



Societal challenges for parents of autistic children

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Abstract: *The purpose of this short communication is to educate society on moral and emotional front in terms of expected behaviour of people towards autistic children as well as their parents. In doing so, the study has used document analysis and unstructured interview as main data gathering tool. The collected data were analysed using analytic induction. The outcome of this study revealed several striking facts. Two major findings need to be mentioned here. Firstly, 77% of the selected samples showed indifference to the issue of autism and autistic children. Secondly, 55% of the selected parents of autistic children had insurmountable stress firstly because of comparing their children with those children who are autistic; secondly because of comparing their children with those children who are recovering and thirdly because of comparing their children with those children who are not autistic. Given the traumatic state of parents, the study forwards six suggestive measures for society and the parents of autistic children.*

Keywords: *autism, autistic child, parents, behaviour, stress.*

1. INTRODUCTION:

With unprecedented rise in autism in recent years, autism has increased 178% since 2000. According to the CDC data, one percent of the world population is autistic (Zauderer, 2022). Parenting in itself is the toughest challenge in a human's life and parenting an autistic child is one of the toughest challenges in the parents' life. Not only parents, it affects the entire family and all the near and dear ones of the autistic child. Apart from financial, physical and emotional care and support, the parents of autistic children undergo insurmountable social stress at the hands of society. In the pursuit of giving proper care most of parents forget their other life related priorities and remain glued to their autistic children. Especially with growing age, some autistic children may live alone with little support; whereas, some may require more support as they cannot live independently because of severity of autism.

2. LITERATURE REVIEW:

Not surprisingly, autism has become a normal condition as 1 in 56 children is being diagnosed with autism and ensuing interventions and therapies help a great number of children with autism to live a purposeful life. According to previous research, moral and social support are two types of support provided to families of children with ASD (Laili and et.al, 2021). The research of Laili pinpoints on the challenges and support for parents of autistic children with autism spectrum disorder at workplace. According to Agyekum (2018) parents adapt to their situation by accepting the situation of their wards, depending on God for strength, receiving support and encouragement from some family members and friends, joining support groups, as well as taking leave from work to help their children seek proper medical care. According to Cook & Ogden (2021), inclusion of children with special educational needs remains a challenge for educators as they lack the confidence and knowledge to support autistic pupils which cause adverse effects on their education.

Families play an important role in promoting and supporting autistic people to thrive and feel included in society (Thomas, 2021). She further adds that care and help often available has been severely limited as a result of the pandemic, with family members spending more time in limited spaces with their autistic child than usual (ibid). If parents cannot accept their children's condition, they frequently experience chronic internal stress (Gentles et al., 2019). It is the moral obligations of both employers and co-workers to extend maximum support to the parents of autistic children at workplace. The social system plays an essential role in motivating and improving positive attitudes in the parents of children with ASD in carrying out their daily routine (Sharif & Jamil, 2019). Although there are many other



developmental disorders which present parents with ongoing grief, autism is unique in several ways. First, this disorder has no clear biological marker, unlike many other developmental disabilities. Second, because it is characterized by problems of social interaction, such as forming attachments and showing affection, parents of children with autism are often denied some of the fundamental rewards of parenthood. Consequently, autism has been considered as one of the most complex and intractable developmental disorders with which families may have to cope (Bashir and et. Al, 2014). While for working parents, they receive two types of support at work that can help increase positive motivation: from their employers and their co-workers (Pinna et al., 2020).

In yet another report of Ludlow and et. al. (2021) , it found five challenges for the parents of autistic children: (i) Dealing with challenging behaviour; (ii) dealing with judgements from others; (iii) lack of support; (iv) impact upon the family; and (v) coping and the importance of appropriate support. This study also emphasized a fact where the parents themselves believe they still require additional support. Pertinently, according to advocate Kristi Campbell, as cited in Brazier (2016), asked a number of parents of autistic children about their expectations of other people to know or do towards them and their autistic children. The following are the reported facts as retrieved from the respondents.

- Not feel awkward being around a child with autism
- Understand that autism does not look the same in every individual
- Love their children and understand that they have their own way of being smart
- Accept that children with autism express themselves in unusual ways
- Refrain from judging the parents for not addressing their child's unusual behavior.

Ultimately, the parents would like to see more empathy, and for other parents to accept their children just as they would like their own children to be accepted (ibid).

3. MATERIALS AND METHODS:

This qualitative study has used document analysis and unstructured interview as prime data gathering tools to collect the required data in response to the stated research questions. The collected data were analyzed using analytic induction.

