Gac Méd Caracas 2025;133(Supl 1):S299-S310
DOI: 10.47307/GMC.2025.133.s1.26

Mental Health and Family Dynamics of Caregivers of People with Autism

Salud mental y dinámica familiar de cuidadores de personas con autismo

Maira A. López-Castellar[1]*, Diana M. Hernandez-Lagos[2]

SUMMARY

Introduction: *This systematic review synthesizes the available scientific evidence on the impact on the mental health and family dynamics of caregivers of people with autism spectrum disorders (ASD).* **Materials and methods***: It was relevant to include one applied research study and 21 articles that met the inclusion criteria, with a sample of 724 primary caregivers and 143 families distributed across 16 countries on four continents: Latin America, Europe, Asia, and Africa. The information was organized using a methodological matrix that considered the following details: authors, year of publication, keywords, name of the journal or repository, geographical location of the study, methodology employed, sample, and results of each study.* **Results:** *The findings show that families and caregivers of people with a diagnosis of ASD suffer changes at a personal level, in family and social dynamics, and that they may experience psychological distress as evidenced by clinically significant mental health symptoms, especially feelings of sadness, anxiety, frustration, and confusion.* **Conclusion:** *The mental health of families and caregivers of people with ASD is affected depending on its level and the additional presence of other disabilities. In 90 % of cases, mothers are the ones who assume the role of main caregivers, having to face psychological discomfort.*

Keywords: *Mental health, families, caregivers, autism spectrum disorder (ASD).*

RESUMEN

Introducción: *En la presente revisión sistemática se sintetiza la evidencia científica disponible sobre el impacto en la salud mental y la dinámica familiar de cuidadores de personas con Trastornos del Espectro Autista (TEA).* **Materiales y métodos:** *Fue pertinente incluir 1 investigación aplicada, y 21 artículos que cumplieron con los criterios de inclusión, con una muestra de 724 cuidadores principales, y 143 familias, distribuidos en 16 países de 4 continentes: América Latina, Europa, Asia y África. La información fue organizada por medio de una matriz metodológica teniendo en cuenta la siguiente información: Autores, Año de publicación, palabras clave, nombre de la revista o repositorio, ubicación geográfica del estudio, metodología implementada, muestra y resultados de*

DOI: https://doi.org/10.47307/GMC.2025.133.s1.26

ORCID: 0000-0002-9761-840X[1]
ORCID: 0009-0000-0679-6431[2]

[1] E-mail: malopez57@areandina.edu.co
[2]E-mail: dhernandez56@areandina.edu.co

[1],[2]Fundación Universitaria del Área Andina. Valledupar, Colombia,

* Corresponding author: Maira A. Lopez - Castellar, Professor at the Fundación Universitaria del Área Andina, Psychology Programme. E-mail: malopez57@areandina.edu.co

Recibido: 19 de enero 2025
Aceptado: 17 de marzo 2025

cada estudio. **Resultados:** *Los hallazgos demuestran que las familias y los cuidadores de personas con diagnóstico de TEA, sufren modificaciones a nivel personal, en la dinámica familiar y social, llegando a presentar malestar psicológico evidenciado en síntomas clínicamente significativos a nivel de salud mental, especialmente: sentimientos de tristeza, ansiedad, frustración y confusión.* **Conclusión:** *La salud mental de las familias y cuidadores de personas con TEA se ve afectada dependiendo del nivel de este y la presencia adicional de otras discapacidades. En un 90 %, las madres son quienes asumen el rol de cuidadoras principales, teniendo que enfrentar malestar psicológico significativo.*

Palabras clave: *Salud mental, familias, cuidadores, autismo, (TEA).*

INTRODUCTION

The terminology of autism has its Greek origin, αυτος (auto), which refers to oneself; on the other hand, ισμός (ismós) means 'to submerge in oneself' or 'to introvert', indicating an intentionality of withdrawing from the outside world (1). Consequently, the General Assembly of the United Nations (UN) since 2007 established the 2nd of April as the World Autism Awareness Day, intending to make the population aware of this condition, generating a change of attitude for the acceptance of these people and thus defending their participation rights, transforming imaginaries into a social inclusion (2).

The American Psychiatric Association (APA), using the consultation guide of the diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM5) (3), denominates autism within the classification of neurodevelopmental disorders and conceptualizes it as a constant deficit in the areas of socialization, communication, and social interaction. The impairments are perceived according to their severity, as described in the levels of communication and behaviors below. At level 1, people with this diagnosis require support in communication because they find it difficult to take the initiative to engage in conversations and may be perceived by others as a person with little social interest and atypical in the reciprocity of conversations, they also present repetitive or stereotypical and routine behaviors with inflexibility in one or more environments. People diagnosed at level 2 require significant support in understanding verbal and non-verbal communication, exhibit inflexibility in adapting to changing routines, and have limited attention spans. Finally, those in level 3 require permanent accompaniment due to the complexity of their needs, which are often basic. From an oral perspective, there is no interest in communicative exchange, and they are perceived as asocial individuals with restricted and repetitive behaviors (4).

