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Exploring Parenting Experiences: Fathers and Mothers Raising a Child With Autism

Simmi Santha
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Walden University

College of Education and Human Sciences

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Simmi Santha

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Walden University

2026

Abstract

Exploring Parenting Experiences: Fathers and Mothers Raising a Child With Autism

by

Simmi Santha

MA, Annamalai University, 1997

BS, Osmania University, 1995

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Developmental Psychology

Walden University

February 2026

Abstract

The experiences of parenting a child with autism spectrum disorder (ASD) have been widely studied in Western contexts. Still, limited research has explored how sociocultural factors shape these experiences in India. This qualitative study aims to address this gap by exploring and comparing the lived experiences of mothers and fathers raising a child with ASD in Kerala, India. The purpose of this study was to investigate how gender roles, cultural expectations, and social structures impact parental adaptation, coping, and caregiving practices. Bronfenbrenner's ecological systems theory and Crenshaw's ideas of intersectionality provide the conceptual framework of this study. Using an interpretative phenomenological analysis design with reflexive thematic analysis, semistructured interviews were conducted with 12 participants (i.e., six couples, comprising six mothers and six fathers, who were interviewed independently) who are parenting children diagnosed with ASD. The findings indicated that mothers primarily managed emotional and physical caregiving responsibilities, including therapy coordination and educational support, whereas fathers assumed supportive, yet secondary roles focused on financial and practical needs. These gendered caregiving patterns reflect Kerala's sociocultural norms that valorize maternal sacrifice and paternal provision. Parents demonstrated resilience despite experiencing stigma, isolation, and inadequate institutional support. The implications for positive social change include promoting culturally responsive, gender-sensitive, and family-centred interventions that strengthen community awareness and improve access to coordinated autism services in India.

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Dedication

The completion of this doctoral journey is an extraordinary privilege made possible through the generous support, guidance, and contributions of many individuals.

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Chapter 1: Introduction to the Study

Introduction

Across the globe, parents raising children with autism spectrum disorders (ASD) undergo unique experiences. Effective care for autistic children requires substantial time and targeted therapeutic interventions (Shah & Mathur, 2018). Furthermore, interventions are most effective when developed and implemented based on an understanding of parenting challenges, as increased support to parents leads to improved care for individuals with autism (Estrin et al., 2023; Viana et al., 2021). Parenting an autistic child in conservative, collectivist cultures like those in Asia involves unique challenges, including societal pressures and the prioritization of family honor (Shorey et al., 2019; Wang et al., 2023). Chinese parents often employ avoidance and discipline to manage their child's behaviour, reflecting cultural values and the goal of social integration (Wang et al., 2023). In Nepal, like India, mothers of autistic children face physical, emotional, and social challenges compounded by economic hardships due to caregiving (Acharya & Sharma, 2021). Indian society's view of disability as a tragedy leads to families hiding the diagnosis to avoid stigma, causing a range of emotional turmoil for families (Tripathi, 2016). Considering these challenges and customizing the support alone would lead to meaningful interventions that could potentially bring about socially significant family changes. Several studies have attempted to examine the current situation of support and interventions.

A study in Kerala highlighted superficial interactions between parents and therapists, stressing the need to empower parents to be better involved in their children's

therapy (Ramachandran, 2020). Parents can be better supported in caring for their children with autism by thoroughly understanding their challenges and strengths. However, experiences may vary between fathers and mothers. The question was, “What are the unique experiences of fathers and mothers raising a child with autism, and how do they compare with each other?” Studies conducted globally and in India have attempted to understand parenting experiences. Fathers in India struggle to express emotions due to cultural expectations, while mothers often feel isolated and face difficulty accessing services, especially in rural areas, due to geographical and financial constraints (Minhas et al., 2015). A recent study by Johnson and Kumar (2022) in Kerala highlighted maternal experiences, including strained marriages, mothers being unfairly blamed, and both mothers and fathers being labelled as inadequate parents. Additionally, there is a need for more comprehensive and accessible services, as well as an overall improvement in the quality of social life. As much as parents’ experience raising a child with autism is an essential aspect of being considered in the care of individuals with ASD, it is to be noted that limited research is currently available exploring the individual experiences of parents globally, and in India.

The global issue of inadequate representation of both fathers and mothers in ASD research emphasizes the need for localized studies and understanding (Aylward et al., 2021), particularly in culturally diverse areas like Kerala. A survey by Poovathinal et al. (2016) in Kerala found an autism prevalence of 23.3 per 10,000 among 1 to 30-year-olds, underscoring the need for services. However, educational and therapeutic resources are often inadequate and disorganized, even in major cities (Aluri & Karanth, 2002), pushing

parents to become lay experts (Ramachandran, 2020). Divan et al. (2012) advocated for creating affordable intervention models that prioritize collaboration between trained community workers and parents. Although parent–professional partnership is necessary, several factors, such as unequal power dynamics, the variation in what parents need or want (Mittler et al., 1986), insensitivity to cultural variances (Kalyanpur & Harry, 1999), and differing parent–professional experiences (Sheehey & Sheehey, 2007), add to the complexity of forming effective partnerships. Thus, to achieve an effective partnership, it is essential to understand the experiences of parents who are involved in the care of a child with ASD.

This chapter opens with an overview of the research literature on parenting a child with ASD. It identifies the existing gaps in understanding the experiences of both fathers and mothers and explains the necessity of the study. It also introduces the problem statement, purpose statement, and research question. Further, it delves into the multifaceted impacts of ASD, emphasizing the necessity of early detection and intervention. It highlights the critical role of family and societal dynamics in managing ASD, focusing on the state of Kerala in India. In addition, the chapter provides an overview of the theoretical foundation, the nature of the study, definitions, assumptions, scope, delimitations, limitations, and significance. It concludes with a summary of the key points and a transition into Chapter 2.

Background

ASD presents challenges in social skills and repetitive behaviours, with symptoms often appearing before age one and becoming pronounced by ages 2 to 3. These

symptoms sometimes mimic attention deficit hyperactivity disorder or obsessive-compulsive disorder (Aylward et al., 2021). Although diagnosis rates of ASD by the age of 48 months rose from 58% in 2014 to 71% in 2018 (Aylward et al., 2021; Legg & Tickle, 2019), diagnosis may not be given until school age due to these signs being missed by untrained caregivers. The lack of knowledge about autism and its signs is detrimental to parents taking the necessary steps for early intervention. In a study by Aylward et al. (2021), the authors found that in Latinx communities with limited English in the United States, over 85% reported a lack of ASD knowledge, pointing to systemic barriers in education on developmental disorders. Early detection is essential for early intervention; however, there is a wide disparity seen in countries across the globe in the detection and diagnosis of autism. Studies conducted in Kerala, where I conducted my research, revealed significant variation in the estimated prevalence of autism. This is most likely influenced by community awareness of childhood neurodevelopmental disorders, patterns of seeking help, the availability and quality of services, as well as various sociodemographic variables (Antony et al., 2023). Parents raising a child with autism undergo different experiences, which may or may not include chronic stress, anxiety, and depression from the continual demands of care and the social isolation stemming from stigmatization (Bonis & Sawin, 2016; Shepherd et al., 2018). These challenges are compounded in Kerala due to its cultural context, patriarchal practices, socioeconomic challenges arising in lower and middle-income families, and lack of adequate support and resources.

Gender inequality manifests in numerous ways in India, stemming from various social customs perceived as conventional due to religious or cultural traditions deeply rooted in history. In Kerala, mothers of children with autism often bear the brunt of caregiving, with minimal to no support, leading to high levels of stress and burden (Johnson & Kumar, 2022). Paternal involvement in raising children is embedded in the social and cultural norms of communities. In many low- and middle-income countries like India, fathers have a limited role in child-rearing, even for neurotypical children (Jose et al., 2021). Several other factors, such as co-morbidities, low socioeconomic status, and living in a joint family, contribute to parental stress. The research gap in understanding the impact of ASD across diverse cultural and socioeconomic backgrounds in Kerala, mainly how gender roles influence treatment and caregiving, underscores the need for culturally sensitive approaches and interventions tailored to the unique challenges faced by families with children with ASD (Desai et al., 2012; Divan et al., 2012). I examined these research gaps and determined the need for this study.

Research Gaps and the Need for This Study

Compared to other parents, parenting a child with ASD has been shown to result in lower parenting confidence, higher stress, and more health issues (Karst & Van Hecke, 2012). Families also face financial strain, time pressures, higher divorce rates, and reduced overall well-being (Karst & Van Hecke, 2012; Malhi et al., 2022). Karst and Van Hecke (2012) emphasized that the stress parents of children with ASD face can negatively affect both the child and intervention success. Most interventions prioritize child outcomes, overlooking the family's role, which impacts both short- and long-term

therapy results. Addressing family dynamics is critical to understanding these connections. Increased respite care for parents leads to effective interventions and improved outcomes.

Raising a child with ASD can significantly affect the marital relationship in various ways. Vohra et al. (2014) found that caregivers face significant obstacles in accessing services, negatively impacting family dynamics, including the couple's bond. In a recent study by Brien-Bérard and des Rivières-Pigeon (2023), the authors propose that parents raising children with autism employ coping strategies such as taking time, seeking information, and reappraising situations. However, these strategies led to relationship problems and increased stress when one partner failed to contribute equally to family life. Ramisch et al. (2014) emphasized that effective communication and shared expectations are crucial to marital satisfaction, as fathers and mothers often encounter these challenges in different ways. While wives preferred action-oriented strategies, husbands emphasized the importance of emotional support and shared duties. Sim et al. (2019) noted that relationship satisfaction, founded on shared beliefs, teamwork, and shared experiences, is crucial for family resilience. Despite challenges, couples demonstrated personal and relational growth, which is essential for navigating the stress of raising a child with ASD. Brien-Bérard and des Rivières-Pigeon (2023) suggested that further investigation is needed to examine the factors enabling couples to overcome the accompanying hurdles. According to Urkmez et al. (2023), further research is needed to explore the experiences of diverse groups of parents who face marginalization within school settings. Shorey (2019) conducted a meta-synthesis, revealing that most research

focuses on mothers' perspectives primarily because they are the primary caregivers, especially in Asian culture. This creates a biased view favouring Asian mothers, highlighting the need for more studies on Asian fathers' parenting perspectives. As a practitioner in the field of ASD, I have witnessed the difference in interactions of fathers and mothers with the interventionist. I have observed that culturally diverse mothers are more often engaged in conversations and discussions, whereas fathers tend to remain silent and aloof. Despite the interventionist's attempts, fathers did not contribute much to the conversations. This observation sparked my curiosity about the lived experiences of fathers and mothers, and I attempted to explore relevant studies.

While exploring studies conducted on the topic of the lived experiences of parents raising children with autism, I observed that few studies have examined the similarities and differences in the lived experiences of fathers and mothers. Moreover, I found only a few studies that were explicitly conducted in the sociocultural context of Kerala. Kerala's high literacy rate and healthcare infrastructure create a unique scenario for managing ASD. However, several studies have emphasized the importance of early screening and diagnosis, as well as the importance of culturally adapted tools, support systems, and enhanced parent-professional partnerships (Ramachandran, 2020; TS et al., 2018). Understanding each parent's perspective is the stepping stone to creating the necessary support systems unique to the needs of fathers and mothers, leading to effective care of a child with ASD. Thus, this study is much needed, with the potential to provide the scholarly community with relevant information and suggestions for effective interventions.

Objectives and Significance of the Study

Parents of children with autism face challenges that are often linked to their child's behaviour and the level of community support available. Understanding these behaviours and how families cope is essential for providing adequate care. Parental sensitivity and synchronization are crucial in interventions, emphasizing responsiveness to infant cues and coaching roles (Crowell et al., 2019; Patel, 2014). The process of diagnosing autism presents additional difficulties, including overcoming stigma. These challenges can significantly impact parental well-being and the child's behaviour, emphasizing the need for targeted interventions and support (Hall, 2012; Reed & Osborne, 2012; Russell & Norwich, 2012; Sartor et al., 2023). Overall, the complexity of parenting a child with autism calls for research that guides effective support systems. The emphasis is on understanding the unique challenges faced by mothers and fathers of children with ASD, which is essential in analyzing family dynamics and pivotal for the creation and execution of specialized assistance tailored to their unique needs.

This research can enhance the planning and provision of services for children with ASD. According to Cooke et al. (2020), healthcare professional training should incorporate ongoing education programs focused on increasing awareness of the challenges associated with parenting a child with ASD. Moreover, services for children with autism should be adaptable, easily accessible, integrated, well-coordinated, seamless, and developed in collaboration with service users and families. Cooke et al. also emphasized the importance of transparent and readily available information regarding services for children with ASD, which should be accessible to parents and

caregivers throughout their interactions with healthcare professionals. This study explores the support that can be provided, significantly enhancing the lives of children with ASD. As identified in a similar study by Johnson and Kumar (2022) in Kerala, the current study's findings can inform policymakers in creating effective caregiver support policies, highlighting the importance of parent support groups and family therapies for enhancing mental and social well-being. This can be achieved by tailoring support programs to address the unique needs of both mothers and fathers. Furthermore, the study's findings can inform policymakers and practitioners about the importance of considering cultural and gender-specific factors when designing interventions. This can lead to more effective and holistic approaches that not only support the psychological well-being of parents but also contribute to the overall development and well-being of autistic children. Additionally, it can highlight the need for public autism awareness and sensitization programs, as well as inform town and city planners in designing autism-friendly public spaces. Moreover, it may serve as a foundation for additional research. The comprehensive understanding from this research can ultimately enhance the quality of life for families affected by autism in Kerala and similar cultural contexts. The studies I examined revealed a problem that warranted further investigation.

Problem Statement

ASD is a complex neurodevelopmental condition that presents significant challenges to the individuals directly affected by it and their families and communities. It significantly affects children's social, communication, and behavioural development. This often leads to stigma and discrimination, exacerbating the challenges faced by these

children and their families. Such societal attitudes can lead to isolation, misunderstanding, and a lack of support from the broader community. Recognizing and addressing these issues is crucial for developing effective support strategies for individuals with ASD and their families.

In India, a country with a population of nearly 1.3 billion, where roughly one-third are children under the age of 15, the challenges in addressing ASD are immense. Based on medical data, it is estimated that over 2 million people in India might be affected by ASD (Chauhan et al., 2019). The societal norms and gender roles in India are crucial in understanding and developing suitable interventions for autism care. These dynamics significantly influence how mothers and fathers approach the care of their children with ASD. Low- and middle-income countries, such as India, often have scarce support services for ASD. The challenges faced by parents of children with ASD in these settings are more pronounced compared to those with children meeting typical developmental milestones. This disparity highlights the need for targeted research and intervention strategies in populous low- and middle-income countries.

This study, conducted in Kerala, India, aimed to explore the differing perspectives and roles of mothers and fathers in raising children with ASD. The research examined various aspects, including stress, coping strategies, access to support, and treatment strategies. It sought to understand whether maternal and paternal views converge or diverge on these critical issues, thereby unravelling the complexities within family dynamics. This research aimed to inform targeted interventions and support systems that respect diverse parental perspectives and values. It aimed to contribute to a more

effective and holistic approach to autism in Kerala. By understanding the unique challenges and perspectives of both mothers and fathers, the study aimed to contribute to the development of culturally sensitive and effective interventions. Addressing ASD challenges requires a multifaceted approach, including early detection, family involvement, and an understanding of societal and cultural dynamics. Insights from studies in Kerala, such as mine, are crucial for developing culturally sensitive interventions.

The gender-driven dynamics in Indian society are fundamental in the context of autism care. Mothers and fathers may have different perspectives and roles in managing ASD, influenced by societal norms and expectations. Understanding these dynamics is vital for developing suitable interventions that support both parents in their approach to autism care. Furthermore, the global context of ASD, especially in low- and middle-income countries like India, underscores the need for more research and tailored interventions. The scarcity of support services in these regions places an additional burden on families. Therefore, interventions must be designed with consideration for the limited resources available in such settings. This research, along with similar initiatives, aims to provide a more comprehensive and inclusive approach to autism care. By respecting diverse parental perspectives and addressing the unique challenges faced in different cultural and economic contexts, we can contribute to a better understanding and management of ASD. This, in turn, can lead to more effective support systems, improved quality of life for individuals with ASD and their families, and a more inclusive society that understands and accommodates the needs of those with neurodevelopmental

disorders. In sum, the complexities of ASD care and management require a holistic approach that considers early detection, family involvement, societal attitudes, and gender dynamics, none of which are in effect in Kerala. This leads to the study's purpose.

Purpose of the Study

Research in regions like Kerala, India, is pivotal in informing targeted interventions and support systems. Such efforts contribute significantly to a more effective and empathetic approach to autism, ultimately fostering a society where individuals with ASD can thrive and may influence them to reach their fullest potential. Given the cultural context of Kerala, one might expect professional authority and parental compliance (Ramachandran, 2020). However, the gender inequality prevalent in Kerala, along with the religious beliefs and practices, often sees mothers and fathers having opposing viewpoints, further leading to disagreements with each other and even more difficulty in forming effective partnerships. I aimed to understand these agreements and disagreements that parents have. This qualitative study explored the multifaceted experiences of both mothers and fathers raising autistic children in Kerala and compared these experiences. It delved deeply into parents' cultural nuances and diverse perspectives, highlighting how gender roles, societal expectations, beliefs, attitudes towards various treatment methods, behaviour management techniques, and dietary practices influence their experiences. The research also addressed the intersectionality of different social factors and how they intersect with parenting an autistic child. A significant focus was on understanding the coping mechanisms parents develop to manage stress. Furthermore, the study investigated the dynamics of agreement and

disagreement between mothers and fathers in their parenting approaches and understanding and acceptance of treatment strategies outlined by professionals. Fathers and mothers were interviewed separately. The study provides a comprehensive and insightful understanding of these aspects through semistructured interviews and thematic analysis. This approach was designed to fill the existing gaps in research by thoroughly examining the unique challenges and strategies employed by fathers and mothers in Kerala to navigate the complexities of autism.

Research Question

How do the lived experiences of fathers and mothers raising a child with ASD in Kerala differ in terms of stress, coping mechanisms, access to support, and treatment strategies?

Theoretical and Conceptual Framework for the Study

The theoretical and conceptual framework that guided this study is Bronfenbrenner's bioecological model of human development, proposed by Urie Bronfenbrenner in 1979. This model incorporates a process-person-context-time (PPCT) framework, which builds upon his earlier ecological systems theory and Crenshaw's (1989) intersectionality theory.

According to Bronfenbrenner and Ceci (1994), the PPCT model expands on Bronfenbrenner's earlier ecological systems theory by integrating the dynamic interplay of four dimensions that influence human development. The *process* refers to the proximal processes, the primary mechanisms through which development occurs, such as interactions between a child and their environment (e.g., a child playing with a parent).

These processes are most effective when they are regular and sustained over a long period of time. *A person's characteristics* can influence how they react to and engage with their environment, including their genetic dispositions, temperament, and intelligence. *Context* encompasses the various environmental layers, ranging from the immediate setting, such as family and school, to broader contexts, including community and culture. Lastly, *time* includes both the chronological lifespan and the historical period in which the person lives, acknowledging that personal and societal changes over time impact development.

The original ecological model focused on various environmental systems and their impact on children. In contrast, the bioecological model introduces a more nuanced understanding of these interactions by emphasizing the role of proximal processes. This newer model highlights that these interactions significantly influence development, which involves increasingly complex and reciprocal activities between the developing individual and the people, objects, and symbols in their immediate environment. This emphasis shifts from viewing the environment as a backdrop to viewing it as an active participant in the developmental process. The bioecological model also incorporates the notion of heritability as a measure of how genetic factors influence developmental outcomes within specific environments, thereby adding a genetic dimension to the understanding of the interaction between an individual and their environment.

Furthermore, the bioecological model emphasizes the importance of the stability and consistency of these proximal processes, highlighting how their effectiveness is contingent upon individual characteristics and the broader environment, which can vary

significantly. For instance, interventions designed to enhance developmental outcomes are likely to have a greater impact in environments lacking resources, demonstrating how the same genetic potential can yield different outcomes based on environmental conditions. This model advocates for a comprehensive research approach that encompasses diverse genetic and environmental contexts to fully comprehend the complex interactions that shape human development, challenging traditional views that may overly emphasize genetic determinism and highlighting the significant role of the environment in these processes. This approach deepens our understanding of developmental dynamics and highlights the potential for interventions to support developmental processes in varied contexts more effectively.

Crenshaw's (1989) intersectionality theory emphasizes family diversity, recognizing how gender, culture, socioeconomic status, and other factors intersect to shape distinct experiences and challenges. This approach offers a nuanced understanding of each family's distinct situation, illustrating how socioeconomic status affects resource access while cultural beliefs and gender roles influence perceptions and responses to autism.

Bronfenbrenner's bioecological theory and Crenshaw's intersectionality theory provide rich, complementary frameworks for designing and analyzing a study on the lived experiences of mothers and fathers raising a child with autism in Kerala, India. These theories can inform the study's design and analysis in several ways.

Bronfenbrenner's bioecological theory emphasizes the multiple environmental systems and the dynamic interactions within these systems that influence individual

development. For a study on parents raising children with autism, this theory can guide the examination of various contextual layers impacting these experiences:

- **Microsystem:** This involves the immediate environments interacting directly with the individuals. I analyzed how family dynamics, home environment, and immediate social settings, such as neighbourhood and support systems interactions, influence the lived experiences of parents raising a child with autism in Kerala.
- **Mesosystem:** This includes interactions between various microsystems. I investigated the relationships between family members, work, healthcare workers, educators, and social support systems, such as parent support groups, and how these interconnect to affect parental experiences.
- **Exosystem:** These settings indirectly affect the individual, such as the workplace, social, educational, healthcare policies, or community services for disability support. I understood how these broader social and institutional policies impact the parents' ability to manage care and advocate for their children.
- **Macrosystem:** This encompasses cultural, economic, and legal norms, social values, and influences. In Kerala, I explored the specific cultural beliefs about disability, stigmatization, and societal acceptance and how these factors shape attitudes toward autism and influence parental experiences, including stress or coping strategies.

- Chronosystem: This involves time, including life transitions such as a child's development and historical changes, societal attitudes, and policy developments. I examined how changes, such as advancements in autism awareness and shifts in local health policies, have affected these families.

Intersectionality provides a framework for understanding how various forms of social stratification, such as class, gender, race, and other axes of identity, intersect to create unique experiences. Applying Crenshaw's theory of intersectionality to this study in the context of Kerala helped give further detailed insight in the following ways:

- Gender: I examined the differences in experiences, expectations, and societal pressures between mothers and fathers. This is mainly because gender roles in Indian culture might influence how caregiving responsibilities are distributed and perceived.
- Socioeconomic status: I analyzed how economic resources affect access to services like healthcare, education, and specialized support and how these, in turn, impact the family's quality of life and stress levels.
- Cultural factors: I considered how local beliefs about autism and disability intersect with national policies and global views to influence parental experiences. This might include religious beliefs, traditional health practices, and local community support structures.
- Regional differences: Since Kerala has unique cultural and social dynamics within the broader Indian context, I examined how regional characteristics affect these families.

Applying these theoretical frameworks significantly deepened the understanding of the complex realities faced by families raising children with autism in Kerala, providing nuanced insights that can inform more targeted and effective support strategies. Both theories encourage a holistic understanding of the parents' experiences, considering both the individual and family levels, as well as the broader societal and cultural contexts. By integrating Bronfenbrenner's bioecological systems theory and Crenshaw's intersectionality theory, the study adopted a comprehensive approach to explore the complex, multifaceted experiences of mothers and fathers in Kerala, accounting for the individual, familial, societal, and cultural factors that influence their caregiving journey. By employing Bronfenbrenner's and Crenshaw's frameworks, researchers and practitioners can gain a deeper insight into the unique experiences of families with autistic children in Kerala. This integrated theoretical framework enables a nuanced understanding of the challenges and supports encountered by parents, facilitating targeted recommendations for policy and practice supporting families of children with autism in culturally sensitive ways. It allowed for analysis that was sensitive to the complexities of individual lives, acknowledging that a confluence of various systemic and intersectional factors influences the challenges and experiences of raising an autistic child. This approach not only highlighted the importance of considering a wide range of influencing factors but also underscored the need for tailored interventions and support systems that are responsive to the diverse needs of these families. It serves as a reminder that understanding human development, particularly in complex situations such as autism within a family, is especially crucial in regions like Kerala, India. This requires an

appreciation for the interconnectedness of various systems and the multiplicity of social identities and categories.

Nature of Study

The study employed a qualitative research design, focusing on interpretative phenomenological analysis (IPA) and thematic analysis to address its research questions. I combined IPA's commitment to holistically exploring experiences with thematic analysis, which identified patterns and themes across the dataset, ensuring that the study captured the complexity of the participants' experiences, including emotional, cognitive, and social dimensions, as well as emergent themes. This was essential when comparing the experiences of fathers and mothers, as it acknowledges and respects the multifaceted nature of their roles and experiences.

IPA was apt for this study as it delved into the profound, detailed personal experiences of parents in Kerala, which captures the complex emotional, cognitive, and social dynamics involved in raising a child with autism. This method was ideal for contrasting the intricate experiences of fathers and mothers. Further, IPA emphasizes understanding personal experiences phenomenologically, which explores how cultural, social, and familial dynamics in Kerala shape parents' perceptions and caregiving roles. It also interprets these experiences within the sociocultural context, providing insights into how societal norms and gender roles affect parenting a child with autism. Moreover, IPA utilizes smaller sample sizes and facilitates thorough analyses of individual experiences, essential for a study aiming to detail the distinct experiences of different parental groups within Kerala's unique cultural setting. The method's flexibility and sensitivity made it

suitable for addressing sensitive topics, such as autism caregiving, ensuring a respectful and confidential environment that allows participants to share openly.

According to Smith and Shinebourne (2012), IPA is a qualitative research method in psychology that explores individuals' lived experiences and perceptions, particularly in complex or novel situations. Originating from phenomenology, hermeneutics, and idiographics, IPA deeply engages with personal narratives to understand how individuals perceive and make sense of their experiences. This method is highly effective for exploring areas where standard constructs are insufficient, particularly in scenarios involving significant personal challenges or changes, often referred to as "hot cognition." Researchers employ a rigorous, case-by-case analytical approach, where each narrative is individually scrutinized to maintain the contextual integrity and nuances of the participant's experiences. This helps identify unique themes within each account and facilitates the discovery of standard patterns or variances across different narratives.

