Role of Parents in Supporting Their Children with Autism Spectrum Disorders

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Abstract

This study helps parents to identify autistic child that are considered incompatible with life and describes the phases of grief and how they impact grieving parents. It analyzes the needs of families following an autistic child. The study then shows the most ethical issues encountered when caring for ASD child and summarizes care needs for ASD who have experienced a stuff time and extra care for their ASD child. Each child with ASD needs specific, individualized, holistic medication, treatment, diet, and schooling for their tantrums, behavioral issues, and social interaction. Psychologically, marital relationship significantly for development during a child's development, as parents must communicate and give them support with their ASD child.

Key words: Parental Involvement, Autism Spectrum Disorders, Holistic Medication

Introduction

Children with Autism Spectrum Disorder (ASD) feel difficulty in communication in interaction with people around them. Evidently, it hinders their education and learning before the age of three years. Such children are show poor sensory responses, and are engaged in stereotype movements. It is differentiated from the emotional disturbance of children as the it is related with physical growth and mental abilities and the latter is associated with psychological development. Health professionals use DSM-5 as reference for diagnosing ASD and other mental & behavioral conditions. If the ASD is addressed at early stage it can reduce its symptoms and improve intellectual ability of the children. It was observed that ASD intervention starting from 18-30 months age of children and more than 20 years' follow-up appeared an effective strategy. If parents intervene at early stage(s) of ASD, the children can learn new (social) skills and improve their abilities easily.

Children with ASD need more attention and support of their parents than their normal siblings. In this regard, it seems necessary to promote awareness among parents about ASD and its effects on children's lives. Mostly, the parents need to understand that their children with ASD can learn new skills and cope with their needs if properly intervened and treated. Hence, the training of parents on how to extend active support to their children seems to be of great significance. It also would have lasting effects on functioning of the children with different disabilities.

In this study, we compare autistic children and their needs. Unfortunately, Case'1's parents were separated when he was born, and he lives with their father and grandmother, grandmother takes care and Case'2' lives with their parents, and their mother is a responsible parent good care of him well. According to Burrell and Borrego (2012), children with ASD particularly benefit from having family members or parents participate in therapy since they can offer needed intervention (Dunlap, 2005; Brookman-Frazee, 2004; McDiarmid & Bagner, 2005). In addition to providing information about the child's strengths and preferences as well as significant family values and routines, parents are particularly significant since the time they spend with their children can result in educational possibilities (Symon, Buschbacher, Fox, & Clarke, 2004).

Additionally, it is observed that parents can extend effective support in continuing the treatment. Incorporating parents into treatment make them help their autistic children at home. It improves their belongingness and assistance they need. The more the parents support their autistic children, the more they improve. This study will address many aspects associated with treatment outcome and therapeutic recommendations, along with parents' involvement in treatment and their association with children (Symon, 2001).

According to Volkmar, Lord, Bailey, Schultz and Klin, 2004, over the past ten years, there has been a sharp rise in the prevalence of ASD. Similarly, the Center for Disease Control and Prevention, 2009 reported that one out of 110 children had ASD. This situation asserts that parents and other stake holders should address the issue of the children with ASD on priority basis through positive behavior support. The challenges of raising an ASD kid have an impact on families; therefore, support of the parents in treatment enhances parent and family functioning.

Literature Review

There are some functional challenges associated with ASD children. The most pressing include internalizing behavior issues (Hartley et al., 2008) and externalizing behavior problems (Reeve & Carr, 2000; Horner, Carr, Strain, Todd & Reed, 2002; Hartley, Sikora & McCoy, 2008) along with un-supportive interaction of parents (Solomon, Ono, Timmer, & Jones, 2008). Children with behavioral issues also have trouble interacting with their parents. Children with high-functioning ASD exhibit little to no social-emotional comprehension, according to research (Bauminger, 2002). They might want to interact with people, without knowing to establish and maintain connections. They might not be able to develop deep bonds with their parents. When a child exhibits disruptive behaviors, the parent-child bond may suffer (Fox, Vaughn, Wyatte, & Dunlap, 2002). Because behavioral issues are often sustained by their surroundings and the reactions, they elicit from those around them, they are challenging to modify (Horner et al., 2002).

