International Journal for Multidisciplinary Research (IJFMR)



E-ISSN: 2582-2160 • Website: <u>www.ijfmr.com</u> • Email: editor@ijfmr.com

Perceived Social Etiquette Challenges Experienced by Parents of Children with ASD: A Qualitative Exploration

Eva Bridget Pasangha¹, Dr. Greeshma Rajgopal²

¹Department of Psychology, CHRIST (Deemed to be University), Bangalore, Karnataka, India ²Assistant Professor, Department of Psychology, CHRIST (Deemed to be University), Bangalore, Karnataka, India

Abstract

Background: Parents of children with Autism Spectrum Disorder (ASD) face unique challenges navigating social etiquette, compounded by societal expectations and cultural factors. These social dynamics often lead to stigma and isolation, making it critical to understand the lived experiences of these parents in managing social norms. This study explores how parents of children with ASD perceive and manage social etiquette, particularly within varying cultural contexts.

Methods: This qualitative exploratory study involved semi-structured interviews with ten parents of children diagnosed with ASD. Participants were selected using purposive snowball sampling. Thematic analysis, based on the framework of Braun and Clarke (2006), was employed to identify recurring themes related to social etiquette challenges, cultural influences, and the effectiveness of intervention programs.

Findings: Parents reported significant emotional stress, social isolation, and anxiety related to societal judgement of their child's behaviour. Cultural norms both aggravated and alleviated these challenges, depending on community awareness and acceptance of ASD. Many parents felt unsupported by existing intervention programs, highlighting the need for culturally sensitive approaches.

Conclusions: The study underscores the need for improved community awareness and culturally informed support systems to reduce stigma and enhance the social experiences of parents raising children with ASD. **Future Implications:** The findings of this study have significant implications for the future development of culturally sensitive interventions and enhanced community support systems. By addressing gaps in awareness and understanding, policymakers can create inclusive environments to alleviate parental stress. Furthermore, integrating tailored support programs and long-term resources can empower parents while fostering improved outcomes for children with ASD in diverse cultural contexts.

Keywords: Autism Spectrum Disorder, social etiquette, parents, cultural influences, stigma

Background

Autism Spectrum Disorder (ASD) presents significant challenges in social communication, restrictive behaviours, and sensory sensitivities (National Autistic Society, 2024). Parents of children with ASD face complex societal expectations, particularly regarding social etiquette, often leading to stress, stigma, and isolation (Buescher et al., 2017). Symbolic Interactionism explains how misunderstandings of their child's behaviour can lead to stigmatisation (Blumer, 1969). Parents frequently encounter negative perceptions



due to their child's behaviour, often misunderstood as misbehaviour or poor parenting (Henderson et al., 2020; Papadopoulos, 2021).

While research has explored parental burdens, the specific challenges related to social etiquette are understudied (Jones, 2018; Papadopoulos, 2021). Previous studies have focused on broader societal and emotional challenges without addressing day-to-day experiences (Lai & Oei, 2014). The existing literature emphasises community support and understanding, yet little is known about how parents perceive and manage social etiquette in various cultural contexts (Tawankanjanachot et al., 2024).

Cultural factors further complicate the issue, as social norms and expectations vary significantly between communities (Hoodbhoy et al., 2019; Willis, 2014). In some cultures, disabilities like ASD are associated with stigma or moral judgement, placing additional emotional burdens on parents (Yeh & Inose, 2002; Gordon et al., 2017). Parents often face challenges advocating for their child's needs in systems that may not be equipped to accommodate differences (Laugeson et al., 2009).

The paucity of research on the intersection of cultural norms and social etiquette challenges highlights a significant gap in the literature. This study aims to address this gap by exploring the perceived social etiquette challenges faced by parents of children with ASD and the role cultural factors play in shaping these experiences. The goal is to inform the development of more effective and culturally sensitive support systems.

Research Design

Sample

The sample for this qualitative exploratory study consisted of ten parents whose children had been diagnosed with Autism Spectrum Disorder (ASD) according to the DSM-5 criteria. These parents were primary caregivers, including biological mothers, fathers, and legal guardians. The participants were selected through purposive snowball sampling, as this method allowed for effective recruitment of participants from hard-to-reach populations (Atkinson & Flint, 2016). Each participant had been the primary caregiver of a child with ASD for at least one year and was fluent in English. Parents who were diagnosed with any mental illnesses were excluded from the study.

Method

Research Problem and Objectives

The present study seeks to explore how parents of children with ASD perceive and manage social etiquette expectations, how cultural factors shape these challenges, and how current intervention programs address these issues. The objectives of this study are as follows:

- 1. To understand the perceived social etiquette challenges experienced by parents of children with Autism Spectrum Disorder (ASD).
- 2. To explore the role of cultural factors on the perceived social etiquette challenges faced by these parents.
- 3. To evaluate the effectiveness of current interventions and support programs in helping parents manage social etiquette challenges.

Procedure

Data was collected through semi-structured interviews conducted in person at convenient locations. Interviews lasted 30-60 minutes and were audio-recorded with consent. Participants were provided with



informed consent forms and assigned pseudonyms for anonymity. The interview guide, developed through literature review and expert consultation, contained open-ended questions about social etiquette challenges, cultural factors, and perceptions of support programs. Ethical approval was obtained from the IRB of CHRIST (Deemed to be University) and all protocols adhered to APA ethical guidelines.

Tools/Measures

Semi-structured interviews were the primary data collection tool. An interview guide, developed and validated through pilot interviews and expert consultation, covered perceived social etiquette challenges, the role of cultural factors, and perceptions of current interventions. The interview guide was consistently used, and audio recordings were transcribed verbatim to ensure data reliability.

