



GSJ: Volume 10, Issue 8, August 2022, Online: ISSN 2320-9186
www.globalscientificjournal.com

A PSYCHOLOGICAL ANALYSIS OF THE CHALLENGES BEING FACED BY MOTHERS TAKING CARE OF CHILDREN ON THE AUTISM SPECTRUM

By

Fadzai Makaya

Departmental Secretary

Department of Arts, Culture and Heritage Studies, Zimbabwe Open University (ZOU), Zimbabwe

phadzaimakaya@gmail.com

***Davison Maunganidze** (corresponding author)

Former student & Alumni member, Zimbabwe Open University, Harare Zimbabwe

davymzw@gmail.com

ABSTRACT

The research paper provides a narrative that explores and explains the difficulties faced by mothers of autistic children. According to the study, mothers of autistic children face a wide range of difficulties. These difficulties include actions like head banging, self-harm, academic difficulties, and other opportunistic issues. The study suggested that professionals interact more with the affected families during the condition's diagnosing phase. It is important to establish and equip special schools to care for autistic children. Finally, instructors should be educated about the disease.

Key Terms: *Autism spectrum disorder (ASD), Assessment, Mother, Diagnosis*

INTRODUCTION

Many parents struggle to care for their children, especially if the youngster has an unique condition like autism, the researchers observed with concern. Lustig (2002) claims that parents of children with developmental delays go through higher levels of parental stress, which is frequently correlated with how severely their child behaves. Autism is a developmental condition that has an impact on behaviors, communication, and social interaction. Children between the ages of 18 months and three years are diagnosed with it (Nassimi, 1995). Every 91 live births, a kid with an autistic spectrum disorder is born (Barons, 1998). The cause of autism has long been unknown. Studies must be conducted to have a deeper knowledge of this phenomenon. The psychological implications of raising a child with ASD are examined in this study.

The researchers found that there was an increase in the number of autism cases being reported across the nation, and on April 1, 2013, a campaign was launched to promote public awareness of autism. The purpose of the study was to determine whether caring for a child with autism has any psychological side effects.

RESEARCH METHODOLOGY

The case study method and both qualitative and quantitative research were used in this study (Boorg and Gail 1983). The case study approach was chosen by the researchers because it was the most adaptable of all research plans and allowed for the investigation of empirical events while maintaining the comprehensive qualities of real-life events. A written report that provides specific information about a person, group, or thing and their growth across time is known as a case study research design (Boorg, 1999). Most of the time, a questionnaire was utilized to get feedback from both parents and caregivers. Additionally, the autistic children were observed both at home and in a care facility using the observation instrument, which was also employed in this study.

LITERATURE REVIEW

Autism Spectrum Disorder

A collection of developmental problems known as autism spectrum disorders (ASDs) can pose serious social, communicative, and behavioral difficulties. People with ASDs process information differently in their brains than non-ASD individuals (Lustig, 2002). This means that the severity of an ASD might vary greatly depending on the individual. ASD sufferers often exhibit similar symptoms, such as difficulty interacting with others. However, there are variations in the onset, severity, and precise form of the symptoms (Zaidman-Zait, Miranda and Zumbo, 2010). Three major facets of a child's life are impacted by autism spectrum disorders (Spearman, 2001):

- Social interaction
- Communication - both verbal and non verbal
- Behaviours and interests

Each child with an ASD will have his or her own pattern of autism. ASDs begin before the age of 3 and last throughout a person's life, although symptoms may improve over time. Within the first few months of life, some children with an ASD display early signs of potential issues. Others might not experience symptoms for 24 months or more. Some ASD kids appear to develop normally up until the age of 18 to 24 months, at which point they cease learning new things or start losing the things they already know (Lustig, 2002).

A child's development can occasionally be delayed from birth. Some kids appear to grow normally before they abruptly lose their language or social skills. Others exhibit typical growth up until they are able to express strange thoughts and preoccupations through language. A loss of language is the main handicap in some kids. Others appear to be characterized by strange behaviors (such as spending hours lining up toys) (Zumbo, 2010). According to Whitaker (2007), up until recently, the diagnostic manual (DSM - IV) of the American Psychiatric Association's criteria served as the basis for categorizing ASDs. Asperger's syndrome, Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS), and Autistic disorder are the three primary subtypes of ASD, according to the CDC (2002).

Parents of children with developmental disabilities experience higher levels of stress than parents of typically developing children (Fidler, 2003). Webster and colleagues (2008) found that the scores in the Parenting Stress Index were above 85th percentile in over 40% of parents of children with developmental delay, indicating significant parenting stress. Despite a considerable amount of data on stress in parents of children with disabilities, there is still no consensus on the conceptualization of this phenomenon (Perry, 2004). The theoretical framework adopted in a number of studies is the transactional model of stress and coping (Lazarus & Folkman, 1984). In this approach, stress is a particular type of an individual's relationship with the environment, which the individual appraises as putting certain demands or overextending his/her resources, and thus threatening his/her well-being (Lazarus & Folkman, 1984).

A child's development can occasionally be delayed from birth. Some kids appear to grow normally before they abruptly lose their language or social skills. Others exhibit typical growth up until they are able to express strange thoughts and preoccupations through language. A loss of language is the main handicap in some kids. Others appear to be characterized by strange behaviors (such as spending hours lining up toys) (Zumbo, 2010). According to Whitaker (2007), up until recently, the diagnostic manual (DSM - IV) of the American Psychiatric Association's criteria served as the basis for categorizing ASDs. Asperger's syndrome, Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS), and Autistic disorder are the three primary subtypes of ASD, according to the CDC (2002).