This type of disorder is part of the so-called neurodevelopmental disorders, as its basis is neurobiological; it is often linked to alterations or dysfunctions at the sensory level and other neurodevelopmental characteristics. It is also usually expressed in conjunction with neuropsychiatric disorders, epilepsy, and sleep disorders. Currently, it can be said that its prevalence is 1 in 36 people, with a male predominance. The ratio between the sexes is 3.8 to 1 (5). Hervás ratifies the above when mentioning in his study that for every 3 boys, there is 1 girl with autism; however, when doing clinical studies, this alteration of neurodevelopment can be identified with a higher proportion regarding prevalence, always predominating in boys (6).

Among the aspects presented by Hervás is that during the first ages of life, more than 50 % of the cases registered are linked to neurodevelopmental alterations. This author, from an evolutionary approach, maintains that people with the diagnosis present hyperactivity, inattention, and impulsivity; on the other hand, 1/3 of patients present significant affections about language development, and approximately 1/3 present intellectual disability (6). The National Institute on Deafness and Other Communication Disorders (7) states that these manifestations become important signs for the detection of autism spectrum disorder, appearing frequently between 12 and 18 months of age, and manifestations have even been found much earlier. Although there is no cure, there are currently a variety of treatments from different disciplines, an aspect that focuses on improving the quality of life of the diagnosed person and their family, which is important considering that for some authors (6), the ages of adolescence and adulthood can become milestones for cognitive and communicative skills. Still, disorders can also be expressed at the emotional level, which is associated with suicidal ideation and behavior, as well as other problems that compromise mental health.

For its part, the family, as a biopsychosocial unit, is fundamental for the education, training, and socio-emotional development of each member, fostering the creation of fraternal and paternal bonds that enable them to be resilient in the face of changes (8). The functioning of family dynamics in the face of a diagnosis can have negative impacts on the system, which is why each member, depending on the life cycle stage in which they find themselves, has certain properties that characterize them and enable them to fulfill their specific role. Siblings, for their part, are considered sources of companionship, a bridge for interpersonal relationships, security and complicity.

From this perspective, the importance of autism within the context of mental health is not limited to the own manifestations of this disorder, and much less to the variety of the spectrum; families also assume great challenges that can generate complications at a social and emotional level, generating problems in mental health, which motivated the purpose of the study that consisted of analyzing the scientific evidence available on the impact on mental health and family dynamics of caregivers of people with Autism Spectrum Disorders (ASD).

MATERIALS AND METHODS

The following stages were completed: identification, selection, eligibility, and inclusion of scientific literature using scientific information systems such as Redalyc. The scientific databases include PubMed, Scopus, Scielo, Dialnet, Springer Nature Link, and Taylor & Francis Online. The following descriptors were considered for this search: 'Well-being and mental health of families with people with ASD', 'Mental health of caregivers of people with autism', 'Autism', 'Mental health and autism', and 'Family dynamics of caregivers of people with ASD'.

Selection of the studies

The selected studies are published in scientific journals. Regarding the inclusion criteria, they are studies on the well-being and mental health of families and/or carers of people with any type of autism. It was pertinent to include one applied research study and 21 articles that met the criteria, which involved 724 main caregivers and 143 families (comprising mothers, fathers, and siblings) from 16 countries across four continents: Latin America, Europe, Asia, and Africa. For the organization and data analysis of these documents, it was necessary to implement a methodological matrix in Microsoft Excel. This register included the following information: authors, year of publication, keywords, name of the journal or repository, geographical location of the study, methodology implemented, sample selection, and the results of each study (Figure 1).

The Inclusion and exclusion criteria were used to determine that the articles aligned with the study's objectives based on the titles and details outlined in each abstract, including the population, methodology, and findings.

RESULTS

Once the 21 studies had been selected, it was observed that the predominant type of research was of a cross-sectional, qualitative nature, with the most commonly used design being phenomenological, accompanied by narrative approaches. In terms of data collection techniques, interviewing is the most widely used. Among the measurement instruments used were the Parenting Stress Index-Short Form, the Beach Center Family Quality of Life Survey, and the Beck Depression Inventory-II. The continent of greatest reference was America, specifically Latin America, followed by Europe, Africa, and Asia. Table 1 presents the selected studies, organized by author and year, keywords, journal, geographical location, methodology, sample selection, and results for each study.

