Demography India
Vol. 51, No. 1 (2022), pp. 109-125 ISSN 0970-454X

Awareness, Challenges and Coping Strategies of the Parents having Children with Autism Spectrum Disorder (ASD) in Mumbai, India

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Abstract: In India, empirical evidence on awareness, challenges, and coping strategies adopted by the parents of children with ASD are inadequate. This study aims to understand the awareness, challenges and, coping strategies of parents with ASD in Mumbai, India.Data gathered through a qualitative study using the grounded theory approach was used for this analysis. Theoretical sampling procedures were followed to carry out the in-depth interview of parents (N=10). Informed consent procedures were followed, and only those who voluntarily consented to the interview were interviewed. The data was analyzed through NVivo 10. The relationship among emerging themes, categories and codes was studied through an iterative process using memos, graphic representation, and a mind map. Results showed inadequate awareness among parents, who face numerous challenges, both due to the inherent hurdles of having a child with ASD and the impact of a largely indifferent society that often hinders the integration and acceptance of such children. Parents attempt diverse coping strategies, primarily support-seeking strategies, to address the challenges they face with their children with Adhere is a need for awareness generation on ASD, which will help early diagnosis and appropriate management by parents. Parents are also required to be counseled and trained for the most appropriate form of parenting style, which subsequently will ensure better care of the children with ASD.

Keywords: Autism Spectrum Disorder, Awareness, Challenges, Coping, Parents, India

Introduction

Autism Spectrum Disorder (ASD) is often defined as the range of conditions characterized by some degree of impaired social behaviour, communication, language, and a narrow range of interests and activities that are both unique and carried out repeatedly. An estimate shows that 0.76% of the world's children had ASD in 2010; however, there is a lack of evidence in low- and middle-income countries(Baxter et al., 2015). In India, the number of children affected by ASD has increased from 2 million in 2008 to 10 million in 2013(Arora et al., 2018). The actual number may differ as (a) most of the earlier studies on ASD are hospital-based and thus lack information on the prevalence estimates(Jain et al., 2013; Kommu et al., 2017; Singhi Pratibha, 2001), (b) there is lack of uniformity in the application of fully validated and translated autism diagnostic tools (Rudra et al., 2014), and (c) under-recognition of the disorder due to a delay in the diagnosis at a young age (Daley & Sigman, 2002). Evidence suggests more than 20 individual, familial, pre-, peri- and neonatal risk factors for ASD (Gardener et al., 2009, 2011; Guinchat et al., 2012; Kolevzon et al., 2007). Children with ASD show raised behavioural problems than children with other developmental disorders (Estes et al.,

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2009). ASD has direct and indirect cost implications on the nation (Barnett & Masse, 2007); however, the primary sufferers remain the child and the family.

Given the primarily unsupportive societal attitude of disability in general, parents often resort to the initial hiding of an autistic child, followed by considerable stress due to the child's socially challenging behaviour and future(RCI, 2012). Children with ASD face various challenges that can significantly negatively impact parent and family functioning, including stress and social and communication deficits among all family members (Rao & Beidel, 2009). Evidence suggests that parents of children with ASD have a higher divorce rate than parents without any child with a developmental disability (Hartley et al., 2010). Children with ASD are also identified as risk factors for mothers' anxiety and depression(Tony Brown & Hastings, 2002). Parents experience challenges at personal and social levels across various contexts, including increased personal stress, effects on interpersonal relationships, and increasing isolation (Altiere & Von Kluge, 2009; Wang et al., 2011). Parental stress is also influenced by the adjustments to the reality of the child's condition, housing, and finance (Gray, 1994). Having a child with ASD is associated with many difficulties in caregivers, including decreased parenting efficacy, increased parenting stress, and increased mental and physical health problems besides significant financial strain and time pressures on families(Karst & van Hecke, 2012). Autism is again found to have a persistent impact on the family, its economic status, and sibling and significantly modifies each family member's lifestyle (Begum & Mamin, 2019).

