



IMPACT ON QUALITY OF LIFE OF PARENTS CARING FOR CHILD WITH AUTISM SPECTRUM DISORDER

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ABSTRACT **Background:** Many parents experienced considerable problems combining daily activities with care, had financial problems or suffered from depressive mood in raising child with autism.

Aim: To assess the parents experiences in raising a child with ASD. Material and method: Questionnaire, a scale composed of 10 items relating to core and behavioral symptoms of autism and quality of life of parents.

Result: Findings revealed that parents who have a child with autism experienced multiple challenges in different aspects of care, impacting on parents' stress and adaptation.

Conclusion: The burden on parents of raising a child with ASD is too high. Outreaching professionals who provide practical assistance are most highly valued.

KEYWORDS : Autism spectrum disorders, Parents, Childhood, Adaptive behaviours,

Introduction:

Parenting of children with Autism can be more stressful and challenging than parenting children with typical development. They frequently reported higher levels of anxiety^{1,2}, higher levels of depression^{2,3}, and more health-related problems. Symptoms of autism typically appear during the early years of childhood, when parents realize that their child has not achieved the expected milestones of child development. Meeting the high care demands of affected children requires much time, effort and patience.⁴ This often results in psychological distress, depression, anxiety and other mental or physical health problems among their parents.^{5,6,7} Demands put on parents of a child with ASD do not decrease when the child gets older. Moreover the child's lack of social empathy may cause many misunderstandings and conflicts in their family life. Several studies report that rigid, oppositional and aggressive behaviours are highly prevalent, as is the overlap with ADHD, sleeping and eating disorders^{8,9,10}. Therefore, one may understand that parents experience the rearing of a child with ASD as tremendously burdening making them more vulnerable to develop a depression or an anxiety disorder^{11,12}. Therefore, the present study was done to find out the following questions: what are the parents experiences in raising a child with ASD? Which problems do they encounter?

Materials and methods:

Primary inclusion criteria were parents with a child who was already identified as meeting criteria for ASD. To fill this need, we developed the Questionnaire, a scale composed of 10 items relating to core and behavioral symptoms of autism. The answers were in their language. Our sample consisted of 30 children with a clinical diagnosis of autism spectrum disorder or typically developing children between 4 and 10 years of age recruited for a study of sleep and behaviour in children with ASD. Questions were asked to the parents regarding the life they are living after their child has been diagnosed with the disorder.

Sr. no	Question
1	How did the Autism Spectrum Disorder show itself in your child?
2	When did you notice something was the matter?
3	Your child has been diagnosed now: how did this process unfold?
4	What were you feelings when you were told your child had an Autism Spectrum Disorder?
5	What happened after your child was diagnosed?
6	How is your child now?
7	In retrospect, what would you like to change in the kind of help you received?
8	How does all of this affect you and your family?
9	Do you consider your child's inability to engage in friendships as a major problem?
10	Do you feel that the burden put on you is far too high?

Result:

Questions answered were having different answers by each parent for all questions. They define the quality of life they are living with their child. The answers given were as follows:

Answers:

- He felt totally misunderstood all day long.
- We didn't understand him, and he didn't understand us.
- He will explode at the slightest provocation.
- You have to fight hard for your child.
- Even as a parent you see what your child needs, but others always know it better than you.
- You will never rest, there are always things that you have to fight for.
- The burden and there is the feelings of guilt.
- I felt completely isolated.
- As a parent you tend to become less creative to think out something new.
- There's an incredible anger against people who dare to suggest that everything is hopeless.
- I was still dealing with the fact that we had this horrible word now labelling our child.
- Her illness has caused many rows within the family as they doubt the diagnosis and just think
- She's in need of a smack.
- You can't go and visit your friends, you can't admit anybody.
- He looks like a normal child, people don't see the autism and don't understand.

Quality of life of parents were assessed using the following questions with 'yes' or 'no' answer.

Sr. no	Question	Answer(%)	
		Yes	No
1	In general would you say your health is good.	22	78
2	Does your health now limit you in your activities?	67	33
3	During the past 4 weeks have you had any problems with your work or other regular activities as a result of your physical health?	58	42
4	During the past 4 weeks, were you limited in the kind of work you do or other regular activities as a result of any emotional problems (such as feeling depressed or anxious)?	21	79
5	During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?	77	23
6	Have you felt calm and peaceful most of the time?	47	53
7	Did you have a lot of energy most of the time?	39	61

8	Have you felt downhearted and blue sometime?	73	27
9	During the past 4 weeks, did your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?	64	36
10	Do you think that religious beliefs is a coping strategy and as a support, helping to accept and raise a child with ASD	71	29

Discussion-

The present article aimed to review identify the factors that influence or are associated with parenting stress among parents of children with ASD. Parents are often relieved when they get an ASD diagnosis because it confirms what they had already suspected for a long time. Moreover, it confirms that their parenting is not the cause of the child's behavioural problems. Unfortunately, the lack of understanding in people in their social environment does not diminish after the diagnosis has been made. Parents experience this lack of accepting as a particularly heavy burden.¹³

The majority of the parents feel that taking care of their child and their family is beyond them. Parents of children with ASD experience worse physical and mental health stress and problems. Parents are greatly worried about the future of their child. They fear that it will not be able to live an independent life once being an adult.¹⁴ Most parents fear that their child will end up being socially isolated. There is also the issue of stigma from the public, which was strongly perceived to be due to the normal appearance of the child. This then resulted in the public's misinterpretation of the child's behaviour attributable to autism, as misbehavior.

All participants felt safe enough to express themselves freely. All parents underline they would not want to do without their child for the world, the burden on them is often far too high. Primary care services should be aware that these kind of outreaching services are needed to help parents to keep their families afloat, help them cope and monitor the efforts and temper their frustrations.¹¹ As ASD cannot be cured, such a home visiting approach tuning into the real needs of the parents could prove utterly beneficial in helping families to raise children with ASD.

Conclusion:

This study showed that while many parents in our sample derived fulfillment from providing care for their child with an ASD, this caregiving affected their own lives considerably and in a variety of ways. Parents often experienced problems with combining care with other daily activities, had financial problems or suffered from depressive symptoms. Hearing parents out to identify their individual family needs and not just the affected child should also be encouraged to direct services that are resourceful and necessary to the family.

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