

Perception On the Quality of Life of Families with Children With ASD Condition

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Abstracts: This is a qualitative study that addresses the perceptions on the quality of life of families with children with Autism Spectrum Disorder (ASD), who are cared for in an early care center of a regional university in Temuco, Chile. The research is based on a constructivist paradigm with a single case design. Semi-structured, in-depth interviews were used for data collection, and the analysis was carried out through open and axial coding, using ATLAS.ti 8.0 software. The results show that the ways in which families cope with this are conditioned by the diagnosis and level of support according to the DSM-5 that their son or daughter with ASD needs, which has repercussions on their family dynamics, which in turn conditions the expectations on the development, on their achievements and, especially, on the self-realization of their son or daughter. Given that extremes are chosen, overprotection stands out, where there is a lot of dependence and, on the other hand, a very permissive parenting style, where parents or caregivers associate all behavior to the condition and do not understand that not all behaviors are due to the condition, but that it also depends on the upbringing, routines and access to support networks.

Keywords: Quality Of Life, Autism Spectrum Disorder, Early Care, Family Expectations, Support Networks.

1. INTRODUCTION

Quality of life research is an emerging field within the social sciences that allows us to understand the subjectivities and intersubjectivities constructed by diverse individuals and social groups regarding their living conditions in multiple contexts. Studies on quality of life provide a background for governments, through public policies, to contribute to the common good and to the satisfaction of the needs and issues that arise from historically excluded groups (e.g., women, sexual diversities, Afro-descendants and indigenous peoples).

In this scenario, quality of life is the evaluation that the person makes on his or her level of well-being in domains of existence, considering its consequences and implications in everyday life (Guzmán & Orozco, 2020). In this sense, quality of life implies a perception of each person's situation within cultural, value-based frameworks; in relation to goals, expectations, standards and interests as multidimensional constructs (Cunha de Araújo et al., 2016; Lima-Serrano et al., 2016; Martínez et al., 2016; Pi Osoria & Cobián 2016).

The literature on the perception of quality of life reports studies in multiple fields, concentrating preferably in the areas of health, education and economics. In this direction, research focuses on the quality of work life, performance and stress in different professionals and specialties (Castellano & López 2021; Lumbreras-Guzmán et al., 2020; Montero et al., 2020; Vidotti et al., 2019); on the perception of quality of life of people with pathologies (Accinelli et al., 2021; Aguilar et al., 2020; Ayuso et al., 2022; Hernández-Vásquez et al., 2021) and on the quality of life of age groups such as children, youth, adults and older adults (Aparicio-Baquen et al., 2021; Guzmán et al., 2021; Villarreal et al., 2021). In recent years, a strong interest in comparative quantitative and family quality of life studies on children and youth with Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder

(ADHD) and various mental and behavioral disorders has emerged (Lima-Serrano et al., 2016; Maradiaga & Calvo, 2021; Mazurkiewicz & Marcano, 2021; Quintero-Olivas et al., 2021; Vera et al., 2016).

Concordant with the same interest in the document of the 2021/2022 Human Development Report, prepared by the United Nations Development Programme (UNDP), which places Switzerland, Norway, Iceland, Hong Kong (China), Australia, Denmark, Sweden, Ireland, Germany and the Netherlands in the tenth place of countries with the best quality of life. On the other hand, the standard of living of people in Chile is ranked 42nd, being the best evaluated country in Latin America, followed by Argentina (43rd), Uruguay (58th) and Costa Rica (58th), among others.

Taking up the situation in Chile and specifically analyzing the southern zone in La Araucanía Region, the results account for an Urban Quality of Life (UqoL) Index –conducted in 2019–, which showed that the perception of working conditions is 58.27%; socio-cultural conditions 55.29%; connectivity and mobility 69.32%; health and environment 54.18%; and housing and environment 47.19%.

