

Ethical and Pragmatic Issues of Quality of Life: Experience of Autistic Children's Parents in Algiers

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Abstract

Autism is a neuron developmental disorder complex that appears in early childhood, characterized by a general disorder of development, a disorder of social interactions, communication and some unusual behavioural characteristics. Specialists are constantly refining and improving their diagnostic criteria to establish an ideal classification that the scientific and medical community can use, two theoretical approaches are used: ICD-10 and DSM-5. All these symptoms affect the quality of life of parents on the plan: psychological, physical and social. In Algeria, the number of autistic cases is between 400,000 and 500,000. "There are three to four boys for every girl". When a child is born with a disability, has a developmental delay or is diagnosed with autism, this causes major upheaval in the lives of the parents, who must learn to adapt to a "different" child, even if 'they are worried about his well-being and his future. The purpose of this study is to measure the impact of autism on the parents' quality of life in Algiers and the factors that influence them. The first theoretical part will review the conceptual framework of autism, the statistics available in Algeria, and, on the other hand, the conceptual framework of the quality of life, with its main components: physical, mental and social well-being. The second, practical part, we conducted a survey by parents of children with autism and then interpreted the results to determine the impact of a child autistic on the quality of life of parents. According to our study, there is a proportional relationship between the degree of autism severity and the repercussions on the parents' health; we notice from the results ($\text{Sig} = 0.00 < 0.05$) that there is a relationship between the type of autism and the impact on the parents' physical health. The V Cramer test shows that there is a strong relationship. The survey was made from April 16, 2019, to May 5, 2019, intended for the 103 parents of autistic children who live in the region of Algiers.

Keywords: Autistic Child, Quality of Life, Comparative Study, ICD-10, DSM-5.

JEL Classification: C42, I12, I31.

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1. Introduction

Autism is a term used to describe a complex group of developmental brain disorders known as Pervasive Developmental Disorders (PDD); there are several terms to describe autism. Autism appears from the first year of life with the first subtle and variable manifestations that turn into clear symptoms around 2 or 3 years, and sometimes much later (Pascal et al., 2007). Specialists are constantly refining and improving

their diagnostic criteria to establish an ideal classification that the scientific and medical community can use, two theoretical approaches are used: ICD-10¹ and DSM-5² (Bertrand, 2008). In the ICD-10, autism is classified as a PDD, defined as follows: “PDDs are a group of disorders characterized by qualitative alterations in reciprocal social interactions and modes of communication, as well as a restricted, stereotyped and repetitive repertoire of interests and activities. These qualitative anomalies constitute an invasive characteristic of the functioning of the subject, in all situations³. PDD is characterized by the great diversity of its symptomatologic expression (Nathalie & Danièle, 2009).

In DSM-5 Autism entitled “Neuro-developmental disorders”, the criteria have been reviewed: they now combine interaction disorders and communication disorders and consider the sensory, cognitive, and language characteristics observed in many people with ASD. Their possible association with a medical or genetic pathology or another developmental disorder is also specified (Rogé, 2003). The population would vary between 90 and 120 individuals out of 10,000, or about 1% of the population, and even more, or at least 75 million autistic people in the world, which corresponds to the population of a country⁴. “Autism is a disorder of the conjunction between neurons affecting the functioning of the brain at various levels” (Mahi, 2017), beginning before the age of 3, it affects social interactions, communication, and behavior (Cappe, Pedoux, Poirier, Downes, and Nader-Grosbois, 2019).

In Algeria, the number of autistic cases is between 400,000 and 500,000 cases⁵. “There are three to four boys for every girl”. When a child is born with a disability, has a developmental delay, or is diagnosed with autism, this causes major upheaval in the lives of the parents, who must learn to adapt to a “different” child, even if they are worried about his well-being and his future (Card Senechal & Catherine Des Rivières, 2009). This disability influences their quality of life because they play a key role in their development, the latter is totally dependent on them throughout their life, and their main role is to meet their complex needs. However, certainly important and decisive elements seem to be overlooked, minimized, or marginalized, such as the suffering of parents of autistic children, which remains minimized and poorly taken into consideration, particularly within Algerian society (Khaled, 2011). Caring for an autistic child in Algeria is a challenge because of the lack of means of care and qualified personnel, the student costs of care, and the absence of state care, all these factors make life difficult for parents. And even unmanageable, which is why we want to study the impact of this child on the quality of life of his parents.