The sort of handicap a child has is related to parental stress (Gupta, 2007). Several authors have noted that moms of autistic children have higher levels of stress than mothers of children with other developmental disorders, such as Down syndrome, fragile X syndrome, profound intellectual disability (Hastings, 2004), and parents of kids without developmental issues but who need specific medical care (Boyle, 2007). or children who develop normally (Daley, 2004). Two-thirds of the moms of autistic children in Tomanik, Harris, and Hawkins's (2004) study showed heightened stress levels. Another eye-opening fact is how frequently parents themselves describe raising an autistic child as "stressful."

Psychological effects of taking care of a child with Autism

One of the most challenging things a parent will ever have to do is raise a child with autism. It is a physically and emotionally exhausting challenge, causing worry to the person caring for the child, according to Barons (2001). Bringing up an autistic child frequently results in marital issues, issues with other kids, and career instability. Unfortunately, there are no effective therapies for autism, thus the family is mostly responsible for the child's upbringing, developmental issues, and behavioral issues. Although we cannot change the cause of the issue, there are things that family members may do to lessen the severity of the abnormal behavior and improve the child's coping skills

According to Barons (2001), parents of autistic children report more stress than those of children with learning difficulties. A person with autism might not communicate their basic needs or wants in the way that one might anticipate. As a result, parents are left to speculate. Is the young person sobbing because they are thirsty, hungry, or ill? Both a parent and kid experience frustration when requirements cannot be ascertained. As a result of their dissatisfaction, the youngster may act aggressively or harm themselves, endangering their safety and the safety of other family members (such as siblings) (Siegel, 1997).

Autism traits and obsessive behaviors worry parents since they seem strange and interfere with performance and learning, according to Beidel (2009). A growing number of parents are parenting kids who have been diagnosed with autism, and these families frequently face both financial and social difficulties. The basic struggles that parents of disabled children face include daily care obligations, financial difficulties, receiving the right assistance, and providing a suitable education. A high divorce rate may result from the added stress, which can have a negative impact on the entire family. The prevalence of autism has decreased from 1 in 5,000 fifteen years ago to 1 in 150 today, according to the Centers for Disease Control and Prevention. Although an ASD diagnosis can change a parent's hopes for their child, they should remain upbeat. In the last 15 years, much has been discovered about ADS, and research into its causes and treatments is still expanding (Plienis, 1992). The challenges and demands of parenting an autistic child are unique. Recently, there have been more initiatives to involve parents of autistic children in interventions. Parents of children with impairments endure more parenting stress and worry than parents of children who are usually developing (Innocenti, 2001). Parents of autistic children report much greater levels of stress and are more likely to experience depression even among parents raising children with impairments. These findings may be explained by the fact that children with autism frequently engage in atypical behaviors and have increased sensory sensitivity, and that parenting stress is linked to both the frequency and severity of children's rigid behavior.

Parents' expectations and attitudes about parenting, according to Pargament (2001), start before to the birth of their kid and are changed as a result of interactions with their growing child. Parental stress and depression are negatively associated with parenting capability, or the parents' way of interpreting feelings of competence in the parenting role, according to research on autism (Pargament, 2001). This is because children with autism behave in ways that are unusual and difficult to predict. Understanding self-efficacy has been linked to maternal wellbeing and has been found to lessen the negative psychological effects of child behavior on mothers' anxiety and despair. A more positive perspective on parenting a child with autism may result in a more supportive involvement.

Causes of stress in parents of children with autism

Barons (2001) identified three main categories of characteristics that influence parents of autistic children to have elevated levels of stress: (3) Social attitudes toward people with autism and a lack of understanding for the issues they and their families face. (1) Child characteristics, particularly behavioral symptoms associated with autism and behavioral problems. (2) Inadequate professional support and unsatisfactory relationships between parents and professionals from the stage of autism diagnosis to limited access to medical and educational services for the child.

Beck (2004) states that autism is characterized by the coexistence of three groups of symptoms, including restricted and repetitive behavior patterns, impaired social relationships and communication (American Psychiatric Association, 2000). For parents, each of the developmental challenges listed above may be extremely distressing. The relationship between the severity of children's impairment and the stress experienced by parents of autistic children is still up for debate. Some researchers claim to have found this connection (Hastings & Johnson, 2001; Hoffman et al., 2008). However, not all scholars have supported their findings (Tobing & Glenwick, 2002), and some even claim that the degree of the child's autism symptoms is a relatively unreliable predictor of parental stress (Konstantareas & Papageorgiu, 2006). Methodological concerns, such as sample size, selection criteria, internal differentiation in the study groups of parents and children, as well as the instruments used to measure the children's developmental problems, appear to be the primary causes of this discrepancy in research findings.

Furthermore, it is yet unknown what specific behavioral and developmental issues a child may have that contribute to parental stress (Richards, 1999). Deficits in socio-emotional development that are widespread are undoubtedly the hallmarks of autism. They stand out in particular in the lowered capacity of individuals with autism to initiate and maintain interaction (Volkmar et al., 2004). Even those with high-functioning autism (HFA) struggle with substantial interpersonal interactions, however the nature and severity of these issues may vary. Low levels of the child's pro-social behavior are associated with the severity of the parents' stress, according to studies on parents of children with non-autistic developmental disorders (Richman et al., 2009). Deficits in social relatedness may be a severe hardship for parents, as Davis and Carter's (2008) research of parents of newly diagnosed children with autism spectrum disorders (ASD) showed. Similar findings were made by Kasari and Sigman (1997), who discovered a connection between a child's attentiveness to the experimenter and the level of parental stress.

