



## **THE BURDEN OF CARE: MENTAL HEALTH STRUGGLES AMONG PARENTS OF CHILDREN WITH AUTISM**

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**Abstract:** Numerous situations necessitate social adjustments within families, and the birth of a child represents a fundamental instance. However, no matter how prepared a family is, none is prepared enough for the birth of a child with ASD and the challenges that comes with it. The complexities associated with the birth and upbringing of an autistic child intertwine intricate array of challenges both within the family unit and within the broader societal context. Asides, confronting societal isolation, parents grapple not only with comprehending the intricacies of autism but also with primary questions regarding causality, management strategies, avenues for support, and the uncertainties of their children's future. This constant struggle manifests in persistent stress, anxiety, and depression, as substantiated by existing research, which underscores a higher prevalence of these mental health challenges amongst parents raising children with Autism Spectrum Disorder (ASD) in comparison to their counterparts raising typically developing children. This study meticulously employed a systematic search approach across two prominent databases, Cinahl Ultimate and PsycINFO. After the application of rigorous exclusion and inclusion criteria, the review and assessment of articles from these databases encompassed the selection of 10 articles, elucidating pertinent insights. The findings revealed a recurring pattern of increased level of stress, depressive symptoms, and anxiety adverse mental health outcomes among parents raising children with ASD due to an interplay of innumerable numbers of factors. This complex interplay of factors included the critical influence of social support both formal and informal, societal lack of understanding culminating in isolation and stigmatization, behavioural challenges exhibited by ASD children which make them constantly fall below societal expectation, coping mechanisms adopted by parents, socioeconomic factors which serves as a predictive elements for ASD severity, and fear of the future which plays a pivotal roles in influencing parental mental health outcome. In conclusion, enhancing the mental health outcomes of parents navigating the challenges of raising children with ASD necessitates a comprehensive and collaborative approach involving all societal stakeholders. The implementation of robust policies and structures stands imperative to provide sustained and consistent support for this specific cohort of parents.

**Keywords:** Autism spectrum disorder, social adjustment, child birth, stress, anxiety, societal isolation

### **Introduction**

Many situation calls for social adjustment within families. One of such situations is the birth of a new child. Many families put a lot of effort into preparing for a new addition to the family. Adjustments in finances, social life, living arrangements and support systems are made in readiness for the new addition. Members of the family try to envisage the uniqueness of the needs of the new addition. They prepare for the event by reading books, attending mentoring and counselling sessions and generally making mental notes of what they think will be involved in meeting their child's needs of. However, no matter the amount of preparation, no family is fully ready for the mental and psychological demands a new child in the family brings with him and more specifically, nothing prepares any family for the burdens of nurturing a child with the diagnosis of the any form of disability. Raising a child with any form of disability poses extreme stress for the parents and carers of such a child (Joon, Kumar and Parle, 2021), although the amount of stress experienced may depend on how severe the disability of the child presents, the general effect on the productivity and well-being of the family cannot be overemphasised. Every type of disability presents with its own unique characteristic and demands in different children, this in turn determine the extent of challenge confronted by the immediate family and carers of such children. According to Dabrowska and Pisula (2010) studies have found that parents raising children with disabilities experience more stress than parents raising children with no disability. One common disability in the world is the autism spectrum disorder. According to Dabrowska and Pisula (2010) "Autism spectrum disorder commonly referred to as autism is a heterogeneous, multi-factorial, developmental disability in which an unusual pattern of development takes place during infant and toddler years". "ASD is characterised by challenges to two - way social communication and interaction, as well as restricted, repetitive patterns of behaviour or interests" (American Psychiatric Association, 2013). It affects people across all socioeconomic, ethnic, and racial groups, with a prevalence that has been steadily increasing in recent years. ASD is usually detected in early childhood, and its effects extend beyond the individuals with the disorder to significantly impact their families and caregivers. Raising a child with ASD can be a unique and demanding experience. The struggles related with raising an autistic child can manifest in various ways, including the need for specialized care, frequent behavioural and emotional difficulties, and difficulties with communication and social interactions. As a result, the mental health of parents who have autistic children is an area of increasing concern. Hence, a good understanding of the mental health implications of parenting children with ASD is crucial for providing appropriate support and interventions. The physical, psychological, and emotional demands of raising a child diagnosed with ASD can have intense effects on parental well-being and overall quality of life. This is reinforced by Catalano D et al. (2018) who explained that parents of children diagnosed with Autism Spectrum Disorder (ASD), who are usually the main carers, are highly predisposed to a condition called the "caregiver syndrome" or "caregiver stress." This results from prolonged and continuous caring for a person with chronic illness, this then leads to a feeling of anger, guilt, rage, or exhaustion. Consequently, this cumulates into change in behaviour, from positive and loving to harmful and indifferent, as a result of the continuing demands of taking care of a dependent individual. Furthermore, the daily stressors and challenges of parenting a child with ASD can become intense for some parents and as a result, some research has found that parents and carers of children with Autism Spectrum Disorder (ASD) regularly undergo significant anxiety, stress, and depression the failure to address their mental health needs may have severe repercussions for their psychological, physical, and social well-being, as well as the adaptive functioning of the family unit and the developmental progress of the child with ASD (Catalano D et al. 2018). According to World Health Organization (2023) 1 in every 100 children shows signs of autism but it is not usually diagnosed early. The National Autistic Society in the United Kingdom (2023) stated that 1 out of 100 people in the United Kingdom including both

