

## Exploring the Experiences of Parents Caring for Children with Autism Spectrum Disorder in Nepal

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### Abstract

This study aimed to explore the experiences of parents caring for children with Autism Spectrum Disorder (ASD). Ten parents (three males, seven females) with at least seven years of ASD caregiving experience were purposively sampled. In-depth interviews, recorded with consent, were conducted and transcribed, supplemented by phone interviews. Manual analysis of the data revealed common themes and patterns, offering insights into the challenges and experiences of ASD caregiving in Nepal. Parents in Nepal invest significant time and resources into their children's well-being, but identifying atypical behavior, particularly in children with ASD, might lead to stress and complications. Challenges in effective parenting stem from cultural, economic, and knowledge gaps in ASD caregiving. While sharing culture and essential caregiving knowledge aids in stress management, it's insufficient. Local governments and community groups might be offered accessible resources. Similarly, comprehensive support networks, stress management courses, instructional materials, and targeted interventions are necessary to address family-related stress effectively.

**Keywords:** Parental stress; caring practice; children with ASD; family relation; support; stress management

## 1. Introduction

Parenting a child with autism spectrum disorder (ASD) can be both rewarding and challenging. Many parents experience heightened stress levels due to the unique demands of caring for a child with ASD. Empirical research shows that over 90% of parents report behavioral issues with their children, with half reporting severe anxiety and two-thirds reporting clinical depression (Bitsika & Sharpley, 2004). Lack of proper knowledge and the unique features of ASD create additional stress for Nepalese parents.

Parents who have children with special needs often experience a high level of stress in their lives. This is particularly true for parents of children with ASD, as studies have shown (DesChamps et al., 2020; Saccà et al., 2019). In a systematic review conducted by Ilias et al. (2018), it was found that there are six major factors associated with parenting stress: financial challenges, concerns about the child's future, social support, severity of autistic symptoms, and religious beliefs.

Furthermore, a scoping review by Al-Oran & Khuan (2021), which examined 27 published articles, revealed a strong link between the core symptoms of ASD, such as behavior problems and socio-communication impairments, and high levels of parenting stress. These aforementioned factors directly impact the care provided to children with ASD. Research has shown that deficiencies in language and cognitive abilities (IQ) do not significantly influence the stress experienced by parents. Instead, it is the combination of pervasive behavioral, functional, and emotional challenges associated with ASD that contributes to high levels of parental stress.

The severity of the child's symptoms also plays a role in this stress, particularly in terms of sociability and sensory/cognitive awareness (Allen et al., 2013). While many studies have focused on parental stress resulting from children's behavior and parental perceptions, there has been less attention given to the stress experienced by parents due to the complexities of caring for children with ASD caring practices.

Autism is still considered a relatively new condition in Nepal. Unfortunately, children with autism often do not receive prompt medical attention. There is a lack of public awareness about autism in the country, which leads to misunderstandings and doubts about its existence and origins (Shrestha & Santangelo, 2014).

Specifically, awareness about autism is virtually non-existent, especially in rural areas of Nepal. It is common for symptoms to be recognized late, with parents typically identifying them around the age of 30 months. Following recognition, there is an additional delay of approximately 30 months before an official diagnosis is made, resulting in an average age of diagnosis of around 56 months. This delay is partly due to limited knowledge among physicians and health professionals (Shrestha & Santangelo, 2014), which adds to the stress experienced by parents in caring for their children.

On basis of literature search, there has been limited research conducted on this topic in Nepal. A study with a small sample size is insufficient to fully understand the actual level of parental stress involved in caring for their children. Further in-depth research is necessary to

explore the relationship between parental stress and behavioral issues or difficulties with social interactions (Al-Oran & Khuan, 2021) in order to better support their well-being, as this study aims to do.

Similarly, parents of children with ASD greatly benefit from coping strategies such as social support and personal coping techniques, as evidenced by the continuous levels of stress experienced by these parents (Sim et al., 2018). Sharing knowledge and solidifying this knowledge through dissemination is fruitful. The stress endured by these parents can have detrimental effects on family dynamics. However, the majority of research has been conducted in specific cultural contexts, often in Western nations. It is crucial to investigate how cultural variations impact parenting stress and coping mechanisms.

