

Autism - Beyond the child- Taking care of the parent's Quality of life

Authors

B. Koshy³, N. Srinivasan¹, S. Raghavan², S. Philip Oomen⁴

1. Postdoctoral Fellow, 2. Associate Professor, 3. Professor, 4. Professor and Head, Department of Developmental Pediatrics, Christian Medical College, Vellore, Tamil Nadu

Correspondence: Dr. Nitin Srinivasan, E mail: tinsler7.ns@gmail.com

Children diagnosed with autism spectrum disorder (ASD) have impaired social functions, exhibit repetitive, stereotyped, and self-stimulatory behaviour, and often exhibit a significant delay in the development of verbal interactions.^[1]

The diagnosis of ASD can leave parents feeling shocked, confused and overwhelmed. Parents may experience a wide range of emotions, including denial, anger, guilt and sadness. They may feel like they have failed their child, or they may blame themselves for their child's condition. Parents may also worry about their child's future, wondering if their child will ever be able to live a normal life.

Stress experienced by parents of ASD children during parenting are significantly more and challenging than those with neurotypical children, especially in resource constraint settings like in India. It is estimated that many parents of children with ASD have to face additional issues such as stigma and psychological problems of stress and depression due to their child's behaviour, including poor quality of life.

In 1993 the World Health Organisation defined Quality of Life (QoL) as an individual's "perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".^[2] QoL is a multidimensional concept which includes health and non-health-related



functional domains. Various models of QoL are available, a widely accepted model for assessing QoL in the context of disabilities has been put forward by Schalock et al. This model proposes eight core QoL domains: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional wellbeing, physical wellbeing, and material wellbeing.³

In a qualitative study by Saleh et al, looking at views of parents of ASD children, their responses fell into four out of eight of Schalock's domains; self-determination, emotional well-being, physical well-being, and material well-being. The major concerns were those pertaining to their children's future. Many wanted their child to achieve typical milestones, such as living on their own. With regard to emotional well-being, the discussion centered around personal fulfilment. Within this subtheme, parents equated QoL with being happy and with the absence of stress and problems. Pertaining to physical well-being, they

mentioned the lack of it, complaining that they were more often physically exhausted.⁴

Also, a study by Selvakumar N et al indicated the presence of depressive, anxiety, and stress symptoms among the mothers of children with ASD which can also lead to poor QOL.^[5,6]

Correspondingly, given that it is recognized that parents and families are essential to the well-being of children with ASD, researchers, policymakers, and service providers need to recognize the importance of supporting them and allowing for their involvement in the intervention for their children. Parental support groups helps considerably in boosting a parent's sense of control over his/her well-being and for acquiring parenting techniques in these subgroup to prevent further issues impairing their physical and mental health. Further, the overall health can be improved to a great extent by measures like providing more support like home services for parents. Finally, healthcare professionals should discuss with parents the financial burden, options for financial resources and address the unmet needs of lower socio-economic families, as well as referring them to the relevant authority for availing appropriate assistance.

Therapies available for parents are:^[7]

- 1) Cognitive Behavioural therapy: Problem solving education (PSE), Problem Solving Skills Training (PSST): There is statistically significant reduction of parental stress.^[8]
- 2) Mindfulness therapy: Acceptance and Commitment Therapy (ACT): Parents showed reduction in mindful attention awareness scores, a trend towards lowering of stress.^[9]
- 3) Parent training (PT): Parent Family Intervention (PFI)
- 4) Areas focussing on Post-traumatic Growth: Solution-focused Brief Therapy (SFBT):

through psychoeducation with emphasis on positive psychological changes (such as development of spirituality, patience, compassion and strength).^[10]

Recommendations: Despite the challenges that come with an autism diagnosis, there are ways for parents to cope and manage the stress that comes with it. Here are some suggestions:

- 1) Educate yourself about autism: Learning more about autism can help parents understand their child's condition and how it affects their behaviour, communication, and development. Understanding autism can also help parents advocate for their child's needs and communicate more effectively with teachers, therapists, and other professionals.
- 2) Seek out support: Parents of children with autism can benefit from connecting with other parents who have similar experiences. Support groups, online communities, and parent networks can provide a space for parents to share their experiences, ask questions, and receive emotional support.
- 3) Take care of yourself: Caring for a child with autism can be stressful and exhausting, so it's essential for parents to take care of themselves. This can include getting enough sleep, eating a healthy diet, and engaging in activities that promote relaxation and stress relief, such as exercise, meditation, or hobbies.
- 4) Advocate for your child: As a parent, it's crucial to advocate for your child's needs and rights. This may involve communicating with educators, healthcare professionals, and government agencies to ensure that your child has access to appropriate support, services, and accommodations.
- 5) Celebrate your child's achievements: Finally, it's essential for parents to celebrate their

child's achievements, no matter how small they may seem. Recognizing your child's progress and accomplishments can help you stay positive and motivated during challenging times.

An autism diagnosis can be a challenging and emotional time for parents. The diagnosis may leave parents feeling overwhelmed, isolated, and

unsure about their child's future. However, there are ways for parents to cope with the stress and manage the challenges that come with raising a child with autism. By educating themselves, seeking out support, taking care of themselves, advocating for their child, and celebrating their child's achievements, parents can help their child reach their full potential and lead a fulfilling life.

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