

CHAPTER 2

Review of Literature

This literature review chapter delves into the detailed experiences of parenting stress within the context of raising children with ASD. It begins by exploring the heightened stress levels parents face when managing the unique needs of their children with ASD, emphasizing how these challenges can significantly impact their overall well-being.

The discussion then shifts to the various factors influencing parenting stress in families with children on the spectrum. Following this, particular attention is given to the distinct and often greater stress experienced by mothers, who frequently serve as primary caregivers.

Furthermore, this chapter emphasizes the importance of understanding the critical role of social support in alleviating the burden on mothers of children with ASD. It also addresses the barriers these mothers encounter when trying to access support, whether due to societal stigma, lack of resources, or systemic limitations.

The discussion further explores the range of coping behaviours mothers adopt, from adaptive strategies that foster resilience to maladaptive responses that can exacerbate stress. The ability to cope effectively is shown to be pivotal in maintaining both parental and child well-being.

The chapter concludes by reviewing intervention studies aimed at supporting parents, particularly mothers, of children with ASD. These interventions range from psychosocial to behavioural programs, each with varying degrees of success in reducing parental stress and improving coping mechanisms. This review lays the groundwork for understanding the complex interplay of stress, support, coping, and intervention, all of which are essential for improving the quality of life for families of children with ASD.

Stress

Stress in general

Stress is a complex and multifaceted concept that is integral to understanding human behaviour and health (Pearlin et al., 2005; Slavich et al., 2016). It is described as the body's reaction to any type of demand or challenge, be it emotional, psychological or physical (Schneiderman et al., 2005; Sharma & Pal, 2021). This response can be

triggered by various stressors, which are any events or environments perceived as threatening or demanding (Brosschot et al., 2018).

Stress can either be acute or chronic. Acute stress is temporary stress triggered by sudden threats or difficulties. It is the body's rapid response to a perceived danger, commonly known as the "fight-or-flight" reaction, whereas chronic stress develops when the stressor continues for a prolonged period (Chu et al., 2019). Acute stress leads to increased heart rate, elevated blood pressure, and a boost in energy supplies (McEwen, 2000; Chu et al., 2019). Chronic stress, however, can cause long-term damage, such as hypertension, heart disease, and metabolic disorders (Yao et al., 2019; Chu et al., 2019). Acute stress can lead to temporary anxiety and mood disturbances (Bryant et al., 2011), while chronic stress is associated with persistent anxiety, depression, and other mental health disorders (Marin et al., 2011). Cognitive functions such as memory, attention, and decision-making can be impaired under chronic stress conditions (Sandi, 2013). Moreover, stress can influence behaviours, contributing to unhealthy coping mechanisms like substance abuse and social withdrawal (Simpson, 2018).

The Transactional Model of Stress and Coping, formulated by Lazarus and Folkman in 1984, offers an in-depth perspective on how individuals navigate stressful situations. Unlike static models, this approach views stress as a dynamic and ongoing process that results from the continuous interplay between a person and their environment. It emphasizes that stress is not just an external event but a subjective experience that depends on how individuals perceive and interpret their ability to cope with specific challenges. Central to this model are three core concepts: primary appraisal, secondary appraisal, and coping strategies. In the primary appraisal process, individuals evaluate the importance of a situation, classifying it as irrelevant, favorable, or stressful. This initial assessment determines whether the situation poses a threat, a challenge, or is of no concern. If a situation is deemed stressful, the process moves to secondary appraisal. In this stage, individuals evaluate their available resources and potential options for coping with the stressor. This involves an introspective assessment of their personal strengths, skills, and social support networks, as well as the effectiveness of their past coping mechanisms. Coping strategies are then employed based on the outcomes of the primary and secondary appraisals (Lazarus & Folkman, 1984). By framing stress as a dynamic interaction between individuals and their environment, the Transactional Model highlights the importance of cognitive appraisal in determining stress responses. It emphasizes that the way individuals perceive their ability to manage

stressors significantly impacts their emotional and psychological well-being (Folkman et al., 1986). This model provides a valuable framework for developing interventions aimed at enhancing coping skills and resilience, ultimately promoting better mental health outcomes.

Parenting stress

Parenting stress refers to the feelings of tension or unease that arise from the challenges and responsibilities involved in raising a child (Hayes et al., 2013). It includes the emotional, psychological, and sometimes physical strain parents undergo when trying to meet their children's needs (Crnic & Low, 2002). While general stress can arise from various life domains, parenting stress is intrinsically linked to the demands of caregiving, nurturing, and guiding children's development (Liles et al., 2012).

Parenting stress arises from various sources, including child-related, parent-related, and contextual factors. Child-related factors such as challenging behaviours (Manimegalai & Parameswari, 2015), developmental concerns (Voigt et al., 2009), and academic pressures (Soltis et al., 2015) can significantly heighten stress levels. Parents may also experience stress due to perceived inadequacies in their parenting abilities (Riesch et al., 1997) and pre-existing mental health issues like anxiety or depression (Downey & Coyne, 1990). Contextual factors further exacerbate stress, with limited social support (Koeske & Koeske, 1990; Raikes & Thompson, 2005), financial difficulties (Puff & Renk, 2014), and challenges in balancing work and parenting responsibilities (Cunningham-Burley et al., 2005) contributing to the overall burden. These combined factors make the parenting role demanding and complex, requiring effective coping strategies and support systems.

Parenting Stress in child with special needs

Parenting typically developing children is inherently stressful, however parenting children with special needs presents even more profound challenges (Petrongolo, 2014). Parents of children with special needs often face heightened demands due to their children's unique medical (Caicedo, 2014), behavioural (Rosenzweig et al., 2002), and developmental requirements (Jovanova & Radojichikj, 2013). These parents are required to provide more intensive and specialized care, which can significantly amplify their stress levels. Having children with special needs, such as developmental disabilities, vision and hearing impairments, chronic medical conditions, and behavioural challenges,

has been linked to increased parental stress levels (Jovanova & Radojichikj, 2013; Hintermair, 2006; Cousino & Hazen, 2013; Miodrag & Hodapp, 2010; Drews et al., 2003). The additional responsibilities and pressures can exacerbate the usual parenting stress, leading to more severe psychological and emotional impacts.

Parenting stress in ASD

When it comes to parenting a child with ASD, the challenges and stress levels can be even more pronounced. This is because ASD is characterized by challenges in communication and behaviour, which can be particularly demanding for caregivers (Foo et al., 2015; Tathgur & Kang, 2021). These children may have difficulty understanding and expressing their needs (Frauenberger et al., 2012), leading to increased frustration and behavioural issues that parents must manage daily (Ho et al., 2012). Additionally, the lack of predictability and the need for constant supervision can be overwhelming, contributing to heightened stress levels (O’Nions et al., 2018; Glazzard & Overall, 2012). Parents also face social stigma and isolation, as their child's behaviours can be misunderstood or judged by others (Broady et al., 2017). Furthermore, accessing appropriate services and interventions for children with autism can be more challenging and time-consuming, adding to the overall stress (Smith-Young et al., 2020). Moreover, the co-existing conditions make it even more challenging for parents to manage their children's needs (Maskey et al., 2013).

Numerous research studies have shown that the cumulative effect of these demands and challenges contributes to the heightened stress levels reported by parents of children with autism compared to those parenting children with other disabilities.

In a study by Dumas and his team, caregivers' assessments of parenting stress, child behavior issues, and emotional distress were evaluated in 150 families with children diagnosed with autism, behavioral disorders, Down syndrome, or typical development. The findings revealed that parents of children with autism experienced significantly higher levels of parenting stress, both statistically and clinically, compared to those in the other groups (Dumas et al., 1991).

In a different study by Valicenti-McDermott and colleagues, parental stress was evaluated in families of children with autism and other developmental disabilities, with a focus on its association with comorbid symptoms in children. The study involved 50 families of children with autism and 50 families of children with other developmental conditions. The results showed that parents of children with autism experienced notably

higher levels of stress than those with children in the other developmental disabilities group (Valicenti-McDermott et al., 2015).

In a study by Dabrowska and Pisula (2010), the stress profiles of mothers and fathers of preschool children with autism, Down syndrome, and typical development were explored. The findings revealed that parents of children with autism experienced higher levels of stress compared to those with children in the other groups. Similarly, in a study by Pastor-Cerezuela and colleagues (2021), the researchers aimed to compare parental stress and resilience in parents of children with autism spectrum disorder, Down syndrome, and typical development. The results showed that parents of children with autism spectrum disorder experienced higher levels of stress compared to those in the other groups. A meta-analysis of research examining parenting stress in parents of children with and without ASD (Hayes & Watson, 2013) further shares many other studies that indicate parents of children with autism experience higher stress than parents of children with other disabilities (Blacher & McIntyre, 2006; Eisenhower, Baker, & Blacher, 2005; Griffith et al., 2010; Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007).