There is limited empirical evidence on ASD and its implications for children and families in the Indian context. Moreover, evidence on awareness, challenges, and coping strategies adopted by the parents of children with ASD are further inadequate. Existing studies primarily focused on symptoms and profiles of children with ASD in schools, developmental disabilities of these children, and the accompanying social ostracism and stigma families encounter(Dhar, 2009; Edwardraj et al., 2010; Gupta & Singhal, 2004; Kembhavi, 2009). A study in Goa revealed that parents face tremendous difficulties raising children with ASD due to competing commitments, leading to initial social withdrawal and discrimination at the community level(Divan et al., 2012). With increasing ASD cases, expanding the existing evidence base with more empirical research in various geographical and socio-cultural contexts in India is pertinent. Parents are central to every aspect of children's development, and, thus, a better understanding of their knowledge, attitudes, challenges, and coping strategies towards raising children with ASD holds significance. This study aims to understand the parents' awareness, challenges, and coping strategies with ASD children in Mumbai, India. The results are deemed to contribute to the existing limited empirical evidence on ASD in India. Additionally, the results may be helpful for policies and programmes aimed at the welfare of children with ASD.

Materials and Methods

Data gathered through a cross-sectional qualitative study in Mumbai, India, in 2018 was used for this analysis. The study used the grounded theory approach (Long et al., 2006) to address the objectives.The grounded theory approach with the potential to offer insights into how things happen is suitable in situations where little is known about a particular topic or phenomenon or where a new approach is needed in a familiar setting(Dahlgren, Emmelin, & Winkvist, 2007; Daymon & Holloway, 2010). Theoretical sampling (Glaser, & Strauss, 1967) procedures were followed to identify the respondents (i.e., parents) for the interview. Firstly, the schools exclusively involved in teaching ASD children were approached. Once the schools gave their consent to participate in the study and the teachers agreed to the interview, the researchers further requested the school authorities connect them with parents willing to participate in the study. Informed consent procedures were followed, and only those who voluntarily consented to the interview were interviewed. A pretested semi-structured checklist was used for the in-depth interviews. The interviews were audio-recorded after written consent from the respondents. Ten in-depth interviews (IDIs) were conducted with parents with ASD children, and the decisions to stop at 10 IDIs were influenced primarily by information saturation. Saturation signifies that a researcher can be reasonably ensured that further data collection would yield similar results(Long et al., 2006; Van Rijnsoever, 2017). Saturation is again described as the point in data collection and analysis when new incoming data produces little or no new information to address the research question (Guest et al., 2006). In this study, coding and analysis of the gathered data were done concurrently with the data collection to assess the emerging codes and evolving themes. By the time 10 IDIs were completed and analyzed, it was implicit that similar codes were getting repeated and the possibility of new codes or themes emerging from further interviews were least likely. As additional interviews were perceived not to add much value to the research question, the researchers decided to stop interviewing more parents.Literature suggests that for a single face-to-face interview approach, an average number of 10-30 participants is adequate for data(Baker & Edwards, 2012; Bernard, 2012; Crouch & McKenzie, 2006; Green & Nicki, 2018; Kuzel, 1992; Marshall et al., 2013; Meyrick, 2006; Morse, 1999; Saunders, 2017).

The first author conducted all the interviews. The transcriptions were done by the first author and were verified by the second author for correctness and completeness. The interview recordings supplemented the field notes for the finalization of the transcriptions. NVivo 10 (Castleberry, 2014) was used for organizing and coding data. Codes from the data were identified and defined iteratively. We started with open coding of the 'meaning units' followed by the axial coding. The purpose of axial coding was to begin reassembling fractured data during open coding. In axial coding, categories were related to their subcategories to form more precise and complete explanations about phenomena under study. After theoretical saturation, a selective coding process was followed to integrate and refine categories. The major categories are finally integrated to form a larger theoretical scheme explaining the risk factors of ASD and the challenges and coping strategies of the parents. The relationship among emerging themes, categories and codes wasstudied using memos, graphic representations, and mind maps through an iterative process. Anonymous direct quotes were used as examples of particular themes to substantiate the findings, where appropriate.