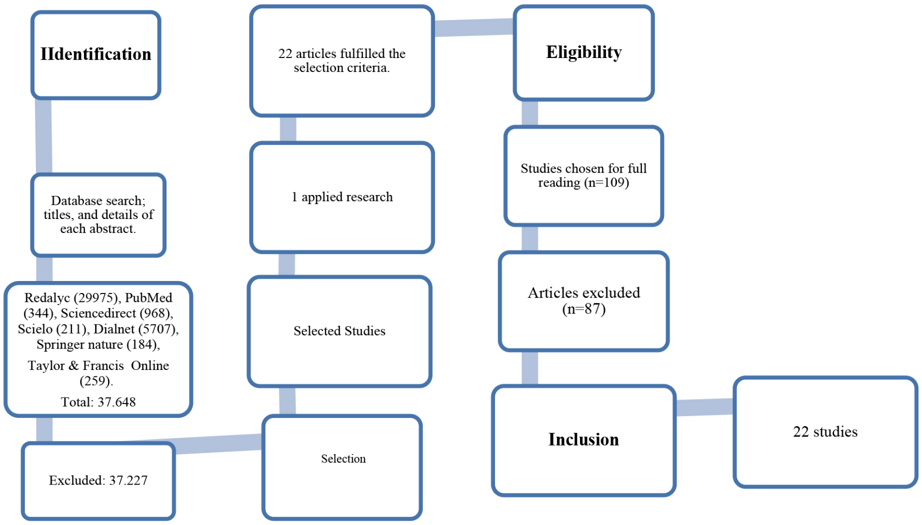

Figure 1. Flowchart of elements ot the selection process.

Challenges and Changes in Family Dynamics due to the Diagnosis of ASD

Currently, there is a predominant focus on the study of the different types of treatment for autism and an important limitation in studies that address the perceptions of families with people diagnosed with ASD (9-10).

At the Latin American level, transnational studies are found on the experiences of families with autistic people (11); through an analysis of 48 families from Chile, Argentina, Peru and Guatemala, the changes that arise within the family are revealed, when having to modify their daily routine, and face the stigmas of other family members and friends. These aspects end up affecting the mental health of the primary family environment of people with ASD, as they experience feelings of sadness, frustration, anxiety, and confusion.

Through the narratives of five families, the transformation of the family dynamics associated with learning of the diagnosis of a child with ASD in Colombia was revealed (12); upon learning of the diagnosis, emotions such as sadness, worry, fear, hopelessness, and mood swings come to the surface. These emotional responses allowed the search for changes in the quality of life that would provide favorable responses for the person with ASD and the entire family system, oriented to redirect the family dynamics for the benefit of mental health, promoting the socio-affective aspects, assuming fraternal and parental responsibilities with specific roles, prioritizing effective communication, and understanding the behavior of the person with ASD and its manifestations to implement standards, rules and discipline.

In Nicaragua, a study was conducted to investigate the relationship between five siblings of individuals with autism spectrum disorder (ASD) (13). The results indicate that the family bond between siblings enhances social, communicative, expressive, and autonomous skills, facilitating the modeling and imitation of behaviors, which in turn promotes emotional well-being. Older siblings perceive siblings with a diagnosis of ASD as limiting their ability to have a common life. In comparison, younger siblings or peers often perceive it as natural when relating to one another. As for fathers and mothers, they observe that children without a diagnosis play a role with their siblings similar to that of their parents, being protective, willing to serve, teach, educate, and supply needs. Although the above can be perceived as something positive, the reality is that when assuming this responsibility, there are symptoms of stress and anxiety due to the challenges and demands of the needs they assume.

Table 1. Relevant information of selected articles.

Authors and year of publication	Palabras Clave	Revista	Ubicación geográfica	Metodología	Muestra seleccionada	Resultados
(9)	TEA, Social Responsibility, Perception, Social Inclusion, Mass Media.	Psychology Quaderns.	Málaga - España.	Qualitative data collection through non-probabilistic and strategic sampling.	20 people with family members diagnosed with ASD, as well as the diagnosed people themselves. They were distributed as follows: 17 parents of children with autism and three adults diagnosed with the disorder.	Families perceive that the lack of information, economic and social support affects their mental health. Psychological discomfort is reflected through feelings of frustration, demotivation, loneliness and sadness.
(10)	Autism spectrum disorder; COVID-19; Family dynamics; Interpretative phenomenological analysis.	Research In Developmental Disabilities.	Reino Unido.	Semi-structured interviews were implemented in which they talked about their family before, during, and after receiving the ASD diagnosis. The interview transcripts were analyzed using interpretive phenomenological analysis.	8 pairs of parents and siblings (16 people).	Although dyads, they are consumed by the diagnosis. For their part, neurotypical siblings are also immersed in psychological distress.
(11)	Autism Spectrum Disorder, Life Changing Events, Family Relationships, Early Diagnosis.	Chilean Journal of Occupational Therapy.	Chile, Argentina, Perú y Guatemala.	The methodological perspective used was the constant comparative method.	48 families from Chile, Argentina, Peru, and Guatemala.	Families of people with ASD suffer changes in the routine of their daily activities and stigmatization by family and friends. Among the clinically significant symptoms is the presence of feelings of sadness, anxiety, confusion, and frustration.
(12)	Teachers: Autism, Family Dynamics, Autism Treatments, Transformation, and Family.	Pedagogical Horizons	Medellín, Colombia.	Qualitative research approach with a narrative design.	Five families, and in each one, there is a member with ASD.	Ignorance of the implications of the diagnosis can cause emotional imbalance and changes in family dynamics, which involve shifts in roles as children assume high-effort responsibilities and take on the challenges typically associated with caregivers.
(13)	Family experience, Autism Spectrum Disorder, role of siblings, psychosocial repercussions, intervention strategies.	FAREM-Estelí Scientific Magazine.	Estelí, Nicaragua.	Qualitative study of an exploratory and descriptive type with a phenomenological approach.	5 families that met the intentional non-probabilistic sampling criterion.	It is observed that fathers and mothers of people with ASD entrust the responsibility of care to other siblings. The overload and early life cycle of sibling caregivers, although they ultimately adapt, have effects that are identified mainly at a psychological and social level.
(14)	Autistic Disorder, Relationships between Siblings, and Family Dynamics.	Network of Scientific Journals from Latin America and the Caribbean, Spain, and Portugal.	Brasilia.	Descriptive study with a qualitative approach.	Semi-structured interviews were implemented with seven sisters of people with disorders	The sisters of people with ASD, although within the family nucleus they build
(15)	Child psychology, parent-child relationship, child development, mental health, evaluation.	Journal of Psychology of the Autonomous University of the State of Mexico.	México.	Quantitative, analytical, observational and cross-sectional study.	Autistic, selected by snowball sampling.	Fraternal relationships of affection, companionship and care are affected by how the presence of the disorder is communicated to them. Realizing that his brother is different when living together allows feelings of sadness to appear when seeing how the family dynamics are