Factors influencing stress

Behavioural Challenges. The behavioural and developmental traits of children with autism can significantly impact the stress levels of their parents. Studies have shown that specific child characteristics, such as severity of symptoms, behavioural problems, and co-occurring conditions, play a crucial role in determining the extent of parental stress. For instance, research by Lyons et al. (2010) found that children with severe autism symptoms, including limited communication skills and repetitive behaviours, often require more intensive and constant caregiving, which can heighten parental stress. Similarly, Manning et al. (2011) reported that mothers of children with autism experience more stress when their children exhibit challenging behaviours. This phenomenon has been corroborated by numerous other studies (e.g., Hastings & Johnson, 2001; Abbeduto et al., 2004; Bromley et al., 2004; Bitsika & Sharpley 2004; Benson, 2006; Lecavalier et al., 2006; Davis & Carter, 2008).

Co-occurring Conditions. Moreover, many children with autism have additional conditions and managing these co-occurring conditions alongside autism can add significantly to the overall stress burden on parents. For example, anxiety disorders are prevalent among children with autism, with studies showing that up to 40% of children with autism also meet the criteria for an anxiety disorder (Van Steensel et al., 2011). The presence of anxiety can exacerbate autism symptoms (Avni et al., 2018), making daily

routines more challenging and increasing parental stress. For instance, children with autism and anxiety may have heightened fears and phobias, leading to more frequent meltdowns and resistance to change (Maskey et al., 2014), which parents must constantly manage. Apart from that, over the past decade, there has been increasing interest in the co-occurrence of attention-deficit/hyperactivity disorder (ADHD) and autism spectrum disorder (ASD). Symptoms of ADHD, including hyperactivity, impulsivity, and inattention, can make behavioural management and educational support more challenging, thereby adding extra demands on parents (Rosenberg et al., 2011; Davis & Kollins, 2012).

Furthermore, sensory sensitivities in which children with autism often experience can lead to extreme discomfort and behavioral reactions, requiring parents to create and maintain sensory-friendly environments. Managing these sensitivities often involves extensive planning and adaptation, which can be stressful for parents (Ben-Sasson et al., 2009).

Sleep disorders are also frequently observed in children with autism. A study by Mazurek and Sohl (2016) found that sleep anxiety was positively correlated with both irritability and hyperactivity. This sleep deprivation can significantly affect parental well-being and their capacity to manage daily stressors.

Gastrointestinal (GI) issues, such as chronic constipation, diarrhoea, and food intolerances, are also reported in children with autism (McElhanon et al., 2014). These GI problems can cause discomfort and pain for the child, leading to behavioural issues and requiring parents to manage specialized diets and treatments. The ongoing management of these health issues adds another layer of complexity to caregiving.

Overall, the presence of co-occurring conditions significantly increases the caregiving demands on parents of children with autism. These additional challenges require constant vigilance, adaptation, and specialized interventions, contributing to the overall stress burden experienced by parents.

Lack of Support and Unhelpful Coping Responses. While child characteristics play a significant role in determining the stress levels of parents of children with autism, other factors also contribute to the overall burden. These include the availability of social support and the individual characteristics of parents, such as their coping mechanisms and resilience.

Emotional, practical, and financial support from family members, friends, and the community is vital for parents of children with autism (Gupta & Singhal, 2005; Derguy

et al., 2015). However, many parents report a lack of understanding and support from their social circles (Luther et al., 2005; Broady et al., 2017). The absence of family and social support can leave parents feeling isolated and overwhelmed (Myers et al., 2009; Das et al., 2017). Without a strong support network, parents may struggle to find time for self-care and respite, leading to increased stress and burnout (Connolly, 2019; Mc Grath, 2019). The constant demands of caregiving without adequate relief can exacerbate feelings of frustration and exhaustion.

Access to healthcare professionals, therapists, educators, and respite care services is essential for managing the complex needs of children with autism (Russa et al., 2015; Cooke et al., 2020). Unfortunately, many parents face barriers in accessing these services, such as long waitlists, high costs, and a shortage of qualified professionals (Wallace-Watkin et al., 2023; Jones et al., 2017; Fong et al., 2022). The lack of consistent and quality professional support can leave parents without the necessary guidance and assistance to navigate their child's condition. This can increase the caregiving burden, as parents must manage challenging behaviours and developmental delays on their own, contributing to higher stress levels.

Effective educational programs, therapeutic interventions, and tailored support services are crucial for the development and well-being of children with autism (Klin et al., 2015; Estes et al., 2019). However, access to these resources is often limited by geographic location, financial constraints, and the availability of specialized programs (Yingling et al., 2018; Lee & Meadan, 2021). The lack of appropriate educational and therapeutic resources can hinder a child's progress and place additional strain on parents who must compensate for these gaps. Without adequate support, parents may struggle to address their child's unique needs, leading to increased anxiety and stress.

Moreover, the ability of parents to cope with the stress of raising a child with autism is also significantly influenced by their coping mechanisms (Lai et al., 2014; Shepherd et al., 2018). When parents lack effective coping strategies, the challenges of caregiving can become overwhelming (Lee, 2009). Maladaptive coping strategies, such as avoidance or denial, can exacerbate stress by preventing parents from addressing issues proactively (Hastings, 2002; Seymour et al., 2013). This can lead to a cycle of increasing stress and anxiety, as problems remain unresolved and accumulate over time. The absence of adaptive coping mechanisms, such as seeking support and actively solving problems, leaves parents ill-equipped to manage daily stressors, resulting in heightened levels of distress (Baker, 2020; Pepperell et al., 2018).

Understanding these factors is crucial for developing effective support systems and interventions for parents of children with autism. By addressing the unique challenges posed by the child's characteristics, enhancing support systems, and promoting healthy coping mechanisms, we can help reduce the stress experienced by these parents and improve their overall well-being.

Maternal Stress in ASD

While the stress experienced by parents of children with ASD is significant, mothers often face a greater burden. Numerous studies have shown that the stress levels can vary between mothers and fathers. In a study by Ozturk et al. (2014) that explored parenting factors in mothers and fathers of children with ASD, the findings revealed that both mothers and fathers experience elevated parenting stress. However, mothers reported higher levels of depression than fathers. Similarly, Hastings et al. (2005) found that mothers reported higher levels of depression. Likewise, Davis and Carter (2008) observed that mothers had consistently higher parenting stress and depression scores compared to fathers. Dabrowska and Pisula (2010) also found that mothers of children with autism exhibited higher levels of parental stress compared to fathers.

Hastings (2003) found that maternal stress was associated with the child's behavioural issues and the father's mental health, which might be explained by the interconnected nature of family dynamics. Mothers, who often serve as the central figure in managing the household and the child's needs (Ciciolla & Luthar, 2019), might be more affected by both the child's behaviour and the overall emotional climate of the family, including the father's well-being.

Fathers, on the other hand, were found to be more distressed by externalizing behaviours (e.g., aggression, tantrums) rather than internalizing or regulatory issues (e.g., anxiety, self-regulation difficulties) of the child. This difference could be attributed to traditional gender roles where fathers may feel a stronger responsibility for managing overt behavioural problems, which are more disruptive and visible (Davis & Carter, 2008). Moreover, the higher levels of stigma reported by mothers than by fathers (Gray, 2002b) could be due to the fact that mothers typically have more direct interactions with social networks, schools, and healthcare providers. This increased exposure may make them more susceptible to experiencing and perceiving stigmatizing behaviours from others, adding to their stress.

These findings suggest that the stress experienced by mothers and fathers of children with ASD may be influenced by differing roles, expectations, and interactions

with their children. One potential reason for the link between maternal stress and a child's social skills is that mothers often spend more time engaging in social and communicative activities with their children (Giallo et al., 2013). As primary caregivers (Phetrasuwan & Shandor Miles, 2009; Cetinbakis et al., 2020), mothers frequently assume the role of managing daily routines, addressing behavioural issues, and coordinating medical and therapeutic interventions (Ciciolla & Luthar, 2019; Montes & Halterman, 2007). This increased responsibility, coupled with the emotional toll of navigating societal expectations and potential isolation, can lead to elevated levels of stress (Phetrasuwan & Shandor Miles, 2009; Liu & Cui, 2024; Safe et al., 2012).

Furthermore, research has consistently shown that mothers of children with autism face higher levels of stress than those of children with other developmental conditions. In a study examining the relationship between different developmental conditions—typically developing, undifferentiated developmental delays, Down syndrome, autism, and cerebral palsy—and maternal well-being, it was found that mothers of children with autism reported higher parenting stress than mothers in any other group (Eisenhower et al., 2005).

