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ORIGINAL ARTICLE

ASSESSMENT OF THE QUALITY OF LIFE OF CHILDREN WHO ARE IN THE SPECTRUM OF AUTISM

AVALIAÇÃO DA QUALIDADE DE VIDA DE CRIANÇAS QUE ESTÃO NO ESPECTRO DO AUTISMO

EVALUACIÓN DE LA CALIDAD DE VIDA DE NIÑOS QUE ESTÁN EN EL ESPECTRO DEL AUTISMO

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ABSTRACT

Objective: to evaluate the quality of life of children who are on the spectrum of autism. ***Method***: this is an evaluative, descriptive and exploratory study with the quantitative and qualitative approach. The scenarios of this research were the Association of Friends of the Autistic, the Association of Parents and Friends of the Exceptional and the Center for Child Psychosocial Care, in Caxias-MA. Structured observation and interview with caregivers of children on the autistic spectrum were carried out. ***Results***: the quality of life of the children was satisfactory, with 74.2%. Caregivers have a concept about autism spectrum disorder and others define autism according to the experiences and traits developed by children. It has been found that tantrums, nervousness, self-harm, and hyperactivity are common to most interlocutors. ***Conclusion***: parents or caregivers of these children believe that they can have a good quality of life and develop behaviors common to all children. ***Descriptors***: Quality of Life; Children; Autistic Spectrum.

RESUMO

Objetivo*:** avaliar a qualidade de vida de crianças que tão no espectro do autismo. ***Método*:** estudo avaliativo, descritivo e exploratório, com abordagem quantitativa e qualitativa. Os cenários desta investigação foram a Associação de Amigos do Autista, a Associação de Pais e Amigos dos Excepcionais e o Centro de Atenção Psicossocial infantil, em Caxias/MA. Realizou-se a observação estruturada e entrevista com cuidadores de crianças que estão no espectro autista. ***Resultados*:** percebe-se como satisfatória a qualidade de vida das crianças, com 74,2%. Os cuidadores possuem um conceito formado sobre o transtorno do espetro do autismo e que outros definem o autismo de acordo com as experiências e traços desenvolvidos pelas crianças. Verificou-se que birras, nervosismo, autoagressão e hiperatividade são comuns para a maioria dos interlocutores. ***Conclusão: os pais ou cuidadores dessas crianças acreditam que os mesmos possam ter boa qualidade de vida e desenvolver comportamentos comuns a todas as crianças. ***Descritores*:** Qualidade de Vida; Crianças; Espectro Autista.

RESUMEN

Objetivo*:** evaluar la calidad de vida de niños en el espectro del autismo. ***Método*:** estudio evaluativo, descriptivo y exploratorio, con enfoque cuantitativo y cualitativo. Los escenarios de esta investigación fueron la Asociación de Amigos del Autista, la Asociación de Padres y Amigos de los Excepcionales y el Centro de Atención Psicosocial infantil, en Caxias-MA. Se realizó la observación estructurada y entrevista con cuidadores de niños que están en el espectro autista. ***Resultados*:** se vio como satisfactoria la calidad de vida de los niños, con 74,2%. Los cuidadores poseen un concepto formado sobre el trastorno del espectro del autismo y otros definen el autismo de acuerdo con las experiencias y trazos desarrollados por los niños. Se verificó que enfados, nervosismo, autoagresión e hiperactividad son comunes a la mayoría de los interlocutores. ***Conclusión: los padres o cuidadores de esos niños creen que los mismos puedan tener buena calidad de vida y desarrollar comportamientos comunes a todos los niños. ***Descriptores***: Calidad de Vida; Niños; Espectro Autista.

