased level of stress in fathers than mothers as couple (Harper. Et al 2013). But different other studies have insisted that there is a significant difference in the stress levels of fathers and mothers.

When families were examined who had children with autism, cultural factors were given importance. In majority of the cases the lack of knowledge about autism in our society, has made parents to face a lot of stigma and they were influenced by cultural beliefs as well, which make them blame themselves for the child's condition. Since there is lack of support and lack of adequate knowledge available at the society at large, the families struggle to make sense of their child's behaviour, which is responsible for increasing the levels of stress in parents (Van Hackey 2012).

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A number of studies have investigated parenting stress in parents of children with which was conducted in the western and European contexts. The findings of these resources denotes to the greater awareness and support for the autism communities in the western world. On the contrary the knowledge in Asian countries is growing and is need of receiving necessary support. It is imperative that how support may be created towards autism community in the under investigated Asian countries.

A further limitation to existing research is that the fathers involved tend to be interviewed alongside mothers as a combined 'parent' experience (Ryan and Salisbury 2012.). Couple interviews, whilst useful in their own right, cannot always capture individual perspectives and needs, and do not always present individuals with the opportunity to raise matters that are of concern to only them and which they might not have shared with their partner. As such, a couple interviews may only capture a negotiated or public front, rather than the personal perspective. Recent studies of fathers and fatherhood suggests that the experiences of fatherhood and motherhood can be fundamentally different, which might be explained by gendered embodiment and social and moral norms attached to gendered parenting (Doucet 2009; Ives 2014). This suggests that what we know about mothers in this context cannot uncritically be assumed to apply to fathers. Further, a recent study by Ives (2014) suggests that some fathers, cognisant of moral discourse around parenting, might not see their own worries and concerns as sufficiently important or legitimate to rise. It is therefore important that fathers are engaged with as fathers, and not just as one-half of a parenting dyad, so that their own, and possibly different, concerns and support needs can be considered.

With most of the current understanding of ASD parents' experience coming from mothers, further exploration of fathers' experience is needed and this could improve the support offered to families by increasing the awareness of father-specific issues amongst health and social care professionals. The current study therefore aimed to explore the experience of being a father of someone with ASD in order to enable service providers to better understand the father perspective.

To a certain extent, the findings from this review are comparable to that yielded from the Western context (Thomas et al., 2016), particularly in regards to social support, severity of autism symptoms, and financial difficulties. However, cultural variations or economic differences were found to underlie the differences in how these factors were uniquely manifested or experienced in South East Asian countries. For instance, poorer policy and economic support for mental health and special needs in the Asian region may have exacerbated the difficulties and challenges faced by parents of children with ASD in these countries in comparison to those in a Western context. Moreover, the stigma and discrimination toward autism, that is relatively more prevalent in an Asian context, might influence how parents of children with autism are further challenged with these issues. (Ilias et al., 2016).

Furthermore, in the region, parents with lower levels of educational and socioeconomic statuses may be further more disadvantaged, identifying later the symptoms of autism and facing greater risk of stress, depression and hopelessness. As researches suggested that parents from lower socio-educational backgrounds may be a particular group that needs to be targeted and supported in terms of education on the early warning signs of autism and child development in general (Moh and Magiati, 2012).

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Caring for someone with autism presents significant challenges to both the care giver and child/person with autism: they may become distressed when routines are disturbed, and have difficulties expressing their needs. Medical comorbidities are also very common, which includes a higher prevalence rate of epilepsy and sleep disorders when it is compared to the general population. Furthermore, with the majority of adults with autism always remain dependent on their family members/ caregivers. The role of a parent as a caregiver pervades throughout life time. Both the parents of children with autism show higher levels of parenting stress and psychological distress than parents of normally developing children, as well as a higher prevalence of both depressive and anxiety symptoms (Singer and Floyd 2006). These increased levels of stress, and feelings of parental incompetence, can be responsible for significantly reducing affective parental attachment to children with autism, for both mothers and fathers. Children under the spectrum are normally distant from their parents as the communication pattern is automatically minimal which intern becomes stressful for parents as they feel they don't get the warmth from their child. The UK National Institute for Health and Care Excellence guidance on the management of autism acknowledges these kind of difficulties and their pervasion through parental experiences, and they state that parents of offspring with autism should be provided regular personal, social and emotional support in forms of Support groups. (National Institute for Health and Care Excellence 2013). As parents constantly face these challenges of caring for their children, an important emotional mediator is psychological acceptance of their child and the condition. This process involves developing an awareness of, and embracing, difficult events without unnecessary and potentially distressing attempts to change their frequency or content. The enduring nature of behavioural problems in children with autism, conventional short-term coping mechanisms, for example either avoidant or problem-focused strategies, are not helpful and indeed very harmful over time for parents. When we normally compare parental empowerment, a problem-focused coping method, for acceptance, it was found that only psychological acceptance can mediated the effects of a child's behavioural difficulties on parental mental health problems. Similarly, acceptance of autism or any other disability. Quantitatively, there has been an increase in the acceptance of autism has been found to, which mediates the relationship between challenging behaviour and parental wellbeing, reducing psychological distress in mothers and fathers separately (Jones et al. 2014).

