

Dispelling Public Misconceptions about Autism in the Algerian Society: Case of Saida City**Mayada SENOUCI^{*1}; Rabha RAOUTI².**¹- Djillali Liabes University of Sidi Bel-Abbes; (Algeria)Email: *mayadasenouci@gmail.com*²- Dr. Moulay Taher University of Saida; (Algeria).Email: *raouti_r@yahoo.fr*

Received:10/11/2022; Accepted:27/11/2022; Published:15/12/2022.

Abstract:

Social isolation, discrimination and outright rejection are among the most prevalent encumbrances that autistic individuals face in their lives. Hence, autistics are regularly stigmatized against worldwide, and most of the time this stigma constitutes a real intercultural challenge for the patients and their caregivers. It could even cause an extreme damage to the patients' well-being. In fact, stigma against autism is born out of people's conceptions and emerging culture in society. Accordingly, the present study examines the various perceptions of Algerians towards autism and autistic individuals. To collect data, the researcher interviewed autistic children's parents and three autism specialists. Findings' analysis of the study points to a severe stigma and false conceptions about the disorder in the Algerian society. These results have practical implications that may help in enhancing the social life of autistic individuals, and contribute in de-stigmatizing this spectrum.

Key words: Algerian society; Autism; Misconceptions; Saida city; Support.

الملخص:

عرض المفاهيم الخاطئة للمجتمع الجزائري حول التوحد

دراسة حالة: مدينة سعيدة

العزلة الاجتماعية، الرفض وعدم التقبل هي أكثر ما يتعرض له الأفراد المصابين بالتوحد حالياً، وفي أغلب دول العالم يعتبر اضطراب التوحد مصدراً للإزعاج والضرر. هاته المواقف تعرض المصابين بالاضطراب إلى ضغط نفسي شديد قد يصل إلى الضرر الجسدي والعقلي. بطبيعة الحال أغلب هاته الأفكار هي وليدة المجتمع والثقافة. لهذا السبب يتم من خلال هذه الدراسة تحليل وعرض مختلف الأفكار والآراء التي يبينها المجتمع الجزائري عامة ومجتمع مدينة سعيدة خاصة عن مرض التوحد والأفراد المصابين به. من أجل جمع المعلومات اللازمة للدراسة تم إجراء عدة مقابلات شفوية مع عدد من الآباء ومختصين في التوحد. النتائج المحصل عليها أظهرت أن معظم الجزائريين لديهم أفكار قبلية خاطئة عن التوحد وآراء مغلوطة عن ماهيته وطبيعة الأفراد المصابين به. النتائج قد تساعد في فهم المرض وتحسيس الناس بضرورة فهم الاضطراب ودعم الأشخاص المتوحدين.

الكلمات المفتاحية: المجتمع الجزائري؛ التوحد؛ المفاهيم الخاطئة؛ مدينة

سعيدة؛ الدعم

Introduction:

Autism Spectrum is a neurodevelopmental disorder characterized by significant deficits in social interaction and communication, as well as repetitive and rigid behaviour and lacking interest patterns. Kanner (1943) was the first to identify autism as a syndrome. In a seminal paper, he described eleven children who had "extreme autistic aloneness," or an inability to relate to others, including their parents; an obsessive desire for sameness; severe language disorders such as non-functional use of speech, pronominal reversal, and echoing; stereotyped and repetitive play; an excellent rote memory; normal physical appearance; and onset in early infancy. Today the spectrum is considered as the fastest-growing neurobiological developmental condition in the entire world.

Moreover, in many societies, autistic individuals are treated unsympathetically for multiple reasons, primarily due to certain misconceptions, stereotyped beliefs and myths people have used to describe autism. This stigma and low levels of social support were the most powerful predictors of depression, reduced social connections and anxiety in autistic patients. Therefore, this study is meant to explore and investigate Algerians' attitudes and perceptions of autism as a disorder and of people with autism as members of society. To gather the necessary data, the researcher interviewed parents of autistic children, escorts, and three experts in the field: a psychologist, a social therapist, and the president of the Autism Association in Saida city. Further, since the primary concern of this research is to investigate the assumptions and conceptions of Algerians about autism spectrum, this article offers an overview of the theoretical dimensions of both autism spectrum disorder and its social acceptance in community. Hence, It attempts to answer two major questions: How do Algerians perceive and conceive autism, and why? Later on, the findings were analyzed thematically and qualitatively.