In another study where mothers of children with Down syndrome, autism, and mixed aetiology intellectual disabilities assessed their child's adaptive and problem behaviours, parenting stress, and positive perceptions, children with autism were rated as having more problem behaviours and lower social competence compared to the other groups. Mothers of children with autism reported higher stress levels and lower positive perceptions of their child than mothers of children in the other groups (Griffith et al., 2010).

Similarly, Valicenti-McDermott et al. (2015) examined the stress levels in mothers of children with autism and other developmental disabilities. Their findings revealed that mothers of children with autism reported significantly higher stress levels than those of children with other developmental disabilities.

In addition to the studies mentioned, numerous other research works corroborate these findings, indicating that mothers of children with autism experience higher levels of stress compared to mothers of children with other disabilities (Blacher & McIntyre, 2006; Brobst et al., 2009; Estes et al., 2009; Rao & Beidel, 2009). These studies consistently highlight the unique and significant challenges faced by mothers of children with autism which can be attributed to the complex and demanding nature of autism.

These challenges include managing communication difficulties, behavioural problems, and co-existing conditions, all of which contribute to the higher stress levels reported by these mothers. Recognizing and addressing these specific stressors is crucial in developing effective support systems to alleviate the burden on these families.

Support

Understanding Social Support

Cobb (1976), defines Social Support as “information leading the person to believe that he is cared for and loved, esteemed and valued, and is a member network of communication and mutual obligation.” Social support is a multifaceted, evolving, and multidimensional concept that partially overlaps with social relationships. It encompasses both the overall structure through which supportive connections occur and the types of resources accessible via these relationships (Lin, 2002). Social support can be further classified based on the type of assistance provided through social connections: instrumental support, which involves help with everyday tasks such as childcare, household chores, shopping, and financial assistance; informational support, which involves providing guidance and information for specific needs, such as job opportunities and available services (Cutrona & Russell, 1990, as cited in Langford et al., 1997); and emotional support, which includes empathy, sympathy, and a safe space for sharing personal issues (House, 1981, as cited in Langford et al., 1997).

The Social Support Theory by Cohen and Wills (1985) emphasizes the significant role of social support in enhancing an individual's well-being, offering two primary mechanisms through which this support exerts its influence. The first mechanism, known as the Main Effect Model, posits that social support has a direct and positive impact on an individual's well-being at all times, irrespective of their stress levels. This model suggests that simply being part of a supportive network—whether comprising friends, family, or community members—contributes to improved mental and physical health. The constant presence of social support fosters a sense of belonging, security, and self-esteem, all of which are critical for overall well-being. People who feel supported generally experience higher levels of happiness and satisfaction, and they are better equipped to handle life's challenges, leading to enhanced general health and well-being. The second mechanism, the Buffering Effect Model, provides a more detailed view by suggesting that social support acts as a protective buffer specifically during periods of

stress. According to this model, the positive effects of social support are particularly pronounced when individuals are dealing with stressful situations. During such times, social support helps mitigate the negative impacts of stress on an individual's well-being. This support can take various forms, including practical assistance, emotional comfort, advice, and reassurance. These forms of support enable individuals to cope more effectively with stress, reduce their perceived stress levels, and recover more quickly from stressful events. By providing practical assistance, such as helping with tasks or offering financial aid, social networks can alleviate the burden of stressors. Emotional comfort, such as empathy and understanding from loved ones, can help individuals feel less isolated and more capable of managing their stress.

Social support is integral to overall well-being and plays a significant role in both mental and physical health. Its importance can be understood through various dimensions and contexts. For instance, social support is crucial for maintaining and enhancing psychological well-being (Taştan, 2013). It helps mitigate the effects of stress and anxiety, providing a buffer against the emotional toll of challenging life events (Lao et al., 2014). Research shows that individuals who have strong social support networks tend to experience lower levels of depression and anxiety (Budge et al., 2013; Viseu et al., 2018; Scardera et al., 2020). Emotional support, in particular, offers a sense of belonging, reducing feelings of loneliness and isolation, which are significant risk factors for mental health issues (Sorkin et al., 2002).

social support has been connected to a range of positive health effects. Those with strong social networks generally have enhanced physical health, lower blood pressure, and a decreased risk of chronic conditions such as cardiovascular diseases (Kawachi et al., 1996; Seeman, 1996; Uchino, 2006). Supportive relationships can encourage healthier lifestyles, including regular exercise, balanced diets, and adherence to medical treatments (Cohen, 2004; Chao, 2022). Apart from that, one of the most critical functions of social support is its role in helping individuals cope with stress (Schwarzer & Knoll, 2007). When facing stressful situations, having people to rely on can provide practical solutions and emotional comfort. This support can reduce the perception of stress and help individuals manage their responses more effectively. Moreover, studies have shown that social support is a key predictor of happiness and life satisfaction across various cultures and age groups (Kasprzak, 2010; Nauffal & Sbeity,

2013; Gerson, 2018; Yalcin, 2015). Social support is a vital factor in building resilience, which is the ability to bounce back from adversity. People with strong support systems are better equipped to handle life's challenges and recover from setbacks. This resilience is fostered by the knowledge that one is not alone and can rely on others for help and encouragement (Jang, 2012; Juliano & Yunes, 2014; Khalid, 2021).

Social support networks provide not only immediate assistance but also long-term resources for coping and adaptation (Mccoll et al., 1995; Wellman & Guilia, 1996). Certain groups, such as the elderly, individuals with chronic illnesses, and parents of children with special needs, particularly benefit from social support. For these populations, social support can significantly improve quality of life and reduce caregiver burden (Luther et al., 2005; Marini, 2011; Grossman & Webb, 2016).

Understanding the Need for Social Support in Mothers of Children with ASD

Mothers of children with ASD face unique challenges that necessitate different types of social support. These challenges can significantly impact their mental and physical well-being, making robust support systems crucial. Understanding the specific needs of these mothers helps to highlight the importance of various forms of social support. Since caring for a child with autism presents unique challenges leading mothers to experience significant stress due to the constant demands of the condition, emotional support is crucial in helping these mothers cope, offering empathy, understanding, and a safe space to share their experiences and feelings.

For instance, a study by Pepperell et al. (2018) found that mothers of children with autism often find venting and expressing their feelings to loved ones to be very helpful in addressing their problems and managing stress. This finding aligns with the results of a study by Ekas et al. (2010), where 119 mothers of children with ASD reported that family support was linked to increased optimism, which, in turn, predicted more positive maternal outcomes and fewer negative ones. Additionally, social support from various sources—such as partners, other family members, and friends—was associated with lower levels of depression, negative affect, and parenting stress.

The increased caregiving responsibilities, which often include managing therapies, educational needs, and daily care, can be physically and mentally exhausting.

These responsibilities limit time for self-care and personal activities, making instrumental support essential (Bi et al., 2022). Practical help with childcare, household chores, and other tasks can lighten the load and provide mothers with much-needed respite (Benson, 2012; Bi et al., 2022). Furthermore, raising a child with autism can be financially demanding due to the costs associated with therapies, medical care, and specialized education. This financial strain adds to the overall stress and burden (Parish et al., 2015; Geldenhuys, 2019; Papadopoulos, 2021). Instrumental support, such as financial assistance programs and help with navigating insurance and funding options, can alleviate some of the economic pressures faced by these families. In line with this, a study by McIntyre and Brown (2018) involving 78 mothers of children with ASD found that a mix of formal and informal supports was perceived as beneficial. The utilization of social support was influenced by sociodemographic factors, child behaviour problems, satisfaction with the autism diagnostic process, and access to information about ASD.

The demands of caring for a child with autism can also lead to social isolation, as many mothers find it challenging to maintain social connections and participate in social activities (Safe et al., 2012; Currie & Szabo, 2020). This isolation can exacerbate feelings of loneliness and depression (Woodgate et al., 2008). Social companionship is vital, offering opportunities to engage with others, build friendships, and feel part of a community, thereby reducing their sense of isolation (Ludlow et al., 2012). Moreover, mothers of children with autism often need specific information about the condition, available treatments, educational resources, and support services (Mackintosh et al., 2005). Access to accurate and timely information is critical for making informed decisions about their child's care. Informational support helps by providing guidance, sharing knowledge about autism, and connecting mothers to relevant services and resources (Weissheimer et al., 2021). Advocating for their child's needs within educational and healthcare systems can be time-consuming and emotionally draining for mothers of children with autism (Smith-Young et al., 2022). Informational and instrumental support in the form of advocacy training, legal advice, and assistance in navigating bureaucratic processes can empower mothers and improve outcomes for their children. For instance, a study conducted by Reinke and Solheim (2015) with 14 mothers revealed that the Internet and online engagements are vital sources of emotional and informational support. The mothers reported a sense of care and acceptance through these platforms and mentioned receiving crucial information that assisted them in

handling challenging circumstances. Although the mothers of children with ASD had varied perspectives and understandings of their experiences, they all acknowledged and appreciated the benefits of using the Internet for emotional and informational support.