The development of relationships with parents is a significant area in which the development of children with autism differs from that of typically developing children. According to studies, most of these children's mothers evaluate their child's emotional reciprocity lower than mothers of children with other disabilities and believe that their child's signs of attachment are insufficient (Abbeduto et al. 2004; Hoppes & Harris, 1990). Despite the fact that women claim they would prefer their kids to show more signs of attachment, other problems that mothers face seem to have more of an impact on the development of parental stress. Hoffman and colleagues (2009) observed no differences between moms of generally developing children and mothers of autistic children on the Attachment Subscale of the Parenting Stress Index (PSI). In the study, moms of autistic children reported significant levels of stress on all other PSI subscales (both in the parent and child domains); their results on the measure of demands resulting from connections with the child were comparable to those of mothers of generally

developing children. In the Child's Domain, mothers of autistic children performed best: their mean PSI scores in these subscales were in the 99th percentile.

Cognitive issues impacting autistic children include issues with social interaction and communication (e.g. Joseph et al., 2002). However, it seems that the child's intellectual growth is not a factor in determining the level of parental stress. Significant functioning autistic or Asperger syndrome children's parents also face high amounts of stress (Mori et al., 2009; Rao & Beidel, 2009). The child's behavioral issues rank among the most crucial indicators of parents' stress (Bishop et al., 2007; Estes et al., 2009; Herring et al., 2006; Tomanik et al., 2004). Numerous issues like these are evident in autistic children, including violence and self-harm (Matson & Rivet, 2008). The biggest indicators of parental stress include self-harm, aggression, and other destructive behaviors (Richman et al., 2003; Dunlap & Robbins, 1994). Parents are also upset by their child's stereotyped and self-stimulating behaviors. Depending on the child's age, specific behavioral issues can actually increase parental stress levels. Parents of preschoolers are more likely to highlight self-stimulation and tantrums than parents of teenagers, who name destructive behavior and withdrawal from touch as their top concerns (Dunlap & Robbins, 1994).

In addition to directly posing issues by risking the child's safety or the safety of others or by causing property damage, the child's difficult behaviors may also cause parents to become isolated from their neighbors (Worcester et al., 2008). Additionally, parents frequently feel helpless due to their child's unpredictable and incomprehensible answers to their efforts to calm him down: "What worried me the most was his weeping, and I would do anything to prevent it. He despised kisses, so I was unable to hold him or comfort him when he was weeping (Grodzka, 1995, p. 217). As a result, the relationship between problematic behaviors and parental stress might be complicated. Better understanding of the connections between these events would undoubtedly aid in the development of more efficient methods of supporting parents. Parental burdens may also increase as a result of impaired adaptive functioning, including decreased daily living abilities (Fitzgerald et al., 2002; Tomanik et al., 2004). Children who struggle with basic self-care abilities need additional help with activities like dressing, eating, and maintaining daily hygiene.

Diagnosis, relations with professionals and parental stress

Lack of adequate professional support is one of the main reasons parents of autistic children experience stress. Parents encounter difficulties when seeking medical assistance from specialists even before their child's developmental deficits have been diagnosed. It is sufficient to note that the child is typically evaluated by more than four professionals prior to diagnosis, with the mean time to diagnosis being about 2-3 years (Siklos & Kerns, 2007). One of the main causes of this situation, among many others, is the general lack of knowledge among professionals (including doctors and psychologists) about the course of young children's development and its disorders, as well as the lack of awareness of symptoms indicating serious developmental difficulties. Another significant problem is the lack of diagnostic and treatment facilities providing specialized assistance to people with ASD.

According to Norton and Drew (1994), autism is typically only identified when parents demand a thorough evaluation of their child. This finding was supported by Canadian data, which showed a connection between the

mother's education and the child's autism diagnosis (Croen et al., 2002). According to data gathered from parents, they appear to start worrying about their child's growth around the first half of the child's second year of life (De Giacomo & Fombonne, 1998). The child's communication issues, particularly the lack of speech, as well as unusual social behavior and play patterns typically cause them concern (Charman et al., 2001; Goin-Kochel).

The lengthy and delayed diagnostic process is frustrating for parents, and they are dissatisfied with the level of expertise that professionals have in autism spectrum disorders (Brogan & Knussen, 2003; Mansell & Morris, 2004; Osborne & Reed, 2008). The way they are handled by specialists may add to their stress that is already caused by anxiety about their child. They must endure lengthy wait periods at specialized facilities and are given inconsistent advice on how to assist their child.

Their problems are exacerbated by poor interpersonal skills of some professionals (Hatkins, 2001). Support for parents is also inadequate during and immediately after the diagnostic process. When a kid is diagnosed with autism, parents often struggle to cope. (Avdi et al., 2000; Midence & O'Neill, 1999) Their reactions range from relief that the situation is now understood, through shock, disbelief, or denial, to severe melancholy and depressed mood. Many people need expert assistance because they can't handle the circumstance on their own (Wachtel & Carter, 2008).