children and adults have been diagnosed with autism. It is worthy of note that autism is a spectrum condition, which means that it can present in many different ways and with varying levels of severity. While some people with autism can live a normal life, others live as dependents all their life (WHO, 2023). As a result, it cannot be denied that parents responsible for nurturing children with ASD are under tremendous stress, high levels of anxiety, depression, worry and poorer quality of life (Herrema R et al. 2017) and hence, the area of their mental health is an area of growing concern.

### **Objective of the study**

To understand how parents cope with the challenges and stressors associated with raising autistic children, this will be measured using the level of stress, anxiety and depression among parents of children with ASD as compared to parents of typically developing children.

### **Conceptual framework**

The existing body of academic work has extensively documented the profound impact of Autism Spectrum Disorder (ASD) on the psychological well-being of both children diagnosed with ASD and their parents. Although a substantial amount of literature exists exploring the psychological effects of ASD on children, relatively fewer studies have delved into the intricate relationship between raising a child with ASD and the mental health of their parents. Existing research has primarily concentrated on quantifying the levels of anxiety and stress experienced by parents grappling with the challenges posed by ASD within their families. This study aims to critically review the available evidence and clarify the complex relationship between parenting a child with autism and its implications on the mental health of the parents. This comprehensive analysis will encompass an exploration of the quality of life experienced by parents in such circumstances, the support system accessible to them, and the prevalence of anxiety and depression within this demographic. A thorough examination of the literature unequivocally corroborates the existence of a direct and confirmed link between raising a child with ASD and the mental well-being of parents. Smith et al. (2023) posits that social participation, a significant measure of an individual's engagement in community-based social activities, constitutes an essential factor in fostering positive child development, enhancing quality of life, and promoting overall health and well-being. It plays a crucial role in establishing connections with others, active participation in community life, and the cultivation of meaningful friendships. Smith et al. (2023) have detected that families raising children with ASD encounter significant challenges in multiple domains. Foremost among these challenges is the perpetual struggle these families face in meeting societal expectations, often falling short and consequently experiencing feelings of frustration and perceived inadequacy. Families continuously grapple with the pressure to conform to societal norms, which, in turn, prompts a state of constant vigilance and apprehension regarding their child's ability to conform to accepted behavioural standards in social settings. This sentiment resonates with the findings of a study conducted by Hoogsteen and Woodgate (2013), wherein parents of children with ASD similarly attributed societal misunderstandings and the concealed nature of autism as contributing factors to their predicament. Consequently, many parents adopt avoidance as a coping mechanism, abstaining from participating in social events, with cascading implications for their own quality of life, sense of belonging, and availability for respite. A surprising, yet pivotal, bi-directional consequence of this coping mechanism is its unplanned impact on the social skills of children with ASD. It emerges that parents who resort to avoidance as a coping strategy inadvertently nurture ASD children who exhibit pronounced behavioural challenges and deficient social aptitude. This unexpected finding is further validated in the research conducted by Zaidman-Zait et al. (2018), who discovered that children with ASD, whose parents employed disengaged, emotion-focused coping mechanisms, exhibited poorer school