The process of IPA requires meticulous data collection, typically through semistructured interviews, which allow for an in-depth exploration of personal stories in a flexible, conversational format. In-depth interviews, as characterized by Rubin and Rubin (2012), are more comprehensive. These one-on-one interviews aim to uncover deep insights about an individual's experiences, motivations, feelings, and opinions. They are typically longer and more detailed, allowing participants to discuss their experiences in a comprehensive and reflective manner. Semistructured interviews involve predetermined questions that guide the conversation. However, these interviews are not rigid; they enable me to adapt to emerging topics during the dialogue, providing a rich

and detailed examination of the participant's perspective. Further, this highlights the participants' areas of interest and encourages them to share their experiences and perspectives in their own words. I utilized in-depth interviews to gather comprehensive accounts of lived experiences. Moreover, I framed questions that allowed exploration of the various systems (bioecological model) and intersecting identities (intersectionality). After the interviews, I applied the six steps identified by Braun and Clarke (2006) to conduct a thematic analysis of the data.

Braun and Clarke (2006) outlined that thematic analysis involves identifying, analyzing, and reporting patterns (themes) within the data. The process is meticulous: carefully reading and re-reading the data, coding it in segments, and then grouping these codes into broader themes. This method is flexible and widely used in qualitative research due to its ability to provide a rich, detailed, and complex account of the data. In the initial phase of the structured thematic analysis outlined, researchers immerse themselves in data through detailed reading and re-listening to interviews, making extensive notes on content, language, and context. These notes also consider the interviewer's potential influence on the interaction, based on personal characteristics such as gender and social status. Key phrases and emotional cues are highlighted, building a rich foundation for initial analysis that captures the essence of the data. During the next phase, researchers refine their initial notes to identify emergent themes that represent psychological concepts at a higher level of abstraction, while staying connected to the specifics of participants' accounts. This stage exemplifies the hermeneutic circle, where the interpretation of parts informs the understanding of the whole dataset. Researchers

then examine these themes for connections and conceptual similarities, grouping them into coherent clusters that accurately represent the data. In the final phase of thematic analysis, researchers organize emergent themes into clusters that form a structured thematic analysis, ensuring themes are robust and relevant. Major themes and subthemes are listed, along with linked transcript excerpts, to facilitate easy verification and a detailed, efficient analysis process. For those using qualitative data analysis software, this phase involves digitally linking themes to pertinent transcript passages to streamline the analysis. I used thematic analysis to identify themes across different layers of the bioecological model and intersections identified through intersectionality. Furthermore, I sought patterns and variations in experiences based on various system interactions and identity intersections.

In this study, I combined IPA's commitment to holistically exploring experiences with thematic analysis, which identified patterns and themes across the dataset, ensuring that the study captured the complexity of the participants' experiences, including emotional, cognitive, and social dimensions, as well as emergent themes. This was essential when comparing the experiences of fathers and mothers, as it acknowledged and respected the multifaceted nature of their roles and the diverse experiences they had.

In summary, using IPA and thematic analysis, I was able to triangulate findings, enrich interpretations, and ensure the robustness of their conclusions. IPA's emphasis on in-depth, phenomenological exploration and thematic analysis, interpreted within specific sociocultural contexts, made it an ideal approach for a comparative study of fathers' and mothers' experiences of raising a child with autism in Kerala. It provided a nuanced and

comprehensive understanding of their unique challenges, coping mechanisms, and support needs, which other qualitative methods may not capture as effectively.

Definitions

Autism spectrum disorder: ASD, as per the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*), by the American Psychiatric Association, is characterized by ongoing difficulties in social communication and interaction across various settings, alongside restricted and repetitive behaviours or interests. Symptoms emerge in early development but may become more apparent when social demands surpass abilities or are hidden by later-learned coping strategies.

Parenting experiences: Parenting experiences encompass the joys, challenges, and learning moments encountered while raising children. This includes celebrating milestones, navigating behavioural challenges, making decisions about their upbringing, and forming deep bonds. These experiences vary widely, shaped by individual, cultural, and family factors, marking a growth journey for both parent and child.

Collectivistic culture: Collectivistic cultures prioritize group needs and goals over individual interests, with individuals identifying themselves through social groups, such as family or community, rather than personal achievements (Triandis, 1995). Core values include harmony, interdependence, and cooperation, with social behaviour shaped by collective norms and duties to preserve group cohesion and relationships.

Individualistic culture: Individualistic cultures prioritize individual autonomy, goals, and achievements over group needs, with personal identity rooted in one's traits and accomplishments rather than group affiliations (Hofstede, 1980). Core values include

independence, self-expression, and choice, with societal encouragement for personal success and judgment based on individual achievements.

Cultural perception: Cultural perception reflects how culture shapes individuals' interpretation, cognition, and behaviour toward their environment and social interactions (Masuda & Nisbett, 2001). It influences how people see others, interpret social cues, and understand reality, affecting everything from visual perception to moral judgment based on their cultural backgrounds.

Gender roles: Gender roles are the norms dictating appropriate behaviours and attitudes for individuals based on their gender, affecting self-expression, interactions, and self-perception (Eagly & Wood, 1999). These roles, which are culturally specific and variable over time, reflect societal beliefs about gender.

Study Assumptions

In this study on the lived experiences of mothers and fathers raising a child with autism in Kerala, I made a few assumptions. First, I assumed that the sample chosen for the study would provide the information I sought. I assumed that the participants had fully and completely answered questions and did not conceal any information. I also assumed that the information provided by the participants was trustworthy. The reliability of responses from fathers and mothers is crucial, as this research relied on collecting and interpreting this information. Finally, I assumed that the results of the study can be generalized to other parents across Kerala who are raising a child with autism.

Scope and Delimitations

The scope of the research study was based on the differences in lived experiences of mothers and fathers raising a child with ASD in Kerala, focused on understanding the unique experiences, challenges, coping mechanisms, and support systems available to these families. This included examining the cultural perceptions of ASD, the impact of societal norms on parenting practices, the stresses experienced by fathers and mothers, coping strategies utilized, intervention strategies used, and the accessibility of healthcare and educational services. The emphasis was on identifying the barriers and facilitators to obtaining appropriate care and support. By collecting qualitative data through surveys and interviews, the research provided insights into the lived individual experiences of these parents, contributing to the development of culturally sensitive interventions and policies to better support them. The participants in this study were mothers and fathers of children diagnosed with ASDs in the past 16 years. The inclusion criteria for participants were (a) English- or Malayalam-speaking fathers and mothers, (b) fathers and mothers who have a child 3-16 years of age, (c) the child must have a diagnosis of ASD (as per the *DSM-5* criteria) or autism (as per the *DSM-5*), and (d) fathers and mothers must be involved in the upbringing of their child with autism.

The exclusion criteria for participants were (a) non-English or Malayalam speaking fathers and mothers, (b) illiterate fathers and mothers, (c) fathers and mothers who have children with a diagnosis of autism older than 16 years of age, and (d) fathers and mothers of children with autism under 16 years of age who are not involved in the upbringing of the child with autism.

Conducting this research entailed several delimitations, as I excluded fathers and mothers who are not literate, may not be directly involved in their child's upbringing, and have children older than 16. Moreover, because I have lived outside of Kerala in North America for more than 26 years, this may have affected the interpretation and relevance of the findings, as well as the language and cultural barriers necessitating translation, which may have limited the depth of engagement and challenges in accessing a diverse and representative sample due to geographical and social constraints. The stigma associated with ASD may have also impacted participation rates and the openness of responses. Furthermore, methodological choices were adapted to the local context, taking into account privacy concerns and societal norms, while ethical considerations necessitated navigating dual approval processes. Additionally, logistical complexities such as the need for local collaborators, resource allocation for translation, and data collection, as well as technological accessibility for participants, may have limited the study's scale and depth. The applicability of the findings may be limited to Kerala, necessitating careful consideration when interpreting and generalizing the results to other contexts. Despite these challenges, the research offers valuable insights into the experiences of families with ASD in Kerala, underscoring the need for culturally informed support mechanisms.

Study Limitations

In the present study, several challenges were anticipated, the most significant being the recruitment of participants who met the study's inclusion criteria. This task was particularly demanding due to the specific nature of these criteria, which may have

limited the pool of available participants. Furthermore, there were several steps in the study for collecting primary data. This involved obtaining agreements from autism centers, a process often marred by bureaucratic and logistical complexities. Additionally, recruiting interview participants was expected to be challenging, given that individuals may have needed more time to commit time for interviews. The eligibility criteria for English or Malayalam speaking parents were another limitation.

Another significant constraint was the geographical separation between my location in Canada and the study area in Kerala, India. This distance posed logistical difficulties, notably in coordinating with participants during my visit to India. The issue was compounded by the need to manage different time zones for virtual interviews, which affected the availability of some participants.

Another anticipated challenge was my biases towards people in Kerala, given that I am originally from this province in India and share the culture of the people of Kerala. In addition, I have been working with the parents of children diagnosed with autism for over 20 years and have formed some opinions from my experience in the field regarding how fathers and mothers of individuals diagnosed with autism raise their children on the spectrum.

The challenges listed above could significantly impact the interpretation of the study's findings. The limited participant availability may have resulted in a smaller, possibly less diverse sample, potentially affecting the generalizability of the findings to the broader population of parents with autistic children in Kerala. The logistical complexities of coordinating interviews across different time zones might have further

constrained the depth and breadth of data collected, impacting the study's depth of insight into the lived experiences of the target demographic. Moreover, my familiarity with Kerala could have introduced cultural bias, leading to an interpretation of data that matches my preconceptions and potentially missing nuances that an outsider might notice. My background in working with parents of autistic children may have also become a drawback in the study, causing me to favor evidence supporting my beliefs on parenting practices and overlook contradicting data, leading to confirmation bias. Additionally, my connections and biases in Kerala may have influenced participant selection, resulting in a nonrepresentative sample of parents with autistic children, which could have led to sampling bias. Lastly, there was a risk of observer bias as my personal experiences and opinions may have skewed my interpretation of data, leading to outcomes more reflective of my views than actual participant experiences.

To overcome these challenges, a series of measures was implemented. Utilizing local networks and community organizations in Kerala helped recruit participants and overcome cultural and logistical barriers. Partnerships with local autism support groups and healthcare providers eased access to suitable participants. Additionally, offering flexible interview options and times, given the difference in time zones, likely boosted participant engagement. Leveraging technology, such as scheduling apps and providing multiple interview platforms, addressed obstacles related to geography and differing time zones. Implementing a mix of strategies such as triangulation, employing blind procedures for unbiased data analysis, and soliciting peer reviews enhances the validity of the findings. I committed to self-reflection to acknowledge personal biases, underwent

cultural sensitivity training, and collaborated with a diverse research team to maintain a balanced view. Transparency about the methodologies and biases, and maintaining a reflexive journal, upheld the study's integrity. Acknowledging these limitations in the findings was essential for framing the results and their relevance, ensuring the interpretations and conclusions were firmly based on an awareness of these limitations.

Significance

The study's insight into the lived experiences of parents raising children with autism in Kerala has significant practical implications for interventions, policies, and practices, both locally and in similar contexts.

By highlighting gender-specific experiences and societal influences on caregiving, the findings can guide the development of gender-sensitive support strategies that respect cultural norms while addressing the unique needs of both mothers and fathers. The significance of this study lies in its potential to fill a critical knowledge gap concerning the perspectives of mothers and fathers raising children with autism, particularly in the cultural setting of Kerala. Understanding the diverse viewpoints of parents is crucial. Mothers and fathers might experience and approach their caregiving roles differently, influenced by gender-based expectations and societal norms. This study aimed to uncover these nuances, offering a deeper understanding of how each parent perceives and navigates their role. Such insights are essential in a cultural context like Kerala, where cultural norms and expectations often deeply influence family roles and responsibilities. By exploring these differences, the study could provide tailored support strategies that acknowledge and respect these unique viewpoints.

For intervention, the study emphasized the need for customized educational programs and stress management workshops tailored to parents' specific stressors. Community support groups could be established or enhanced to provide a platform for sharing experiences and strategies, fostering a supportive network that mitigates the isolation often felt by these parents. Furthermore, service providers could develop customized parent training programs to facilitate a thorough understanding of ASD and practical, evidence-based intervention strategies.

Regarding policy implications, the research could drive the creation of comprehensive support systems for families in Kerala. This may involve allocating resources for specialized training programs for healthcare providers, focusing on family-centered care and effective communication with parents, and creating funds to support families that cannot afford the necessary therapeutic interventions. Policies could be designed to ensure families have access to affordable and comprehensive autism care services, recognizing the diverse needs and challenges highlighted by the study.

Autism treatment centers could leverage the study's findings to tailor their services effectively. They could use these insights to design programs that address parents' specific needs and concerns, ensuring a more holistic approach to autism care. This could include personalized communication strategies and the involvement of parents in the care and decision-making process, ensuring that interventions are both child-centric and family-focused.

On a broader scale, the study's findings can influence global practices by illustrating the importance of considering cultural nuances in autism care and support. By

acknowledging the universal yet diverse challenges parents face, the insights can contribute to a more inclusive and understanding approach to autism care, encouraging the adoption of similar research-informed practices in other regions and cultures. The study's potential to inform specific interventions, policies, and practices highlights its value for understanding parents' experiences in Kerala and shaping more effective and empathetic support structures for families navigating autism worldwide.

Summary

This study explored the differing experiences of parents raising a child with ASD, a complex developmental condition marked by social communication challenges and repetitive behaviors. Signs of ASD often become evident by age two or three, with diagnoses sometimes delayed due to limited-service access. Parenting a child with ASD is particularly challenging in collectivistic cultures, where societal norms can increase difficulties, leading to varied coping strategies and emotional impacts. Differences in the experiences of mothers and fathers can hinder access to services and the implementation of strategies. Understanding ASD in cultural contexts and improving service access, especially for underserved communities, is essential for supporting families. Ongoing research is needed to develop tailored interventions, considering the differing experiences of raising a child with autism by fathers and mothers.

Chapter 2: Literature Review

Introduction

ASD is rising and presents challenges for individuals, families, and communities. This study examined the impact of ASD on parents in Kerala, India, highlighting the role of family and societal support. Autism prevalence varies in South Asia, ranging from 0.09% in India to 1.07% in Sri Lanka, with an average of 0.58%, reflecting disparities in diagnosis and awareness. In India, rising ASD cases are linked to increased awareness and improved diagnostics. Recent studies estimate that autism affects around 1% of children under 10 in India, with early detection becoming more common. However, older individuals may be underdiagnosed, emphasizing the need for further research, standardized criteria, and greater awareness to improve support and intervention.

ASD significantly affects children's social, communication, and behavioural development, often leading to stigma, worsened by societal views in India that see disability as a family tragedy to be concealed (Acharya & Sharma, 2021). Kerala faces a significant lack of awareness and stigma surrounding ASD. In addition, cultural norms, individual beliefs, and gender roles contribute to varying experiences in parenting a child with autism. In raising a child with special needs, expecting mothers to be the primary caregivers results in significant stress, burnout, and social isolation (Divan et al., 2012). Research has shown that parenting behaviours directly influence behaviour problems in children with ASD (Osborne et al., 2008). Further, discrimination against these children and their families creates physical, emotional, social, and economic challenges (Tripathi, 2016). Such societal attitudes lead to isolation, misunderstandings, and inadequate

community support. Early detection and intervention can reduce morbidity, enhance education and cognitive development, decrease the likelihood of lifelong disability, and improve the overall quality of life for those affected. (Poovathinal et al., 2016). Parents and caregivers are the first interventionists in a child's life. Understanding the experiences of fathers and mothers raising a child with autism is pivotal in equipping them with the necessary support and resources. Collaborative efforts among caregivers, specialists, and communities are vital for providing evidence-based, individualized support that fosters inclusivity for those with ASD. In Kerala, where this study took place, addressing societal norms and gender roles is crucial for effective interventions for individuals on the autism spectrum. Community-based programs and awareness initiatives can help reduce stigma and provide better support to families. Further, such initiatives are significant as they shape how mothers and fathers approach caring for their autistic children (Desai et al., 2012; Divan et al., 2012).

Kerala was chosen for this study owing to my connection to the region and familiarity with its culture and language. I have interacted closely with many families raising children with autism and have understood that, despite Kerala's high literacy rate, challenges in autism care persist. Research conducted in the region may offer insights applicable across India and in similar global contexts. Although there are a few existing studies conducted in Kerala exploring the experiences of mothers raising a child with autism, there is no extant research exploring the experiences of both mothers and fathers. This study aimed to explore how mothers and fathers in Kerala perceive their roles in raising children with ASD, examining aspects such as belief systems, stress, cultural

influences, gender roles, education, treatment and behavior management strategies, and other challenges. Understanding these perspectives sheds light on family dynamics and will help inform more effective and holistic autism care approaches that respect diverse parental viewpoints.

In this chapter, I provide an overview of the literature search strategy, which will provide detailed information about the methods used to curate the literature review. Further, this section of the chapter will provide more insight into the literature search conducted on studies in Kerala about the similarities and differences in the lived experiences of fathers and mothers raising children with autism. Following the literature search, the theoretical foundation of Bronfenbrenner's bioecological model of human development, which includes the PPCT framework and Crenshaw's intersectionality theory, is presented. The relevance of these theories in the research and a justification of how they were applied to the study are also provided. Following that, the conceptual framework will discuss specific phenomena and research findings of scholars that were used in this study.

Literature Search Strategy

I searched the Walden University Library online database for journals, articles, published dissertations, and books. The search engines used in the literature review curation were EBSCO, Psych Central, PsycINFO, PsycArticles, ProQuest, ProQuest Digital Dissertations, ERIC, and Google Scholar. The key search words and phrases included *Autism Spectrum Disorders/ASD/Autism*, *Parenting/raising/caretaking a child diagnosed with autism*, *Parenting/raising/caretaking a child with autism in Kerala*,

Fathers and mothers raising/parenting/caretaking a child with autism, Gender roles in caregiving in Kerala, Autism in Kerala, Economic and financial strains associated with ASD in Kerala, Prevalence of ASD in South India, Prevalence of Autism in Kerala, Stress factors for parents of children with ASD in Kerala, Intersectionality and Autism, Diagnosis of ASD, Parenting challenges in raising a child with autism, Interventions for ASD, Cultural barriers, Stigma and ASD, Low-income families and Autism, Parenting styles prevalent in Kerala, and Stories/narratives/experiences/lived experiences of parents raising a child with autism in Kerala, and stories/narratives/experiences/lived experiences of fathers and mothers raising a child with autism in Kerala.

Inclusion and Exclusion Criteria

The inclusion criteria for the resources were ‘peer-reviewed’ and published between 1989 and 2024, prioritizing research from 2019 to 2024. These articles were selected based on the topic’s pertinence and publication’s recency. Empirical literature from older publications aligning with the foundational theories which informed the study were also chosen. Any resource that was not peer-reviewed and published before 1989 was excluded from this study. I referred to articles from 1989 because the theory underpinning this study was established in that year.

Findings and Analysis

I found limited existing research focusing on the individual experiences of mothers and fathers raising a child with ASD in Kerala. To address this, I broadened my search by including studies conducted in other parts of India and other countries. This search helped to find more research on this topic. Further, I included research on the

experiences of parents raising a child with autism, even if they were interviewed together. The lack of studies in Kerala exploring the individual experience of mothers and fathers raising a child with autism highlights a significant gap in research, emphasizing the necessity of this study.

Relevance and Applicability

I found several articles from India and other countries that explored the lived experiences of parents raising a child with autism who were interviewed together. I found a few studies in Kerala that explored just the mother's experiences and a few articles from other countries that explored just the father's perspectives. I ensured that the sources directly addressed the research question and that the scope matched the study's needs, avoiding overly broad or narrow sources. Additionally, I checked whether the study's context and sample size were relevant and evaluated if its findings could logically apply to the research. I thoroughly analyzed these studies to inform their research, which included the distinct perspectives of both mothers and fathers.

In conclusion, the rigorous search strategy employed, utilizing the Walden University Library online database and various search engines, ensured a comprehensive collection of relevant literature for this study. By adhering to strict inclusion and exclusion criteria, I focused on high-quality, peer-reviewed sources that aligned with the foundational theories and current trends in ASD research. Despite the limited existing research specifically on ASD in Kerala, expanding the search scope provided valuable insights into the experiences of parents raising children with autism in diverse contexts. This study highlights the significant gap in research on this topic, particularly regarding

the distinct perspectives of both mothers and fathers, underscoring the necessity and relevance of this investigation. The thorough evaluation of sources' direct relevance and applicability to the research question ensures a robust foundation for the study, with the potential to contribute meaningfully to the existing knowledge on ASDs.

Theoretical Foundation

A combination of Urie Bronfenbrenner's bioecological model of human development, including a PPCT framework proposed in 1993, and Crenshaw's theory of Intersectionality proposed in 1989, guided this study. In Bronfenbrenner's bioecological theory, the process underscores proximal processes as fundamental mechanisms driving development, such as interactions between a child and their environment (e.g., playing with a parent), emphasizing the importance of consistent and prolonged engagement. *Person* incorporates individual characteristics such as genetics, temperament, and intelligence, shaping how individuals interact with their surroundings. *Context* encompasses various environmental layers, from immediate settings like family and school, to broader contexts like community and culture. Lastly, *time* considers both chronological lifespan and historical periods, recognizing how personal and societal changes influence development over time. Unlike the original ecological model, the bioecological model emphasizes proximal processes, highlighting their central role in development. It stresses the significance of interactions between the developing individual and their immediate environment, including people, objects, and symbols, as dynamic and reciprocal activities. This shift reframes the environment from a passive backdrop to an active participant in the development process. Furthermore, the

bioecological model integrates heritability, acknowledging the contribution of genetic factors to developmental outcomes within specific environments, thereby adding a genetic dimension to understanding individual-environment interactions.

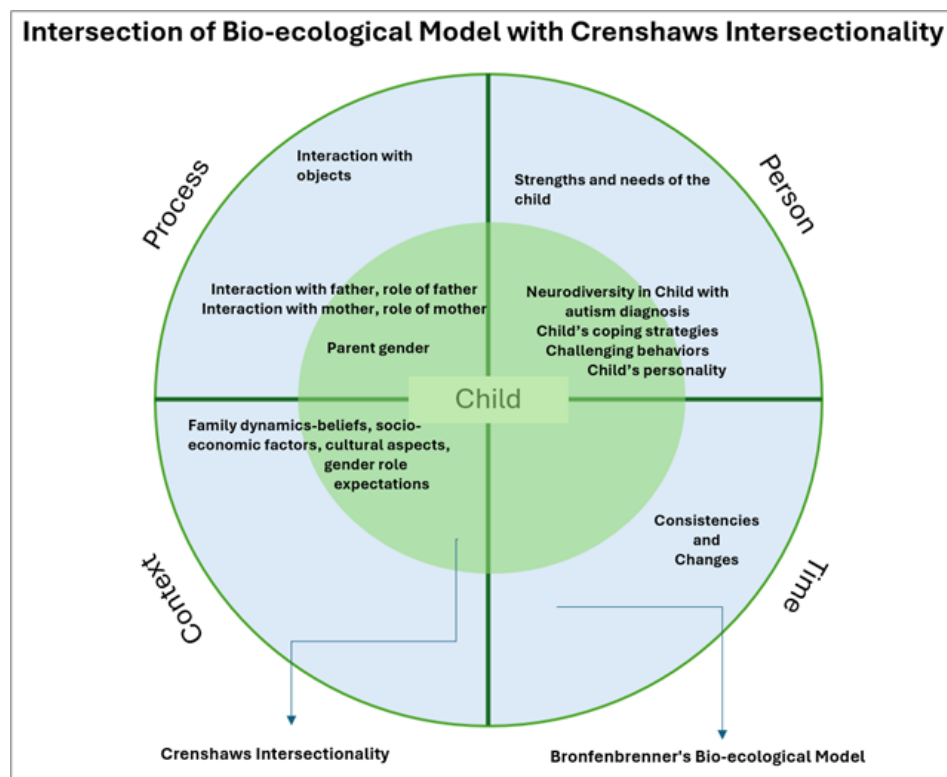
On the other hand, Kimberlé Crenshaw's intersectionality theory, established in 1989, emphasizes family diversity by recognizing how various factors, such as gender, culture, socioeconomic status, and others, intersect to create unique experiences and challenges. This approach provides a nuanced understanding of each family's distinct circumstances, illustrating how socioeconomic status affects access to resources and how cultural beliefs and gender roles influence perceptions and responses, particularly in the context of autism. A study conducted through the lens of Crenshaw's theory will further inform policymakers of the need to understand parental experiences by studying both fathers' and mothers' experiences individually. Bronfenbrenner's bioecological theory and Crenshaw's intersectionality theory offer complementary frameworks for creating and examining a study focused on the experiences of mothers and fathers raising a child with autism in Kerala, India. These theories guided various aspects of the study's design and analysis.

In a study, similar to the proposed study, by Camilleri (2022), which explored the lived experiences of fathers raising a child with autism, Bronfenbrenner's ecological theory of proximal process was pivotal in addressing the central research question. According to Camilleri (2022), the theory shaped the understanding of how fathers influence their children's immediate environments, such as interactions with caregivers. Additionally, it guided the assumption that a father's involvement in various family

dynamics impacts his experience. The literature review found studies based on the family systems theory and family resilience theory. I did not find any study based on Crenshaw's theory of intersectionality. This could be because few studies have been conducted in a culturally diverse society like Kerala, India. After gaining a thorough understanding of how Crenshaw's theory of intersectionality could be meaningfully included to guide this study, I identified that a combination of Bronfenbrenner's bioecological theory and Crenshaw's intersectionality theory best suited this study, as they complement each other. The visual representation of the intersection between the two theories is presented in Figure 1.

Figure 1

Intersection of Bio-ecological Model With Crenshaw's Intersectionality



The bioecological model informed and guided this research, which focused on the experiences of fathers and mothers. The experiences of parents include interactions between the child and their environment (Process), the role of the child's characteristics, including their IQ and personality traits (Person), the impact of broader societal structures (Context), and the influence of time on development (Time). For example, how do the quality and consistency of interactions between parents and children with autism affect the child's development? The intersectionality theory informed and guided the research question, which explores the experiences of fathers and mothers, including examining how different identity categories intersect to affect experiences, such as how the intersection of socioeconomic status, gender, and cultural background influences parental strategies in managing autism.

Sampling

Using the bioecological model, I stratified the sample across different environments (urban vs. rural, different socioeconomic backgrounds) to understand how these contexts influence developmental outcomes. Intersectionality theory prompted me to consider diverse parental identities and experiences. I ensured that the sample included an equal number of mothers and fathers from diverse socioeconomic statuses and cultural backgrounds to achieve equal representation across different strata. This helped improve the validity and reliability of the study's results.