Additionally, it needs to be stressed that, regardless of how parents react at first, the diagnosis is just the beginning of their adaptive process. Due to, among other reasons, the absence of any outward indicators of a handicap in the child's appearance, Siegel (1997) adds that accepting the child's autism is a long-term process. As a result, even after the diagnosis, some parents are still skeptical of the accuracy of the diagnosis. They experience a life of uncertainty while "arriving" at the ultimate diagnosis, which is made worse by the fact that they frequently hear conflicting information about the nature of their child's issues and the prognosis for future growth. Many parents are unaware of the effects a diagnosis will have on their children and their families, even after it is definite. Their ability to adjust to the new environment is considerably hampered by a lack of adequate support.

Despite the fact that children have been diagnosed with autism for a long time, the availability of autism-specific services and professional support is still inadequate. Darrel (2009). According to research done, for example, in the USA (Wachtel & Carter, 2008), Belgium (Renty & Roeyers, 2004), and Poland (Wachtel & Carter, 2008), this issue exists in a wide range of nations (Rajner & Wroniszewski, 2000). As a result, it frequently falls on the parents to arrange for the child's support needs as well as medical, educational, and other services (Renty & Roeyers, 2006; Sharpley et al., 1997; Weiss, 2002, for examples). This means that the parents are left to handle treatment coordination, advocacy, and decision-making on their own (Wachtel & Carter, 2008). As a result, they have too many responsibilities, which can make them feel inept and worry about whether they choose the best course of action for their children.

Lack of sufficient respite care is another issue for parents, according to Novak (2007). Parents are exhausted with additional obligations on top of their normal childcare responsibilities and lack time to complete other tasks and satiate their own and their family's needs. This directly impacts employment decisions as well. Nearly 40%

of parents of children with ASD said in the Montes and Halterman survey from 2008 that issues with childcare had a substantial impact on their professional choices and careers. In the case of parents of high risk and generally developing children, the proportion was significantly lower.

Social attitudes towards people with autism and parental stress

There's no denying that parents of autistic children must deal with issues caused by their child's developmental handicap and challenging behaviors, as well as upsetting reactions from others to the child's behavior and a general lack of understanding of autism (Harrison, 2006). Parents regularly find themselves in uncomfortable situations due to the contrast between their child's appearance, which shows no evidence of a disability, and his behavior, which is viewed as aberrant and "weird" (e.g. Gray, 2002b; Portway & Johnson, 2005).

Lobst et al. (2009) state that the child's behavior is frequently interpreted as a sign of inadequate parenting: "You're being a lousy mother. He acts in that way because you don't correct him. You wouldn't run into issues if you handled things in this manner. You know, that kind of crap doesn't help (Farrugia, 2009, p. 1018). Social rejection of a kid's behavior frequently results in stigmatization of the child, feelings of humiliation for the parents, and the exclusion of the parents from customary social activities (Farrugia, 2009). Lack of knowledge about the illness is one of the factors that affects attitudes and behavior toward people with autism. There is still much to learn about autism (Huws & Jones, 2010). There is much work to be done in this area to change negative perceptions of people with autism, especially since it has already been shown that the amount and style of information provided about the disorder has a significant impact on perceptions and the degree of acceptance for those who have this disability (Lobst et al., 2009).

Boyd (2002) discovered that moms of autistic children's adaption is greatly aided by informal assistance. Unfortunately, this kind of assistance is frequently hard to come by. When a child has functioning issues, parents are frequently left to care for their children alone and without assistance from even close family members. Their friendships and acquaintanceships suffer as a result of the stress of caregiving. Their social circle is typically considerably smaller (Farrugia, 2009).

However, these problems also include the unique situations faced by parents of autistic children. Certain aetiological theories, such as the aforementioned "refrigerator mother" idea, may be the source of parental self-blame for their child's autism. On the other side, worry for the child's future is linked to the fact that persons with autism are far more likely than those with other diseases to experience social isolation and lack of support from peers.

Individual Characteristics of parents and stress

Zumbo (2010) claims that a number of personal qualities and the sex of the parents play a significant role in influencing the stress that parents of autistic children experience (such as coping strategies and style, and sense of coherence). The next section discusses these elements' contributions to the stress that parents endure.

Mothers have been the main subjects of studies on the stress that parents experience when raising a child with autism. The goal was to identify a stress profile that was both stable and group-specific. In one of the earliest studies on the subject, Holroyd and McArthur (1976) compared the stress felt by mothers of autistic and Down syndrome children. Mothers of children with autism reported stress related to taking the child to public places, the child's almost complete dependence on care, and the lack of access to specialized services, in addition to common problems related to health, depressive mood, sense of being overburdened, pessimistic view of the future, and limited family opportunity.

In their examination of moms of children with autism, children with physical disabilities, and healthy children, Bouma and Schweitzer (1990) found similar findings. Mothers with children with autism reported greater stress due to issues with the kid's cognitive development, the requirement for continual supervision, and the idea that their child would require care indefinitely. Their autistic child's behavioral issues were another important factor in their stress levels.

Regardless of the child's age, intellectual development, geographic location, or cultural background, Koegel et al. (1992) found a rather stable pattern of difficulties faced by moms of children with autism. The child's future, cognitive development, dependency on care, and social exclusion were the main sources of stress. On seven of the 15 subscales of the Questionnaire of Resources and Stress (Pisla, 2007), mothers of children with autism scored more stressed than mothers of children with Down syndrome (Holroyd, 1987). The child's problematic personality traits and overprotection/dependency of the child were revealed to have the greatest variations between groups. The need of their child on outside care also caused mothers of autistic children greater concern. The same outcomes were attained by Dale and Jahoda and Knott (2006).