According to Reeve and Carr (2000) children learn to recognize circumstances in which they can receive rewards from parents and other adults for engaging in undesirable actions. The coercion model of the Patterson (1982) explains the emergence and persistence of behavioral issues leads towards developmental impairments. Children with ASD, for instance, have extremely tight schedules and habits. If these routines are disrupted, they may start to display behavioral issues like weeping, complaining, or tantrums. When a parent reprimands a child for complaining or engaging in other undesirable behaviors, the child may start screaming, which ultimately leads to the parent caving in to the child's demands. It encourages the behavior of both the parent and the child. According to research, children's behaviors tend to worsen and intensify throughout time (Buschbacher et al., 2004).

Because of the aggressive and unpleasant nature of the interaction, there are more issues in the parent-child relationship. Parents with children with ASD face stress in numerous other areas of their lives in addition to issues with the parent-child bond. Child reliance, physical restrictions, cognitive impairment, caregiving responsibilities, interference with everyday activities, and long-term childcare responsibilities are the main causes of parental stress in this demographic. Compared to their counterparts of the same age without disabilities, children with disabilities have more needs in terms of social, financial, and physical care. Family habits or traditions may change, more time is spent organizing events, there are limitations on events or activities that can be attended, and the family is under more stress. Marital satisfaction may suffer as a result of the family's increased stress and strain. Research indicates that among women of children with ASD, marital satisfaction is adversely connected with parenting stress, particularly the perception of the severity of the child's disability and behavioral issues (Brobst, Clopton, & Hendrick, 2009).

Additionally, it has been discovered that parental depressive symptoms, parenting stress, and parenting efficacy in women and depressive symptoms and parenting stress in fathers are associated with marital quality (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). Recently diagnosed parents of children with ASD are already more likely to experience despair and feel inadequate as parents. The higher prevalence of depression among parents of children with

developmental disabilities may be partially explained by the association between marital quality and depression. Parents of children with autism have generally been reported to have higher levels of depression than parents of children with usual development; nevertheless, throughout time, contradictory findings about parental depression have been discovered. The entire family, including the parents of children with autism, may suffer as a result of these stressors and other contributing elements and outcomes. Effective treatments can lessen these detrimental impacts on the child, family, and peers of an individual with ASD. According to research, there are a few key elements that enhance the success and general results for kids with ASD and their families.

Factors Related to Parental Involvement

When family members or other individuals participate in treatment instead of just specialists (Horner et al., 2002; Buschbacher et al., 2004; Ingersoll & Dvortcsak, 2006). Parents are particularly crucial in supporting children with ASD (Campbell & Kozloff, 2007). Parents can help with goal-setting and educational planning, offer crucial assessment, diagnostic, and instructional information, and effectively carry out treatment (Campbell & Kozloff). It is demonstrated that these children benefit from early intervention, which would unavoidably require parental engagement (McConachie & Diggle, 2007).

USDHHS (2008) says that parents are often first to notice symptoms and play a crucial role in therapy to improve the likelihood that a child will have a good prognosis. Parents are the most crucial group to include in intervention initiatives since children with ASD will spend most of their early interactions and educational experiences with them (Prizant et al., 2003). Involving parents in their child's care might also be beneficial. Increased positive affect (Solomon et al., 2008), decreased stress (Symon, 2001), and enhanced self-efficacy (Feldman & Werner, 2002) have all been observed when parents are given the chance to acquire and apply skills that will enhance their child's functioning. Additionally, results showed reduced parental stress, increased confidence, and more positive parent-child interactions when parents are viewed as partners or collaborators with clinicians in parent education programs where they assist the clinician in creating goals and treatment plans (Brookman-Frazee, 2004).

