

Parental perspectives on the lived experience of having a child with autism spectrum disorder in Sri Lanka

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Abstract

Introduction: Autism spectrum disorder (ASD) is thought of as a childhood developmental disorder. However, significant costs resulting from the loss of productivity of families have long-lasting consequences. There is a lack of published research on parental perspectives of the living experience with ASD in Sri Lanka.

Objectives: To identify parental perspectives on the challenges and experiences of raising a child with ASD in the Sri Lankan context.

Method: A qualitative descriptive study was conducted in the outpatient services of the Provincial General Hospital in Ratnapura, Sri Lanka. Thirty purposefully selected parents of children having ASD participated and one-third were fathers. The sample had parents from urban, semi-urban and rural areas. Professionals, semi-skilled and skilled workers were also selected. Participants represented different ethnic and religious backgrounds. Written informed consent was taken from all and ethical clearance was obtained from the Ethics Review Committees of the Faculty of Medicine, University of Kelaniya and Provincial General Hospital Ratnapura. The focused semi-structured interviews were conducted by a trainee speech and language therapist. Recorded interviews were transcribed verbatim into Microsoft Word and analysed thematically.

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Results: The 30 participants were aged from 35-46 years. The thematic analysis revealed several prominent themes about the parental experience. These themes were emotional stress and impact on the marital relationship, coping strategies and positives related to parenting a child with autism, dealing with challenging behaviours, perceived stigma and worries about future functioning, limited access to health and educational services, financial and caregiving burden.

Conclusions: Most parents expressed negative perspectives on emotional stress, impact on the marital relationship, dealing with challenging behaviours, perceived stigma, limited access to health and educational services, financial burden, caregiving burden and worries about future functioning of their children. However, having a child with autism has allowed a few parents to develop coping strategies and positives related to their family relationships.

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Introduction

Children with autism spectrum disorder (ASD) are deficient in social communication and have restricted, repetitive behaviour¹. Although ASD is thought of as a childhood disorder, costs due to loss of productivity of individuals and their parents have long-lasting consequences². It has been found that parents of children having ASD reported lower family functioning, a greater degree of psychological distress and lower quality of life³. Deficits in social communication were associated with overall parenting stress, maternal distress was associated with regulatory problems and fathers with externalizing behaviours⁴. There is a lack of published research on parental perspectives of the living experience with ASD in Sri Lanka. Hence this study was conducted to explore problems of parents having a child with ASD.

Objectives

The objective of the study was to identify parental perspectives on the challenges and experiences of having a child with ASD in the Sri Lankan context.

Method

A qualitative descriptive study was conducted in the outpatient clinic services of the Provincial General Hospital in Ratnapura, Sri Lanka. The District of Ratnapura is situated in the Sabaragamuwa Province of Sri Lanka and has a population of over one million people. More than two-thirds of the population are Sinhalese followed by Tamils and Muslims as ethnic groups. The population is distributed in urban, semi-urban and rural regions and the district is comprised of 17 Divisional Secretariat divisions.

Purposefully selected parents of children having ASD 3-6-years of age who are residing in Ratnapura District were invited to participate. Majority of the children attending the outpatient services with a diagnosis of ASD were of this age group. Thirty parents were recruited. ASD had been diagnosed previously according to the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders and they were attending the clinic for follow-up visits. One parent was selected for a child. Parents with children who had other medical disorders were excluded. One-third of the participants were fathers. The sample had parents from urban, semi-urban and rural areas and there

was at least one parent from each Divisional Secretariat area. Professionals, semi-skilled and skilled workers were selected representing a third of the entire sample. About two-thirds of the participants were Sinhalese and the rest from minority ethnic groups. At least one third were considered to have severe symptoms clinically and another third of mild severity.

Ethical issues: Ethical clearance was obtained from the Ethics Review Committees of the Faculty of Medicine, University of Kelaniya (ERC No. P/52/02/2019) and permission from the Provincial General Hospital Ratnapura. Written informed consent was taken from all participating parents.

The focused semi-structured interviews were conducted by a trainee speech and language therapist in a manner most convenient to the participants, either face-to-face or over the phone for 60 minutes. All interviews were audio-recorded with prior written consent. The interview guide for this study, which is shown in table 1, included 10 questions and were based on literature reviews of challenges and parental experiences in other countries⁵.

Table 1: Questions for the interview on parental perspectives on the lived experience of having a child with autism spectrum disorder

1. What is your understanding of autism?
2. What do you feel about having a child with autism?
3. What are the problems experienced by you because of having a child with autism?
4. How do you feel about these problems?
5. What are the negative and positive contributory factors?
6. What are the most significant things that affect the family?
7. What factors are manageable to you?
8. What are the strategies used when coping with the problems of your child?
9. What do you think about the available services for helping you and your child?
10. What do you feel about the available support for the child's education?