Additionally, considering the influence of family dynamics, community support networks, and socioeconomic variables may enhance our understanding. However, multicultural diversity, differing living standards, a lack of awareness about disabilities, particularly autism spectrum disorder, and distinct support systems separate Nepal from Western cultures and social contexts. Therefore, it necessitates distinct studies to identify parental stress and caregiving practices of children with ASD in Nepal, which was accomplished by this study.

Regarding this connection, the study aims to fulfil the gap by exploring the experiences of parents caring for children with Autism Spectrum Disorder (ASD) and parental stress. These findings highlight the significant impact of parenting stress on caregiving practices for children with ASD. The results of this study will contribute to a better understanding of the experiences of parents who care for children with ASD and provide support for developing stress management skills, which can be beneficial for other parents in managing their own mental pressure. This study aims to explore the experiences of parents caring for children with Autism Spectrum Disorder (ASD) and investigate the ongoing parental stress associated with caring for children with ASD.

## **2. Literature Review**

Caring for children with Autism Spectrum Disorder (ASD) presents unique challenges for parents, impacting their emotional, social, and financial well-being. Research highlights various coping mechanisms, stress factors, and the importance of support systems in navigating these challenges. Parents often face significant emotional distress due to the demands of raising a child with ASD. Common coping styles include problem-focused strategies, which are more prevalent among parents, while avoidant and emotion-focused styles are also noted (Rana & Das, 2024). Caregivers report feelings of fear, guilt, and confusion, necessitating strong support networks (Bonjibon et al., 2024).

Parental burnout is a condition characterized by mental exhaustion and fatigue that arises from accumulated stress. A study by Sim et al. (2018) established a connection between family stress in caring for children with ASD and its challenges, such as reduced sociability, difficulty accessing therapy, strained co-parent relationships, and significant out-of-pocket expenses. Similarly, Desimpelaere et al. (2023) found that parents experiencing burnout are

more likely to employ need-threatening parenting techniques, such as psychological control, when their children exhibit challenging behaviors.

Parental health, caregiver expertise, and family support as well as a lack of professional support and misconceptions or a lack of proper knowledge about caregiving practices are key factors that differentiate high- and low-level anxious and depressed parents (Bitsika & Sharpley, 2004). Addressing cultural beliefs, promoting awareness, providing professional support, seeking social support, fostering positive communication, utilizing behavior management techniques, and engaging in mindfulness activities or positive affirmations are essential for managing parental stress.

Educational attainment plays a crucial role in parental stress levels; higher education correlates with lower stress (Ha et al., 2024). Additionally, parents of firstborn children with ASD experience greater stress compared to those with subsequent children, indicating the influence of family dynamics on caregiver well-being (Ha et al., 2024). Dira et al. (2024) stated that establishing emotional support groups and community awareness campaigns is vital for empowering caregivers. These initiatives can enhance knowledge about ASD and improve self-reliance among parents, ultimately fostering a more supportive environment for families (Abo Baker, 2024). While the challenges are significant, the resilience and advocacy of parents can lead to positive outcomes for both themselves and their children, emphasizing the need for continued research and support in this area.

### **3. Materials and Methods**

The pursuit of scientific inquiry has been acknowledged as crucial to the methodologies and scientific data utilized (Khatri, 2020). This study employed a narrative study design, which proved valuable for collecting stories and individual experiences (Creswell, 2012) related to caring for children with ASD. Verbatim accounts and personal narratives were primarily utilized to interpret the contextualized data.

Purposive sampling was utilized to select a small sample (Patton, 2001) of individuals who possess a minimum of seven years of experience in caring for children with ASD at home and have enrolled their children in a care center. The study included ten parents, consisting of three males and seven females, from two organizations. One organization is a privately-run care center located in Urlabari Municipality in the Morang district. This center charges a fixed fee for treatment or care and operates for six hours per day from Sunday to Friday, excluding Saturdays. The other organization is publicly-operated and is supported by the Damak Municipality in Damak. It offers free services and easy access to anyone with children having ASD or Down syndrome. Similar to the private center, this organization also provides six-hour services.