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INTRODUCTION

Autism is a complex neurobiological developmental disorder, presenting its signs normally within the first 2 years of life. For the diagnosis, it is necessary to have central characteristics such as social change, verbal and nonverbal communication, and characteristic patterns of behavior that tend to be repetitive and ritualistic. The behaviors may vary in degree of impairment, which characterizes a spectrum of severity (autistic spectrum).[1]

However, some autistic children (known as wise) stand out in specific areas such as art, music, memory, math, or perceptual skills with jigsaw puzzles. When these abilities appear, they are usually precocious, but they have no function and do not help in the rest of their development. Female subjects tend to have lower intelligence scores than males, regardless of the degree of manifestation of the syndrome.[2-3]

Early diagnosis is directly related to the initiation of treatment and the implementation of interventions, based on improved functional development and decreased behaviors seen as inadequate. To that end, techniques and methods based on behavioral principles are used, such as the ICD-10 Classification of Mental and Behavioral Disorders, the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), and the Checklist for Autism in Toddlers. Thus, the specialist physicians (psychiatrist and child neuro-psychiatrist) are the only professionals qualified to perform the diagnosis, since they have competence in the clinical and diagnostic aspects related to mental disorders.[4-5]

The person on the spectrum of autism is a citizen like any other and needs to have all their rights protected, so struggles by health and education professionals, parents and family members of autistic and organized civil society, have boosted the creation of Law Number 12,764, of December 27, 2012, establishing the National Policy for the Protection of the Rights of People with Autism Spectrum Disorder. The Law seeks to ensure dignified life, physical and moral integrity, free personality development, security and leisure, and protection from all forms of abuse and exploitation.

Regarding the family aspects, in most cases, the parents note that there is something strange about the child, but they cannot determine what, especially when they do not have other children to compare development references. Therefore, usually, when they are alerted by relatives and friends about the existence of some disturbance with their children, they react with anger.[6]

The quality of life is a human conceptualization, having in its meaning the highest degree of satisfaction found in family, love, social and environmental life and the existential aesthetics. It is presumed by the capacity to make a synthesis association of all the elements that a given society considers its standard of comfort and well-being.[7]

The high index of people diagnosed with autism evidence the need to carry out studies on the subject that even today are still scarce considering the complexity of the syndrome. It is not only a need for parents of autistic children and health system and education professionals knowing what autism is. Helping for people on the spectrum of autism may come from the greater knowledge of the population about the etiology, characteristics, and strategies of psychosocial intervention.[5]

OBJECTIVE

- To assess the quality of life of children who are on the spectrum of autism.

MÉTHOD

This is a descriptive and exploratory study with a quantitative and qualitative approach, carried out by the Association of Friends of the Autistic (AMA), the Association of Parents and Friends of the Exceptional (APAE) and the Center for Child Psychosocial Care (CAPSi) in Caxias-MA. The places were chosen because they are a reference in the treatment of autistic people, they have the service of specialized professionals aimed at the best development of the patients, they have a wide range of therapies, such as speech therapy, occupational therapy, and psychopedagogy; attending patients of all age groups.

There were 31 participants in the research. The inclusion criteria were to be parents or caregivers of children aged 0 to 11 years old with autistic spectrum and to accept willingly participating in the research since according to the Statute of the Child and Adolescent, children between 12 and 19 years old are Adolescents. The exclusion criteria were not to participate in the study or to care for people older than 11 years old. Thus, the study had 31 participants.

The data collection took place in two moments: a structured observation, of the participant type, was carried out, which verified aspects related to both the structure and the work process developed in the

associations, as well as the established links with family and children assisted, based on an instrument created by the researchers. Next, an interview with the parents and/or caregivers of the children was carried out, subdivided into two parts: the first one consisting of a questionnaire about caring for children on the autism spectrum, involving subjective questions, seeking to establish discussions about the difficulties/obstacles and facilities in the coexistence with autistic children, and in the last one, a validated instrument was applied, used in the evaluation of the quality of life of autistic children, called Child Quality of Life Scale.

This instrument is composed of four domains divided into function, questions related to school activities, meals, when lying down, and going to a doctor (1; 2; 4; 5; 8); Family, questions about family relationships and about oneself (3; 10; 13; 16; 18); Leisure, holiday requirements, birthday and relations with grandparents (11; 21; 25); And autonomy, which refer to independence, relationship with peers and school evaluations (15; 17; 19; 23; 24). The questions of numbers 6, 7, 9, 12, 14, 20, 22 and 26 are not included in the four domains because they are of isolated importance.[8] The evaluation scores can vary from 0 to 3 corresponding, respectively, to the very unhappy, unhappy, happy, very happy. The sum of these values results in a total, using the cut grade 48, and below an impaired quality of life of the study population is considered.[9]

The data from the structured observation were presented in Figures, demonstrating the importance of each aspect observed for the development of the work in the institutions. Regarding the interviews with parents and/or caregivers, the information collected from the first stage, with open questions about autistic child care, was submitted to Content Analysis.[10]

The data removed from the Quality of Life Assessment Scale (AUQEI) are the database, by typing information in the Statistical Package for the Social Sciences (SPSS) (version 18.0 for Windows) software, and subsequently consolidated by descriptive statistics techniques (absolute and relative frequencies) and presented in Tables. It was proceeded to discuss the findings based on the literature produced on the topic.