As children with autism grow, their needs may change, and planning for the future becomes a critical concern for parents (Friedman et al., 2013; Sosnowy et al., 2018). Mothers often worry about their child's long-term care, independence, and quality of life (Marsack-Topolewski & Graves, 2020). Emotional and informational support in planning for the future, including vocational training, independent living options, and long-term care facilities, is essential for reducing anxiety about what lies ahead (Gray, 2002). The significance of family support in this context is further underscored by a study by Bromley et al. (2004), which found that over half of the 68 mothers signs of considerable psychological distress, a condition strongly linked to low levels of family support and the challenges of raising a child with severe behavioural issues.

Feeling competent and confident in their caregiving role is vital for mothers of children with autism (Mohammadi et al., 2018). Social support enhances parental self-efficacy by providing validation, encouragement, and practical advice (Higgins et al., 2023). Supportive networks help mothers feel more capable and empowered in their parenting role, leading to better outcomes for both the mother and the child (Ryan & Cole, 2009; Martínez-Rico et al., 2022). Social support helps build resilience, enabling mothers to adapt and thrive despite the challenges they face. Resilience is fostered through a supportive network that offers consistent encouragement, practical help, and emotional sustenance. This resilience is crucial for maintaining the well-being of the mother and ensuring ongoing, effective care for the child (Bekhet et al., 2012)

Challenges and Barriers in Accessing Social Support for Mothers of Children with ASD

Mothers of children with ASD often face numerous challenges in accessing the social support they need. One of the primary barriers is the limited availability of services (Chiri et al., 2012; Babatin et al., 2016; Wallace-Watkin et al., 2023). Many families encounter long waitlists when trying to access specialized services such as therapy, early intervention programs, and diagnostic services. These delays can increase stress levels for mothers who need timely support for their children (Smith-Young et al.,

2020). Additionally, families living in rural or remote areas may have limited access to these specialized services, often requiring them to travel long distances or forgo necessary support altogether (Antezana et al., 2017; Wallace-Watkin et al., 2023).

Inadequate government support and funding further compound these challenges. Many families struggle with the financial burden of caring for a child with autism due to the high costs of therapies, medical care, and specialized education (Parish et al., 2015; Geldenhuys, 2019; Papadopoulos, 2021). Insufficient financial assistance and complex bureaucratic processes make it difficult to obtain the necessary support. Navigating the systems for government assistance, insurance coverage, and specialized services can be overwhelming, acting as a significant barrier for many mothers (Resch et al., 2010; Crossman et al., 2020).

Social isolation and stigma are also prevalent challenges. Mothers of children with autism often face judgment and misunderstanding from others, leading to feelings of social isolation (Currie & Szabo, 2020). This lack of awareness and acceptance within the community can make it difficult for them to seek or receive support. Additionally, the demanding nature of caregiving often leaves little time or energy for social interactions, exacerbating feelings of loneliness and depression (Safe et al., 2012; Currie & Szabo, 2020). The absence of a supportive social network further isolates these mothers, making it harder for them to access the help they need (Khanlou et al., 2017).

Emotional and psychological barriers significantly hinder mothers of children with autism from accessing support. Feelings of guilt, shame, or cultural factors may lead them to avoid seeking help (Cho & Gannotti, 2005; Neely-Barnes et al., 2008; Zuckerman et al., 2014), believing they should manage on their own. These barriers can prevent them from accessing resources that could alleviate stress and improve well-being.

Another major challenge is the inconsistent and insufficient professional support available. Many healthcare providers, educators, and social workers lack adequate training in autism, leading to gaps in understanding and support (Morris et al., 2019; Lipinski et al., 2022). Additionally, fragmented services across healthcare, education, and social sectors make it difficult for mothers to navigate and obtain the comprehensive care they need (Johnson et al., 2020; Como et al., 2020).

Information gaps significantly hinder access to support for mothers of children with autism. Many struggle to find accurate, timely, and relevant information about autism and available services (Zuckerman et al., 2014; Magaña et al., 2013). The lack of

centralized, easy-to-access resources, combined with misinformation, often leaves them confused and stressed (Zuckerman et al., 2014; Magaña et al., 2013).

Lastly, the lack of tailored support services means that many mothers do not receive the specific help they need. Generic, one-size-fits-all approaches fail to address the unique circumstances these mothers face, leaving significant gaps in the support they receive.

To summarize, mothers of children with ASD experience heightened stress due to various factors, including behavioral challenges, lack of social support, and financial burden. Studies indicate that these stressors not only impact maternal well-being but also influence family dynamics and overall caregiving efficacy. Understanding these stressors is crucial for identifying effective coping strategies. Research suggests that while some mothers adopt adaptive coping mechanisms such as problem-solving and seeking support, others may resort to maladaptive responses like avoidance and self-blame. The following section explores these coping strategies in detail.

Coping

Overview of Coping

Pearlin and Schooler (1978) defined Coping as “behaviour that protects people from being psychologically harmed by problematic social experience.” Coping involves a dynamic and ongoing interaction between the person and the environment, where the individual actively tries to balance demands with available resources (Lazarus & Folkman, 1984). The concept of coping has been extensively studied particularly in the context of stress. Understanding coping strategies is crucial as they play a significant role in determining how effectively individuals can navigate difficulties and maintain psychological well-being.

Stress and coping theory (Lazarus & Folkman, 1984) initially identified two primary forms of coping: problem-focused coping, which involves actively addressing the source of stress through strategies such as planning, gathering information, and making decisions; and emotion-focused coping, which aims to manage negative emotions through techniques like distancing oneself, seeking emotional support, or engaging in avoidance behaviours (Folkman, 2012). Later, Carver and colleagues (1989) expanded this framework by including active coping, planning, restraint coping, seeking social support for instrumental reasons, and suppression of competing activities under

problem-focused coping. They also categorized positive reinterpretation and growth, religion, humour, acceptance, and seeking social support for emotional reasons as part of emotion-focused coping. Additionally, they introduced a third category, dysfunctional coping, which includes focusing on and venting emotions, denial, behavioural disengagement, mental disengagement, and alcohol or drug use (Baqtayan, 2015).

Researchers have highlighted that coping strategies, particularly problem-focused and emotion-focused coping, play a crucial role in how individuals navigate and manage stress in their lives (Baker & Berenbaum, 2007; Chao, 2011; Ryan, 2013; Cong et al., 2021). The importance of these coping mechanisms lies in their ability to help individuals maintain psychological balance and resilience in the face of adversity (Leipold & Greve, 2009; Anghel, 2020). By actively addressing the source of stress through planning, gathering information, and making decisions, problem-focused coping can bring about tangible changes in the situation, reducing the overall level of stress and fostering a sense of mastery and competence (DeLongis & Newth, 2001; Jabbar et al., 2024).

Emotion-focused coping, on the other hand, is vital in scenarios where the stressor cannot be easily changed or eliminated, such as dealing with the loss of a loved one or a chronic illness (Folkman & Moskowitz, 2004; Aldwin, 2009). In these situations, managing emotional responses becomes paramount to prevent the stress from becoming overwhelming (Denollet et al., 2008). Techniques like seeking emotional support (Chamber et al., 2001), practicing relaxation (Raban-Motounu, 2019), and reframing (Sanhaji, 2021) the situation can help individuals maintain emotional stability and continue functioning effectively despite the stress.

However, researches have highlighted the use of maladaptive or dysfunctional coping strategies can have the opposite effect, leading to an increase in stress and further complicating the individual's mental health (Bittner et al., 2011; Holton et al., 2016). Strategies such as avoidance, denial, or substance abuse may provide temporary relief, but they often exacerbate the problem over time, leading to a cycle of worsening stress and psychological distress (Holahan et al., 2005; Silva et al., 2015; Gerrard et al., 2012). Thus, while coping is essential, the type of coping strategy employed is crucial in determining whether stress is managed effectively or allowed to escalate.

It is important to recognize that there is no universally good or bad coping strategy; rather, the appropriateness of a coping response depends on the specific context and nature of the stressor (Stephenson & DeLongis, 2020). What might be an effective coping strategy in one situation could be less effective or even counterproductive in another (Bonanno & Burton, 2013). The key is to develop a flexible range of coping strategies and to learn how to apply them appropriately based on the circumstances. By doing so, individuals can enhance their resilience and improve their ability to navigate a wide range of stressful situations.

Coping mechanisms are influenced by a variety of factors, including personality, past experiences, social support, cultural background, and socioeconomic status (O'Brien & DeLongis, 1996; DeLongis & Holtzman, 2005; Chun et al., 2006; Tweed & Conway, 2006; Adams et al., 2004). These strategies are often learned and reinforced through interactions with family, peers, and the broader cultural environment. Furthermore, the diversity of coping strategies across different populations reflects the varied stressors and resources available to different groups. Studies have shown that different age groups tend to cope with stress in distinct ways, influenced by the types of stressors they face and the resources available to them (Keefe & Williams, 1990; Martin et al., 2008; Hampel & Petermann, 2005).