This subject we want to submit to our reflection is a very important theme nowadays. Because of our interest in the lived experience of parents, we have not chosen, within the framework of our study, to try to explain the impact of the autistic child on the quality of life of his parents. This study aims to identify the difficulties and challenges parents face to determine the different repercussions of autism on the well-being of parents, their physical and psychological health, and their social life. To carry out our work in the field, we based ourselves on descriptive analysis, highlighting the presence of an autistic child and the change that results from this handicap on the family in general and the parents. This observation that we have just mentioned brings us back to trying to answer the key question: “What is the impact of an autistic child on the quality of life of his parents?”

2. Literature Review

A child's autism has a major impact on the quality of life of the whole family. It involves significant changes in several areas of daily life such as leisure, social, friendly, family and couple relations, work, physical and mental health, and material well-being⁶.

2.1. The Well-Being of Parents of Children with Autism. The feeling of psychological well-being takes on a particular meaning when dealing with families of autistic children (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, Murphey, 2004). It changes meaning depending on the type of disability of the child. Parents of children with autism appear to be at higher risk for depressive symptoms. Indeed, having a child with autism in the family poses a real problem of psychological well-being, especially for mothers. (Hatta, Derôme, De Mol, and Gabriel, 2018).

¹ The International Classification of Diseases – tenth version, published by the World Health Organization (WHO),

² The Diagnostic and Statistical Manual of Mental Disorders – fifth edition, adopted in 2013 to replace DSM-IV and translated into French in 2015.

³ Diagnostic criteria for research, ed. Masson, 1994. Retrieved from: https://www.cnsa.fr/documentation/cnsa-dta-2016_web.pdf consulted on: 04/20/2019 at 12:05.

⁴ <http://lechodalgerie-dz.com/autisme-400-000-personnes-affectees-en-algerie/>, consulted on: 05/20/2019

⁵ <http://lechodalgerie-dz.com/autisme-400-000-personnes-affectees-en-algerie/>, consulted on 05/20/2019

⁶ <https://www.cairn.info/revue-la-psychiatrie-de-l-enfant-2009-1-page-201.htm>, consulted on 15/05/2019

The parents of an autistic child are generally faced with difficult situations: agitation and shouting, stereotypies and self-mutilation, difficulties in learning about food and education, and insomnia. When the autistic symptoms are intense, the child is deprived of his motor skills, and in his social integration - difficulties of movement outside his habitat. The disorders of the autistic child related to his development and his socialization, as well as the daily stress related to the handicap of the child, have a significant impact on the quality of life of the parents, in particular on the organization of their daily life, hobbies, etc. because the education of this child limits the time devoted to oneself, requiring a rigid and tiring organization of life (Bobet and Boucher, 2005). In our study more than half of the mothers of autistic children because of the daily difficulties related to the autistic disorder of their child sacrifice their professional life (Cape et al., 2009).

The Parents' Experience

Mental Health of Parents (The Parents' Experience). Studies have shown that being a parent of a child with a disability. A child with a pervasive developmental disorder is often associated with high-stress levels, impaired mental health, and impaired physical functioning (fatigue or even exhaustion) in both mothers and fathers (Baker, Brightman, 2008). The parents' mental health depends on the symptom's severity and the importance of the repercussions of the autistic disorder on their daily life. Indeed, the more severe the autistic symptoms, the greater the repercussions on daily life and the parents' mental health. On the other hand, the author shows that "informal" social support (Family; friends, etc.) reduces the negative effects of autistic disorder on the daily life and mental health of parents; this effect of "informal" social support is more important when the autistic symptoms are weak (Schopler, Lansing, Waters, 2001).

Fear for the Future. Often parents are worried and anxious about the future of their child, which affects their quality of life. They often wonder, after their disappearance, who will take care of him. A concern that puts them in a position of a hard present to bear and a frightening future. The mother changes her whole life, after the diagnosis to devote it to the education of her child, everything passes into the background, and her personal life and her professional life are invaded by concerns for the child and her future. On the other hand, the life of the fathers is less affected than that of the mothers. Their professional situation has not changed; in addition, they must preserve their work to meet the needs of the family related to the education and care of the child. Parents think of ensuring, in the future, a single responsibility, which is the financial independence of their disabled child.