Analysis

Data was analysed using thematic analysis (Braun & Clarke, 2006). The six-step process involved familiarisation, initial coding, theme searching, theme review, theme definition and naming, and final report production. Data was coded manually and grouped into categories like "emotional burden," "cultural expectations," and "support program perceptions." A second researcher conducted an independent audit for reliability and bias minimization. Member checking and triangulation were employed to enhance validity. This rigorous process ensured the depth, complexity, consistency, and reliability of the analysis.

Results

Quotations from the interviews, expressed in the participant's own words, are included in the themes discussed.

Name ID	State	Gender	Marital Status
MRM	Goa	Female	Married
VG	Goa	Female	Married
DV	Goa	Female	Married
Р	Karnataka	Female	Married
CJ	Tamil Nadu	Male	Married
MSP	Karnataka	Female	Separated
NA	Goa	Female	Married
RV	Karnataka	Female	Married
VQ	Goa	Female	Married

Table 1 Sociodemographic Details of the Study Sample

International Journal for Multidisciplinary Research (IJFMR)

E-ISSN: 2582-2160 • Website: www.ijfmr.com

• Email: editor@ijfmr.com

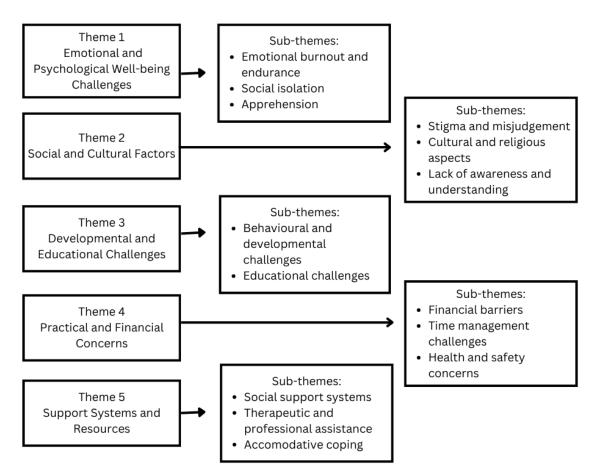


Fig. 1 Diagrammatic of the themes and subthemes within the thematic framework

Theme 1: Emotional and Psychological Well-being Challenges

When it comes to overcoming the social etiquette obstacles they encounter, parents of children with autism spectrum disorder (ASD) need to be especially concerned about their emotional and psychological wellbeing. This global theme captures the range of psychological strains and emotional difficulties that result from these parents' daily experiences, including handling stigma, adjusting to society expectations, and adjusting to the uncertainty surrounding their child's future. There can be severe emotional fatigue, worry, and feelings of loneliness as a result of the strain of always anticipating and responding to both their child's needs and society reactions.

Emotional burnout and endurance

Parents of children with Autism Spectrum Disorder (ASD) often experience a complex array of emotions, including concern, guilt, frustration, and emotional exhaustion (DV, 2024). The daily challenges of raising a child with ASD, particularly in social settings, can be overwhelming, leading to significant psychological burden. This burden can manifest as increased worry, despair, and long-term stress, which can further impair their social interactions.

One significant challenge faced by parents is the constant fear of judgment from others. Due to the unpredictable nature of their child's behavior, parents often avoid social events to minimize the risk of negative reactions. As DV (2024) expressed, "difficult in going outside when you know other people staring because your child is not behaving in a way he should be like, yes, standard rule." This quote highlights the societal pressure to conform to behavioral norms and the anxiety that arises when a child's





behavior deviates from these expectations.

The fear of judgment can lead to social isolation, as parents may withdraw from social interactions to avoid potential discomfort and criticism. This isolation can exacerbate feelings of loneliness and alienation, as NA (2024) described: "since it's classified as a disability, it's like it can make you feel very alone." This quote emphasizes the social stigma associated with ASD and the impact it can have on parents' sense of belonging and support.

In addition to managing their child's behavior, parents often struggle with their own emotional well-being. The constant demands of caregiving can lead to emotional and mental exhaustion. As MSP (2024) stated, "helping him was actually taking a toll on my head also." This quote underscores the significant toll that parenting a child with ASD can take on parents' mental health. The constant stress, worry, and fatigue associated with this role can have long-lasting negative consequences.

Social Isolation

Parents of children with ASD often face social isolation due to a lack of societal understanding and acceptance of their child's behavior. To avoid judgment or unwanted attention, many parents refrain from attending social events where behaviors such as loud vocalizations, repetitive motions, or difficulties following social norms might occur.

One parent described their challenges: "...he has a lot of behaviours like self laugh. Okay. Or, you know, just running around, climbing, you know, jumping or inappropriately laughing at situations where it is sometimes very difficult for me to control him..." (MSP, female, 2024). Such behaviors, characteristic of children with ASD, are frequently misunderstood, increasing parental stress and vulnerability to judgment. This fear of negative attention often leads to social withdrawal, depriving both the child of developmental social opportunities and the parents of essential support and interaction, further deepening feelings of isolation and loneliness.

Apprehension

Parents of children with Autism Spectrum Disorder (ASD) grapple with profound future uncertainty, characterized by persistent anxiety about their child's long-term independence and social integration. Their concerns are multifaceted, encompassing potential challenges in social interactions, academic progress, and independent living.