The project was approved by the Research Ethics Committee of the Center for Higher Studies of Caxias-CESC-UEMA with the Certificate of Presentation for Ethical Appreciation (CAAE) of n° 42337414.7.0000.5554, in accordance with the norms advocated by CNS Resolution 466/12 and its complementary ones.

RESULTS

In the structured observation, they verified relevant aspects about Organization of the work environment; Level of satisfaction of the patients in relation to the service provided and Involvement of caregivers in the therapies offered the children, according to the figures below:

AMA	APAE	CAPSi
- Open area working as a reception, with 4 chairs and a coffee table; 1 bathroom; 1 meeting room and lectures; 1 service room, with 2 chairs, 2 cabinets, 3 cushions; - The place is clean and airy. - The materials used in the therapies are left on the floor of the room and also stored in the cabinets.	- Divided into 2 sectors: *Education: Structure with 15 classrooms, with adapted chairs, teacher's table and chair and a melamine table; 1 toy library; 6 rooms (Multimedia, Computer, Coordination, Teachers, Board and Administration) 01 Auditorium; 01 dining-halls; 01 courtyards; 06 common bathrooms; 02 adapted bathrooms. *Health: 02 receptions; 05 offices (03 doctors, 01 nursing and 01 dental); 06 therapy rooms (01 of physiotherapy, 02 of speech therapy, 01 of occupational therapy, 01 of psychopedagogy, 01 of psychology and psychiatry); 02 rooms of Social Assistance; 11 common bathrooms and 02 adapted bathrooms. - The materials used in the therapies are organized in the treatment rooms, stored in cabinets, shelves and some are arranged on the floor. - The environment is clean and organized.	- Open area, wide and wooded; another covered area, in which the institution's events are held. - Reception places: 1 reception; 05 practice rooms (nursing, speech therapy, psychology, occupational therapy and psychopedagogy); 01 social service room; 01 kitchens; 01 warehouses; 01 dispensing; 01 coordination room; 01 file room and 08 bathrooms.

Figure 1. Structured Observation Layout for the item Organization of the work environment. Caxias (MA), Brazil, 2015.

AMA	APAE	CAPSi
It was observed that the caregivers intermittently follow the activities, since most of them leave the child and at the scheduled time come back to look for them, due to the fact that in their presence the children end up not concentrating on the activities, but in some cases caregivers remain in the association but not in the care room.	Regarding the involvement of caregivers in the offered therapies, it was concluded that participation occurs intermittently, that is, in some cases it is necessary to be present in the accompanying rooms, such as in cases where the child is agitated and the professional cannot keep the attention of the same in the therapies, or when it is initiating the accompaniment and the child is not accustomed the presence of strange people.	The involvement of caregivers in the therapies occurs only in cases of persistence by the children in not participating in the follow-up.

Figure 2. Structured Observation Presentation regarding the involvement of caregivers in the therapies offered. Caxias (MA), Brazil, 2015.

After the application of the forms, the content and interpretation of the findings were organized into five Categories: a) Understanding of caregivers about Autism, b) Behavior of the child that most bothers/pleases, c) Difficulties faced in the care of the child with autism D) Participation of the child who is on the autistic spectrum in the recreational activities of the school, e) Awareness of the caregivers on the Quality of Life of children with ASD.

♦ **Category 1:** Understanding of caregivers about Autism

> *It is a syndrome affected by genetics where the child may have motor problems, in speech and between their neurological systems. (C5)*
>
> *The child has difficulty speaking, difficulty in attention, difficulty in socializing, there are several characteristics the person fits. (C11)*

The aforementioned interlocutors have knowledge about the main concepts and commitments arizing from autism, mainly regarding difficulties in social interaction, communication, and behavior, being the main areas affected by the autistic spectrum.