Both the parent and the child benefit from these results, which should open up more possibilities for the family. Certain evidence indicates that certain families gain more from parent training than others, though it is unclear how or to what degree parents must be active in order to receive these benefits. Certain traits of parents have been found in several studies to have an impact on the advantages of parent education. Before the start of treatment, parents with greater levels of education, marital status, and socioeconomic standing were found to have more expertise and skills and to have anticipated fewer difficulties applying them. According to Robbins, Dunlap, and Plenis (1991), children from intact, two-parent households made the greatest improvement in treatment, while children with parents who reported higher levels of stress made less progress. Parental benefits have also been observed to vary based on the type of treatment. Compared to parents who were educated to employ alternative treatment methods, parents who employed crucial response training procedures with their kids were happier, more engaged, had less stress, and had more

enjoyable interactions with their kids. Treatments must also be feasible for the family. Research Units on Pediatric Psychopharmacology (RUPP), 2007, evaluated the treatment viability, parental acceptance, and parental satisfaction of a parent training approach for parents of children with ASD.

Parental satisfaction with therapy and session attendance were used to measure feasibility. The findings showed that parents attended 93% of the required training with moderate to high level of satisfaction. Ingersoll and Dvortcsak (2006) found that parents were generally satisfied with a special education program that incorporated parent training in addition to treatment. Significantly, parents stated that parent mentoring was the most beneficial element (Ingersoll & Dvortczak). Parents felt valued and involved in their child's care, according to other therapies that included them (Buschbacher et al., 2004).

In addition to feeling at ease and content with the care their kid receives, parents must see themselves as important contributors to the therapy process. Given the numerous benefits of treatment for both the parents and the kid, it is obvious that parental participation is essential to a positive result. Parents could be included in several ways, tho. The diagnosis of symptoms and the active role of parents in treatment have been discussed.

Parent Roles in Treatment

Many therapy modalities have been developed to treat children with ASD because of its widespread impacts. As was already said, ASD symptoms have been successfully reduced when parents are included in therapy, and treatments that incorporate parent training components have demonstrated positive results (McConachie & Diggle, 2007). Researchers have discovered that parental engagement in treatment has numerous positive consequences, but this does not imply that treatments without parents are useless (McConachie & Diggle). Additionally, greater good treatment outcomes are positively correlated with more rigorous treatment involvement (Anderson & Romanczyk, 1999).

Making parents learn the skills maximizes the assistance that kids receive. It facilitates the parents and the children appropriately (Brookman-Frazee et al., 2006). Parenting strategies are the most often targeted in therapies for such children. Since parenting techniques were not the main presenting issue nor the main objective of treatment, they might not have been the focus of care for children with ASD. However, due to their current externalizing behavior issues and the degree to which it hinders their functioning, children with ASD may benefit from treatments that emphasize parenting techniques (Hartley et al., 2008).

Given the high prevalence of disruptive behaviors in children with ASD, the elevated levels of parenting stress, and other detrimental familial factors that impact them, it seems problematic that parents of children with ASD would not be taught skills comparable to those of parents without developmental disabilities. Teaching parents how to reduce behavioral issues could be beneficial for ASD therapies, as it could lessen the burden of parenting. Families of children with impairments may benefit from support or respite from treatment involvement. Treatments that

were traditionally utilized for parents of children with behavioral issues are being extended to treat children with ASD, and several therapies regularly engage parents in the treatment of children with ASD (McDiarmid & Bagner, 2005).

Parents must be included at every stage of the treatment process since they are crucial to success and a favorable prognosis. According to a review of parent-implemented therapies for young children with ASD, parent education can enhance the child's communication and social skills as well as the parent-child bond and parent functioning (McConachie & Diggle, 2007). There are several methods in which parents might participate in treatment. In order to weigh the advantages of each and choose the best course of action for that child's care, it is crucial to consider how they might be included.

