CHAPTER 1

Introduction

Parenting is often described as one of life’s most rewarding experiences, offering profound joy and fulfilment. The process of nurturing a child, guiding their development, and witnessing their growth and achievements is a source of immense pride and satisfaction for many parents. However, parenting also comes with its fair share of challenges. The demands of raising a child can be overwhelming, involving significant emotional, physical, and financial investments. Balancing the needs of the child with personal responsibilities, maintaining a healthy family environment, and ensuring the child's overall development can create a complex and often stressful experience for parents.

When a child has special needs, the challenges associated with parenting can become even more pronounced. Special needs children often require additional attention, specialized care, and tailored support, which can place additional strain on parents. The emotional and psychological impact of dealing with a child's special needs can affect the entire family dynamic, including the parent's mental health and overall quality of life. This heightened stress is often compounded by societal pressures, stigma, and the perceived inadequacy of existing support systems.

Overview of Autism Spectrum Disorder (ASD)

In 1912, Paul Eugen Bleuler who is a Swiss Psychiatrist, first used the term "autism" in the *American Journal of Insanity*. He based the term on the Greek word "autos," meaning "self," to describe what he identified as a form of schizophrenia manifesting in childhood, a condition he also named (Blake et al., 2013). Among his patients, he observed tendencies towards social withdrawal, diminished interest in others, and difficulties in effective communication (Zauderer, 2023). It was not until the 1940s that autism gained recognition as a distinct condition. In 1943, American psychiatrist Leo Kanner published a seminal paper titled “Autistic Disturbances of Affective Contact” in the journal The Nervous Child (Blake et al., 2013) outlining a group of 11 children, comprising eight boys and three girls aged between 2 and 8, who consistently exhibited a strong inclination towards solitude since infancy. These children demonstrated a strong desire for routine, repetitive behaviours, limited imaginative capacity, and language challenges, such as mutism, echolalia, or pronoun reversals. Bleuler differentiated this condition from childhood schizophrenia, highlighting a higher prevalence among males (Blake et al., 2013; Harris, 2018; Moller, 2023). Termed "early infantile autism" by Kanner, his research serves as the cornerstone of contemporary autism studies (Moller, 2023). In 1944, Hans Asperger, an Austrian paediatrician, recognized a less severe variant of autism. He penned an article in German detailing four boys, aged 6 to 11, who exhibited symptoms akin to those described by Kanner. This condition eventually became identified as Asperger's syndrome (Blake et al., 2013; Zauderer, 2023).

Over the years, this disorder has been referred to by various terms. In the 1968 edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-II), autism was classified as a form of childhood schizophrenia (Rapoport et al., 2009). The DSM-III, published in 1980, introduced the term "Infantile Autism" (Volkmar et al., 1986) This terminology shifted in the DSM-III-R, also released in 1980, where Infantile Autism was replaced with Autistic Disorder, characterized by a "pervasive lack of responsiveness to other people" (Bodea & Lubetsky, 2011). The DSM-IV, published in 1994, categorized the disorder into four subtypes: Asperger’s Disorder, Pervasive Developmental Disorder-NOS (Not Otherwise Specified), Rett’s Disorder, and Childhood Disintegrative Disorder. In 2013, the DSM-V consolidated these subtypes under a single umbrella term: Autism Spectrum Disorder (ASD), including various conditions previously known as early infantile autism, Kanner's autism, atypical autism, pervasive developmental disorder, high-functioning autism, childhood disintegrative disorder, and Asperger's disorder (Gleeson, 2024).

Currently, The American Psychiatric Association (2013) defines Autism Spectrum Disorder (ASD) as a neurodevelopmental condition characterized by significant variations in its manifestation, depending on the severity of the condition, developmental level, and age. The term "spectrum" is used to capture this variability. ASD is marked by persistent challenges in social communication and interaction, as well as repetitive behaviours, interests, or activities. These symptoms typically appear in early childhood and can significantly impact daily functioning.

Prevalence Rates of ASD

Over the past few decades, the prevalence of Autism Spectrum Disorder (ASD) has risen significantly due to changes in diagnostic criteria, increased awareness, and improved screening methods. While early prevalence studies estimated ASD at approximately 2 to 4 cases per 10,000 children in the 1960s and 1970s (Lotter, 1966; Treffert, 1970; Rutter, 2005), contemporary estimates indicate a much higher prevalence. A meta-analysis covering data from 29 countries between 1994 and 2019 revealed considerable variability in prevalence rates, with the highest rates reported in the United States, Sweden, and Denmark, and the lowest in Taiwan, France, and China (Talantseva et al., 2023).