The study's results indicate a drastic stigma and subconscious biases of the disorder in Algerian society. Many people have incorrect beliefs and hurtful stereotypes about

autism, which can lead to serious damage in the lifespan of autistic individuals as well as their caregivers and family members. Last but no mean least, the data of the current study advocates some theoretical and practical implications for improving the social lives of people with autism. Finally, findings can contribute to de-stigmatizing efforts on this spectrum and promote how people treat autistic individuals.

1- Autism Spectrum According to Developmental Theories:

Over the last 20 years, psychologists have attempted to develop unifying theories of the central deficit seen in people with ASD. While research in these areas is common, no single theory can truly explain all of the behaviors displayed by any individual with ASD. Accordingly, viewing strengths and challenges through any of these lenses, however, may provide some insight into appropriate interventions for teachers, parents, and individuals on the spectrum. Furthermore, a better understanding of deficits can help us see challenging behaviors in a different light (Merrill, 2022).

a- Theory of Mind (ToM)

The Theory of Mind assumption developed by Simon Baron-Cohen is one of the most widely used and researched theories of autism. This theory was created by researchers who were looking into distinctiveness that may or may not be unique to the human species. The idea was that someone with a theory of mind should be able to identify mental states in themselves and others and use this information to predict other people's behavior (Premack & Woodruff, 1978 as cited in López, 2022). Therefore, a deficit in this theory results in individuals on the autism spectrum performing less well on tasks that require "mind reading" compared to their typically developing peers. For instance, ASD patients may struggle in explaining their behaviors, perceiving emotions, predicting the behaviors of others, and understanding that behavior impacts how others think

and feel.

b- Weak Central Cohesion Theory

Another psychological theory of ASD is that people on the spectrum have Weak Central Cohesion (WCC). According to the WCC theory, people on the spectrum struggle to integrate information at different levels and, as a result, fail to integrate detail into global entities (Frith, 1989). Some describe this as being unable to "see the forest through the trees." This theory has been used to describe both assets and deficits in people with autism spectrum disorder. This would explain why people with autism frequently develop very strong skills in math or science but struggle to grasp the gist of a story. As a result of a WCC deficit, individuals with ASD may experience difficulties in areas such as fixing details and reading conception and generalizing information learned to different domains.

c- The Social Theory:

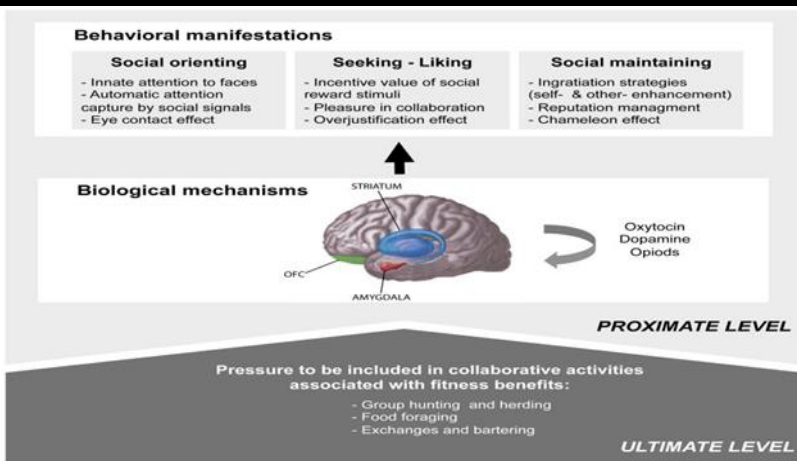
This theory draws our attention like no other scope. It signifies that attention priorities social signals, and interactions are intrinsic, and that social maintaining pervades intercultural behavioral responses. This notion was highlighted by Chevallier, when he stated: "social motivation theory provides a credible framework accounting for social impairments in ASD. By concentrating on deficits, social motivation account faces similar shortcomings as the ToM. Both of these social theories indeed fall short of explaining nonsocial deficits in ASD" (Chevallier et al, 2012, p.03).