Data Collection

Data collection methods included in-depth interviews focusing on parents' daily interactions with their child (Process), their perceptions (Person), cultural and social

influences (Context), and changes over time (Time). The interview guide (see Appendices A and B) consisted of questions that addressed the types of interactions fathers and mothers have with their children who have autism. Further questions were asked to capture the consistency, duration, bidirectionality, and quality of interactions. In addition, the questions aimed to understand the temperament of fathers and mothers, their engagement with their environment, and their responses to various life situations. Furthermore, the questions explored how parental traits, such as resilience, knowledge about autism, and stress management, influence their interaction styles and coping mechanisms, providing an in-depth insight into their experiences. Additionally, the questions were designed to capture the social and cultural contexts in which fathers and mothers interact with their children. These questions were designed to study the changes in the interactions and experiences of fathers and mothers during their children's development. Questions were designed to assess beliefs and socioeconomic status that impact the experiences of fathers and mothers raising a child with autism. Understanding the multiple environmental systems and the dynamic interactions with these systems, influencing individual development, was necessary. A thorough understanding can lead to suggestions for essential modifications of the environment to bring out the expected outcomes of fathers and mothers raising a child with autism.

Analysis

Bioecological Model: The data gathered through the interviews were analyzed to identify how various systems (microsystem, mesosystem, exosystem, macrosystem)

interact and influence the developmental processes. For instance, I explored how family dynamics and school environments collectively support or hinder the child's growth.

Intersectionality Theory: I employed thematic analysis to identify emerging themes from the data related to culture, gender, and societal norms. For instance, I analyzed how societal norms around gender influence the roles and responsibilities assumed by mothers and fathers.

Integrating these frameworks offered a comprehensive approach to understanding and supporting families in Kerala, acknowledging the complex interplay of individual, familial, societal, and cultural factors. This nuanced understanding underscores the need for tailored interventions responsive to diverse needs, emphasizing the importance of considering intersecting systemic factors in supporting families of children with autism.

Literature Review Related to Key Variables and Concepts

Prevalence of Autism in Kerala

Research on ASD prevalence in semi-urban South Indian communities, including Kerala, implies growing awareness and diagnosis of ASD (Arun, 2017). Poovathinal et al. (2016) reported an ASD prevalence of 23.3 per 10,000 in a semi-urban community in Kerala, aligning with a previous state-wide survey that found a prevalence of 1 in 500 and an incidence rate of 1 in 91,000. Another study by TS et al. (2018), using community health nurses and the M-CHAT-R in Kerala, identified 5.5% of toddlers as being at risk for ASD. The rising prevalence in Kerala, a culturally diverse state, highlights the need for adequate support for parents raising children with autism.

Arun (2017) emphasized the need for culturally sensitive approaches to ASD diagnosis, treatment, and parent-professional relationships in Kerala. Despite Kerala's high literacy rate and vital healthcare infrastructure, challenges in autism care persist. The literature search revealed limited research on autism in Kerala, with most studies focusing on prevalence and medical aspects. Few studies, such as Ramachandran's (2020), in which parents were interviewed about their relationships with therapy providers, addressed the personal experiences of parents raising autistic children. Ramachandran's study highlighted the importance of parents becoming knowledgeable about autism. Another relevant study by Johnson and Kumar (2022) focused on maternal experiences, identifying themes of strained marriages and impaired social relations. The scarcity of research on ASD in Kerala reflects the broader issue of underrepresentation in culturally diverse regions. To guide the study, I reviewed similar research from other parts of India and globally. With autism on the rise in Kerala and limited studies on parental experiences, there is a clear gap in research that this study aimed to address.

Parenting a Child With Autism

Parenting Challenges

Parenting children with ASD involves significant time, effort, and specialized interventions (Shah & Mathur, 2018), along with varying support needs (Shepard et al., 2018). In conservative, collectivist cultures like those in Asia, these challenges are intensified by the stigma around ASD and societal pressure to maintain family honor (Shorey et al., 2019; Wang et al., 2023). A study by Minhas et al. (2015) highlighted the varied societal attitudes in countries like India and Pakistan that parents encountered

regarding ASD. The authors reported that some community members were unsympathetic, using derogatory terms such as “mad” or “idiot,” while others advocated for kindness and understanding. Further, stigma and fear of mistreatment led to a restricted life for many children. According to Minhas et al., traditional healers were often the first contact, offering guidance and relief. In addition, many parents attribute the condition to God's will and see care as a divine duty, reinforced by spiritual healers. In societies such as that which exists in India, it is seen that most parents have limited information about ASD. This limited knowledge, combined with societal stigma around a child who behaves differently, prompts parents to seek solace in faith healers as a first resort. Additionally, they struggled to connect communication and social issues to behavioural problems. They often lacked strategies to manage or interact with their children, sometimes resorting to physical restraint for behavioural problems. Parents who serve as the primary caregivers often lack the essential information needed to raise a child with autism. Further, mothers are often left to care for their child with ASD with limited involvement from fathers.

Camilleri (2022) stated that positive father involvement reduces parental stress, enhances family cohesion, and benefits children with autism. Moreover, it has a positive impact on a child's social responses, language development, symbolic play, and overall development. Furthermore, fathers play a crucial role in the psycho-social development of children with communication and social interaction challenges. Father's positive involvement is not what is regularly witnessed by professionals. It is mainly the mothers who are seen to be involved in reaching out to professionals and seeking interventions.

Understanding fathers' perspectives and roles in child-rearing is essential. However, research in understanding parents' experiences globally has focused primarily on the mother's experiences. Fathers who need different support than mothers, including social, practical, financial, professional, and respite (Seymour et al., 2020), have been neglected in studies conducted on experiences of raising a child with ASD (Lashewicz et al., 2017). Studies have shown that around one in six fathers needs additional professional support for their mental and physical health. Despite the need for a thorough understanding of their experiences to provide them with appropriate support, there is limited extant research on fathers' experiences in raising a child with autism. Traditional gender roles may explain the underrepresentation of fathers, their work commitment, or even the cultural expectations for men to speak less. This underrepresentation needs to be addressed, as both fathers and mothers have unique experiences of raising a child with ASD.

Parents of children with ASD experience higher stress levels than other parents due to the constant demands of caregiving (Shepherd et al., 2018). This stress often leads to chronic anxiety and depression, exacerbated by sleep disruptions common in children with ASD and the social isolation caused by stigma (Bonis & Sawin, 2016). Additionally, navigating healthcare and education systems while advocating for proper services is challenging and time-consuming (Cooke et al., 2020). A study by Divan et al. (2012), conducted in Goa, India, aimed to explore the impact of raising a child with ASD. Their key findings revealed significant strain on families, leading to initial withdrawal and reintegration into social networks. Further, the impact extends beyond the personal

sphere to include discrimination within the community. In a study by Patel et al. (2022), the authors found that receiving a neurodevelopmental disorder diagnosis in early childhood is stressful, emphasizing the need for psychological support for parents due to elevated stress levels and interconnected effects on the family. Additionally, parents respond to these challenges by seeking support from various networks and healthcare providers. However, professionals across sectors demonstrate low awareness of the unique needs of families living with ASD, resulting in significant economic and emotional burdens.

Recognizing and addressing caregivers' stressors, including managing familial relationships, inadequate support systems, financial strains, and societal stigma, is essential, especially in diverse cultural and socioeconomic contexts (Malhi et al., 2022). Moreover, fathers and mothers experience and deal with the challenges of raising a child with autism differently, and their experiences need to be examined individually. Although several studies in India and across the globe have attempted to understand the lived experiences of parents of children with autism, there are no such studies in Kerala, highlighting the need for this research. This study examined factors that impact parental experiences and can inform interventionists and policymakers regarding the need for adequate support systems. Despite the many challenges that fathers and mothers face raising a child with autism, numerous studies have reported parenting triumphs as well.

Parenting Triumphs

A meta-synthesis by Lashewicz et al. (2017) revealed that several studies emphasize how parents of children with ASD cherish the joys and unique moments of

progress, noting that these experiences often foster personal growth, empathy, and stronger family bonds. Furthermore, they focus on celebrating their children's individuality rather than trying to "fix" them. Many parents report personal growth and a strengthened family bond due to the experience of parenting a child with ASD (Crowell et al., 2019). They develop advocacy skills and a deep understanding of their child's strengths and challenges, leading to the discovery of benefits and positive reflections on their caregiving journey (Adams et al., 2023). This resilience among caregivers of children with ASD is crucial to mitigating the negative impact of stress and psychological distress associated with caregiving (Adams et al., 2023). Although there are instances of triumphs reported by parents raising a child with autism, there are no such studies in Kerala. I wanted to examine such triumphs and share the positive experiences with the scholarly community.

A review of the existing literature revealed a recurring theme: the influence of gender, culture, societal stigma, and resource limitations in regions such as Kerala. The following sections provide a detailed exploration of these factors:

Gender Roles in Caregiving

Gender roles in India are deeply rooted in cultural and religious traditions, shaping family dynamics and responsibilities (Desai et al., 2012). Further, distinct roles are delineated in India, with men often viewed as the primary providers and women as the primary caregivers.

When it comes to raising children with ASD, these traditional gender roles play a significant role in shaping the experiences of parents. In Indian families, mothers

frequently shoulder a disproportionate burden of caregiving for children with ASD, leading to increased stress and social isolation (Desai et al., 2012). This can adversely affect their well-being and the quality of care they provide. On the other hand, fathers are typically seen as providers and often have minimal involvement in direct caregiving tasks (Divan et al., 2012). This nonchalant attitude towards raising a child with autism can lead to fathers missing out on crucial aspects necessary for the child's optimal development. Another study by Brien-Bérard and des Rivières-Pigeon (2023) attempted to gain a deeper understanding of how couples manage the challenges of raising a child with ASD. The study revealed that mothers proactively approach child-related issues, whereas fathers often withdraw from family life, focusing instead on work and leisure activities. Furthermore, individual coping strategies that best suit the person reduce stress and result in better support for the child, couple, and family. However, unequal contributions to family matters can create relationship issues and raise parental stress levels. This imbalance in caregiving responsibilities is further compounded by cultural pressures and societal norms that dictate acceptable behaviour for mothers and fathers, influencing their involvement and coping strategies in managing ASD-related challenges. Fathers are often neglected in research and support systems despite playing a crucial role in the family dynamic. This neglect can result in a lack of support for fathers, who may struggle to find their place in the caregiving framework. Understanding the nuanced role of gender in parenting children with ASD in Indian families is crucial for developing culturally sensitive support systems and interventions that cater to the entire family's needs (Desai et al., 2012; Divan et al., 2012).

In the culturally diverse state of Kerala, these dynamics are particularly pronounced. Mothers often face twice the caregiving responsibilities for their autistic children, leading to strained relationships with their spouses and affecting family planning (Johnson & Kumar, 2023). The increased caregiving responsibilities and societal expectations of being a “good mother” heavily impact their professional and labour market choices, limiting their social engagement due to stereotypes and negative behaviours from society. Further studies are needed to understand the diverse experiences of fathers and mothers, as well as the support systems they currently have in place. The study examined the individual perspectives of fathers and mothers through separate interviews. It examined the differences in caregiving roles and societal pressures between mothers and fathers, taking into account their unique experiences. By doing so, the study aimed to provide relevant information for targeted practices that incorporate both mothers’ and fathers’ perspectives and needs. For instance, creating forums for fathers and mothers separately to share their parenting experiences and strategize about their children’s futures could be a valuable outcome (Lashewicz et al., 2017). This approach acknowledges each parent’s challenges and promotes a more balanced and supportive caregiving environment.

Cultural Barriers and Stigma

Cultural factors significantly shape parents’ experiences with ASD, with heightened stigma in some societies affecting how families seek support and receive empathy (DePape & Lindsay, 2015). Lashewicz et al. (2017) highlighted the role of culture in shaping fathers’ experiences, emphasizing the need for practices that help them

navigate parenting challenges and transcend cultural stereotypes. Estrin et al. (2023) suggested that limited community awareness about autism increases stigma, stress, and delays in diagnosis and support. In collectivist cultures like India, the elevated status of doctors and power distance norms impact parent-professional interactions (Daley, 2004; Hofstede, 1980). Moreover, autism is often viewed as a family failure, leading to delayed treatment due to the societal focus on family reputation (Liu et al., 2010). Given the distinct gender roles embedded in the cultural fabric in India, mothers and fathers are likely to experience these challenges differently. A study by Malhi et al. (2022) suggested that fathers in India face difficulties expressing emotions, and mothers often face isolation and challenges accessing services. It is also to be noted that cultural beliefs shape the interventions sought by parents for their child with autism, with Western cultures favouring behavioural therapies and non-Western cultures leaning toward traditional practices (Daley, 2004). Socioeconomic factors also influence ASD care, with low-income communities often facing resource shortages and awareness gaps (Mandell & Novak, 2005).

In India, while perceptions of ASD are progressing, stigma persists, delaying diagnosis and treatment (Daley, 2004). This stigma often results in mothers being unfairly blamed for their child's condition (Johnson & Kumar, 2022), leading to social isolation for families affected by autism. I explored the role of cultural barriers and stigma in Kerala, as perceived by both fathers and mothers individually. The study examined the local beliefs that intersect with national policies, which shape parental

experiences. I also investigated how Kerala's unique dynamics influence the challenges families face in raising children with autism.

Economic and Financial Strains

Mandell and Novak (2005) underscored how the confluence of culture and socioeconomic factors affects the accessibility and quality of care for individuals with ASD. In families with limited resources, raising a child with ASD can impose high costs, including medical treatments, behavioural therapies, and specialized education (Estes et al., 2013; Mandell & Novak, 2005). Economic circumstances significantly impact the relationships between parents and professionals, particularly in Low and Middle-Income Countries (Divan et al., 2012). Moreover, the scarcity of professionals and high expenses might compel parents to take on the role of their child's therapist, prompting organizations to adopt parent-mediated programs to broaden their reach (Divan et al., 2012). Recognizing the challenges in offering autism support in India, Divan et al. (2012) proposed developing cost-effective interventions prioritizing collaboration between parents and trained community workers to meet parents' comprehension and expectations. Respecting diverse parental perspectives and addressing the distinct challenges encountered in various cultural and economic settings can contribute to a better understanding and management of ASD. This approach can lead to the development of more effective support systems, enhanced quality of life for individuals with ASD and their families, and a more inclusive society that caters to the needs of individuals with neurodevelopmental disorders. Moreover, the financial burden and

societal stigma associated with ASD can contribute to stress and strain within families, underscoring the need for comprehensive support systems (Divan et al., 2012).

I examined the individual experiences of fathers and mothers regarding economic and financial strains. The study examined the economic resources that affect access to essential services, impacting family well-being, and informed policymakers on how to support families.

Interventions and Supports

Addressing ASD challenges requires early detection, family involvement, and an understanding of societal and cultural influences. Limited awareness among families and healthcare providers delays recognition and treatment (Minhas et al., 2015). Furthermore, specialist services are scarce and primarily found in urban areas, with stigma affecting families and children with autism. In Kerala, educational and therapeutic resources are often insufficient or disorganized, which can delay diagnosis and effective management (Aluri & Karanth, 2002; Poovathinal et al., 2016). Additionally, caregivers often receive little specialized training to meet their children's needs, which limits the optimal interventions available to them. Parents sometimes feel excluded from therapeutic programs due to cultural norms and gender roles influencing parental responsibilities (Gupta & Singhal, 2005). Moreover, financial strains and economic challenges are especially pressing for parents to raise children with ASD compared to those with typically developing children (Divan et al., 2012). In a study by Ramachandran (2020), which interviewed parents of autistic children in Kerala, a need emerged wherein parents were encouraged to become more knowledgeable about autism, essentially becoming lay

experts. The state's unique challenges and dynamics in managing ASD are evident from that study. Furthermore, the relationship between parents of autistic children and therapy providers in Kerala is critical, as highlighted by Ramachandran, who revealed a lack of deep, personalized interactions between parents and professionals. The study showed that parents, while actively participating in their child's training, often feel relegated to mere informants instead of being active decision-makers, indicating a need for more empowering partnerships. In another recent study, Johnson and Kumar (2022) found a pressing need for more comprehensive and accessible services for individuals with ASD and their families.

A study that further explores the individual experiences of fathers and mothers regarding intervention and support services is crucial for developing culturally sensitive, effective interventions. The study findings should inform policymakers to enact policies supporting fathers and mothers raising a child with autism that are tailored to their specific needs. Furthermore, the results may suggest the need for parent support groups and family therapies to enhance caregivers' mental and social well-being. The study may lead to insights into the ways fathers and mothers can be empowered to become effective interventionists, as well as suggestions for autism awareness programs and the creation of autism-friendly public spaces. The study's results may also aid urban planners in designing public spaces that accommodate individuals with autism spectrum disorder. Lastly, it could serve as a foundational resource for similar research endeavours in Kerala, which are much needed in the future.

Summary and Conclusions

The literature review on ASD in India, with a focus on Kerala, reveals critical research gaps, especially in understanding the individual perspectives of mothers and fathers raising a child with autism together in a culturally diverse region. Several studies have explored the experiences of parents interviewing together or just one parent. These studies have highlighted challenges faced by families raising children with ASD. The current study presents a crucial opportunity to address gaps by understanding the nuanced experiences of fathers and mothers raising children with ASD. This research highlights the significant roles that cultural norms, societal expectations, and gender dynamics play in shaping parental experiences. It highlights the significant stress and isolation faced by caregivers, particularly mothers. In cultures such as Kerala, mothers often assume the primary caregiving role, and fathers tend to have a relatively low level of involvement. The need for early detection and intervention is highlighted in extant research. Further, culturally sensitive and gender-specific support systems emerge as a critical theme. This study aims to fill a significant gap by exploring both mothers' and fathers' perspectives, providing a holistic view of the challenges and triumphs encountered in parenting children with ASD. Focusing on a region with unique cultural dynamics and high literacy, like Kerala, this research has the potential to offer insights that could inform more effective interventions, enhance individualized community support for mothers and fathers, and ultimately improve the quality of life for families affected by ASD. The outcomes could guide policymakers, inform community-based programs, and influence

future research, making a substantial contribution to autism care and support in Kerala and other culturally diverse regions.

Chapter 3: Research Method

Introduction

This qualitative study explored the intricate experiences of both mothers and fathers raising children with autism in Kerala, examining how stress, coping mechanisms, access to support, and treatment strategies affect their parenting. It explored the challenges posed by raising a child with ASD, particularly in the culturally diverse region of Kerala. In this region, traditional roles often designate mothers as primary caregivers, and mothers experience significant marital strain and discrimination, blaming their child's condition (Johnson & Kumar, 2022). Studies worldwide have shown that fathers raising a child with autism express concerns about their children's future livelihood. The limited studies on fathers' experiences primarily focus on Western contexts (Camilleri, 2022). The present study attempted to understand the stress that mothers and fathers face and their experiences raising a child with communication and social difficulties, along with maladaptive behaviours associated with ASD. A key focus was on understanding the coping mechanisms that parents develop to manage stress, the dynamics of agreement and disagreement between mothers and fathers regarding their parenting approaches, access to or lack of access to support, and the acceptance of treatment strategies outlined by professionals. Fathers and mothers were interviewed separately to offer a comprehensive understanding of these aspects. This approach aimed to fill existing research gaps by thoroughly examining the unique challenges and strategies that parents in Kerala employ to navigate the complexities of autism spectrum disorder.

This research aimed to improve understanding of the different stresses and coping mechanisms developed by fathers and mothers, which can help reduce parenting stress and enhance psychological well-being, ultimately benefiting the child's development. The methodology involved qualitative IPA and thematic analysis structured to capture the nuanced perspectives of fathers and mothers raising a child with autism in Kerala. The study investigated how different social factors intersect with the unique challenges of parenting an autistic child. It further examined how mothers and fathers align or differ in parenting approaches and acceptance of professional treatment recommendations. The outcomes provide critical insights into the cultural context of parenting children with autism in Kerala, informing support strategies for healthcare professionals.

Research Design and Rationale

The research question for this study was: "How do the lived experiences of fathers and mothers raising a child with ASD in Kerala differ in terms of stress, coping mechanisms, access to support, and treatment strategies?" The study employed a qualitative research methodology, explicitly utilizing IPA and thematic analysis to explore parents' deeply personal experiences.

The central phenomenon under investigation was the lived experiences of parents raising children with autism in Kerala, focused on their emotional, cognitive, and social dynamics and how cultural, social, and familial influences shape these experiences. Parenting a child with autism is inherently challenging due to behavioural concerns, difficulties in accessing specialized care, and a lack of community acceptance (Shattnawi et al., 2020). These challenges are compounded by the unique cultural and social

dynamics in Kerala, a state in southern India known for its distinct familial structures and caregiving practices.

Parents of children with autism face significant emotional strain, often experiencing high levels of anxiety and depression, particularly mothers (Zhou et al., 2019). They endure feelings of burden, distress, vulnerability (Papadopoulos, 2021), hopelessness, and pessimism about the future (Alamdarloo & Majidi, 2022). This emotional toll affects their cognitive dynamics, impacting their thoughts, decision-making, and mental health. The stress of raising a child with autism impairs parents' perceptions and coping mechanisms, resulting in poorer family functioning (Pisula & Porebowicz-Dorsmann, 2017; Walton, 2018; Zaidman-Zait et al., 2017; Zhou et al., 2019) and lower satisfaction with family life (Kim et al., 2018; Walton, 2018). The continuous emotional strain can lead to cognitive overload, hindering daily task management and long-term planning for their child's needs. In Kerala, limited social support and resources (Desai et al., 2012; Edwardraj et al., 2010; Maloni et al., 2010) further isolate these families, thereby complicating their ability to cope. The stigma associated with autism, varying with symptom severity (Liao et al., 2019), exacerbates social isolation and reduces community involvement. Cultural norms in Kerala place primary caregiving responsibilities on women (Sarrett, 2015), increasing stress for mothers, especially those with younger children, firstborns, comorbidities, lower socioeconomic status, higher education, and those living in joint families (Thomas et al., 2020). The lack of spousal support intensifies stress and reduces maternal acceptance, negatively impacting social interactions (Jose et al., 2021). Although parents globally

face similar challenges, Kerala's cultural dynamics influence coping and caregiving, differing from Western contexts where structured support systems and greater community awareness are more common (Benson et al., 2008; Lutz et al., 2012; Rapp & Ginsburg, 2011). This environment influences how caregivers perceive and manage their child's autistic traits, affecting daily routines and family dynamics (Sarrett, 2015).

Emotionally, parents of children with autism experience significant strain. High levels of anxiety and depressive symptoms are typical, particularly among mothers (Zhou et al., 2019). They frequently face feelings of burden, distress, vulnerability (Papadopoulos, 2021), hopelessness, and negative expectations for the future (Alamdarloo & Majidi, 2022). The emotional toll has a significant impact on their cognitive dynamics, affecting their thoughts, decision-making processes, and overall mental health. Cognitively, the stress of raising a child with autism impacts parents' perceptions and coping mechanisms. Parents often exhibit poorer family functioning (Pisula & Porebowicz-Dorsmann, 2017; Walton, 2018; Zaidman-Zait et al., 2017; Zhou et al., 2019) and lower satisfaction with leisure and family life (Kim et al., 2018; Walton, 2018). The continuous emotional and mental strain can lead to cognitive overload, affecting their ability to manage daily tasks and plan for their children's long-term needs.

Socially, parents in Kerala navigate a complex landscape marked by limited social support and insufficient educational, therapeutic, and respite resources (Desai et al., 2012; Edwardraj et al., 2010; Maloni et al., 2010). The lack of support further isolates these families, making it difficult for them to cope with the demands of raising a child with autism. The perception and experience of stigma are significant, varying with the

severity of the child's symptoms and autism behaviours (Liao et al., 2019). This stigma affects social interactions, leading to isolation and reduced community involvement.

Cultural and familial influences in Kerala add another layer of complexity to these dynamics. In Kerala, cultural norms dictate that women are primarily responsible for caregiving (Sarrett, 2015). This expectation places a significant burden on mothers, who report high levels of stress and caregiving burden. Factors contributing to this stress include the child's lower age, being the firstborn, the presence of comorbidities, lower socioeconomic status, higher maternal education, and living in joint families (Thomas et al., 2020). Additionally, the lack of spousal support exacerbates stress and lowers maternal acceptance levels, leading to difficulties in social interactions (Jose et al., 2021).

Parents of autistic children globally face similar challenges, but local cultural customs and dynamics flavour the coping and caring processes in Kerala (Desai et al., 2012). Unlike in Western contexts, where more structured support systems and greater community awareness may exist (Benson et al., 2008; Lutz et al., 2012; Rapp & Ginsburg, 2011), parents in Kerala navigate a more insular and less supportive social environment. This influences how and when caregivers accept the chronicity and stability of their child's autistic traits, shaping their daily routines and family structures (Sarrett, 2015).

The research tradition for this study was qualitative, focusing on IPA followed by thematic analysis, which was particularly suited for this study as it allowed for an in-depth exploration of individuals' personal and subjective experiences (Pietkiewicz & Smith, 2014). This approach was designed to uncover how individuals make sense of

their personal and social worlds. The primary aim is to provide insights into how a given person, in each context, makes sense of a particular phenomenon. Typically, IPA involves detailed examinations of personal experiences, drawing on participants' own words to describe these experiences (Smith & Shinebourne, 2012).

IPA is chosen for its strength in handling complex psychological issues deeply embedded in personal contexts, making it ideal for exploring the nuanced experiences of parents handling the challenges associated with raising autistic children. This methodology enables researchers to capture parents' detailed and nuanced narratives, providing a comprehensive understanding of their perspectives and experiences. IPA's focus on smaller sample sizes facilitates an intensive examination of each participant's narrative, thereby generating detailed insights into the lived experiences of these parents (Alase, 2017). Furthermore, IPA identified commonalities among the participants' lived experiences. Thematic analysis complemented IPA by identifying and analyzing patterns across the data, providing a structured way to interpret broader themes across individual experiences (Braun & Clarke, 2006).