Statement of the Problems

Children with autism spectrum disorders are receiving a wide range of therapy and treatments. However, there is typically little to no empirical data to support these regimens. There is no known cause or treatment for autism spectrum disorders. Treatments for ASD must address almost every aspect of development and adaptive behavior, whereas treatments for other diseases and disorders can concentrate on a small number of symptoms. Some children on the spectrum respond poorly to therapy, while others show little to no change. The "standard of care" cannot be prescribed by physicians or therapists because there isn't a routine that works for every child. Parents play a significant role in choosing the therapies to employ with their children in the absence of a clear treatment plan. They consider a wide range of options, some of which are readily accessible and others of which require significant financial and labor expenditures. Undoubtedly, parents seek advice from their children's physicians and educators, but a greater proportion told us that they look for knowledge on their own—from other parents of autistic children, websites, books, autism organizations, and newsletters; thus, the study is designed to find out the support of parents for their artistic children.

Objectives of the study

The objectives of the study were;

- To find out the effect of medication for the treatment of ASD.
- To explore the impact of consistency in treatment is necessary.
- To find out the impact of parental relationship on the development of an autistic child.

Hypothesis of the study

The hypotheses of the study were;

- Medication is paramount for the treatment of ASD
- Consistency in treatment and medication is necessary for progress.
- There is a significant parental relationship for the development of an ASD child.

Research Methodology

Research Design

The research design of the current study was a comparative qualitative case study design to compare factors, e.g., support from family, life experience, caregiving patterns, and developmental contexts of two children diagnosed with autism. The study focused on two individual children (cases) and explored each child (case) within their natural environment of family and social circle. A comparative approach was selected as appropriate because it make researcher helpful to examine how different factors shape the daily lives of the children with autism.

Case Selection

The two children, Case 1 and Case 2, with autism were selected purposively in the study. The purpose of selecting two children was to understand in depth understanding of the different family environments and the effects of family support on the life experiences of the children with autism.

Case 1

Case 1 was a child who was living with his father and grandmother. His mother left him when he was only six months old, and after that she did not contact him. Meanwhile, his grandmother took the responsibility of primary caregiving, and she became highly involved in meeting his needs whenever he needed her.

Case 2

Case 2 was a child who was living with his parents (both father and mother) in a family-supported environment. His mother had a key role in his caregiving and development. His mother supported him in treatment, diet, schooling, and daily life activities. He had a sister of 5 years old who provided him with social, emotional, and practical support.

Data collection

Data were collected through direct observation and semi-structured interviews. The direct observation was focused on the children’s everyday interactions with family members and social interactions. The semi-structured interview was conducted with the caregiver to obtain detailed information about the children's history, family environment, treatment, and schooling.

Comparative analysis

The data collected from the observation and the semi-structured interview were analyzed comparatively in two cases. The analysis of the data examined the structure of the family environment, caregiver support, emotional and educational environment, and treatment. The researcher analyzed each case individually to make a comprehensive analysis of the children's treatment and experiences. Then both cases were comparatively analyzed to identify the similarities and differences in their treatment.

Findings

- It was found that case 1 received inconsistent caregiving and less parental involvement, while case 2 experienced consistency in caregiving and parental involvement.
- It was found that case 1 had no consistency in treatment and had limited progress in development, whereas case 2 had consistency in medication, counselling, and therapy. Case 2 showed better behavioral management.
- It was found that case 1 had changed schools many times, and at the end, case 1 received home-based schooling, while case 2 experienced good schooling and continued his schooling till grade 9th with average progress.
- It was found that case 1 was dependent on nonverbal communication, whereas case 2 spoke short sentences and developed functional conversation.
- It was found that case 1 had difficulties in behavioral development, while case 2 ‘s problems with behavioral management remained manageable through continuous family support and therapy.
- It was found, with the comparison of both cases, that case 2 experienced parental involvement, regular treatment, continuous education, and behavioral management cause better development in case 2. On the other side case 1 received inconsistency and remained dependent.

Discussion and Conclusion

Discussion

As we have discussed, the method of comparison between two case studies. In the following, you will see a detailed comparison of the case history of two boys diagnosed with a mild level of autism spectrum disorder. The similarities and differences in each of them will be compared to get a detailed result on how it affected their overall progress and how the parents played a vital role in this study. In the following comparison, we’ll be referring to both boys as Case 1 and Case 2. By comparing using different themes to determine similarities and differences between the cases and how they will determine the results that occurred.