2- Behavioural Characteristics of Autism:

Autism behavioral symptoms are typically identified in childhood and persist throughout a person's life. A qualitative impairment in social communication in general and behavioural communication in particular, is one of the primary diagnostic symptoms of autism. Social communication is the

primary means of establishing interpersonal relationships. Indeed, all other functions of communication are ultimately subordinated to social communication. An individual, who is able to communicate and regulate his emotions, as well as behave in a socially appropriate manner, is more likely to form new friendships and form good peer relationships (Im-Bolter & Cohen, 2007). However, when a one's communicative development deviates from the norm for unknown reasons, specific social barriers and impairments emerge. For instance, Williams, an autistic woman, has described her own experience as an autistic person and her understanding of other autistic people she has met in an exceptional way. She wrote in her remarkable second book: "Autism is just an information processing problem that controls who I appear to be. Autism tries to stop me from being free to be myself. Autism tries to rob me of my life, of friendship, of caring, of sharing, of showing interest, of using my intelligence, of being affected ... it tries to bury me alive." No italic style.

Therefore, a social behavioral profile can be defined as a set of psychological dispositions and biological mechanisms that predispose an individual to preferentially orient to the social world (social orienting), seek and enjoy social interactions (social reward), and work to foster and maintain social bonds (social maintaining). At its most basic, social motivation is an evolutionary adaptation designed to improve an individual's fitness in collaborative environments (Chevallier et al., 2012) (see figure one). Furthermore, Social motivation might constitute an evolutionary adaptation geared to enhance the individual's suitability for collaborative environments and interactional connections.

**Figure1.Behavioral manifestations**

Retrieved from

<https://europepmc.org/articles/PMC3329932/figure/F1>

3- Interventions and Therapy:

At first glance, some people with autism may appear to have an intellectual disability, sensory processing issues, or problems with hearing or vision. To complicate matters further, these conditions can co-occur with autism. Nevertheless, it's critical to distinguish autism from other disorders since a precise and prompt diagnosis of the disorder can serve as the foundation for an effective program of education and care. Therefore, from the perspective of health care, the goal of screening is to identify children for whom effective treatments are available and may be more beneficial than treatments started later. There is no one effective treatment for ASD due to the wide range of problems that affected individuals face. There are very few evidence-based medication alternatives available for kids with ASD at the moment. Though, working closely with a doctor or other health care provider is crucial to choosing the best treatment program. Strictly speaking, there is

no medically proven treatment for autism. ASD is regarded as a chronic neurological condition. However, intense, structured skill teaching, often known as behavioral intervention, is currently the principal research-based treatment for ASDs. In order to help the youngster attain his or her greatest potential, it is crucial to start this intervention as soon as feasible (Autism Society of America, 2014). Accordingly, approaches in allied health, behavioral, medical/pharmacotherapy, educational, and complementary and alternative medicine are frequently used to treat ASD (Rockville, 2011).

4- Social Acceptance:

There is evidence to support the advantages of people accepting autistic individuals across the spectrum. Parents' acceptance of their child's autism and positive emotions toward their child, for example, do not correlate with child characteristics such as developmental level or autism severity as measured by experimental measures. Instead, higher autism severity, as determined by the parents' questionnaire-based report, sometimes has an inverse relationship with their acceptance of their child's autism, implying that subjective perception rather than empirically demonstrated factors may drive acceptance. As a result, an increase in autism symptoms over time correlates with increased social acceptance of a person's autism (Kapp, 2018).