There is no denying that fathers may face major difficulties when raising a kid who has autism. However, we still have a limited understanding of how their difficulties are caused by the child's developmental deficiencies. In a nearly two-decade-old study, Rodrigue et al. (1992) showed that dads were aware of the impact the kid had on family members' capacity to meet their personal needs as well as on overall family activity. In further research, it was discovered that fathers of autistic children experience more stress than fathers of usually developing children (Baker-Ericzén et al., 2005). The stress profiles of mothers and fathers have only seldom been compared in studies so far

Tehee et al. (2009) discovered that mothers experienced noticeably higher levels of stress than fathers. According to Moes et al. (1992), moms were more stressed about the child's behavior, physical development, self-sufficiency, and parenting issues. Other findings suggest that stress in mothers is interrelated with their child's social skills, while no such relationship was found in fathers (Baker-Ericzén et al., 2005). Hastings (2003) showed that stress level in mothers was associated with the child's behavioural problems and the father's mental health, while the stress in fathers was not related to either the child's behaviour or mother's mental health.

Regarding behavioral issues, women were more impacted by the child's regulating issues while fathers were more upset by the child's externalizing issues (Davis & Carter, 2008). The fact that moms viewed stigmatizing behaviors of other people substantially more than did fathers is a supplement to these findings (Gray, 2002b). Therefore, it would appear that moms are more sensitive than fathers to hostile behavior of others toward the child. The information presented above shows that we currently know very little about the disparities in parental

stress experienced by mothers and fathers of autistic children. According to research, scores are higher in more of the domains assessed than in those of fathers, indicating that mothers feel more stress overall.

Parents' stress levels are connected with how they handle stress (Hastings & Johnson, 2001). It should be highlighted, however, that not enough study has been done on the connections between parental stress in parents of children with autism and their stress management in general. Lyons and colleagues (2010) examined the relationship between the severity of autism and parents' coping mechanisms in one of very few research on the topic. The child's autism severity was the best indicator of stress. However, coping mechanisms also have a significant impact on the wellbeing of parents of autistic children. Smith et al. (2008) concluded that the wellbeing of mothers of toddlers with autism correlated with using less emotion-focused coping and more problem-focused coping, regardless of the severity of the child's deficits.

Hastings et al. (2005) made a distinction between four key coping dimensions: active-avoidance coping, problem-focused coping, positive coping, and religious/denial coping in a study on coping techniques in parents of preschool and school-aged children with autism. One of those aspects, active-avoidance coping, was connected to both parents' high stress levels and psychopathology. Additionally, some evidence points to a connection between increased parental stress and religious coping (Tarakeswahr & Pargament, 2001). Lower stress is thus linked to problem-oriented coping (Lustig, 2002), reformulation and seeking out informal assistance, as well as coping by putting an emphasis on family cohesion and cooperation (Hastings & Johnson, 2001). (Jones & Passey, 2005).

Problems associated with diagnosis of Autism

Currently, there is no specific medical test to identify Autism (Keller, 2008). Doctors and other medical experts base their diagnoses on observation, discussions with parents, doctors, and therapists about the child in question. Keller (2008) claims that they look at a core set of three behaviors that frequently characterize the illness. The first is social interaction, or a child's capacity to communicate with both parents and peers. Thirdly, doctors look at repetitive behaviors and if a child has a small area of interests that may be exclusive from others. Second, linguistic interactions, youngsters may have difficulty expressing demands and communicating, typically depending on grunts and pointing (Novak, 2007). It is uncommon for one doctor to decide and make a diagnosis because autism is such a diverse illness with numerous levels of severity. Professionals frequently have to collaborate and exchange observations and notes.

First, hearing tests are typically one of the first tests to be finished because vocal communication may be an issue. Following the completion of the hearing tests, a thorough neurological examination is conducted, along with cognitive and linguistic testing. Typically, neurologists, speech therapists, and psychiatrists are engaged. At the conclusion of testing, parents should actively participate in discussions with medical professionals regarding the prognosis and jointly determine how to proceed with treatment (Carter, 2008). However, almost all medical professionals concur that an early diagnosis is crucial for the treatment of autism because it offers doctors and therapists the chance to start addressing the many obstacles that both the kid and parent will face right away. It is crucial for all parties to collaborate and communicate during the testing process. The Autism Society of America advises parents to approach the diagnosing process using a four-pronged strategy.

Childs' characteristics as source of parenting stress

According to Keller (2008), parents of autistic children report more stress than those of children with mental impairment or Down syndrome (Holroyd & McArthur, 1976; Donovan, 1988). This could be as a result of the distinctive traits that people with autism display. A person with autism might not be able to communicate their most fundamental needs or wants. As a result, parents are left to speculate. Does the sobbing infant appear to be unwell, thirsty, or hungry? Both the parent and the child feel frustrated when the parent is unable to ascertain the needs of the youngster. As a result of their dissatisfaction, the youngster may act aggressively or harm themselves, endangering their safety and the safety of other family members (e.g. siblings). Parents are concerned by stereotypical and compulsive behaviors since they seem strange and interfere with functioning and learning.