Coping mechanisms vary not only across age groups but also among different roles and life circumstances. One such role that demands particular attention is that of a caregiver. Caregivers, especially those caring for individuals with chronic illnesses or disabilities, encounter unique stressors that necessitate specialized coping strategies (Hamama-Raz & Hamama, 2015; Motaharian et al., 2015). This caregiver burden can be overwhelming, making effective coping mechanisms crucial for maintaining the caregiver's mental health and well-being (Khanna et al., 2011; Carona et al., 2014).

Coping in Mothers of Children with Autism

Mothers caring for children with ASD often find themselves navigating a complex and demanding landscape that requires a diverse range of coping strategies. Unlike typical caregiving scenarios, raising a child with ASD involves managing a broad spectrum of challenges. Given the multifaceted nature of these demands, understanding the coping mechanisms that mothers adopt becomes essential in assessing their impact

on both maternal well-being and the quality of care provided. Research indicates that the ways in which these mothers cope with daily stresses not only influence their mental and emotional health but also play a crucial role in shaping their overall caregiving experience (Benson, 2010; Carter et al., 2009).

Some studies have highlighted the importance of problem-focused coping strategies among mothers of children with ASD. Benson (2010) found that mothers who engaged in active coping, such as planning and seeking instrumental support, were better able to manage stress. This approach enables mothers to take control of their situation, creating structured routines and managing their child's behaviour more effectively. Research by Kuhaneck et al. (2010) further supports this, showing that mothers who educate themselves, plan ahead, and collaborate with their spouse experience more effective coping. Additionally, Zaidman-Zait (2020) found that mothers who used active engaged coping strategies were more likely to experience mutual positive affect with their child, underscoring the importance of problem-focused approaches. However, Rasoulpoor et al. (2023) observed that, despite its effectiveness, problem-focused coping was the least utilized among mothers, with many gravitating towards emotion-focused and avoidant strategies

Emotion-focused coping strategies are also commonly used by mothers of children with ASD, especially in situations where the stressor cannot be changed. Benson (2010) identified several emotion-focused coping mechanisms, including cognitive reframing, which involves acceptance, positive reframing, and the use of religion. These strategies help mothers manage their emotional responses and find meaning in their caregiving role. Al-Kandari et al. (2017) found that mothers frequently relied on religion, acceptance, and positive reframing as their primary coping strategies. These approaches can provide a sense of peace and help mothers navigate the emotional challenges of raising a child with autism. However, the use of emotion-focused coping is not without its drawbacks. Abbeduto et al. (2004) reported that emotion-focused strategies like denial, venting, and behavioural disengagement were positively correlated with depression symptoms in mothers. Similarly, Miranda et al. (2019) noted that engagement coping and behavioural difficulties played a crucial role in linking ASD symptoms to parenting stress. The influence of coping strategies was especially significant when combined with limited social support.

Despite the benefits of adaptive coping strategies, some mothers may resort to maladaptive coping mechanisms, which can exacerbate stress and negatively impact their mental health. Benson (2010) highlighted that disengagement strategies, such as substance use, behavioural disengagement, and denial, are associated with increased stress and poorer mental health outcomes. Similarly, studies by Predescu et al. (2013) and Seymour et al. (2014) demonstrated that maladaptive strategies like self-blame, catastrophizing, and disengagement are linked to heightened emotional distress and irrational beliefs. These findings underscore the risks associated with relying on maladaptive coping, which can lead to increased psychological distress and reduced caregiving efficacy.

The role of social support in coping is paramount. Smith et al. (2008) found that social support plays a critical role in reducing feelings of isolation and mitigating the negative effects of stress on mental health. Mothers of children with ASD who engage in social networks, both in-person and online, benefit from the exchange of practical advice, emotional support, and validation. Qodariah et al. (2016) discovered a positive correlation between higher levels of patience and effective coping strategies among mothers, suggesting that social support can enhance resilience and improve coping outcomes. Moreover, Carter et al. (2009) found that social support is negatively associated with depression symptoms, underscoring its protective effect on mental health. However, as Miranda et al. (2019) indicated, the effectiveness of engagement coping may be limited in the absence of robust social support systems.

The coping strategies used by mothers of children with ASD have a profound impact on their quality of life. Malhotra et al. (2020) found that mothers who employed adaptive coping strategies, such as seeking social support, planful problem-solving, and positive reappraisal, reported higher quality of life scores. In contrast, those who relied on confrontative coping, distancing, and self-blame reported lower quality of life. This suggests that the nature of coping strategies adopted by mothers significantly influences their overall well-being.

Other Reviewed Studies

Name of study, Authors & Year	Aim	Methods	Main Findings	Remarks
Moderators of Stress in Parents of Children with Autism (Dunn et al., 2001)	To examine the relationship between stressors, social support, locus of control, coping styles, and negative outcomes among parents of children with autism.	Sample: Parents with an autistic child between the ages of 3 and 15 years were asked to participate. Those who completed measures included 39 mothers and 19 fathers ranging in age from 25 to 67 years.	Results stated that mothers of children with autism who perceive receiving higher levels of support, especially from spouses and relatives, report lower levels of depression-related somatic symptoms and fewer marital problems.	This review has contributed to the foundation of the study in understanding the factors contributing to stress and the importance of social support.
Depression in mothers and fathers of children with intellectual disability (Olsson & Hwang, 2001)	To investigate the prevalence and severity of parental depression in families of children with ID and in control families.	Parental depression was assessed using the Beck Depression Inventory (BDI) in families with children with autism and/or intellectual disability (ID), and in control families.	Mothers of children with autism experienced more distress than mothers of children with intellectual disabilities without autism.	This review has contributed in understanding stress of mothers of children with autism.
Stress in UK Families Conducting Intensive Home-Based Behavioral Intervention for Their Young Child with Autism (Hastings & Johnson, 2001)	To address issues of stress, coping, and support	141 Participants in this research responded to a questionnaire mailed to their home	Higher levels of autism symptomatology were associated with higher reported stress.	This review help contributed in different aspects of stress, coping and support.
Family System and Coping Behaviors: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic	The study deals with strain on the family system, as well as the level of coping and types of coping behavior of the parents, in families with a child diagnosed as having an	Thirty-seven families and 66 parents were involved in each case, and four psychological tests were used.	It was found that lower levels of coping were associated with higher levels of strain on the family system, that the level of strain on the family system was greater in the families with a	This review helped building the foundation of understanding the different coping behaviors in

children (Sivberg, 2002)	autistic spectrum disorder (ASD) as compared to families in a control group		child with an ASD, and that the two groups differed in their pattern of coping behavior.	family who has children with ASD.
Gender and coping: the parents of children with high functioning autism (Gray, 2003)	To analyse the different meanings of the disability for mothers and fathers and describes the various strategies that parents use to cope with their child's disability	This paper presents a qualitative analysis of the role of gender and coping among parents of children with high functioning autism or Asperger's syndrome in an Australian sample	Factors that contribute to parental stress are feelings of loss of personal control, adjustments to the reality of the child's condition, housing and finance, absence of spousal support, informal and professional support	This review helped in identifying the different coping strategies parents of children with disability tend to use.
Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder (Higgins et al., 2005)	To examine the relationship between ASD characteristics, family functioning and coping strategies.	A Survey- Primary caregivers of a child with ASD from a regional and rural area in Victoria, Australia (N = 53) was surveyed concerning their child with ASD, family functioning (adaptability and cohesion), marital satisfaction, self-esteem and coping strategies.	Results suggest that these caregivers had healthy self-esteem, although they reported somewhat lower marital happiness, family cohesion and family adaptability than did norm groups.	This review helped build foundation of coping strategies in this study.
Factors associated with stress in mothers of children with autism (Duarte et al., 2005)	To investigate the determinants of maternal stress in mothers of children with autism.	A case control study- Mothers of 31 children with autism from mental health clinics were matched by child age/gender and mother age to 31 mothers of children	Results showed that poor expression of affect, little interest in people, being an older mother, and having a younger child also contributed to	This review has contributed in understanding stress of mothers of children with autism.

