



IJSRM

INTERNATIONAL JOURNAL OF SCIENCE AND RESEARCH METHODOLOGY

An Official Publication of Human Journals



Human Journals

Review Article

December 2020 Vol.:17, Issue:2

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Living with Autism: Challenges and Resources



IJSRM
INTERNATIONAL JOURNAL OF SCIENCE AND RESEARCH METHODOLOGY
An Official Publication of Human Journals



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Submitted: 07 November 2020
Revised: 27 November 2020
Accepted: 17 December 2020



HUMAN JOURNALS

www.ijsrm.humanjournals.com

Keywords: Communication Barriers, Care Management, Stigma, Family and Caregiver Roles, Sleep Disorders, Quality of Life

ABSTRACT

Background: Autism affects people in different ways. Living with autism is experienced differently for individuals because each person's uniqueness allows for a broad scope of understanding this phenomenon. Looking from the outside, the overall syndrome of autism is related to a kaleidoscope. Yet, there are many secondary conditions, hence the countless pictures discovered while looking through the kaleidoscope. The secondary conditions are referred to as speech and language difficulties, intellectual disability, sleep problems, attention problems, epilepsy, anxiety and depression, and difficulties with fine and gross motor skills. **Purpose:** Purpose of this review was to identify the challenges of living with autism. **Method:** This was a review of pertinent literature using databases from the University library online resources. **Findings:** Findings include challenges such as communication barriers, stigma, sleep issues, and poor quality of life for the individual. Family role in autism care and care management are also significant factors. **Conclusion:** Not only is autism a complex disorder, but the care needed is complex as well. With a multidisciplinary approach to management and a sound support system, a person living with ASD can live a long and healthy life.

1. INTRODUCTION

Autism spectrum disorder (ASD) is a developmental disability that has many other secondary conditions [1]. These conditions that relate to ASD include speech and language difficulties, intellectual disabilities, sleep issues, attention issues, epilepsy, anxiety and depression, and difficulties with fine and gross motor skills (see Figure 1). For a better understanding, the word “spectrum” in ASD refers to the wide range of symptoms and severity. The severity of this disorder is broken down into three levels, mild, moderate, and severe. Level one (mild) requires the least amount of support, level two (moderate) involves ample amount of support in certain areas of care, and level three (severe) entails extensive support in all areas of care. Unfortunately, ASD does carry a lot of stigma leading to isolation and unresolved diagnoses typically due to the lack of knowledge regarding ASD. The lack of knowledge can act as a barrier. So, to help day-to-day situations, certain coping mechanisms can ease the transition. For someone struggling with autism, maintaining past routines like bedtime and wake time, mealtimes, hygiene, chores, and practicing self-care like taking short breaks throughout the day, practicing breathing exercises, participating in physical exercise, journaling, and continuing prescribed medications can be advantageous. The Center for Autism & Related Disorders (CARD) stresses comprehension to effectively advocate for patients who have autism. With ASD being a genetically contingent disability and 1 in every 160 persons globally diagnosed with ASD, this highlights the importance of understanding this mental illness. Being knowledgeable can impact the ability to interact and care for a person with autism. In all, this review will investigate how it is like to live with ASD.

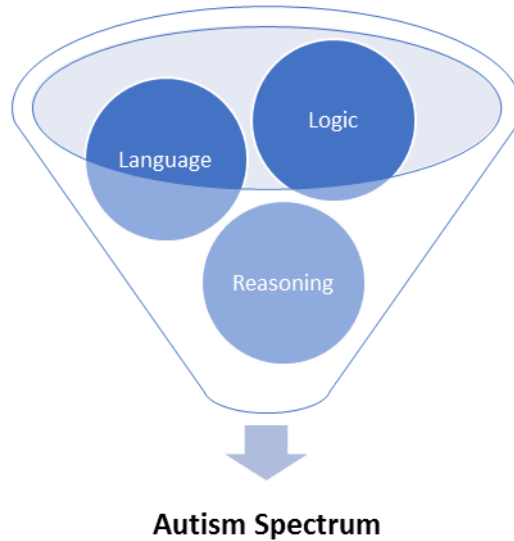


Figure No. 1. Behavioral syndrome observed in autistic children resulting from abnormal left-brain function