According to the Centers for Disease Control and Prevention (CDC), ASD now affects approximately 1 in every 36 children in the United States, reflecting a significant increase from earlier estimates of 1 in 100 children nearly two decades ago (Maenner, 2021). Globally, ASD prevalence is estimated at around 1 in 100 children (Zeidan et al., 2022). In India, where children under 15 years constitute nearly a third of the population, the estimated prevalence of ASD is approximately 1 in every 68 children aged 2-9 years (Panda & Panda, 2019), suggesting that over 2 million individuals may be affected (Krishnamurthy, 2008).

This increasing prevalence highlights contemporary challenges such as disparities in diagnosis, access to specialized services, and the need for more inclusive educational and healthcare systems, particularly in low-resource settings. Addressing these challenges requires greater awareness, policy-level interventions, and research-driven strategies to ensure timely diagnosis and support for individuals with ASD and their families.

Diagnostic Features of ASD

According to DSM-V, the key characteristics ASD involve persistent challenges in two main areas: social communication and interaction, and restricted, repetitive patterns of behaviour, interests, or activities. These symptoms are typically evident from early childhood and significantly impact daily functioning. The degree of functional impairment varies based on individual characteristics and environmental factors. Manifestations of ASD also differ widely in severity, developmental level, and age, which is why the term "spectrum" is used to describe the disorder. This variability underscores the need for personalized approaches to support and intervention for individuals with ASD.

Social Communication and Interaction. In terms of social communication and interaction, individuals with ASD often exhibit deficits in social-emotional reciprocity, which include participating in regular conversations, limited expression of interests, emotions, or affect, and finding difficulty in initiating or engaging in social interactions. Nonverbal communicative behaviours, such as eye contact, understanding gestures, and facial expressions, are also impaired. Furthermore, individuals with ASD frequently struggle with developing, maintaining, and understanding relationships, making it difficult for them to form and sustain social connections.

Restricted, Repetitive Patterns of Behaviour, Interests, or Activities. These can include repetitive body movements, the repetitive use of objects, or repetitive speech. There is often a strong preference for consistency, reflected in rigid adherence to routines, such as needing to take the same route or eat the same food every day. Moreover, individuals with ASD may develop extremely narrow and intense interests that are unusual in their focus, such as an intense attachment to uncommon objects. Sensory sensitivities are also common, with individuals exhibiting hyper- or hypo reactivity to sensory input, such as sounds or textures, or displaying unusual sensory interests like frequent sniffing or handling of objects, or intense fascination with lights or motion.

Comorbidities

According to DSM-V, ASD is frequently associated with intellectual impairment and structural language disorder. Approximately 70% of individuals with ASD may have one co-occurring mental health condition, while 40% may experience two or more co-occurring mental health conditions. Apart from that, ASD is also often associated with other medical and psychological conditions, such as epilepsy (Bolton et al., 2011), attention-deficit/hyperactivity disorder (ADHD) (Green et al., 2016), anxiety disorders (Mayes et al., 2011), and gastrointestinal issues (Coury et al., 2012).

Management and Treatment

Management and treatment of ASD involves a combination of therapies, interventions, and support services tailored to meet the individual needs of each person. The commonly used approaches are as follows:

Behavioural and Communication Therapies

Applied Behaviour Analysis (ABA). A widely used therapy that encourages positive behaviours and discourages negative ones. It helps improve various skills, including social, communication, and learning skills (Brams, 2008; Larsson, 2013; Anderson & Carr, 2021; Mambuca, 2022; Hodgson et al., 2022).

Speech Therapy. Aims to enhance communication abilities, encompassing spoken language, nonverbal cues, and social engagement. (Batool & Ijaz, 2015; Oliveira et al., 2018; Twistiandayani et al., 2019; Osman et al., 2023).

Occupational Therapy. Assists individuals with ASD in acquiring essential skills for everyday activities and employment, including tasks like dressing, eating, and socializing (Case-Smith & Arbesman, 2008; Bumin et al., 2015).

Social Skills Training. Teaches children and adults with ASD how to interact more appropriately with their peers and others (Weiss & Harris, 2001; Bellini & Peters, 2008; Bohlander et al., 2012).

Educational Interventions

Individualized Education Programs. Customized educational plans created to address the specific needs of each child with ASD in school settings (Eikeseth & Klintwall, 2014; Odom et al., 2021).