Parents repeatedly question their child's future prospects, as exemplified by one parent's reflective query: "...thinking so much about his future. What will happen when he is a teenager? What will happen when he is an adult? Will he be able to do this?" (DV, female, 2024). This anxiety is compounded by concerns about limited support systems, as another parent poignantly notes: "...But that kind of a school setup will only be available to them till they're maybe 13 or 14 years old. After that, most of the kids just end up sitting at home with absolutely no. No facility, nowhere to go, nothing." (MRM, female, 2024).

These ongoing worries about potential social difficulties and lack of opportunities—such as "...down the line. I may face a lot of issues when she's around her friends and like that" (CJ, male, 2024)—create a constant emotional burden. The unpredictability of ASD can make parents feel helpless, potentially hampering their ability to enjoy the present and plan for the future.

The core of their anxiety lies in the fundamental questions: Will their child build meaningful connections? Succeed academically? Obtain employment? Live independently? This uncertainty creates a persistent state of emotional distress, where parents struggle with the fear that despite their best efforts, their child's future remains fundamentally unpredictable.



Theme 2: Social and Cultural Factors

The experiences and obstacles faced by parents of children with autism spectrum disorder (ASD) are significantly shaped by the social and cultural factors that influence them, especially when it comes to managing social expectations. This global theme includes the broader social and cultural factors that impact how people view and treat parents and their children. The problems these parents encounter in social contexts can be attributed to a variety of factors, including social challenges, cultural and religious considerations, and degrees of awareness and understanding within the community. These elements frequently impact the level of support or isolation parents receive and have a big influence on how well they are able to speak out for the needs of their children.

Stigma and Misjudgement

Parents of children with Autism Spectrum Disorder (ASD) frequently encounter significant social stigma rooted in widespread misunderstandings about the condition. This stigma manifests through unsolicited advice, social avoidance, and direct criticism of their parenting, creating a challenging social landscape.

In public settings, parents constantly feel scrutinized for their child's behaviors that deviate from typical social expectations. As one parent described the intense social pressure: "...*he couldn't hold still and he had stims and those kinds of things. There were a lot of looks...*" (NA, female, 2024). These judgmental stares force parents into uncomfortable positions of either explaining their child's behaviors or enduring public criticism.

The social stigma creates a profound sense of isolation, as another parent articulated: "*They will be looking as a strange. They don't want to involve. They don't want to ask.*" (P, female, 2024). This fear of judgement makes parents hyper-aware of social perceptions, often leading them to withdraw from social interactions to avoid potential discomfort or criticism.

The persistent scrutiny and misunderstanding surrounding ASD not only increase parents' anxiety but also systematically isolate them from potential support networks, creating a challenging social environment that compounds their emotional challenges.

Cultural and Religious Aspects

Cultural and religious contexts significantly impact how parents of children with Autism Spectrum Disorder (ASD) navigate social settings and receive community support. Some cultures harbor strong stigmas about disabilities, potentially creating complex challenges for parents balancing cultural expectations with their child's needs.

Religious and cultural beliefs can sometimes offer alternative explanations for ASD, such as viewing the condition as a result of moral or spiritual deficiencies. This perspective can lead to misguided interventions, as illustrated by one parent's quote: "...*religious retreat, and these people will cure your child*" (MRM, female, 2024). Such beliefs can discourage parents from seeking professional therapeutic interventions.

The challenges extend to societal expectations, particularly in religious settings. One parent noted the difficulty of managing her child's behaviors: "...child is not taught to sit quietly in the church. This child is talking in the church" (VG, female, 2024), highlighting the tension between cultural norms and the realities of ASD.

Interestingly, some traditional cultures may offer unexpected support. As one parent observed: "*I mean people used to stay in village they are following the backward cultures. But this backward cultures are helping these kids*" (P, female, 2024). This perspective suggests that traditional community structures can provide crucial support networks for families navigating ASD.



Ultimately, parents must carefully negotiate the complex intersection of cultural expectations, religious beliefs, and their child's individual needs, often facing significant social and emotional challenges in the process.

Lack of Awareness and Understanding

Community awareness and understanding of Autism Spectrum Disorder (ASD) profoundly impact the social experiences of children and parents. The level of awareness significantly influences the support and accommodations families receive in various social settings.

One parent noted a positive trend: "...*compared to five years back, ten years back, the understanding has improved*..." (CJ, female, 2024), highlighting the potential for increased awareness to reduce stigma and improve social interactions.

However, persistent misconceptions remain. Some communities perpetuate harmful narratives, as illustrated by one parent's experience: "*They will tell the mother of the autistic child, you didn't go to church every day when you were pregnant, and that's why you ended up having a child who's autistic and things like that.*" (MRM, female, 2024)

The challenges of invisible disability are particularly acute, with one parent noting: "...*if the child doesn't look dysmorphic or if the child doesn't show, you know, very strong emotions or, I mean, what to say, very serious behavioural issues, people don't understand*..." (MSP, female, 2024)

Educational settings are especially critical, as demonstrated by another parent's concern: "...*what happens teachers again, who are not aware*" (VG, female, 2024). This underscores the importance of professional training and awareness in supporting children with ASD.

Ultimately, community understanding plays a crucial role in creating supportive environments that accommodate the unique needs of children with ASD and their families.

Theme 3: Developmental and Educational Challenges

The global theme of Developmental and Educational Challenges centres on the major obstacles that parents of children diagnosed with Autism Spectrum Disorder (ASD) must overcome in order to manage the behavioural and developmental needs of their child and to successfully navigate the educational system. Due to their frequent range of behavioural problems and developmental delays, children with ASD can be difficult to work with in traditional educational settings. In order to give their kids the best chances for development, education, and social integration, parents must recognize these difficulties and take appropriate action. This theme includes the challenges parents face in managing their children's behaviour, reaching developmental milestones, and overcoming obstacles in the classroom.