In the context of this study focusing on the detailed personal experiences of parents in Kerala raising children with autism, other qualitative research designs were less suitable for several reasons. *Ethnographic designs*, which provide a descriptive analysis of culture and specific ethnic groups (Salvador, 2016), would overemphasize a single group and overlook individual perspectives. This approach was inappropriate for exploring participants' lived experiences within the phenomenon. *Grounded theory* aims to discover or construct a data-based theory (Tie et al., 2019). This approach was

unsuitable for this study's problem, purpose, and research questions because it seeks to capture participants' lived experiences as they are told, rather than generate a theory grounded in the data. *Narrative inquiry* focuses on storytelling, with the researcher presenting participants' stories based on their worldview and social realities. This method involves co-creating stories with participants, allowing the researcher to live alongside them and listen to their stories (Nasheeda et al., 2019). However, narrative inquiry was not suitable for this study because it would not capture the most accurate form of participants' lived experiences as directly told by them. *Case studies* offer vignettes that enable readers to develop a vicarious experience through the information shared by participants (Creswell & Creswell, 2017). Typically, case studies are from the researcher's perspective and are based on how participants convey the information. This design was not appropriate for the study's research questions, problems, and purpose because it would present the information based on the researcher's interpretation rather than a first-person account from participants. The *quantitative approach* involves the statistical analysis of numerical data, which requires a deeper understanding and nuance to comprehend subjective, individualized experiences. Rich, descriptive data representing the subtleties of individual viewpoints are necessary for lived experiences; hence, the quantitative approach was not appropriate for this study.

IPA utilizes in-depth interviews to explore the first-hand experiences of the phenomenon under study. In this study, I interviewed mothers and fathers to understand their experiences of raising a child with autism. IPA suggests working with a small sample size, reading nonverbal cues in addition to the in-depth interview to gain a deeper

understanding of the phenomenon, and identifying common elements among participants. The commonalities were then analyzed further in the thematic analysis process. Combining IPA and thematic analysis ensured a robust approach to understanding the complex experiences of fathers and mothers in Kerala, acknowledging the multifaceted nature of their roles and experiences. It helped me capture unique personal narratives and common patterns across these narratives. This dual approach enhanced the depth and breadth of the analysis, ensuring that the research captured the complexity of participants' experiences while remaining grounded in their actual accounts.

Role of the Researcher

In this study, the role as the researcher was primarily that of an observer-participant. This involved engaging with participants during data collection through intensive interviews, while not directly influencing their daily lives. My main objective was to understand and document participants' lived experiences without influencing their natural behaviours or responses, which was essential for capturing the authentic perspectives of parents raising children with autism in Kerala.

Researcher Relationships and Ethical Considerations

I had no personal, professional, supervisory, or instructor relationships with the participants, nor did I hold any position of power over them. That lack of hierarchy helped minimize power differentials, ensuring that participants felt comfortable and free to share their genuine experiences without fear of judgment or repercussions (Pietkiewicz & Smith, 2014).

Managing Biases and Ethical Issues

I implemented several strategies to manage potential biases, including reflexive journaling and engaging in reflexivity, triangulation, and peer review. *Reflexive journaling* involved maintaining a reflexive journal throughout the research process to document my thoughts, assumptions, and potential biases. This helped me remain aware of how my perspectives might influence the study and to take steps to mitigate any undue impact, which promoted reflexivity and helped in the mitigation of potential biases.

Triangulation, which means using multiple data sources and methods (e.g., interviews and hand-written notes) to cross-verify the information gathered, ensured a comprehensive and unbiased understanding of the participants' experiences. I conducted a peer debriefing to further enhance the credibility of the research. I also reached out to colleagues and mentors to review and critique the research design, data analysis, and findings, which provided an external check on the research process and further minimized any biases.

Although member checking was originally proposed and planned, I did not conduct it as outlined in the Institutional Review Board (IRB) application.

Several ethical considerations were in place, including obtaining informed consent, ensuring that all participants fully understood the nature of the study, their role in it, and their right to withdraw without penalty. I ensured that the informed consent process was straightforward, comprehensive, and explained in the participants' preferred language, highlighting the voluntary nature of participation and the confidentiality of their information. The potential risks and benefits were also included in the informed

consent. I mentioned that participation in the study may involve risks such as emotional distress from discussing personal experiences, concerns about confidentiality, time commitment, and potential social stigma. I also included the benefits, such as personal reflection and therapeutic effects, which contribute to knowledge and community awareness about raising children with autism. Sharing their stories can empower participants, potentially enhancing support networks among them. Similarly, confidentiality was maintained, ensuring that all participant information was protected by anonymizing data and removing identifying details to safeguard participants' privacy. Moreover, I was empathetic when discussing topics that may be stigmatized or taboo within the cultural context. These considerations are discussed further in the Ethical Procedures section.

Cultural sensitivity was ensured by approaching the study with respect for local norms and values and being mindful of gender roles and societal expectations that may influence participants' experiences. Although I am from the same culture, I have lived away from it for over 26 years now. To mitigate any biases, I conducted thorough research on Kerala's cultural, social, and familial norms, values, and practices to gain a deeper understanding of the participants' lives. I also consulted with cultural experts, local scholars, and community leaders to gain a deeper understanding of cultural nuances and potential sensitivities. While recruiting participants, I approached potential participants respectfully, using culturally appropriate language and methods of communication. Furthermore, I conducted culturally sensitive interviews, employing respectful and mindful interview techniques that were sensitive to cultural norms,

including proper greetings, body language, and forms of address. Interviews were conducted in the participant's preferred language. I built rapport with participants to create a trusting environment and showed genuine empathy during interviews, listening attentively without judgment. I presented findings that respected the cultural context and acknowledged the participants' contributions.

Incentives were provided to participants to acknowledge the time and effort they invested in the study rather than as a means of coercion. The nature and value of these incentives, including Amazon gift cards worth 500 Indian rupees (INR), were communicated during the consent process to ensure transparency. The purpose of offering incentives was to recognize participants' contributions and maintain their autonomy, which in turn fostered voluntary participation in the study. By addressing these ethical considerations and implementing strategies to manage potential biases, this study aimed to provide a respectful, accurate, and insightful exploration of the experiences of parents raising children with autism in Kerala. This approach contributed to a deeper understanding of their unique challenges and support needs, ultimately informing the development of better-targeted interventions and policies.

Methodology

Participant Selection Logic

The population for this study comprised fathers and mothers of children diagnosed with ASD who reside in Kerala, India. This demographic was selected to examine the distinct experiences and challenges these parents face within a rich cultural environment influenced by traditional gender roles and societal expectations. The study

utilized *purposive sampling* to select individuals who met predetermined criteria relevant to the research question. This method was appropriate because it targeted parents of children with ASD, ensuring the collection of detailed, context-specific insights essential for understanding the nuances of parenting in Kerala. Participants were selected based on the following criteria: They had to be mothers and fathers of children diagnosed with ASD (excluding those with comorbid conditions) who are involved in raising their child with autism. The age of a child with ASD must be between 3 years and 16 years. They had to be residents of Kerala. They had to be willing to engage in in-depth interviews. They had to be proficient in Malayalam or English. Based on the above criteria, the eligibility of participants was verified during initial contact, where relevant questions were asked to confirm eligibility. Mothers and fathers provided this information, based on which eligibility was confirmed.

IPA studies prioritize quality over quantity, making smaller samples more effective (Pietkiewicz & Smith, 2014; Smith & Shinebourne, 2012). Smith and Shinebourne (2012) recommended recruiting three to six participants for meaningful insights. Twelve participants, evenly split between mothers and fathers (six couples raising a child with autism), were included. This number was determined by IPA requirements, which favor more focused sample sizes to facilitate thorough exploration of individual experiences. A total of six mothers and six fathers participated in a comprehensive thematic analysis, allowing the study to remain within a manageable scope and enabling me to understand their experiences in-depth. Theoretical saturation is reached when no new concepts, relationships, or dimensions emerge during analysis

(Patton, 2015). Although this study's theoretical saturation was expected with a small sample of six fathers and six mothers, I determined whether saturation was achieved by analyzing interviews as they were completed. As saturation had been reached with six mothers and six fathers, no additional participants were interviewed.

Instrumentation

The primary instrument in a qualitative study is the researcher, who develops the interview questions. I collected data from participants via one-on-one interviews.

Participants shared their perspectives on their parenting experiences, particularly in the diverse cultural context of Kerala, focusing on stress, coping skills, access to support, and treatment strategies. This was achieved through semistructured, open-ended interview questions that I developed for each construct, based on relevant literature. I created semistructured interview questions for use in one-on-one interviews. Some sample interview questions were as follows:

- “Please introduce your son/daughter; tell me about him/her.”
- “What do you and your son/daughter do together?”
- “Think back to your child's birth and describe your feelings about the upcoming birth.”
- “What are some things you hoped to do with your child after their birth?”
- “Moreover, tell me your experience as a parent of a child with autism.”

Procedures for Recruitment, Participation, and Data Collection

I recruited participants through local autism support organizations, special education centers, and healthcare providers in Kerala. Recruitment involved distributing

study information via email and announcements, with potential participants completing a screening questionnaire to determine eligibility. Formal invitations to participate were sent via phone or email. Comprehensive study information, including objectives, procedures, and ethical considerations, was provided, and informed consent was obtained through written or verbal methods, ensuring clarity and adherence to ethical standards (Pietkiewicz & Smith, 2014). I analyzed interviews as they came in to determine data saturation. Participants were informed about the study's purpose and scheduled individual interviews if they met the inclusion criteria. Consent forms were emailed and returned before the interviews.

Each participant was scheduled for a 60- to 90-minute semistructured interview, which was audiotaped and transcribed. Interviews explored personal experiences through a flexible interview plan guided by semistructured questions with prompts for elaboration (Pietkiewicz & Smith, 2014). Interviews allowed for comprehensive themes and patterns to emerge, with continuous monitoring to ensure data saturation and adequate sample size. The research was conducted respectfully, yielding meaningful insights into the lived experiences of parents managing ASD in Kerala (Creswell & Creswell, 2017). The interviews were private conversations held during one-on-one in-person meetings, video calls, or phone calls. During the interviews, I asked semistructured questions related to the research questions. Participants were informed that the interviews would be audiotaped and transcribed. In addition, I incorporated several strategies outlined by Pietkiewicz and Smith (2014). First, I started with a light warm-up conversation to ease the interviewee's tension before moving into more personal topics. Second, I prepared an

interview plan as a flexible guide that includes essential questions or topics for discussion. Additionally, I prepared prompts for situations where participants need more directions to elaborate on open-ended questions. Lastly, I was cognizant that my questions focused on sensory experiences, thoughts, memories, and personal interpretations. During the interview, I managed silences comfortably, allowing time for reflection and being attuned to all forms of communication, including verbal and nonverbal cues.

Interviews were recorded and transcribed, followed by participant debriefing and opportunities for follow-up interviews. After the interviews, I listened to and created notes from the individual recorded interviews. These notes included my impressions of participants' perspectives on the constructs related to the research questions, as expressed in the audiotaped semistructured interviews. The data collected from interviews and group observations fell under the qualitative audio and visual material (Creswell & Creswell, 2017). At the end of each interview session, participants were debriefed, given the opportunity to ask questions, and provided with contact information for further assistance. Follow-up interviews were scheduled if needed to clarify or expand on initial responses, ensuring comprehensive data collection and analysis. Data from the interviews were analyzed to understand the participants' perspectives, with notes created from the recorded interviews. Participants were debriefed, given the opportunity to ask questions, and provided with contact information for further assistance. Follow-up interviews were scheduled as needed to ensure comprehensive data collection and analysis (Creswell & Creswell, 2017).

Data Analysis Plan

In qualitative research, data analysis is conducted simultaneously with data collection (Ravitch & Carl, 2019). I transcribed the audiotapes of the interviews verbatim and compared the transcription to the audiotape for accuracy (Ravitch & Carl, 2019). To analyze the data, I employed a combination of IPA and thematic analysis, as outlined by Braun and Clarke (2006) and Pietkiewicz and Smith (2014). This approach involved identifying, analyzing, and reporting patterns (themes) within the data while interpreting how participants understood their experiences. The connection of the data to specific research questions was central to this process. The semistructured interviews addressed the following research questions: What are the primary sources of stress for mothers and fathers raising children with autism in Kerala? How do cultural and societal expectations influence the parenting roles of fathers and mothers? What coping strategies do fathers and mothers employ to manage the stress associated with raising a child with autism? How do fathers and mothers perceive the support and resources available to them?

After transcribing the data, I immersed myself in the data through detailed reading and re-listening to the recorded interviews. This immersion involved making extensive notes on content, language, and context, considering the influence of their characteristics, such as gender and social status, on the interaction. This comprehensive note-taking provided a rich foundation for initial analysis and helped capture the essence of the data. Key phrases and emotional cues were highlighted, building a rich foundation for initial analysis that captured the essence of the data (Pietkiewicz & Smith, 2014). Next, I generated initial codes by segmenting the data and identifying notable features relevant to

the research questions. These codes reflected both explicit statements and underlying meanings. Following this, I searched for themes by grouping these codes into broader themes representing higher-level psychological concepts and patterns within the data. This process exemplified the hermeneutic circle, where the interpretation of parts informed the understanding of the whole dataset. During this stage, I stayed connected to the specifics of participants' accounts, ensuring that the analysis captured the detailed and holistic aspects of their experiences.

In the reviewing themes phase, I ensured that the identified themes accurately represented the data and were relevant to the research questions. This involved refining themes to improve their clarity and coherence. Each theme was then clearly defined and named to capture the essence of the participants' experiences and perspectives. Subthemes were identified where necessary to provide a detailed and nuanced account. This phase involved examining these themes for connections and conceptual similarities, grouping them into coherent clusters that accurately represent the data.

I treated discrepant cases by carefully reviewing all data to identify cases that deviate from emerging patterns or themes. I then explicitly coded these discrepant cases using unique identifiers to distinguish them from other data points. Next, I examined each discrepant case in detail to understand its context and content. This examination involved comparing discrepant cases with existing themes to determine whether they revealed new insights, challenged current themes, or highlighted gaps in understanding. I examined the significance of each discrepant case to determine whether it offered new perspectives or insights. I documented and transparently reported all discrepant cases, including how

they were identified, coded, and analyzed. Ultimately, I refined the findings based on insights gained from analyzing discrepant cases, thereby ensuring a comprehensive understanding of the research topic. By following these steps, I ensured that my analysis was thorough, considered all data, and enhanced the credibility and depth of their study. This comprehensive approach improved the credibility and validity of the research findings and provided a rich, detailed account of the lived experiences of parents raising children with autism in Kerala.

In the final analysis phase, I organized emergent themes into clusters to form a structured thematic framework. Significant themes and subthemes were listed with linked transcript excerpts for easy verification. This process facilitated a detailed and efficient analysis, ensuring the study encompassed the complexity of participants' experiences. I carefully interpreted data with an awareness of cultural context, avoiding ethnocentric judgments or misinterpretations. By carefully managing discrepant cases, the study ensured a robust and nuanced analysis that accurately reflected the diversity and complexity of participants' experiences.

Issues of Trustworthiness

In qualitative research, there are four fundamental aspects of reliability or trustworthiness: credibility, transferability, dependability, and confirmability (Krefting, 1991; Lincoln & Guba, 1985). *Credibility* plays a crucial role in shaping the outcomes of research endeavours (Morrow, 2005). This study established credibility by employing suitable methodologies, including triangulation, researcher reflexivity, extended engagement with participants and data, and peer debriefing (Lincoln & Guba, 1985;

Morrow, 2005). Triangulation involves combining data from different sources to validate or supplement the collective information on the phenomenon under investigation (Krefting, 1991). I gathered data for this study through individual interviews with multiple participants, demographic information obtained from these participants, and handwritten notes recorded during the interviews. I then compared these varied data sources to encompass all aspects of the phenomenon expressed by the participants. I continued to engage in reflexivity as an ongoing process by remaining mindful of their personal assumptions, preconceptions, and biases throughout the study (Morrow, 2005). Furthermore, I utilized sustained engagement to enhance credibility. It included dedicating ample time to immerse in the culture, establishing trust with participants, thoroughly comprehending the scope of the targeted phenomena, and identifying any potential misinformation or misinterpretation caused by biases from either the researcher or the informant. I also dedicated significant time to conducting one-on-one interviews, as well as follow-up interactions, transcribing the interviews, and thoroughly examining the transcripts. Member checking is a method used to bolster the study's credibility, involving the presentation of research data to participants for validation and verification (Krefting, 1991). Member checking was not conducted after interviews. Instead, in individual interviews, I employed probes to seek clarification or further elaboration of information. I also conducted peer debriefings, during which I held analytical discussions with an impartial peer, such as a colleague who was not involved in the project.

In this study, I conducted research on the experiences of fathers and mothers raising children with autism in Kerala. The research was conducted in various towns.

These towns were selected based on their geographic diversity and representation of communities. The research context included detailed information about the socioeconomic status of the communities, the availability of healthcare resources, and the cultural norms and values prevalent in Kerala settings. Additionally, I provided insights into the characteristics of the participants, such as their age, education level, and relationship to the children with autism. This information helped contextualize the findings and understand how the unique features of the community impact caregiver experiences.

Transferability refers to the extent to which research findings are applicable to various contexts (Morrow, 2005). This research addressed transferability by describing the research environment, methodologies, participant demographics, my involvement, and reflexive journaling, which includes documentation of my thoughts throughout the research. This will help readers understand and evaluate the relevance of the findings, providing essential elements to replicate them in other settings.

Dependability was ensured by reflexive journaling, meticulously documenting all research activities, processes, data, and elements, and creating an audit trail (Shenton, 2004). This comprehensive documentation provided readers with an understanding of how the study maintained adherence to proper research protocols, encompassing aspects such as design, implementation, data collection, management procedures, and reflective practices. Firstly, a detailed research proposal was developed outlining the study's objectives, research questions, theoretical framework, and methodology, along with the rationale for choosing IPA and thematic analysis over other qualitative methods. Next, a

semistructured interview guide (see Appendices A and B) was developed and documented, and comprehensive field notes on interview context and reflections were provided. All interviews were securely recorded, and organized interviews were systematic. Then, a secure system for storing raw data was implemented, and a log was created to track all data collection activities, including dates, locations, and participant codes. The coding process was detailed, and reflective memos were maintained to capture insights and changes. An audit log of all analytical decisions was also maintained. Lastly, I engaged in regular peer debriefing with colleagues and supervisors to review and challenge the research process, incorporating their feedback into the study.

Confirmability ensures that research outcomes accurately reflect the authentic phenomenon, rather than the biases or presumptions of the researcher (Morrow, 2005). To ensure confirmability, the interpretative phenomenological process outlined by Smith and Shinebourne (2012) was utilized, accompanied by continuous documentation of self-reflective procedures, including reflexive journaling, to sustain awareness of biases. I engaged deeply with the data by conducting multiple readings of transcripts and annotating them with initial thoughts and potential themes to capture the interpretative process. I adopted a double hermeneutic approach by documenting both the participants' perspectives and my interpretations, acknowledging personal biases. The emergent themes were developed by identifying initial themes and refining them iteratively to ensure they accurately reflect participants' experiences. Triangulation was employed to verify consistency and accuracy by comparing data from multiple sources to validate the findings. Transparency was maintained by providing detailed descriptions of the research

process, using direct quotes to illustrate themes, and including reflective commentary on my influence and efforts to mitigate bias. These steps ensured a robust audit trail for dependability and confirmability, enhancing the study's credibility and trustworthiness.

Ethical Procedures

Given the sensitive nature of interviewing parents about their experiences raising children with autism, I took utmost care in ensuring that participants feel comfortable and supported throughout the research. First, I ensured compliance with the established guidelines by adhering to the Ethical Standards of the American Psychological Association (2010) to guide psychological research activities. This entailed obtaining appropriate approval from the Walden University IRB. Once the IRB granted approval, I created and distributed study flyers to ASD organizations, community centers and WhatsApp groups in Kerala, providing comprehensive information on the study's purpose, participation criteria, and participant confidentiality.

Next, all prospective participants were thoroughly briefed on the potential study risks, the voluntary nature of their participation, and their right to withdraw from the study. Then, I clearly explained the process, procedures, and risks involved in the research to the selected participants. Information was provided in written and verbal formats to accommodate different communication preferences. I secured informed consent from participants, including consent for audio and visual recordings, by clearly detailing the sensitive questions that may be asked so that they knew what they were agreeing to. The nature of the study, their voluntary participation, and their right to withdraw without retaliation were also clearly stated in the consent form. Furthermore, I

informed them that to safeguard participant privacy and confidentiality, all data, including demographic information, consent forms, audio recordings, and interview transcripts, were securely stored in a locked file cabinet at their residence. Electronic files were password-protected on a secure computer accessible only to me. All communication and interviews with participants were conducted exclusively by me. Each participant was given a choice of interview format and decided to be interviewed in person, by phone, or via video call. After that, I planned to conduct pre-interview preparation to inform the participants that they could skip questions they felt uncomfortable answering or pause the interview at any time. Interviews were conducted in predetermined private locations to ensure participant anonymity, with interviewee names replaced by numerical identifiers. I took a trauma-informed approach during the interview, empathetically listening to the participant, being mindful of any signs of distress, and reminding the participant that they were free to pause the interview or skip any question that stirred an uncomfortable feeling. In every interview step, I conducted check-ins with the participants to ensure they felt comfortable with the research process and offered relevant support as needed. At the end of the interview, I thanked the participants for their time and handed them the Amazon gift card.

Lastly, following the completion of the study, all research data will be retained for a period of 5 years in accordance with Walden University's research protocol. After this period, the physical documents will be shredded, and the digital files will be permanently deleted using data wiping software. Cloud-stored data will be deleted in accordance with the provider's protocols. An audit will confirm secure destruction and be documented for

compliance and participant confidentiality. It is essential to note that participants had no working or familial relationship with me, despite the study being conducted in my country of birth.

Summary

In this chapter, I provided a detailed description of the research design and methodology, the researcher's role, issues of trustworthiness, and the ethical procedures for the study. The purpose of the study was to use an IPA and thematic analysis to understand and describe the experiences of mothers and fathers raising a child with autism. This approach examined how participants perceived their parenting experiences, especially in the diverse cultural context of Kerala, focusing on their stress, gender roles, beliefs, resources available to support a child with ASD, coping skills, and relationships with their child. I am aware of possible personal assumptions and biases regarding the phenomenon under investigation in this study, due to both personal and professional interests. I engaged in the process of bracketing any possible biases across epochs. This chapter presented the study methodology, covering recruitment procedures, sampling strategy, criteria for participant selection, and sample size and saturation. Further, it covered data collection instruments and data management procedures. Interpretative phenomenological and thematic analysis processes were discussed as the data analysis plan that would be used for the study. IPA offers insight into individual experiences, while thematic analysis identifies broader patterns. These methods were selected to capture the complexity of participants' experiences in an authentic manner. Alternative qualitative designs were considered but deemed unsuitable. By employing IPA and

thematic analysis, this study aimed to contribute both theoretically and practically to understanding and supporting parents in Kerala facing the challenges of raising children with autism. I also addressed the issue of trustworthiness and the strategies employed to establish credibility, dependability, and confirmability for the study. Additionally, in this chapter, I outlined the ethical procedures for adhering to APA-established standards for conducting research, obtaining IRB approval, and addressing issues related to participants' confidentiality and proper data storage and management. In Chapter 4, I will delve into the setting of the study, participants' demographics, data collection procedures, analysis methods, and findings related to the experiences of parents raising children with ASD in Kerala.

Chapter 4: Findings

Introduction

In this chapter, I present the qualitative study on how mothers and fathers in Kerala experience parenting a child with ASD. The analysis comprises data collected through semistructured interviews of mothers and fathers who shared their emotional and social parenting experiences in Kerala's distinctive cultural and societal environment. The research question for this study was: "How do the lived experiences of fathers and mothers raising a child with ASD in Kerala differ in terms of stress, coping mechanisms, access to support, and treatment strategies?"

The analysis used a combination of IPA and reflexive thematic analysis to capture profound, detailed personal experiences and the complex emotional, cognitive, and social dynamics of parenting a child with ASD. I guided the analysis using Bronfenbrenner's bioecological systems theory and Crenshaw's intersectionality theory, emphasizing the influence of environmental systems and intersecting social identities on parental experiences. This further revealed how mothers and fathers perceived, experienced, and responded to the challenges and triumphs associated with raising a child with ASD.

This chapter describes the study's setting and demographics, providing context for interpreting the findings. Then, it outlines the data collection and analysis procedures, demonstrating the depth and validity of the interpretative process. The next section presents the superordinate (i.e., major) themes and theme clusters (i.e., subthemes) that emerged from the data, and direct quotes from the participants to keep the authenticity of their experiences. Each theme is explored in relation to the theoretical frameworks,

demonstrating how social and cultural influences intersect in the daily lives of these participants. Chapter 4 concludes with a summary and cross-theme synthesis. This highlights patterns of similarity and differences in fathers' and mothers' experiences, leading into the discussion, implications, and future directions in Chapter 5.

Setting

I conducted virtual, voice-only interviews from their homes in Kerala, India, and back in Canada. The interviews were conducted at low volume in a soundproof, private room to ensure the participants' confidentiality. I used password protection and waiting rooms to avoid unauthorized entry during the virtual interviews. Participants were also positioned in quiet, distraction-free rooms during interviews. For confidentiality purposes, spouses were not present during the interviews, and no information given by one spouse was disclosed to the other. To my knowledge, there were no unusual disruptions in data collection that would have affected participation.

Demographics

Participants were selected based on a list of criteria relevant to the research question. All participants were individual mothers and fathers of children diagnosed with ASD who were involved in raising their child with autism. The participants were residents in Kerala and proficient in Malayalam or English. Their child with ASD was between 3 and 16 years of age at the time of the interview. The eligibility of participants was verified during the initial contact. The target sample size for the study was 12 participants (i.e., six couples, comprising six mothers and six fathers), and this target was met.

Data Collection

Data collection was conducted over a period of 12–13 weeks. I received approval from Walden University’s IRB (IRB Approval No. 06-10-25-0501593) to conduct research on June 10, 2025. As stated earlier, I collected data from 12 participants between July 1 and September 27, 2025. The duration of the interviews varied from 30 minutes to 1 hour. Data collection was initiated by contacting multiple professional networks in Kerala by email and WhatsApp groups of parents of children with autism in Kerala. I contacted each group’s administrator, introduced myself, provided an overview of their research, shared the flyer, and requested permission to distribute it within the group. Once I received approval from the administrator, I distributed the recruitment flyer to the group. Some groups requested that the post, once posted, needed approval from the administrator as well. Additionally, individuals connected with local autism support organizations, special education centers, and healthcare providers throughout Kerala assisted in distributing the recruitment flyer. A combination of more than one recruitment approach was used since the population for this study was relatively niche.

