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Quality of Life in Children with Autism

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Abstract:
Researchers have increasingly focused on the concept of quality of life since the beginning of the second half of the 20 th century. This term intersects with several other concepts such as happiness, well-being, and wellness, which refers to the individual's freedom from abnormal behavioral patterns, psychological and mental disorders, and illnesses. This concept encompasses several dimensions, including mental health, physical health, social relationships, and autonomy. These dimensions apply to both ordinary individuals and those with disabilities or specific disorders. Among these disorders is autism, which is a neurodevelopmental disorder that appears in children within the first three years of life. It results in speech and communication disorders, social isolation, lack of response to new stimuli, and the experiences they go through. To improve the quality of life for this group, it is essential to identify all the problems faced by children with autism in all areas of life to assess their condition and understand their needs to develop their abilities.
Keywords: Quality of Life, Dimensions of Quality of Life, Autism, Problems of Children with Autism.

Introduction:

Childhood issues and their problems are fundamental concerns that occupy a prominent place and serve as a key indicator of the progress of modern societies. These issues also reflect the extent of development in various aspects of psychological, health, and social care for children in general.

However, there is a group of children who require special care due to specific disabilities such as hearing impairment, visual impairment, physical disabilities, or various disorders such as intellectual disability and autism. This latter group, characterized by distinct features, differs from both ordinary children and those with other disorders. Autism is one of the developmental disorders affecting growth from early childhood, typically within two and a half to three and a half years. It is marked by persistent deficits in communication and social interactions, social and emotional reciprocity deficits, stereotyped movements (e.g., hand-flapping, finger-snapping, object-spinning), verbal development issues accompanied by abnormalities in speech form and content, echolalia, and an inability to cope with change. These children often exhibit varying levels of anxiety and fear in response to minor environmental changes and have impaired cognitive abilities.

To address these cases, specialists focus on improving the quality of life for this group, recognizing their unique needs and deviations from typical behavior. The concept of quality of life is relatively new in the psychological field and intersects with other concepts such as happiness, wellness, and well-being. It is measured through several indicators, including the individual's psychological state, health (both physical and mental), level of independence, social relationships, interaction with their environment, self-regulation, emotional balance, the extent of support available from their social network, and adaptability.

To enhance the quality of life for this group, it is essential to assess the needs of these children and provide alternatives after studying their psychological, cognitive, linguistic, and social aspects. Understanding the problems they face, which hinder their adaptation, independence, and sense of satisfaction and well-being, is crucial both for them and for those who care for them.

Evaluating autism relies on a set of behavioral indicators and developmental history. Initially, the specialist often gathers information through family interviews and by observing the child's behavior. However, to confirm the diagnosis, specialists use scales, tests, and measures that help them identify the nature and severity of the disorder and determine the specific type of autism the child has. The diversity and variation in symptoms from one child to another are due to the multiple and varied factors causing the disability, including genetic, hereditary, biological, neurological, chemical, and environmental factors.

Specialized programs aim to provide comprehensive rehabilitation for the child in all areas of development, enabling them to acquire skills that help them adapt and become independent. These programs focus on developing linguistic and social skills and reducing negative behaviors.

1- Definition of Quality of Life:

The concept of quality of life is linked to several similar notions such as happiness, psychological comfort, and life satisfaction. It is a complex concept because it is associated with different dimensions and is dynamic, changing from one period to another. Additionally, it varies from one individual to another and from one situation to another.

- **Quality of Life in Linguistic Terms:**

The word "quality" originates from the verb "جاد" (jaada), which means "to improve" or "to make good." Quality refers to making something good, which is the opposite of poor quality. It signifies enhancing and making something better. (Salah Khidr Khalaf Allah and others, 2015: p. 8).

- **Definition by Bonomi, Patrick, and Bushnell (2000):**

Researchers have emphasized that quality of life is a broad concept influenced by interrelated aspects of subjective and objective factors related to health status, an individual's psychological state, the degree of independence, social relationships, and the relationship with the environment in which they live. (Messaoudi, A., 2015: p. 205).