The Couple and Conjugal Life. Married life is not spared and has experienced an obvious break-in, communication is hampered because everything revolves around the problem of the child; often disputes and conflicts, if the wife avoids addressing this subject and experiences her distress, in silence and withdrawal, the husband expresses it in all clarity.

Family and Social Relations. An entangled relational type characterizes the functioning; rigid governs by autism symptoms; where everything revolves around the latter, the family lives in isolation and a feeling of loneliness. She rarely responds to family invitations; for lack of availability, she must manage to be able to respond. Either the father or the mother must leave; the other must ensure custody. The strength of the ties and the union of family members, to be able to manage the situation; although a therapeutic work on this site seems to us to be essential, to help the family to function in a more flexible and less costly way.

The role of those around you is difficult to bear; stigmatization, comments, and questioning only amplify parents' suffering and their withdrawal and isolation. In conclusion, it is important to say through this clinical illustration that autism is far from being a simple disorder that affects a person, but which affects ties, family life, and relationships. It determines a way of life and requires a whole family, social, and even institutional adaptation.

3. Methodology

Our approach includes two steps. The first relates to the presentation and purification of the database. In the second step, we apply the univariate analysis and the bivariate analysis respectively.

3.1. Presentation of Data. The survey was made from April 16, 2019, to May 5, 2019, for parents of autistic children who live in the Algiers region. The information was collected through a questionnaire and collected during face-to-face interviews. To prepare our database, we carried out a coding using the answers from our questionnaire; this coding is intended to meet the requirements of certain analysis then, we entered data into this software afterward we started the treatment.

Parents of autistic children interested in the study were asked about the risk factors mentioned in the literature (socio-demographic data of parents and autistic children, parents' working time, number of children, type of childhood autism, etc.). In total, a sample of 103 parents of autistic children shows that out of 103 parents surveyed, more than 84% who participated in the study are mothers. We begin by presenting in what follows, the methodology, the survey plan, and the database.

3.2. Sampling. The sample was drawn according to a stratified random survey to respect the geographical map of autism centers in the willaya of Algiers and the proportion of the population of parents of autistic children. The survey concerns the impact of an autistic child on the quality of life of his parents.

3.3. Description of Database Attributes. The data comes from a survey of parents of autistic children coming to consult. From a long questionnaire, we extracted 45 explanatory variables. Description of Database Attributes.

3.4. Exploratory Study

Alpha Test “Reliability Test”. We start with the alpha test; the objective of this test is to: “Measure the internal consistency (or reliability) of the questions asked. Its value is between 0 and 1, being considered “Acceptable” from 0.7”

Table 1. Reliability Test

Reliability Statistics	
Cronbach's Alpha	Number of items
0.74	45

Source: Compiled by the authors

We test the fidelity of the 45 variables; the value of the coefficient is 0.74 which exceeds the minimum threshold required of 0.70. We can say that we obtain, for this scale composed of 45 items, a satisfactory internal consistency in the whole population (all the parents).

The Socio-Demographic Characteristics of Parents of Autistic Children. The analysis results show that out of 103 parents surveyed, more than 84% participating in the study are mothers, most parents surveyed (92.2%) have an average age of 38 years, and the rest (7.8%) parents have an average age of 27 years.

The distribution of parents by the level of education indicates that: Almost ¾ of parents have a university level and ¼ dispersed between the higher level and the middle/primary level, implying that most of the parents surveyed are well educated. For marital status, most parents 81% live together, and 19% are divorced, this number of 20 people who are divorced cannot be negligible. For the work of spouses, most parents work since 84% of parent’s surveyed work. More than half 61% of the mothers of autistic children work full time, and the rest, 39%, work part-time. It implies that the autistic child must be in a crèche or a school when their parents work. For the distribution of parents according to the number of children, the average number of children is 2.3. This result reflects the reality of the number of children in Algerian families, which is 2.8 according to the WHO (2012). The difference of 0.5 can be explained by the fear of having another autistic child.

4. Results

4.1. The Statistical Characteristics of the Autistic Child

The Distribution of Autistic Children According to Demographic Characteristics. According to our study, autistic boys represent (82%) of the total population studied (4 times more than autistic girls 18%). This result confirms the world statistics of "in a population, there are four (04) autistic boys for a single autistic girl” (Khaled, 2011). The distribution of autistic children according to their age group in our sample indicates that the majority class is that of children between 9-14 years old, i.e., a rate of 36.9%, then children aged 5-8 years with a rate of 35%, and the rest are +14 years old and -5 years old.