TEACCH (Treatment and Education of Autistic and Communication related handicapped Children). A structured teaching approach that uses visual cues to help children with ASD understand and organize their environments (Panerai et al., 2002; Virues-Ortega et al., 2013).

Medications. Although there is no cure for ASD, certain medications can be used to alleviate symptoms like depression, hyperactivity and anxiety (Huffman et al., 2011; Doyle & McDougle, 2012).

Dietary and Nutritional Interventions. Some families and practitioners explore dietary changes and nutritional supplements, although the effectiveness of these interventions can vary. Common approaches include gluten-free and casein-free diets (Sathe et al., 2017; Karhu et al., 2020).

Alternative and Complementary Therapies. These may include music therapy (Marquez-Garcia et al., 2021), art therapy (Schweizer et al., 2014), animal-assisted therapy (O’Haire, 2013), and sensory integration therapy (Lang et al., 2012).

Parental and Family Support. Support groups and training programs for parents and families can provide valuable resources and emotional support. These programs help families understand ASD better and develop strategies to manage challenges effectively (Sofronoff et al., 2004; Bearss et al., 2015; Masse et al., 2016; O'Donovan et al., 2019).

Impact of ASD on the Family System

Autism Spectrum Disorder (ASD) can profoundly affect family systems in diverse and complex ways, with impacts varying widely depending on several factors.

Psychological Impact

Parents often face relentless stress due to the complex needs of a child with autism. This stress comes from various sources, including managing challenging behaviours (Davis & Carter, 2008; Lyons et al., 2010; Manning et al., 2011), navigating the healthcare (Fong et al., 2022; Wallace-Watkin et al., 2023) and educational systems (Yingling et al., 2018; Lee & Meadan, 2021), and coordinating multiple therapies. The pressure can be compounded by a lack of time for self-care and relaxation, leading to chronic stress (O'Nions et al., 2018; Glazzard & Overall, 2012). The persistent stress can contribute to mental health issues such as anxiety and depression (Bitsika et al., 2013). The constant demands and worries about their child's future can overwhelm parents, affecting their overall emotional well-being (Reddy et al., 2019). This stress can sometimes lead to symptoms like fatigue and irritability (Giallo et al., 2013). Furthermore, receiving an autism diagnosis can trigger a grieving process as parents adjust to new expectations and the reality of their child's needs. This period of mourning involves coming to terms with the loss of the idealized vision of their child's future and accepting the realities of their condition. The process of acceptance can be long and emotionally taxing (Lutz et al., 2012; Fernańdez-Alcántara et al., 2016).

Social Impact

Families of children with ASD often experience significant social impacts, primarily due to social isolation and stigma (Kinnear et al., 2016; Broady et al., 2017). Managing a child's behaviour in public or dealing with potential negative reactions from others can lead families to limit their social interactions, resulting in social withdrawal and a decreased sense of community and connection (Gray, 2006). The demands of caregiving can also strain connections with friends and extended relatives, as they may not fully grasp the challenges faced by the family, leading to strained or diminished relationships over time (Shivers et al., 2019). Additionally, families may face judgment and misunderstanding from those who lack knowledge about autism, manifesting as negative comments, intrusive questions, or unfair assumptions about the child's behaviour or the parents' parenting skills (Broady et al., 2017; Iadarola et al., 2019).

Economic Impact

Families of children with ASD often face significant economic impacts due to the financial burden and employment challenges associated with caregiving. The cost of therapies and treatments, medical care, special education, and other related services, can be substantial, leading to financial strain (Lavelle et al., 2014; Buescher et al., 2014). Additionally, one or both parents may be required to cut back on their working hours or even quit their jobs to provide care for their child, which impacts the family's income (Cidav et al., 2012; Saunders et al., 2015). Parents may also need to forgo career advancement opportunities or switch to more flexible but less rewarding jobs to accommodate their caregiving responsibilities, further exacerbating the economic challenges they face (Marsack-Topolewski & Samel, 2024; Balachandran & Bhuvaneswari, 2024).

Marital Impact

The stress and demands associated with caregiving can result in increased conflict between partners, as differences in parenting styles, coping mechanisms, and levels of stress exacerbate disagreements. Parents may also have differing approaches to dealing with stress and their child's needs, which can lead to misunderstandings and tensions if not managed effectively (Shtayermman, 2013; Brown et al., 2020; Chan & Leung, 2020).

Mother’s Experiences in Raising a Child With ASD

Both mothers and fathers experience stress when raising a child with ASD, but studies show that mothers tend to report higher levels of stress and depression than fathers (Hastings et al., 2005; Dabrowska & Pisula, 2010; Ozturk et al., 2014). This suggests that the stress levels of mothers and fathers may be influenced by their differing roles, expectations, and interactions with their children.

