

Psychosocial Adaptation in Parents of Children Diagnosed with Autism Spectrum Disorder

Rayzza Uzátegui-Gamarra  & Eli Malvaceda-Espinoza* 

Universidad San Ignacio de Loyola, Lima, Perú

ABSTRACT – The objective of this study was to describe the experiences of psychosocial adaptation in parents of children diagnosed with autism spectrum disorder. A qualitative study of the phenomenological design was conducted using in-depth semi-structured interviews with 12 participants. The results illustrate that psychosocial adaptation can be explained through categories such as stressors, support received, perception of the situation, expectations developed, and strategies used to handle the situation. In conclusion, adaptation involves experiencing feelings of guilt, sadness, frustration, and anger, among others; however, this is followed by acceptance, seeking to provide the child with skills, thereby improving their social adjustment. Perceived support from family and spouses is identified as substantial.

KEYWORDS: Family adaptation, Autism Spectrum Disorder, Diagnosis, Qualitative research, Family.

Adaptación Psicosocial en Padres de Hijos Diagnosticados con Trastorno del Espectro Autista

RESUMEN – El objetivo de este estudio fue describir la experiencia de adaptación psicosocial en padres de hijos diagnosticados con trastorno del espectro autista. Se realizó una investigación cualitativa de diseño fenomenológico, haciendo uso de la entrevista semiestructurada en profundidad a 12 participantes. Los resultados ilustran que la adaptación psicosocial se explica a través de categorías tales como, factor estresante, apoyo recibido, la percepción de la situación, las expectativas desarrolladas y las estrategias utilizadas para manejar la situación. Se concluye que la adaptación implica experimentar sentimientos de culpa, tristeza, frustración, enojo, entre otros, sin embargo, posteriormente se logra la aceptación, buscando dotar de habilidades al hijo, mejorando su ajuste social. Se identifica al apoyo percibido de la familia y cónyuge como sustancial.

PALABRAS CLAVE: adaptación familiar, trastorno espectro autista, diagnóstico, investigación cualitativa, familia.

One out of 160 children in the world has been diagnosed with Autism Spectrum Disorder (ASD), a condition that develops during the early years of life (World Health Organization, 2022). In Peru, according to the National Council for the Equality of Persons with Disabilities (Ministerio de la Mujer y Poblaciones Vulnerables, 2020) there are 7,058 people diagnosed with ASD. While many with ASD function without any severe difficulties, others do not, which leads to emotional struggles for the concerned families. Thus, although the birth of a child is a crucial life-changing moment when there is an ASD diagnosis, entire family dynamics change as they are not prepared to cope

with it; this also has repercussions on each member of the family (Guevara & Gonzalez, 2012).

ASD is defined as a developmental disorder that affects communication, language, and a person's ability to communicate and engage with others (American Psychiatric Association, 2013). Likewise, aspects such as identifying behaviors, the age at which they are detected, and their severity should also be considered (Sumalavia-Casuso, 2019). A situation that tends to increase stress in parents is ignorance of specific parenting styles and problems in managing a child's behavior. As Bonis (2016) pointed out, many factors influence parents' actions, such as early

* E-mail: emalvaceda@usil.edu.pe

■ Submetido: 22/02/2021; Aceito: 18/03/2022

diagnosis which will generally allow for more preparation. Similarly, Miranda et al. (2019) noted that aspects such as behavioral problems influence stress for parents, as well as the severity of the diagnosis and that these problems are linked to the perception and support they receive. Besides, there is uncertainty (Uljarevic et al., 2016), prejudices regarding the diagnosis, negative impact on the family, and tension between the parents, along with the fact that it is likely that, if there are more children, they will require attention and support too (Corcoran et al., 2015). Concerning the above, evidence was found that shows that mothers of children with ASD experience higher levels of stress and anxiety than mothers of children diagnosed with some other conditions (Bonis, 2016; Krakovich et al., 2016; Miranda et al., 2019; Pozo, 2010; Zúñiga & Asturias, 2015).

Parents' process is complex because they never fully recover (Rabba et al., 2019). According to Aguilar-Villota et al. (2018), mothers go through a grieving process classified as "natural." They quickly adapt to the diagnosis, and their coping capacity is affected because they need to respond to the child's needs. Therefore, parents' psychosocial adaptation is an important process to study.

Psychosocial adaptation is a dynamic process in which a person responds in a certain way based on the context to ultimately regain control of the situation and their life (Barroilhet-Diez et al., 2005). In the present context, when parents receive the diagnosis, a very important change occurs in the family environment, affecting its dynamics. In addition to general care, there are increased financial constraints in providing aid to improve the skills and performance of the person with ASD; this is related to the overall context of the diagnosis, the severity of the diagnosis, and the personality of the parents (Albarracín et al., 2014; Bohórquez et al., 2008; Pozo, 2010; Rogge & Jansen, 2019). Hence, a child with a disability can destabilize the family dynamics, leading to changes in all areas and priorities (Grau & Espada, 2012).