integration outcomes compared to their counterparts whose parents adopted more engaged strategies. This outcome is contradictory, given the conventional assumption that shielding children from societal judgment and pressure of conformity would bolster their self-efficacy; however, it emerges as a more damaging approach for both children and, consequently, the mental health of their parents. Smith et al. (2023) research offers compelling insights into the profound issue of a deficient sense of belonging among parents of children with Autism Spectrum Disorder (ASD). These parents and caregivers find themselves ensnared in a disconcerting struggle characterized by isolation and detachment from both their immediate families and society at large. Such sentiments are basically tied to the parents' perception of an overarching lack of comprehension regarding autism within their social setting, coupled with their perceived incapacity to meet society's expectations. The authenticity of this finding is substantiated by the work of Blanche et al. (2015), who discovered that parents often perceive their children as being unfairly labelled and treated differently, leading them to withhold their children's diagnosis and employ a multitude of tactics to shield their child's behaviour in public as a tactic to prevent members of the society from catching a glimpse of their reality. Furthermore, parents contend with the inadequacy of community facilities, which are perceived as either overly stimulating or inadequately accommodating for their children's unique needs. Consequently, they grapple with an overwhelming sense of neglect and unsupportiveness from their communities, culminating in a profound impact on their sense of self-worth and belonging. Hoogsteen and Woodgate (2013) corroborate this aspect by revealing the pivotal role of societal misunderstanding in nurturing parents' feelings of isolation and estrangement.

### **Methodological Analysis of Selected Studies**

#### **Smith et al. (2023)**

Smith et al. (2023) adopted a phenomenological approach and employed semi-structured interviews to investigate the experiences of participants. This method allows for a deep exploration of the subject matter, capturing rich, qualitative data. Rigorous data analysis techniques were employed to bolster credibility, trustworthiness, reliability, and dependability. However, this study has several limitations. The sample size is relatively small, potentially impacting the generalizability of the findings. Furthermore, the research may suffer from researcher bias in data interpretation. A key concern is the homogeneity of the study demography, primarily consisting of English-speaking couples, limiting diversity and generalizability.

#### **Hoogsteen and Woodgate (2013)**

Hoogsteen and Woodgate (2013) utilised a hermeneutic phenomenological approach, enriching the study with a theoretical foundation to measure human experiences accurately. Ethical approval and a diverse participant sample strengthened the research. Semi-structured interviews were used to facilitate participants' free expression of feelings, fears, challenges, and beliefs. Additionally, the data extraction process was rigorous and suitable for the study design. Nevertheless, this study has its limitations. It is constrained by limited demographic diversity, with a predominant Caucasian representation and a Canadian context, reducing its broader applicability. The study does not explicitly detail the measures taken to avoid biases, and there is a lack of transparency regarding the interview collection and the study's timeframe.

#### **Cameron and Cooper (2020)**

Cameron and Cooper (2020) demonstrated transparency in their recruitment process, obtaining informed consent from participants and conducting interviews in comfortable settings. The study's ethical considerations were ensured through approvals from the NHS and higher education institutions. An interpretative phenomenological approach to data analysis enabled an in-depth understanding of participants' experiences. However, the study

grapples with limitations. The sample size is relatively small, potentially limiting the applicability of findings. The interpretation of results based on expertise introduces the possibility of bias. Furthermore, the study does not provide a thorough explanation of adherence to data security policies.

#### **Zaidman-Zait et al. (2018)**

Zaidman-Zait et al. (2018) leveraged on a large and diverse longitudinal study to enhance the generalizability of their findings. Ethical considerations were prioritized, and participants were well-informed and consented to their involvement. The longitudinal nature of the study allowed the observation of changes in outcomes over time. Established and validated measures contributed to the study's validity. However, the research is limited by a narrow age restriction (2-4 years old), potentially excluding older children from the study's scope. The time differences in the longitudinal study may introduce confounding variables. Additionally, the study's focus on child behaviour and parental stress may overlook other essential factors. The use of self-reported data poses a risk of bias. Importantly, the study lacks a detailed discussion on validity and reliability.