Behavioural and Developmental Challenges

Parenting a child with Autism Spectrum Disorder (ASD) involves navigating complex behavioral and developmental challenges that often create significant stress for families. Children with ASD frequently display atypical social interactions and behaviors that can draw external judgment, as illustrated by one parent's observation: "...have overheard, you know, someone saying that he's a little odd, he's a little different" (VQ, female, 2024).

Public interactions can be particularly challenging. As one parent described a difficult moment: "*He just threw a tantrum and the entire crowd was looking at me...*" (MSP, female, 2024). Another parent highlighted the emotional complexity, noting the struggle of "...*how to handle your child or have you to handle a person who is like sometimes asking like, oh, your child is behaving this way or there's something wrong with him...*" (DV, female, 2024).



Developmental delays present additional challenges, including difficulties with communication and skill development. One parent poignantly shared: "...she is still nonverbal. So because of that even she'll get irritated. We will also get irritated sometime..." (P, female, 2024). Another parent emphasized the demanding nature of support, stating: "...So that needs a lot of patience and dedication. It is very easy to say from outside, but to actually execute it on a repeated manner forms that that is very time consuming" (CJ, male, 2024).

Parents must continuously manage their child's behavioral issues while simultaneously navigating social stigma, feelings of guilt, and the emotional strain of providing constant support. The journey requires extraordinary patience, dedication, and resilience in the face of numerous challenges.

Educational Challenges

Parents of children with Autism Spectrum Disorder (ASD) face significant challenges navigating the educational system. As one parent noted: "*I did face a lot of hurdles, like when I was trying to put the kids in school...*" (NA, female, 2024), highlighting the difficulties in finding appropriate educational placements.

The challenges are compounded by limited awareness and understanding among educators. One parent shared: "*I did try to share the diagnosis with the teachers who hadn't heard of it and who refused to believe it because my son was hyperactive*" (NA, female, 2024). This lack of understanding can lead to inappropriate responses and inadequate support.

Social integration presents another critical concern. A parent poignantly expressed the deep anxiety: "*Will there be a time where there will be a person, where there will be a child who will come to him and say, you are my friend*..." (DV, female, 2024). This quote underscores the social challenges children with ASD face and the emotional toll on parents.

Transitions between educational stages prove particularly challenging. As one parent noted: "...my son's teacher and I are not exactly on the same page. You know, not. Don't follow, don't have the same mindset with regards to how autism should be seen and supported and things like that" (MRM, female, 2024).

Parents must continuously advocate for specialized services, including individualized education plans, therapy, and social support, while navigating a system often ill-equipped to meet their child's unique needs. The process requires extraordinary persistence, emotional resilience, and dedication to ensuring their child receives appropriate educational support.

Theme 4: Practical and Financial Concerns

The varied logistical, financial, and safety issues that parents of children with autism spectrum disorder (ASD) deal with are covered under the global theme of Practical and Financial Concerns. It frequently takes a lot of time, money, and careful consideration of health and safety concerns to raise a child with ASD. These connected issues can aggravate the stress and challenges parents face, impacting their general wellbeing and capacity to meet their child's needs. These families' everyday lives and long-term planning are significantly impacted by the practical difficulties of managing time, money, and health and safety concerns.

Financial Struggles

Parents of children with Autism Spectrum Disorder (ASD) face significant financial challenges due to the high costs of specialized therapies and support. One parent candidly noted: "*Everybody cannot pay to the therapy centre, right? It is very expensive...*" (P, female, 2024), highlighting the substantial economic burden of essential interventions.



The financial strain often extends beyond therapy costs, frequently requiring parents to make challenging career sacrifices. As one parent expressed the emotional weight of this decision: "...you didn't give him enough time. You didn't, you didn't dedicate enough time for him. You just went to work." (MSP, female, 2024)

These financial pressures can force parents to work fewer hours or leave their jobs entirely, creating a complex trade-off between financial stability and caregiving. The resulting economic constraints can limit a child's access to crucial therapies, extracurricular activities, and social interactions, potentially increasing isolation and reducing the family's overall quality of life.

The cumulative effect is a profound financial and emotional challenge that requires extraordinary resilience from families supporting children with ASD, as they navigate the complex landscape of specialized care and support.

Time Management Issues

Caring for a child with Autism Spectrum Disorder (ASD) demands extensive time management, often leading to significant parental exhaustion. As one parent candidly shared: "*I feel very drained out towards the end of the day*..." (MSP, female, 2024), highlighting the overwhelming daily challenges.

Constant coordination of therapy sessions, medical appointments, and educational support leaves little room for personal respite. Parents must continually advocate for their child's needs, as illustrated by one parent's powerful statement: "*I try to stop and tell them that this child is a child with special needs, so he. He needs to be accepted. I don't go to lecture, but I just say, just tell them. When they get judgmental, I just say, please understand that all children are not the same. He's a very special child.*" (MSP, female, 2024)

The emotional and practical demands of continuous advocacy, coupled with managing unpredictable behavioral challenges, create a persistent state of stress. Parents often find themselves sacrificing personal time, relationships, and self-care to meet their child's complex needs.

This relentless caregiving journey requires extraordinary emotional resilience, as parents navigate complex social, medical, and educational systems while supporting their child with ASD.

Health and Safety Concerns

Parents of children with Autism Spectrum Disorder (ASD) face significant health and safety challenges requiring constant vigilance. As one parent described routine management: "*You have to sleep today. He'll be like, no, I'm not sleepy...We have to keep motivating him so that he can be proper*" (RV, female, 2024), highlighting the exhaustive effort required to maintain basic daily structures.