2- Dimensions of Quality of Life:

Mohammed Al-Sarasi Asmaa and others discussed the dimensions of this concept in an article on quality of life, which include:

2.1. Physical Health: This involves physical capability and the ability to move and travel. It is reflected in an individual's ability to perform daily activities, work, sleep, rest, and the degree of suffering and pain experienced.

2.2. Mental Health: This is characterized by freedom from psychological pressures and problems such as high levels of anxiety, increased symptoms of depression, feelings of sadness and helplessness. It is reflected in body image and general appearance, the positive or negative emotions experienced by the individual, and even their ability to pay attention, think, and remember.

2.3. Environment: This includes material resources, family environment, health and social services, the efficiency of health insurance programs, and the provision of financial support.

2.4. Social Relationships: This pertains to the quality of social relationships, the sense of belonging and closeness to family members, and the individual's ability to form human relationships characterized by self-confidence, respect, and freedom from social adjustment problems.

2.5. Independence: This is the ability of an individual to take care of themselves, be self-reliant, make decisions, and regulate their behavior while interacting with others. It also includes their ability to face difficulties and crises and to value and respect themselves.

3- Concept of Autism:

Autism was described in early childhood in 1943 by American child psychiatrist Leo Kanner, based on two primary characteristics: isolation (loneliness) and the need for sameness (similarity), which are accompanied by:

3.1. Communication Disorders: Early impairments in nonverbal communication, leading to the absence of spoken language and disturbances in its structure and pronunciation.

3.2. Socialization Disorders: Self-isolation, apparent indifference towards others, failure to seek out others in times of distress, and difficulty with symbolic and pretend play.

3.3. Narrow Interests: Stereotypical movements and rituals, resistance to change, and fixation on certain forms and objects.

These disorders must appear before the age of three and are often accompanied by intellectual disability, normal intelligence, or even exceptional abilities in certain areas, leading to what is known as savant syndrome. (Hochman, J., 2009, p.100).

According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), autism spectrum disorder (ASD) includes a range of symptoms:

- Deficits in communication and social interaction across multiple contexts.
- Restricted, repetitive patterns of behavior, interests, or activities.

- Symptoms present in the early developmental period.
- Symptoms cause clinically significant impairment in social, occupational, or other important areas of functioning.

These disorders are not explained by intellectual disability or global developmental delay, although intellectual disability and ASD frequently co-occur. To diagnose both intellectual disability and ASD, the social communication level should be below what is expected for the general developmental level. (Story, B. & Story, A., 2020: p. 82).

4- Levels of Severity in Autism Spectrum Disorder:

Children with autism vary in the degree and severity of their disorder and its type. The following table illustrates the differences in symptoms based on the severity levels of autism spectrum disorder (ASD).

Severity Level	Social Communication	Repetitive Stereotyped Behaviors
Level 3: Requiring Very Substantial Support	Severe deficits in verbal and nonverbal communication skills cause significant impairments in functioning, with very limited initiation of social interactions and minimal responses to social overtures from others. For example, the individual may have very limited speech, rarely initiates interactions, and if they do, it is in unusual ways solely to meet their needs. They respond minimally to direct social approaches.	Inflexibility of behavior, extreme difficulty coping with change, or repetitive stereotyped behaviors that significantly interfere with functioning in all areas. There is marked distress and significant difficulty in changing focus or action.
Level 2: Requiring Substantial Support	Marked deficits in verbal and nonverbal communication skills, with social impairments apparent even with support in place. There is limited initiation of social interactions and abnormal or reduced responses to social overtures from others. For example, the person may speak in simple sentences, have interactions limited to narrow interests, and exhibit unusual nonverbal communication.	Inflexibility of behavior, difficulty adapting to change, or repetitive stereotyped behaviors that occur frequently enough to be noticeable to an outside observer. These behaviors interfere with functioning in many contexts, causing frustration and difficulty in changing focus or action.
Level 1: Requiring Support	Without support, deficits in social communication cause noticeable impairments. There is difficulty initiating social interactions and clear examples of atypical responses to social overtures from others. There may also be a decreased interest in social interactions. For instance, an individual who is able to speak in full sentences may engage in communication, but their attempts to interact with others often fail, and their efforts to make friends are usually odd and	Inflexibility of behavior causes significant interference with functioning in one or more contexts. There is difficulty transitioning between activities, problems with organization and planning, and impediments to independence.

	unsuccessful.	