Recorded interviews were transcribed verbatim into Microsoft Word, with all identifying information removed, and analysed thematically. Interviews were conducted in Sinhala which is the native language. Then the interviews were transcribed in Sinhala and translated into English. Answers to questions were broken down into thought units, or the smallest amount of meaningful information that expresses a complete idea. Thought units identified were typically one or two sentences in length. Thought units were analysed and organised into themes based on content using operational definitions. All the themes were identified after the analysis. The principal investigator then used the operational definitions to independently code 100% of the data and calculated the inter-rater reliability.

Inter-rater reliability was calculated on a point-by-point basis.

Results

Thirty parents were invited and all of them participated in the study. The parental ages ranged from 35-46-years. There were teachers, doctors, nursing officers, homemakers, and clerks among the mothers who comprised two-thirds of the sample. Among the fathers, there were police officers, drivers, carpenters, farmers and semi-skilled manual workers. All participants came from intact families where the mother and father had lived constantly with their children. The themes identified within the data and examples are shown in table 2.

Table 2: Themes identified and opinions in verbatim from the interviews on parental perspectives on the lived experience of having a child with autism spectrum disorder

Theme	Selected opinions in verbatim
Emotional stress and impact on the marital relationship	<p>“When the doctor told me that your baby is diagnosed with autism, I fell into deep grief, and I was lost, so stressed.”</p> <p>“I have seen several other kids behave like my child; then felt what a shame. At that time, I was pregnant. I felt scared whether my next baby would also get a condition like this, so, I told my husband I want to die.”</p> <p>“I felt angry towards my wife because she is always with the child. She forgot my needs. Because of her behaviour, finally, I thought I will file for divorce.”</p> <p>“Day by day, due to our child our conflicts increased. As a mother, she could not tolerate the child’s behaviours. So, she decided to leave us.”</p>
Coping strategies and positives related to parenting a child with autism	<p>“At times I am pleased as a mother when comparing my child with others who have autism, my child is not severe like them. That is a relief to me.”</p> <p>“I went to the temple and worshipped Lord Buddha, to get relief from all burdens.”</p> <p>“I went to the church and prayed for my child, and God will perform a miracle.”</p> <p>“We always try to identify our duties and responsibilities of each other. Our child is unique to us. Our child is everything to us.”</p> <p>“Having a child with autism has strengthened our family relationships. My child is a gifted child to me. I always try to ignore negatives and try to look wisely towards the future.”</p>
Dealing with challenging behaviours	<p>“If he wants something, we need to somehow give it to him instantly. If not, he gets distraught and put up a tantrum, screaming on the floor for half an hour.”</p> <p>“I try to avoid giving attention to him when he does bad things. But it is very hard at times.”</p> <p>“He was not eating rice at all. This is because it was not crispy. So, it was challenging for me to plan how I should feed him every day according to his preferences.”</p>
Perceived stigma and worries about future functioning	<p>“He grabs things and breaks some of them into pieces, but I do not hit him and accept that the child is doing these because of autism, but people look at you and they probably think, I am a bad parent.”</p> <p>“I want him to feel he is part of the society; I want people to see him doing things and think he has got a right to be there.”</p> <p>“I just try to get my child to a place where nobody can look at him; No one can see and blame me, because my child may do something strange.”</p> <p>“Most of the time, I am worried about what will happen to my child in the future. Who would care about my child's life? Can he work independently, when we are not alive?”</p> <p>“There are so many worries in my mind, can he live independently, hold a job and maintain a relationship in the future?”</p>
Limited access to health and educational services	<p>“I was confused, so I took him to a traditional healer. I had taken my son to many places without getting a cure. So, I had to try everything.”</p> <p>“I went to several hospitals, and they told me that my child was not sick, I knew there is a problem with him and them not detecting it. I went to see a traditional healer.”</p> <p>“There are limited speech therapy and occupational therapy services available in our area. Because of that, we have to wait for a long time in between sessions.”</p> <p>“I tried many schools for my child, but most of them rejected my child because she has autism.”</p> <p>“I don’t like for him to attend a mainstream school, there were both typical and atypical children in that school, I did not want this because my child was getting bullied.”</p>
Financial burden And caregiving burden	<p>“Some days we were at the traditional healer's practise and spend a lot of money for their rituals.”</p> <p>“We had to sell all vehicles we owned because we had to spend so much for the traditional therapies of my child.”</p> <p>“He is not toilet trained, so I have to stay with him throughout the day, or I have to get support from my husband's parents when I go out to work.”</p> <p>“I do not have time to go to work as there is no one to look after my child, or I have to look for someone to help me paying money.”</p>

Emotional stress and impact on the marital relationship

This theme considered emotional distress caused by having and raising a child with ASD and influence on the marital relationship due to this burden as shown in table 2.