Behavioral unpredictability presents ongoing safety concerns. One parent shared the complexities of managing challenging behaviors: "...he has a lot of behaviours like self laugh. Okay. Or, you know, just running around, climbing, you know, jumping or inappropriately laughing at situations where it is sometimes very difficult for me to control him..." (MSP, female, 2024).

These constant safety demands exact a significant emotional toll, often leading to social isolation. As the same parent poignantly noted: "*I feel very lonely sometimes*..." (MSP, female, 2024), reflecting the emotional burden of perpetual vigilance.

Parents must meticulously navigate sensory sensitivities, potential wandering behaviors, and unpredictable actions, requiring extraordinary patience and continuous supervision to ensure their child's safety and well-being.



Theme 5: Support Systems and Resources

When it comes to overcoming the social etiquette challenges they encounter, parents of children with autism spectrum disorder (ASD) depend heavily on their support networks and other resources. This global theme includes the different support systems, expert services, and coping mechanisms that parents use to deal with the challenges of raising an ASD child. It emphasises how crucial it is to put in place solid support networks, have access to therapy and expert help, and be able to adjust to and accept their child's specific needs. These elements are essential for building resilience and a feeling of community among parents as well as for assisting them in overcoming the emotional, social, and practical difficulties related to ASD.

Social Support Systems

Support networks are crucial for parents of children with Autism Spectrum Disorder (ASD), providing emotional, social, and practical assistance. As one parent reflected: "*Earlier I used to be upset, but I always received a lot of support from family and friends*" (VQ, female, 2024), highlighting the importance of compassionate support.

Support groups offer particularly valuable resources. One parent noted: "...through these support groups, we find out also about different resources" (MRM, female, 2024). These networks provide opportunities to share experiences and discover new services.

Uniquely insightful support comes from groups led by individuals with ASD themselves. As one parent shared: "...group is run by a group of adulthood autistic adults, and they sort of answer questions of parents looking to find out why their child is behaving in a certain way" (NA, female, 2024).

These support systems are essential in helping parents navigate the complex challenges of ASD, reducing isolation, and providing practical guidance and emotional comfort through shared experiences and understanding.

Therapeutic and Professional Assistance

Therapeutic and expert assistance is a crucial component of the support network for parents of children with ASD. Access to professional interventions like occupational therapy, speech therapy, behavioral therapy, and counseling significantly impacts a child's development and equips parents to address social and behavioral challenges. As one parent noted, "I had therapy with a therapist, and he was a cardiac pathologist. So from that he started noticing his improvement" (RV, female, 2024), illustrating the transformative potential of professional intervention, regardless of the therapist's field.

Therapy centers play a dual role, benefiting both children and parents. They provide tailored interventions for challenges like poor social skills, sensory processing difficulties, and communication issues, while also offering counseling to parents. "...there are also a lot of therapy centres that provide support to the child, give therapies to the child, and also, you know, give counselling to the moms, the parents" (MSP, female, 2024). This holistic support helps families manage ASD, reducing stress and improving overall quality of life.

Therapy centers also act as knowledge hubs, guiding parents through various resources and services. One parent shared, "I'm using the therapy centre and I used to discuss with the therapist... She'll be giving some ideas and I'm putting my child in all the three therapies so I can get some points from all the three therapists, bt, ot and speech" (P, female, 2024). This collaborative approach empowers parents to navigate multiple therapies and create informed care plans, enhancing their confidence and advocacy skills.

However, access to professional aid is often inequitable, influenced by geography, financial capacity, and service availability. Financial constraints are a significant barrier, as highlighted by a parent: "Everybody



cannot pay to the therapy centre, right? It is very expensive..." (P, female, 2024). The high cost of specialized therapies disproportionately affects families in underprivileged areas, underscoring the need for affordable, accessible services to support all families managing ASD.

Accommodative Coping

Parents of children with ASD navigate two critical processes: acceptance and adaptation. Acceptance involves an internal process of coming to terms with the diagnosis and its implications, while adaptation focuses on making practical adjustments to meet the child's needs, such as modifying schedules, home environments, and expectations. Together, these processes significantly influence parents' emotional and psychological well-being. As one parent shared, "So it was like a long journey understanding what it is, how it is, and then there is a acceptance time..." (DV, female, 2024). This highlights the gradual and often challenging nature of acceptance, which evolves through continuous learning and adjusting to the realities of ASD.

Peer support plays a vital role in helping parents navigate acceptance and adaptation. Connecting with others who have shared similar experiences provides both emotional relief and practical advice. "...parents of children who have ASD and who have other diversities, they are very helpful because they understand that, you know, everyone's in this together..." (NA, female, 2024). This sense of solidarity helps parents feel less isolated and equips them with valuable strategies to manage challenges.

Counseling and support groups further aid parents by offering structured guidance to process emotions and develop flexible coping mechanisms. These resources help create a balanced approach to acceptance and adaptation, enabling parents to provide a nurturing and supportive environment for their child.

Discussion

For clarity on the results obtained and the objectives of the study, this has been divided into three sections. *Parental Perceptions and Management of Social Etiquette Expectations in Daily Life with Autistic Children*

Parents of children with Autism Spectrum Disorder (ASD) face significant emotional and psychological challenges tied to societal expectations and norms. Research highlights pervasive stress, anxiety, and depression among these parents, stemming from difficulties managing their child's behavior in social settings (Baker-Ericzen et al., 2005). For instance, parents report frustration over their child's inability to adhere to social norms during public events, a stressor exacerbated by societal pressure to conform (Estes et al., 2009). The added emotional burden of anticipating negative public reactions often leads to feelings of isolation and frustration (Gray, 1994).