Continued in pag. S304…

…continuation Table 1. Relevant information of selected articles.

Authors and year of publication	Palabras Clave	Revista	Ubicación geográfica	Metodología	Muestra seleccionada	Resultados
						modified in terms of the relationship with the mother, since she is the one who assumes the role of main caregiver, her attention is focused on the patient with ASD.
(16)	gender, objective burden, subjective burden, psychological distress, caregivers, autism spectrum disorders.	Journal of Clinical Medicine.	España.	Cross-sectional design.	219 informal primary caregivers (CPIs).	The overload perceived by caregivers is greater when compared to caregivers who have other types of disabilities. The level of independence influences the caregiver's perception; the greater the impact of the overload, and therefore, the condition on mental health.
(17)	Autism spectrum disorder, parental stress, quality of family life, and depressive symptoms.	Spanish Disability Magazine.	Uruguay.	A cross-sectional study in which the Parenting Stress Index-Short Form, the	Convenience sample of 250 caregivers of family members with ASD.	There are differences between genders in the care of children diagnosed with ASD. Mothers are usually the ones who bear the greatest responsibility, having to dedicate more time to this task, and report worse mental health compared to the father figure.
(18)	Autism spectrum disorder (ASD); family impact; family effects; family functioning; quality of life.	Behavior Analysis and Modification.	España.	Beach Center Family Quality of Life Survey and the Beck Depression Inventory-II. 106 main caregivers participated, mostly mothers (87.4%), who reported	106 main caregivers, mostly mothers (87.4%).	Parents experience depressive symptoms associated with high levels of parental stress and distress.
(20)	Autism, Family, Diagnosis, Case study, Psychosocial.	Invest. Pens. Crit.	Panamá.	Mixed design with a greater qualitative emphasis, involving the analysis of multiple case studies. The instruments used were the questionnaire for Families of People with Autism and the Family Repercussion Instrument (IRFA).	8 main caregivers (men and women) of parental figures (father-mother; mother; grandfather) of children diagnosed with ASD.	In caregivers and families, the areas most sensitive to the diagnosis of ASD in one of their members are Family communication and sociopsychological. The reason why family communication, roles, and affectivity change. Social coexistence and community participation will also decrease.
(21)	Child care, Autistic Disorder, Parents.	Autism, Family, Diagnosis, Case study, Psychosocial.	Chile.	Qualitative, interpretive paradigm, phenomenological design.	7 parents, distributed as follows: 6 mothers and one father, between 25 and 49 years old.	Parents, not knowing ASD, experience fear and prejudice. The lack of support and guidance from health-promoting institutions is perceived as a form of abandonment, yet it also presents an opportunity to improve the adaptation of parents and caregivers.
(22)	quality of life, parental stress, coping strategies, ASD.	Child care, Autistic Disorder, Parents.	Coruña, España.	Quantitative.	50 caregivers of people with ASD aged between 2 and 35 years.	Caregivers present clinically significant levels, mothers are the most affected.

Continued in pag. S305…

…continuation Table 1. Relevant information of selected articles.