		without mental health problems, drawn from public schools and a primary care unit.	increased stress levels. Although having a child with autism was the main factor responsible for stress, the presence of the other factors further increased maternal stress.	
Psychological Functioning and Coping Among Mothers of Children With Autism (Montes & Halterman, 2007)	The objectives of this study were to describe the psychological functioning, physical and mental health, family communication, and parenting support of mothers of a child with autism compared with other mothers on a population basis	A Population-Based Study- Mothers of 61 772 children who were 4 to 17 years of age were surveyed by the National Survey of Children's Health, 2003.	Mothers of a child with autism were highly stressed and more likely to report poor or fair mental health than mothers in the general population, even after adjustment for the child's social skills and demographic background.	This review helped build the foundation of understanding the psychological wellbeing of mothers.
Predictors of Perceived Negative Impact in Mothers of Children With Autism Spectrum Disorder (Bishop et al., 2007)	To identify Predictors of Perceived Negative Impact	Mothers of 110 children with autism spectrum disorders (ASD) were interviewed with the Child and Adolescent Impact Assessment when their children were approximately 9 years old.	Regression analyses revealed that African American mothers reported lower levels of perceived negative impact of having a child with ASD than did Caucasian mothers and less perceived social support were also significant predictors of higher perceived negative impact.	The findings in this study emphasize the importance of looking beyond individual child characteristics and viewing parent burden in terms of a broader social context that includes issues of culture and social support
Stress and psychological wellbeing among parents of children with autism spectrum	To investigate the prevalence of parental stress and psychological wellbeing	A preliminary cross-sectional study which randomly selected parents with	About 90.4% of parents had significant parenting stress, and 53.8% of parents showed	This review contributed to a clearer perspective on parenting stress and

disorder (Nikmat et al., 2008)	among parents with autistic children and their associations with dimensions of support system	clinically diagnosed autistic children	clinical disturbance in psychological wellbeing.	psychological wellbeing of parents of children with autism.
Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay (Estes et al., 2009)	To investigate the relative contribution of child characteristics including diagnosis, problem behavior, and adaptive functioning, to increased maternal parenting stress and psychological distress in mothers of children with autism.	Longitudinal study Children consisted of 51 diagnosed with autism spectrum disorder (ASD) and 23 with developmental delay without autism (DD)	Results indicate that child problem behaviors were positively associated with both parenting stress and psychological distress	This review has contributed to the understanding of family processes and has provided evidence suggesting mothers of children with developmental disabilities, particularly autism, maybe at risk for a range of challenges to their psychological functioning.
Factors Contributing to Stress in Parents of Individuals with Autistic Spectrum Disorders (Tehee et al., 2009)	To explore the experiences of parents of individuals with autistic spectrum disorders (ASDs), and examines the influences of parent gender and child age on perceived stress, stress and coping, child-rearing involvement,	Questionnaires assessed general perceived stress, involvement, stress and coping related to caregiving, social support, and amount of information/ education accessed in 23 mothers and 19 fathers of 3- to 18-year-old individuals with ASDs.	When compared with fathers, mothers were significantly more stressed, more involved, and reported higher levels of stress and coping related to caregiving	The review helped in understanding that providing parents with information may improve their access to support services, hence improving their ability to cope and effectively reduce stress levels.

	support and information/ education accessed.			
Parenting Stress and Closeness Mothers of Typically Developing Children And Mothers of Children with Autism (Hoffman et al., 2009)	To compare the stress level and closeness in Mothers of Typically Developing Children And Mothers of Children with Autism	Sample: 104 mothers of children with autism 324 mothers of typically developing children	Mothers of children with autism were reported to have higher levels of stress than mothers of typically developing children.	The high levels of stress indicated the importance of effective interventions to help them to cope successfully with the demands of parenting a child with autism.
Parenting Stress in Mothers of Children With Autism Spectrum Disorders (Phetrasuwan & Shandor Miles, 2009)	To describe the sources of parenting stress in mothers of children with Autism Spectrum Disorders (ASD) and examine the relationship between parenting stress and maternal psychological status (Depression and well-being).	A descriptive correlational design was used. Data were collected via mailed questionnaires	Mothers who experienced high stress were also reported to have depressive symptoms and lower levels of well-being	This study helped in identifying specific sources of stress related to parenting a child with ASD.

Intervention Studies

Research has increasingly focused on developing and evaluating interventions to alleviate the stress experienced by parents of children with autism. These interventions vary widely in their approach, and methodologies. This section reviews notable

intervention studies, highlighting the strategies employed and their effectiveness in reducing parental stress.

Some interventions are specifically designed for mothers, who often bear the primary caregiving responsibilities, while others include both parents, acknowledging the joint role in supporting their child's development. Additionally, there are interventions that primarily focus on the child but are parent-assisted. These interventions recognize the strong connection between a child's behavioural, communicative, or developmental challenges and the well-being of their caregivers. By involving parents directly in the therapeutic process, these interventions play a crucial role in enhancing the coping strategies, confidence, and overall mental health of the caregivers, ultimately benefiting the entire family dynamic.

Behavioural-focused Interventions

Behavioural-focused interventions are designed with the primary goal of addressing the specific behavioural, communicative, and developmental challenges that children with ASD encounter. These interventions often involve parents as co-therapists or include them in the training process (Koegel et al., 2002). By engaging parents in the therapeutic process, these programs not only target the child's growth and development but also provide substantial benefits to the parents (Beaudoin et al., 2014; Prata et al., 2018). As parents are trained to implement therapeutic techniques and strategies, they become more empowered and confident in managing their child's challenges (Wang, 2008; Deb et al., 2020; Kaiser et al., 2022). The progress the child makes whether in communication, behaviour management, or social interaction leads to a significant reduction in parental stress (Shine & Perry, 2010). This decrease in stress is linked to the alleviation of the constant concerns and anxieties that parents typically face regarding their child's future, well-being, and ability to navigate everyday life as evident in many research studies.

Including Both Parents. Benedixen et al. (2011) conducted a quasi-experimental study on an in-home parent training intervention for parents of children with autism, involving 19 fathers and 19 mothers. The intervention, which focused on training fathers who then trained mothers, aimed to improve parent-child interaction. The Parenting Stress Index-Short Form (PSI-SF; Abidin, 1990) revealed a significant reduction in mothers' stress levels post-intervention, while fathers' stress showed less improvement.

The study suggests that enhancing a child's interaction skills can alleviate mothers' caregiving stress, especially with active paternal involvement. Building on the concept of improving child outcomes to benefit parents.

Dunn et al. (2012) tested an occupational therapy contextual intervention aimed at improving children's participation in daily activities. Using a repeated-measures pretest–post-test design, 20 parents were trained in strategies to support their child's participation. The study used the PSI-SF to measure parental stress and the Parenting Sense of Competence Scale (PSOC; Johnston & Mash, 1989) to assess parental self-efficacy. Results showed significant decreases in parental stress and increases in parental self-efficacy, indicating that as the child's participation improved, so did the parents' confidence in their caregiving abilities.

The role of parental involvement was further emphasized in the study by Braiden et al. (2012) which evaluated a TEACCH-based (Treatment and Education of Autistic and Related Communication Handicapped Children) Early Intervention Programme involving 31 parents of 18 preschool children with autism. The eight-week program trained parents as "co-therapists" for home-based interventions. Results showed a significant decrease in parental stress and improvements in children's language skills.

Similarly, D'Elia et al. (2014) conducted a 24-month longitudinal study with 30 preschool children using the TEACCH program, finding a significant reduction in parental stress. This highlights the crucial role of parents in the rehabilitation process for effective treatment outcomes.

Another intervention method, Parent-Child Interaction Therapy (PCIT), was investigated by Budd et al. (2011). This 13-session program aimed at promoting positive parenting practices and improving children's social and communicative skills resulted in decreased behaviour problems, enhanced parent-child interactions, and reduced parental stress, demonstrating the efficacy of structured behavioural interventions in 12 families.

Estes et al. (2014) conducted a randomized controlled trial to assess the effects of a parent-coaching intervention using the Early Start Denver Model (P-ESDM) on parenting stress and competence. The P-ESDM focuses on building positive relationships between children with ASD and their parents by teaching interactive principles, such as gaining attention, encouraging communication, and integrating these strategies into daily routines. Over 13 one-hour sessions, parents were coached on these techniques. The study found that parents of newly diagnosed young children who received P-ESDM

coaching reported significantly lower stress levels and higher sense of competence compared to those receiving standard community interventions.

Hodgetts and McConnell (2013) examined the experiences and outcomes of a behavioural family intervention, the Standard Stepping Stones Triple P (SSTP), involving 10 mothers and 5 fathers of children with disabilities. The SSTP program, though structured, was tailored to meet each family's specific goals and circumstances. The intervention aimed to enhance parental competence in managing disruptive behavior, reduce negative parenting practices, improve parental well-being, foster better problem-solving skills, and strengthen parental relationships regarding parenting roles. Conducted over 10 one-hour sessions, the study utilized the Depression-Anxiety-Stress Scales (DASS; Lovibond & Lovibond, 1995) and the Difficult Behaviour Self-Efficacy Scale (Hastings & Symes, 2002) to measure outcomes. Results showed significant improvements in parental well-being and self-efficacy (Hodgetts & McConnell, 2013).