All 12 participants provided their consent for a voice-only, virtual interview conducted via Zoom Communications. The consent forms are stored in a locked cabinet in my office at home. Once the participants acknowledged the consent form by providing written consent, they scheduled the interview and subsequently sent a Zoom link to their WhatsApp account. At the time of the interview, the participants clicked the link to join the Zoom, voice-only interview. Before the interview began, I informed the participants that their participation was voluntary and that they could withdraw from the study at any

time. After they were comfortable enough to begin, I informed them that they were about to start recording and then asked the interview questions. Once the interviews were completed, the recordings were stopped and stored on a password-protected hard drive, marking the end of the data collection process.

Data Analysis

I maintained a spreadsheet to track the participants' data collection and analysis. This spreadsheet included each mother's and father's interview status (i.e., in progress/complete), the transcription status (i.e., in progress/complete), and their analysis progress (e.g., tracking general thematic notes, mind maps, and comparison charts). This allowed them to stay well-organized throughout the data analysis process. I manually transcribed each of the virtual interviews and the Malayalam interviews into English. To maintain translation accuracy, I translated the interviews myself, as I identify as a bilingual translator with cultural competence, not just linguistic skills. I also used back-translation (i.e., translate to the target language, then independently back to the source language) to verify translation accuracy. I initially transcribed it in Malayalam and then translated it into English for the analysis.

To analyze the data, a combination of IPA and thematic analysis, as outlined by Braun and Clarke (2006) and Pietkiewicz and Smith (2014), was employed. As previously mentioned, IPA is particularly well-suited for exploring parents' lived experiences, as it focuses on how individuals make sense of significant life events and prioritizes depth over breadth through detailed, idiographic analysis. Following the IPA sequence, I first made notes documenting descriptive observations from each

participant's interview. I then identified emergent themes within each case, highlighting key patterns and meanings in the participants' accounts. Next, I explored connections within each case to examine how these themes related to one another and reflected each participant's overall experience. Then, I created idiographic write-ups that provided a detailed narrative of each parent's perspective, along with a cross-case analysis to identify patterns, similarities, and differences across the data, while remaining sensitive to their individual experiences.

Combining IPA with thematic analysis allowed me to explore both the individual narratives that IPA provides and to identify broader patterns across the parent sample that thematic analysis facilitates. This dual approach enhanced rigour by enabling me to honor each parent's unique experience while also synthesizing common themes that may inform support services and interventions. The flexibility of thematic analysis complemented IPA's interpretative framework, allowing themes to emerge both inductively from the data and deductively from existing theoretical understandings of parental adaptation and caregiving experiences. This analytic approach involved several stages: initial noting of participants' accounts, identifying emergent themes, exploring connections within each participant's case, developing idiographic write-ups, and a cross-case synthesis to identify patterns and differences across participants. This process allowed for an in-depth examination of how participants understood their individual experiences of parenting a child with autism in Kerala. Applying the data to specific interview questions was also crucial to this process, ensuring the analysis remained relevant.

After transcribing the interviews, I familiarized myself with the data by repeatedly reading the virtual interview transcripts. I made detailed notes on language, tone, and context while reflecting on their position (e.g., how their gender and social status may have influenced interactions). This immersion phase formed the foundation of the rich and detailed analysis (Pietkiewicz & Smith, 2014). Initial coding involved identifying the features and meanings of the data related to the research questions. These codes were subsequently organized into broader thematic categories. Through the hermeneutic circle, understanding individual parts informed the interpretation of the whole dataset. Superordinate themes and theme clusters were finally categorized into a meaningful structure supported by transcript extracts. This helped ensure that the findings reflected the lived experiences of parents raising children with autism in Kerala while being culturally sensitive.

Discrepant Cases

A few discrepant cases were analyzed separately to challenge underlying assumptions, reveal alternative perspectives, and increase the credibility of the findings. Generally, most participants reported similar experiences in accessing therapy, their coping mechanisms, and maintaining a positive mindset. Although discrepancies were not significant, differences were observed within each couple's perceptions, as circumstances varied from couple to couple.

Evidence of Trustworthiness

The reflective and systematic analytic process improved the trustworthiness of the study's conclusions. Trustworthiness in qualitative research ensures that the findings

accurately capture and represent participants' lived experiences rather than the researcher's assumptions (Lincoln & Guba, 1985). This study established trustworthiness through credibility, dependability, confirmability, and transferability (Krefting, 1991).

Credibility

Participant triangulation, reflexivity, and prolonged engagement with the data were employed to achieve an in-depth understanding of the data. I compared my findings with multiple sources of data, such as interview recordings and notes. Furthermore, I employed multiple perspectives, including comparisons between all mothers and all fathers, as well as within- and cross-case analyses of couples. This allowed me to gain a comprehensive understanding of participants' experiences. Reflexive journaling protected against personal bias, while sustained engagement allowed time to build trust and capture authentic perspectives. Member checking, which involves participants reviewing a summary of the theme and engaging in peer debriefing, was not conducted as per the IRB application.

Dependability

Dependability was achieved by accurately documenting and maintaining a clear audit trail of all research activities. Throughout the research process, I kept all documents on a password-protected external drive. Regular discussions with peers and supervisors helped to verify that all interpretations made were correct and had logical connections to the data.

Confirmability

Confirmability was achieved through self-reflexivity, triangulation, and transparent reporting of the analytical process. Following the IPA framework (Smith & Shinebourne, 2012), I documented reflective memos and compared data across sources to reduce bias and improve objectivity. I consistently submitted sections of data analysis to the dissertation committee members for review and feedback, demonstrating triangulation. Additionally, I took versioned codebook snapshots, memo timestamps, and decision records to create an audit trail.

Transferability

Transferability is defined by the degree to which findings can be generalized to other situations, populations, and environments (Lincoln & Guba, 1985; Morrow, 2005). Although this research was not concerned with issues related to generalizability, transferability was enhanced by providing rich descriptions of research participants, setting, and context. The participants in this study were individuals from several towns in the Kerala province, with varying levels of socioeconomic status and educational backgrounds. Detailed contextual information, including family dynamics, cultural values, and community infrastructure, was provided to help readers assess whether these findings could have implications in similar contexts. Reflexive notes and documentation of researcher engagement also contribute to understanding how interpretations were shaped within this specific cultural and geographic context. These approaches combined ensured that this research is reliable, consistent, and based on authentic experiences of parents raising children with autism in Kerala.

Through a detailed review and analysis of the participants' lived experiences parenting a child with autism, I identified 10 themes for the mothers and 11 themes for the fathers, which addressed the research question. The superordinate (i.e., major) themes found within the mothers include *Emotional Burden and Diagnosis Shock*, *Social Scrutiny and Stigma*, *Time Scarcity and Self-Neglect*, *Institutional and Therapist Limitations*, *Multimodal and Alternative Interventions*, and *Home-Based Therapy and Maternal Leadership*, as listed in Table 1. They comprised a total of 43 theme clusters (i.e., subthemes). The superordinate (i.e., major) themes revealed within all the fathers include *Emotional Restraint and Denial*, *Financial and Role Strain*, *Societal Expectations and Stigma*, *Family and Spousal Teamwork*, *Institutional Skepticism*, *Early Intervention and Structured Follow-Through*, *Division of Care*, *Hopeful Reframing and Normalization*, and *Responsibility and Protection*, as listed in Table 2. They comprised a total of 27 theme clusters (i.e., subthemes). I created these themes by making detailed, annotated notes based on the recorded interviews for each mother and father within every couple. This procedure allowed me to visually organize recurring ideas, emotions, and patterns of meaning. Finally, I have provided a Venn Diagram (see Figure 2) merely as a visual overview and comparison of mothers' and fathers' experiences.

Next, I constructed a cross-case Mother-Father matrix for the six couples (see Tables 3-8) to further compare their lived experiences, coping strategies, and perceptions of therapeutic approaches. Participant accounts are embedded throughout the subsequent sections to illustrate how the superordinate themes and theme clusters emerged from their lived experiences.

Table 1*Superordinate Themes and Theme Clusters (Mothers Only - RQ1.1-RQ1.10)*

Core thematic domain	Superordinate theme	Theme cluster (subthemes)	Participant identifier
Sources of Stress	Emotional Burden and Diagnosis Shock	Initial sadness, disbelief, guilt, responsibility, and fear of the future	PM1, PM2, PM3, PM4, PM5, PM6
	Social Scrutiny and Stigma	Public pity, judgment in public spaces, avoidance of social gatherings, and selective disclosure	PM1, PM2, PM3, PM4, PM5, PM6
	Time Scarcity and Self-Neglect	Limited personal time, balancing multiple children, disrupted routines, and career sacrifice.	PM1, PM3, PM4, PM5, PM6
Coping Mechanisms	Spiritual and Emotional Regulation	Prayer, temple visits, music/dance, meaning-making, meditation, belief in divine entrustment	PM1, PM3, PM5, PM6
	Acceptance and Adaptive Expectations	From grief to acceptance, focusing on “small wins,” letting go of comparisons	PM1, PM2, PM4, PM5, PM6
Access to Support	Family-Centered Emotional Support	Reliance on husband, parents, siblings, and limited daily practical support	PM1, PM2, PM3, PM4, PM6
	Institutional and Therapist Limitations	Lack of qualified therapists, discontinuity of care, learning to replicate therapy at home, and ineffective therapies	PM1, PM3, PM4, PM6
Treatment Strategies	Multi-Modal and Alternative Interventions	Speech, occupational, behavioral, homeopathy, Ayurveda, therapy modifications over time	PM1, PM2, PM4, PM5, PM6
	Home-Based Therapy and Maternal Leadership	Continuous implementation, environmental labelling, therapy as lifestyle	PM3, PM4, PM5, PM6
Meaning-Making and Growth	Transformation Through Motherhood	Advocacy for others, spiritual growth, patience, resilience	PM4, PM5, PM6

Table 2*Superordinate Themes and Theme Clusters (Fathers Only - RQ1.11-1.21)*

Core thematic domain	Superordinate theme	Theme cluster (subthemes)	Participant identifier
Sources of Stress	Emotional Restraint and Denial	Initial denial, internalized stress	PF3, PF5, PF6
	Financial and Role Strain	Work-family imbalance, limited time at home	PF3, PF4, PF6
	Societal Expectations and Stigma	Public scrutiny, comparison to neurotypical children	PF1, PF5
Coping Mechanisms	Pragmatic Adaptation	Dividing responsibilities with spouse, focusing on routines, and emotional regulation	PF1, PF2, PF3, PF5, PF6
	Spiritual and Philosophical Reframing	Prayer, gratitude, philosophical outlook, meaning-making	PF3, PF5, PF6
Access to Support	Family and Spousal Teamwork	Partner as main caregiver, mutual adjustment, sibling guidance	PF1, PF2, PF3, PF4, PF6
	Institutional Skepticism	Limited trust in therapy centers	PF1, PF3, PF6
Treatment Strategies	Early Intervention and Structured Follow-Through	Prompt therapy enrollment, consistency, and faith in recovery	PF1, PF4, PF5
	Division of Care	Mothers lead implementation; fathers manage logistics and reinforcement	PF1, PF2, PF4, PF6
Meaning-Making and Growth	Hopeful Reframing and Normalization	Present-focused acceptance, normalization of the child's progress	PF3, PF5, PF6
	Responsibility and Protection	Provider and protector role	PF3, PF4, PF6
Discrepant Cases	Denial of Stress or Hardship	Father normalizes experience, rejects problem framing (e.g., PF2)	PF2

Results

Superordinate Theme 1 (Mothers Only) - RQ1.1: Emotional Burden and Diagnosis Shock

RQ1.1 emerged concerning questions about the initial reactions to diagnosis and emotional processing. This theme encompasses clusters of initial sadness, disbelief, guilt, responsibility, and worry about the future, which are common stressors for mothers. All six mothers (PM1-PM6) reported experiencing an overwhelming emotional toll following the diagnosis of their child's autism. Several described experiencing a "gut punch" moment, where hopes of motherhood were met by an unfamiliar and often stigmatized reality. For some mothers, the diagnosis sparked self-blame, where they questioned what they had done wrong during pregnancy or during their child's early years of development. Others described being in disbelief, struggling to make sense of the diagnosis and the impact it would have on their lives.

The early postdiagnosis stage was marked by intense anxiety, doubt, and uncertainty, with mothers expressing concerns for their child's long-term future, inclusion within society, and independence. PM4 commented,

The diagnosis completely shattered me. I worried constantly: Would he be like other children? What would his future hold? How would he communicate? Would he be able to study or attend school? These questions consumed me. I was anxious all the time and found myself crying frequently.

Similarly, PM1 described her emotions at the moment of diagnosis, explaining that she was constantly crying when told by a doctor that she must get her child diagnosed. For

many, the emotional burden was also compounded by the lack of clear guidance or quality professionals to help them navigate their new reality after the diagnosis. PM1 revealed that she had no prior knowledge or exposure to autism and that the symptoms were initially difficult to interpret because of her daughter's otherwise "normal" physical appearance.

RQ1.1 Representative Quotes

"The diagnosis completely shattered me. I worried constantly: Would he be like other children? What would his future hold?" (PM4)

"I was constantly crying when told by a doctor that I must get my child diagnosed." (PM1)

"I questioned what I might have done wrong during pregnancy or early development." (PM2)

"The symptoms were difficult to interpret because of her otherwise normal appearance." (PM1)

"I worried whether he would be able to study or attend school." (PM4)

Brief Synthesis: This theme reflects mothers' shared experiences of emotional distress, disbelief, and anxiety that followed their child's diagnosis.

Superordinate Theme 2 (Mothers Only) - RQ1.2: Social Scrutiny and Stigma

RQ1.2 was shaped by conversations around social interactions and community perceptions, especially within the South Asian community. Every participant (PM1-PM6) mentioned experiencing some level of social judgment, pity, or public scrutiny, often in ordinary settings such as temples, schools, or family gatherings. Some mothers described

their desire to avoid public life altogether, expecting disapproving glances, questions, or sympathy from those passing by. For instance, PM6 explained, “The biggest challenge is coping with people’s sympathy. I do not need their sympathy. I demonstrate that I am not interested in receiving their sympathy, or if possible, I’ll remove myself and my son from those situations.” Likewise, PM3 mentioned experiencing sympathy from her friends, whom she no longer spends time with as often. PM2 expressed similar experiences of sadness, noting that when her child exhibits behaviours like screaming at public functions, it either appears as though others are making fun of them or sympathizing with them.

A recurring coping mechanism was impression management - mothers spoke about preparing their child to appear more “typical,” or controlling the environment to reduce the possibility of being judged. The pressure to appear “normal” or to shield their child from stigma was emotionally taxing, but many felt compelled to perform this role. PM1 shared,

When people see this [her child’s uncontrollable laughing], of course, it stands out and questions are raised, and we feel difficult as we have to explain things to people and the stories that go with it. So, what we try to do is to escape from that kind of situation. I do not give others the opportunity to talk about her or let others ask about her; I move away before that.

Some mothers (PM4, PM5) even carefully chose what and when to disclose about their child’s diagnosis. For instance, PM4 used an alternate explanation to avoid openly labelling her child with autism. She explained,

I did not tell many people about his condition. Even at school, I only mentioned that he had some speech difficulties. It was only after he made significant progress that I openly discussed his autism. I did not want people to know my son had challenges.

This approach served as a shield for their emotions, allowing mothers to avoid difficult conversations or feelings of pity. Although necessary, the mothers framed this balancing act as burdensome, highlighting their complex navigation in managing social stigma.

RQ1.2 Representative Quotes

“The biggest challenge is coping with people’s sympathy. I demonstrate that I am not interested in receiving it, or if possible, I will simply remove myself and my son from those situations.” (PM6)

“When people see this [her child’s uncontrollable laughing], of course, it stands out and questions are raised. We try to escape from that kind of situation.” (PM1)

“I did not tell many people about his condition. Even at school, I only mentioned that he had some speech difficulties. I did not want people to know my son had challenges.” (PM4)

“When her child screams in public, others either make fun of her or pity them, which is emotionally difficult.” (PM2)

“I feel sad when people sympathize instead of understanding.” (PM3)

Brief Synthesis: This theme highlights how mothers navigate constant social scrutiny and stigma, striking a balance between visibility and emotional self-protection.

Superordinate Theme 3 (Mothers Only) - RQ1.3: Time Scarcity and Self-Neglect

This theme represents mothers' ongoing struggle to balance their child's intensive care with other responsibilities. Mothers (PM1, PM3-PM6) described most days filled with therapy sessions, very structured routines, and constant monitoring, leaving little to no time for themselves. Many gave up careers, postponed personal goals, or struggled to care for other children. For instance, PM3 shared,

I used to have a plan to work, but because there's no one to take care of the child, I had to let go of that. You can think about the situation that arises, that whatever hopes you have in your child are destroyed.

Furthermore, PM5 explained that logistical difficulties, such as being unable to drive her child, made it challenging to consistently take her child to therapy centers, so she adapted by implementing whatever she could at home. Recognizing the importance of consistency during her child's early development, she took a leave from work for 3-4 years to be more present to help her child.

The theme also relates to routine disruption. Mothers noted the unpredictability of their days and the never-ending exhaustion. Self-care, hobbies, and social connection were often put on hold indefinitely. PM6 encapsulated this experience:

Our lives were suddenly disrupted when he came into our family because no one made a plan, "How will I parent a special needs child?" The kids simply arrive, and life changes, right? ... I would say that being a special needs parent is never easy. It's very exhausting and all-consuming. These are scheduled to the point where I can't change one thing. As you know, my friends used to sometimes say,

“You can never just do things like impromptu anymore,” and I’m like, no, I can’t just walk out and go to a movie. Sometimes that’s frustrating, sometimes it’s okay. The care is always hands-on, beginning with administering medications or supplements, helping him get dressed, and feeding him. Like all those independent activities designed to make him independent, it took a great deal of time.

Other mothers (PM1, PM3) shared that they have to alter their schedules and lack quality time for themselves. PM3 explained how her daily routine revolves entirely around her child’s needs and moods, with her family supporting this prioritization. She explained that even if it means others miss meals or plans get delayed, her child’s emotional state comes first. PM3 remains constantly vigilant to subtle changes in his expressions or moods and adjusts the day’s schedule accordingly, often putting all other activities on hold to accommodate his needs.

RQ1.3 Representative Quotes

“I used to have a plan to work, but because there’s no one to take care of the child, I had to let go of that.” (PM3)

“Being a special needs parent is exhausting and all-consuming. You can’t just walk out and go for a movie.” (PM6)

“My daily routine revolves entirely around my child’s needs and moods.” (PM3)

“Sometimes that’s frustrating, sometimes it’s okay. The care is always hands-on, beginning with medicines or supplements, getting him dressed, and feeding him.” (PM6)

“I had to take leave from work for several years to help my child.” (PM5)

Brief Synthesis: This theme captures how mothers experience extreme time pressure and self-neglect while dedicating themselves fully to their child's care.

Superordinate Theme 4 (Mothers Only) - RQ1.4: Spiritual and Emotional Regulation

This superordinate theme explores how mothers found emotional equilibrium through spirituality, faith, music, and self-reflection. Mothers (PM1, PM3, PM5, PM6) turned to prayer, temple visits, or other traditional rituals as their coping mechanisms. For example, PM1 shared that she used to visit temples regularly and pray in the morning and evening, which helped relieve much stress. Others described music and dance as healing outlets. When asked about how she prioritizes her time and energy, PM6 revealed,

For me, definitely spirituality was a very big aspect of coping and adapting. ... I would say that, actually, it began as a coping strategy, but it has now evolved into something that has truly transformed and given my life so much meaning. So it is not just with [child's name], ... the resilience that he built. ... Whatever situation life throws at you, I'm able to respond to that situation in a much calmer way, in a much more—like it really takes a lot to make me feel very upset and very irritated now because of the fact that you've been through that kind of coping strategy. ... I've realized that it's [also] important for me to prioritize myself. ... I do that at least once or twice a week, where I do something that I want to do, which is irrelevant to anyone else. It has nothing to do with therapy, or my other child or anything, it is just what I want to do.

Beyond religious or cultural practices, this theme also encompasses meaning-making, which involves reframing their child's diagnosis as a spiritual test or divine purpose. Several mothers described a transformation from feeling grief to strength, and this was supported by a belief that they were "chosen" for this role. PM4 expressed this sense of divine purpose, stating, "We must understand that God entrusted us with this child. We should live for our children. We can accomplish so much for them." Similarly, PM5 explained,

Initially, when I learned about the diagnosis, it was a shock. I thought, "How can my child be like this?" But I overcame that reaction. I developed the conviction that if God gave me a child like this, it's because I have the capacity to handle it. That belief propelled me forward. I knew that with proper training, an autistic child can also perform well. He will be able to accomplish many things.

Clearly, PM5's shock with her child's diagnosis was eventually replaced by confidence in her own strength and purpose in life. This experience was true for many of the mothers as they were able to reframe their challenges through spirituality and meaning-making. This provided them with resilience and hope amid caregiving demands and future uncertainties.

RQ1.4 Representative Quotes

"For me, definitely spirituality was a very big aspect of coping and adapting. It began as a coping strategy but evolved into something that has transformed my life."

(PM6)

“If God gave me a child like this, it’s because I have the capacity to handle it. That belief propelled me forward.” (PM5)

“I used to visit temples regularly and pray both morning and evening, which helped relieve much of my stress.” (PM1)

“We must understand that God entrusted us with this child. We should live for our children.” (PM4)

“Whatever situation life throws at me, I can respond calmly because of these coping strategies.” (PM6)

Brief Synthesis: This theme illustrates mothers’ use of spirituality, faith, and meaning-making to regulate emotions and find resilience through caregiving.

Superordinate Theme 5 (Mothers Only) - RQ1.5: Acceptance and Adaptive Expectations

A very prominent journey for many mothers (PM1, PM2, PM4-PM6) began from grief to acceptance. This theme represents their shift in mindset from focusing on what their child cannot do to embracing what they can do, while appreciating small wins. PM6 specifically shared that the small accomplishments take on significant meaning and become reasons for celebration, highlighting the importance of recognizing and valuing every minor achievement in her daughter’s progress. PM6 further explained,

I would say the hardest part for me was the acceptance part of it. So, once you accept that you have a diagnosis, it’s not going away. But the diagnosis doesn’t mean that my life or my child’s life cannot be happy and cannot be meaningful. ... So it may not be the life I had thought about before he was born, but in many

ways, it is a much richer life. ... Then knowing that my child has strengths was a big game changer for me. That everything is not about what he cannot do, but so much of it is what he can do, and the type of person he is.

Letting go of neurotypical milestones was described as both painful and liberating. PM1 emphasized the importance of shifting your mindset and recognizing that acceptance involves understanding that the diagnosis is a permanent and unchanging aspect of your life. She explained that acceptance is very crucial and that every family's experience is unique and shaped by different levels of autism severity. This makes comparisons with others unhelpful and unnecessary for one's path to acceptance.

RQ1.5 Representative Quotes

“The hardest part for me was the acceptance part of it. Once you accept, life can still be happy and meaningful.” (PM6)

“Knowing my child has strengths was a big game-changer for me. Everything is not about what he cannot do.” (PM6)

“Acceptance means realizing that the diagnosis is permanent but that every family's journey is unique.” (PM1)

“We learned to focus on small wins rather than comparisons.” (PM4)

“I began to appreciate every minor achievement in my child's progress.” (PM6)

Brief Synthesis: This theme reflects mothers' transition from grief to acceptance, redefining success through adaptive expectations and small, yet significant milestones.

Superordinate Theme 6 (Mothers Only) - RQ1.6: Family-Centred Emotional Support

This theme highlights the significance of emotional support provided by close, immediate family members. Most mothers (PM1-PM4, PM6) reported that their husbands, parents, and siblings were their primary sources of emotional and logistical support, although the day-to-day caregiving was primarily undertaken by the mothers themselves. PM5 revealed that her husband and parents, explaining that this foundation of support was essential for her to continue caring for her child with confidence and effectiveness. PM1 described limited support at home, managing most caregiving tasks independently, especially when her husband was away for work. She noted that while her brother and sister offered some assistance during family gatherings and were emotionally available when needed, she felt primarily responsible for her child.

In most cases, fathers offered practical help or financial support, while the extended family provided relief occasionally. However, mothers also noted the limits of assistance from family members, often feeling reluctant to leave the child with others. PM4 shared that she was the sole person who was able to handle her son's care, stating, "I was the only one who could really manage him. My husband struggled to accept that our son had autism. Even when I tried to discuss it with him, he was reluctant to acknowledge it." Although her husband contributed financially and had recently helped with hospital appointments because of her injury, PM4 still emphasized that her child remains highly dependent on her, and her husband maintained a level of emotional distance from the caregiving process. She also revealed the emotional toll this dynamic

took on her, often crying in front of her therapist, who provided her with comfort during those times. PM6 further acknowledged that, while her husband is very involved, it is still the mother who takes primary responsibility for supporting the child's development in both academic and life skills.

RQ1.6 Representative Quotes

“My husband and parents were my main sources of support. That foundation helped me continue confidently in caring for my child.” (PM5)

“While my husband is very involved, it is still the mother who takes primary responsibility for supporting the child's development.” (PM6)

“I was the only one who could really manage him. My husband struggled to accept our son's autism.” (PM4)

“I received emotional help from my brother and sister during family gatherings, but the main responsibility remained with me.” (PM1)

“My family is supportive but limited in daily practical help; most of the work is mine.” (PM3)

Brief Synthesis: This theme highlights the importance of emotional and logistical support from close family members, while underscoring the continued central caregiving role of mothers.

Superordinate Theme 7 (Mothers Only) - RQ1.7: Institutional and Therapist

Limitations

Mothers (PM1, PM3, PM4, PM6) frequently described systemic barriers within formal therapy and educational institutions. Their accounts reflected a shared frustration

with the lack of adequately trained therapists, staff turnover, and the discontinuity of care. These limitations often reduced the effectiveness of interventions and placed an additional burden on parents, particularly mothers, to compensate for such shortcomings.

PM3 described visiting multiple therapy centers but consistently encountering inexperienced therapists who struggled to manage her son's hyperactivity:

I have gone for therapy to two to three different places. He's a boy and what I have noticed is that there are new/young therapists in all these places. Be it occupational therapy or all therapy, they are unable to manage someone as hyperactive as him. Only if there are experienced therapists who totally understand what he's going through will it make a difference. ... So since I am only able to do therapy with him and able to control him. Since it is not necessary that he is cooperating in therapy, I just decided to take it in my hands and do it myself. ... Because I implemented the therapies at home, whatever success we have met with, we have it.

She emphasized that only highly trained professionals could truly understand and work effectively with children like hers. In the absence of such expertise, she felt compelled to take over the therapeutic process herself. This reflects a broader trend in which parents assumed quasi-professional roles due to inadequate services.