In-depth interviews were carried out following the establishment of interpersonal contact, consideration of contextual factors, and conversational flexibility (Denzin & Lincoln, 2018). Throughout the interview process, the interviews were audio-recorded with the participants' verbal consent. Each participant was physically interviewed three times during the data collection period.

In addition, a phone interview was conducted with three participants to gather further information. The transcription was initially done using the Google Voice transcriber in the Nepalese language. The necessary information was then translated into English using Google Translator, and the researcher made any necessary adjustments to ensure contextual accuracy. Subsequently, the interview data was coded individually, followed by the creation of a unified code section. Common themes were identified by consolidating the codes, which aided in the development of a comprehensive understanding. The information was manually analyzed by identifying similarities and differences.

To ensure the ethical consideration, participants were first informed of the study's objectives, and the protocol for maintaining confidentiality was explained to them (Creswell, 2007). Verbal consent was then obtained before interview conduction. Participation was entirely voluntary, with participants having the right to withdraw from the interview at any time if they encountered any discomfort. Participants were assured that the information provided would be used solely for research purposes and not for any personal or harmful intent. This approach helped establish a strong foundation of confidentiality. The interviews were conducted individually in a quiet setting to ensure privacy, and all data were presented anonymously.

#### **4. Results**

In Nepalese culture, the birth of a child is often met with joy and high hopes for the future. Consequently, parents invest their time, money, and resources to ensure that their children are well-cared for, taking into consideration their economic status and level of awareness. Parents' aspirations, expectations, and accord are channeled into the upbringing of their children. However, if they discover that their child has a disability, it can cause a devastating impact on their state of mind. The resulting shock was unpredictable and created a significant upheaval.

Managing their everyday lives becomes challenging, leading to disruptions such as loss of appetite, sleeplessness, and irrational thinking for the parents. One educated parent has shared his personal experiences, outlined below. 'Ever since the child came into the womb, there was joy and happiness in my heart. He was considered a future support. Janmada's happiness was instantly ruined by his unusual behaviour. Abnormal behavior became difficult in caring and chest pains suddenly started. Hunger and sleep also disappeared.'

Another Bhamin group of parents shared an experience. 'Many mutts ran to the temple to make it easy to maintain normal life and ensure its future. Remember the gods. we also sacrificed pigeons, goats, and chickens. To no avail. Even now, it is sometimes believed that some difficulty or lack of religion in a previous birth has resulted.'

To ensure a well-functioning and nurturing environment, parents have shared their experiences in interviews, revealing that they engaged in various religious practices. These practices involved praying to Hindu deities such as Shiva, Krishna, Brahma, and Hanuman, as well as performing animal sacrificed involving pigeons, goats, and chickens. Although concrete results have not been observed. Parents firmly believed that any abnormal behavior in their children is a result of their "prarabdh" (karmic consequences from past lives). Such beliefs have



also a positive impact on their overall mindset, offering support for maintaining a caring and sharing family dynamic.

Additionally, these beliefs helped alleviate parental stress and promoted healthier behaviors in their day-to-day lives. The cultural belief system played a significant role in parental caregiving practices and in managing their mental well-being. Moreover, the adjustment of children greatly influenced parental support systems and their ability to lead normal lives. Children diagnosed with autism spectrum disorder often struggle with adapting to new situations. Observers who were unfamiliar with autism might find it difficult to comprehend their behaviors.

These children typically have limited interest in social interaction and sharing their experiences. Due to their slower learning pace, they may struggle to adjust and adapt to new environments and situations. Consequently, forming new habits became a challenging endeavor for them. It was rare for these children to acquire new habits or skills in less than three months, which further complicates their ability to adjust to new people or environments. The primary focused of parental care is to support and assist these children in their adjustment process. The parents themselves might experience elevated levels of stress due to the limited success their children may encounter.

One Dalit parent shared their experience that supports understanding behavior of autism spectrum disorder. 'Taking care of a child is very challenging. A child with autism should never be left alone because his behavior cannot be predicted. If he is out of sight for a moment, the child is either running down the street or playing with weapons. He is dangerous. Not having the rational ability to distinguish between good and bad, one is playing with danger.'