(Turki Mail Al-Sumaihi, H., 2021: p. 544) .

The term "spectrum" signifies the evident variations in the disorder, akin to the colors of the spectrum that represent different shades in their intensity. This concept or analogy refers to the differing symptoms of the disorder, which vary in their patterns and severity. The American Psychiatric Association adopted this terminology in its gradual effort to develop the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), one of the most prominent modern classifications recently acknowledged by researchers in the fields of psychology and autism spectrum disorder (ASD).

The revised classification in the DSM-5 is an update from the fourth edition, which included five subcategories: Autism Disorder, Asperger's Syndrome, Rett Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Rett Syndrome was recently removed from the DSM-5 due to the discovery of its causative gene, MECP2. Consequently, the classification now includes four categories. In 2013, the American Psychiatric Association revised the DSM-5, reclassifying autism spectrum disorder into four categories instead of five. (Hyzir, S., 2020: p. 125).

- **Autistic Disorder:** This is the first and most common type of autism spectrum disorders, and it is the main focus when discussing this disorder. It was discovered by Kanner (Kanner, 1943), but it was initially viewed as something else.
- **Asperger's Syndrome:** Also known as Asperger's Disorder, this syndrome typically resembles mild autism but does not involve any significant delays in cognitive and linguistic development. It was discovered by Hans Asperger.
- **Childhood Disintegrative Disorder (CDD):** In this disorder, a child experiences normal development from birth, usually for a period ranging from two to ten years, followed by a loss of previously acquired skills.
- **Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS):** This category involves general or widespread developmental delays that cannot be classified under any other diagnostic category, and the child does not exhibit stereotypical behaviors.
  (Abdullah Muhan, A., 2014: p. 107).

5- Early Symptoms of Autism During the Initial Stages of Development:

Parents of children with autism often report that the absence of language or the loss of previously acquired language during the second year of life is the first sign of a problem. Parents are concerned about the possibility of the child being deaf because, like most children with autism, they seem unaffected by the sounds and words of others, including their parents' speech. Many parents recall that their child was not responsive to communication, did not engage well with adults, did not participate in role-playing games, and failed to develop joint emotional interest. By the age of one, many children later diagnosed with autism do not respond to their names and cannot make eye contact (Ronda, J.A., 1997, p. 642).

According to researcher Abdullah Muhammad, there are several indicators that a child might display during the first year of life, which parents can use to recognize the disorder. Some behaviors can be observed from the first few months, while other indicators may be noticeable during the second year, suggesting the presence of a disorder or problem. However, it is not necessary for a child to exhibit all the symptoms of autism; displaying most of them is sufficient for diagnosis. Parents should seek specialists for early diagnosis and intervention to prevent the situation from worsening.

Some general symptoms during the early development of a child with autism, as mentioned by Dr. Tarek Amer, include:

- Difficulty in breastfeeding
- Unusually quiet behavior or continuous crying and screaming
- Lack of eye contact with the mother or in response to any environmental stimuli
- Limited or rare babbling
- Delays in walking and talking, and cessation of language development
- Interest in strange and trivial objects with a lack of both verbal and non-verbal communication, whether in expression or comprehension
- Resistance to changes in daily routines
- Abnormal behaviors such as anger or aggression towards oneself or others.

6- Problems of Children with Autism:

6.2. Social Isolation and Deficiencies in Social Interaction Skills: Children with autism are characterized by isolation and a severe inability to respond to others. It appears that they live within themselves, showing little to no attention to the presence or absence of others. When people are near them, they may treat them as objects rather than humans; for example, a child might grab someone's hand to turn on a light switch without any interaction.

These children do not respond to caregivers; they do not tend to hug their mothers, smile, or express joy at their presence. They do not like being held and behave as if no one is around them, failing to respond when called or to engage in conversation. Children with autism struggle with simple social skills due to their limited ability to imitate others (Amer, T., 2008: p. 64).

The social skill deficits continue for individuals with lower-functioning autism, presenting more challenges in complex social situations. These individuals persist in avoiding contact with others, coupled with a limited understanding of many social roles and contexts, making their social interactions and roles extremely difficult for them (Kamel Mohamed, A., 2003: p. 20).