Profile of the respondents

Eight of the ten interviewed parents were mothers of children with ASD. One father and grandmother of children with ASD was interviewed among the remaining. The mean age of the mothers was 32 years, and that of fathers was 36 years. Most of the parents were educated beyond graduation level. Most fathers were found employed in either government or private sectors, while most mothers were found to be homemakers. Six families were economically better-off, while the others did not provide that information. Eight of the families were Hindus, and one each followed Islam and Jainism. Most of the children whose parents were interviewed belong to the 4-7 years age group, boys (six out of ten), and first-order births (nine out of ten).

Results

The analysis resulted in three themes (Figure 1): Inadequate awareness regarding ASD (ignorance, denial of facts, symptoms will be automatically cured, symptoms are normal, unplanned pregnancy, pregnancy complication, treatment during pregnancy, a financial problem during pregnancy, stress during pregnancy), challenges (trouble with sustaining employment, maternal depression, trouble with financial expenses, stigma of having an ASD child, difficulty in dealing with society), and coping strategies (changing profession, changing lifestyle, defying societal norms towards ASD children, stress management through positive attitude and patience, and interaction with people having ASD children).

Inadequate awareness regarding ASD

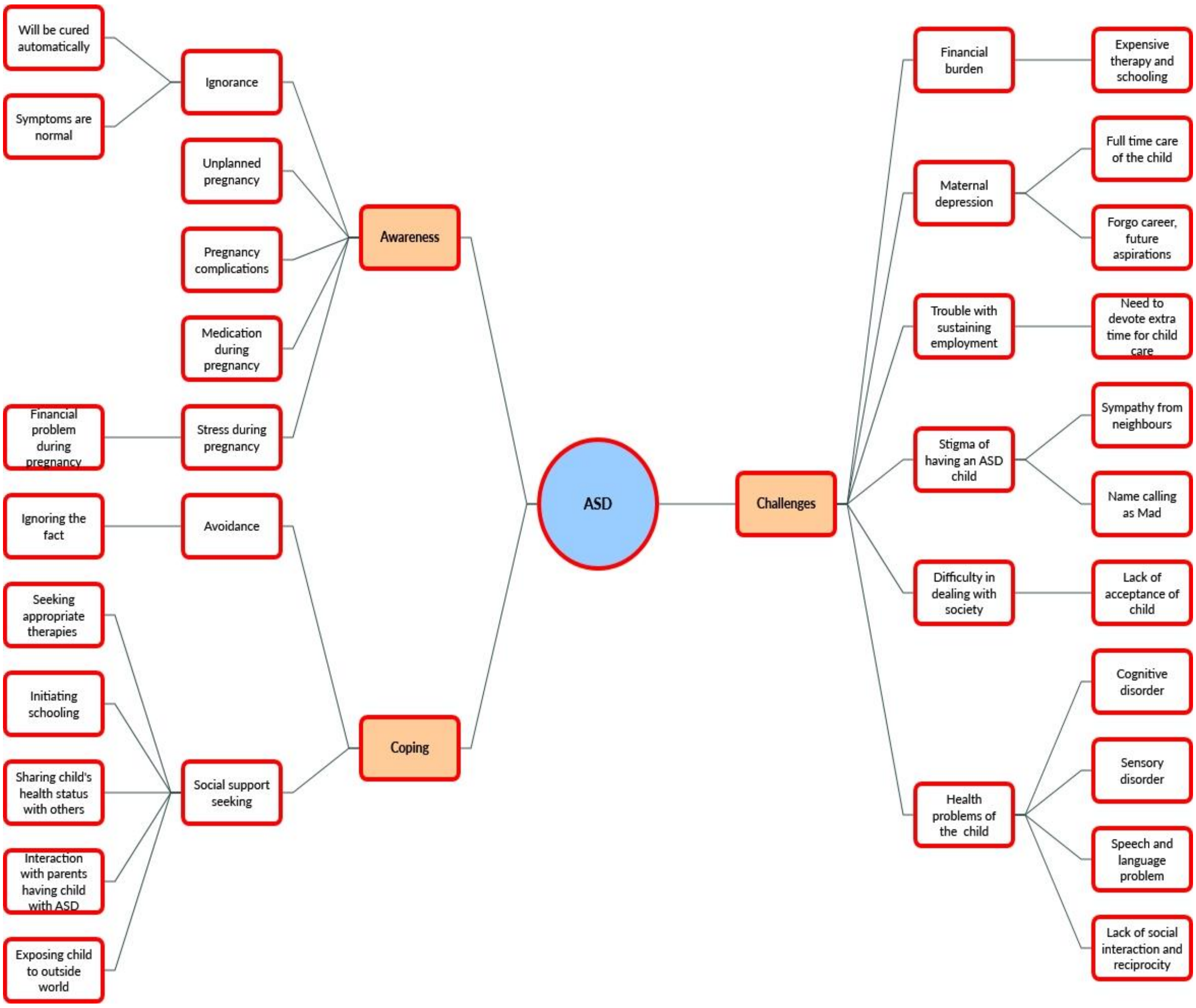
All the interviewed parents were ignorant about ASD before their children's diagnosis. The children were diagnosed with ASD between 3-4 years. Most parents perceived a range of factors such as stress during pregnancy, financial problems during pregnancy, unplanned pregnancy, pregnancy complications, and medication during pregnancy as the risk factors of ASD. However, a few parents were clueless and unsure about the reason behind their child being with ASD.