Authors and year of publication	Palabras Clave	Revista	Ubicación geográfica	Metodología	Muestra seleccionada	Resultados
(23)	Family members, caregivers, disease burden,ASD,autism, quality of life	quality of life, parental stress, coping strategies, ASD.	España.	Systematic review.	11 articles on the study of the burden of disease in relatives of people with ASD.	The
(24)		Family members, caregivers, disease burden, ASD, autism, quality of life	Distritos de Bağcılar y Bahçelievler de Estambul	They employed semi-structured interviews conducted via telephone, WhatsApp, and Zoom video chat, along with a phenomenological approach,to gain a deep understanding of the caregivers' experiences. Themes were identified through descriptive analysis.	10 families with children who are students of special education schools in the Bağcılar and Bahçelievler districts of Istanbul.	Having a child diagnosed with ASD causes mental health problems in parents, especially in mothers, who are the ones who receive the greatest impact and responsibility of the diagnosis, which is why it is considered health care not only for the person suffering from the disorder but also for their caregivers, especially the mother.
(25)	Autism; Family; Parents' opinions; Social work.		Veracruz, México.	Study with a quantitative, non-experimental, descriptive, and transversal approach. The instrument used was the Zarit Caregiver Overload Scale.	40 participants, relatives of individuals with ASD who met the criteria: indeterminate sex, aged between 18 and 60 years.	The presence of overload is attributed to physical and mental exhaustion, a consequence of caring for a family member with ASD. Therefore, it is considered a factor that generates stress.
(26)	Primary caregiver overload; autism spectrum disorder.	Autism; Family; Parents' opinions; Social work.	Colombia.	Mixed study based on an exploratory sequential design.	10 parents of people diagnosed with Autism Spectrum Disorder, aged between 27 and 54 years	The parents showed the ability to face the challenges of having a child with ASD, feeling decisive in seeking social and professional support and positive thinking.
(27)	Autism spectrum disorder,Perceptions, coping strategies,	Primary caregiver overload; autism spectrum disorder.	Ghana.	Qualitative phenomenological study with exploratory descriptive research design. To analyze the data, a content analysis procedure was implemented.	Ten participants were selected through a purposive sampling technique.	The family's quality of life is economically affected by having a child with ASD, facing demanding emotional, financial, educational, and social situations. Therefore, it causes symptoms of stress and anxiety in caregivers.
(28)	Autism spectrum disorder, caregiver burden, psychological impact, coping strategies, Ghana.	Gogent Education.	Ghana.	Qualitative method: data were collected through semi-structured interviews.	20 intentionally selected informants. The target population is caregivers of people with ASD.	Caregivers require accompaniment and support from professionals. Caregivers of people with ASD experience mental and physical health problems, where psychological distress is clinically significant.
(29)	Autism, Autism Spectrum Disorder (ASD), caregivers, quality of life.	Medical Record of the Center.	Municipality of Santa Clara, Cuba.	Qualitative approach, utilizing a descriptive, longitudinal, and prospective study design.	Nine primary caregivers of patients with Autism Spectrum Disorder (ASD).	Primary caregivers of people with ASD take on a challenge that causes physical and emotional exhaustion, sleep problems, impact on the continuity of the life project, and inactive social life. The above is an impact on the dimensions of quality of life.
(30)	Empathy, EA, prosocial behaviors, and depression.	Psykhe (Santiago).	Chile.	This is a cross-sectional, non-experimental study involving two groups, utilizing data from self-administered surveys.	210 people.	It was found that greater depressive traits and greater cognitive empathy predict that the participant has an AD sibling. Furthermore, it was observed that greater empathy in those who have an AD sibling is not related to greater prosocial behaviors.

Source: analysis carried out by the authors.

According to Lourenço et al., in Brazil, based on the description and analysis of an interview with seven sisters with siblings diagnosed with ASD, they found that living together becomes complex due to the emotional changes, hyperactivity, and aggressiveness characteristic of ASD. Although the participants describe the family dynamics as a harmonious space, they acknowledge the presence of changes in the relationships, especially with the mothers, as they become the primary caregivers, thereby limiting their interaction with other family members. Finally, the need for professional support aimed at all members of the family nucleus is highlighted, as failure to do so increases the possibilities of presenting psychological suffering (14).

Who takes on the role of caregiver for people with ASD?

Although the family is the primary caregiver for people with ASD, mothers are the main caregivers (15,16). A sample of 250 carers of people with ASD in different care centers in Spain shows that women carry the greater burden compared to men. Considering that women devote more time to caregiving, they reflect psychological discomfort, which ends up negatively affecting their mental health (16). On the same continent, specifically in the United Kingdom, through a qualitative study with a sample of eight pairs of parents and siblings of people with ASD, it was demonstrated that there is an effect on the well-being of the family when being responsible for the care of the person with ASD. At the same time, neurotypical siblings assume and recognize their role as members of the family (10), aspects that become predictors of psychological distress.

It is observed that the majority of caregivers of people with ASD are women, according to a study conducted in Uruguay (17), where parental distress characterized by dysfunctional interaction between parents and children was found. This stress is higher when the person with autism presents severe disability and is less complex when they present with mild or moderate disability. Primary caregivers experience higher levels of stress due to limitations in learning, communicating, and relating to people with ASD because of their emotions, behaviors, thoughts, and feelings.

The degree of dependency also plays an important role when talking about the experiences of families with autism, and especially of their primary caregivers, where mothers usually assume this role. Vázquez and Rosas (15), through a quantitative, analytical, observational and cross-sectional study using a convenience sample of 219 main caregivers of people with autism, register that 96 % of them are mothers with a higher probability of suffering perceived overload (PCOS) in relation to the degree of independence of the person with ASD.