METHODOLOGY

Aim

- To review empirical papers and relevant literature in order to find out the challenges that fathers face in raising a child with Autism Spectrum Disorder.

Objectives

The primary objective of this review paper was to find out the challenges fathers face while they become the caregivers of children with Autism. The current study focuses on the relevant literature and empirical studies to find above mentioned cause as most of the studies conducted focus of mothers as caregivers and the challenges faced by them.

DISCUSSION

The present study reviews two studies namely A Review of Fathers' Accounts of Their Experiences of Parenting Children with Disabilities and Raising Children with Autism Spectrum Disorder: A Study on Parenting Styles and Techniques. Another article was also reviewed in the namely The Experiences of Fathers Who Have Offspring with Autism Spectrum Disorder. The three studies are done on the basis of empirical data and review of relevant literature in different cultures across the world, i.e. Asia and Western world. On an

extensive review it was found that parenting a child with Autism can be very stressful for a father as well the mother. A number of detailed researches have mentioned or highlighted the impact on the problems of mothers who are primary care givers to their children. The level of stress the mothers go through is very important since a child at home with autism. This is because in a country like India, there are a lot of issues as the culture is very diverse, and in most families the set up is still of a joint family. The factor which adds fuel to the fire is lack of knowledge on a lot of disorders be it psychological or developmental along with stigma attached with these issues. The mother in the Indian culture is always blamed as any kind of sins done by her in her past or present life. The mother with all these issues hovering around is prone to feelings of hopelessness, guilt, and low mood, frustration from unsupportive family members and to top it off financial instability.

CONCLUSION

Now when we come to the main highlight of this review i.e. the difficulties faced by fathers in parenting a child with autism. Since a very long time it has been generalized that the father is someone who is just responsible for putting food on the table and child care is the department to be looked after by the mother. But the current trend is slowly changing. Fathers have been seen rather significant evidence has been put forward that they have started to actively take part in the parenting of a child with the above mentioned difficulty and split the roles and responsibilities with the spouse. Even though there is a change in trend but the exceptions present are still at large. There are a lot evidences where and studies conducted empirically on fathers showing shocking discoveries where parenting becomes stressful. When a child is born with a disability automatically the scenario changes for both the mother and the father. The effort is twice as much, care is more than usual and expenses go up as the Individualized Educational Programs, occupational therapies and consulting a paediatrician is more than usual. When we compare the Indian scenario on the basis reviews done in the same area, keeping in mind the Indian context we can draw this conclusion that the number of studies conducted on fathers of children with autism the empirical data is really low. But an assumption can be made that fathers would also go through immense stress, lack of cooperation from friends and family members. This situation can be a triggering factor for depression, substance abuse etc. as the fathers have to work harder when they have a child with autism at home, plus the stigma and stereotypes can impact a father's mental health in general. The challenges automatically increases as the father is busy managing the expenses, working hard he has automatically less time to give to his child. In the case of autism the interaction of the child is automatically minimal and even the father wants to spend time with the child it gets jeopardised. There are of lot of behaviour issues in most cases of autism and managing a child alone can be a tedious task, which might cause difficulty in the marriage of the couple with a child at home and the blame game on each other would also start.

Research Implications

The main agenda of the current review is to focus/ study the challenges faced by fathers in parenting a child with autism spectrum. The other articles or literature gives a good baseline to study the topic further. The studies/articles which have been mainly reviewed here are based on the Western World and few parts of Asia. But in order to study the topic further in the Indian context its very much necessary to conduct empirically based studies to come to a definite conclusion as a range of factors might play role and pose as challenges in father's life or might not have an impact at all.

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Conflict of Interest

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