From a subjective perception perspective, quality of life is represented in the concept of Subjective Well-being (SW), which expresses the satisfaction of people and their degree of satisfaction with specific global aspects of their existence, therefore, it is part of health in its most general sense and is manifested in all spheres of human activity. Placing ourselves in Chile, specifically in the capital of La Araucanía Region, with an UqoL of 53.62% (Hurtado, 2019). In this context, in order to provide the conditions for early care, the University Early Evaluation and Stimulation Center (*Centro de Evaluación y Estimulación Temprana Universitaria*, CEETU) of the Catholic University of Temuco was established in 2002 to respond and contribute to the urgent needs of people, especially families with sons and daughters with ASD.

The CEETU team focuses on prevention, care and early intervention, at no cost, and serves children from birth to 6 years old. Child development should be monitored by caregivers for the early detection of signs that indicate detriment to their optimal development, which is why timely care is essential in order to maximize the potential of each child's abilities and skills. In view of such background, and given that quality of life is a desired state of personal wellbeing conditioned by personal and environmental factors (Fernández et al., 2015 Maradiaga & Calvo, 2021), it is essential to know the perception of quality of life of families with children with ASD, who are cared for by the interdisciplinary team in the CEETU, in order to approach the understanding of the processes and experiences of the state of subjective well-being of families, information that is used as input for the evaluation and redesign of support strategies and that contribute to strengthening the genuine family commitment in early care of their children.

2. THEORETICAL APPROACH

2.1. Autism Spectrum Disorder from A Neuroscientific Perspective

The American Psychiatric Association (APA, 2021) includes in the fifth version of its Diagnostic and Statistical Manual of Mental Disorders (DSM-5) various neurodevelopmental disorders, among which it recognizes intellectual disability (ID), communication disorders, attention-deficit/hyperactivity disorder (ADHD), learning disorders, motor disorders, tic disorders and autism spectrum disorders (ASD). Under the denomination of neurodevelopmental disorders are grouped various clinical conditions characterized by an atypical development of some or multiple cognitive skills and complex behaviors that are acquired during childhood and adolescence (Carrasco & Rojas-Barahona, 2017).

In recent decades, ASD diagnoses have increased significantly worldwide, and it is estimated to affect between 1% and 2.4% of people under 18 years old (Zablotsky et al., 2015). Although it is considered a frequent clinical condition, with an approximate global trend of 1 in 160 children with some level of autism, it is still an underdiagnosed condition, taking time to detect until the emergence of its comorbidity with other psychiatric disorders such as anxiety or depression (Celis & Ochoa, 2022). The various conditions that encompass ASD are characterized by the difficulty to adequately develop processes of social interaction and communication, along with a limited, reiterative pattern of behaviors, interests and activities (Carrasco & Rojas-Barahona, 2017).

In this context, neuroscience studies contribute to a better understanding of how the nervous system functions and neurodevelopmental disorders. In particular, studies based on electroencephalography evidence a correlation between deficient activity of the mirror neuron system (MNS) and difficulties in verbal and nonverbal communication, motor problems and emotional empathy in people diagnosed with ASD (Giraldo, Restrepo & Arboleda, 2018). Indeed, the discovery in 1988 of specular or mirror neurons, by Giacomo Rizzolatti's team, has been fundamental for understanding the social nature of the human brain and learning (Oyarce, Huaiquián & Sanhueza, 2022).

In the late 1980s and early 1990s, Rizzolatti and his collaborators at the University of Parma studied, by means of microelectrodes, the individual electrical activity of neurons of the premotor cerebral cortex and their role in biological action (Burgos & Cabrera, 2021; Hickock, 2014). In this regard, it was found that premotor cortex neurons are activated milliseconds before motor cortex neurons and, therefore, prior to the action taking place (Sylwester, 2017). Neuroscientists named this group of neurons as mirror or specular neurons, since they are activated when an action is performed, such as when a motor act is observed; they also located more neurons of this type in the inferior parietal cortex, which gave rise to the parieto-frontal circuit of mirror neurons (Ferrerres & Abusamra, 2019).