A severe behavioral manifestation of autism or a high need for support does not preclude a high subjective quality of life. Perspective however, it is also associated with higher well-being on the autism spectrum. Children and adults who have more subtle autism symptoms, greater emotional awareness, closer friendships, and higher cognitive abilities perceive their autism as more severe in people with abilities, and they

experience more anxiety and depression. This could be due to increased self-awareness as well as increased victimization among individuals with less obvious disability or supervision, as well as more distressed reactions to bullying. Furthermore, rather than the self-perceived degree of autism, mistreatment may account for distress. Thus, adults' perceptions of their quality of life are related to their level of social support rather than endorsed autistic traits. (Kenny et al., 2016). In this respect, Levitt's, and from the perspective of the autism neuro-divergent label, wondered: "which aspects of the negative influence of society on disability (other than barriers to inclusion) are particularly worth focusing on and how can these be effectively addressed?" (2017, p. 4). This goes in line with what Boyd claimed: "The cumulative results of several studies illustrated that informal support appeared to be a more effective stress-buffer than formal support, and persons Who received support related better emotionally to others" (2016).

5- Methods:

Sample of the Study:

We examined data collected by addressing a personal semi-structured to three caregivers of children with autism, some of them parents whereas the others were escorts. Besides, the researcher interviewed three experts in the field of autism, these were: a social therapist, a psychologist working in an autism center, and a president of an autism association at Saida city, Algeria. The following table presents the profile of our participants:

Table1. Participant's profiles

| Participant Name | Relation with Autism | Experience in the Field |
|-------------------------|--|--|
| Malika, L. | President of an Autism Private Center. | 10 years. |
| Hiba, B. | A psychologist at the Center | 3 years. |
| Saliha, K. | A Social Therapist | 5 years. |
| L,M. | A Parent of an Autistic Child | 7 years (the age of her son is 9years old). |
| S, D. | A Parent of an Autistic Child | 8 years (the age of her daughter is 10 years old). |
| Alia, T | An Escort at the Center of Autism | 10 years. |

Table Resource: by the author.

Data Collection Procedures:

So, as mentioned earlier, the researcher adopted semi-structured interviews as a main tool for collecting the required data. The questions addressed to the interviewees were various; some questions were about the different views the participants carry about autism, its social symptoms, and its impact upon the lives of individuals with the spectrum. Other questions assessed the way Algerians view autism, how they treat autistic people in their community, and how can their conceptions and assumptions affect the wellbeing of autism patients? This table highlights the main questions, the researcher addressed to the interviewees. The questions are paired with their themes as follow:

Table.2 Questions and Themes

| Questions | Themes |
|---|-------------------------------------|
| How do you define autism? | Understanding Autism |
| What are the most noticed behavioral characteristic of the condition? | Understanding Autism |
| How do parents of an autistic child conceive and perceive the spectrum of their child? | Parents' Acceptance |
| Do relatives and friends help in caring of individuals with autism in our community? | Family Support |
| As experts and caregivers, what are your opinions about the assumptions of society members toward autism? What are their different reaction concerning the disorder? | Societal Stigma |
| As experts and caregivers, what are your opinions about the assumptions of society members toward autism? | Societal Stigma |
| What are the different reactions, you may notice, when people meet an autistic person for the first time? What are their common feedbacks concerning the disorder? | Lack of Awareness |
| Do they accept children with autism in public schools, and under what conditions? | Educational Support |
| Can you explain to me how does this illness damage the social life of the patient? How can social and public understanding help people with autism and their caregivers to survive with the condition? | Importance of Social Support |

Table Resource: by the author

A further remark that is worthy to mention here, is that the interviews were done in the Arabic language, and then translated to English by the researcher.

Data Analysis and Interpretation:

Thematic Analysis:

As it was mentioned earlier, in this study the authors used qualitative research method to collect data because this method permits the evaluator to study selected issues, cases, or events in depth and details; the fact that data collection is not constrained by pre-determined categories of analysis contributes to the depth and detail of qualitative data (Patton,

1993). Additionally, qualitative research method is widely used in healthcare research studies because it mainly targets human experiences, thus giving a better and deeper understanding of human morals which are complicated. Moreover, thematic analysis is the most commonly used method in qualitative data analysis approaches for identifying, describing and interpreting themes to offer 'thick descriptions' of lived experience (Braun and Clarke, 2006).