♦ **Category 2:** Behavior of the child that most bothers/pleases

> *Always when we say something to him, as my son I love you, he comes and hugs me. (C7)*
>
> *The behavior of my son that I like best is the affection, he loves to hug, kiss and it makes me feel good. (C8)*
>
> *He is affectionate. (C11)*
>
> *What bothers me most is hyperactivity. (C12)*
>
> *Aggressiveness with himself. (C21)*
>
> *The tantrum. (C23)*

For the caregivers, the behavior of autistic children is tantrums, irritation, self-harm, and hyperactivity, and they also report that the behavior of children who are most fond of them is a show of affection and care. It is believed that one factor influencing these responses is that one of the characteristics of ASD is the difficulty in establishing affective bonds. Therefore, in the beginning, caregivers believed that it would be impossible to maintain a loving relationship with children, but in some cases, with adequate therapeutic follow-up, the behavioral aspects of autism are altered and attenuated.

♦ **Category 3:** Difficulties faced in the care of the child with autism

> *Physiological needs of her, I have to guess the time she wants to go beyond wearing diapers. (C4)*
>
> *Difficulty in which he has to express himself, initiative. (C5)*
>
> *He does not communicate because he only speaks loose words. (C6)*

It is noticed that the absence or difficulty in maintaining verbal communication is something with a very negative impact regarding the daily care of the child since in these cases the caregivers need to try to guess and/or interpret the child's need, taking to a high level of stress for both.

♦ **Category 4:** Participation of the child who is on the autistic spectrum in the recreational activities of the school

> *He studies and participates in all activities, in his treatment he cannot be excluded or stop participating in these social activities. (C5)*
>
> *The study, take part, I questioned them there, he participates. (C7)*
>
> *He participates in all the activities proposed by the school, but there are those that he develops greater resistance, such as sitting with the children to listen to stories. (C8)*

The participation of autistic children in recreational activities offered by the school can be somewhat difficult at first because it involves factors clinical characteristics of the autistic spectrum with the difficulty in socialization as the main one that can lead to

social isolation. However, it was verified that most of the caregivers stated that the children participate in such activities, which can be a reflection of a good professional follow-up performed by the teachers or coordinators and encouragement of the parents.

♦ **Category 5**: Awareness of the caregivers on the Quality of Life of children with ASD

> *She has a good health, she is not a sick person, she is cheerful in the house, she plays, only in walking up and down is already a great quality of life of her. (C2)*
>
> *The joy of him, he also is not suffering other problems because I have seen many very sick and have other problems. (C7)*
>
> *The quality of life of my daughter is that she sleeps well, has a healthy diet, has her moments of leisure and mainly is always smiling. (C10)*
>
> *She has a healthy food, has her moments of leisure, she studies; I do everything so that she has a normal life as every child. (C22)*

As can be observed in the perception of caregivers, the good quality of life of children is linked to being able to enjoy basic conditions, such as health, food, leisure, education and access to medical care when necessary. In fact, the factors cited contribute to a good quality of life especially in the case of children, since these items are basic for maintaining physical and mental well-being.

Tables 1, 2 and 3 refer to the application of the AUQUEI Scale by reference to the answers given by topic, in the 26 questions, a total score and the mean of answers, divided by domains and the score reached in the AUQEI scale of each one of the participants, respectively.

Table 1. Presentation of data regarding the number of responses by topics of the AUQUEI Scale. Caxias (MA), Brazil, 2015.

How do you think your child feels:	Very unhappy	Unhappy	Happy	Very happy	Does not applied
1) At the table together with the family	2	5	12	12	0
2) At bedtime	1	6	17	7	0
3) When playing with siblings, if having	1	7	16	6	1
4) At night when sleeping	0	4	20	7	0
5) In the classroom	1	5	19	6	0
6) When seeing a picture of himself	0	4	13	12	2
7) At times of play, during school play	0	3	18	10	0
8) When going to a doctor's appointment or with another health professional	4	12	13	2	0
9) When practicing sports	2	4	8	11	6
10) When thinking about the parent or person who represents him	0	2	7	22	0
11) On the birthday	0	0	14	12	5
12) When doing homework	5	8	12	1	5
13) When thinking about the mother or person who represents him	0	0	12	19	0
14) When hospitalized in a hospital	5	5	1	3	17
15) When playing alone	0	0	8	23	0
16) When he or someone important talks about him	0	5	13	7	6
17) When sleeping outside the house, if he sleeps	2	4	13	5	7
18) When someone asks him to do something he knows how to do it	0	7	15	8	1
19) When friends talk about him	2	6	17	3	3
20) When he takes the pills	4	14	9	4	0
21) During vacations	2	6	14	9	0
22) When thinking or talking when he has grown up	0	1	5	1	24
23) When away from the family	7	10	8	1	5
24) When receive and/or deliver his school	0	1	2	2	26
25) When being with the grandparents	0	1	12	18	0
26) When watching television	1	1	11	16	3