Parental Relationship

It is significant that parental sensitivity and attachment in children with ASD; more social children are more capable of showing attachment behaviors, which elicit more responsive parenting (Judith A. Crowe, NOV 2018). It is important for both a normal child and a child with special needs. Case 1: Grandmother giving him inconsistent treatment. Case 2: Mother gives him consistent treatment. One common factor we identified in both cases was that the connection between the parents of both children was father was distant. The father was not positively involved with the children. There was little to no affection at all. This might be a cause of their delayed development.

Maternal Issues

Mother's health can affect the baby in many ways, be it physical or psychological. The psychological aspects of major mothering problems include miscarriages, post-natal depression, and adolescent motherhood. (Paola Mariotti 2012). The mother of Case 1 had sleeping issues due to stress or depression from her relationship with her husband. Hence, she started taking self-prescribed antidepressants. On the other hand, the mother of Case 2 had high blood pressure issues, which were genetic in her case; hence, she took medicine to control her blood pressure.

Birth Condition

Autism is present at the time of birth, and there is no valid research stating that having different birthing conditions can affect a child. Autism Spectrum Disorder is classified as a neurodevelopmental disorder in which multiple genetic and environmental factors play roles in the expression of the disorder. Case 1 was born through cesarean delivery (C-section), while Case 2 was born via normal birth.

Parental Concern

Acceptance can be difficult for parents whose child is diagnosed as different from others. The lack of acceptance can affect the amount of effort they make to help their child live a better life and improve various indicators related to stress, depression, and behavior problems. (A Scientific Mapping in Web of Science 2021) The guardian of Case 1 was still in denial. Even after he was diagnosed with autism spectrum disorder due to their impatience, he could not attend proper therapy or education. In the case of Case 2, only his mother had genuine concern towards his treatments and therapy. She paid proper attention to his treatment and education. The father had a neutral concern towards his child and was only present for economic support.

Early Diagnoses

The Earlier a disability is diagnosed, the easier it is to treat. Early intervention is better to give priority to the main symptoms as soon as the condition is identified, especially in early childhood. (Roy McConkey, May 2020). Both cases were diagnosed by the age of 3 years. In the case of Case'1' he was diagnosed directly as Autistic while Case 2 was first taken to an Ear Nose Throat (ENT) specialist and diagnosed as hearing that the parent notices him responding to only the things, he liked so he was taken for a reassessment and was diagnosed to have normal hearing. After the third test, they took him to a psychologist at the age of 3 years, and he was diagnosed as autistic.

Economic Status

The economic status of the family can affect many aspects of the treatment; informal care and education costs appear to be a major component for parents with children with ASD. (Nicky Rogge, Juliette Janssen 2019) It rarely affects their cognitive development. Both children belonged to a middle-class family who could afford the treatments required to help their kids cope better with their needs.

Developmental Problem

Autism Spectrum Disorder does not affect the physical development of a child, so it's hard to be diagnosed before language development is delayed and before restricted and repetitive behaviors appear. (A Scientific Mapping in Web of Science. Brain Sci. 2021). In both cases, the boys did not show any physical developmental delay of any sort. When the speech developed, both parents noticed visible problems in the language development of their children. They had problems during communication. Social interaction problems were also present.

Diet Issues

Proper diet is very important for children with special needs as well as normal children to help them grow healthy. Therapists provide a special diet plan to the parents of an autistic child to help them avoid inappropriate foods caused by an overdose of specific foods like sugar and gluten; diet might be able to do so much more than influence our physical health. (Paul Whiteley, Mark Earnden, Elouise 2014) The parents of Case '1'did not follow any diet plan and provided the child with an imbalanced diet. The child had a high intake of sugar on a daily basis from juices and other sweet snacks. On the other hand, the parents of Case '2' gave him medicines as prescribed by the therapist. They gradually increased the dose of the medicine and decreased it when the child was able to cope with irritability on his own, and gave him control diet.