2. BACKGROUND

ASD is defined as “a complex neurobiological and developmental disability that typically appears during a child’s first three years of life” [1]. This disorder expresses persistent social communication deficits and social interaction by restricted and repetitive behaviors, interests, or activities. People with this disorder have behaviors that demonstrate a lack of interest in social responses, eye contact, or facial expressions. Other symptoms may include "stereotypical repetitive speech, obsessive focus on specific objects, over-adherence to routine or rituals, hyperactivity or hypoactivity to sensory input, and extreme resistance to change” [1]. Genetics do play a role in ASD. If someone in the family has ASD, this puts a child at a higher risk of developing this disorder. ASD is more likely to occur in males than in females. Interventions are necessary for this disease and are aimed at improving social interaction and communication skills, “Without intensive intervention, individuals with severe autism spectrum disorder may not be able to live and work independently” [1]. Along with nonpharmacological interventions, only two drugs are approved to help alleviate the symptoms associated with ASD, risperidone and aripiprazole. These medications treat only the irritability and do not target the core symptoms of this disorder. It is vital to assess how the family is coping with this diagnosis. Stress on the family varies based on the severity of the impairment the child displays. It is essential to educate

the family about realistic goals for their child. Additional resources and services may help alleviate stress.

3. LITERATURE REVIEW

The database used for this literature review includes the university library, where peer-reviewed studies were searched. The review focused on what it is like to live with ASD and its challenges along the way. A few topics discussed includes stigma, communication barriers, family and caregiver roles, sleep disorders, care management, and quality of life.

3.1 Stigma Plays a Role in Autistic Individuals and their Caregivers

Within the lives of autistic individuals and their caregivers, stigma plays a prominent role in challenges. With the common external stigma exerted from bystanders, self-stigma is also a probable effect of the families raising an autistic individual, "Parents and carers can feel blamed for their child's behavior, feel socially excluded and isolated and suffer from low self-esteem and poor psychological well-being" [2]. Expanding on the blame the parents feel on atypical behavior, decreased self-esteem is the root cause of reduced confidence in their parenting abilities due to the thought of their children undermining. Not only do guardians experience these negative consequences, but stress is also reportedly higher than being faced with other disabilities. Since noble caregivers are more vulnerable to self-stigma and self-blame because it might be their first-ever encounter with autism, early diagnosing and interventions must be made. SOLACE is an intervention that comprises nine different sessions and includes theory, group discussions, short video clips, exercises, and examples of parent/carers' experiences. SOLACE is broken down into an introduction, coping with autism stigma, positive meaning of caregiving, resilience, self-esteem, social support, compassion, and acceptance, coping with autism stigma part two, the next steps, and the focus group. Overall, a respectful and supportive environment is encouraged to receive the best benefit of this intervention.

3.2 Communication Barrier Includes Limited Verbal Skills

Children with ASD struggle with communication and have limited verbal skills. Many interventions can be used to improve communication skills related to ASD. Ensuring a milieu environment is important to help encourage communication. Augmentative and alternative

communication (AAC) "encompasses any form of nonspeech communication, including sign language, picture symbols, gestures, and speech-generating devices" [3]. One disadvantage of AAC is that it does not provide the child with opportunities to communicate independently verbally. This is best when used to gain the child's trust but needs to advance to a different intervention when appropriate. Opportunities to initiate (OTI) "involves manipulating the environment, violating the child's expectations, or other approaches that encourage a student to initiate communication" [3]. An example of OTI would be providing a child with a juice box without a straw. This forces the child to use communication skills and independently ask for a straw. Providing opportunities for students to respond (OTR) "not only increases student communication, but can also increase student engagement, improve achievement, and decrease problem behaviors" [3]. An example of OTR would be asking the child how they are doing and waiting for an appropriate response. This intervention is not best when used alone. The child benefits from OTR and OTI when they are used together to improve independent communication skills.