Another ethnic group of parents shared their experience of learning formation. It shows the challenges of instruction for children with autism spectrum disorder. 'Autism is a difficult condition in children. Even if there is some improvement in those children, it will be too late. Usually, it takes three months for a child to improve or develop a habit. For example, it took my baby three months to get used to pointing in a direction or object. It is a complex and difficult task. These are responsible for more stress'

Similarly, acceptance holds significant value in managing unnecessary thoughts. Parents who accepted the situation tend to feel more at ease, which in turn enhances their work performance. It supported to create opportunities for them to connect with similar groups or individuals who have gone through similar experiences. On the other hand, parents who chose to conceal information about their children's behavior were only delaying the process of providing proper care and impeding the development of essential knowledge and habits. This approach is both complex and hinders progress.

Neighbors and friends, who were often curious about unusual behavior, silently observed such situations. Consequently, parents or caregivers experienced heightened levels of stress. However, by embracing the context and practicing acceptance, they effectively managed their responsibilities while maintaining a fresh perspective. The following narrative from one participant further justifies this point.

‘Some parents refuse to acknowledge their child's autism. They keep their knowledge hidden from friends and the public. It is regarded as a religious or sinful issue or one of shame. Because of what they did in the past, they attempt to conceal it. However, This is often due to religious or societal reasons, as it is seen as a shameful or sinful issue. However, by concealing it, they only worsen their own suffering increases as they conceal it more. Others are interested in this topic. This topic is of interest to others.’

Acceptance and economic status play a significant role in creating a stressful home environment. The general care that was provided to typical children is insufficient for those with autism spectrum disorder. The participants stated that these children require 24-hour care, which leaves caregivers with no opportunity for other professions or jobs. Parents with children who have ASD often missed out on work opportunities or lose their jobs. Additionally, there is a need for increased investment in this area. The participants explained in the interviews that care centers for these children charge high fees, and everything required for children with disabilities was expensive.

Due to the high costs and financial limitations, many families have not access the necessary care for their children. The resulting economic crisis contributed to a stressful home environment. According to one participant, the majority of parents with disabled children were regular users of medication, with the financial crisis being a significant factor in increasing parenting stress.

A participant of the Rajbanshi community shared their experience which is significant to understanding the context. Human nature is also strange. People are trying to play more in the nature where there is a weakness. Due to the lack of a sense of service, people have transformed into animalistic nature, i.e. children who have a high level of emotional and emotional development, need more support and kindness. People have made a business out of it. Organizations that care for children with autism seem to reap the highest financial benefits. The fee they charge is usually above 15000 per month. They charge more than 25000 for providing training related to caring for the parents. Look, the backs of those who are in trouble are being broken. Children have not been able to reach the care centres.

A participant from an ethnic community shared a similar experience. ‘Before the baby was born we had a shop and I had a small job. After the birth of the child, I had to leave my job because of his condition and I had to take care of him every moment. On the one hand, there is a lack of money and the cost of the child has increased. On the other hand, due to having to give him more time, he has not been able to give time for employment and other income-generating work, so the economic and social pressure is increasing.’

The economic status of parents plays a significant role in determining the type of care facility they can access for their children. Based on the experiences of participants, families with a lower economic status often did not have access to high-quality care options. Additionally, there is a disparity in the availability of care centers between urban and rural areas. If care centers could offer discounts, it would result in additional costs for transportation and other expenses, such as providing meals and appropriate clothing for the children. Parents believed that having well-trained teachers who can effectively care for and educate children with autism spectrum disorder would help reduce costs and save time and money in their local communities.

This expectation is reasonable and aligns with the goal of ensuring equal access to education for all while also alleviating the economic stress experienced by parents. Conflict among family members often leads to misunderstandings. These conflicts usually arise due to an overwhelming amount of household chores or failure to complete tasks on time. Female participants, who have identified the causes of family conflict, mentioned that they used to complete all household tasks before the birth of their child with ASD. However, now they were busy taking care of the children most of the time and have less time for other family members and housework.

Consequently, the workload for other family members has increased, while their expectations have remained the same as before the child's birth. Male parents tended to put more pressure on female parents. Taking into account the complexities of child care and the expectations placed upon them by their families, female participants feel a greater pressure to perform their duties. The following is a verbatim account of the consistent experiences shared by female participants. "Economic and social pressure is the cause of family discord. In the beginning, the seeds of conflict are brought out by the talk of the child, and later, the discord increases with the addition of family and religious traditions. Men have created more mental pressure on women."