Social withdrawal is a common coping mechanism for parents, driven by a fear of judgment and stigma. This avoidance, while shielding the child from societal misunderstandings, intensifies parental isolation and limits access to supportive networks (Kogan et al., 2008; Siller & Sigman, 2008). Stigma not only reduces community engagement (Gordon et al., 2017) but also hinders the child's social development by restricting exposure to diverse interactions, further entrenching the cycle of isolation and stress.

Apprehension about the future, particularly regarding the child's independence and societal integration, is a recurring theme. Parents express deep concern about their child's ability to live independently, pursue education, and form meaningful relationships, reflecting chronic stress tied to developmental uncertainties (McStay et al., 2014). This future-oriented anxiety, compounded by fears of inadequate support and societal exclusion, profoundly impacts parents' psychological well-being and ability to manage daily responsibilities (Cohen & Simon, 2013; Lundqvist et al., 2017).



The findings emphasize the need for comprehensive support systems to address parental isolation, alleviate stigma, and provide reassurance regarding the child's future. Tailored interventions can reduce stress, enhance parental coping strategies, and promote both immediate and long-term well-being for families (Murray et al., 2016).

The Influence of Cultural Factors on Social Etiquette Challenges Faced by Parents of Autistic Children Social stigma significantly shapes the experiences of parents raising children with Autism Spectrum Disorder (ASD). Rooted in misconceptions and a lack of understanding, stigma manifests through unsolicited advice, avoidance, and criticism, reflecting societal attitudes that marginalize disabilities (Corrigan & Watson, 2002; Mak & Cheung, 2010). These experiences often lead to heightened stress and isolation, as parents become acutely aware of judgmental reactions. Stigma also limits access to support and resources, compounding parental challenges (Gray, 1994; Gordon et al., 2017).

Negative societal attitudes and stigma contribute to social exclusion, isolating families and creating barriers to community integration and support (Siller & Sigman, 2008). Cultural and religious beliefs further complicate these challenges. In some cultures, ASD may be associated with moral or spiritual failings, leading to guilt and shame for parents (Kumpfer & Alvarado, 2003; Yeh & Inose, 2002). Religious perspectives that emphasize spiritual cures can impede access to professional interventions, adding another layer of difficulty (Patterson et al., 2010). Addressing these cultural dynamics through culturally sensitive support is essential to mitigating stigma and misunderstanding.

Community awareness and understanding of ASD play a pivotal role in improving parents' experiences. Higher awareness levels lead to greater support and accommodations, reducing stigma and enhancing resource availability (Gordon et al., 2017). Awareness programs, sensory-friendly environments, and staff training initiatives foster inclusivity and alleviate stress for families (Cox et al., 2016). These measures emphasize the need for community education to create environments that better support individuals with ASD and their families (Siller & Sigman, 2008).

The Role of Intervention Programs in Supporting Parents' Social Etiquette Challenges

Support systems, including family, friends, support groups, and online communities, are crucial for helping parents of children with Autism Spectrum Disorder (ASD) manage social etiquette challenges. These networks offer emotional support, practical advice, and a sense of community, reducing isolation and empowering parents (Baker-Ericzen et al., 2005; Kogan et al., 2008). Support groups enable parents to share experiences, exchange strategies, and access resources, enhancing their coping abilities and resilience (Siller & Sigman, 2008; Cox et al., 2016).

Therapeutic and professional assistance is equally vital. Specialized therapies, such as occupational, speech, and behavioral interventions, support the child's development while equipping parents with strategies to handle challenging behaviors and social situations (McStay et al., 2014; Cohen & Simon, 2013). However, limited access to quality services due to geographic or financial constraints can heighten parental stress, emphasizing the need for affordable, comprehensive programs (Estes et al., 2009).

Educational programs also play a key role by increasing understanding of ASD and providing practical tools for managing social etiquette challenges (Patterson et al., 2010). Workshops and online resources enhance parental skills, improve advocacy, and foster broader community understanding, reducing stigma and increasing support (Gordon et al., 2017). Integrating education into intervention strategies supports inclusive environments, helping families navigate social expectations effectively (Cox et al., 2016).



Conclusion

The study highlights the significant psychological, emotional, and social challenges faced by parents of children with Autism Spectrum Disorder (ASD), including stigma, isolation, future uncertainty, and the emotional toll of caregiving. Parents often encounter judgment and misunderstanding in social situations due to their child's unpredictable behaviors, underscoring the need for greater public awareness and empathy to reduce stigma and enhance community support.

A central finding is that societal reactions and resulting social isolation contribute substantially to parents' psychological burden. Persistent anxiety about their child's future—concerning independence, education, and social integration—is compounded by inadequate long-term resources, intensifying emotional strain. The research emphasizes the importance of tailored support systems and intervention programs that address both the child's needs and provide essential emotional and social support for parents, ensuring the well-being of the entire family.

Contributions of the Study

Understanding Social Etiquette Challenges: One of the major contributions of this study is its focus on the social etiquette challenges faced by parents of children with ASD. Previous research has explored general emotional and social difficulties, but this study uniquely delves into how parents manage societal expectations, such as behavioural norms, in various public and social contexts. This nuanced understanding is critical for developing more inclusive communities and interventions.

Highlighting Cultural Influences: The study acknowledges the impact of cultural factors on parents' experiences. For example, it shows how collectivist societies may provide better community support, while more individualistic cultures can increase isolation. This contribution encourages future research to consider cultural sensitivities when designing support programs for families affected by ASD.