#### **Alnazly and Abojedi (2019)**

Alnazly and Abojedi (2019) meticulously defined inclusion criteria, adhering to ethical standards. Calculated sample sizes reflected an attempt to achieve good representation. Transparently documented data collection processes and consent procedures enhanced the study's reliability. Established scales were employed to bolster the study's validity. However, the study's use of convenient sampling introduces selection bias. The limited geographical scope of recruited participants restricts generalizability. The reliance on self-reported data may introduce response bias. The internal consistency scores in this study were lower than those in other similar studies, raising questions about the study's reliability.

#### **Study Design**

A methodological approach integrating the combination of keywords and search terms was employed to systematically search databases in a methodically structured manner. The primary objective was to discern articles and studies encompassing a diverse array of methodologies pertinent to the investigation, with the capacity to address the research inquiries effectively (Noble and Smith, 2018). This strategic selection is underpinned by the overarching goal of a systematic review: to meticulously identify, scrutinize, amalgamate, and critically evaluate the extant body of knowledge. Such an undertaking serves the pivotal purpose of equipping professionals, policy architects, and decision-makers with insights to substantially mitigate health disparities (Ganeshkumar and Gopalakrishnan, 2013).

#### **Study Design**

A systematic review was planned to collect and analyse a range of studies characterized by diverse methodologies. The search encompassed electronic databases including CINAHL ultimate and PsycInfo database. Various combination of keywords were employed, ultimately culminating in the selection of articles. The inclusion criteria dictated consideration of articles with keyword from the topic, articles published between 2013 and 2023, composed in the English language. Exclusion criteria were set by factors such as age, availability of full text, analysis focused on ASD children rather than their parents, and studies focused on population beyond the specified population set in the inclusion criteria. After applying further filters and exclusion criteria, 19 articles remained. Ultimately, 10 articles were chosen for inclusion. The details of the selection process are presented in the PRISMA flowchart below

#### **Findings and discussion**

#### **Social Support (Formal or Informal)**



Parent of children suffering for ASD face unique challenges daily in their personal life and even in the society, hence the impact of social support cannot be over emphasised, according to (Wang, 2021), parents and caregivers of people with ASD experience an elevated level of anxiety, stress and uncertainty. These factors are commonly known to influence quality of life and individual's mental health. Social support is multifaceted and presents in different forms such time spent with others relaxing and resting, attending social events or engaging in social interaction, receiving help for respite, or fulfilment gained from relationships or personal life. The aforementioned are strong predictors of the quality of life a person lives and they influence individual's mental health. Zaidman-Zait et al. (2018) assert that parents of children with ASD, struggling with deficient family dynamics, limited access to social support, and inadequate family-centered care are at an elevated risk of psychological distress and depression. This finding aligns with the conclusions drawn by McConkey and Samadi (2012), explaining that mutual support among parents of ASD children, coupled with professional assistance, contributes significantly to stress reduction associated with caregiving responsibilities. Thus, the assertion emerges that the role of social support is pivotal in shaping the societal adaptation and well-being of parents entrusted with the care of ASD children. Furthermore, it is imperative to acknowledge the dual aspects of social support outlined by Zaidman-Zait et al. (2018) as formal and informal. Both aspects play an integral roles in the lives of individuals. Informal social support stems from familial, friendly, or support group networks, affording parents the avenues to articulate their emotions, seek respite through social engagement, or solitary respite, and thereby mitigating feelings of isolation. Substantiating this, Hayes et al. (2022) established a positive correlation between community support, an informal variant, and parental mental health. This finding aligns with existing literature illustrating the pervasive influence of social support on the mental health of parents navigating the challenges posed by ASD. Also, a longitudinal study by Smith, Greenberg, and Seltzer (2011) revealed that high-quality social support correlated with diminished depressive symptoms among parents of children with ASD. Moreover, peer-support emerged as a pivotal factor in parental mental well-being, as illustrated by McConkey and Samadi (2012). Their research demonstrated that parents fostering interpersonal bonds and maintaining communication subsequent to an ASD training experienced reduced stress levels and exhibited reduced reliance on emotional coping mechanisms in response to stressors. The phenomenon of peer support and group interaction among parents of children with Autism Spectrum Disorder (ASD) is notable, as it conveys a sense of connection and kinship derived from the shared understanding among such parents. This shared experience enables them to openly articulate the challenges and problems associated with raising children with ASD without succumbing to feelings of shame, guilt, or fear. This assertion finds corroboration in Clifford (2011) investigation, wherein a support group was employed as an intervention for parents of children with ASD. Although the finding revealed a divergence among participating parents, with one subset attesting to the efficacy of the support group, while another subgroup expressed a lack of perceived benefits, however, most of the participants attested to the benefit of social support. Another salient dimension of social support deserving consideration is formal social support, also denominated as professional social support. This mode of assistance manifests through collaboration with professionals such as therapists, psychologists, and counsellors. These experts proffer invaluable guidance, strategies, and support to aid parents in navigating the distinctive challenges entailed in raising a child with ASD (McConkey and Samadi, 2012). A persistent concern voiced by parents in this context pertains to the perceived lack of professional support subsequent to their child's ASD diagnosis. Many parents conveyed a sense of despair due to the solitary nature of their journey, with medical practitioners often confining their role to delivering the diagnosis without extending further support. This sense of isolation, characterized metaphorically as existing in a "world of their