Similarly, another educated parent shared their experiences: "If municipalities or local organizations provide training to parents about autism and emotional and behavioral disorders and how to develop new respect and habits, it will be easier for us to raise children and develop the necessary habits. Would have been Lack of knowledge and skills to raise children in the right way is causing unnecessary stress".

A participant of ethnic groups share that "Not knowing how to raise a child, I pinched, beat and reprimanded him, which was not practical. In this way, the child was treated inhumanely because I did not know how to raise or care for the child."

Proper child care practices are hindered by a lack of knowledge and skills in caring for children. This issue was not adequately addressed in school curriculum or informal programs. Interviews revealed the need for information on this topic. Due to their lack of knowledge and skills, parents resorted to physically disciplining their children through pinching, beating, and reprimanding. However, after gaining knowledge in child care, they felt ashamed for their previous misbehavior. Parents reported facing numerous challenges in training their children to develop good habits, work independently, and maintain good health, all due to their lack of proper knowledge and skills.

Consequently, their stress levels have increased. On the other hand, after acquiring knowledge and skills in proper child care, parents felt more comfortable and exhibit more appropriate behavior towards children with ASD. They shared their knowledge with new parents and those with limited access, which has proven to be beneficial in the knowledge-sharing process. We encouraged and promoted this type of knowledge sharing. Furthermore, we expect support from the local government or municipality in enhancing parents' knowledge and skills. Sharing knowledge and skills is the most effective way to manage stress in the child care process.



One parent who engaged in teaching in secondary school gave a figure of parent's depression which mentioned here: Due to the uncertain future of the child, abnormal behaviour, and unlimited parenting role for caring, parents including me experience mental pain. I too have felt pain to the point of depression at times. Unlike other parents, however, my child's school has 20 children with autism. Sixty percent of their parents have levels of depression that require medication. They are taking medicine because they cannot manage themselves. Similarly, more than 25 percent of parents have family problems. In that too, women are more victims.

Self-management is considered the most effective method for regulating one's behavior. A significant number of parents with children who have ASD faced mental health challenges and relied on medication to manage their daily behavior due to a lack of self-management and mindfulness. Likewise, prominent families have experienced conflicts between parents, resulting in a breakdown of the family structure and a loss of trust. Female parents, in particular, faced critical conditions and be more vulnerable than males.

Consequently, children with ASD or emotional and behavioral disorders often lack proper parenting and care, leaving their future uncertain and making them susceptible to being victimized. To promote effective parenting and ensure proper care, it is crucial to provide stress management programs for parents and educate them about child care. This will help establish democratic norms and values while safeguarding the rights of children with ASD.

## **5. Discussion**

Nepalese parents prioritize their children's care and future aspirations, allocating resources wisely. They dream of a happy life for their children, but when they find abnormal behavior, the child's dependency and uncertain future disrupt their dreams. This complexity creates mental stress, leading to disturbances in behavioral regulation and children's care practices. A study by Maridal et al. (2021) explored the consistency of these results and found high levels of psychological discomfort and burden among Nepalese caregivers of children with nonverbal developmental disorders (NDD). Perceived caregiver burden increased suffering, but support from close friends and medical professionals reduced it.

Similarly, identification and acceptance play a crucial role in creating a stressful home environment for parents with autism spectrum disorder. Creating a stressful home environment often occurs when parents struggle with identification and acceptance. Feelings of denial, resistance, or avoidance can lead to increased tension and conflict within the family. For example, when parents were not succeeding in identifying their children's status, they participated in different types of cultural events like praying and sacrificing animals. They also consulted different types of spiritual and medical professionals. This process takes more time, money, and hard work, which creates more mental pressure and difficulties in caring for their children.

Similar results were found in other studies. Due to delayed learning, a lack of interest in social engagement, and sensory sensitivity, children with ASD experience difficulties when transitioning to new environments. They may require more time to learn or develop typical

habits, such as hand washing before and after meals. Without knowledge of ASD and specific instructional skills, an average person may struggle to effectively teach them. A study conducted in India by Bashir et al. (2014) found that managing problematic behaviors, teaching communication, imparting life skills, ensuring their safety, and preparing them for adulthood are all extremely challenging tasks for parents of children with ASD.