> *At that time (during pregnancy), there was so much stress like family pressure, previous miscarriage and financial pressure, which might have affected the baby's growth or mind leading to autism.*

> *I had a continuous problem of cold during pregnancy. I used to use XYZ drop to open my nose before going to sleep. That might have led to this (ASD of the child).*

> *I wanted this child, but we did not plan. I had a pregnancy problem, then after, this child was born.*

Figure 1: Mind Map of ASD



The parents' initial reaction was often denial to accept that the child has ASD, followed by confusion over consultation with the doctor. The data reveals that almost all the parents initially were not ready to accept something wrong with their children and felt the need for medical consultation. It was also found that initial symptoms of ASD were often perceived as normal issues that automatically get solved with the child's growing age. This shows ignorance among parents and delayed appropriate treatment/therapy seeking.

> *We initially thought that maybe he has a hearing problem because he did not respond to anything. He also didn't make eye contact. He is living in his own world.*

> *We thought that is the way he lives. But we took it seriously when he was 2.5-year-old. Because until that time, we were giving him the time to pick up with time.*

In another instance, parents ignored the ASD symptoms with their child and went for medical consultation only after serious concern from the school teacher.

> *We did not notice it then; she never used to talk. She started walking at the age of 18 months. We thought she is one of those children who start walking a bit late and talk less. We did not take it seriously, did not know about her condition, so we used to feed her forcefully by hand. We did not understand her condition. We went for a doctor consultation after repeated advice from the teacher.*

Challenges and coping strategies

Most of the children with ASD had range of issues like cognitive disorder, sensory disorder, speech and language problems, and lack of social interaction and reciprocity behaviour urging constant attention of the parents/caregivers. Some of them had attention-seeking behaviour on the cognitive front, while others wanted their own space and usually got irritated if interrupted.

> *No, he does not respond immediately; sometimes, it takes 2 to 3 calls.*

Sensory problems of these children were evident from the interaction with the parents. Most parents believed that their children were sensitive to sound, skin touch, while at the same time, some of them could not feel pain or at least did not express it, urging parents to be extra vigilant.