Mental health impact on families and caregivers with ASD

Changes in family dynamics, difficulties in different areas of life, and the perception of the many changes that arise in response to the care required by people with ASD can lead to psychological distress, directly affecting mental health. The World Health Organization (WHO) (18) defines mental health as a mental state of well-being in which the human being has the opportunity to develop personally, socially, and in the community, as well as economically. It is not necessary to have a mental disorder or diagnosed illness to experience low levels of well-being; mental states related to distress also have significant effects on the mental health of families and caregivers of autistic people.

A systematic review carried out in Spain, which examined 44 studies published between 2009 and 2023 to find out the impact on the family of having a member with ASD (19), found the constant presence of: breakdowns in family functioning, weakening of relationships between couples that ended up generating separation and/or role substitution. As for the children, they tend to become confused and take on responsibilities for which they are not prepared, according to their individual life cycle. The mismanagement of these situations and the lack of guidance and education in the care of people with ASD allow conflicts to emerge that end up affecting the family and social environment. Psychological distress always appears after physical and mental exhaustion and social isolation, negatively affecting the mental health of family members and especially of the main caregiver.

Considering this problem, a study on the psychosocial impact of the diagnosis of autism spectrum disorder (ASD) on primary caregivers (20) delved into relating the variables associated with the diagnosis. Finally, it evaluated the following areas: socio-economic, socio-psychological, family functioning, and mental health status. The sample consisted of eight male and female primary caregivers of parental figures (father-mother; mother; grandparent) of children diagnosed with ASD. The results showed that the first person to be concerned about the child's changes was the mother, with 50 %. In the results, the most severely affected area was socio-psychological and family functioning. In contrast, the socioeconomic and mental health areas were found to be at moderate to high levels of development.

The importance of investigating the mental health of caregivers and families of people with ASD has led to narrating the experiences of parents. Montecino et al. (21) refer to the complexity of adaptation due to a lack of knowledge about the disorder and the areas involved that affect its functionality. Anxiety and emotional changes are feelings of fear that destabilize parents. They are part of the factors that influence the manifestation of irrational ideas associated with prejudice, stereotypes, stigmatization, bullying, and discrimination that their children could receive. A lack of training in techniques and strategies to regulate behavioral changes and satisfy desires, needs, or impulses can lead to frustration. In addition, they encountered professionals with no experience in dealing with the problem, which led to insecurity in the health service and dissatisfaction in rehabilitation, including the high costs of the service. Finally, parents opted for self-training and encouraged the extended family to acquire knowledge to opt for the use of tools that favor the development of the person with ASD in the personal, family, educational, social, community, communicative and behavioral areas, which generated a significant impact on the assimilation, acceptance and awareness of ASD.

In terms of parental well-being, this population is characterized by being susceptible to suffering stress, where hopeless thoughts play an important role in the sense of security and protection that they provide to the person with ASD, in relation to the availability of necessary resources at an economic, personal, and professional level. Among the clinically relevant manifestations is emotional distress, leading to a feeling of insecurity in handling the responsibility they exercise as parents (22,23).

A recent study conducted in Istanbul, focusing on the challenges of families with people diagnosed with autism, found that parents, especially, face serious mental health problems in Turkey due to family disputes, social discrimination, and economic issues. Among the possible causes of the difficulties they face is social exclusion, which, when combined with criticism, leads to alienation from their communities (24).

Studies carried out in Europe on coping, stress, and quality of life of primary caregivers of people with ASD show chronically high levels of parental stress. Through an analysis of 50 caregivers of people with ASD between the ages of 2 and 35, it was possible to determine that parental stress is statistically reflected in 82 % of cases, an aspect that influences quality of life, especially in psychological, social, and environmental areas. These data allow us to determine that the main caregivers are the most affected. Among the factors that probably determine these significant clinical manifestations is the coping capacity implemented especially by the main caregivers, with social support and positive reappraisal being adaptive strategies, which end up becoming protective factors for mental health, while strategies such as emotional avoidance and aggression become risk factors that negatively impact quality of life, especially at a social, environmental and psychological level. Finally, it is determined that the life cycle of people with ASD is not associated with these results (22).

Overload as a psychological state and therefore an important aspect when addressing the mental health of caregivers of people with autism, according to a non-experimental quantitative investigation composed of 40 family members, resulted in a 92.5 % overload in primary caregivers, where 82.5 % turn out to be female, mostly housewives, therefore, mothers are usually the ones who assume the role of caring not only for household chores but also for the person diagnosed with ASD, statistics that associate the greatest morbidity and mortality for the caregiver (25).

From Colombia, Parada et al. (26), in 2021, managed to conclude that parents of people diagnosed with autism experience parental stress due to the complex situations they must face, changes in family dynamics, and social interactions. The poor management of sadness, anger, and frustration ends up significantly affecting the mental health of this population.