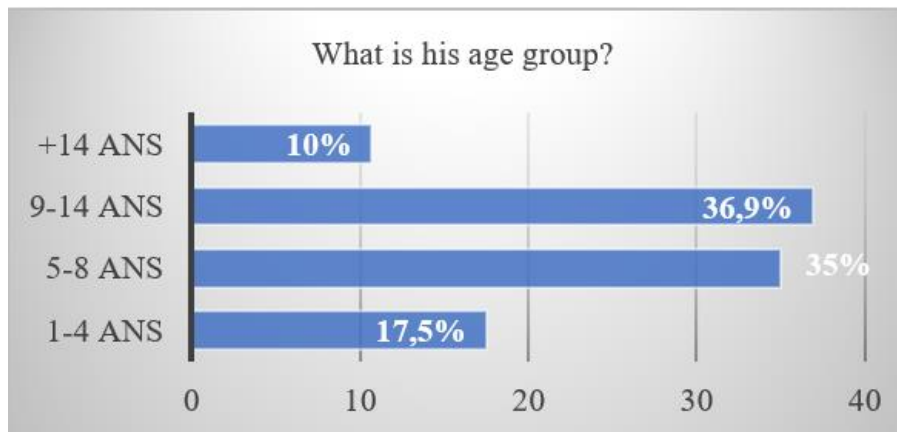


Figure 1. Distribution of Autistic Children According to Their Age Group

Source: Compiled by the authors

For the distribution of autistic children according to their rank in the siblings, we note in our study that most autistic children are elders, although there is no genetic explanation for this result, we cannot neglect that: Parents with a first autistic child have a higher chance of having another autistic child compared to those without autistic children.

Symptoms Noticed in Children. We notice that children with autism have relatively the same symptoms with slight differences; the latter depends on the type of autism because each type has its unique symptoms. Still, there are three general symptoms: Behavioral disorders, which are 39.8%, communication disorder, 36.9%, and social integration disorder, 57.30%, the most dominant symptom. There are other problems that the parents mentioned: sleep disturbance, hypersensitivity or insensitivity to pain, and abnormal gaze. Most parents indicate that the most dangerous symptom is the absence or delay of language because language is the function that allows expression; once this function does not work, these children would have difficulties in the future, which also influences parents.

Table 2. Symptoms Observed in Children

Terms	Percentage
Absence or rarity of smiling	19,4%
Gaze abnormalities	40,8%
Stereotyped and repetitive behavior	39,8%
Lack of communication	36,9%
Absence of reaction to the call of his first name	47,6%
Solitary activities; Lack of social integration	57,3%
Absence or delay of language	55,3%
Cries and cries	32%
Hypersensitivity or insensitivity to pain or caresses	36,9%
Sleep disorder	43,7%

Source: Compiled by the authors

The Discovery of Autism in Children. The results indicate that more than half of the parents (57%) discovered their child's disorder, 36% through their doctors, and 7% through their teachers. It implies that autism cannot be negligible, and an average person can discover the disorder from a few symptoms also, in our population, 57% of children have a severe type of autism which may be remarkable by parents before being diagnosed by the doctor.

The Type of Autism of the Child and the Age of Diagnosis. The analysis results show that 47% of children have severe autism, 17% medium type, and 36% mild type; these results could be a source of parental stress. For the age of diagnosis of autism in children According to the results obtained, we note that 29% of children were diagnosed before the age of 3 years because autism can be diagnosed at 18 months. Still, generally, doctors report it at age 3 (28%). Almost half of the children have been diagnosed after age 3; this finding falls back to the autism type. When autism is mild, diagnosis may be delayed as parents will have doubts. Still, when autism is severe, it can be diagnosed early, that is, before the age of 3. The earlier the diagnosis, the more likely the children will be to be treated, and this implies an improvement in the quality of life of the parents.

The Schooling of the Child. The results of our survey show that ¾ of autistic children are in school, and ¼ of them are not in school. More than half of school children care for in-state centers and 44% of them are in private schools.