This is a problem for families of autistic children. Due of the child's difficulty to remain still for long amounts of time, set dinnertimes may not be successful. Sleeping issues might cause disruptions to bedtime rituals. Families may be prevented from attending events together by maladaptive behaviors. For instance, Mom might have to stay at home while Dad drives the child to soccer practice. The marriage connection may suffer from inability to carry out family-oriented activities. Additionally, because of the high demands of parenting and the scarcity of skilled assistance to care for an autistic child in their absence, couples frequently find themselves unable to spend time alone.

RESEARCH FINDINGS AND DISCUSSION

35 percent of participants were male and 65 percent were female in terms of demographics. The youngsters were between the ages of 0 and 17 and older. 26 percent of the children were under the age of five, 9 percent were between the ages of six and ten, 44 percent were between the ages of eleven and sixteen, and 22 percent were 17 or older. None of the parents or caregivers were younger than 24 years old; instead, 9 percent were between 25 and 30 and 43 percent were between 31 and 40. Thirteen percent of the parents were over the age of 51, and 35 percent of the parents were in the 45–50 age range. None of the parents or caregivers had an education higher than a "O" Level, which is the maximum level reached by parents or caregivers. A diploma was the highest degree held by 35% of the parents or caregivers. The highest degree held by parents or caregivers ranged from 22 percent of parents with a master's degree to 43 percent of parents with a bachelor's degree.

The causes of parental stress

According to the study, 26% of parents or other caregivers indicated that one of the things that causes stress in kids is their personality. Developmental issues that may be extremely upsetting for parents include process diagnosis and a lack of awareness of the condition. 9 percent of parents or caregivers reported feeling stressed out during the disorder diagnosis procedure, according to the study. According to the research, social attitudes about the kid have been found to be the main source of stress for parents and other caregivers, having an impact on 43% of them. The lack of awareness of the condition appears to be stressing 22% of the parents. Nine percent of the 23 participants—parents or other primary caregivers—appear to be impacted by the child's obsession. The results showed that 13% of the parents experienced flapping hands, body swaying, or body spinning. More than

any other aspect of the child, tantrums caused 74 percent of parents or other caregivers stress. 13 percent of the parents reported having trouble getting their kids to talk to them.

Twenty two (22) percent of the parents attempted to respond to the question, "Are there any obstacles between the autistic child and other non-autistic siblings?" and stated that there were. Parents reported that 35% of the time there were no issues with other siblings, and 43% of the time there were issues between the autistic child and other siblings. Regarding their autistic child's education, 22% of the parents said that their child had received education outside of the classroom. 78 percent of parents reported that they do not provide any further education for their children outside of school.

87 percent of parents said their autistic child does play with other children. 13 percent of parents have said that their child occasionally refuses to play with other children, however none of the parents have stated that their child does not want to play with other children. 35 percent of parents have not yet gotten sufficient professional support, compared to 65 percent of parents who have. Seventy-eight percent of parents reported difficulties in locating professional assistance, while only twenty-two percent of parents reported no problem. 26 percent of parents report having no trouble speaking with their children, while 9 percent report having some difficulty. 65 percent of parents do occasionally find it difficult communicating with the child.

Thus, 65% of parents spend between 1 and 5 hours with their children, while 17% spend between 6 and 10 hours per day with their children. The average parent of an autistic child spends 10 to 15 hours a day with them. None of the parents, however, claimed to lack any formal education or professional expertise about their autistic child. 56 percent of parents reported having high educational or professional knowledge about their child, compared to only 43 percent of parents who said they knew their child only somewhat well.

At the autism Trust, 23 children were observed for one week, six hours per day, in addition to completing a questionnaire. Both at school and at home, one youngster was watched. The focus of the observation method was on child traits that can stress out the parent, difficulties between the autistic child and other siblings, and social perceptions of people with autism. These observations revealed that the majority of the kids (56%) shown obsessive interest and had tantrums. Twenty-two percent (22%) shown some intense attention, while another 22 percent flailed their arms, rocked their bodies, or spun about. One of the youngsters, who was seen both at home and at school, demonstrated that he occasionally experienced difficulties in playing and communicating with other siblings.

In the meanwhile, evidence from data analysis supports the theory that raising a kid with autism has certain psychological effects on parents and other caregivers. The study's findings indicated that caring for a child with autism spectrum disorder can induce stress in parents. Innocent (2001) found that parents of children with impairments suffer more stress and anxiety as parents than parents of children who are usually developing.

The study found that parents perceived the traits of their children as the cause of their stress. Barons (2004) stated that autism is characterized by the coexistence of three sets of symptoms: impaired social relationships and

communication, as well as constrained and repetitive behavioral patterns; hence, this was perceived as the cause of parental stress. The study also showed that parents and other caregivers appeared to experience stress as a result of the disorder's diagnosing procedure. Bishop et al. (2007) and Sharply et al. (1997) both state that parents are dissatisfied with the length and delay of the diagnostic procedure as well as the understanding of experts about autism spectrum disorders.

The study's conclusions showed that parents and other caregivers have felt stressed out by society attitudes regarding children. Farrugia (2009) asserts that when society disapproves of a child's behavior, the parents are frequently stigmatized, ashamed, and excluded from typical social interactions. The study also discovered difficulties between the sibling of the autistic child and others. Some of the parents claimed that their autistic children don't interact with other kids while they play. The majority of siblings of children with autism spectrum disorders (ASDs) perform better than others, according to Abidin (1990). Many even end up being fairly beneficial to the household's daily operations. Some develop into zealous protectors of their brothers and even decide to choose professions that assist people with disabilities.