Coping strategies and positives related to parenting a child having ASD

This theme included ways of coping of parents to manage difficulties related to raising a child with ASD and positive psychological adaptations in them as shown in table 2. Certain parents stated that they find that they are more compassionate and more empathetic toward others.

Dealing with challenging behaviours

Behaviours that in intensity, frequency, or duration threaten the quality of life of the individual or others are considered challenging. Most of the participants expressed the challenging nature of their children's difficult behaviours as shown in table 2. Examples they mentioned included aggressive behaviour, repetitive behaviour, temper tantrums, hyperactivity, picky eating, and lack of social interactions.

Perceived stigma and worries about future functioning

Opinions associated with perceived disgrace and shame related to the child with autism were considered here. Many of the participating parents of children with autism have felt stigmatised as shown in table 2.

Limited access to health and educational services

The concerns about limitations in health and educational services are mentioned here as shown in table 2. It was challenging to find a place for the child in a suitable school and some cases, parents had to travel a long distance with their children to ensure appropriate schooling.

The financial burden and caregiving burden

The strain borne by the parents in economical and in physical care were included here as shown in table 2. The care responsibilities left no time for paid work, domestic chores and other siblings may have been neglected.

Discussion

This is the first time that the lived experience of parents with children having ASD is reported from Sri Lanka. Many of the participants in our study expressed the emotional distress they experience related to their children's diagnosis and clinical features. Studies conducted in other countries have shown that parents of a child having ASD experiences greater stress compared to parents of a typically developing child⁶. Several parents stated

that caring for their child with autism affected their marital relationship in a negative way leading to conflicts and even separation. A study conducted in the USA about the marital interactions of parents with a child having ASD found that a day with higher negative interactions was associated with significant stress for both parents⁷. Many parents worried about the future social and occupational functioning of their children and they used religious activities as coping strategies. A Kenyan study had reported emotion-focused coping methods utilised by parents of children having ASD that consisted of belief in certain supernatural powers and spiritual healing techniques⁸. In the future, the child health services in Sri Lanka may have to consider systematised psychological support for parents which may be based on local cultural practices as well.

Facing and dealing with challenging behaviour related to autism was a major concern to many of our participants. Mealtimes and refusal of certain food types were mentioned. Similarly, in a study in Florida USA, parents of children with ASD reported that their children had more difficulties with concerns about eating, mealtime locations, craving certain food and being picky eaters compared to typically developing children⁹. Parents need to be trained in home-based early interventions techniques to develop skills in their children¹⁰.

Among our participants, the stigma was described mainly related to the judgement of others and rejection for school admission. In a qualitative study conducted in Australia, it was found that the families reported perceived stigma related to autism in four domains, lack of knowledge, judgement, rejection and lack of support¹¹. Child mental health professionals in Sri Lanka should address these discriminations by conducting more public awareness programmes. Limitations in access to health and educational services were mentioned by many participants in our study. Child and adolescent mental health services and trained experts are greatly limited in Sri Lanka^{12,13}. Out of 25 administrative districts in the country, there are only five districts with a health service comprising a child and adolescent psychiatrist. This has led to major challenges in providing services for children with neurodevelopmental disorders and psychological trauma¹⁴. The health and educational services for children with ASD are limited even in certain settings in the Western world. A set of caregivers in Canada have stated access to behavioural therapy was limited and they were worried about the lack of trained therapists in schools¹⁵.

Despite Sri Lanka having a free health service, the financial burden in many participating parents seems to be partly related to spending on traditional healers. Accessing traditional healing practices for developmental disorders is also seen in other countries such as Egypt¹⁶. Traditional practices such as thovil, a demonic ritual of exorcist nature have been reported in rural Sri Lanka earlier for ASD¹⁷. Obtaining therapy services and spending on traditional healing practices have led to some families having to sell their valued properties. Besides, the caregiving burden had prevented some of them from attending work, which has contributed to further economic difficulties. In a longitudinal survey in Australia, it has been shown that mothers of schooling age children with autism were significantly less likely to be working compared to other mothers¹⁸. It would be beneficial if the government could provide financial and technical support for self-employment allowing some parents to earn from home.

A strength of the study was parents were allowed to express their opinion either face to face or via phone. Further, the parents may have felt at ease expressing their concerns especially to a trainee clinician not attached to the hospital. As a limitation, it would have been better if the sample size was higher. The opinions may have changed if we also included families with single parents and clients not attending regular clinics.

Conclusions

Most parents expressed negative perspectives on emotional stress, impact on the marital relationship, dealing with challenging behaviours, perceived stigma, limited access to health and educational services, financial burden, caregiving burden and worries about future functioning of their children. However, having a child with autism has allowed a few parents to develop coping strategies and positives related to their family relationships.

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