> *He does not feel pain properly. He will never tell us when he gets hurt because he cannot communicate properly. Once he got burned his fingers, that time also he did not feel anything, not even cry, so we have to be more careful.*

Parents further viewed that most children had concerns around social interaction or reciprocity; specifically, they could not communicate effectively and avoid eye contact and social smile. However, a few of them reportedly improved after therapy.

> *Now he does this (eye contact) before he did not. The treatment has improved him. …. Moreover, he is happy in his world.*

All parents reported speech & language problems of children as a significant issue. Seven of the parents continued to struggle with the language problems of their children, while three of them revealed gradual improvement in their children's speech after undergoing specific therapy. There were also those children who either did not speak or repeat the words.

> *Yes, there is a verbal problem with him. He sings and repeats the poems. He even had a spinning problem, but now (after therapy), it has improved a lot.*

Analysis revealed that most parents use sign language or parallel talk to interact with the ASD children, as the doctors prescribed. It was, however, realized that parents always understand what their child wants no matter how the child is, right after their birth. To quote a parent:

> *We usually spend time together daily. We understand him correctly. We understand our child's feelings when he is hungry,stubborn, not feeling good, and suffering from fever. It has automatically come in understanding.*

Data further found that parents had left their gainful employment or changed their profession to address the child's needs and requirements. The realization of the problem and subsequent change in lifestyle was stressful for parents. Some tried to address this through the change in profession or regular interaction with people with similar concerns. To quote a respondent:

> *I have made manyadjustments. I left my job after his (child) diagnosis. I started my business after some time because if you think of one thing, only it will give you frustration, so I spend some time there too. Plus, I have a perfect group of moms whose children have autism.*

Mothers were found as the primary caregivers who sacrificed their carrier and future aspirations to take care of the children with ASD. The only exception was when the grandmother was the caregiver, as the parents were least interested in the child and were not giving time. She had to forgo her desires, including going outside even for a shorter duration to address the needs of this child. She expressed that-

> *We did not know about her situation initially, so we used to think that everything would be fine with her, but now it is not the same. I spend all day with her. I need to see her all needs; what to feed her, when to give her a bath and every other thing. It takes all my day. I get tired. I can notfind time for myself. I can notfind time to go out. When anyone asks me to come to their home, or any parents call me, I can not go. I get only Sunday when her mother gets off from her tuition work. However, she is attached to me more than her mother, so she troubles her mother. Her mother gets irritated, so she asks me to be with her only and not go anywhere.*

Data revealed a sense of stigma attached to having a child with ASD, which sometimes prevented parents from taking their child outside to hide her/his ASD characteristics from others. Parents also perceived that they often experienced a sympathetic look from their circle, though they hardly interact.

> *Otherwise, they (neighbours) do not talk much, but we feel like they behave with pity like OMG, it is so sad, how it can happen to you.*

Insensitive societal perspective towards ASD children again puts parents under stress. It was noted that neighbours either stop interacting with parents or stop allowing their children to play with this child with ASD. Data also revealed shaming children with ASD 'mad' and telling parents to keep them inside the house. Parents believed that society hardly understands children with ASD and their condition.

> *Society people do not try. They speak crazy and say to their children, do not go to her. In a word, if I say they said, she is "mad". Very few people understand her and try to talk to her.*

> *When people come to talk to her, she does not answer... Because of her behaviour, parents do not allow their children to come to her. They ask me to teach her manners, and if I can not then, I should keep her at home.*

Data indicate exceptions to understanding nature towards children with ASD by people outside the family is concerned. However, it was believed that the affectionate attitude towards children with ASD is only for the too young children, whose disorder hardly affects others.