4. RESULTS AND DISCUSSION:

Having analysed the collected data that comprised six pertinent websites, six newspaper articles, and six parents with autistic children, the study found that Indian society is far behind in meeting basic needs and requirements of special child. The countries with highest autism rates or higher than 100 out of every 10,000 children according to Zauderer (2022) are as follows:

Country	Prevalence per 10,000 Children
Qatar	151.20
United Arab Emirates	112.40
Oman	107.20
Bahrain	103.30
Saudi Arabia	100.70
Kuwait	97.70
Jordan	92.10
Syria	91.90
Afghanistan	91.20
Palestine	91
Sweden	90.80
Libya	90.60
Yemen	90.40
Iran	90.30
Sudan	90.10



Based on the above data, we analyze the following facts:

- The countries with highest autism rates are mostly in the Middle East regions.
- The countries with the low autism rates are in Europe.
- Prosperity and poverty do not seem to be a decisive factor in autism.
- Non-vegetarian food may perhaps be accountable for autism as seen in the cases of Middle East countries. However, this claim needs revisit.
- The majority of tech-savvy countries also report high rates of autism. The reasons could perhaps be attributed to prolonged exposure of children to electronic devices.

In addition to the above striking facts, the outcome of this study also revealed several striking facts. There are two important facts that need to be discussed here. Firstly, 77% of the selected samples showed indifference to the issue of autism and autistic children. Secondly, 55% of the selected parents of autistic children had insurmountable stress firstly because of comparing their children with those children who are autistic; secondly because of comparing their children with those children who are recovering and thirdly because of comparing their children with those children who are not autistic.

5. FINDINGS:

Having analyzed the collected data, the study revealed several striking facts. The following are nine important findings:

- Autism, which is also known as *Autism Spectrum Disorder (ASD)*, is a neurodevelopmental or psychological disorder caused by lack of social interaction showing repetitive patterns of behavior, interests, or activities (WHO, 2023).
- Autism is not detected in early childhood. Many people with autism can live independently, whereas some need lifelong care and support.
- The children with autism require not only family care and support but equally from community and society with higher sense of inclusivity.
- Due to lack of knowledge and understanding, society judge autistic children and their parents unfairly.
- Parents of autistic children are often emotionally disturbed because of their children's behavior in public places and also because such children have tough time at night for sleeping.
- Added to a disturbed life both mentally and physically, the parents of autistic children not only remain worried about coping and caring of their children in future but more importantly they develop a great sense of guilt in themselves and blame themselves for their children's condition.
- Such parents remain stressful firstly by comparing their children with those children who are autistic; secondly by comparing their children with those children who are recovering or doing better, and thirdly by comparing their children with those children who are not autistic.
- The worse comes to the worst when the parents of autistic children do not get adequate and appropriate care and support from society and government.
- The parents of autistic children suffer from emotional crisis for themselves and also suffer from sensitivity crisis towards fellow parents.

6. RECOMMENDATIONS:

In the light of the parents' sufferings, the researcher forwards five recommendations followed by five recommendations as suggested by Allarakha (2021) for the parents or caregivers as follows:

Recommendations for Parents

- Do not lose hope. Stay positive and keep your hopes alive and continue with possible occupational, speech, and behavioural therapy.
- Expose your child to the outer world and let him/her mingle with other children more and more with some caution.
- Talk as much as you can with your child and also meet parents of autistic children.
- The parents of autistic children need more mental toughness as they need to give lifetime support to their children.



- Do not give mobile to your children or expose them tv or other entertainment device for longer duration. Make them busy with physical games and interaction.
- Take a break from stress if you or your partner are overly stressed. It may be painting or a short walk.
- Let your family and friends (especially those who listen) know your state of affairs. Sharing experiences, including challenges and solutions, truly helps. This may help them understand your situation better and provide the support you need.
- Join support groups for parents of children with ASD. You may also join online groups or follow blogs, vlogs or pages that provide helpful content.
- Consider taking some courses that may help with parenting autistic children. Educating yourself about your child's condition will put you in a better position for managing it.
- Do not be overindulgent. Your autistic child needs space and autonomy as well. Let them be on their own when they are in a safe environment. Let them explore and learn.

Recommendations for Society

- Society should abstain from making any taunts or Karmic allegations on the parents of autistic children.
- Parents of normal children should not distance themselves from the parents of autistic children as it impairs their morale.
- Society should embrace autistic children and their parents wholeheartedly.
- Involve autistic children in social activities.
- Make a community forum to discuss and address autism in society.

7. CONCLUSION :

The crux of this short communication is to underline the fact that although the parents with autistic children suffer from emotional and sensitivity crisis, it is the moral obligation of society to stand by the autistic children and their parents. The reason is such parents do not expect sympathy but normal behavior towards themselves and their children. Considering the insensitivity of society, I recommend proper counselling for society through which a human be transformed into a better human with more sensitivity, care, concern, support, and empathy for fellow humans. Most importantly, the better the parents of autistic children take care of themselves, the more they can nourish their children to grow without great anxieties.

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