Understanding Autism:

Interviews with the staff and parents have starkly highlighted and conveyed the different experiences they have lived in autism spectrum caring; contextually, from different care states. Moreover, all of them have encountered various social obstacles and barriers while dealing with autism and society. Primarily, the findings from interviewing showed that the participants were, likely, sharing the same idea about the nature of autism as a lifelong neurodevelopmental cognitive disorder with different levels, they all believed that autism is severe enough to interfere and change daily life of the individual in the condition.

According to the staff most autism patients develop neuropsychiatric and behavioral symptoms and signs at some points during the course of the disease. For instance, the most displayed are:

- * Lack of eye contact with others, and Stiff facial expressions
- * Acting differently from their elder siblings
- * Preferring isolation.
- * Severe hyperactivity and lack of attention.
- * Language impairment, imitation and echolalia.
- * Sudden behaviors such as laughing, shouting, and screaming for no obvious reason.
- * Looking at the corner when feeding and lack of spontaneous smile.
- * Behavioral disturbances: impatience, agitation, pressure, anxiety, frustration, and anger.

Parent Acceptance:

All participant agreed that having a child diagnosed with autism can create a sever shock for his /her parents, especially at the beginning. Some have declared that at some points of time, they have struggles and “going insane” vibes. L. M, a parent of an autistic boy admitted that: “After what they told me about my son diagnosis, I kept thinking ‘why me? All my other children are normal, why this boy? What did I do wrong? Was it my fault? I felt so helpless and scared....but later on I have prayed to Allah to help me and my boy. I have decided to take this disease as an exam from God, and I will stand by my son side till the end”. Same thing for the mother of an autistic girl who stated that after receiving the diagnosis from the autism centre, and during the two first years, it was so hard to deal with the disorder emotionally and physically, she felt so tired, but after a while and with the help of the center and the support of specialist, she did better.

To sum up, eventually, this disorder is not an easy condition to accept. Feelings of parent may vary from one family to another, but all are sharing the states of loneliness, sadness, fear and denial, exhaustion, and even guilt. Actually, these feelings are not positive at all, parents should do their best to accept the condition of their siblings in order to be able to help them living with autism in a better way.

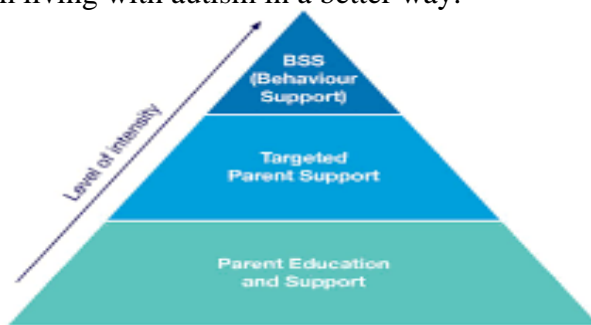


Figure 2. Levels of parents' support.

Retrieved from <https://www.wkms.org/education/2014-05-28/paducah-autism-support-group-helps-parents-understand>.

Family Support:

According to experts and parents, family members rarely offered help except with what they have described as verbal rather than actual support. They keep providing misconceptions close minded ideas and traditional assumptions. Unfortunately, most of relatives in our society, do not believe that autism even existed, and they completely ignore the issue and called it “aggressive behaviour of kids”. In the same vein a parent declared that: “when we meet as a family in occasional events, our relatives ask their children to keep avoiding my daughter. They fear that autism can affect the behaviors of their siblings”. Thus, in many contexts, parents do not take their autistic children with them out; they keep them at home or at the center. Although they are not ashamed of their kids, they just do not want to put him/her in embarrassing or hard situations.

Accordingly, the analysis of the parent’s views has evidenced profoundly the social barriers and the sensitive obstacles that encounter autistic patients and their parents with relatives and friends of the family. Despite that, families suppose to be the first sources of sympathy and help.



Figure3. Parents acceptance of autism.

Retrieved from <https://www.wkms.org/education/2014-05-28/paducah-autism-support-group-helps-parents-understand>.

Societal Stigma and Lack of Awareness:

Autism is severe enough to interfere with the daily life of the patient and even changes it. Unfortunately, in our society people have stereotyped beliefs about individuals with autism; this can lead to inappropriate treatments toward them.