It is seen that the item with the most “very unhappy” answers, that is situations in which the child shows discontent or appear angry, referring to how the child feels "when he is away from the family". Thus, it is perceived that even though it is difficult to establish affective bonds, the autistic person feels the need to be close to the family.

Table 2. Distribution of average responses per domain in relation to the organization of the AUQUEI Scale topics. Caxias (MA), Brazil, 2015.

Variables	Total	Average
Function	300	1.93
Family	333	2.14
Leisure	204	2.19
Autonomy	180	1.41
Total	987	7.67

According to what is presented in Table 2, it is possible to observe the domains in which they have responses with major and minor means. The leisure item, composed of 3 questions, is the one with the highest average answers, which implies that according to the caregivers, the happiest moments of the children on the autistic spectrum are those related to leisure, such as: “On his own birthday,” “On vacation,” and “When he's with his grandparents.” This result is consistent with the findings by Pfeiffer and Silva in a study with children with cystic fibrosis who have the same age group studied.[11]

In relation to the family domain, the questions refer to the child's feeling, “playing with the brothers”, “when he thinks about the father or person who represents him”, “when he thinks about the mother or person who represents him”, “when someone important talk about him,” and “when someone asks him to do something he knows how to do it.” The mean number of responses obtained was 2.14, remembering that the maximum possible mean is 3. Thus, the domain reaches the second highest average, demonstrating that in the perception of caregivers, autistic children, even with socialization difficulties, are able to establish a link with family members close to him.

Table 3. Score distribution corresponding to AUQEI application (Autoquestionnaire Qualité de Vie Enfant Imagé). Caxias (MA), Brazil, 2015.

Caregivers	Total	Average	Score
C1	39	1.77	46.09
C2	30	1.36	35.44
C3	56	2.43	63.30
C4	41	1.78	46.34
C5	59	2.26	59.00
C6	52	2.16	54.16
C7	48	2.18	56.72
C8	44	1.83	51.32
C9	50	2.17	56.51
C10	44	1.83	47.27
C11	47	1.95	50.90
C12	40	1.90	49.52
C13	50	2.17	56,51
C14	55	2.39	62.17
C15	32	1.60	41.60
C16	38	1.58	41.16
C17	30	1.57	41.05
C18	43	1.87	48.75
C19	43	1.79	46.58
C20	58	2.52	65.56
C21	44	2.09	54.47
C22	59	2.56	66.68
C23	50	2.38	59.52
C24	52	2.38	61.90
C25	45	1.87	48.74
C26	39	1.85	48.28
C27	54	2.16	56.16
C28	48	2.18	56.72
C29	45	1.95	50.86
C30	43	1.86	48.60
C31	42	2.00	

Table 3 shows the average and final scaled score applied to caregivers of children on the autism spectrum. The cut-off point for AUQEI is 48, so scales with scores below this value are considered to indicate that the child has impaired quality of life. Thus, 23 (74.2%) of the 31 scales answered had a score equal or greater than 48 and 8 (25.8%) had less than 48.