own," was explained by Woodgate, Ateah, and Secco (2008) as leading to heightening parental anxiety, despair, and hopelessness. This anxiety is consistent with the sentiments expressed by parents in the study conducted by Hoogsteen and Woodgate (2013), who articulated their reliance on personal coping strategies postdiagnosis, attributing this self-reliance to the systemic absence of a supportive framework for them and within the community. These parents firmly believed that a structured system offering comprehensive support could have mitigated their stress and facilitated a less challenging journey. Consequently, the existing literature clearly establishes social support as a pivotal determinant of mental health and overall well-being. Cohen and Wills (1985) highlight the significance of social support in serving as a protective buffer against stress, offering emotional sustenance and diverse forms of support to individuals, thereby facilitating effective coping mechanisms and mitigating adverse health consequences. The obvious link between elevated social support and diminished stress in the face of strenuous life events, such as the demanding responsibilities associated with caregiving, emphasises the imperative of cultivating a robust social support infrastructure to foster resilience and enhance mental well-being. However, despite the consensus regarding the valuable effects of social support on the mental health of parents raising children with Autism Spectrum Disorder (ASD), different perspectives emerge within the scholarly discourse. Notably, Bi et al. (2022) posit a contrary position, contending that the efficacy of social support is contingent upon the subjective perception of the support recipient, this position is gleaned from the finding of Clifford (2011) where although a group of parents found social support beneficial but some perceived it not beneficial. Consequently, the effectiveness of social support for parents of children with ASD assumes a subjective dimension, influenced by individual perspectives. As such, an individual may find themselves placed within an expansive social network that is amenable to extending support, yet concurrently experience heightened anxiety owing to individual biases and perceptions pertaining to the adequacy of understanding, supportiveness, or utility of the proffered assistance (McConkey and Samadi, 2012). Moreover, divergent studies underscore the preference of parents for informal support vis-à-vis formal support structures. This contention posits that support, when oriented towards the familial unit and tailored to individualized needs, produces more favourable outcomes than generic, structured support mechanisms. Accordingly, a nuanced comprehension of the intricate interplay between stress, mental health, anxiety, depressive symptoms, and social support offers the prospect of tailoring support mechanisms to suit the personal needs of each family, thereby optimizing the efficacy of the support provided.

#### 4.2 Lack of Understanding (Social Isolation and Stigma)

Another prominent theme found across the literature pertains to the pervasive societal lack of understanding and subsequent feelings of isolation encountered by parents dealing with the challenges of raising a child diagnosed with Autism Spectrum Disorder (ASD). The distinctive nature of the challenges natural in parenting children with ASD renders them susceptible to societal misconceptions, thereby exerting a profound impact on parental mental health. In the investigation conducted by Hoogsteen and Woodgate (2013), a conspicuous determinant of parental stress emerged in the form of societal ignorance and lack of understanding. Parents articulated anxieties regarding the societal imposition of standards, norms, and expectations governing child behaviour. The consistent deviation of their children with ASD from these conventional benchmarks subjected them to judgmental gazes, disapproving comments, and public embarrassment, creating an ongoing struggle for parents to align with societal expectations. Consequently, a pervasive sense of isolation filled the parental experience, as they contended with the relentless pressure to downplay and excuse their children's atypical behaviours. Moreover, societal unfamiliarity with autism engenders stigmatization and segregation, further emphasising the profound sense of