In the African continent, particularly in Ghana, through an exploratory study of a qualitative nature and with a sample of 10 caregivers (biological mothers), it is identified that they face various challenges at a social, financial, emotional and medical care level, all of this in relation to their obligations to be able to provide the necessary care for their children with ASD. A new challenge mentioned in this study is education and training. The result of the interaction of these challenges becomes real barriers to opportunities for social interaction and ultimately becomes a risk factor for the quality of life and mental health of families, caregivers, and the person with autism (27). A second study was conducted in the same geographical location, using 20 caregivers as the sample. The results of this study support the existence of psychological stress, social isolation, and financial difficulties that impact the mental health of those who perform the role of caregiver (28).

In a study carried out in Cuba, it was found that at the level of mental health, the dimensions of quality of life that are most destabilized correspond to physical and emotional symptoms. Physical appearance is also affected by the caregivers of people with ASD. The aforementioned factors make it difficult for these individuals to achieve the goals set in their life projects, compounded by the lack of space to rest and social isolation (29).

In Chile, a comparative study of the reaction that people exert when observing their brother with ASD, (30) shows that they have greater capacity only in cognitive empathy, specifically in the fantasy subcategory that is characterized by having values of social cohesion and inclusion, so having a brother with ASD favors social adaptation, allows the development of soft skills and prosocial behaviors. On the contrary, in the association of empathy and depression, siblings present depressive traits due to risk factors in daily life, challenges, and environments that generate stress and anxiety.

DISCUSSION

Regarding mental health, the findings of the present review agree that the mental health of families and caregivers of people with a diagnosis of the autism spectrum suffer changes at a personal, family, and social level, leading to psychological discomfort evidenced by clinically significant symptoms.

Different studies carried out in several Latin American countries (12,14,16,24) identified negative effects on the mental health of families and caregivers of people with ASD. Among the significant symptoms are mood changes, which lead them to experience feelings of sadness, anxiety, frustration, and confusion. Although there is diversity in the makeup of families, studies show that mothers are mostly the main caregivers (17-18).

Vázquez and Rosas (15), when analyzing a convenience sample of 219 primary caregivers of people with ASD, confirm once again that mothers are usually 96 % of the ones who assume these functions and that the perceived overload is related to the degree of independence of the person with ASD. The level of autism and comorbidity with some type of disability increases the level of complexity in care management. The degrees of stress increase drastically when autism presents severe disability and are less complex when it is accompanied by mild or moderate disability (7,31-34).

Siblings are also part of the family nucleus. Therefore, they assume some type of responsibility in caring for people with ASD. When assuming these responsibilities, they also tend to present stress and anxiety (12). In the worst case, parents transfer this responsibility to their children without considering the life cycle in which they find themselves.

In parallel, these results correlate with studies carried out in Europe, Asia, and Africa (15,18-22), where it was possible to verify, through the analysis of neurotypical parents and siblings, the effects of psychological discomfort due to the overload produced by caring for people diagnosed with ASD.

CONCLUSION

The mental health of the families and caregivers of people diagnosed with ASD are affected depending on the level of autism, and the clinically significant symptoms increase when they present with some disability depending on their level of complexity. In 90 % of cases, mothers typically assume the role of primary caregiver, and it is observed how family dynamics change after the diagnosis is learned.

Among the clinically significant symptoms are psychological discomfort, anxiety, feelings of sadness, and frustration, leading to isolation. Social stigma also plays a significant role in shaping the perception of the caregiver role and satisfaction with the support received from those around them.

The mental health effects of families and caregivers must be further studied since the studies are limited and often focus on people diagnosed with autism, leaving aside the suffering and discomfort experienced by families and caregivers.

Expression of gratitude

Special mention to the psychology program of the Fundación Universitaria del Área Andina, located in Valledupar, Cesar headquarters. They are a source of inspiration.