It has been discovered that parents struggle to locate qualified expert assistance. Lack of proper professional support is one of the major causes of stress for parents of autistic children, according to Bishop et al. (2007) and Sharply et al. (1997). Some parents were more prone to worry since they did not know what to anticipate from their children due to a lack of awareness about the disease. One of the main causes of this situation, according to Siklos and Kerns (2007), is the general lack of knowledge among professionals about the disorders that affect young children's development and their causes, as well as their lack of familiarity with the symptoms that indicate serious developmental difficulties.

CONCLUSIONS

In light of the aforementioned data, the study comes to the following conclusions:

- Caring for an autistic child has psychological impacts.
- Stress was a side effect of caring for an autistic child.
- The difficulties with diagnosis was one of the child features that were also identified as sources of parenting stress.
- Although it was discovered by other researchers that siblings do not always have issues, there were difficulties between the autistic child and other siblings. Other siblings may occasionally prove to be quite useful in running the household on a daily basis. Some grow into strong siblings' advocates and even pursue careers helping those with impairments.
- Another source of stress for parents was discovered to be societal perceptions of people with autism.

RECOMMENDATIONS

The following advice was given in light of the research's findings.

- In order to encourage other siblings to be optimistic, parents should respond positively to their special needs child.
- Support networks. A therapist could arrange follow-up appointments to provide support for siblings of an autistic child.
- In order to promote parents' important contributions to their children's education and to prepare them to serve as therapists in their children's intervention programs, families and schools must work together.
- Parents need to learn how to speak up for their kids and offer advice and support to other parents.
- Additional research could be done to look into the effects of autism that go beyond psychological ones.

REFERENCES

- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). *Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome*. *American Journal on Mental Retardation*, *109*, 237–254.
- Abidin, R.R. (1990). *Introduction to the special issue: the stresses of parenting*. *Journal of Clinical Child Psychology*, *19*, 298-301.
- Abidin, R.R. (1995). *Parenting Stress Index Professional Manual*, 3rd edition. Psychological Assessment Resources, Inc., Odessa, FL.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: W. H. Freeman.
- Baron, R. M. & Kenny, D. A. (1986). *The moderator–mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations*. *Journal of Personality and Social Psychology*, *51*, 1173-82.
- Beck, A., Hastings, R.P., Daley, D. (2004). *Pro-social behavior and behavior problems independently predict maternal stress*. *Journal of Intellectual & Developmental Disability*, *29*, 339-349.

- Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.
- Bruininks, R.H., Woodcock, R.W., Weatherman, R.F. (1996). *Scales of Independent Behavior – Revised*. Itasca, IL: Riverside Publishing.
- Bugental, D.B., Blue, J., & Cruzcosa, M. (1989). *Perceived control over caregiving outcomes: Implications for child abuse*. *Developmental Psychology*, 25, 532- 539.
- Bzoch, K. R. & League, R. (1991). *Receptive-Expressive Emergent Language Test (REEL)*, 2nd edn. Pro-Ed, Austin, MN, USA.
- Carter, A.S., & Briggs-Gowan, M.J. (2006). *Manual of the infant-toddler socialemotional assessment*. San Antonio: Harcourt Assessment.
- Centers for Disease Control and Prevention (2009). *Prevalence of autism spectrum disorders—autism and developmental disabilities monitoring network, United States, 2006*. *MMWR*, 58(SS10), 1-20.
- Chakrabarti, S, & Fombonne, E. (2005). *Pervasive developmental disorders in preschool children: Confirmation of high prevalence*. *American Journal of Psychiatry*, 162, (6), 1133-1141.
- Chang, S. W. (2010). *How motherhood perception of the mothers who have ADHD children affects their parenting stress*. Published master's thesis, Si-Ji University, Hua-Lian, Taiwan. (In Chinese).
- De Brock, A.J. L.L., Vermulst, A.A., Gerris, J.R.M., & Abidin, R.R. (1992). *Nijmeegse Ouderlijke Stress Index*. Lisse: Swets en Zeitlinger BV. 140
- Derogatis, L.R. (1994). *Symptom checklist-90-Revised*. Minneapolis, MN: National Computer Systems.

- Dillenburger, K., Keenan, M., Gallagher, S., & McElhinney, M. (2002). Autism: intervention and parental empowerment. *Child Care in Practice*, 8, 216-219.
- Ding, Y., Yang, L.Y., Salyer, K., Harper, H., Guo, J.P., Liu, H., & Feng, Y.H. (2010). *Assessing needs and challenges reported by caregivers and teachers of children with autism spectrum disorders in China. The Journal of International Association of Special Education*, 11, 4-14.
- Einfeld, S.L., & Tonge, B.J. (1995). *The Developmental Behavior Checklist: The development and validation of an instrument for the assessment of behavioral and emotional disturbance in children and adolescents with mental retardation. Journal of Autism and Developmental Disorders*, 25, 81-104.
- Eisenhower, A.S., Baker, B.L., & Blacher, J. (2005). *Preschool children with intellectual disability: Syndrome specificity, behavior problems, and maternal well-being. Journal of intellectual disability research*, 49, 657-671.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X. & Abbott, R. (2009). *Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. Autism*, 13, 375-387.
- Feldman, M., McDonald, L., Serbin, L., Stack, D., Secco, M.L., & Yu, C.T. (2007). *Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay. Journal of Intellectual Disability Research*, 51, 606-619.
- Fong, C. Y. G. & Huang, A. (2002) *Public awareness, attitude, and understanding of epilepsy in Hong Kong Special Administrative Region, China. Epilepsia*, 43, 311- 316.
- Griffith, G.M., Hastings, R.P., Nash, S., & Christopher, H. (2010). *Using matched groups to explore child behavior problems and maternal well-being in children with Down syndrome and autism. Journal of Autism and Developmental Disorders*, 40, 601-619.
- Greenberg, J.S., Seltzer, M., Krauss, M., Chou, R.J., & Hong, J. (2004). *The effect of quality of the relationship between mothers and adult children with Schizophrenia, Autism, or Down Syndrome on maternal well-being: The mediating role of optimism. American Journal of Orthopsychiatry*, 74, 14-25.