Mothers often take on the primary caregiving role for children with autism, managing daily routines, addressing behavioral issues, and coordinating medical and therapeutic treatments (Phetrasuwan & Shandor Miles, 2009; Cetinbakis et al., 2020; Ciciolla & Luthar, 2019; Montes & Halterman, 2007). This extensive involvement in caregiving tasks can lead to significant physical and emotional strain (Huang et al., 2014; Marsack-Topolewski & Church, 2019). The constant need to monitor and respond to their child's needs often leaves mothers with little time for self-care, contributing to higher levels of stress and burnout (Sekułowicz et al., 2022).

Research has consistently found that mothers of children with autism face higher stress levels compared to mothers of children with other developmental conditions (Eisenhower et al., 2005; Griffith et al., 2010; Valicenti-McDermott et al., 2015). This increased stress is often due to the unique challenges associated with autism, such as communication difficulties, social skill deficits, and behavioural problems (Hastings, 2003; Phetrasuwan, & Shandor Miles, 2009). These challenges require a high level of vigilance and specialized strategies to manage, further increasing the burden on mothers.

Moreover, cultural norms and conventional gender roles frequently impose extra pressure on mothers to be the primary nurturers and caregivers (Sharma et al., 2016; Williams et al., 2017; Amanullah et al., 2020). This can lead to emotions of self-blame and incompetence when they struggle to manage their child's needs, exacerbating their stress levels (Vats et al., 2023). Fathers, while also affected, may not experience the same intensity of daily caregiving responsibilities and societal expectations, potentially contributing to the differences in reported stress levels (Ozturk et al., 2014).

Key Theoretical Frameworks

This study is guided by two key theoretical frameworks: the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) and the Social Support Theory (Cohen & Wills, 1985). The Transactional Model emphasizes how individuals appraise and respond to stress, highlighting the role of cognitive appraisal and coping strategies in shaping psychological outcomes. This framework is particularly relevant for understanding how mothers of children with ASD perceive and manage stress. Complementing this, the Social Support Theory posits that social support serves as a buffer against stress, either by directly enhancing well-being or by mitigating the adverse effects of stress through emotional, informational, or instrumental support. Together, these frameworks provide a foundation for examining the impact of psychosocial interventions on maternal well-being and stress management.

Problem Statement

The impact of ASD on the family is significant, affecting each family member differently, with mothers often bearing the primary caregiving responsibility. This role places mothers in a position where they are required to manage the daily routines, address behavioral issues, and coordinate various medical and therapeutic interventions for their child. Such responsibilities can be overwhelming and contribute to elevated stress levels. Research indicates that mothers of children with ASD report higher levels of stress compared to other family members, including fathers (Hastings et al., 2005; Dabrowska & Pisula, 2010; Ozturk et al., 2014). This disparity suggests that the stress experienced by mothers and fathers may be influenced by their differing roles, expectations, and interactions with their children.

Cultural expectations and traditional gender roles often confine women to the domestic sphere, leading to a perceived inequality in child-rearing responsibilities. This cultural framework places an additional burden on mothers, who are typically seen as the primary caregivers. As a result, they face greater pressure to meet the needs of their children, which can lead to heightened stress levels. Mothers are often expected to manage not only the child's immediate needs but also to ensure long-term planning for their child's development and well-being. The expectation to fulfil these roles often comes with limited recognition or support, further exacerbating their stress. In India, societal attitudes toward disability often exacerbate the challenges faced by mothers of children with ASD. Autism remains widely misunderstood, and stigma can lead to blame, judgment from extended family, and pressure to conform to societal expectations of "normalcy." Unlike in Western contexts, where professional support is more accessible, Indian families often rely on informal networks such as relatives or religious groups, which may not always offer evidence-based guidance.

In addition to these challenges, mothers frequently lack adequate support from their spouses or other family members. This lack of support can leave them feeling isolated and overwhelmed, as they struggle to cope with the demands of raising a child with autism. Effective coping mechanisms are often not readily accessible or known to these mothers, making it even more difficult to manage the daily stressors they encounter. Furthermore, they face significant financial burdens due to the cost of medical treatments, therapies, and specialized educational services required for their children.

The societal stigma associated with raising a child with autism adds another layer of difficulty, as mothers may feel judged or misunderstood by those around them.