isolation experienced by both parents and children. This societal separation correlates with heightened depressive symptoms among parents, who perceive themselves as constantly out of place and excluded from social spheres, consequently opting to avoid public events to prevent embarrassment arising from their children's behaviour (Papadopoulos, 2021). The perpetual need for conformity to societal standards emerges as a significant stressor, fostering elevated levels of stress and anxiety in parents grappling with societal judgments. A critical aspect of societal misunderstanding lies in parental information deficits regarding ASD—its nature, causative factors, and effective strategies for aiding and managing ASDdiagnosed children. Notably, Smith et al. (2013) and Hoogsteen and Woodgate (2013) document instances wherein parents candidly admitted to a lack of knowledge concerning autism, a condition obscured by its invisible manifestations. This informational vacuum compelled parents to proactively seek understanding independently, expending considerable effort in "Making the Invisible, Visible." The inconspicuous nature of autism emerges as a pivotal factor in societal misunderstanding, wherein the absence of tangible evidence of disability prompts misconceptions among community members and extended family. Specifically, autistic children's meltdowns in overstimulated environments are misattributed to spoiled or indulgent parenting, amplifying societal misjudgements (Wong, 2023) and further characterizing parents as deficient in their caregiving role (Neely-Barnes et al., 2011). Moreover, numerous parental accounts emphasise the shortage of facilities tailored to accommodate the unique needs of children diagnosed with Autism Spectrum Disorder (ASD). Public spaces designed for recreational engagement predominantly cater to typically developing children, thereby excluding ASD children. This omission worsens the sense of isolation experienced by both children and their parents, as the overstimulation characteristic in such environments prevents meaningful participation in outdoor activities. Consequently, the curtailed opportunities for respite contribute to parental burnout and caregiver burden, exerting harmful effects on their mental health. Furthermore, a study by Neely-Barnes et al. (2011) reported that parents experience blame from the society and some members of their family for their children's autism which leads to stigmatisation and social isolation. Gray (2002) opined that stigmatisation can either be felt or enacted, according to him both parents are susceptible to stigma however, mothers tend to experience a higher level to stigmatisation especially enacted stigma than fathers as mother are seen to be more responsible for raising children more than fathers Another important context to this however is finding by Farrugia (2009) in which he found that many parents of children with autism spectrum disorder face stigma in public situations because people find it hard to understand their children's differences. Empowering themselves with medical knowledge became an instrumental strategy for parents to counteract stigmatization. This medical discourse gains widespread acceptance within the autism community, effectively resisting negative connotations associated with stigma, especially when disseminated to influential entities who comprehend and acknowledge it. Hoogsteen and Woodgate (2013) reinforce this perspective, reporting that elevating public awareness of autism mitigates stigmatization and fosters community-based support for parents. Additionally, it was found that in response to stigmatization, parents deploy various coping mechanisms to safeguard their mental well-being. Some opt for direct confrontation when confronted with derogatory comments, while others strategically choose their battles. Certain parents maintain active social participation despite the challenges, while a subset opts for social isolation as a pre-emptive measure to avert stigmatization. Regardless of the chosen coping strategy, it is imperative to underscore that societal misunderstanding plays a pivotal role in the elevated prevalence of depressive symptoms among parents of children with ASD, elucidating the profound impact of societal perceptions on the mental health of this set of parent will be beneficial in developing strategies that could help develop a society that is committed to ensuring the best outcome for these population (Benson, 2023)