DISCUSSION

Regarding the caregivers' understanding of autism, Silva emphasizes that the family's greater understanding of ASD favors the development of the child and allows him to acquire independence and feel valued. Thus, it is understood that there is a close relationship between the knowledge about the characteristics of autism by family members as a facilitator of the emotional health of the child with autism.[12]

The behavior of the child that most disturbs the caregivers in the difficulty faced by autistic mothers related to aggressiveness. It is emphasized that behaviors such as agitation, shouting, aggression or self-harm constitute obstacles in the family's access to public places. Moreover, the hyperactivity presented in autistic children maintains different characteristics from those manifested in patients with Attention Deficit Hyperactivity Disorder (ADHD), since, in a general way, autistic movements, such as exacerbated agitation or excessive movement has no function. The pleasure is in the agitation, the movement is done in a random way, without function. In ADHD, whose main characteristic is the child seeking incessantly to engage in different activities with defined purposes, because, in the case of people with ADHD, physical hyperactivity is a direct consequence of mental hyperactivity.[13]

In a study of behavioral problems in autistic children, mothers of children with autistic disorder stated that children like to be with them and others close to them, but prefer not to be intimate with individuals they have little contact, a circumstance that can minimize the social isolation characteristic of people with ASD. The authors perceived this evidence as an adaptation of parents to the difficulty of socializing their children, in which they were able to discover the loving facets of their child, focusing on ways to help them deal with problems.[14]

The difficulties faced in caring for autistic children are: the language and verbal and nonverbal communication of autistic people are deficient and are very different from the usual patterns because they have a repetitive and stereotyped language, unable to initiate and maintain a conversation. Echolalia, repetition of sounds several times and at inopportune moments, also a characteristic referring to the communication of individuals that are on the autistic spectrum. In immediate echolalia, the autistic child repeats almost immediately what he had just heard after the verbalization of another person.[15]

In the participation of the child who is on the autistic spectrum, it is essential that the workers have a specialized training in the recreational activities of the school, allowing them to know the characteristics and possibilities of these children's activities. Thus, for the inclusion and learning of the autistic spectrum to be truly possible, it is necessary for the teacher to be willing to change his conceptions of teaching learning and to recognize that the inclusion of this in regular education will bring benefits to the autistic, as well as for other students, incorporating a new vision about the world and people.[12]

On the Perception of caregivers on the Quality of Life of children with ASD, in a study evaluating the perception of mothers about the quality of life of children with cerebral palsy, the interlocutors state being related to the social welfare, with emphasis on food, health, education, as well as social and material aspects.[16]

It is necessary to consider that for the family the idea of normality is omnipresent to relate the thematic qualities of life, family, and autism. The perception of the child's differences and the diagnosis of autism mobilize in the family the need for adjustments and reorganization, oscillating between acceptance and rejection, hope and anguish.[17]

It is also noticed that in some speech the leisure is cited as an indicator of the good quality of life of the child. The authors report that leisure has been increasingly recognized as an important indicator of the quality of life, characterizing it as a situation of promoting development and well-being. It is also an opportunity for the exercise of citizenship, where social inclusion and the transposition of prejudices and barriers can occur.[18]

In the application of the AUQUEI Scale, in Table 1, stimulating the formation of affective connections is essential for the autistic since they have to create a strong and lasting bond, a fact that arises from the child's need to feel safe and protected, and this is vitally important for an emotional attachment and

guidance to the child's healthy social, affective, and cognitive development.[19]

Of the 31 subjects interviewed, 23 pointed out that “when they play alone”, children demonstrate that they feel “very happy”, given comprehensible when it comes to autistic children since the difficulty in social interaction is one of the main commitments of the syndrome. In a study of autistic children, we observed peculiar characteristics during moments of play, such as the lack of sharing of play and lack of interest in playing with another person, preferring to play alone.[1]

Regarding the family domain, Table 2 emphasizes that its questions refer to the child's feeling, “playing with siblings”, “when he thinks about the father or person who represents him”, “when he thinks about the mother or person who represents him”, “when someone important talks about him,” and “when someone asks him to do something he knows how to do it.” The mean number of responses obtained was 2.14, remembering that the maximum possible mean is 3. Thus, the referent domain reaches the second highest average, demonstrating that in the perception of caregivers, autistic children, even with socialization difficulties, are able to establish a link with family members close to him.