Addressing Long-Term Uncertainty: A core contribution of this study is its detailed exploration of the anxiety parents feel about their child's future. The concerns regarding education, employment, and social inclusion reflect a significant gap in long-term resources for individuals with ASD. By highlighting this gap, the study contributes to ongoing conversations about how educational and social systems can be improved to support the lifelong development of individuals with ASD.

Bridging the Gap between Parental Support and Child-Centric Interventions: While many existing interventions focus on the child's developmental needs, this study highlights the importance of offering emotional and psychological support to parents. The emphasis on parental well-being calls for a holistic approach that includes family-centred intervention programs, improving both the child's and the parents' quality of life.

Limitations of the Study

While the study offers valuable insights, several limitations should be acknowledged:

Small and Homogeneous Sample: The study's sample size is limited, and the participants come from a relatively homogeneous background. This limits the generalizability of the findings, particularly across different socioeconomic and cultural contexts. Future research could benefit from larger, more diverse samples to capture a broader range of parental experiences.

Qualitative Nature of the Study: The study's qualitative design, while providing deep insights into parental experiences, limits the ability to quantify the extent of social stigma or emotional distress faced by parents. A mixed-methods approach that includes quantitative measures could offer a more comprehensive understanding of these challenges.



Focus on Parents' Perspectives: This study primarily focuses on parents' perceptions and does not incorporate the perspectives of professionals, educators, or the children themselves. Future research could include these perspectives to provide a more holistic view of the challenges faced by families of children with ASD.

Lack of Longitudinal Data: The cross-sectional nature of the study means that it captures a snapshot of parents' experiences at a single point in time. Longitudinal research that follows families over several years could offer deeper insights into how these challenges evolve as the child grows older and moves through different life stages.

Implications for Future Research and Practice

The findings of this study suggest several areas for future research and practical applications. Researchers should investigate how community education programs can reduce stigma and foster more supportive environments for families affected by ASD. Additionally, future research should explore how cultural differences shape parents' experiences and inform the development of culturally sensitive intervention programs. There is also a need for research on long-term support mechanisms for individuals with ASD as they transition into adulthood, particularly focusing on employment, independent living, and social inclusion.

For practitioners, the study highlights the importance of offering more than just child-centric interventions. Therapy and support programs must integrate family-focused approaches, offering emotional and psychological support to parents. Educational systems should also be reformed to provide continuous support to children with ASD beyond early education, preparing them for adulthood with appropriate resources and opportunities for growth.

References

- Baker-Ericzen, M. J., Brookman-Frazee, L., & Stahmer, A. C. (2005). Stress levels and coping strategies among parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 35(5), 671-681. <u>https://doi.org/10.1007/s10803-005-0006-8</u>
- 2. Blumer, H. (1969). Symbolic interactionism: Perspective and method. Prentice-Hall.
- 3. Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.
- Buescher, I., Kim, Y. S., & Cidav-Zarraga, I. (2017). Social anxiety and depression in parents of children with autism spectrum disorder (ASD): A meta-analysis. *Clinical Psychology Review*, 55, 87-104. <u>https://doi.org/10.1016/j.cpr.2017.05.002</u>
- 5. Cohen, A., & Simon, M. (2013). Understanding and managing the impact of stress on families with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(2), 270-279. https://doi.org/10.1007/s10803-012-1586-4
- 6. Cohen, S., & Simon, J. (2013). Parental stress and future uncertainties: The experience of parents with children diagnosed with ASD. *Journal of Family Psychology*, *29*(4), 509-520.
- Corrigan, P. W., & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice*, 9(1), 35-53. <u>https://doi.org/10.1093/clipsy.9.1.35</u>
- 8. Cox, A., Gross, J., & Strong, M. (2016). Community inclusion and acceptance of individuals with autism spectrum disorder. *Autism Research and Treatment*, 2016, 1-10. <u>https://doi.org/10.1155/2016/1036589</u>