PM6 similarly commented on the lack of institutional support and how their weekends were fully occupied with appointments, leaving little room for family leisure or recovery: "Our social outings have practically zero because weekends are spent on therapy for him. We'll also homeschool him to some extent because the system doesn't

really support him or challenge him in any way.” This self-reliance became a necessary adaptation to institutional shortcomings, with the family replicating educational and therapeutic practices at home.

Across these narratives, mothers expressed a strong sense of having to make up for institutional gaps themselves. While some did so successfully, the overarching sentiment highlighted systemic inadequacies that have disproportionately shifted the burden of care and intervention onto families, particularly mothers, who were left to compensate for under-resourced and indiscriminate systems.

RQ1.7 Representative Quotes

“I have gone for therapy to two to three different places. New therapists couldn’t manage someone as hyperactive as my son.” (PM3)

“Since it is not necessary that he cooperate in therapy, I decided to take it into my hands and do it myself.” (PM3)

“Our weekends are spent on therapy for him. The system doesn’t really support or challenge him in any way.” (PM6)

“There’s a lack of qualified therapists and too much staff turnover.” (PM4)

“Because of the lack of consistent care, I learned to replicate therapy methods at home.” (PM1)

Brief Synthesis: This theme portrays mothers’ frustration with underqualified professionals and fragmented institutional support, leading many to assume therapeutic responsibilities themselves.

Superordinate Theme 8 (Mothers Only) - RQ1.8: Multi-Modal and Alternative**Interventions**

This theme encompasses the use of diverse therapeutic strategies, including both mainstream and alternative approaches, such as speech therapy, applied behavior analysis (ABA), occupational therapy, Ayurveda, naturopathy, and homeopathy. Most mothers (PM1, PM2, PM4-PM6) described trying various interventions, either one at a time or simultaneously, motivated to leave no stone unturned to support their child's development. PM1 reflected this sentiment:

To overcome this autism and for it to be gone, I have accessed homeopathy, different medicines. When people say different things, we get a little tempted because, at first, I just wanted my child to start talking. ... For about 4 years, we continued the therapies, and a recent assessment showed that all the therapies that were given were of no use to my child.

Mothers even adjusted their routines, diets, and home environments to align with their child's progress or setbacks. One mother (PM6) described navigating both traditional and alternative therapeutic strategies to respond to her son's complex needs. She engaged her son in conventional therapies, including occupational therapy, physical therapy, ABA therapy, and speech-language therapy. While occupational and physical therapy were beneficial, she saw limited value in continuing speech therapy and thus chose to prioritize alternative communication methods over verbal speech goals.

In addition to these, PM6 invested in a wide range of alternative treatments, including acupuncture, Ayurveda, homeopathy, and naturopathy. She tailored her son's

diet to reduce certain behaviours and incorporated more holistic treatments to improve his overall health. PM6 explained, “I would say that both sides work. It’s a mixed bag, sometimes things work, sometimes things don’t work, but you sort of keep trying.” The implementation of these interventions occurred alongside intensive hands-on caregiving. PM6 described the intense level of involvement needed to support her son’s daily routines and encourage independence:

The care is always hands-on, beginning with administering medicines or supplements, getting him dressed, and feeding him. Like all those independent activities designed to make him independent, it took a great deal of time. ... Now, toileting is semi-independent, like putting on his clothes, which is semi-independent. All the care was like parenting a baby, like everything you must do for the child.

Collectively, these accounts illustrate how mothers navigated a demanding and varied terrain of treatments, balancing formal treatments and therapies, care provided at home, and alternative treatments to meet their children’s complex and evolving needs.

RQ1.8 Representative Quotes

“In order to overcome this autism and for it to be gone, I have accessed homeopathy and different medicines. In the beginning, I wanted my child to just somehow talk.” (PM1)

“We continued therapy for four years, but the assessment showed they were of no use to my child.” (PM1)

“Both sides work-it’s a mixed bag, sometimes things work, sometimes they don’t, but you keep trying.” (PM6)

“I tailored his diet and used holistic treatments like Ayurveda and naturopathy.” (PM6)

“It required significant effort, but we saw improvements through consistency and persistence.” (PM4)

Brief Synthesis: This theme highlights mothers’ proactive exploration of diverse therapeutic and alternative interventions to address their child’s evolving needs.

Superordinate Theme 9 (Mothers Only) - RQ1.9: Home-Based Therapy and Maternal Leadership

For many mothers (PM3, PM4-PM6), therapeutic work extended far beyond formal sessions. They explained transforming the home into an active therapeutic environment by labelling items, consistently asking their child questions, developing routines, and integrating therapy into their daily lives. In this way, their home became an extension of the clinic, and the mother took on the role of lead therapist. PM4 explained this dynamic clearly: “I would sit with the therapists, carefully observe their techniques, return home, and implement what they taught us.” While PM4 reported a relatively positive experience with formal therapy, she emphasized the limited time her child spent in clinical sessions - often only 30 to 45 minutes. She highlighted how the majority of therapeutic work rested on parents’ shoulders outside these sessions. For example, during commutes, she engaged her child by naming roads, vehicles, rivers, and bridges to reinforce learning, noting that she could see improvements within days.

In a similar vein, PM5 faced logistical challenges with distant therapy centers, which compelled her to take initiative and adapt therapies at home. Despite the challenges associated with strictly adhering to all recommendations, she managed what she could, supported by several years of leave from work to provide consistent care. Additionally, PM6 shared that the school system's inability to adequately support or challenge her son compelled her to homeschool him, thus significantly increasing the demands on her time and energy. This intense and constant involvement was a defining feature of the mothers' caregiving experience, with many mothers reporting a shift from traditional parenting roles to those of interventionists and therapists. Although this role brought them a sense of empowerment, it also resulted in substantial fatigue and pressure for many mothers.

Some common strategies involved proactive engagement in therapy, advocating for their child, and ensuring carry-over of therapeutic techniques at home. Mothers became "home therapists," applying the strategies they learned in clinics to their everyday lives. PM4 explained,

We were advised to pursue two types of therapy: applied behavioural intervention [*sic*]¹ and speech therapy. Once we started, he began to improve. It required significant effort. We had to withhold items until he verbalized his requests, which gradually built his communication skills.

¹ applied behavior analysis

Furthermore, this theme reflects mothers' strong sense of ownership and vigilance. Many self-initiated, independently researched, questioned, and tailored interventions to better fit their child's specific needs. Advocacy was often emotionally charged, where most mothers pushed for inclusive education, challenged therapists' approaches, and educated extended family members. For example, PM6 extensively used online resources such as Google to inform decisions and strategies, demonstrating their active role in navigating their child's diagnosis and complex care.

RQ1.9 Representative Quotes

"I would sit with the therapists, carefully observe their techniques, return home, and implement what they taught us." (PM4)

"I had to take leave from work for several years to consistently help my child at home." (PM5)

"We were advised to pursue two types of therapy-ABA and speech therapy-and we saw improvements once we started." (PM4)

"The school system didn't support him, so I started homeschooling my son."
(PM6)

"Our care became constant; we applied therapy techniques during every routine at home." (PM3)

Brief Synthesis: This theme illustrates how mothers extended therapy into their homes, taking on leadership roles as primary implementers and advocates for their children's development.

Superordinate Theme 10 (Mothers Only) - RQ1.10: Transformation Through Motherhood

For half of the mothers (PM4-PM6), caregiving led to personal transformation, with mothers becoming stronger, more patient, and purposeful. Some described taking on advocacy roles, educating others, or guiding newer parents. Others described having the ability to recognize developmental challenges in other children they encounter and offer guidance to families facing similar situations. For example, PM4 explained, “I’ve developed the ability to recognize developmental issues in other children. ... I’m able to advise parents to seek medical consultation when I notice concerning characteristics or behaviours.” For PM6, this experience brought about rewarding changes that extended beyond the realm of caregiving. She expressed,

The ability to experience joy in the moment is something that any child with a disability gets you. ... It has made a change of career. I was working in an IT company, now I’m working very much with disabled people, whether that’s academic or advocacy.

This transformation illustrates how caregiving reshaped these mothers’ identities, deepening their empathy, resilience, and commitment to advocacy. For many, raising a child with autism served as a catalyst for personal growth and community involvement, motivating them to assist and empower other families on similar journeys. Ultimately, their experiences reveal how motherhood can cultivate strength, meaning, and connection in the face of adversity.

RQ1.10 Representative Quotes

“I’ve developed the ability to recognize developmental issues in other children and advise parents to seek consultation.” (PM4)

“This journey changed my career-I now work closely with disabled people.”
(PM6)

“Caring for my child has made me more patient and empathetic.” (PM5)

“It gave me a purpose to guide other parents who face similar situations.” (PM4)

“It’s made me appreciate joy in the moment and grow spiritually.” (PM6)

Brief Synthesis: This theme captures mothers’ personal transformation through caregiving, marked by increased empathy, patience, and advocacy for others.

Superordinate Theme 11 (Fathers Only) - RQ1.11: Emotional Restraint and Denial

This theme emerged from fathers’ initial responses to their child’s diagnosis and the internal emotional processes that followed. Instinctive denial or delayed emotional processing was described by participants (PF3, PF5, PF6), frequently coupled with a desire to “keep it together” for the family. For example, PF3 discussed his ability to handle and process grief and pain, indicating a strong belief in emotional resilience. He further explained his tendency to manage shocks by detaching from his emotions, illustrating a coping mechanism based on reason and control: “The way I am, the way I deal with any shocks that come my way, I immediately get involved with that shock, and I take my feelings out of it.” Such responses reflect a broader pattern among fathers of suppressing emotional processing.

Fathers often tend to internalize their stress and emotions, showing a reluctance to express them honestly, particularly in front of their spouse or children. PF5 spoke on the emotional turbulence that followed his child's diagnosis and how he controls his feelings for his family's sake:

We tend to compare children of the same age; however, philosophical[ly], we think. Then our moods also change, and there will be outbursts too. After all, we are all human beings. It is better not to show it to your child or partner. They will be going through the same mood, or even worse. I managed to come out of that disappointment.

This theme emphasizes fathers' deliberate self-control, as well as the emotional toll it takes on them. Even if there were disappointment and dissatisfaction, these were frequently repressed or focused inward to spare other family members from additional suffering.

RQ1.11 Representative Quotes

“The way I deal with any shocks that come my way-I immediately get involved with that shock and take my feelings out of it.” (PF3)

“It is better not to show disappointment to your child or partner. They are going through the same or worse.” (PF5)

“We tend to compare children, but we should not show it; I managed to come out of that disappointment.” (PF5)

“I try to keep emotions in check and focus on stability for the family.” (PF6)

“Emotional restraint is how I protect my family from further distress.” (PF3)

Brief Synthesis: This theme shows how fathers internalize emotional strain and use self-control to maintain family stability during the adjustment period.

Superordinate Theme 12 (Fathers Only) - RQ1.12: Financial and Role Strain

A major source of stress described by fathers was the dual responsibility of maintaining financial stability while also being emotionally and physically present for their family. Fathers (PF2, PF3, PF4, PF6) frequently expressed feeling overburdened by their emerging caregiving duties as well as their conventional role as providers. PF3 reflected on how the collapse of his business exacerbated the pressure at home, particularly as his wife was deeply emotionally affected by their child's needs. He felt compelled to maintain a constant presence, not only to support his child but to emotionally support the family. His experiences illustrated how financial instability interacts with emotional obligations, giving the father's job more significance and urgency.

PF6 described the challenge of working from home while also juggling caregiving duties:

On the days when I'm working from home, then work is broken up into two compartments. One is when he's at school, and the second is when he's asleep. Sometimes it's not just possible to work when he's around because he's always wanting something. ... You know, it's like you can't concentrate on your work. So, then I do the jobs around the house, which require less concentration at that time.

This highlights the ongoing struggle to balance parenting responsibilities and professional commitments, particularly in situations where traditional work-life boundaries are blurred. As an example of the type of role strain and adjustment that many fathers reported, PF6 adjusts by switching to less cognitively demanding tasks during high-interaction periods.

Beyond their time and energy, the cost of therapy and care became a significant source of stress. The burden of continuing medical expenses and the corresponding shame or sacrifice were both expressed by PF3 and PF4. PF3 voiced his concerns about their financial limitations and their effects:

We have one thought that maybe there are treatments that are beyond what we are doing for our child, and because of a lack of funds and our situations, we cannot access such support. There is a guilt[y] feeling about this.

Similarly, PF4 described the redistribution of household priorities to ensure therapy costs were met, despite modest earnings:

It was my wife who took care of my son. I had to go to work. She was the one who took him to the center on the scooter. We had to restrict our other household expenses. A significant portion of our income was needed to cover the center's expenses, not because the center was expensive, but because our earnings were relatively low.

Through resource reallocation, routine modifications, and a heavy reliance on maternal care to compensate for fathers' physical absence due to work, this phrase highlights the everyday logistics and silent sacrifices families make. Across these

narratives, fathers discussed feeling overburdened by their roles and attempting to help out where they felt most responsible, such as financially and logistically, but frequently felt powerless when it came to providing emotional or therapeutic care.

RQ1.12 Representative Quotes

“Work is broken into two parts-when he’s at school and when he’s asleep.” (PF6)

“We had to restrict our other household expenses. A significant portion of our income was needed for therapy.” (PF4)

“There’s a guilty feeling about not being able to access more support because of financial limits.” (PF3)

“Sometimes it’s not possible to concentrate on work when he’s around because he’s always wanting something.” (PF6)

“The cost of therapy became a constant pressure, forcing lifestyle adjustments.” (PF3)

Brief Synthesis: This theme reflects fathers’ balancing of provider duties with emotional and caregiving responsibilities amid financial and time constraints.

Superordinate Theme 13 (Fathers Only) - RQ1.13: Societal Expectations and Stigma

Fathers (PF1, PF3, PF5) discussed the pressures of society and the constant scrutiny from the public on their child’s behaviour, growth, and appearance. According to several fathers, their child was often evaluated based on neurotypical norms, especially because the child seemed “normal” on the surface, which made the condition more difficult for others to comprehend or accept. PF1 discussed the prevalent misconceptions

surrounding autism in public places. He pointed out that a lot of people mistake autism for more obvious medical disorders like cerebral palsy. Others frequently overlook the fact that his child has autism since she does not display any overt physical symptoms of the disorder, which is indicative of a lack of understanding. According to PF1, people frequently have preconceived notions about neurodevelopmental disorders and expect children with such diagnoses to look or behave a certain way. He conveyed frustration over this misunderstanding, as well as the resulting confusion and judgment - a sentiment echoed by other fathers.

PF3 revealed that although he is not directly impacted by public opinion, he remains highly conscious of how his child may impact other people in social situations. He clarified, saying, "I'm always thinking that others should not have a problem because of my child. Otherwise, it does not impact me personally because we don't plan on doing anything without him." Despite his concerns, he emphasized that his family is not ashamed or hesitant to include their child in all aspects of their life:

We are not ashamed or shy to present him to someone [in public]. We take him everywhere. Even if a guest comes to our house, only those who like him should come to our house. Those who accept him should only come to our house as guests.

His comments reflect a sense of pride in his child, while also recognizing the importance of being cautious when interacting with others. This balance between openness and protecting the family from potential judgment highlights the complex social dynamics fathers face when raising a neurodivergent child. It emphasizes their

continuous attempts to promote acceptance in their local communities as well as in the wider community.

PF5 expressed a more guarded approach to social life, expressing a heightened sense of protectiveness in public spaces. He shared:

Socially, as a parent of an autistic child, we must guard them. When we see a child of the same age, we, as human beings, become sad. In social life, it also has its impact. When others see the state of my child going to a restaurant or a wedding, we must be cautious, and we are also the best people to protect him. We are the best people to understand his needs.

PF5 highlighted the emotional impact of comparisons with other children and the need to navigate social environments carefully, as misunderstandings or judgmental comments might occur. Across these accounts, fathers described a shared experience of being cautious about how others perceive their child, through misinterpretation, criticism, or unwarranted comparisons and how they adapt in social and public situations accordingly.

RQ1.13 Representative Quotes

“People often mistake autism for cerebral palsy because there are no obvious physical signs. That misunderstanding frustrates me.” (PF1)

“I’m always thinking that others should not have a problem because of my child. Otherwise, it does not impact me personally.” (PF3)

“We are not ashamed or shy to present him to anyone. We take him everywhere.” (PF3)

“When others see the state of my child in public, we must be cautious. We are the best people to protect him.” (PF5)

“Socially, as a parent of an autistic child, we have to be guarded.” (PF5)

Brief Synthesis: This theme reflects fathers’ awareness of public perception, revealing efforts to balance pride and protection while navigating social misunderstanding.

Superordinate Theme 14 (Fathers Only) - RQ1.14: Pragmatic Adaptation

A prominent coping strategy among fathers (PF1, PF2, PF3, PF5, PF6) was to approach the parenting journey with practicality and routine-based adaptation. Fathers described taking on roles such as managing schedules, coordinating logistics, and dividing responsibilities with their spouses. For instance, PF1 described how he and his wife divided daily childcare duties based on their work schedules - he takes responsibility for morning routines, including preparing the children for school and dropping them off, while his wife handles picking them up later in the day. This shared, pragmatic approach enabled them to manage their household efficiently while supporting each other in their respective roles.

This theme also reflects an emphasis on emotional regulation, remaining composed, not panicking, and focusing on what can be controlled. Instead of ruminating on uncertainties, these fathers channelled their energy into structure and stability. PF1 constantly emphasized adapting a forward-looking mindset, characterized by asking, “What’s next?” He focused on accepting the current situation while still setting

manageable, short-term goals for his child's progress, illustrating a practical and resilient approach to coping with reality.

PF5 similarly spoke about the importance of intentional structure and planning as a means of coping and caregiving. He explained:

We must design and strike a balance purposefully. Whether you have an autistic or non-autistic child, we have to plan education, intelligence, mental health, physical activities-everything has to be planned. And our personal routine should be completed in the morning before he is ready for his activities. In the early morning, our yoga and personal schedules will be completed, and we will be available for him. His needs must be designed and planned according to his interests.

His description reinforces the theme of pragmatic adaptation, showing how structure and planning are used not only to support the child's development but also to maintain the well-being of the parents. By prioritizing early completion of their own routines, PF5 and his spouse create space to be fully present for their child's needs - further illustrating the deliberate, organized, and forward-thinking mindset many fathers adopted in response to their parenting challenges.

RQ1.14 Representative Quotes

“We divide daily duties based on schedules-my wife handles afternoons, and I manage mornings and drop-offs.” (PF1)

“We have to plan purposefully-education, mental health, physical activity-all must be structured.” (PF5)

“I try to remain composed and focus on what can be controlled rather than the uncertainties.” (PF1)

“Early morning, our yoga and personal schedule are completed so we can be available for him.” (PF5)

“Routines help us manage stress and stay balanced as a family.” (PF6)

Brief Synthesis: This theme emphasizes fathers' focus on structure, routine, and logical adaptation as coping mechanisms for maintaining stability in family life.

Superordinate Theme 15 (Fathers Only) - RQ1.15: Spiritual and Philosophical Reframing

For several fathers (PF3, PF5, PF6), spirituality and philosophical reflection played a central role in how they came to terms with their child's diagnosis. Rather than focusing solely on medical or behavioural explanations, these fathers engaged in meaning-making processes that helped them emotionally and mentally reframe their experiences. This reframing often involved prayer, spiritual beliefs, or a broader life philosophy that fostered acceptance and peace of mind.

PF3 described prayer as a personal tool for inner peace and emotional regulation, rather than a means to seek specific outcomes. He shared:

I give importance to prayers. That means I am not really thinking of the outcome of the prayer, what is the result I am getting? I don't know about it. But for my own self, for my own peace of mind, my own satisfaction, I will pray so I don't need to get someone else's help. Someone bigger than human beings is what I fall

back on. For example, to open a nut, we use a tool, and if that tool doesn't work, we use a bigger tool. Similarly, I've taken prayers as a tool.

Similarly, PF5 explained how he and his wife initially struggled with societal perceptions and internal fears. However, over time, they began to adopt a more philosophical view of their situation:

Initially, we were worried about what people would say. All these were our initial fears. But my wife and I began to think that God had given us such a child because we could take care of him. We began examining it more philosophically. Tell people openly that the child needs more attention. Then others will also behave accordingly.

Rather than searching for concrete answers or solutions, these fathers leaned into a mindset of acceptance, often rooted in a belief that their experience had a higher purpose or meaning. This shift in perspective from confusion and despair to acceptance and inner peace appeared to serve as a turning point in their emotional journey, allowing them to find strength in faith, personal reflection, and the belief that they were chosen or prepared for this role.

RQ1.15 Representative Quotes

“I give importance to prayers-not for the results, but for my own peace of mind.”
(PF3)

“We started thinking that God has given us such a child because we were capable of taking care of him.” (PF5)

“Prayer is my tool to find strength when nothing else works.” (PF3)

“We tell people openly that our child needs more attention so they can understand and behave accordingly.” (PF5)

“Faith helps me stay grounded, not desperate for outcomes.” (PF6)

Brief Synthesis: This theme highlights fathers’ use of spirituality and philosophy to reframe their experiences with acceptance, purpose, and inner peace.

Superordinate Theme 16 (Fathers Only) - RQ1.16: Family and Spousal Teamwork

Five fathers (PF1-PF4, PF6) emphasized the critical role of teamwork within the family unit, particularly with their partners, in managing the demands of raising a child with autism. Fathers described a system of mutual adjustment and emotional reciprocity, where one parent would step in when the other was emotionally or physically depleted. This dynamic of shared responsibility became foundational in sustaining both daily routines and long-term resilience. PF6 captured this sense of mutual emotional support when he explained: “Parents have the support for each other in this case. One of us, if we lose patience, the other one is more patient, vice versa.” This complementary relationship enabled families to remain steady in moments of stress, fatigue, or uncertainty. In many cases, caregiving roles were distributed pragmatically: mothers often took a lead in direct intervention and daily care, while fathers managed household logistics, work responsibilities, and provided emotional grounding for the family.

Beyond the marital relationship, some families also drew strength from the involvement of siblings. PF6 spoke about the emotional bond between his children, noting the supportive role of the older sibling:

No, I think it is the support we get from our older daughter. She's also very, very fond of him, and they have a very good relationship. Okay, there isn't much communication in that sense, right? Still, they have a very strong bond with each other. ... I think that all of us have a close-knit family, which in turn becomes our strongest support system.

This sense of shared caregiving extended across the family, with siblings offering both companionship and practical support, reinforcing the family's internal cohesion. Similarly, PF1 expressed that their younger child can buy him time and reduce his stress levels. He also hopes that his child's sibling will grow into a future source of support for his older sister with autism. He shared that, while the expectation may be optimistic, it provides him with reassurance about the future: "We can at least have a hope that he's there ... to have a look at her in our absence." PF1 acknowledged the emotional and logistical challenges families often face in deciding whether to have a second child, especially when their first child has high support needs. However, for his family, having another child was both a practical decision and a source of emotional balance, offering the hope of continuity and care beyond the parents' involvement.

Across accounts, this team-based model of caregiving reflected a distributed and cooperative approach. Spouses supporting each other, siblings stepping in where possible, and the entire family unit working together to navigate daily life. These narratives reveal not only the practical strategies families adopt but also the deep interdependence and shared resilience that sustains them.

RQ1.16 Representative Quotes

“Parents have the support of each other in this case. When one of us loses patience, the other becomes more patient.” (PF6)

“My wife and I divide responsibilities so we can manage home and therapy better.” (PF1)

“We get a lot of help from our daughter, who has a very strong bond with her brother.” (PF6)

“Our younger child helps reduce our stress; it gives us hope for continuity in the future.” (PF1)

“We rely on teamwork to maintain emotional balance at home.” (PF3)

Brief Synthesis: This theme emphasizes the importance of family unity and spousal cooperation in maintaining emotional balance, thereby enabling families to share caregiving responsibilities and enhance their overall resilience.

Superordinate Theme 17 (Fathers Only) - RQ1.17: Institutional Skepticism

Half of the fathers (PF1, PF3, PF6) expressed varying degrees of skepticism toward formal institutions, including therapy centers, professional caregivers, and therapeutic practices. Their concerns centred around the quality, effectiveness, and trustworthiness of services, as well as the high financial and emotional costs involved in accessing them. Many fathers noted that while therapy centers are widely available, finding one that meets their child’s specific needs can be challenging. For instance, PF1 stated, “It’s quite easy to find a therapist center, but it’s quite difficult to find a therapist center which is good.” He also described his unease with overly repetitive or rigid

behavioural approaches, suggesting that children may be trained to perform certain responses (e.g., greeting someone), without truly understanding the social meaning behind the act. He likened this approach to a form of subtle coercion, expressing concern that surface-level compliance may be mistaken for genuine development.

PF3 shared that his family had engaged with therapy services consistently over 4 to 5 years but ultimately stopped because they no longer believed the interventions were having a meaningful impact. According to him, aside from what he described as the child's "natural growth," the therapies did not appear to produce visible improvement. Similarly, PF6 raised questions about the effectiveness of therapy, noting that progress could not easily be attributed to any one factor. He described the challenge of disentangling the impact of formal intervention from the intensive efforts made at home by him and his wife, or from the child's own developmental trajectory:

And, you know, how effective they [therapies] are is a question mark. Because we are doing many things at home with him as well. And therefore, is this development or whatever is taking place due to the therapy or is it due to our or my son's working with my wife? We are unable to conclude.

This uncertainty was compounded by the financial burden of continued therapy and limited access to professionals who were both competent and compatible with the child. He emphasized that finding a therapist the child was willing to engage with was particularly difficult, and that therapeutic success often depended as much on interpersonal connection as professional skill.

Another primary concern among participants was the difficulty in finding trustworthy caregivers. PF6 noted that children with limited verbal communication were unable to report mistreatment or neglect, making them especially vulnerable. He expressed concern that even serious incidents, such as physical abuse, could go undetected. PF6 also highlighted that his son's behavioural rigidity and resistance to unfamiliar routines could be particularly challenging for caregivers, reducing the pool of suitable options.

Taken together, these accounts reveal a shared sense of unease and caution among several fathers regarding institutional involvement in their children's care. Their experiences reflect a preference for close parental oversight and a reliance on family-led strategies, often rooted in concerns about trust, therapeutic fit, and unclear outcomes.

RQ1.17 Representative Quotes

“It's quite easy to find a therapy center, but it's difficult to find one that is truly good.” (PF1)

“After 4 or 5 years, we stopped therapy because we didn't see meaningful improvement.” (PF3)

“We are unsure if progress is from therapy or from what we do at home with him.” (PF6)

“Finding a trustworthy caregiver is hard since our child can't explain if something goes wrong.” (PF6)

“We prefer close parental oversight because we can't always trust outside help.” (PF1)

Brief Synthesis: This theme captures fathers' doubt about the quality and effectiveness of institutional therapy, leading to greater reliance on family-led intervention and caution in external trust.