Autistic children form affective bonds differently from children without autism, since they seek protection through the formation of attachment behaviors so they elect support figures that can still be classified as affective bonding.[21]

In addition to the triad of compromises that characterize autism affecting aspects of socialization, communication, and repetitive and ritualistic behaviors, there are still several factors that interfere with the independence of people on the autistic spectrum, such as impairments in shared attention and imitation that limit the ability of the individual to observe others to learn, being necessary skills to live independently.[22]

In Table 3, the results of this study are in agreement with those found by Gonçalvez et al., who carried out a study with the purpose of evaluating the quality of life of children with Duchenne muscular dystrophy in their perception and their caregivers, in which also used AUQEI for both. The conclusion of the study confirms that the quality of life of the children is the same if analyzed from their point of view and from the point of view of the mothers, that is, mothers and children share the same opinion, both judged it as good quality of life.[23]

When using the AUQEI to assess the QOL of autistic children under their perception and compared it with the results of normal children, they verified that there is no difference between the mean of the AUQEI scores of autistic and non-autistic children. Thus, the general QOL are equal for both groups, indicating positive QOL. Thus, they concluded that, far beyond the expectations of others, and/or functional difficulties, the autistic child in his perception of the world is happy regardless of his functional deficits.[24]

CONCLUSION

Autistic Spectrum Disorder is a complex syndrome and those who have it may suffer from prejudice and limitations. Parents or caregivers believe that they can have a satisfactory quality of life and develop behaviors common to all children. There was a lack of studies on the quality of life of autistic children. Further research would be of great relevance to society and, above all, to autistic people and their families, as it would most likely reveal important aspects of their well-being, which could lead to the development of actions that would improve the quality of Life.

It is emphasized that investing in the training of parents or caregivers of autistic people about the syndrome, would be of great value for the improvement of the daily life of both, as it would facilitate the understanding of the parents/caregivers on the peculiarities of the disorder.

The possibility of evaluating the quality of life of children who are on the autism spectrum is of crucial importance for the targeting of strategies for the monitoring of children with autism spectrum, both in the perception of managers and health professionals, as well as the caregivers, agents directly involved and more often with these children.

REFERENCES

1. Nettina SM. Práticas de Enfermagem. 9th. Rio de Janeiro: Guanabara Koogan; 2012.

2. Classificação Estatística Internacional de Doenças e Problemas Relacionados à Saúde. 10 th ed. São Paulo: Edusp; 2007. 212p.

3. Hockenberry MJ, Wilson D W. Fundamentos de enfermagem pediátrica. 9 th ed. Rio de Janeiro: Elsevier; 2011.

4. Silva ABB, Gaiato MB, Reveles LT. Mundo singular: entenda o autismo. Rio de Janeiro: Objetiva; 2012.

5. Surian L. Autismo: informações essenciais para familiares, educadores e profissionais da saúde. 2 th ed. São Paulo: Paulinas; 2010.

6. Williams C, Wright B. Convivendo com Autismo Síndrome de Asperger: estratégias práticas para pais e profissionais. São Paulo: M.Books do Brasil; 2008.

7. Minayo MCS, Hartz ZMA, Buss PM. Qualidade de vida e saúde: um debate necessário. Ciênc Saúde Coletiva [Internet]. 2000 [cited 2014 Oct 09];5(1):7-18. Available from: www.scielo.br/pdf/csc/v5n1/7075.pdf

8. Resende WB, Rangel VO, Frontarolli AC, Araújo RRH, Silva CHM, Pinto RMC, et al. Psychometric Properties of the Autoquestionnaire Qualité De Vie Enfant Imagé (AUQEI) Applied to Children with Cerebral Palsy. PLoS One [Internet]. 2015 [cited 2014 Oct 09];10(2):1-10. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4324774/pdf/pone.0115643.pdf

9. Barreire SG, Olcinei AO, Wilma K, Miako K, Vera LCGS. Qualidade de vida de crianças ostomizadas na ótica das crianças e das mães. Jornal Pediatria [Internet]. 2003 [cited 2014 Nov 21]; 79(1): 55-62. Available from: www.scielo.br/pdf/jped/v79n1/v79n1a10.

10. Bardin L. Análise de Conteúdo. 3th ed. Lisboa; 2006.

11. Pfeifer LI, Silva MA. Avaliação da Qualidade de vida em crianças com Fibrose Cística. Revista do Nufen [Internet]. 2009 [cited 2014 Sept 10];01(02):118-30. Available from:www.scielo.br/scielo.php?script=sci_arttext&pid=S180637132011000200008

12. Silva MCBL, Brotherhood RM, editores. Autismo e inclusão: da teoria à prática. V EPCC Encontro Internacional de Produção Científica Cesumar; 2009 27 a 30 de outubro; Maringá, Brasil; 2010.