Minjarez et al. (2012) conducted a study to assess the impact of a Pivotal Response Training (PRT) group therapy program on parents of children with autism, focusing on how the program influenced parental stress and empowerment. Seventeen families participated in a 10-week group therapy designed to teach parents how to apply PRT, particularly targeting their children's language challenges. The study used the PSI-SF (Abidin, 1990) and the Family Empowerment Scale (Koren et al., 1992) to measure outcomes. Results showed significant improvements from pre- to post-treatment, with parents reporting reduced stress levels and increased feelings of empowerment following the program.

These studies collectively highlight the diverse approaches to intervention, each emphasizing different aspects of parental involvement, training, and support, ultimately contributing to reduced stress and enhanced competence among parents of children with autism. Additionally, they highlight the critical role of behavioural-focused interventions in improving both child and parent outcomes. Many other research studies further demonstrate the importance and efficacy of behavioural-focused approaches, reinforcing the need for continued exploration and application of these strategies to support families dealing with autism (Keen et al., 2007; Küçüker, 2006; Leung et al., 2013; Sofronoff & Farbotko, 2002; Whittingham et al., 2009; Wong & Kwan, 2010).

Mindfulness- focused Interventions

Mindfulness-based interventions have increasingly been recognized as valuable tools for helping parents of children with autism and other special needs manage stress and improve overall well-being. These interventions, which focus on enhancing present-moment awareness and emotional regulation, have been widely studied, with research consistently showing their effectiveness in reducing stress, anxiety, and depression among parents and caregivers. The following studies exemplify the growing body of evidence supporting the use of mindfulness-based approaches in this context.

Including Both Parents. Benn et al. (2012) conducted a randomized controlled trial to evaluate the effectiveness of a 5-week mindfulness training (MT) program for parents and educators of children with special needs. The study included 70 participants, comprising 32 parents and 38 educators. The Five Facet Mindfulness Questionnaire (Baer et al., 2006), a 39-item validated measure of mindfulness, was used as the primary assessment tool. Results indicated that participants who completed the MT program experienced significant reductions in stress and anxiety, along with increased mindfulness, self-compassion, and personal growth, both at the end of the program and at the 2-month follow-up, compared to those on the waiting list.

Similarly, Ferraioli and Harris (2013) conducted a study comparing two intervention approaches for parents of children with autism: a behavioural skills approach and a mindfulness-based model. Fifteen parents, matched based on their levels of stress, were randomly assigned to one of the two groups. Both groups participated in an 8-week program that included educational sessions, discussions, role-playing, and homework assignments. Parental stress and overall health were measured before the treatment, immediately after, and at a 3-month follow-up. The results showed that only the mindfulness group experienced statistically significant improvements in both stress levels and global health outcomes after the intervention. While the skills group did not show significant changes, the effect sizes indicated moderate to large potential benefits from the treatment.

Blackledge and Hayes (2006) conducted a within-subject, repeated measures study to evaluate the impact of a 2-day (14-hour) Acceptance and Commitment Therapy (ACT) workshop on 20 parents or guardians of children diagnosed with autism.

Participants were assessed at four different points: three weeks before the workshop, one week before, one week after, and three months following the intervention. The results showed significant reductions in general distress and depression levels, as measured by the General Symptom Index (GSI) and the Beck Depression Inventory-II (BDI-II), immediately after the workshop. These psychological improvements were largely maintained over the three-month follow-up period. Kowalkowski (2012) further investigated the benefits of ACT in a study comparing it to treatment as usual (TAU) in mothers of children with autism. The ACT group exhibited significant reductions in parental distress and general psychological symptoms, as measured by the Parental Stress Index-Short Form (PSI-SF) and General Symptom Index (GSI), from baseline to post-intervention. These findings suggest that ACT-based group therapy can play a crucial role in helping parents navigate the challenges of raising children with autism.

Including Only Mothers. Singh et al. (2006) conducted a study involving three mothers who participated in a 12-week mindfulness course to examine its effects on their children's behavior and their own parenting satisfaction. The course focused on teaching the philosophy and practice of mindfulness to help mothers develop greater awareness and acceptance in their parenting. Results showed that the mothers' mindful parenting significantly decreased their children's aggression, noncompliance, and self-injury, while also increasing the mothers' satisfaction with their parenting skills and interactions with their children. This study highlights the potential benefits of mindfulness-based interventions for improving both child behavior and parental satisfaction

Dykens et al. (2014) conducted a study involving 243 mothers of children with disabilities, who were randomly assigned to either a Mindfulness-Based Stress Reduction (MBSR) program or a Positive Adult Development (PAD) program focused on positive psychology practices. Both groups participated in 6 weeks of group sessions, meeting weekly for 1.5 hours. The mothers were assessed at six different points: before, during, and up to 6 months after the treatment. The results showed significant reductions in stress, depression, and anxiety, along with improvements in sleep and life satisfaction for both groups. However, mothers in the MBSR group experienced even greater improvements in anxiety, depression, sleep quality, and overall well-being compared to those in the PAD group.

In a proof-of-concept study by Singh et al. (2014), the effects of mindfulness-based positive behaviour support (MBPBS) training were assessed on three mothers and their adolescents with ASD. The 8-week MBPBS program included a series of meditations aimed at personal transformation. The results indicated that the adolescents' challenging behaviours decreased while their compliance behaviours increased in line with the mothers' training. Additionally, there were statistically significant reductions in the mothers' stress levels correlated with the MBPBS training.

These studies collectively demonstrate the effectiveness of mindfulness-based interventions in reducing stress and improving mental health among parents of children with autism and other special needs. The growing body of research in this area provides strong support for the continued use and development of mindfulness-based programs tailored to the unique needs of these parents. Indeed, many more studies have further explored and confirmed the benefits of mindfulness-based approaches, solidifying their place as valuable tools in supporting parental well-being (Hahs, 2013; Ruiz-Robledillo et al., 2015).

Psychoeducational-focused Interventions

Psychoeducational interventions for parents of children with autism include a range of strategies designed to provide information, develop skills, and enhance coping mechanisms to reduce stress and improve quality of life. These interventions often include educational components, skill-building sessions, and techniques aimed at managing stress and improving emotional well-being. The effectiveness of these approaches is evidenced by various research studies.

Including Both Parents. Samadi et al. (2012) conducted a study involving two groups of parents of children with ASD, comprising a total of 37 participants. The parents participated in seven group-based sessions that not only provided information about ASD but also emphasized the importance of families sharing their experiences and learning from each other. The study employed a pre-post, cross-over design to assess the specific effects of the course. The improvements observed in the first group of parents were successfully replicated in the second group, and these positive changes were maintained up to 15 weeks after the course concluded. While individual experiences varied, parents generally reported reduced stress, improved emotional well-being,

enhanced family functioning, and an increased use of problem-focused coping strategies. These positive outcomes were largely attributed to the growth of informal support networks among the parents and their increased sense of empowerment.

Chiang (2014) examined the effectiveness of a 10-week parent education program aimed at reducing parenting stress and improving parental confidence and quality of life in parents of Chinese American children with autism spectrum disorders. The study, which included 9 mothers and 2 fathers using a pre- and post-test group design, involved weekly 120-minute group sessions. Findings revealed a significant reduction in parenting stress, along with improvements in parental confidence and quality of life, particularly in the physical health and environment domains, as measured by the World Health Organization Quality of Life Questionnaire (WHOQOL).

Patra et al. (2015) conducted a study involving 18 parents who participated in a 12-session program, with each session lasting 2 hours. The results demonstrated improvements across all domains of parenting stress and knowledge. Notably, both the social stress score and the total stress score showed significant improvement following the intervention.

Building on the emphasis on skill development, Dababnah and Parish (2016) evaluated the effectiveness of The Incredible Years Parent Program, which focuses on developing parental skills in problem-solving, coping methods, stress management, and communication. The study involved 16 mothers and 1 father who participated in 12 individual sessions, each lasting 2 hours. Using the Parent Stress Index (PSI), the results showed a significant decrease in parental stress following the completion of the program.

Including Only Mothers. Anclair and Hiltunen (2014) introduced a different therapeutic approach using Cognitive Behavioural Therapy (CBT) combined with Acceptance and Commitment Therapy (ACT) to support two mothers of children with autism. The intervention consisted of 17 individual sessions where the mothers were guided toward new insights and emotional re-learning through techniques like cognitive restructuring, behaviour experiments, and emotion regulation, combined with ACT methods such as acceptance, value-based decision-making, and cognitive diffusion. The effectiveness of the intervention was measured using the Shirom–Melamed Burnout Questionnaire (SMBQ), which assesses burnout across four subscales—Mental Fatigue,

Cognitive Weariness, Tension, and Listlessness—and the Montgomery–Åsberg Depression Rating Scale (MADRS) for depression. The results showed a significant reduction in both burnout and depression symptoms, demonstrating the efficacy of this tailored therapeutic approach in addressing the psychological challenges faced by mothers of children with autism.