Additionally, these families face high levels of stress, a high likelihood of misunderstandings and assumptions, as well as feelings of blame and guilt regarding their child's diagnosis. Consequently, providing parental care becomes even more challenging as parents struggle to establish routines and adapt to new surroundings, leading to increased stress and mental disturbances. Parents may need to offer additional support, structure, and patience to help their child successfully navigate unfamiliar situations.

Seeking guidance from professionals, accessing resources and support networks, and practicing self-care are important strategies for parents to manage the stress associated with caring for a child with ASD while also supporting the child's development and well-being. Similarly, it is crucial to develop the necessary knowledge and skills related to caring for children with ASD through the support of local government or agencies such as schools and NGOs. Ooi et al. (2016) synthesized 50 peer-reviewed and published articles and found that parents who acquired knowledge through studying or sharing with others were more effective in managing the challenges of raising children with ASD and handling their own mental pressures.

Having a good understanding of caring for children with ASD is essential for providing better care and managing stress. Consistent findings by Saccà et al. (2019) suggested that the presence or absence of guidelines and the difficulties in obtaining a diagnosis may impact parents' level of stress. Similarly, financial support is also a crucial factor in child care and stress management.

The financial situation of parents impacts their access to higher-quality care facilities for their children, especially in metropolitan areas where such facilities may be limited. As noted by Ou et al. (2015) and Bonid (2016), significant work and financial difficulties are linked to ASD. So, impoverished families face challenges accessing these facilities and quality resources. If care centres offered discounts, they have no access due to additional fees, such as transportation costs, learning or supporting materials and hidden costs of parents such as the cost of tea or beak fast.

As a result, to manage properly the necessary resources for the proper care of a child with ASD, mental pressure has been created on the parents. As expected of parents, ensuring education rights and reducing parental worry can be achieved by employing qualified instructors, and improving the overall quality of care. Delays in doing chores and an excessive quantity of housekeeping sometimes lead to family tensions. The female participants now emphasize childcare and family obligations, having previously handled all home activities before their child's diagnosis of ASD.

Some overloads are added for male parents. They expected that these would be completed by female participants. On the other hand, female parents also expected more

support from the family. As a result, female parents are becoming more victims and face unwanted mental pressure which creates mental and behavioral issues in their life. As noted by Ramdinmawii & Kaur (2017), stress levels are greater in mothers with ASD than in father. Stress, social support, and life happiness were shown to be significantly positively correlated in the study.

Effective parenting techniques are hindered by a lack of childcare knowledge and expertise, especially when it comes to children with ASD. Informal programs and school curricula sometimes overlook these important topics, making it difficult for parents to navigate, leading to increased tension and stress within the family. However, parents' relationships with their children who have ASD can be greatly improved by gaining the necessary information and skills. Bonis (2016) found that providing academic support and knowledge about autism spectrum disorder to parents resulted in improved parenting and better management of mental disturbances.

Therefore, it is beneficial to provide knowledge to new or inexperienced parents. Local governments should play a role in this process by offering easily accessible materials, training sessions, and instructional initiatives designed to enhance the parenting abilities of children with ASD. By fostering better family environments and supporting parental education, communities can improve the lives of children with ASD.

For example, self-management is crucial for regulating behavior in children with ASD, but many parents struggle with mental health issues and interpersonal conflicts. According to Iadarola et al. (2019), misconceptions about ASD contribute to caregiver stress, and navigating cultural and service challenges further adds to parental stress. Providing care for individuals with ASD can disrupt family dynamics, and female parents, in particular, are more vulnerable and uncertain about their children's future. Implementing stress management programs and enhancing childcare knowledge are important steps to strengthen parenting skills and protect parental rights.

These initiatives not only benefit the well-being of parents but also contribute to creating a nurturing environment that promotes the development and success of children with ASD. The sample size of ten parents in the study may not adequately represent the diverse range of experiences and challenges faced by all parents caring for children with ASD in Nepal. A larger sample size would enable a more comprehensive understanding of the various factors that influence parental stress and caregiving practices. Additionally, the study relied solely on in-depth and phone interviews for data collection. Incorporating multiple methods, such as observational studies or surveys, would provide additional insights and enhance the credibility of the findings.