6.2. Linguistic Weakness:

Children with autism, particularly those with less severe forms of the disorder, can increase the frequency of their communication attempts and begin to develop some language skills before the age of five. The failure to acquire language by this age is a strong indicator of autism spectrum disorder (ASD). Between 1943 and 1946, Kanner was the first to observe that children with autism often repeat words and sentences spoken by others. This classic feature of autistic language, known as echolalia, is common among children with productive language deficits. Generally, the child echoes what they hear immediately or shortly after hearing it, using the same words and intonation as the original speaker. This behavior has functional value, as echolalia can help children with autism maintain their role in ongoing conversations or respond when they do not understand what is said or have not yet acquired the practical or linguistic skills to respond appropriately.

Kanner also noted that children with autism tend to use words with special or unique meanings that are not used by others. Another prominent feature of language use in children with autism is pronoun reversal. They refer to themselves using "you" and to the second person in the conversation as "I." Although pronoun reversal is not exclusive to children with autism, it is a notable indicator in diagnosing the disorder. Pronoun reversal reflects the difficulty children with autism have in understanding the concept of self and others in the context of conversational role exchange between the speaker and the listener.

(Rondal, J.A., 1997, p. 642).

6.3. Stereotypy and Limited Activities and Interests:

Restricted, repetitive behaviors are a third distinguishing feature of autism spectrum disorder and are a prominent deficit easily noticeable by parents or anyone interacting with a child with autism. These repetitive behaviors typically begin around the second year of life. Examples include continuously turning lights on and off, transferring a toy from one hand to the other, or walking around the room feeling the walls. A child might repeatedly play with one object with one person, and their general physical movements might include hand flapping, arm bending, or banging their head against a wall. These children may also display violent aggressive behaviors or self-injurious actions, and they clearly lack an awareness of safety for no apparent reason. Their physical movements are often unusual, such as flapping their hands and arms like a bird, jumping in place, walking on tiptoes, pulling their legs together so they seem connected, or spinning around for extended periods. When concentrating or staring at something, they may exhibit increased hand and leg movements, and generally, their movements lack agility, whether in walking, climbing, or balancing (Abdullah Muhammad, A., 2014: p. 99).

6.4. Deficits in Performing Some Independent and Life Skills:

Children with autism often exhibit deficiencies and awkwardness in performing many behaviors that ordinary children of the same age and social-economic level can do. At the age of five or ten, an autistic child may be unable to perform tasks that a two-year-old can do. They may struggle to care for or protect themselves or feed themselves, needing assistance with eating, dressing, and undressing. When given a toy, they may put it in their mouth or continuously tap it with their hands or fingers. They also fail to understand or recognize potential dangers, and symptoms such as bedwetting, incontinence, eating problems, and insomnia are common among children with autism (Shakir Majeed, S., 2007: p. 45).

Autistic children often have sleep disorders, including delayed sleep onset and night awakenings, as well as eating disorders characterized by selective preferences based on unusual criteria such as color or shape of food. They also struggle with cleanliness, show significant delays in self-reliance, and have a poor understanding of body signals for toileting needs (Story Ben Story, A., 2020: p. 88).

6.5. Weak Response to External Stimuli:

Children with autism often appear as if their senses are unable to transmit any external stimuli to their nervous system. If someone passes by, laughs, coughs, or calls their name, they may seem not to see or hear, as if they are deaf or blind. With increased familiarity, it becomes clear that they are unable to respond to external stimuli, leading to failures in acquiring language and other means of communication such as imagination, memory, problem-solving, and comprehension.

This applies to various sensory modalities such as sight, touch, and taste. Autistic children may mix shapes and backgrounds, distribute their gaze without focus, and struggle to distinguish between temperatures or flavors. They may find it hard to associate symbols with sounds.

Children with autism often do not exhibit visible pain responses and do not recognize dangers, repeatedly exposing themselves to harm despite the injuries they sustain. They may react to low sounds that others barely hear or cover their ears to avoid certain sounds. They avoid being touched and sometimes display fascination with certain sensations, such as exaggerated reactions to light and smells (Shakir Majeed, S., 2007: p. 11).