Superordinate Theme 18 (Fathers Only) - RQ1.18: Early Intervention and Structured Follow-Through

While some fathers expressed skepticism toward formal institutions (as discussed in the previous theme), others reported notably positive experiences, particularly when therapeutic interventions were initiated early and implemented consistently. This theme reflects the perspectives of three fathers (PF1, PF4, PF5) who emphasized the importance of timely action, routine, and structured engagement as critical factors in their child's developmental progress.

PF4 described a strong commitment to therapeutic guidance, noting that his family meticulously followed every recommendation made by the therapy center. According to PF4, he attributed his child's improvement to this disciplined follow-through and underscored the urgency of seeking help without delay:

However, we must pay attention to such children and take the necessary action immediately. We should never think that it will be okay when they grow up.

There are government centers offering therapy and treatment for this. There is a 90% recovery. I am talking from experience.

He also reflected on the early emotional strain they experienced and spoke highly of the supportive environment provided by the center. According to PF4, the family

attended every session diligently, and therapy only concluded when professionals deemed the child had made sufficient progress:

For 2 years, we experienced great mental stress. After the sessions, we felt much more relieved. Everyone at the center was very friendly to us. They treated my son like their own. My wife was also treated like their own sister. My son was also treated well there. We did not miss any class. We attended every session very diligently. They allowed us to stop only after the Centre was convinced of our 100% recovery.

Similarly, PF5 emphasized the importance of routine and planning to meet the child's developmental needs and the family's overall well-being. He described how early therapeutic action, primarily through multiple speech therapy sessions, was valuable due to the professionals' competence. He emphasized the need for families to be clear about their expectations and to choose services that align with those needs:

For his mental health, we were able to take remedial measures from a very early stage - therapy. There were speech therapists, too. There were many sittings. We should make our requirements very clear. We must consider whether the therapist or the institution can give us what we need.

He also described the need to balance their personal routines purposefully to be available for the child, reflecting an intentional effort to structure their daily lives around caregiving responsibilities. PF1, though less detailed, similarly expressed the importance of planning and a proactive mindset. His approach aligned with the broader values

expressed by other fathers in this theme, namely, the significance of maintaining focus on the present, setting short-term goals, and structuring daily routines to support progress.

Across these narratives, the fathers conveyed a shared belief in the value of early and consistent intervention. Their accounts pointed to the perceived effectiveness of therapy when paired with routine, planning, and dedication. For many, this structured approach was not only a practical strategy but also a reflection of their enduring faith in their child's capacity for growth and recovery.

RQ1.18 Representative Quotes

“We followed every instruction from the center carefully, and our child improved through consistent therapy.” (PF4)

“We must pay attention to such children early and take necessary action immediately.” (PF4)

“We made sure our expectations were clear with therapists to get what we needed.” (PF5)

“For his mental health, we took remedial measures very early, especially speech therapy.” (PF5)

“Routine and structure keep the entire family stable while supporting progress.” (PF1)

Brief Synthesis: This theme highlights the perceived benefits of early and consistent intervention, where structured follow-through and discipline foster developmental progress.

Superordinate Theme 19 (Fathers Only) - RQ1.19: Division of Care

Most fathers (PF1, PF2, PF4, PF6) described a caregiving arrangement characterized by a clear, though often unspoken, division of responsibilities between themselves and their spouses. In most cases, mothers assumed the lead in therapy implementation and daily intervention efforts, while fathers contributed through practical and logistical support. This included transporting the child to appointments, coordinating schedules, managing household routines, and reinforcing therapeutic practices at home.

PF4 explained that his wife primarily cared for their son during the day, including taking him to therapy sessions, while he focused on work responsibilities. He emphasized that his wife followed all the therapy center's recommendations and attended every appointment without fail. Similarly, PF6 shared that while he was involved in transporting their child and occasionally communicating with the therapist, his wife was primarily responsible for researching therapy options and maintaining direct engagement with the professionals:

So, any therapy center is difficult to find ... my wife usually researches these things. Moreover, my role is to take him up and bring him back, and, you know, speak with the therapist occasionally. However, it is done chiefly between my wife and the therapist.

PF2 acknowledged a similar dynamic in his household. While his wife took their child to therapy and managed the day-to-day interventions, he ensured that he remained informed by checking in regularly: he described asking her whether she had taken their child to sessions and frequently calling to stay updated on progress. He stated that he

fulfilled his responsibilities and viewed this communication as part of staying involved in caregiving.

Across these accounts, the care division was often shaped by practical factors such as work schedules and individual strengths. Fathers generally positioned themselves as facilitators or anchors in the family system, contributing stability and structure, while their spouses managed the more intensive therapeutic and emotional labour. This division was often described as complementary, mutually supportive, rather than unequal.

RQ1.19 Representative Quotes

“My wife usually researches therapy centers; my role is to take him there and bring him back.” (PF6)

“She follows the therapist’s instructions carefully while I focus on work and logistics.” (PF4)

“I ask my wife about sessions regularly and stay updated to remain involved.” (PF2)

“We split duties naturally-she leads therapy, and I handle practical responsibilities.” (PF1)

“This division allows each of us to contribute where we are strongest.” (PF4)

Brief Synthesis: This theme demonstrates how fathers and mothers divide caregiving roles pragmatically, balancing emotional and logistical responsibilities within the household.

Superordinate Theme 20 (Fathers Only) - RQ1.20: Hopeful Reframing and**Normalization**

Half of the participants (PF3, PF5, PF6) described a gradual shift in perspective where their expectations and perceptions of their child's development evolved. Instead of viewing progress through the lens of neurotypical milestones, these fathers began to reframe their child's growth as "normal for them." This normalization process allowed for reduced stress, more acceptance, and a greater appreciation of their child's individual pace and personality.

PF3 emphasized that their parenting approach was rooted in understanding and adjusting to each child's unique potential, rather than imposing rigid developmental expectations:

Our hope was not to make him the most intelligent person. By seeing both of our children, we believe that every kid has the potential to grow in their own way. We are not people who are adamant that our kid has to grow in a certain way.

PF5 reflected on the early years of stress that stemmed from holding high expectations. Over time, however, he described coming to terms with a more realistic and compassionate mindset: "This was in the initial years. After three or four years, I became accustomed. Then I thought, how much can I expect from my child? Everything depends on our mental strength and our child's happiness." Another father (PF6) expressed a similar view, encouraging the idea that autistic children should not be forced to conform to standard developmental norms. PF6 spoke about embracing difference as something meaningful:

I think what we have to realize when we deal with autistic children is that they have a lot to give. Hmm. Moreover, they are, in their own way, individuals ... You cannot make a fish climb the tree, right? So let us not try to fit all our children into one mould. There is no one mould for all the children. Each child is different. Moreover, let us try to enjoy the difference.

In this context, hopefulness was quiet but persistent - a belief that progress would come, even if gradually and in non-linear ways. PF3 explained how he and his wife maintained ongoing optimism through small milestones, without being overwhelmed by long-term uncertainty:

Every month, we started hoping that the next month would be better. So even now, although 10 years have passed, it is almost like 2 years have passed for us. Hopelessness never impacted both my wife and me.

Across these accounts, fathers described a reframing of expectations - not as a lowering of standards, but as a redirection of focus toward what truly mattered: their child's happiness, uniqueness, and minor signs of progress. This normalization and steady optimism offered emotional resilience and a more sustainable way of navigating their parenting journey.

RQ1.20 Representative Quotes

“Every kid has the potential to grow in their own way. We’re not adamant about one path.” (PF3)

“After a few years, I became accustomed and focused on my child’s happiness rather than expectations.” (PF5)

“Each child is different-you cannot make a fish climb a tree.” (PF6)

“We maintain hope every month that the next month will be better.” (PF3)

“Hopelessness never impacted us because we learned to value steady progress.”

(PF3)

Brief Synthesis: This theme captures fathers’ transition toward acceptance and optimism, reframing expectations to align with their child’s individuality and pace.

Superordinate Theme 21 (Fathers Only) - RQ1.21: Responsibility and Protection

This theme captures how fathers (PF3, PF4, PF6) internalized their role as protectors and providers, emphasizing a deep sense of duty to ensure the family’s emotional, physical, and financial stability. Their narratives reflected a commitment to shielding both their autistic child and the broader family unit from external and internal challenges.

PF3 articulated this belief clearly, framing the caregiving role as a moral and emotional responsibility. He described children with developmental difficulties needing protection and care, not blame. He emphasized that when such a child is born into a family, the responsibility to protect and nurture them is self-evident and must be accepted without question: “They reach in a person’s hand and they should be protected and taken care of, and that is our way of thinking and aim.” Similarly, PF6 described the emotional process he experienced following his child’s diagnosis. He acknowledged initial sadness, eventually giving way to a powerful protective instinct. He identified this as a natural extension of his parenting role: “A feeling of protection, protective instincts took over. Because you are the parent, your role is to protect the child from harm”. In articulating

these roles, the fathers reinforced conventional ideals of fatherhood, positioning themselves as the steady backbone of the family - responsible for safeguarding its emotional, financial, and physical well-being.

PF4, while not expressing these feelings explicitly, conveyed this same sense of responsibility through his practical decisions. He explained that without hesitation, all financial resources were directed toward his child's well-being. Although they did not receive outside financial support, he felt confident they had enough to care for their child. He emphasized that their existing resources were fully dedicated to that purpose. He also added that despite their difficulties, they never felt overwhelmed or incapable of handling the situation. The importance of the child's health, he said, far outweighed any desire to save money, and their family viewed every challenge as manageable within their means.

Across these accounts, fathers positioned themselves as central figures in maintaining the family's resilience. Their protective mindset extended beyond physical safety, encompassing financial planning, emotional reassurance, and a steadfast readiness to shoulder the weight of their family's needs.

RQ1.21 Representative Quotes

“They reach into a person's hand, and they should be protected and taken care of.” (PF3)

“A feeling of protection took over because you are the parent-your role is to protect the child from harm.” (PF6)

“All financial resources were directed toward my child's well-being without hesitation.” (PF4)

“We never felt overwhelmed; we saw every challenge as manageable within our means.” (PF4)

“Our main goal is to keep the family safe and emotionally strong.” (PF6)

Brief Synthesis: This theme illustrates fathers’ deep sense of moral and emotional duty to safeguard their family’s well-being, reflecting their role as protectors and providers.

Discrepant Cases (Fathers Only)

While most fathers in the study acknowledged emotional or logistical challenges associated with parenting an autistic child, PF2 offered a contrasting narrative.

Throughout the interview, he consistently downplayed or rejected any notion of hardship, stress, or altered expectations. Instead, he emphasized that he and his wife treat their son “like a normal child”. He repeatedly denied that the autism diagnosis had any significant impact on their outlook or parenting approach. When asked how the diagnosis affected his hopes or feelings as a father, PF2 stated, “Nothing affected us. It does not matter that he has autism. ... No hopes changed.” This normalization extended to his interpretation of daily life as well. Despite spending limited time with his child due to work, he described no strain on the relationship and framed their outings (e.g., temples, parks, restaurants) as sufficient bonding time. He expressed, “No, I do not have any stress. ... I do not have any feelings that, ‘Oh, my child is autistic.’ No, no, no.”

PF2’s responses also stood out in his repeated rejection of difference or difficulty. He concluded the interview by asserting, “No special moments, nothing, because I make him go as a normal child. His activities, his everything. I track him as a normal child.”

While other fathers reflected on emotional processing, shifting expectations, or ongoing adaptation, PF2 maintained a steady narrative that framed his experience as typical, unaffected, and free from challenge. This makes his account a discrepant case within the overall dataset, highlighting the diversity of paternal responses and offering a counterpoint to dominant narratives of struggle, adaptation, or growth through adversity.

Cross-Case Parental Experiences: A Comparative Overview

This section compares each couple's lived experiences, perceptions, coping strategies, and parenting dynamics in response to their child's diagnosis and intervention journey. Each family's experience reflects distinct personal, emotional, and contextual factors. While these accounts are not intended for generalization, they offer more profound insight into the individuality and diversity of parental adaptation, highlighting the nuanced similarities and discrepancies within each couple's experience.

The father normalized the diagnosis early in the first pair (PM1 and PF1). He concentrated on realistic future actions, while the mother reported early distress, sadness, and slow acceptance of the diagnosis (see Table 3). While the father offered secondary support that was constrained by job obligations, the mother was the primary caregiver and actively involved in managing therapy. Socially, the father was indifferent to social criticism, but the mother expressed uneasiness and sensitivity to the opinions of others. Additionally, they reacted differently to the situation: he used music, normalization, and logic, while she turned to faith and therapy for emotional support. In stark contrast to the mother's expressed emotional burden, the father denied experiencing any considerable stress, but both acknowledged family and treatment as important sources of support.

Table 3*Cross-Case Mother-Father Matrix (PM1/PF1)*

Thematic domain	Mother (PM1)	Father (PF1)
Perception of Diagnosis	Shock and sadness; gradual acceptance	Normalized diagnosis; focused on next steps
Parenting Roles	Primary caregiver; deeply involved	Supportive but secondary due to work
Sociocultural Stress	Feels judged; avoids public settings	Unbothered by others' opinions
Coping Strategies	Faith, therapy, emotional adaptation	Rational focus, music, normalization
Support Systems	Family, therapists	Wife's family, therapy network
Notable Discrepancies	Reports stress and sadness	Denies stress; pragmatic outlook

Parents in the second couple (PM2 and PF2) responded differently to their child's regression and diagnosis (see Table 4). The mother described shock followed by gradual acceptance and engagement in therapy, whereas the father treated the diagnosis as inconsequential and continued to view their child as typical. The mother managed daily routines and therapy coordination, while the father provided support when present but was often away due to work. While the father showed no concern for the opinions of others, the mother was conscious of social judgment but eventually learnt to ignore it. These differences were reflected in their coping mechanisms: he depended on normality and regular presence, while she emphasized acceptance and proactive engagement more. At the same time, he relied on normalization and routine presence. The mother's narrative showed emotional adjustment, whereas the father's conveyed detachment and denial of difficulty.

Table 4*Cross-Case Mother-Father Matrix (PM2/PF2)*

Thematic domain	Mother (PM2)	Father (PF2)
Perception of Diagnosis	Shock after regression; gradual acceptance; purpose and pride in child's progress	Denies major impact; treats diagnosis as normal; maintains unchanged hopes and expectations
Parenting Roles	Primary caregiver; organizes therapies and engagement; deeply bonded and child-dependent	Limited direct involvement due to travel; views role as supportive and practical
Sociocultural Stress	Feels social judgment but dismisses others' ignorance; remains self-assured	Unaffected by social reactions; insists child is "normal"
Coping Strategies	Acceptance, therapy focus, continuous engagement	Normalization and attention; believes in giving time and presence
Support Systems	Parents and family; husband supportive but dependent on her presence	Wife and family support; relies on wife's caregiving
Notable Discrepancies	Expresses emotional struggle and adaptation	Denies any stress or difference from typical parenting (discrepant)

For the third couple (PM3 and PF3), the mother's experience centered on intense emotional distress at the time of diagnosis, including fear and uncertainty, which gradually gave way to acceptance through faith, therapy, and self-reflection (refer to Table 5). The father accepted the condition early, maintaining composure and a sense of long-term responsibility. Parenting roles were complementary: the mother took on full-time caregiving and therapy coordination, while the father offered emotional and financial support. The mother described social withdrawal and avoidance of judgment, while the father expressed confidence and disregard for social stigma. Their coping

reflected these emotional differences, with the mother relying on creative expression, music, and family, and the father turning to prayer, faith, and rational reflection. The mother's account revealed emotional exhaustion, whereas the father appeared steady and emotionally restrained.

Table 5

Cross-Case Mother-Father Matrix (PM3/PF3)

Thematic domain	Mother (PM3)	Father (PF3)
Perception of Diagnosis	Distress and fear; gradual adaptation	Initial shock; calm acceptance
Parenting Roles	Primary caregiver; emotionally central	Supportive; acknowledges wife's lead
Sociocultural Stress	Avoids social settings; fears judgment	Unconcerned with stigma
Coping Strategies	Faith, music, and therapy	Religious coping; emotional restraint
Support Systems	Family and therapists	Sister, family, limited professional trust
Notable Discrepancies	High emotional distress	Composed and accepting (discrepant)

In the fourth couple (PM4 and PF4), both parents shared a strong commitment to their child's development but differed in their emotional responses (refer to Table 6). The mother described early distress and anxiety following diagnosis but later developed hope through consistent therapy and improvement. The father remained composed and hopeful, characterizing the diagnosis as temporary and controllable. While the father offered logistical and emotional support, the mother took on the primary caregiving duties, conducting therapy at home and closely monitoring the child's progress. The mother initially concealed the diagnosis due to fear of social judgment, whereas the father encouraged openness and viewed sharing to inspire others. Both relied on faith and

perseverance to cope, though the father's tone was more confident and practical than the mother's initial emotional turbulence.

Table 6

Cross-Case Mother-Father Matrix (PM4/PF4)

Thematic domain	Mother (PM3)	Father (PF3)
Perception of Diagnosis	Distress and fear; gradual adaptation	Initial shock; calm acceptance
Parenting Roles	Primary caregiver; emotionally central	Supportive; acknowledges wife's lead
Sociocultural Stress	Avoids social settings; fears judgment	Unconcerned with stigma
Coping Strategies	Faith, music, and therapy	Religious coping; emotional restraint
Support Systems	Family and therapists	Sister, family, limited professional trust

The fifth couple (PM5 and PF5) shared a strong foundation of faith and resilience, yet expressed these values in different ways (refer to Table 7). Despite her initial shock, the mother embraced the diagnosis as a part of a divine plan, placing a strong emphasis on structure, faith, and regular therapy attendance. After initially struggling with acceptance, the father eventually came to adopt a philosophy that emphasized patience, mindfulness, and family harmony. The father provided support through cooperation and emotional stability, whereas the mother identified herself as the primary caregiver, responsible for scheduling therapy sessions and maintaining routines. Social experiences also differed: the father welcomed openness and normality, whereas the mother shied away from public attention and felt uneasy. This difference was evident in how they coped: the father concentrated on reflection and philosophy, while the mother turned to spirituality and self-control.

Table 7*Cross-Case Mother-Father Matrix (PM5/PF5)*

Thematic domain	Mother (PM5)	Father (PF5)
Perception of Diagnosis	Shock; faith-based acceptance	Reluctant initially; later philosophical
Parenting Roles	Primary caregiver; structured routines	Involved; promotes teamwork
Sociocultural Stress	Avoids scrutiny; asserts strength	Openly discusses child; normalizes needs
Coping Strategies	Faith; self-discipline; patience	Philosophy; yoga; emotional control
Support Systems	Family; school; therapy	Family, especially wife
Notable Discrepancies	Emotionally sensitive	Detached and rational (discrepant)

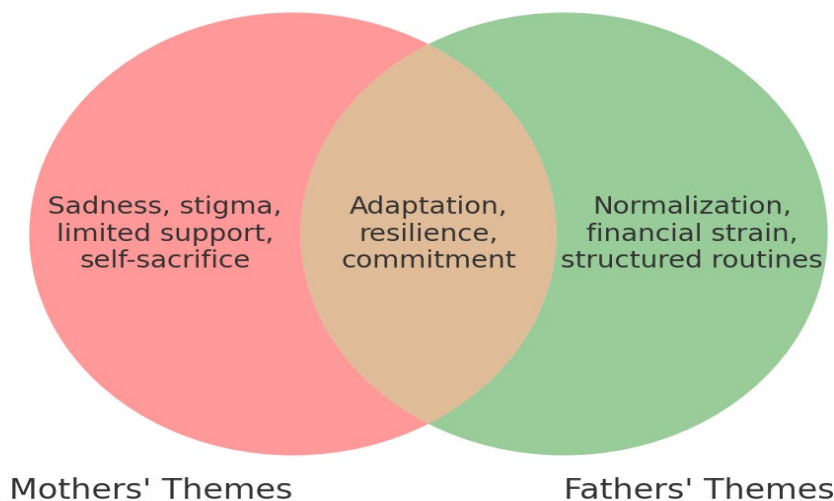
The final couple (PM6 and PF6) faced the dual challenge of autism and Down syndrome. The mother's narrative was marked by emotional depth, spiritual acceptance, and advocacy-driven transformation, while the father's account emphasized practicality, planning, and steady optimism (refer to Table 8). The mother led homeschooling, therapy, and advocacy efforts, describing her child as the source of personal growth. Although he framed his involvement in terms of structure, problem-solving, and logical acceptance, the father was involved and encouraging. Socially, the father was less emotionally impacted and promoted openness regarding the diagnosis, whereas the mother shared experiences of stigma and utilized them as inspiration for inclusion initiatives. Their approaches to coping were different: the father depended on routine and structure, while the mother turned to spirituality and gratitude. Together, their approaches demonstrated complementary adaptation to shared challenges of parenting a child with autism.

Table 8*Cross-Case Mother-Father Matrix (PM6/PF6)*

Thematic domain	Mother (PM6)	Father (PF6)
Perception of Diagnosis	Shock; acceptance through advocacy	Pragmatic and focused on planning
Parenting Roles	Leads therapies; redefined career	Supportive and engaged; follows structure
Sociocultural Stress	Feels stigma; advocates inclusion	Less affected; promotes openness
Coping Strategies	Spirituality and acceptance	Rational acceptance, routine, faith
Support Systems	Family; therapists; advocacy circle	Family, especially wife and daughter
Notable Discrepancies	Emotional and reflective	Pragmatic and goal-oriented

Across all couples, mothers consistently emerged as the emotional anchors and primary caregivers, while fathers portrayed themselves as practical supporters (refer to Figure 1). Mothers tended to express stronger emotional reactions and social sensitivities, framing their experiences as transformative journeys of acceptance and endurance. Fathers, meanwhile, often presented their roles as rational and solution-oriented, focusing on normalization, stability, and forward momentum. Despite these differences, both parents were strongly committed to their child's growth and well-being. Their distinct yet interconnected perspectives provide a deeper understanding of how families navigate the complexities of diagnosis, therapy, and adaptation in everyday life.

Figure 2

Venn Diagram of Mothers' and Fathers' Shared Themes

Note. This diagram represents the overlap and distinctions between the themes emerging from mothers and fathers. Fathers and mothers overlapped most in adaptation, resilience and commitment in the upbringing of their child with autism.

Summary of Findings

Across all six couples, mothers consistently emerged as the primary caregivers and emotional anchors, dealing with stress from diagnosis shock, social scrutiny, and time constraints, while fathers generally took on pragmatic, problem-solving roles. As such, stressors were gendered: fathers emphasized logistical and role-related difficulties, while mothers expressed emotional strain, social pressure, and caregiving obligations. Fathers relied on routines, rational reframing, and shared responsibility with their partners, while mothers relied on faith, therapy, emotional regulation, and meaning-

making. Family, therapists, and spousal cooperation mediated access to support, with mothers leading the implementation of therapy and fathers offering support and guidance.

Treatment strategies were holistic and evolving, combining home-based interventions, formal therapies, and complementary approaches, with mothers directing daily caregiving and fathers ensuring consistency and structured follow-through. Meaning-making and growth represented opposing but complementary perspectives: fathers framed adaptation through normality, hope, and protective engagement, whereas women focused on advocacy, change, and resilience. The relational negotiation of caregiving roles and intra-couple differences was highlighted by the discrepant cases within couples, such as mothers voicing emotional hardship and fathers denying stress or normalizing challenges. As a bridge to Chapter 5, these experiences are interpreted using Bronfenbrenner's ecological systems theory and Crenshaw's intersectionality theory to inform culturally sensitive, family-centred interventions, which collectively show how contextualized, gendered, and relational parental adaptation is in Kerala.

Chapter 5: Discussion, Implications, and Conclusion

Introduction

This chapter provides a comprehensive analysis of the study's findings, relating them to the theoretical foundations, previous research, and the research goals stated in earlier chapters. The purpose of the study was to investigate and compare the lived experiences of fathers and mothers in Kerala, India, raising a child with ASD. The research question being answered was: How do the lived experiences of fathers and mothers raising a child with ASD in Kerala differ in terms of stress, coping mechanisms, access to support, and treatment strategies? By applying Bronfenbrenner's Ecological Systems Theory and Intersectionality Theory, the study revealed how various environmental systems and intersecting social identities, including gender, culture, and socioeconomic class, influence the parenting experiences of mothers and fathers. Through semistructured interviews with six couples, this study examined similarities and differences in parental perceptions, coping strategies, and caregiving dynamics, situating these within the sociocultural realities of Kerala. This chapter presents my interpretation of findings, considering the research questions and theoretical perspectives, and then discusses their implications, limitations, and recommendations for future research. The chapter concludes with reflections on how these findings contribute to the knowledge and understanding of autism care in Kerala, as well as to broader research on parenting, culture, and gender.

To gain a comprehensive understanding of parental meaning-making processes, the study employed an IPA in conjunction with thematic analysis. Twelve participants

(six mothers and six fathers) were interviewed separately to extract detailed, introspective narratives of their experiences both independently and in relation to their partners.

Conducting interviews independently allowed for authentic expression, free from the influence of a spouse. The participants were all from Kerala and represented two-parent households with children ages three to sixteen who had been diagnosed with autism. IPA was particularly used to capture the depth of each parent's subjective experiences within their sociocultural world, while reflexive thematic analysis allowed for the identification of shared and divergent themes between and within each couple. The within-case analysis revealed each parent's unique emotions and sense-making process, whereas the cross-case comparison revealed broader gendered and cultural patterns in parenting. This dual-level approach to analysis enabled an in-depth exploration of individual parental experiences, alongside an interpretive understanding of commonalities and differences among participants.

Iterative reading, coding, and theme development were used to analyze the data. Separate analyses were conducted for mothers and fathers, and then cross-case Mother–Father matrices were developed to find convergences, divergences, and relational nuances within each family unit. These matrices revealed many intra-family differences, indicating that parenting a child with ASD is both a gendered and very personal experience.

Interpretation of Findings

Parenting Through a Gendered and Cultural Lens

According to the findings, mothers and fathers in Kerala have very distinct, yet interconnected perspectives and approaches to navigating autism as a parent. Fathers spoke of practical adaptation, financial responsibility, and emotional control, whereas mothers spoke of extensive emotional labour, daily caregiving, and stigma. The patriarchal social structure of Kerala, where male responsibilities are typically characterized by providing and authority, while caring is traditionally feminized, is reflected in these inequalities. These findings support previous research (Desai et al., 2012; Divan et al., 2012; Jose et al., 2021) and indicate that paternal engagement in caregiving remains limited, even in urban and educated families.