## Coping Mechanism

The relationship between parental mental health and coping mechanisms in parents of children with Autism Spectrum Disorder (ASD) constitutes a complex web requiring thorough exploration for optimum outcomes. Coping mechanisms, as elucidated by Smith et al. (2008) means the strategies individuals employ to navigate situations effectively. Within the existing literature there were two common coping mechanisms employed by parents of children with ASD, broadly categorized as problem-focused (comprising communication, acceptance, planning, humour, cognitive reframing, and seeking help) and emotion-based (encompassing avoidance, substance use, denial, religious denial, etc.) strategies, each yielding distinct outcomes (Al-Oran et al., 2022; Yaacob et al., 2022). Zaidman-Zait et al. (2018) noted that parents confronted with challenges associated with ASD predominantly engage either emotion-focused or problem-focused coping mechanisms. Their research indicated that parents adopting an emotion-focused approach reported elevated stress levels, whereas those employing problem-focused coping demonstrated more favourable mental outcomes. Utilising the Bayesian Information Criterion (BIC), the study classified parents into four profiles. "Profile #1 Elevated Engaged Coping & Average Social Resources" which comprised parents actively utilising problem-focused approaches with limited resources, while "Profile #2 Reduced Coping & Reduced Social Resources" included parents lacking coping strategies and resources. "Profile #3 Average Engaged Coping & Elevated Social Resources" encompassed parents using average coping strategies with elevated social resources, and "Profile #4 Elevated Disengaged Coping & Limited Social Resources" involved parents devoid of social resources, primarily relying on emotional coping. Analysis of data pertaining to these profiles revealed distinct outcomes based on coping strategies employed. Profile #4, characterized by elevated disengaged coping and limited social resources, experienced the highest levels of stress and depression symptoms compared to Profile #3 and #1, which actively utilised in elevated problem-focused coping strategies. Notably, the availability of social resources emerged as a pivotal factor influencing parental outcomes, underscoring the importance of social support in mitigating stress and fostering positive mental health. This assertion aligns with the investigation conducted by Shepherd et al. (2018), clarifying the multifaceted determinants influencing stress levels among parents raising children diagnosed with Autism Spectrum Disorder (ASD). The research by Shepherd et al. (2018) establishes a notable correlation between the chosen coping strategies and the significant impact on stress levels and overall mental health outcomes for parents. This finding is substantiated by the empirical work of Smith et al. (2023), wherein parents skilful at employing a reframed social perspective as a coping mechanism exhibited a notable reduction in stress levels and manifested improved mental wellbeing. Additionally, the study by Yaacob et al. (2022) emphasises the diversity in parental approaches to coping with the daily challenges associated with raising children diagnosed with ASD. Importantly, it identifies that parents who have a positive mindset towards confronting these challenges tend to experience more favourable mental health outcomes. Consistent with these findings, the study conducted by Kiami and Goodgold (2017) reinforces the positive impact of focusing on the child and optimizing the unique circumstances, resulting in diminished stress levels and enhanced mental well-being for parents.

## Conclusion

This study aimed to investigate the complex relationship between autism spectrum disorder (ASD) and the mental health of parents raising children with ASD. The findings revealed a multitude of factors influencing the mental well-being of these parents, with a significant proportion reporting increased stress levels and borderline depressive symptoms. The study employed a thematic approach to explain these influencing factors. Vital to these findings was the key role of social support, encompassing both formal and informal networks. The study featured

social support as a critical predictor of the mental health outcomes for parents of children with ASD. The challenges encountered by these parents, both within societal frameworks and their personal lives, were identified as substantial determinants of their mental health. Informal support mechanisms were instrumental in alleviating stress and fostering a sense of belonging, contributing to positive outcomes. Meanwhile, formal support structures equipped parents with essential strategies to navigate the challenges associated with ASD. Creating a system where parents have a good blend of both would greatly improve their outcome, however, the conspicuous absence of professional support post-diagnosis surfaced as a noteworthy gap in the existing support framework, demanding urgent attention.

### Recommendations

This research offers a broad investigation into the experiences of parents raising children with Autism Spectrum Disorder (ASD), focusing particularly on the complex interplay between the challenges associated with caring for an autistic child and the consequential impact on parental mental health. The findings emphasise the potential effectiveness of reinforcing both informal and formal support structures, advocating for awareness initiatives to eliminate societal misconceptions, and cultivating a sense of public understanding and acceptance. Moreover, the study highlights the significance of recognizing the diverse needs of parents and actively working toward establishing an inclusive and supportive societal setting, thereby playing a pivotal role in enhancing the overall well-being of families navigating the complexities of raising children with ASD. For practitioners, it is advised that parents undergo counselling and knowledge training before, during, and after their child is diagnosed with autism. This approach would bridge the information gap often experienced by parents, particularly in understanding autism. It would help them develop effective coping mechanisms, navigate the complexities of raising a child with Autism Spectrum Disorder (ASD), strengthen their relationship with their child, understand the importance of early intervention, plan for the future, and reduce stress and anxiety.

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