13. Nunes MAF, Santos MA. Itinerário Terapêutico Percorrido por Mães de Crianças com Transtorno Autístico. Psicologia: Reflexão e Crítica [Internet]. 2010 [cited 2014 July 21];23(2):208-21. Available from: www.scielo.br/scielo.php?script=sci_arttext&pid=S0102-79722010000200003

14. Marteleto MRF, Schoen-Ferreira TH, Chiari BM, Perissinoto J. Problemas de Comportamento em Crianças com Transtorno Autista. Psicologia: Teoria e Pesquisa [Internet]. 2011[cited 2014 June 15]; 27(1): 5-12. Available from: http://dx.doi.org/10.1590/S0102-37722011000100002.

15. Marinho EAR, Merkle VLB, editores. Um olhar sobre o autismo e sua especificação. IX Congresso Nacional de Educação- EDUCERE; 2009 26 a 29 de Outubro; Paraná: Brasil; 2010.

16. Vasconcelos VM, Frota MA, Pinheiro AKB, Gonçalves MLC. Percepção de mães acerca da qualidade de vida de Crianças com paralisia cerebral. Cogitare Enfer [Internet]. 2010 [cited 2014 July 29];15(2):44-238. Available from: www.academia.edu/.../Percepção_De_Mães_Acerca_Da_Qualidade_De_Vida_De_Cri...

17. Penna ECG. Qualidade de vida de mães de pessoas com diagnóstico de Autismo. Caderno de Pós-Graduação em Distúrbios do Desenvolvimento [Internet]. 2007 [cited 2015 Feb 10];1(6):1-9. Available from: www.mackenzie.br/fileadmin/Pos_Graduacao/Mestrado/Disturbios.../05-2006.pdf

18. Messa AA, Araújo CO, Freitas CS, Penna ECG, Yasui EM, Aguiar LG, et al. Lazer familiar: um estudo sobre a percepção de pais de crianças com deficiência. Cad. de Pós-Graduação em Distúrbios do Desenv [Internet]. 2005 [cited 2014 June 18];5(1):12-26. Available from: www.mackenzie.br/fileadmin/Pos_Graduacao/Mestrado/...do.../lazer_familiar.pdf

19. Oliveira DS, Moura ARS, Feijó LP, Pinheiro MDC, Brites P, Dorneles S, et al. Interação vincular de pais com filhos autistas. Rev Psicol Cria Adoles [Internet]. 2014 [cited 2014 July 30];02(5):103-113. Available from: http://revistas.lis.ulusiada.pt/index.php/cipca/article/view/659

20. Bagarollo MF, Ribeiro, VV, Panhoca I. An autistic child's play from the cultural-historical perspective. Rev Bras Educ Espec [Internet]. 2013 [cited 2014 Nov 17]; 19(1): 107-120. Available from: www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-65382013000100008

21. Sanches VMC. Luto materno e o vínculo com o filho substituído [dissertação]. São Paulo: Pontifícia Universidade Católica de São Paulo; 2012.

22. Hume K, Loftin R, Lantz J. Increasing Independence in Autism Spectrum Disorders: A Review of Three Focused Interventions. Journal of Autism and Developmental Disorders [Internet]. 2009. [cited 2012 Oct 25];5(1):1-13. Available from: www.ama.org.br/site/images/.../Vejatresintervencoesquecontribuemparaesseaumento.p

23. Gonçalves M, Dylewski V, Chaves ACX, Silva TM, Fávero FM, Fontes SV, et al. Qualidade de vida: análise comparativa entre crianças com distrofia muscular de Duchenne e seus cuidadores. Rev Neurociência [Internet]. 2008 [cited 2014 June 28];16(4):275-9. Available from:

www.revistaneurociencias.com.br/.../Pages%20from%20neuro-16.4-web%5B5%5D.p

24. Elias AV, Assumpção Júnior FB. Qualidade de Vida e Autismo. Arq Neuropsiquiatria [Internet]. 2006 [cited 2014 Nov 07];64(2):295-9. Available from: www.scielo.br/scielo.php?script=sci_arttext&pid=S0004-282X2006000200022

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