Mothers frequently explained that caring for others reshaped their identity and sense of purpose, and their activism and faith helped them transform their hardships into resilience. In contrast, fathers reported a more subdued transformation, marked by tolerance, acceptance, and an evolving sense of responsibility. Both sides demonstrate adaptive coping, which is influenced by societal expectations and internalized gender scripts. In answering the research question, the results indicate that, within the sociocultural context of Kerala, mothers' and fathers' experiences are significantly shaped by gender norms in terms of emotional expression, caregiving roles, and coping mechanisms. This study confirms and expands on prior research by reaffirming the persistent gendered divisions in caregiving (Desai et al., 2012; Divan et al., 2012; Jose et

al., 2021), while also extending the literature through insights into how both mothers and fathers rebuild their identities and resilience within these constraints.

Bronfenbrenner's Ecological Systems Theory

Bronfenbrenner's theory provided a structural lens for understanding how different environmental layers influence parental adaptation. At the microsystem level, the emotional and behavioural core of children's experiences was shaped by the relationships between them and their parents. These everyday interactions also influenced parents' stress and coping mechanisms through therapy sessions, meltdowns, and schooling. Relationships between the home, schools, therapeutic facilities, and extended families affected parental autonomy and support availability at the mesosystem level. Fathers expressed annoyance at institutional inefficiencies, whereas mothers frequently reported conflict with family members and strangers who misinterpreted autism. Systemic obstacles, including insufficient services, a lack of professional training, and inconsistent policy support, increased family stress at the exosystem level, compelling parents to assume professional caregiving responsibilities.

At the macrosystem level, social stigma and caregiving duties were determined by gender expectations and cultural norms. Although the concept of the "providing father" restricted men's emotional expression and direct involvement, the social narrative that a "good mother sacrifices" increased parental guilt and self-blame. Mothers were identified as the primary caregivers in this framework, handling most of the day-to-day tasks associated with therapy, education, and behavioural routines. Despite their assistance, fathers frequently played more supporting or financial roles. Mothers were left to carry

the bulk of the emotional and physical strain of parenting, reinforcing conventional gender hierarchies. Mothers are positioned at the heart of care in these patterns, which reflect how macrosystemic factors impact family life. However, a large portion of their labour is socially unseen. Finally, at the chronosystem level, time and adaptation emerged as crucial. As years passed, both mothers and fathers described emotional evolution - moving from denial to acceptance, and from fear to strength and advocacy. This adaptability aligns with Bronfenbrenner's view that human development occurs through mutual interactions within always-changing environmental contexts. Table 9 summarizes the correspondence between the key system levels of Bronfenbrenner's ecological systems theory and observed patterns, Kerala-specific examples, and their practical implications.

Table 9*Parental Coping and Adaptation Across Ecological Systems in Kerala*

System level	Observed pattern	Kerala examples	Implication
Microsystem	Daily caregiving interactions shape emotional strain and coping.	Mothers managing meltdowns, therapy schedules, and schooling routines.	Interventions should support parents' emotional regulation and day-to-day caregiving strategies.
Mesosystem	Relationships between home, school, and therapy centers affect parental autonomy.	Conflicts with strangers and teachers over misunderstandings related to autism.	Improved coordination and communication across family, school, and therapy systems are essential.
Exosystem	Institutional gaps heighten family stress and force parents to assume professional caregiving roles.	Limited access to trained therapists, effective treatments, and affordable centers.	Policy attention is needed for service availability, funding, and respite care.
Macrosystem	Gender norms and cultural expectations shape caregiving roles and guilt.	"Mother sacrifices" vs. "providing father" ideals reinforcing unequal caregiving.	Gender-sensitive programming and public education can reduce stigma and redistribute caregiving expectations.
Chronosystem	Adaptation evolves over time, reflecting emotional and relational growth.	Parents moving from denial to advocacy and acceptance over years.	Longitudinal supports and follow-ups can sustain resilience as families adapt to developmental changes.

Crenshaw's Intersectionality Theory

Intersectionality offers a complementary lens, illustrating how multiple identities, such as gender, culture, religion, class, and parental role, intersect to shape individual experiences. Mothers, positioned at the intersection of gendered caregiving expectations and social scrutiny, experienced compounding emotional and societal burdens. Fathers, in turn, navigated intersections of masculinity, cultural responsibility, and financial pressure. Crenshaw's (1989) intersectionality theory emphasizes that neither gender nor culture alone can explain these dynamics; rather, it is their intersection that produces the lived complexities observed in families within Kerala.

Although fathers were emotionally marginalized in caregiving situations, they possessed social power in public settings. Despite being essential to day-to-day care, mothers lacked institutional authority. This led to a conflict between empowerment and limitation, which was evident in nearly all the families examined. Notably, PF2 represented a discrepant case. He denied experiencing any stress or difference in parenting, framing his child's autism as entirely "normal." His perspective, diverging from the broader trend of intersecting gendered and cultural strain, underscores the analytical nuance of intersectionality. Even within shared cultural and structural contexts, individual positionalities produce distinct meanings of adaptation and identity. Therefore, the study extended the theoretical discussion of autism caregiving beyond gender toward a more elaborate sociocultural understanding by using intersectionality to capture these overlapping layers of advantage and vulnerability.

Cross-Couple Analyses and Family-Specific Dynamics

The cross-case Mother-Father matrices showed that family systems operated differently even among families from similar cultural and economic backgrounds. Every couple had unique coping mechanisms, relational adjustments, and emotional rhythms. For instance, in certain couples, such as PM1 and PF1, the father's logical composure and the mother's sensitivity were complementary emotional states that characterized caregiving. In others, such as PM2 and PF2, fathers downplayed challenges while mothers expressed grief, creating an emotional disconnect. While PM4 and PF4 demonstrated strong cooperation and shared optimism, PM3 and PF3 were spiritually aligned but exhibited different emotional expressiveness. PM5 and PF5 revealed conflict between faith and stigma management, and PM6 and PF6 represented the most balanced partnership, rooted in mutual empathy and advocacy.

The cross-case discrepancies emphasize that no single intervention or technique is appropriate for all families. Although themes of stress, stigma, and faith recurred, their manifestation differed according to the unique personalities of the spouse and their child, the family dynamics, and other contextual and situational factors. This diversity emphasized the need for flexible, family-centred support strategies that consider each couple's internal dynamics, rather than relying on generalized assumptions about all mothers or all fathers. This variation observed reinforces Bronfenbrenner's ecological insight that no two microsystems are alike and validates the claim of intersectionality, which posits that overlapping, context-dependent identities shape experience. Analytic memos and a detailed audit trail were maintained throughout the cross-case comparison

process to enhance transparency and ensure that interpretations remained grounded in participants' narratives. All case descriptors were anonymized and generalized to preserve non-identifiability, protecting participants' confidentiality while maintaining analytic integrity.

Cultural and Spiritual Dimensions

Almost every participant's story had elements of culture and spirituality, which served as both coping mechanisms and interpretive frameworks. Parents frequently defined their child's autism as a divine test or calling, transforming their stress and suffering into meaning. Treatment decisions were also influenced by spirituality. In line with Kerala's interdisciplinary approach to treating autism, several parents combined prayer, behavioural therapy, Ayurvedic medicine, and other treatments to achieve the improvements they sought. This interaction between faith and care confirms earlier research, which shows that when purposefully incorporated into intervention planning, culturally accepted beliefs can promote resilience. (Patel et al., 2022). However, because spirituality is sometimes perceived as the only solution, it can sometimes delay professional intervention. This illustrates the dual influence of belief systems on both the ecological and intersectional frameworks. Clinicians should acknowledge and integrate families' spiritual perspectives while still reinforcing the importance of timely, evidence-based intervention. Framing professional care as compatible with spiritual growth can encourage treatment adherence and strengthen family engagement.

Transformation and Growth

Despite systemic barriers, many participants reported significant personal growth. Mothers explained how they developed empathy and a sense of purpose, which often led them to extend their support to other families. Fathers expressed their increasing patience and understanding, reflecting moral and emotional development. These transformations illustrate how adversity can give rise to new forms of strength. This theme resonates with resilience theory and aligns with Crowell et al. (2019), who highlight parental attunement as a pathway to self-expansion. Together, these findings affirm that caregiving, despite its many challenges, also offers a transformative space in which both parents redefined their identities and relationships. In this context, both mothers and fathers demonstrated resilience through adaptive meaning-making and emotional attunement, illustrating how caregiving fostered not only coping but also psychological growth. These findings directly address the research question by showing that, although mothers and fathers reported adapting differently, both achieved resilience through distinct yet complementary forms of growth and adaptation.

Limitations

This study, while offering rich contextual insights, has limitations that warrant caution in interpretation. The small, purposive sample of six couples (twelve participants) limits the generalizability of the findings. The reliance on self-reported narratives means that the results reflect participants' perceptions rather than objective or verifiable realities, and causality cannot be established with certainty. Furthermore, member checking was not conducted after the interviews and demographic data was also not

collected. Since interviews were conducted online via Zoom, families without reliable internet access or digital literacy were excluded, potentially skewing the sample toward higher socioeconomic or urban groups. The study also excluded single parents and extended caregivers, whose experiences may differ substantially, particularly given the collectivist nature of family life in Kerala. Furthermore, the age range of the children (three to sixteen years) provides only a partial view of parenting across the lifespan.

Another limitation relates to language and translation nuances. Although interviews were conducted in participants' preferred language (Malayalam or English), some meanings and cultural idioms may have been subtly altered during transcription or interpretation. Such translation-based nuances could influence the depth of phenomenological analysis. Additionally, gender dynamics during interviews may have shaped responses. Fathers might have moderated their emotional expression due to cultural expectations of masculinity, whereas mothers may have felt more comfortable articulating distress. These gendered communication patterns could influence the balance of emotional depth across narratives. The use of IPA, while valuable for depth, also relies heavily on the researcher's interpretation. Reflexivity measures, such as journaling and peer debriefing, were implemented to minimize bias; however, complete neutrality is impossible in qualitative methods. Finally, this study focused solely on families from Kerala, whose unique sociocultural and linguistic identity may not represent the experiences of families in other Indian states. Therefore, the findings should be viewed as context-specific rather than universally representative of the Indian experience of caregiving for individuals with autism.

Future research should address these limitations by employing more inclusive and diverse sampling methods to ensure a more comprehensive understanding of the topic. Studies should incorporate families from different regions of India, including rural and lower-income communities, to capture a broader range of cultural and socioeconomic realities, as these populations may need more support. Future studies that use mixed-method (e.g., combining interviews with standardized surveys) and quantitative designs could provide a more balanced and credible picture of parents' stress, coping strategies, and family relationships by confirming the qualitative themes. Additionally, longitudinal research could investigate how parental adaptation evolves as children with autism transition into adolescence, providing a more comprehensive understanding of family trajectories over time.

However, several trustworthiness strategies described in Chapter 4 helped mitigate these limitations. Credibility was enhanced through triangulation of data sources and prolonged engagement with the narratives. Dependability and confirmability were strengthened through reflexive journaling, peer debriefing, and transparent documentation of analytic decisions. Transferability was supported by providing dense, contextual descriptions of participants' lived realities. Together, these measures helped ensure that the findings remain rigorous, authentic, and grounded in participants' voices despite the study's methodological constraints.

Implications and Recommendations

Clinical/Practice Implications

The study revealed that mothers frequently shouldered most of the caregiving and emotional labour, while fathers often adopted supportive yet peripheral roles. Clinicians working in Kerala and similar cultural contexts must therefore design interventions that engage both parents, acknowledging that mothers and fathers cope differently and require distinct forms of guidance. Findings also showed that spirituality, peer mentoring, and culturally aligned communication play significant roles in family coping. Programs that incorporate these culturally meaningful components may enhance engagement and therapeutic outcomes, especially in communities where faith and family identity are central to coping. Furthermore, recognizing that parenting experiences are shaped not only by autism itself but also by deeply rooted cultural, gendered, and relational factors, clinicians should adopt more empathetic and contextually relevant therapeutic practices. By applying ecological and intersectional perspectives, professionals can gain a deeper understanding of how individual, familial, and societal factors influence parental adaptation.

Policy/Systems Implications

At the systemic level, the study exposes the urgent need for better coordination of autism services in Kerala. Families often compensate for institutional inadequacies by providing unpaid, intensive care, an inequity that must be addressed through policy reforms. Policymakers should therefore prioritize early diagnosis, training for educators and therapists, respite services, and public awareness campaigns to reduce stigma and

misinformation surrounding autism. The findings also point to the importance of community-based approaches. Policy initiatives should include collaboration with cultural and faith leaders, as they hold influence in shaping people's attitudes within the community. Engaging such leaders in public health and inclusion efforts can help normalize autism within broader social spaces, fostering acceptance and reducing social isolation. Finally, by recognizing the intersection of gender, culture, and caregiving stress, system-level reforms must ensure equitable access to services and support, allowing families (especially mothers) to avoid being overburdened by unpaid caregiving responsibilities.

Education/Training Implications

From a scholarly perspective, this research contributes to the limited body of autism literature in India by presenting a dual-gender, family-centred perspective situated in a specific cultural context (i.e., Kerala). Training programs and academic curricula should incorporate culturally grounded research findings, such as these, to better prepare professionals for work in diverse contexts. The study demonstrates that Bronfenbrenner's Ecological Systems Theory and Intersectionality Theory are valuable frameworks for understanding caregiving in non-Western societies, as they reveal how multi-layered influences shape parental adaptation. Educational and training institutions should therefore emphasize these frameworks, equipping future practitioners to consider social norms and gendered expectations in their assessments and interventions. The cross-couple analysis adds an innovative methodological dimension by capturing intra-family discrepancies, showing that even within shared cultural environments, mothers and

fathers experience autism in distinct and deeply personal ways. Training should therefore promote flexible, gender-sensitive approaches that recognize and honor this diversity of family experiences, helping practitioners translate cultural insight into practice.

Future Research

Future research should include single-parent families and grandparents, as these caregivers play major roles in Indian family systems. Expanding to rural and low-income populations will provide a more inclusive picture of autism care in Kerala. Mixed-method and longitudinal designs can examine how stress, marital adjustment, and resilience evolve over time. Additionally, intervention-based studies are needed to develop and evaluate culturally sensitive parent-support programs grounded in local realities, integrating spirituality, community participation, and family systems approaches. Cross-regional comparisons across India could further illuminate how sociocultural variation shapes autism caregiving. As a near-term next step, researchers could pilot a culturally attuned parent-support session in partnership with local therapy centers and community organizations, incorporating spirituality, peer mentorship, and gender-sensitive discussions. This pilot initiative would provide significant insight into the feasibility and cultural relevance of family-centered interventions emerging from the current study's findings.

Conclusions

This study underscores that parenting a child with autism in Kerala is a deeply contextualized, gendered, and evolving experience shaped by the interplay of personal, familial, and cultural forces. Mothers and fathers, though united by love and

commitment, travel distinct emotional paths shaped by societal expectations and structural limitations. The cross-case analyses reveal that each system adapts in unique, dynamic ways. Even within the same cultural framework, no two families experience autism alike.

By integrating Bronfenbrenner's ecological systems theory and intersectionality theory, the study demonstrates that parental adaptation occurs through continuous negotiation among multiple layers of influence. It argues for a culturally sensitive, family-centred model of intervention that values both maternal and paternal perspectives, acknowledging the diversity within families. Ultimately, the findings reaffirm that addressing autism in Kerala requires more than clinical expertise as it demands empathy for the cultural, social, and relational worlds in which families live. Supporting these families means acknowledging their individuality, honoring their strengths, and developing systems of care that reflect their lived realities. The present study shows that mothers and fathers in Kerala experience raising a child with autism differently in terms of stress, coping, support access, and treatment engagement, reflecting both individual and systemic influences. By applying a dual-parent, intra-couple lens, this research uniquely contributes to a culturally grounded understanding of parental adaptation, highlighting how gender, family dynamics, and local context shape the caregiving of children with autism in Kerala.

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Appendix A: Interview Guide (English)

1. **Introduction Question:** "Please introduce your son/daughter with autism. Tell me about him/her."

"What are some qualities or unique characteristics they have?" to elicit more detailed responses.

2. **Activities Together:**

"Could you share some of the activities you both enjoy together? How does this time together impact your relationship?"

3. **Reflecting on Birth:** "If you were to think back to your child's birth, "How did your initial feelings evolve after the diagnosis?"
4. **Hopes After Birth:** "What are some things you hoped to do with your child after his/her birth?" How have these hopes changed, if at all?"
5. **Parenting Experience:** "Tell me your experience as a parent of a child with autism."

"Are there specific experiences that are particularly impactful to you?"

6. **Bond with Child:** "How would you describe your bond with your child?"

"Are there particular activities or moments that strengthen this bond?"

7. **Rewarding Aspects:** "What is rewarding about your experience as a father/mother of a son/daughter with autism?"

"Can you share specific examples that highlight these rewarding aspects?"

8. **Challenges:** "What is challenging about fathering/mothering a son/daughter with autism?"

"How do these challenges affect your daily life?" might help uncover a deeper layer of impact.

9. **Expectation vs. Reality:** "In which ways is the experience of fathering/mothering your child different from what you had thought it would be?"

"How have you adapted to these differences?"

10. **Daily Schedule:** "How would you describe your daily schedule?"

"How do you prioritize your time and energy for family and personal needs?"

11. **Coping Strategies:** "What are some ways you cope with the challenges?"

"Are there specific techniques or supports that are most effective for you?" might guide richer responses.

12. **Support Systems:** "How would you describe the level of support you have in parenting a child with autism?"

“In what ways has this support helped you manage?”

13. **Support Systems - Specific:** “Who or what were some of your support systems in dealing with the challenges?”

14. **Interventions:** “What do you have to say about interventions that you have accessed for your child with ASD? “What has been your experience with the effectiveness of these interventions?”

15. **Implementation at Home:** “Are you able to implement these interventions at home?”

“What challenges or successes have you encountered in implementing them?”

16. **Advice for Parents:** “What would you like to say to other fathers/mothers of children diagnosed with autism?”

Adding, “What do you think is the most important lesson you have learned?” could deepen responses.

17. **Advice for Prospective Parents:** “What would you like to say to would-be fathers/would-be mothers?”

“What would you like them to know about the journey of parenting a child with autism?”

18. **Additional Reflections:** “Is there anything else you would like to share about your fathering/mothering experience with your child with autism?”

Appendix B: Interview Guide (Malayalam)

1. നിങ്ങളുടെ മകനോ/മകളോ ഓട്ടിസമുള്ളവരെ പരിചയപ്പെടുത്തൂ. അവനെ/അവളെ കുറിച്ച് പറയൂ.”

“അവർക്ക് ഉള്ള ചില ഗുണങ്ങളോ അതുല്യമായ സ്വഭാവസവിശേഷതകളോ എന്തൊക്കെയാണ്?” കൂടുതൽ വിശദമായ പ്രതികരണങ്ങൾ ലഭിക്കാൻ.

2. നിങ്ങൾ രണ്ടുപേരും ഒരുമിച്ച് ആസ്വദിക്കുന്ന ചില പ്രവർത്തനങ്ങൾ നിങ്ങൾക്ക് പങ്കിടാമോ? ഈ ഒരുമിച്ചുള്ള സമയം നിങ്ങളുടെ ബന്ധത്തെ എങ്ങനെ ബാധിക്കുന്നു?”

3. ”നിങ്ങളുടെ കുട്ടിയുടെ ജനനത്തെക്കുറിച്ച് ചിന്തിക്കുകയാണെങ്കിൽ, “രോഗനിർണ്ണയത്തിനുശേഷം നിങ്ങളുടെ പ്രാരംഭ വികാരങ്ങൾ എങ്ങനെ വികസിച്ചു?”

4. “ജനനത്തിനുശേഷം നിങ്ങളുടെ കുട്ടിയുമായി നിങ്ങൾ എന്തുചെയ്യാൻ ആഗ്രഹിച്ച ചില കാര്യങ്ങൾ എന്തൊക്കെയാണ്?” ഈ പ്രതീക്ഷകൾ എങ്ങനെ മാറിയിരിക്കുന്നു, എങ്കിൽ?”

5. “ഓട്ടിസം ബാധിച്ച ഒരു കുട്ടിയുടെ രക്ഷിതാവ് എന്ന നിലയിൽ നിങ്ങളുടെ അനുഭവം എന്തോട് പറയൂ.”

“നിങ്ങൾക്ക് പ്രത്യേകിച്ച് സ്വാധീനം ചെലുത്തുന്ന പ്രത്യേക അനുഭവങ്ങളുണ്ടോ?”

6. “നിങ്ങളുടെ കുട്ടിയുമായുള്ള നിങ്ങളുടെ ബന്ധത്തെ നിങ്ങൾ എങ്ങനെ വിവരിക്കും?”

“ഈ ബന്ധത്തെ ശക്തിപ്പെടുത്തുന്ന പ്രത്യേക പ്രവർത്തനങ്ങളോ നിമിഷങ്ങളോ ഉണ്ടോ?”

7. “ഓട്ടിസം ബാധിച്ച ഒരു മകന്റെയോ മകളുടെയോ അച്ഛനോ അമ്മയോ എന്ന നിലയിൽ നിങ്ങളുടെ അനുഭവത്തിൽ നിന്ന് എന്താണ് പ്രതിഫലദായകമായത്?”

“ഈ പ്രതിഫലദായകമായ വശങ്ങൾ എടുത്തുകാണിക്കുന്ന പ്രത്യേക ഉദാഹരണങ്ങൾ നിങ്ങൾക്ക് പങ്കിടാമോ?”

8. “ഓട്ടിസം ബാധിച്ച ഒരു മകനെയോ മകളെയോ അച്ഛനോ അമ്മയോ ആക്കുന്നതിൽ എന്താണ് വെല്ലുവിളി?”

“ഈ വെല്ലുവിളികൾ നിങ്ങളുടെ ദൈനംദിന ജീവിതത്തെ എങ്ങനെ ബാധിക്കുന്നു?” ആഴത്തിലുള്ള സ്വാധീനം കണ്ടെത്താൻ സഹായിച്ചേക്കാം.

9. “നിങ്ങളുടെ കുട്ടിയെ അച്ഛനോ അമ്മയോ ആക്കുന്നതിന്റെ അനുഭവം നിങ്ങൾ കരുതിയതിൽ നിന്ന് വ്യത്യസ്തമാണ്, ഏതൊക്കെ വിധത്തിലാണ്?”

“ഈ വ്യത്യാസങ്ങളുമായി നിങ്ങൾ എങ്ങനെ പൊരുത്തപ്പെട്ടു?”

10. “നിങ്ങളുടെ ദൈനംദിന ഷെഡ്യൂൾ എങ്ങനെ വിവരിക്കും?”

11. “വെല്ലുവിളികളെ നേരിടാൻ നിങ്ങൾക്കുള്ള ചില വഴികൾ എന്തൊക്കെയാണ്?”

“നിങ്ങൾക്ക് ഏറ്റവും ഫലപ്രദമായ പ്രത്യേക സാങ്കേതിക വിദ്യകളോ പിന്തുണകളോ ഉണ്ടോ?” എന്നത് കൂടുതൽ മികച്ച പ്രതികരണങ്ങൾക്ക് വഴിയൊരുക്കിയേക്കാം.

12. “ഓട്ടിസം ബാധിച്ച ഒരു കുട്ടിയെ വളർത്തുന്നതിൽ നിങ്ങൾക്കുള്ള പിന്തുണയുടെ നിലവാരത്തെ നിങ്ങൾ എങ്ങനെ വിവരിക്കും?”

“ഈ പിന്തുണ നിങ്ങളെ ഏതൊക്കെ വിധങ്ങളിൽ കൈകാര്യം ചെയ്യാൻ സഹായിച്ചു?”

13. “വെല്ലുവിളികളെ നേരിടുന്നതിൽ നിങ്ങളുടെ ചില പിന്തുണാ സംവിധാനങ്ങൾ ആരൊക്കെയാണ് അല്ലെങ്കിൽ എന്തൊക്കെയായിരുന്നു?”

14. “എഎസ്സി ഉള്ള നിങ്ങളുടെ കുട്ടിക്കായി നിങ്ങൾ ആക്സസ് ചെയ്ത ഇടപെടലുകളെക്കുറിച്ച് നിങ്ങൾക്ക് എന്താണ് പറയാനുള്ളത്? “ഈ ഇടപെടലുകളുടെ ഫലപ്രാപ്തിയെക്കുറിച്ച് നിങ്ങളുടെ അനുഭവം എന്താണ്?”

15. “ഈ ഇടപെടലുകൾ വീട്ടിൽ നടപ്പിലാക്കാൻ നിങ്ങൾക്ക് കഴിയുന്നുണ്ടോ?”

“അവ നടപ്പിലാക്കുന്നതിൽ നിങ്ങൾ നേരിട്ട വെല്ലുവിളികളോ വിജയങ്ങളോ എന്തൊക്കെയാണ്?”

16. “ഓട്ടിസം ബാധിച്ച കുട്ടികളുടെ മറ്റ് അച്ഛന്മാരോടോ അമ്മമാരോടോ നിങ്ങൾ എന്താണ് പറയാൻ ആഗ്രഹിക്കുന്നത്?”
 “നിങ്ങൾ പഠിച്ച ഏറ്റവും പ്രധാനപ്പെട്ട പാഠം എന്താണെന്ന് നിങ്ങൾ കരുതുന്നു?” എന്നിവ ചേർക്കുന്നത് പ്രതികരണങ്ങളെ കൂടുതൽ ആഴത്തിലാക്കും.
17. “ഭാവിയിലെ അച്ഛന്മാരോടോ അമ്മമാരോടോ നിങ്ങൾ എന്താണ് പറയാൻ ആഗ്രഹിക്കുന്നത്?”
 “ഓട്ടിസം ബാധിച്ച ഒരു കുട്ടിയെ വളർത്തുന്നതിനെക്കുറിച്ച് നിങ്ങൾ അവരോട് എന്താണ് അറിയാൻ ആഗ്രഹിക്കുന്നത്?”
19. “ഓട്ടിസം ബാധിച്ച നിങ്ങളുടെ കുട്ടിയുമായുള്ള നിങ്ങളുടെ അച്ഛൻറെ/അമ്മയുടെ അനുഭവത്തെക്കുറിച്ച് മറ്റെന്തെങ്കിലും പങ്കിടാൻ നിങ്ങൾ ആഗ്രഹിക്കുന്നുണ്ടോ?”