Communication in people with ASD varies from person to person. Still, most people experience some level of difficulty in motor, speech, and language domains where language deficits are correlated with deficits in oral-motor skills [4]. The researchers split up their study by looking at the relationship between motor skills and language abilities in ASD and relationships between motor skills and social interactions. Between motor and language abilities, they found significant associations between the two. More specifically, expressive language and receptive language were positively associated with fine motor skills [4]. They also found that gross motor skills and fine motor skills were significantly associated with social interaction skills. This provides another way to view communication differences across the spectrum to use for treatment interventions.

Since individuals with ASD lack communication skills, it is difficult to understand or portray their feelings and emotions. People who live with this incurable disorder often experience vulnerability in mental health problems such as anxiety and depression. Comprehending feelings allows for survival, attachment, interaction, and growth, but with ASD individuals, it is more helpful to ask what matters to them rather than: What is the matter? The purpose of the study was to understand the manifestations of anxiety and coping strategies. The discussion supported how

all care should be, whether autistic or not, individualized. All participants in the study were very different in the way they presented during the interview. Some could recall and articulate their thoughts and feelings, while others found it to be profoundly painful and struggled to remember. Overall, caregivers should be more understanding, patient, and sensitive.

3.3 Family and Caregiver Role is Challenging

Selman *et al.* [5] discussed common challenges a family faces with a child diagnosed with ASD. ASD can affect a family by causing high-stress levels, depression, and stigma. "Parents described behavioral problems common in autism, such as children having "no sense of danger," running away and having violent outbursts" [5]. This can cause extreme amounts of stress on the family due to their need to constantly watch the child to ensure their safety. The violent outbursts cause stigma and judgment from others while in public places. People may think the parents don't know how to handle their child during these outbursts. "Some parents reported neighbors or friends avoiding their company, while others described how parents of children with autism isolated themselves to protect their children, or to avoid the difficult interactions they encountered when their children did not follow social 'rules'"[5]. This constant stress and judgment can cause stress and even depression and isolation in parents with children diagnosed with ASD. Family dynamics were examined and found that the mothers loved and accepted their child with ASD, while the fathers struggled, denied there was a problem, were unsupportive, or left the family. Most of the participants in this study believed that phrases such as ill, sick, or disabled were negative terms, and the public needs more education to understand this disorder.

Spending quality time with family members creates family growth and allows for fun leisure time. This statement is true for all families; however, within the scope of families with autistic children, multiple barriers impact the ability to do this. Walton [6] concluded that, "Parents of children with autism spectrum disorder reported a similar amount of leisure involvement as families of typically developing children. However, they reported lower leisure satisfaction, poorer family functioning, and less satisfaction with family life" [6]. To create the most remarkable outcome, families living with ASD should focus on quality rather than quantity time to influence family functioning and satisfaction positively.

3.4 Sleep Disorders are Common in ASD

Sleep is essential to life, and lack of sleep is associated with poor attention, memory, learning, and behavior. "Sleep disturbances are found in 70% to 75% of the children with ASD and 45% to 50% of healthy children" [7]. It is essential to understand the importance of sleep and promote healthy sleep habits in children with ASD. If a child with ASD does not get an adequate amount of sleep per night, it can cause behavioral symptoms to worsen, including hyperactivity, mood, and irritability. Gunes *et al.* [7] compared sleep disorders in children with ASD with normal intellectual capacity and intellectual disability. There was no difference in sleep patterns between both groups, and the sleep disturbances observed were textbook sleep disturbances for children with ASD. "Sleep disturbances in ASD include parasomnias like sleepwalking, night terrors, and sleep-related movement disorders as well as bedtime resistance" [7].

Sleep disorders are common among children with ASD. Sannar *et al.* [8] discussed the relationship between sleep duration and awakenings in a hospitalized setting. Sleep issues in ASD patients include decreased sleep efficiency, reduced total sleep time, increased nighttime awakenings, bedtime resistance, and daytime sleepiness [8]. For this research, the data was collected by the staff who documented if the patient was sleeping or awake every 15 minutes and what they were doing if awake. They took into consideration the patient's irritability, lethargy, hyperactivity, stereotypy, and inappropriate sleep, which all play a role in the patient's ability to sleep. During the first half of the patient's stay, they are adjusting to their new environment. Sometimes, being tired from behavioral dysregulation may impact their sleep quality. The researchers found that sleep duration was negatively correlated with irritability, stereotypy, and hyperactivity in the last half of the patient's stay [8]. This proves that children with ASD have increased sleeping problems when those issues are present.