Moreover, the study specifically focused on parental stress and caregiving practices within the cultural and socioeconomic context of Nepal. Consequently, the findings may have limited generalizability to other cultural or geographical contexts without accounting for potential contextual differences.

## 6. Conclusion and Policy Implications

Nepalese parents have high aspirations for their children's well-being and invest significant time, resources, and affection into their care starting from conception. However, when abnormal behavior is discovered in their children, especially those diagnosed with autism spectrum disorder (ASD), it undermines these dreams and introduces complexities and stress into their lives. The process of identifying and accepting ASD can be challenging due to cultural and financial obstacles, which worsen parental stress and hinder effective caregiving.

Parents, particularly mothers, often bear the brunt of these challenges, facing increased mental pressure and role expectations as they prioritize childcare and manage household responsibilities. The lack of knowledge and skills in ASD caregiving exacerbates these difficulties, leading to family tensions and impeding effective parenting practices. Additionally, while sharing cultural knowledge and acquiring necessary caregiving skills are helpful for managing stress, they are not sufficient.

Therefore, addressing these issues requires comprehensive support systems, stress management programs, educational resources, and targeted interventions. Local governments and community organizations can provide accessible resources and training opportunities. Prioritizing parental education and support can foster healthier family environments and build more inclusive communities.

### Author Contributions

Conceptualization : BBK, YP, KPK; Methodology design: BBK, KPK, Literature review: YP, KPK; Tools validation, data collection, writing-original draft: YP & Finalizing the manuscript: BBK.

### Informed Consent Statement

Informed consent was obtained from all subjects involved in the study.

### Data Availability Statement

The dataset used in the study is available upon request from the corresponding author.

### Conflicts of Interest

The authors declare no conflict of interest.

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## References

- Abo Baker, M. M. (2024). Self-reliance of parents caring for children with autism. *Trends in Nursing and Health Care Journal*, 8(1), 48-64.  
<https://doi.org/10.21608/tnhcj.2024.250079.1039>
- Allen, K.-A., Bowles, T., & Weber, L. (2013). Mothers' and fathers' stress associated with parenting a child with autism spectrum disorder. *Journal of Autism Insights*, 5, 1–11.  
<https://doi.org/10.4137/AUI.S11094>.

- Al-Oran, H. M., & Khuan, L. (2021). Predictors of parenting stress in parents of children diagnosed with autism spectrum disorder: A scoping review. *The Egyptian Journal of Neurology, Psychiatry and Neurosurgery*, 57(1), 103. <https://doi.org/10.1186/s41983-021-00345-w>.
- Bashir, A., Bashir, U., Lone, A., & Ahmad, Z. (2014). Challenges faced by families of autistic children. *International Journal of Interdisciplinary Research and Innovations*, 2(1), 64-68.
- Bitsika, V., & Sharpley, C. F. (2004). Stress, anxiety and depression among parents of children with autism spectrum disorder. *Journal of Psychologists and Counsellors in Schools*, 14(2), 151–161. <https://doi.org/10.1017/S1037291100002466>.
- Bonis, S. (2016). Stress and parents of children with autism: A review of literature. *Issues in Mental Health Nursing*, 37(3), 153–163. <https://doi.org/10.3109/01612840.2015.1116030>.
- Bonjibon, J. C., Del Carmen, R. P. M. F., & Sumugat, B. S. (2024). Voices of inclusion: experiences of parents having children with autism spectrum disorder. *Voices of Inclusion*, 146(1), 134-140 <https://doi.org/10.47119/IJRP1001461420246241>.
- Creswell, J. W. (2012). *Educational research: Planning, conduction and evaluating, quantitative and qualitative research* (4th Ed.). SAGE Publications Ltd.
- Denzin, N. K., & Lincoln, Y. S. (2018). *The sage handbook of qualitative research* (5th ed.). SAGE Publications, Inc.
- DesChamps, T. D., Ibañez, L. V., Edmunds, S. R., Dick, C. C., & Stone, W. L. (2020). Parenting stress in caregivers of young children with ASD concerns prior to a formal diagnosis. *Autism Research: Official Journal of the International Society for Autism Research*, 13(1), 82–92. <https://doi.org/10.1002/aur.2213>.
- Desimpelaere, E. N., Soenens, B., Prinzie, P., Waterschoot, J., Vansteenkiste, M., Morbée, S., Schrooyen, C., & De Pauw, S. S. W. (2023). Parents' stress, parental burnout, and parenting behavior during the covid-19 pandemic: Comparing parents of children with and without complex care needs. *Journal of Child and Family Studies*, 32(12), 3681–3696. <https://doi.org/10.1007/s10826-023-02702-0>.
- Dira, P. M., Machailo, R. J., & Scholtz, S. (2024). Caregivers' voices: From the world of autism spectrum disorder. *Curationis*, 47(1), 1-11. <http://dx.doi.org/10.4102/curationis.v47i1.2519>.
- Ha, C. T. M., Nguyen, H. T., Nguyen, A. H. V., & Thien, G. P. T. (2024). Psychological stress in parents of children with autism spectrum disorder. *National Journal of Community Medicine*, 15(06), 451-460. <https://doi.org/10.55489/njcm.150620243909>.
- Iadarola, S., Pérez-Ramos, J., Smith, T., & Dozier, A. (2019). Understanding stress in parents of children with autism spectrum disorder: A focus on under-represented families. *International Journal of Developmental Disabilities*, 65(1), 20–30. <https://doi.org/10.1080/20473869.2017.1347228>.
- Ilias, K., Cornish, K., Kummar, A. S., Park, M. S.-A., & Golden, K. J. (2018). Parenting stress and resilience in parents of children with autism spectrum disorder (ASD) in Southeast