6.6. Cognitive Disorders:

Individuals with autism spectrum disorder suffer from numerous cognitive issues, which can be considered cognitive characteristics, such as deficits in memory, metacognitive abilities, understanding others and emotions, self-awareness, problem-solving skills, and abstract thinking. These deficits can explain the linguistic and social interaction problems exhibited by these individuals, as these usually involve cognitive components, such as the social use of language, asking questions, joint attention, imitation, and imaginative play (Abdullah Muhammad, A., 1994: p. 145).

Autistic individuals have abnormal attention spans, capable of maintaining long attention periods on things that interest them, but facing difficulties with other forms of attention. The first of these difficulties is the challenge of orienting toward people and objects. Autistic children show significant deficits in their ability to distribute attention to detect auditory and visual targets carefully and are less capable of shifting attention compared to their neurotypical peers (Salem Osama Farouk, M., Al-Sayed Kamel Al-Sharbini, M., 2011: pp. 174-177).

According to the same researchers, autistic children have perceptual disorders. They take longer to explore their environment through the senses than their neurotypical peers, due to their lack of imitation and learning from others, inability to engage in relationships, and lack of verbal and social skills. This affects their ability to interpret messages from the environment and contributes to cognitive disorders. Autistic children are detached from reality, focusing only on fulfilling their personal desires and needs, with their thinking centered on self-absorption. They also struggle with information storage.

6.7. Mood Swings and Inappropriate Emotional Responses:

The mood and emotional responses of autistic children differ from those of other children. They often experience sudden mood changes accompanied by fits of laughter or crying without a clear reason. Autistic children are characterized by hyperactivity, especially in their early years, and may engage in aggressive activities or temper tantrums without justification, causing physical harm (e.g., wounds, bruises). They frequently and rapidly shift from one activity to another (Hussein Saleh, Q., 2008: p. 379).

Autistic children may spend long hours absorbed in stereotypical behaviors or isolated, barely aware of their surroundings. They sometimes exhibit aggressive behavior towards family members, family friends, caregivers, or specialists, characterized by primitive and injurious actions. Some may also self-harm by banging their heads against the wall or hitting themselves in various body parts (Salem Osama Farouk, M., Al-Sayed Kamel Al-Sharbini, M., 2013: pp. 142-143).

Autistic children, especially teenagers and adults, often exhibit anxiety symptoms, which seem to be linked to their social challenges and academic experiences. Various hypotheses attempt to explain the presence of anxiety in these cases, attributing it to interaction difficulties and repeated failures in social integration on one hand, and cognitive disorders on the other. Expression methods and social attribution in perceiving and interpreting emotional expressions are linked to their anxiety symptoms.

Additionally, using the Short Sensory Profile, Tomshek and Dunn found that 95% of children with pervasive developmental disorders have sensory system abnormalities, particularly in auditory filtering or tactile sensations. This new research trend focuses on the sensory characteristics observed in autistic children and their relation to social adjustment disorders and anxiety (Baghdadli, A., Bristol Dubois, J., 2014, p. 112).

Researcher Kheda Samira, in her thesis on autism, indicates that some autistic reactions can result from the dysfunction in integrating information from the five senses responsible for gathering environmental stimuli received by hearing, sight, touch, taste, and smell. This dysfunction provides contradictory information about the environment and the child's thoughts, leading to inconsistent ideas and difficulties in organizing sensory information, impairing the child's understanding of their surroundings and forming a clear and accurate picture of their environment. This disorder also affects learning processes and the ability to predict future events, leading to a constant state of anxiety, social adaptation failures, and cognitive disturbances.

6.8. Difficulty in Recognizing Emotional Expressions:

Children with autism often exhibit significant adaptive delays, particularly in socialization, communication, and independence. Current hypotheses link these difficulties to characteristics of metacognitive functioning, with specific focus on emotional expression disorders, visual recognition of facial emotions, and interpreting social situations. Additionally, they lack theory of mind, which indicates difficulties in attributing mental states (intentions, beliefs, desires), not limited to children with autism but also present in other developmental disorders and psychiatric conditions like schizophrenia. Executive functions, such as the ability to mentally plan specific activities, are also impaired. Sensory perception characteristics are considered a cause of adaptation disorders that likely lead to severe anxiety (Baghdadli, A., Bristol Dubois, J., 2014, p. 09).