> *They are very friendly to him. They understand. ... My friend circle is perfect, and understanding so is my building mates and relatives. They all are very good to him. I made them understand his situation andhow would he behave?*

Parents were often found to adhere to the societal restriction on children with ASD. At the same time, a few defied such socially-expected restrictions by regularly taking their children to parks/outside the house. Moreover, some parents concentrated more on things beneficial for the child than on the societal attitude towards ASD. To quote one mother:

> *We do not think much about it. We are only focused on our child's needs and his future. It is their (society's) choice! It is their opinion what they think they can express that way.*

Analysis revealed maternal depression after children were diagnosed with ASD. The maternal depression was further aggravated by financial constraints towards addressing the health and educational requirements of children with ASD. These unforeseen life events often force people to borrow/seek financial help from relatives/friends for a child's schooling and therapy.

> *After diagnosis (child diagnosed with ASD), I had depression and asthma, and I am taking medication for it. Moreover, when we heard about fees, we worried because my husband's salary was not enough for this.*

Data revealed that patience and positive attitude were two other strategies adopted by parents to cope with having children with ASD. Parents perceived that something which was not reversible could be addressed through patience and a positive attitude; otherwise, it would further aggravate and make life miserable. It was also felt that having a child with ASD had enhanced parents' patience to deal with complex life events. To quote a respondent:

> *I learn to adapt myself, which is new to me, and I need to learn it. Moreover, patience, now I have much more patience; in short, Adoption and Patience.*

One of the parents also stated that apart from the patience, she learned how to be in her world and be happy with whatever she has. She was vocal on the advantage of individual attitude and adoption skills over societal perspectives on ASD.

> *I learn a lot. I have not got the right word to describe that. I learn how to adapt myself to what we are because we live in a different world where we always think what others think first than what we really think.*

Another parent viewed that having a child with ASD had made her focus and prioritize things in life. This subsequently helped her address the needs of her child with ASD.

> *Have patience, stay focused, ignore other things, and focus on which one is necessary most (future of the child).*

Again, the belief that a positive attitude towards life would positively influence the child had made many parents adopt positivity under challenging situations.

> *Being positive will help you be happy if you are positive; it will eventually positively help the child.*

Discussion

The study found inadequate awareness about ASD among parents, who face numerous challenges, both due to the basic hurdles of having a child with ASD and the influence of a largely indifferent society that often hinders the integration of ASD children. Parents attempt diverse coping strategies to address their challenges with their children with ASD. The perceived risk factors of ASD found in this study are mainly pregnancy complications, including stress during the pregnancy. Past studies also revealed maternal prenatal medication use, bleeding, gestational diabetes (Gardener et al., 2009), and pre-term births (Agrawal et al., 2018) as the risk factors of ASD. Perinatal and neonatal risk factors like labour complication, pre-term birth, neonatal jaundice, delayed birth cry and birth asphyxia were also revealed as ASD risk factors in India (Mamidala et al., 2013). Our findings on maternal stress as a risk factor for ASD conform to past studies (Beversdorf et al., 2019; Rai et al., 2013). The study found inadequate awareness of ASD among parents, although many have higher education and socio-economic status. The lower awareness of ASD irrespective of income group was also noticed in a past study in Mumbai(Krishnamurthy, 2008). However, a systematic review found that parents' socio-economic condition affects the diagnosis and prevalence of ASD; and the parents from a high income and education category have more awareness and are close to essential services(Adak et al., 2017). Inadequate awareness of ASD symptoms among parents delayed the recognition and appropriate management (Minhas et al., 2015). Further, late diagnosis has been proved as the primary cause for a high spectrum of ASD(Adak et al., 2017).