3.5 Follow up Care Management is Key to Success for Individuals and Family

Once patients with ASD are diagnosed, they go through management and follow up care. People with ASD require support from social care services and medical, behavioral, and developmental interventions to reach their full potential [9]. After diagnosis, parents should be informed about different treatment options, supportive resources, and any major life changes they should be prepared for. The main goals of treatment should focus on developmental, behavioral, and

learning challenges [9]. Children with ASD tend to have greater health care service needs. For example, they should have regular dental check-ups, yet they may require a modified approach based on their sensitivities, anxiety, or language impairments. Gastrointestinal disorders (GI) are higher in children with ASD than in the general population; however, the treatment should be the same as treating a condition in a person without ASD. Like GI disorders, sleep problems affect 50% to 80% of children with ASD [9]. The authors suggest counseling to reinforce behavioral techniques with possible collaboration with a behavioral therapist, which could help with abnormal sleep and daytime behaviors. Another difficulty faced is an anxiety disorder, where about one-half of children with ASD have experienced. If the child is verbal, they may benefit from cognitive behavioral therapy sessions [9].

Complementary and alternative medicine (CAM) approaches are used in approximately 28% to 95% of families affected by ASD. Families are more likely to try CAM therapies if they experience severe ASD symptoms [9]. Clinicians need to be up to date with current evidence as the therapies are rapidly evolving. They also should not replace conventional ASD therapies but rather add the CAM approaches one at a time [9]. CAM is safe and effective and allows for a more personal autonomy for health care decisions. This type of alternative medicine focuses on relaxation and alleviating stress creating more positive emotions which ultimately helps improve the health and wellness of the body.

As many people with ASD are diagnosed at a young age, the parent's role in care and treatment is huge. As parents learn to care for their children with ASD, they may become isolated from friends and family and may not understand their behavior and disability [10]. Around 50% of children with ASD have disruptive behaviors, including tantrums, noncompliance, aggression, and self-injury, amplifying the caregiving burden [10]. This research focused on parent training versus psychoeducation in children with ASD. Over the 24 weeks, the researchers found that parent teaching reduced 14% on the parenting stress index while psychoeducation had a 9.3% reduction [10]. A more significant reduction in parent teaching than the psychoeducation was also true for the caregiver strain questionnaire and parenting sense of competence.

3.6 Quality of Life Should be Individualized for Person with ASD

Smith *et al.* [11] performed a study to examine the quality of life in individuals diagnosed with ASD. Quality of life was measured and found that "perceptions of social interaction were an important factor in both negative and positive perceptions of wellbeing for this group" [11]. Individuals with ASD who were able to communicate and attend higher education rated the higher quality of life scores. Lower quality of life scores was associated with an emphasis on objects, others' presence, and found communication to be stressful. People with ASD have problems with communication, but some still desire social interaction. "An autistic person may have neuropsychological differences that make them more likely to "see things as they are" and take a more honest and straightforward approach towards their objective situation" [11]. This direct approach can make it stressful or frustrating for people with ASD to follow a conversation. For example, if someone were to say it is raining cats and dogs outside to a person with ASD, they would look out the window and be confused as to why they do not see cats and dogs falling from the sky. This may cause stress on the individual for not understanding the conversation they were having. Interventions should be focused on stress management to ensure less anxiety, depression, and isolation. Quality of life is individualized for people with ASD, and it should not be assumed that someone with ASD has a poor quality of life due to their diagnosis.

In a study on mental health and sleep quality, "Autistic adults experience a higher rate of physical and mental health conditions and lower rates of employment and post-secondary education participation than their non-autistic counterparts, which may affect the quality of life negatively [12]. It is also found that at least half of individuals remain living at home well into adulthood. Some physical health issues recorded in evidence include allergies, cardiovascular disease, obesity, neurological conditions, gastrointestinal disorders, and sleeping disorders. The reasoning behind being unemployed or underemployed is generally related to poor community engagement and the possible issuing of mental and physical health problems. The overall purpose of the study was to compare and contrast the contributions of demographic characteristics (age, gender, living arrangements), vocation (employment, study), autistic symptomatology, mental health, and psychological well-being and physical health to the physical, psychological, and social or environmental domains. The study was done through a series of questions cross-sectionally and longitudinally, meaning the data was taken at a given

point of time and then repeated over an extended period to collect the most accurate results to support the author's hypothesis [12].