Although some studies have shown that high-functioning children with autism spectrum disorder can recognize the four basic emotional facial expressions (joy, sadness, anger, and fear), they struggle more with complex expressions like surprise and embarrassment. Furthermore, these individuals generally cannot explain the contexts behind different emotional mental states. On the other hand, individuals with autism spectrum disorder are generally not expressive; they rarely use facial expressions to convey their feelings or share them with others (Story Ben Story, A., 2020: p. 95).

7- Needs of Individuals with Autism:

The concept of quality of life is directly related to satisfying basic needs. Quality of life is linked to a set of essential human needs and the extent to which these needs are met. These needs are crucial for an individual's well-being and cannot be neglected. The more these needs are fulfilled, the more an individual feels psychological comfort and life satisfaction, whether the child is typical or has autism. This concept is common to both disabled and non-disabled individuals. The needs include:

- **Physiological Needs:** Such as eating, drinking, and sleeping.
- **Safety and Security Needs:** Aimed at feeling safe, protected, and free from fear, violence, and aggression within the family or the environment where the individual lives.
- **Social Needs:** Including the need for acceptance by family members and acceptance of their disability.
- **Self-Esteem Needs:** The need for respect and appreciation from others.

Researcher Salem Osama Farouk Mustafa and Al-Sayed Kamel Al-Sharbini Mansour summarized additional needs specific to children with autism:

- **Emotional and Psychological Needs:** Treating them as children with feelings and emotions, providing care, affection, and attention from the family and community.
- **Early Diagnosis and Intervention:** Necessary for early intervention before the condition becomes more complex.
- **Medical and Psychological Services:** Specialized medical and psychological services.
- **Educational Services:** Tailored educational services.
- **Training in Self-Care Skills:** Addressing problems arising from the disorder.
- **Language and Communication Needs:** Focusing on language improvement, receptive and expressive language training.
- **Social Skills Training:** Enhancing social skills and social interactions.
- **Community Integration:** Encouraging them to engage in society and lead a fulfilling life.

Meeting the needs of this group of children depends on several factors, including the child's health condition and the degree of disability, family and environmental support, the family's cultural, social, and financial status, and the level of support the child receives from them.

Conclusion:

As highlighted, children with autism face numerous challenges and deficiencies in cognitive, linguistic, psychological, social, and communication functions. These challenges result in limited abilities to perform specific activities, self-care, and communication, often requiring assistance from others to facilitate their daily lives and fulfill their functions. All of this impacts their quality of life, which is evaluated in terms of two primary dimensions: subjective and objective.

The subjective dimension pertains to personal satisfaction with life, including feelings of quality, happiness, independence, adaptation, and balance. The objective dimension consists of observable and measurable indicators such as physical, mental, and psychological health, social and family relationships, living standards, and social services provided by the state, including healthcare and legal support. All these dimensions play a significant role in an individual's sense of satisfaction and well-being.

Autism, being a behavioral disability that affects all life aspects during developmental stages, impacts both dimensions. It leads to difficulties in verbal and non-verbal communication and learning, complicating interaction, measurement, and assessment. The family's role is crucial in early detection of the disorder, which allows timely and appropriate intervention to minimize negative effects and achieve the best possible adaptation between the child, their family, and environment. This involves accepting the disability, understanding the child's skill limitations and areas for development, providing psychological support, not isolating the child, treating them as a complete individual, meeting their needs, and encouraging independent performance and social relationships.

From a societal perspective, it is essential to raise awareness about the different types of disabilities, their causes, and how to handle them, especially since certain characteristics can indicate autism and facilitate early detection. Symptoms may appear within the first few months of life and develop further in the second and third years, leading to an official autism diagnosis.

Moreover, improving government services for these individuals is vital for optimal care and quality healthcare. Specialists play a role in enhancing the quality of life for these children through early detection, diagnosis, guidance, and support, informing the family about the nature of the problem, teaching them how to communicate with the child, and providing advice on managing the disorder. Ultimately, therapeutic education materializes in a treatment plan that always involves family participation.

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