The challenges of caring for a child with ASD are limitless and affect the parent's mental health and ability to manage the child and family's needs. Lack of societal support, the severity of autism symptoms, financial difficulty, anxiety, and worries about their child's future aggravate parental stress levels. Our results agree with a systematic review unearthing parenting stress and resilience in parents of children with ASD in Southeast Asia(Ilias et al., 2018). Another study conducted in Delhi, India, also revealed the anxiety and worries among parents about children's health and future (Brezis et al., 2015). We found that children with ASD require full-time attention hindering parents’ involvement/participation in regular socio-economic activities in and outside the family. Parents further struggle to manage various relationships within and outside the family due to the increased attention required by their children with ASD. Previous studies on disability (Dhar, 2009; Edwardraj et al., 2010) have also observed social isolation and community intolerance experienced by parents and problems of negotiating public encounters.

Our findings on parents changing their profession and leaving their jobs to cater tothe needs of the child with ASD conforms to the past study in Goa, India (Divan et al., 2012). This study found that the burden of care is almost entirely on mothers, leading to a high level of stress, and the finding is similar to an earlier study (Minhas et al., 2015). A past study in south India also revealed higher depressive symptoms and impaired quality of life among the mothers of children with ASD (Selvakumar & Panicker, 2020). Evidence suggests adverse health consequences of stress on women's health such as digestive disorder, hair loss, ageing skin, sleep disorder, irregular period, decreased fertility and increased risk of heart disease and stroke, negatively affecting career aspirations and economic independence.

Caregiving often requires additional physical, social, emotional, and financial resources (Murphy et al., 2007) and negatively affects family economic status (Rezendes & Scarpa, 2011). As found in earlier studies(Montes & Halterman, 2008; Peacock et al., 2012; Sanders & Morgan, 1997), we also noticed that parents struggle to address the financial needs to cater to treatment and education requirements of the child with ASD. The tests and consultation charges with a range of specialists like neurologist, psychologist, and audiologist besides paediatrician are often perceived as expensive, thus repercussing the family economy. Inability to address the financial needs puts parents under stress and often compels them to borrow/loan from others.

A systematic review on parents' coping strategies with ASD reveals that parents use more avoidance strategies and less social support-seeking strategies than typical children (Vernhet et al., 2019). Our study, however, found more support-seeking strategies by parents, including undertaking therapies for the children, initiating education through special schools meant for such children, attempting socialization of the child through exposure to the outside environment, sharing the child's health status with people outside family rather than hiding, and being part of groups of parents of a child with ASD. We further found parents having a positive attitude, patience and modifying their lifestyle, which is problem-focused strategies, to address the emerging needs of having a child with ASD. An earlier study also revealed positive coping mechanisms despite the impaired quality of life, especially among mothers of children with ASD (Selvakumar & Panicker, 2020).

The study has limitations. The findings are based on a relatively small sample size in a specific context to gather rich descriptive data; therefore, the generalization of our findings should be considered with caution. Moreover, most respondents are mothers from high-income families, suggesting caution in transferability to results to other socio-economic groups. The strengths of this study are that the findings highlight the challenges and coping strategies adopted by parents, which contributes to existing scanty literature on ASD in India. Moreover, our findings are consistent with earlier studies from India and other countries. The findings further indicate the inadequate awareness and coping mechanisms among the parents from high-income households in a metropolitan city, a relatively less explored domain. Results suggest the need for policy and programs to improve the awareness of ASD and de-stigmatizing the child or their parents. Efforts for higher awareness and utilization of existing “Child Health Screening and Early Intervention Services” under the National Health Mission (GoI, MoHFW,2013) would result in early identification and treatment of ASD children and reduce the parent's mental health and financial burden.

Conclusion

To conclude, having a child with ASD affect various aspects of parents' lives including, mental health, career, future aspirations, finances, and community interaction in Mumbai, India. Parents primarily attempt support-seeking coping strategies to address the challenges of raising a child with ASD. Results recommend awareness generation on ASD, which will help early diagnosis and appropriate management by parents and societal acceptance in Mumbai and similar socio-cultural contexts. A high level of parental stress suggests proper counseling, therapy, and training for the most appropriate parenting style, ensuring better care of children with ASD.

Conflict of Interest: None

Funding: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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