REFERENCES

1. Alcalá Gustavo C, Ochoa Madrigal MG. Trastorno del espectro autista (TEA). Rev Fac Med. (Méx.) 2022;65(1):7-20.
2. Carranza-Valdez GE, Acevedo-Alemán J. Trastorno del Espectro Autista y el impacto que se tiene en la dinámica familiar. Intervención del Trabajo Social. Prospectiva. 2025;39:e20213812.
3. Asociación Americana de Psiquiatría. Guía de consulta de los criterios diagnósticos del DSM5. Arlington, VA. 2014.
4. Martín del Valle F, García A, Losada del Pozo R. Trastornos del espectro del autismo. Protocolos diagnósticos y terapéuticos en Pediatría. 2022;1:75-83.
5. Ruggieri V. Autismo y camuflaje. Medicina (Buenos aires). 2024;84(1):37-42.
6. Hervás A. Género femenino y autismo: infra detección y mis diagnósticos. Medicina (Buenos Aires) 2022;82(1):37-42.
7. National Institute on Deafness and other Communication Disorders. Trastornos del espectro autista: Problemas de comunicación en los niños. https://www.nidcd.nih.gov/es/espanol/problemas-de-comunicacion-en-los-ninos-con-trastornos-del-espectro-autista
8. Reyes J, Noguera D, Torres J, Solís F. Vivencia familiar de los hermanos de niños diagnosticados con Trastornos del Espectro Autista. Estelí, Nicaragua. Rev Científ FAREM-Estelí. 2021;10(39):21-43.
9. Cabello Plan S. Autismo en los medios de comunicación: una aproximación a la perspectiva de las familias. Quaderns de Psicología. 2024;26(2):1-18.
10. Critchley E, Cuadros M, Harper I, Smith-Howell H, Rogish M. A parent-sibling dyadic interview to explore how an individual with Autism Spectrum Disorder can impact family dynamics. Res Develop Disab. 2021;111
11. Imperatore E, Nurith K, Gallegos S, Mella S, Riquelme V, Sepúlveda R. Experiencias de familias con niños en el espectro del autismo. Rev Chil Ter Ocup. 2020;20(2):73-84.
12. Amariles Villegas WA, Henao Saldarriaga LI. Narrativas de transformación de dinámicas familiares asociadas a la presencia del diagnóstico de TEA en uno de sus miembros. Horiz Pedag. 2021;23(1):p.1-14.
13. Reyes J, Noguera D, Torres J, Solís F. Vivencia familiar de los hermanos de niños diagnosticados con Trastornos del Espectro Autista. Estelí, Nicaragua. Rev Científ FAREM-Estelí. 2021;10(39):21-43.
14. Lourenço D, Honorato M, Melão R, Oliveira A. Ser hermana de una persona con trastornos del espectro autista. Rev Familia, Ciclos de Vida e Saúde no Contexto Social. 2020;8(1):1-11.
15. Vásquez L, Rosas F. La independencia de niños con trastorno del espectro autista y su relación con la sobrecarga de cuidador. Rev Psicol Univer Autón Edo Méx. 2022;12(29):10-39.
16. Herrero R, Díaz A, Zueco J. The Burden and Psychological Distress of Family Caregivers of

Individuals with Autism Spectrum Disorder: A Gender Approach. J Clin Med. 2024;13(10):1-12.

17. Bagnato M, Hontou C, Barbosa E, Gadea S. Estrés parental, depresión y calidad de vida familiar en cuidadores principales de personas con TEA. Rev Esp Discap (REDIS). 2023;11(2):149-164.
18. Organización Mundial de la Salud. Salud mental: fortalecer nuestra respuesta. https://www.who.int/es/news-room/fact-sheets/detail/mental-health-strengthening-our-response. accedido el 5 de febrero de 2025.
19. Lavado S, Muñoz A. Impacto en la familia del diagnóstico de Trastorno del espectro del autismo (TEA) en un hijo/a: una revisión sistemática. Análisis y Modificación de Conductas. 2023;49(180):3-53.
20. Abadia P, Torres V. Impacto psicosocial del diagnóstico del trastorno del espectro autista (TEA) en los principales cuidadores. Investig Pensam Crít. 2019;7(1):22-39.
21. Montecino C, Arraigada F, Espinoza G, Geoffroy P, Hertel B, Paredes K, et al. Experiencias de padres/madres al cuidado de niños de 5 a 10 años con trastorno del espectro autista. Rev Chil Enferm. 2021;3(1):1-20.
22. Durán M, García M, Fernández J, Sanjurjo B. Afrontamiento, estrés parental y calidad de vida de los cuidadores principales de personas TEA. Rev Estud Invest Psicol Educ. 2016;3(1):60-68.
23. Ramiro S. Estudio de la carga de enfermedad en familiares de personas con TEA. [Master]. Salamanca: Universidad de Salamanca; 2018:33.
24. Rfat M, Koçak O, Uzun B. Parenting Challenges in Families of Children with a diagnosis of autism spectrum disorder: A qualitative research study in Istanbul. Global Social Welfare. 2023.
25. Ríos Martínez H, Votte Hernández A, Peña López M, Salazar Mendoza J, Cabrera Martínez M, Alvarado Escobar L. Sobrecarga en cuidadores primarios de familiares con trastorno del espectro autista. Cienc Latina Rev Científ Multidisc. 2022;6(6):4669-4686.
26. Parada L, Torres L, Guedes P. Percepciones y Estrategias de Afrontamiento en Padres de Personas con Diagnóstico de Trastorno del Espectro Autista en Colombia. [Proyecto de Grado]. Arauca-Arauca: Universidad Cooperativa de Colombia; 2021:124.
27. Appah J, Senoo-Dogbey V, Armah D, Adwoa D, Akorfa L. A qualitative enquiry into the challenging roles of caregivers caring for children with autism spectrum disorders in Ghana. J Pediat Nurs. 2024;76:23-29.
28. Ofori J. Caring for autism in Ghana: Exploring the psychological impact and coping strategies of caregivers. Cogent Education. 2024;11(1):1-18.
29. Pérez M, Pérez L, Henríquez C. Dimensiones de la calidad de vida más frecuentemente afectadas en cuidadores primarios de pacientes con trastorno del espectro autista. Acta Méd Centro. 2020;14(3):1-7.
30. Zúñiga J, Mellado C, Zapata A, Hernández P, Plass M. Estudio Comparativo: Empatía en Hermanos de Personas en el Espectro Autista. Psykhe (Santiago). 2023;32(1):1-14.