These compounding factors contribute to the overall stress experienced by caregivers. The chronic stress endured by mothers of children with ASD can severely impact their mental health, leading to issues such as anxiety, depression, and burnout. These mental health struggles not only impact the mothers' well-being but also hinder their ability to effectively support and nurture their child. When a mother's mental health is compromised, it can diminish her parenting efficacy, reducing her ability to provide the necessary care and support for her child. This, in turn, can negatively influence the overall quality of life for both the mother and the child, creating a cycle of stress and strain within the family unit.

Despite the availability of various intervention programs aimed at assisting children with ASD, there remains a significant gap in comprehensive psychosocial support tailored specifically for the mothers, particularly in India. The researcher, in their role as a psychiatric social worker with extensive clinical practice, has encountered numerous mothers of children with autism who were not receiving any form of intervention for themselves. These repeated encounters underscored the urgent need for dedicated support systems addressing the unique challenges faced by these mothers.

This study is driven by the need to fill this gap by developing a multicomponent psychosocial intervention module specifically designed to address the array of psychosocial problems encountered by mothers of children with ASD. By targeting not just the child’s behavioural and communication difficulties but also the broader factors contributing to maternal stress, this intervention aims to improve the overall well-being of mothers and, by extension, enhance the quality of care they can provide to their children. The proposed intervention includes components such as stress management techniques, building social support networks, providing educational resources about ASD, and strategies for enhancing coping skills.

Structure of the Thesis

Chapter 2: Review of Literature

This chapter provides a comprehensive review of the existing literature relevant to the study, focusing on the theoretical frameworks, empirical findings, and research gaps in the field. The chapter begins with an exploration of fundamental concepts that underpin the understanding of stress, particularly in the context of parenting a child with ASD. It delves into the unique challenges faced by mothers, highlighting the heightened levels of stress they experience due to their caregiving roles. The literature review also examines comparative studies that assess parenting stress in families with children with ASD versus other disabilities, offering insights into the distinctiveness of the stressors associated with autism. Additionally, the chapter addresses the critical areas of support, and coping, shedding light on how these factors interact and contribute to the overall well-being of mothers. Furthermore, the chapter categorizes various intervention approaches, including those focused on the child, parents, and the family as a whole, and evaluates their effectiveness in reducing parental stress and enhancing coping strategies and support system. This review emphasizes the need for further research and the development of tailored interventions, setting the stage for the subsequent chapters in this thesis.

Chapter 3: Methodology

This chapter outlines the research methodology employed in this study. This chapter focuses on the design and structure of the research, including the selection of participants, data collection methods, and the tools used for analysis. It provides an overview of the qualitative and quantitative approaches that were integrated to explore the psychosocial needs of mothers of children with ASD. Additionally, the chapter explains the rationale behind the chosen methodologies and details the procedures followed to ensure the reliability and validity of the data collected. This chapter sets the foundation for understanding how the research was conducted and how the findings were derived.

Chapter 4: Module Development

This chapter presents the findings from the needs assessment conducted as part of this study. The chapter focuses on the detailed qualitative analysis of 10 transcribed interviews with mothers of children with ASD. Through rigorous thematic analysis, five key themes were derived, each representing significant psychosocial challenges and needs identified by the participants. These themes highlight critical areas such as emotional strain, support systems, coping mechanisms, and the unique stressors faced by mothers. The insights gained from these themes are crucial in shaping the development of a comprehensive intervention framework.

Chapter 5: Results

This chapter presents the quantitative findings from the study, focusing on the data collected through pre- and post-intervention measures. It details the changes observed in stress levels, coping strategies, and social support networks among participants. By analysing these metrics, the section highlights the effectiveness of the psychosocial intervention in achieving its objectives. Statistical analyses will be presented to illustrate significant improvements and provide insights into the overall impact of the intervention on the participants' well-being.

Chapter 6: Discussion

This chapter provides a comprehensive discussion of the study's findings. The interpretation of results was framed in the context of the research objectives, examining how the findings contributed to the existing body of knowledge about the psychosocial challenges faced by mothers of children with ASD. A comparison with existing literature highlighted similarities and differences, emphasizing the new insights provided by this study. Practical implications were explored, focusing on how the intervention module could be implemented in real-world settings to support mothers, with recommendations for practitioners, policymakers, and future research.

Chapter 7 Summary and Conclusion

The concluding section summarized the major findings and reflected on the broader implications of the research for enhancing the quality of life for mothers and children with autism. The chapter also addressed the study's limitations, including methodological constraints and potential biases. Recommendations for future research were outlined, identifying areas for further exploration to improve support for mothers.