At present, although the incidence of mirror neurons in linguistic, cognitive, communicative and socialization processes continues to be discussed, there is consensus that specular neurons carry out two types of processing: one linked to imitation, and the other aimed at understanding the goals of movement and action (Ferrerres & Abusamra, 2019; Celis & Ochoa, 2022). In this sense, neuroscientific studies argue that the mirror system allows us to recognize the actions of others and imitate them within ourselves with the purpose of understanding the intentions and behaviors of other people, favors communication, empathy and understanding of metaphors (Raspall, 2017; Sylwester, 2017). Because of the above, mirror neurons constitute the anatomical-functional unit that supports the theory of mind, which explains the human faculty to assign and interpret mental states of other people, anticipate, understand intentions, thoughts, beliefs and emotions of others, to direct and redirect one's own behavior in function of communicative purposes and effective social interaction (Ferrerres & Abusamra, 2019; Raspall, 2017; Zilber, 2017).

Reduced mirror neuron activity compromises in people the development of prosocial behaviors and the establishment of effective interpersonal relationships, which is expressed in a tendency towards social isolation and the absence of empathy in some cases (Raspall, 2017). Studies on mirror neurons demonstrate the deficient neuronal activity of the mirror neuron system in people with ASD, and which may explain, at an anatomical-functional level, the cognitive deficit and decreased imitation capacity that characterizes this neurodevelopmental disorder (Ferrerres & Abusamra, 2019; Gómez-León, 2019; Sylwester, 2017). Likewise, deficient socioemotional reciprocity, deficits in nonverbal communicative behaviors and problems in initiating and maintaining relationships with other people, along with repetitive movements and behaviors, fixed interests and hyper-reactivity to sensory stimuli have been found (Carrasco & Rojas-Barahona, 2017; Celis & Ochoa, 2022).

2.2. Family Quality of Life And Asd

The construct of quality of life includes all members of a family, since it is necessary to ensure the satisfactory life of each of them. There is a recognition that those families of the extended type seem to intervene adequately in family interactions and in the satisfaction of parents with their roles such mother and father. In addition, these families can count on support for the care of the child and economic support for specific situations to face crises (Martínez et al., 2016; Pi Osoria and Cobián, 2016). Thus, the family is a fundamental pillar for children with ASD, since it is necessary that all members can support and interact with them, giving opportunities for diverse experiences; it also favors the family to accept, adapt and understand that one of its members presents this permanent condition. The way in which families assume that one of their sons or daughters has ASD is conditioned by the particularity, that is, by their own beliefs, abilities and ways of interacting with others.

In this sense, families with sons and daughters with ASD present a coping focused on emotion, such as denial and positive reinterpretation, which leads to varying degrees of stress (Lai et al., 2015; Tijeras et al., 2016). In this

scenario, the presence of a member with ASD requires an internal transformation of families, where diverse attitudes and expectations towards the condition of the son or daughter are experienced, which derive in changes in the family structure and dynamics (Manjarrés & Heredich, 2019; Villavicencio & López, 2017). Thus, changes in dynamics affect their perception of quality of life, which has been described and studied in five dimensions: family interaction, parental role, emotional well-being, physical and material well-being, and supports related to the person with ASD (Lima-Serrano et al., 2016; Pi Osoria & Cobián, 2016).

The presence of a son or daughter with ASD affects to present some degree of stress, so that it is more frequent to trigger inadequate functioning at the family level, which affects the development of restricted feelings in daily family activities, increases and becomes more complex to obtain economic income and possibilities to access support and accompaniment services (Fernández & Espinoza, 2019; Jellet et al., 2015). Therefore, a key aspect in the design of experiences and strategies to support families with sons or daughters with ASD is determined by the role of early care service professionals in terms of their ongoing counseling. In this sense, it is essential that families are professionally accompanied in this process of acceptance of the son or daughter with ASD, since those who have experienced this counseling have valued the feeling of welcome perceived in some services and the possibility of sharing their fears and concerns with professionals, who provide reassuring guidance to families, which results in emotional support (Lima-Serrano et al., 2016; Quintero-Olivas et al., 2021; Vera et al., 2016).