4.2. Parents' Quality of Life

Physical Well-Being of Parents

➤ **Expenses in the Presence of an Autistic Child.** The analysis results show that 97% of parents, or almost all, confirmed that having an autistic child leads to additional expenses. For the share of monthly income devoted to the autistic child, the results of the analysis show that 32% of the parents questioned devote 50% or more of their monthly income to their autistic child.

➤ **The Health of Parents of Children with Autism.** According to the results obtained, 37.9% of the parents indicated that their physical health was greatly affected, 36.9% were affected slightly, and 11.7%. Most parents report that their quality of sleep has been affected because the sleep disorder of the autistic child causes the parents to lack sleep; even if the child sleeps all night, the parents have insomnia due to worry, stress, and loss of morale.

The Social and Professional Life of Parents

➤ **The Social Life of Parents of Autistic Children.** According to the results obtained, 67% of the parents declare that they have difficulties in organizing their schedule; the parents cannot accomplish their daily tasks regularly because they cannot prevent a program because of the autistic child who dominates their plans. For the level of change in everyday life, according to our study results, 33% of parents declared that their daily life is moderately disturbed by last-minute changes. 34% of them mentioned that their everyday life has been great and even enormously disrupted, and on the other hand, only 8.7% of parents declare that last-minute changes do not disrupt their daily life. For the relationship of parents with other family members, survey results show that more than half and a half of parents say that the time they spend with other family members has been reduced. For the marital relationship, according to our study results, 38.8% of the parents surveyed declare that the presence of their child has not created tensions within the couple, and 46.6% suffer deterioration in the relationship marital. For outings and leisure, almost ¾ of the parents surveyed (73%) limit their outings and leisure because of their child's symptoms (screaming and crying, lack of language).

➤ **The Professional Life of Parents of Children with Autism.** According to the results obtained, 75% of parents confirmed that having an autistic child led to a drop in professional objectives, because the autistic child needs a permanent presence, and 25% of them did not drop from their goal.

Psychic State of the Parents

➤ **The Level of Parental Stress.** According to the results obtained, most parents feel more stressed than usual (21.4% are extremely stressed than usual).

➤ **Parents' Perspectives on Their Child's Unique Personality.** Most parents (90%) say their child has a unique personality and special talents.

5. Discussion

According to our study, there is a proportional relationship between the degree of severity of autism and the repercussions on the health of the parents, we notice from the results obtained (Sig =0.00<0.05) that there is a relationship between the type of autism and the impact on the parents' physical health, and the V Cramer test shows that there is a strong relationship.

Table 3. Chi-square and V-Cramer Test Between the Type of Autism and the Repercussions on the Health of the Parents

Chi-square tests			
	Value	ddl	Asymptotic significance (two-sided)
Pearson's chi-square	92.31	8	,000
V-Cramer	,669		,000
Number of valid observations	103		

Source: Compiled by the authors

According to the results obtained there is a relationship between the additional expenses and the level of tension within the couple (Sig=0.012<0.05), the test of V-Cramer meanwhile shows that there is a moderate relationship, that is, there is a relationship between the variables despite its weakness.

Table 4. Chi-square and V-Cramer Test Between Expenses and the Relationship Within the Couple

Chi-square tests			
	Value	ddl	Asymptotic significance (two-sided)
Pearson's chi-square	12,824 ^a	4	,012
V-Cramer	0.353		,012
Number of valid observations	103		

5 cells (50.0%) have a theoretical strength less than 5. The minimum theoretical strength is .44.

Source: Compiled by the authors

According to the results obtained, the parents have an average age of 38 years, they are well educated, and the conjugal situation of the parents is slightly influenced by autism, but the spirit of the union which characterizes the Algerian families is always here.

- The average number of children is 2.3; it reflects the reality of the number of children in Algerian families which is 2.8; autistic boys are four times more than girls. It confirms the statistics that “in a population, there are four (04), autistic boys, for only one girl”;
- The autistic child affects the economic stability of the family and affects the quality of life of the parents; the autistic child affects the physical health of the parents and their quality of life;
- Many parents no longer have the time to devote to their development or a professional career; especially mothers, parents avoid activities and leisure because they fear the prejudices of others in a public environment;
- It is important to note that these expenses may be due to the cessation or reduction of working hours of one of the parents to take care of their child, which most often leads to less income within the family; the professional life of fathers is less affected than that of mothers who have relegated their professional goals to the background to take care of their autistic children.

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