Abstract

The purpose of the study was to address the gap in the literature related to fathers’ role and experiences in raising boys with autism in the Indian context. Though the study has tried to homogenise the sample to the best possible extent it does not aim to generalise the results; rather it seeks to get an insight into some facets of the fathers’ experiences.

A qualitative phenomenological approach was used for this study which addressed the three research questions: 1) What are the experiences of fathers before and after the diagnosis of autism? 2) What are the challenges that fathers experience as they raise their child with autism? 3) What are the personal changes that fathers go through as they raise their child with autism? Tied together these research questions sketches the journey travelled by the fathers and gave a sweeping picture of their overall experiences as fathers of children with autism. The study has mapped and constructed the passage of thirteen fathers of children with autism aged between six to 11 through a one on one interview. All the ethical considerations have been followed. The participants were able to provide a rich and detailed account of their experiences of bringing up a child with autism. The analysis was done using Interpretative Phenomenological Analysis.

Six major themes emerged from the study. They are 1) Making sense of early warning signs 2) The impact of diagnosis 3) Negotiating the social world 4) Accepting and accommodating autism 5) Personal transformations 6) Bonding with the child.

One of the earliest behaviours noticed by all the fathers was a delay in speech. None of the fathers resisted going for a diagnosis. In fact, once they found that something was ‘different’ in their child, they relentlessly
pursued the reason for it. The diagnosis of autism was perceived by the fathers as a setback and was described as devastating, confusing, saddening, and shocking. But it also opened new pathways for treatment and interventions and gave them a direction to look for help. Professional’s lack of knowledge of autism was frustrating for some parents. On the other hand, some fathers found the professionals help to be adequate and encouraging. Diagnosis, in turn, also created a fear of having another child. The fears of the child’s social survival and personal independence was present through all the narratives. The concept of karma is prevalent in Indian culture. The fatalistic thoughts of ‘why me’ ran through the minds of all the fathers.

Consistent with the earlier literature ‘isolation’ was felt by the fathers in this study too due to the child’s inappropriate behaviours in public spaces. Initially, all the fathers were distressed but slowly they started observing the progress in the child, and this helped them to accept the shortcomings of the child and move on. They also reorganised their lifestyle to cater to the child’s needs and tried ways and means of balancing the needs of the able sibling. Caregiving was not seen only as mother’s responsibility, and it was shared by the fathers leading to strengthened marital bonding. To accommodate the needs of the child fathers made changes and compromises in their career thus putting the needs of the child ahead of theirs.

Gradually coming to term, fathers had learnt to look at the progress the child made which acted as a stimulant to focus on the positives and developed an ability to see child’s strengths in weakness. Fathers in this study also acknowledged personal changes like becoming more mature, self-confident, patient and a positive person. Fathers looked at themselves as the ‘chosen parent’ a ‘special father.’
A significant thought that all the fathers expressed was a strong belief that they could work wonders with the child if only they did not have the breadwinner’s role to play. All of them wanted to get out of their regular job and spend time and channelise the efforts as they thought the child had the ability to learn.

The study also offers suggestions to therapists and professionals who work with families of autism and provides suggestions for further research.

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