Al-Khalaf, Dempsey, and Dally (2014) conducted an educational intervention program involving 10 mothers of preschool-aged children with ASD. The program aimed to help mothers develop coping strategies for managing daily challenges and reducing stress in everyday situations by enhancing their knowledge of autism and equipping them with practical skills. The intervention consisted of 4-hour sessions held weekly for 4 weeks. To measure the program's effectiveness, the researchers used the Coping Strategy Indicator Scale (CSI), which assesses situational coping through strategies like avoidance, problem-solving, and seeking social support, along with the Parent Stress Index (PSI). The results showed a statistically significant reduction in stress levels and a significant increase in coping skills among the mothers, as evidenced by their improved scores following the intervention.

In a similar vein, Ergüner-Tekinalp and Akkök (2004) evaluated a coping skills training program for mothers of children with autism, focusing on stress, hopelessness, and coping skills. Twenty mothers were divided into a treatment group and a control group. The program, consisting of 8 sessions over four weeks, included stress management, problem-solving, relaxation, positive thinking, and social support techniques. Using the Questionnaire on Resources and Stress (QRS), Coping Strategy Indicator (CSI), and Beck Hopelessness Scale, the study found no significant differences in stress levels or the use of problem-solving and avoidance strategies between the groups. However, significant improvements were observed in the use of social support and reduced hopelessness in the treatment group.

Gika et al. (2012) conducted a pilot case-series study to evaluate the effects of a 6-week daily stress management technique on mothers of children with autism. The study included 11 mothers who were guided in relaxation techniques, including breathing exercises and progressive muscle relaxation. Participants were instructed to practice these techniques for 20 minutes twice daily for the duration of the study. The results showed statistically significant median reductions in perceived and parental stress after completing the 6-week intervention.

These studies illustrate the diverse approaches within psychoeducational-focused interventions, demonstrating their effectiveness in reducing stress and improving the well-being of parents of children with autism. There are many additional research studies that further support the significance of psychoeducational interventions in this context (Farmer & Reupert, 2013; McConkey & Samadi, 2013; Suzuki et al., 2014; McAleese et al., 2014; Elfert, M., & Mirenda, 2015; Magaña et al., 2017).

The diverse intervention programs for parents of children with autism highlight the effectiveness of various approaches in addressing parenting challenges. Overall, these interventions collectively support parents by reducing stress, enhancing coping strategies, and improving overall well-being. The broad range of research highlights the importance of continuing to develop and refine these programs to better support families and improve their quality of life.

Methodological Limitations of Intervention Studies

While the reviewed intervention studies demonstrate positive outcomes in reducing parental stress and enhancing parenting competence, several methodological limitations should be acknowledged. Many studies had small sample sizes, limiting the generalizability of findings, and some lacked control groups, making it difficult to determine whether improvements were directly attributable to the intervention. Additionally, the reliance on self-reported measures introduces potential bias, and the inconsistency in measurement tools across studies complicates cross-study comparisons. Short-term follow-ups raise concerns about the long-term sustainability of these interventions, as many studies assessed outcomes only weeks or months post-intervention without examining whether benefits persisted over time. Most studies were conducted in Western contexts, with limited exploration of cultural differences in intervention effectiveness, and largely focused on mothers, with minimal inclusion of fathers or other caregivers. Furthermore, while some interventions reported secondary benefits for children, the majority did not assess child outcomes, leaving gaps in understanding how reduced parental stress translates into improvements in child development and family dynamics. Future research should address these gaps by incorporating larger, more diverse samples, robust control conditions, and longitudinal designs to better assess intervention sustainability and broader family impact.

Summary of Reviewed Literature

Parenting Stress in ASD

Parenting a child with ASD is particularly stressful due to communication and behavioural challenges, social stigma, and difficulties accessing appropriate services. Studies indicate that parents of children with autism report higher stress levels compared to those of children with other developmental disabilities.

Factors Influencing Stress

Behavioural Challenges. Severe autism symptoms and co-occurring conditions increase caregiving demands.

Lack of Support. Limited social, emotional, and practical support exacerbates stress. Barriers to accessing healthcare and educational resources also contribute.

Unhelpful Coping Responses. Ineffective coping strategies, such as avoidance, can heighten stress and prevent problem resolution.

Maternal Stress in ASD

Mothers of children with ASD often experience greater stress than fathers, influenced by their central caregiving role and greater exposure to social stigma. Research consistently shows higher levels of stress and depression in mothers compared to fathers. Differences in stress levels between parents are linked to their roles, expectations, and interactions with their children.

Support

Need for Social Support in Mothers of Children with ASD

Mothers of children with ASD face unique stressors, making social support essential. Emotional support helps them cope with stress and reduces feelings of isolation. Instrumental support, such as help with childcare and financial assistance, alleviates the physical and economic burden of caregiving. Informational support provides guidance on managing autism and navigating systems, which is crucial for effective care. Support helps build resilience, enhancing maternal self-efficacy and overall well-being.

Challenges and Barriers in Accessing Support

Mothers of children with autism face several challenges in accessing support:

Service Availability. Long waitlists and limited services, especially in rural areas, increase stress.

Financial Strain. High costs of care and inadequate government support create financial barriers.

Social Isolation and Stigma. Judgment and lack of community support contribute to social isolation.

Emotional and Psychological Barriers. Feelings of guilt and shame may prevent seeking help.

Inconsistent Professional Support. Gaps in training and fragmented services hinder access to comprehensive care.

Information Gaps. Difficulty accessing accurate information adds to stress.

Lack of Tailored Services. Generic approaches do not address specific needs, leaving gaps in support.

Effective support systems are crucial for enhancing the well-being and coping abilities of mothers caring for children with autism.

Coping

Overview

Coping refers to behaviours that protect individuals from psychological harm due to challenging social experiences. It involves a dynamic interaction between a person and their environment, where the goal is to balance demands with available resources (Lazarus & Folkman, 1984). Coping strategies are crucial for managing stress and maintaining psychological well-being.

Effective coping strategies are vital for resilience and psychological balance. Problem-focused coping helps in managing stressors directly, while emotion-focused coping aids in handling emotional responses when stressors are beyond control. Maladaptive coping can lead to increased stress and psychological distress, highlighting the need for appropriate coping mechanisms.

Coping in Mothers of Children with Autism

Mothers of children with ASD face unique challenges and use a range of coping strategies. Problem-focused strategies, such as active coping and planning, are beneficial for managing stress and improving caregiving. Emotion-focused strategies, like cognitive reframing and seeking social support, help manage emotional responses but can have drawbacks if used maladaptively. Maladaptive strategies, such as denial and substance abuse, can increase stress and harm mental health. Social support plays a crucial role in enhancing coping outcomes and reducing stress. Adaptive coping strategies are linked to better quality of life, while maladaptive strategies can lower well-being. Interventions promoting effective coping and supporting mental health are essential for improving resilience among mothers of children with autism.

Summary of Intervention Studies

Research has increasingly focused on interventions to alleviate the stress experienced by parents of children with autism. These interventions vary widely in approach and methodology, but they all share a common goal: reducing parental stress and improving overall well-being.

Significance of Interventions

Interventions designed for parents are critical due to the substantial stress associated with raising a child with autism. These programs often target different aspects of parenting and child development, recognizing the interconnected nature of caregiver well-being and child progress. By directly involving parents in the therapeutic process, interventions not only address the child's needs but also enhance the caregivers' coping strategies, confidence, and mental health. This holistic approach benefits the entire family dynamic.

Types of Interventions

Behavioural-Focused Interventions. These programs address specific behavioural, communicative, and developmental challenges faced by children with autism. They frequently involve parents as active participants or co-therapists, empowering them with techniques to manage their child's issues effectively. The engagement of parents in these interventions often leads to a significant reduction in their stress levels as they become more adept at handling their child's needs.

Mindfulness-Focused Interventions. Mindfulness-based approaches have been shown to be effective in reducing stress, anxiety, and depression among parents. These interventions focus on enhancing present-moment awareness and emotional regulation, which helps parents manage their stress and improve their overall well-being. The growing body of evidence supports the use of mindfulness practices as a valuable tool for supporting parental mental health.

Psychoeducational-Focused Interventions. These programs provide education and skills development to help parents manage stress and improve their quality of life. By offering information about autism and strategies for coping, these interventions empower parents with knowledge and skills that enhance their ability to support their child and improve family functioning. Overall, the significance of these interventions lies in their ability to address both the practical and emotional challenges faced by parents. By reducing stress, enhancing coping mechanisms, and improving mental health, these programs play a crucial role in supporting families and improving their quality of life.