This complex and incurable condition is predictably found in younger years and carries on into later adulthood. Not only is autism complex, but the care needed is complex as well. The importance of acknowledging and understanding this disorder is enormous because it is so prominent globally. Individualized care is necessary and vital because it reflects who this individual is by considering their conditions, abilities, needs, routines, and goals. The end goal is for the autistic individual is to live an independent normal life. People who live with autism are said to have a decreased quality of life; however, they can live autonomously with accurate care management and treatment. Stress management is a prominent intervention to cope with life to help achieve a more excellent quality of life. Figure 2 illustrates the various themes found in the literature.

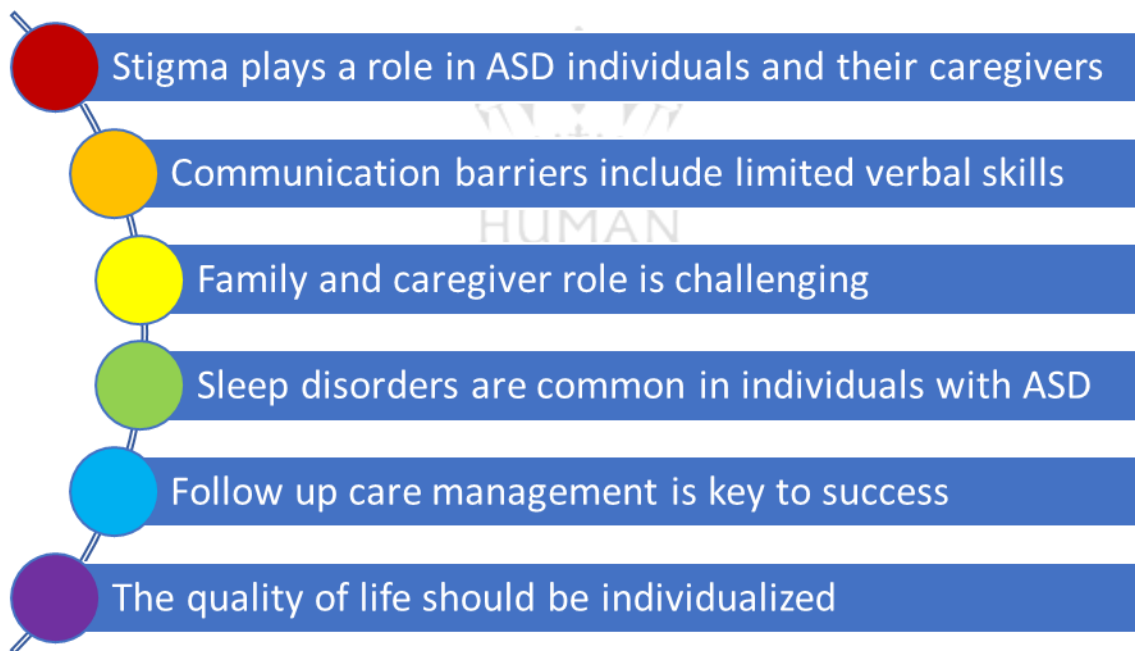


Figure No. 2. Themes found in the literature regarding the life of an individual with ASD and their caregivers.

4. DISCUSSION

When stigma is attached to ASD, a neurobiological disorder, it makes the person's difficulties worse and makes it harder to overcome hardships. Some examples to address stigma include educating yourself and others about this condition, being aware of your attitudes and behaviors toward an autistic individual, speaking careful word choices, focusing on the positive, providing support, and including the autistic persons in all opportunities. Not only should these examples be portrayed by bystanders to reduce stigma but loved ones should also be aware of these resources. By doing so, an upward effect of leisure and life satisfaction, family functioning, and effective communication can be improved. Being more understanding and patient can help an individual with ASD recall and express their feelings and emotions. Encouraging to recognize facial expressions, tone of voice, and body language can help people with autism identify others' emotions and practice communicating feelings, sharing social stories, and regulating emotions can help them personally.