Medication and Treatment

Medication have been used to treat symptom of ASD (Roberto Canitano, Yuri Bozzi 2015) Case'1' guardian gives prescribed medicines for few days, when she was seen no rapid result, she gets over it, when child behavior issue, pain, sleeping issue and self-injury so high again she gets to doctor he prescribed some medicine she gives him for few durations of time get over it. On and off, the medication gave no improvement to the child. When the child was 10 years, she gives him medication on daily bases, when his intervention time is over. Case'2' mother gives prescribed medication and treatment started at 3 years of age continuously till age of 8. His behavior issues settled; now he is very well. He didn't need any dose of prescribed medication and treatment.

Schooling

Schooling plays an important role in the better development of a child in social and psychological aspects. Schooling and education support for ASD has been gaining attention. (Kats, Yefim, Stasolla, Fabrizio Nov 2020) In the Case'1'due to his parents' inconsistency resulting from their impatience to make their child better, he was not able to get proper schooling. At first sent him to a normal school, but since the child had trouble adjusting, he was shifted to a special school. The result was not consistent, so they started giving him home lessons instead. The Case'2' was sent to a normal Montessori setup for the first two years of schooling; later, he started having problems adjusting with his peers, so he was moved to three different schools. A resource teacher was appointed for a month, but rather than independence, the child learnt to be dependent on the teacher

instead. When he reached grade 4, he was shifted to an inclusive setup due to the school; with great cooperation, the child is now in grade 9 with average grades.

Religious Education

The most challenging aspects of religious education for autistic children are abstract ideas. (Ella Rain 2020) Case'1' was not given any commands to achieve religious education at home or from school due to the inconsistency of the parents. The parents did not show any consent regarding this matter and thought it was unnecessary for him to learn this because he is not able to take care of himself. Case 2, on the other hand, got proper lessons regarding his religion. He completed the Holy QURAN in 11 years of age of continuous study. Although he showed many tantrums during the lessons, he was able to achieve it due to consistency; he now also practices Roza (fast) and Namaz (prayers) as well.

Speech Development

Children with ASD tend to be socially less involved, less responsive, and they tend to decline their parents' social initiatives. (Silvia Perzolli November 2020) Case'1'had little to no interest in peers of his own level; he could not develop good language skills, and to this day he still uses non-verbal gestures to communicate with his guardian. The mother of case'2' made several efforts to help her child able to communicate as normally as possible. He has normal language skills; he can speak short sentences and keep short conversations with his family.

Behavioral Issues

Children with ASD display many problem behaviors due to their uneasiness, irritability, anxiety, and rigidity. (Sam Milam 2021) Treating those behaviors is very important for their proper development. Due to unstable therapy, Case'1' was not able to manage his behavior problems. No proper management was made by the parents or family; rather, they increased the behaviors by overly pampering the child and fulfilling each demand. In Case'2 ', the behaviors were managed with medication and behavior therapy, with continuous counseling and the family's support.

Child's Present Condition

Case 1's present progress in different areas. The child is unable to make verbal conversation with other people. In self-help skills, only toilet training is given; besides that, everything is done by the family. The child is completely dependent on his guardian. The Case'2' progress states that some problem traits are still present in the child, but the family can manage them well and train him to cope with them better. A lot of progress is present in the child with the help of family and professionals. He is independent in all areas, able to take care of himself properly. Self-help skills are properly taught, social skills and communication skills are well developed, educational progress is also good, and he is rehabilitated in society very well.

Conclusion

The results of the case study show that the general growth and well-being of a child with autism spectrum disorder (ASD) depend on a positive and harmonious marital relationship between

parents. Better emotional and behavioral development may result from consistent love, care, attention, and shared parental responsibilities. The study also points out that to meet the child's physical and developmental needs, appropriate medical care, frequent follow-up visits with medical specialists, and a balanced diet advised by competent dietitians are required. For children with ASD to have improved development, conduct, and overall well-being in the future, a stable home setting, active parental involvement, professional therapy, and appropriate nutritional care are crucial.

Recommendation

These are the recommendations for ASD child parents:

- Both parents must give proper attention, affection, care, and be responsible toward your ASD child.
- The role of your marital relationship is the foundation for your child.
- Consistency in medication and treatment has given a better life for your ASD child.

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