- Asia: A systematic review. *Frontiers in Psychology*, 9. <https://doi.org/10.3389/fpsyg.2018.00280>.
- Khatri, B. B. (2020). Peer review process in scholarly communication and scientific publishing. *Nepalese Journal of Development and Rural Studies*, 17, 15-19. <https://doi.org/10.3126/njdrs.v17i0.34947>.
- Maridal, H. K., Bjørgaas, H. M., Hagen, K., Jonsbu, E., Mahat, P., Malakar, S., & Dørheim, S. (2021). Psychological distress among caregivers of children with neurodevelopmental disorders in Nepal. *International Journal of Environmental Research and Public Health*, 18(5), 2460. <https://doi.org/10.3390/ijerph18052460>.
- Ou, J.-J., Shi, L.-J., Xun, G.-L., Chen, C., Wu, R.-R., Luo, X.-R., Zhang, F.-Y., & Zhao, J.-P. (2015). Employment and financial burden of families with preschool children diagnosed with autism spectrum disorders in urban China: Results from a descriptive study. *BMC Psychiatry*, 15, 3. <https://doi.org/10.1186/s12888-015-0382-4>.
- Rana, S., & Das, D. (2024). Coping styles among parents of children with autism spectrum disorders. *Journal of Advanced Academic Research*, 11(1), 126-135.
- Ramdinmawii, & Kaur, R. (2017). A descriptive study to assess the level of stress, social support and life satisfaction among parents of children with autism spectrum disorder at selected centres in delhi. *International Journal of Nursing Education*, 9(2), 172. <https://doi.org/10.5958/0974-9357.2017.00058.7>.
- Saccà, A., Cavallini, F., & Cavallini, M. C. (2019). Parents of children with autism spectrum disorder: A systematic review. *Journal of Clinical & Developmental Psychology*, 1(3), Article 3. <https://doi.org/10.6092/2612-4033/0110-2174>.
- Shrestha, M., & Santangelo, S. L. (2014). Autism: Challenge in Nepal. In V. B. Patel, V. R. Preedy, & C. R. Martin (Eds.), *Comprehensive Guide to Autism* (2497–2507). Springer. [https://doi.org/10.1007/978-1-4614-4788-7\\_179](https://doi.org/10.1007/978-1-4614-4788-7_179).
- Sim, A., Vaz, S., Cordier, R., Joosten, A., Parsons, D., Smith, C., & Falkmer, T. (2018). Factors associated with stress in families of children with autism spectrum disorder. *Developmental Neurorehabilitation*, 21(3), 155–165. <https://doi.org/10.1080/17518423.2017.1326185>.