As people with ASD experience challenges communicating to and with others, it is essential to know some aspects that could make it more difficult. A significant finding in the study shows an association of gross and fine motor skills with social interaction skills [4]. Therefore, as people with ASD have difficulties moving like walking or running and smaller movements like holding items in their hands, they struggle more with social interactions. Making sure people with ASD are comfortable in their environment and around people they trust should make them more likely to communicate with the group. This shows the importance of assessing and monitoring gross and fine motor skills in people with ASD.

When children are diagnosed with ASD, education is crucial in properly caring for them. Parent teaching was examined regarding parent outcomes, parental stress, and caregiver strain. There were improvements with both parent teaching and psychoeducation after the sessions, but parent teaching had more remarkable outcomes. Therefore, this shows that the more education a parent or caregiver has, the less stress they experience and the more confident they are caring for individuals with ASD.

A child with ASD's sleep quality is something essential to monitor. As previously discussed, the relationship between sleep duration and total awakenings were studied. It was found that sleep

duration was negatively correlated with irritability, stereotypy, and hyperactivity [8]. Therefore, the worse a person's mood or aggression is, or having repetitive movements or overactivity, the less sleep the person will get. It would be essential to decrease these stimuli as much as possible before bedtime, with either medications or with any soothing therapies.

Children with ASD can develop co-morbidities that are necessary to be monitored. It is important to realize children with ASD may not present with common signs and symptoms normally seen in other patients. As discussed above, special health care needs should be taken care of to prevent further complications. Dental, gastrointestinal, sleep, and anxiety are all important aspects that should be monitored regularly. For dental concerns or checkups, some places offer in-home or school-based dental screening for children with ASD that they may comply better with. For sleep disturbances, melatonin therapy may be used along with other non-pharmacological modalities used for anyone. The treatment of gastrointestinal disorders could also improve abnormal sleep and daytime behaviors [9]. As stated above, if children with ASD are verbal and have cognitive abilities at an 8-year-olds level, they could benefit from cognitive behavioral therapy.

The early developments and experiences for individuals with ASD have a heavy impact on their quality of life as they age. For this reason, it is important to focus on creating quality experiences and use of time rather than the amount of time spent with individuals with ASD. To assist in the growth of characteristics and behaviors into adulthood, caregivers should focus on building positive attitudes and growing self-esteem. Caregivers and parents play such a vital role in these developments, which will become life-long behaviors. Although it is easy to develop frustrations and react to uncooperative situations, thoughtful care should be taken to redirect towards what is important to the individual with ASD. Anxiety, uncertainty, and stress are shared amongst all involved with interactions, but understanding this incurable disease must be taken. Social collaborations, everyday tasks, and quality of health are jeopardized for individuals living with ASD. Understanding this does not need to be acknowledged but should be present in thought and care when interactions occur. As previously stated, physical and mental health are significantly influenced by development at a young age. If supportive and healthy habits are reinforced in adolescence, positive attitudes and behaviors are more likely to be retained as aging and responsibilities come to existence.

5. CONCLUSION

ASD is a complex condition that comes along with many co-morbidities. Some of the main difficulties that were discussed include stigma, communication barriers, family and caregiver roles, sleep disorders, care management, and quality of life. It is common to see external stigma from bystanders, which can put extra stress on caregivers and make them feel blamed for their behaviors. This often leads them to experience depression. On top of that, children with ASD struggle with communication and social interactions. It is vital to make sure they are comfortable in their environment and around people they can trust, including their family or caregivers. As sleep disorders are common in children with ASD, it is essential to promote healthy habits before bedtime. This goes along with good care management and ensuring a good quality of life. Treatment options are usually individualized as each person with ASD experience life differently. Treating anxiety disorders and seeing a behavioral therapist are often included. Overall, these co-morbidities can negatively affect the life of an individual with ASD. With a multidisciplinary approach to management and a sound support system, a person living with ASD can live a long and healthy life.



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