Additionally, autism can cause the individual retirement from work, as well as, breakdowns of communication with others, separation from family, loneliness, and loss of friends.

According to our participants, Algerian people are still unaware of the sensitivity of the disorder; they do not pay attention to the way they treat autistic people. Some may laugh upon them, or get mad and even annoyed when an autistic person demonstrates an abnormal behavior. Furthermore, a large number of Algerians consider autism as mental illness and that autistics are insane people. Actually words are weapons; hence, these false conceptions can hurt the parents and let them feel nervous, shy and embarrassed of their child with autism. Besides, such wrong beliefs about autism can lead an autistic person to be more aggressive and destructive.

Educational Support:

Most of schools in Saida city do not accept children with autism in normal classes; except those who reached advanced levels of self control. Despite that, they also obliged parents to put escorts for their children because teachers can't take care of autistic students.

Importance of Social Support:

A socially just society is one that has social arrangements that allow all of its citizens to do and be what they want without barriers or restrictions based on class, race, gender, ability, or other non-moral categories (Daghustani, 2017). From this view, the psychologist claimed that: "I believe that when a patient gets a sufficient social support from others, this can raise and recall his abilities to fight the disorder with more self-confidence even that can help him to come back a normal and calm person most of time."

So, whenever we want to deal with an autistic subject, we have first to help him/ her to feel relaxed, safe, and comfortable. Additionally, you need to keep your words and expressions simple and easy to understand, and involve him/her as much as possible in positive and enjoyable conversations. Therefore,

safe and successful connection with others can help people in the condition individuals on different highlands.

In the same vein, the social therapist highlighted that social acceptance and effective relations can reduce the individual's behavioral impairment and enhance their recognition and understanding that interaction with others can help the demented individuals on different highlands. Hence, the analysis of participants' feedbacks, reflected that effective social acceptance increases the patients' feeling of independence, self-confidence, and make them feel supported and loved by others; consequently, they easily and confidentially, engage in interactions with others, and exhibit their best efforts to success in the communicative and social processes.

Broader Implications for Social and Institutional Support:

A large number of parents of Algerian autistic children are not capable of taking care of their child socially and financially, and this can have a negative impact on the process of intervention and treatment. Furthermore, and what is worst, is that society members are not comprehensive nor cooperative; consequently, parents find themselves fighting many sides, autism disorder and an unjust society. Therefore, the first step towards better integration of individual with autism in community is through taking action for the acceptance and independence of people with autism. Autism should be made more widely known to the general public through television advertisements, seminars, campaigns and among other means. People in our country continue to have misconceptions about autism and autistic children. They should consider and treat these children as special children, not as atypical and distinct from other children. Hence, accepting these children as they are, and take into consideration their abnormal behaviours can make their lives easier as well as their parents' lives.

In addition, staff and caregivers in centers should be adequately and properly trained. It is because teaching special children is vastly different from teaching other typically

developing children. That is why, in addition to teacher training institutes for regular schools and colleges, there should be training institutes for escorts of disabled children.

Conclusion:

Over the past decade, autism has emerged as a major public health concern all over the world because of the Increases in the reported prevalence of autism. The behavioral symptoms are usually identified through direct observation of the patient behavior. Among the very first indications in the autistic person's behavior, there are personality changes such as: sudden depression, delusions, irritability, restlessness, decreased attention, increased agitation, low judgment and false reasoning. These behaviors may present a real challenge for people with autism to accommodate social interactions and connections. Thus, undoubtedly, more and more autistic people have been seeking educational, medical services, and more crucially they have been looking for a sincere social support that can help them to confront the formidable challenges of the spectrum. Accordingly, this paper was devoted to introduce and highlight the various social perceptions and misconceptions, Algerian people hold about autism disorder.

This study draws out that Algerians carry wrong and false conceptions about the disorder, most of them view as a mental illness. Besides, they believe that autistic individuals are insane, and should be abandoned or neglected in society. Furthermore, we conclude that it is vital to acknowledge and value the roles of parents and caregivers caring for their children with autism within their communities. At later stage, the findings of the study may substantially help in enhancing and promoting the assumptions of the local community toward autism.

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