3. METHOD

The type of research is qualitative, it is based on a constructivist paradigm and the design is a single case study. The purpose is to understand the perception of the quality of life of families with children with ASD, who are cared for in the CEETU, located in Temuco, Araucanía-Chile. In this regard, Strauss and Corbin (2002) argue that qualitative research studies people's lives, lived experiences, behaviors, emotions and feelings, as well as organizational functioning, social movements, cultural phenomena and interaction between nations, which is what was done in this particular study.

In this sense, qualitative methods start from the premise that the world is shaped by representations and attributes. Intersubjectivity is the cornerstone of all qualitative research, since it is used as a daily resource for the interpretation of situations and codes in a reflexive manner. Social reality is shaped by diverse meanings in an intersubjective way through established interpersonal relationships (Flick, 2012).

3.1. Participants And Ethical Dimension

The research required the participation of 40 families from CEETU, center dependent on the Catholic University of Temuco, Araucanía Region, Chile. The study subscribes to the ethical principles contained in the Singapore Statement on Research Integrity (2010). According to this, researcher ethical principles are mainly four: honesty, accountability, professionalism, and stewardship. In this context, researchers fostered an atmosphere of respect and neutrality during the visit; not passing any judgment on the responses and/or behavior of the interviewees, thus allowing the key informants to fully answer the questions, and avoiding any invasive act towards the participants. With the commitment to maintain strict confidentiality of the identity and responses of the participants, assumed names are used in the analysis of verbal data and in the transcription of the interviews.

3.2. Data Collection Instrument

Semi-structured interviews were used for data collection, which offer an acceptable degree of flexibility and allow the expression of the participant's points of view (Flick, 2012). On the other hand, the interview provides possibilities to motivate the interlocutor, clarify concepts, clarify ambiguities and reduce formalisms (Díaz-Bravo et al., 2013), it also gives researchers the freedom to introduce additional questions in order to clarify concepts or obtain more information (Hernández & Torres, 2018). In addition, we opted for in-depth interviews that follow the model of conversation among equals, where there are repeated face-to-face encounters between researcher and informants. This enables encounters oriented towards understanding the participants' perspectives regarding their lives, experiences or situations (Robles, 2011).

3.3. DATA REDUCTION AND ANALYSIS

Jefferson's conventionalism is used for the transcription of the stories. The data were then reduced and analyzed using open and axial coding procedures. The ATLAS.ti 8.0 software, which contains various tools for the qualitative analysis of textual data, was used for the codes. This software allowed the researchers to perform open and axial coding procedures (Lewis, 2004; Hwang, 2008). Open coding made it possible to express the data and phenomena in the form of concepts, which involved classifying the interviewees' expressions through codes. Then, in the axial coding phase, interconnections were established between the codes, being organized into two categories around the research question and objective of the study (Flick, 2012). The categories reveal the perceptions about the quality of life of families with sons and daughters with an ASD condition attended at CEETU, contributing to the understanding of the phenomenon under review.

4. RESULTS AND DISCUSSION

Two categories emerge from the data analysis: perception of quality of life and coping strategies of families with sons or daughters with ASD.

4.1. Quality of life perception

The quality of life of families caring for a son or daughter with ASD is affected by the emotional toll that disrupts the daily lives of the members (Vidotti et al., 2019; Villavicencio & López, 2017). The diagnosis of ASD in a child is an unexpected and stressful event for the family; the general family perception is hopeful. There are differences in the life satisfaction of fathers and mothers, which depends on gender and the degree of depth of ASD (Suriá, 2018). Below are codes that respond to the **Perception of quality of life** category and that were the ones that presented the highest frequency in the narratives:

The **exhaustion** code is expressed in the following narrative:

"I am tired, I try to do my best and the body also takes its toll on you, I had a fractured fibula and last year I had surgery and I was a long time without walking (...) I feel tired, exhausted. As a consequence of that I am very exhausted." [Family 1]

"Tired, stressed, anxious, I feel bad, because of taking care of my son with ASD and my other children, plus the housework and my husband, you know how men are, I have to work and one asks them for some help, but I feel emotionally stressed, I arrived here crying." [Family 7]

Families with a member with ASD need support from professionals such as therapists, special education, due to the overload of experiences or the burden of these emotions and feelings that almost no one talks about, due to the social perception that the family has about the condition of their son or daughter (Tijeras et al., 2016).