- Harty, M., Alant, E., Uys, C.J.E. (2006). *Maternal self-efficacy and maternal perception of child language competence in pre-school children with communication disability. Child: care, health, and development, 33, 133-154.*
- Hassall, R., Rose, J., & McDonald, J. (2005). *Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. Journal of Intellectual Disability Research, 49 (6), 405-418.*
- Jones, T.L., & Prinz, R.J. (2005). *Potential roles of parental self-efficacy in parent and child adjustment: A review. Clinical Psychology Review, 25, 341-363.*
- Kasari, C., & Sigman, M. (1997). Linking parental perceptions to interactions in 39-57.
- Kaufman, A.S., & Kaufman, N.L. (1990). *Kaufman brief intelligence test manual.* Circle Pines, MN: American Guidance Service.
- Minnes, P. & Nachshen, J.S. (2003). *The family stress and coping interview for 145 families of individuals with developmental disabilities: a lifespan perspective on family adjustment. Journal of Intellectual Disability Research, 47, 285-290.*
- Montes, G. & Halterman, J.S. (2007). *Psychological functioning and coping among mothers of children with autism: A population-based study. Pediatrics, 119, e1040- e1046.*
- Moos, R.H., & Moos, B.H. (1986). *Family environment scale manual.* Palo Alto, CA: Consulting Psychologists Press.
- Nachshen, J.S., Woodford, L., & Minnes, L.W. (2003). *The family stress and coping interview for families of individuals with developmental disabilities: a lifespan perspective on family adjustment. Journal of Intellectual Disability Research, 47, 285-290.*
- Newborg, J., Stock, J., Wnek, L., Guibubaldi, J., & Svinicki, J. (1984). *Battelle Developmental Inventory.* Allen, TX: DLM Teaching Resources.

- Preacher, K., & Hayes, A. (2004). *SPSS and SAS procedures for estimating indirect effects in simple mediation models*. Behavior Research Methods, Instruments, & Computers, 36, 717-731.99
- Quine, L., & Pahl, J. (1991). *Stress and coping in mothers caring for a child with severe learning difficulties: a test of Lazarus' Transactional Model of Coping*. Journal of Community & Applied Social Psychology, 1, 57-70.
- Radloff, L. S. (1977). *The CES-D Scale: A self-report depression scale for research in the general population*. Applied Psychological Measurement, 1, 385-401.
- Rojhan, J., Matson, J. L., Lott, D., Ebensen, A. J., & Small, Y. (2001). *The behaviour problems inventory: an instrument for assessment of self, injury, stereotyped behaviour, and aggression/destruction in individuals with developmental disabilities*. Journal of Autism and Developmental Disorders, 31, 577-588.
- Rutter, M., Bailey, A.B., & Lord, C. (2003). *The Social Communication Questionnaire Manual*. Western Psychological Services, U.S.A.
- Ryff, C. D. (1989). *Happiness is everything, or is it? Explorations on the meaning of psychological well-being*. Journal of Personality and Social Psychology, 57, 1069-1081.
- Sanders, M. R. & Woolley, M. L. (2005). *The relationship between maternal selfefficacy and parenting practices: implications for parent training*. Child: Care, Health and Development, 31, 1, 65-73.
- Shu, B.C., & Lung, F.W. (2005). *The effect of support group on mental health and quality of life for mothers with autistic children*. Journal of Intellectual Disability Research, 49, 47-53.
- Sigman, M., Kasari, C., Kwon, J., and Yirmiya, N. (1992). *Responses to the negative emotions of others by autistic, mentally retarded and normal children*. Child Development, 63, 796-807.

- Smith, T. B., Oliver, M. N. I., & Innocenti, M. S. (2001). *Parenting stress in families of children with disabilities*. American Journal of Orthopsychiatry, 71, 257– 261.
- Tobing, L.E., & Glenwick, D.S. (2002). *Relation of the Childhood Autism Rating Scale – Parent Version to diagnosis, stress, and age*. Research in Developmental Disabilities, 23, 211-223.
- Tomanik, S., Harris, G. E., & Hawkins, J. (2004). *The relationship between behaviors exhibited by children with autism and maternal stress*. Journal of Intellectual and Developmental Disability, 29, 16–26.
- Wang, P. (2008). *Effects of a parent training program on interactive skills of parents of children with Autism in China*. Journal of Policy and Practice in Intellectual Disabilities, 5, 96-104.
- World Health Organization: *International Statistical Classification of Diseases and Related Health Problems, 10th Edition*. Geneva, Switzerland, World Health Organization, 2010.

© GSJ