- 9. Cox, A. W., Twardzik, J., & Salvatore, S. (2016). Social support for parents of children with autism spectrum disorders. *Journal of Applied Research in Intellectual Disabilities*, 29(6), 1302-1312. https://doi.org/10.1111/jar.12347
- Estes, A., Munson, J., Dawson, G., & Rogers, S. (2009). Long-term outcomes of early intervention in autism. *Journal of Autism and Developmental Disorders*, 39(10), 1605-1617. <u>https://doi.org/10.1007/s10803-009-0817-0</u>
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, 13(4), 375-387. <u>https://doi.org/10.1177/1362361309105658</u>
- 12. Gordon, K., Pelios, L., & Wilson, K. (2017). Perceived stigma and coping strategies of parents raising children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(9), 2737-2748.
- Gordon, R., Garvey, R., & Marsh, L. (2017). The role of community support in managing autism spectrum disorder: Insights from parents. *Journal of Community & Applied Social Psychology*, 27(4), 372-385. <u>https://doi.org/10.1002/casp.2317</u>
- 14. Gray, D. E. (1994). Coping with autism: A qualitative analysis of parents' strategies. *Journal of Autism* and Developmental Disorders, 24(4), 407-421. <u>https://doi.org/10.1007/BF02172002</u>
- 15. Gray, D. E. (1994). Coping with autism: Stresses and strategies. *Sociology of Health & Illness*, *16*(3), 275-300.
- 16. Henderson, R. C., Matson, J. L., & Gonzalez, M. L. (2020). Mental health concerns in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 76, 101594.
- 17. Hoodbhoy, S., Yousafzai, A. K., & Zaman, S. (2019). Parental perceptions of autism spectrum disorder in the developing world: A systematic review. *Autism Research*, *12*(6), 827-839.
- 18. Jones, G. (2018). Family quality of life for parents of children with autism: The role of social support and unsupportive social interactions. *Autism Research*, *11*(12), 1627-1640.
- Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., & Ghandour, R. M. (2008). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics*, 124(4), 1395-1403.
- 20. Kogan, M. D., Strickland, B. B., & Blumberg, S. J. (2008). Parents' perspectives on autism and the accessibility of services: Findings from the National Survey of Children's Health. *Journal of Autism and Developmental Disorders*, *38*(5), 842-853. <u>https://doi.org/10.1007/s10803-007-0468-7</u>
- 21. Kumpfer, K. L., & Alvarado, R. (2003). Family-based interventions for substance use and misuse prevention. *Addiction*, 98(3), 230-245. <u>https://doi.org/10.1046/j.1360-0443.2003.00204.x</u>
- 22. Kumpfer, K. L., & Alvarado, R. (2003). Family-strengthening approaches for the prevention of youth problem behaviors. *American Psychologist*, *58*(6-7), 457-465.
- 23. Lai, W. W., & Oei, T. P. S. (2014). Coping in parents and caregivers of children with Autism Spectrum Disorders (ASD): A review. *Review Journal of Autism and Developmental Disorders*, *1*, 207-224.
- 24. Lundqvist, L. O., Pärssinen, J., & Lindqvist, R. (2017). Coping with the diagnosis of autism spectrum disorder: A longitudinal study of family adaptation. *Journal of Autism and Developmental Disorders*, 47(7), 2350-2362. <u>https://doi.org/10.1007/s10803-017-3145-x</u>
- 25. Lundqvist, M., Wiman, S., & Henriksson, J. (2017). Future concerns of parents with children diagnosed with autism. *Journal of Autism and Developmental Disorders*, 47(1), 188-197.



International Journal for Multidisciplinary Research (IJFMR)

E-ISSN: 2582-2160 • Website: <u>www.ijfmr.com</u> • Email: editor@ijfmr.com

- 26. Mak, W. W., & Cheung, R. Y. (2010). Self-stigma among parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *4*(2), 184-190.
- 27. Mak, W. W. S., & Cheung, R. Y. M. (2010). Self-stigma among mental health patients in Hong Kong: Implications for recovery-oriented practices. *Social Psychiatry and Psychiatric Epidemiology*, 45(7), 759-765. <u>https://doi.org/10.1007/s00127-009-0130-3</u>
- 28. McStay, R. L., Dissanayake, C., Scheeren, A. M., Koot, H. M., & Begeer, S. (2014). Parenting stress and ASD: Cross-cultural differences in parental perceptions of and responses to autism. *Journal of Abnormal Child Psychology*, *42*(5), 667-678.
- 29. McStay, R. L., Trembath, D., & Brignell, A. (2014). Stress and coping in parents of children with autism spectrum disorders: A review of the literature. *Journal of Autism and Developmental Disorders*, 44(7), 1714-1728. <u>https://doi.org/10.1007/s10803-013-2030-6</u>
- 30. Miller, C. A. (2002). Definitions and dimensions of etiquette. AAAI Technical Report FS-02-02.
- 31. Murray, C., & Greenberg, J. S. (2016). The role of family support in coping with autism spectrum disorders. *Journal of Family Psychology*, *30*(1), 67-76. <u>https://doi.org/10.1037/fam0000168</u>
- 32. Murray, J., Hand, L., & Donnelly, M. (2016). Emotional well-being and future planning among parents of children with autism spectrum disorder. *Developmental Disabilities Bulletin*, 44(1-2), 1-23.
- 33. National Autistic Society. (2024). Autism and social interaction. Autism.org. https://www.autism.org.uk/advice-and-guidance/topics/communication
- 34. Papadopoulos, D. (2021). Mothers' experiences and challenges raising a child with autism spectrum disorder: A qualitative study. *Journal of Autism and Developmental Disorders*, *51*(3), 897-910.
- 35. Schieve, L. A., Rice, C. E., & Boyle, C. A. (2011). Autism and developmental disabilities monitoring network. *MMWR Surveillance Summaries*, *61*(3), 1-19.
- 36. Schieve, L. A., Rice, C. E., & Boyle, C. A. (2011). Risk factors for autism: Socioeconomic status, prenatal stress, and health disparities. *American Journal of Public Health*, *101*(5), 852-857.
- 37. Smith, J., & Crookes, E. (2014). Social isolation and stigma in families raising children with autism. *Autism Research*, *6*(3), 453-462.
- 38. Sterling, L., Dawson, G., Munson, J., & Estes, A. (2008). Long-term cognitive and academic outcomes in children with autism spectrum disorders. *Development and Psychopathology*, 20(3), 789-807. <u>https://doi.org/10.1017/S0954579408000370</u>
- 39. Sterling, L., Dawson, G., Munson, J., Koehler, E., Zhou, X., & Abbott, R. (2008). The long-term impact of early interventions on social and emotional functioning in children with autism. *Autism*, *12*(5), 47-57.
- 40. Whitaker, P. (2002). Supporting families of preschool children with autism: What parents want and what helps. *Autism*, *6*(4), 411-426. <u>https://doi.org/10.1177/1362361302006004007</u>
- 41. Yates, T., & Nelson, M. (2017). Parents' perceptions of autism spectrum disorders: The role of culture and context. *International Journal of Autism and Developmental Disorders*, 42(3), 251-260