The family tries to adapt, reorganize and appropriately help their children, although this does not mean being content with the degree of depth of the ASD that their son or daughter possesses. Many families embraced their children with these needs that remain for life and distress the family, who regret that their children suffer limitations and have fewer opportunities for perception, mobility, communication or autonomy. Families will experience affection and enjoyment with their children (García & Bustos, 2015; Maradiaga & Calvo, 2021).

The **social isolation** code is seen in the following narrative:

"I don't go out anywhere, not even a little walk, I don't have the time and when I do have I prefer to sleep, it has been very difficult for me all my life (...) I became a mom when I was 17, since then I have never had the time to make friends." [Family 4]

“No, nothing, so much trouble, I come home from work and don't go anywhere else in the winter season, now we go out for a little walk, nothing else. Now that I am a mother, I can count on the fingers of my hands the friends that are left (...) and the friends that used to be for talking, now they are gone, we don't see each other much, but we are always in touch.” [Family 2]

Families with children with ASD, whatever the diagnosis, require the activation of support networks from different formal and informal settings in order to have a better quality of life. But even so, it is possible to find social barriers to seeking help, such as problems with transportation, waiting lists, lack of access to health services, discourteous treatment by professionals and not knowing where to find local support programs, as well as having few options of services that provide home care, in addition to scarce coverage of the family's own needs, since most of the attention is focused on the rehabilitation of the son or daughter, and on covering the high cost of various therapies, which implies a higher investment that not all families can afford (Lima-Serrano et al., 2016; Pi Osoria & Cobián, 2016).

Access to friendships depends on the time the son or daughter can stay alone or in the company of other people outside his or her mother, in addition it is also related to the behavior and ease of management they have over him or her. The greater the need for support or supervision, the greater the impediment for the family to participate in social activities. This is one of the reasons why families choose to isolate themselves socially, as it is a safer and more comfortable option (Bedoya & Builes, 2013).

4.2 Coping strategies

The family copes with the arrival of their new son or daughter in different ways, and tries to adapt their expectations according to the characteristics of the child. The following are the emerging codes of the **Coping Strategies** category that presented the highest frequency in the families' narratives.

The code **family support** is seen in the following narrative:

“I think that my family is good, at least I have plenty of support, I have a good relationship with my siblings, and I can always count on my mom, for example, when I have to do paperwork or go to the doctor, and my younger sister is always there for me too, because she is unemployed, so she can help me. I am closer to my family than my partner's family, because his mother has always been more distant, if we don't go to see her, she doesn't go to our home, and my children get along well with her.” [Family 7]

The events that are a consequence of the behavior of the child with ASD due to few hours of sleep, problems at sensory level and constant crises, cause stress to be permanently present in the family, as any other physical and/or psychological demand out of the ordinary, causes an anxious state in the family dynamics, alters the balance and climate (Tijeras et al., 2016; Martínez-Montilla et al., 2017; Vidotti et al., 2019). Herein lies the value of the family unit having professional accompaniment to possess and incorporate new and appropriate coping strategies, to cope with the different stressful events that arise and thus anticipate, avoid complex behaviors and reactions in their son or daughter in an optimal way and regulating family functioning, and therefore, family health (Martínez-Montilla et al., 2017).

Due to the psychological deterioration that occurs within the family, especially emotional, there is a feeling of uncertainty regarding the situation of having a child with ASD; feelings of guilt and/or anger always appear, which directly affect the treatment with their son or daughter. In addition, families develop more tasks, being vulnerable to permanent stress. However, adaptation or maladjustment does not depend on the stress, but on the lack of resources and supports to find the way how to raise their son or daughter diagnosed with ASD (Baña, 2015; Bagnato & Barboza, 2019). The parents perceive that their own emotions seem to influence the emotional reactions and behaviors of their children (Fernández & Espinoza, 2019; Villalba et al., 2012; Whitmore, 2016).

The **religiosity** code is reflected in the following narrative:

“I am focused on being happy, positive, I like that way, I trust a lot in God, and the Lord gives me many blessings, when one asks him, in the case of Mariano, for a healthy child but if it did not turn out as I thought, I am patient.” [Family 12]

The family seeks through spiritual development to access a religious institution that welcomes them that provides them with rituals, activities, experiences and resources that allow them to face these situations from the search for support and emotional containment, as well as the search for answers, because they have to live this difficult family reality. Religion is an essential part of people’s lives, which in some way facilitates coping styles in stressful situations when facing a son or daughter with ASD. This work opens the perspective of how facing situations that change the routine, interactions, priorities affect the family and how they cope in a different way and whether or not they manage to understand and accept the reality that they had to live (Villalba et al., 2012).

The **alternative medicine** code is reflected in the following narrative:

“(…) I started with the gluten-free diet, I learned to make several foods such as rice flour cookies, or almond flour bread, stop consuming drinks or juices with dyes, instead natural juices or water. This change of diet favored his/her concentration and lowered his/her anxiety level.” [Family 8]

Natural medicine and traditional medicine, known internationally as alternative medicine, is part of the universal cultural heritage; of concepts and practices that have been inherited from generation to generation. Among these alternative medicines are homeopathy, phytotherapy, acupuncture, ozone therapy, apitherapy, moxibustion, among others (Plain et al., 2019). In this sense, alternative medicine constitutes an option or also a new coping strategy used by parents in the face of disruptive or health behaviors presented by their son or daughter with ASD (Celis and Ochoa, 2022). In this regard, families feel alone and that the state itself does not grant them access to centers, nurseries, kindergartens, schools or any institution that welcomes or accompanies their parenting process; everything mentioned above shows the need of the families themselves to take charge and this explains the emergence of organizations that in recent years have sought in alternative medicine a natural complement to medicines or drugs prescribed by Western medicine, and that from their experiences have contributed to improve the quality of life of their sons and daughters.

The code of **equal participation** is reflected in the following narrative:

“If I think about it (…) it is my job to do it, my husband has the final say, but usually I am the one who talk about it and I am more democratic.” [Family 27]

Equal shared parental responsibility is the responsible and shared upbringing by families, who are responsible for the development and well-being of their children (Castillo et al., 2020). In fact, the mothers interviewed report an asymmetry in parental responsibility, in that most of them must assume guardianship and responsibility for the care of their children. While fathers assume a role of provider of resources to the detriment of shared parenting, which increases fatigue and exhaustion of mothers, who present greater emotional exhaustion added to feelings of pain, desolation, uncertainty, guilt and shame (Aguilar et al., 2018).

The **verbal mediation** code is reflected in the following narrative:

“Every day (…) when the kids got into a fight, they bite each other, I first explain to them in a loving way that they should not fight, that they should be affectionate, that they should understand that fight is not the way, and then when I explain several times and they do not understand, I get serious, I speak more firmly, and I explain again so that they understand and I repeat it all day, if necessary, so that they understand.” [Family 30]

The concept of mediation has been defined as a process of cooperative conflict resolution, in which two or more people in dispute receive the assistance of one or more impartial third parties, who are the mediators to communicate and reach by themselves a mutually acceptable agreement on the issues in dispute (Armas, 2009). In this context, mediation is a strategy that allows parents to deal with conflicts that arise between a child with ASD and other family members, in particular with siblings who do not easily understand the child's condition.

Finally, the **acceptance** code is reflected in the following narrative:

“When the neurologist said the diagnosis was ASD, we, that day it was terrible, I wanted to cry that day, but then we accepted it with my husband, because at first they tell us something like that and we were more or less, ah, it might be this, and when they tell you no, yes it is, then we, of course, we feel different.” [Family 35]

“In my family, everyone has Asperger's syndrome, even my relatives, my mom and dad have different symptoms and on the dad's side they all also have social alterations, our relationship is more functional.” [Family 18]

These stories show how families go through and experience various forms of acceptance of a son or daughter with ASD. In this sense, initially families evidence a sense of sadness and frustration that over time gives way to resignation and the search for logical explanations that allow understanding this unexpected family event (Suriá, 2018). Therefore, the complexity of the changes aroused within families with sons or daughters with ASD should be analyzed in terms of the phases of acceptance and reorganization through which all family members go through. Since each one of them has different expectations that establish particular ways of functioning. This leads to analyze the multiple ways in which parents look for appropriate styles to face and solve the vicissitudes and challenges of having a child with any condition (Ortega et al., 2010).

CONCLUSIONS

Raising a son or daughter with ASD implies a high emotional demand and emotional toll on the family, where parents have difficulties in establishing interpersonal relationships and equal participation in parenting, which contributes to increased levels of stress, anxiety and hopelessness. This is in addition to the perception that their own emotions seem to influence the emotional reactions and behaviors of their children.

The birth of a son or daughter with ASD is immediately perceived by parents as an extraordinary, unexpected and incomprehensible event. The presence of a son or daughter with ASD becomes a potential factor that disturbs the family dynamics, so trust is essential in shaping the parental style. In raising a son or daughter with ASD, parents are the most involved figures, because they have to face a series of difficulties, both in the emotional and practical fields, which affects the family dynamics.

This problem not only modifies the family context and climate, but also the people who make up the family and the existing relationships among them. Therefore, all members try to adapt and accommodate to a new life, and develop different ways of coping with the situation.

Families go through different stages in the process of accepting a son or daughter with ASD, which will also depend on the professional accompaniment, family support networks, friendships and economic resources available to them. Thus, there are families that, by having family and professional support networks, manage to accept the condition of their son or daughter and allow themselves to enjoy a healthy, welcoming and calm upbringing based on mutual support. The stories of the families interviewed showed an asymmetry in gender roles and shared parenting, where the mother plays the leading role in raising the children, and the father assumes a passive role with little commitment to development, which increases the mother's level of exhaustion, and in the face of which the support of the CEETU professionals and other members of the household is indispensable.

With respect to coping strategies, verbal mediation between families stands out as a widely spread, accepted and promoted strategy in psychology, since it favors communication between members of a family or organization, and allows reaching consensus among those involved. On the other hand, in recent years alternative medicine has become a frequent option among families as a complement to traditional pharmacology, especially to minimize complex behaviors: sleep difficulties, eating problems, poor concentration, aggressive behaviors, among others, and it is a socially legitimized option to promote quality of life. Finally, from the family reports, the relevance of professional support and interdisciplinary accompaniment for those with ASD is evident, which is linked to a better perception of the quality of life in the families and increases the expectations of progress in the son's or daughter's condition.

Finally, it is necessary to continue with studies that contribute to make the condition of children and young people with ASD visible in order to promote empathetic attitudes by society towards those families who live experiences of loneliness, where there is a high fragility in social interactions and bonds that makes them isolate themselves to avoid behaviors that make them uncomfortable or affect the context. Meanwhile, there are always new obstacles that the family must overcome, such as the parental perception that their son or daughter with ASD is permanently a child and, therefore, overprotection makes it difficult to advance in the inclusion and real autonomy of the person with ASD within society. It is hoped that research of this type will constitute inputs for the states for the design of public policies that meet the needs expressed by families with sons and daughters with ASD.

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DOI: <https://doi.org/10.15379/ijmst.v10i5.2429>

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