Therefore, family support is relevant, starting from the identification of signs of a developmental issue, as well as post-diagnosis, when it generates a change in the parent-child relationship wherein parents would have to adjust their expectations from the child (Drogomyretska et al., 2020). According to Ekas et al. (2015), optimism, which refers to positively stated expectations about the future of the family, and the search for emotional support between a mother and

a father are aspects that could strengthen that transitioning relationship. Similarly, the partnership between parents and people outside the family, such as teachers, is beneficial in reducing stress levels in parents and serves as a support tool for the child's development (Dardas & Ahmad, 2015; Krakovich et al., 2016; Magaña et al., 2017).

Other studies (Colic et al., 2019; Hesamzadeh et al., 2015; Paynter et al., 2013; Pozo, 2010; Sumalavia-Casuso, 2019) sought to explain how a diagnosis of ASD impacts parents, using the Double ABCX Model of McCubbin et al., (1983) to analyze family adaptation, based on four factors. Factor aA refers to a stressor, which triggers instability in the family environment. Colic et al. (2019) pointed out that parents with children with ASD respond to the demands of the stressor (diagnosis), facing challenges at the personal and family level to regulate it using internal and external resources; this facilitates their adaptation. There is also factor bB—support—which reflects the resources of the family system before diagnosis and represents the qualities of the members and the supportive social circle (Rubio, 2015). Factor cC indicates how a family perceives and interprets the problem and how they evaluate the stressor and the meaning they give to it. Finally, factor xX represents the strategies used to facilitate the adjustment process, this is related to a family's efforts to manage the demands. In the majority of cases, the starting point is an inadequate adaptation until they finally manage to adapt (Fachado et al., 2013; Vera et al., 2010).

This model is used to analyze the changes related to the diagnosis since they affect parents and other family members. If the family system shows difficulties, it will affect the development of the child with ASD, demonstrating challenging behaviors as a result of coalitions that can present parents added to the mismanagement of resources (Paynter et al., 2013). According to the above, the objective is to describe the experience of psychosocial adaptation in parents of children diagnosed with ASD, after learning about the diagnosis. The study adopts a qualitative approach with a hermeneutical phenomenological design, which refers to the fact that, through the discourses provided by the parents, an attempt will be made to examine and detail the subjective and significant experiences that the participants have concerning this object of study (Creswell & Poth, 2018).

METHOD

Participants

Twelve people participated, including both parents of the children diagnosed with ASD. The participant selection was intentional, with a homogeneous and select group of people who met certain characteristics (Robinson, 2014). The inclusion criteria were as follows: the child had been diagnosed with

ASD by a medical specialist, was between 7 and 17 years old, and resided in the city of Lima. The convenience method was used for participant selection due to the difficulties in accessing the required sample. Also, the participants were contacted on social networking platforms through a group of parents who have children with ASD. The interviews were conducted between the months of April and May 2020.

The participants had the following characteristics: 10 were women and 2 were men, and their ages range between 35 and 55 years, with an average of 45 years. 83% indicate homemaker as an occupation. Half of the participants have completed high school, while the rest are evenly divided between those with technical and university degrees. 75% of the participants were married. The average number of children

they have is two. Also, the average age of their children with ASD at the time of the interviews was 12 years old. Finally, 50% of participants come from districts located in the quartiles of poverty and monetary poverty (quartiles 1 and 2), while the rest are located in the middle and high-income districts (quartiles 3 and 4) within metropolitan Lima (National Institute of Statistics and Informatics, 2020) (Table 1).

Table 1
Distribution of participants

Pseudonym	Age	Occupation	Education level	Marital status	Number of children	Child's current age	Monetary poverty quartile
Guadalupe	40	Head of household	Secondary school	Married	2	8 years old	2
Carla	47	Initial assistant	Technical	Divorced	3	15 years old	3
Mía	40	Head of household	Secondary school	Married	3	10 years old	3
Fernanda	40	Head of household	University	Married	2	17 years old	4
Ana	35	Head of household	Technical	Married	1	7 years old	2
María	36	Head of household	Secondary school	Married	2	7 years old	3
Pedro	50	Head of household	Secondary school	Married	1	12 years old	2
Mauricio	55	<i>Freelancer</i>	University	Married	2	14 years old	1
Paula	54	Head of household	University	Divorced	1	17 years old	4
Sonia	40	Head of household	Secondary school	Widow	2	15 years old	3
Berta	48	Head of household	Secondary school	Married	3	12 and 13 years old	2
Jenny	49	Head of household	Technical	Married	5	11 years old	2

Data collection instrument

The instrument used for this study was the semi-structured in-depth interview (Brinkmann, 2013), there was a guide of basic questions for all the interviews, with the option to re-question or further in-depth in a particular way with each parent, if necessary. A categorization matrix was also developed (Elo et al., 2014) and the Double ABCX Model of Family Adaptation was used (McCubbin et al., 1983). Based on this, an interview guide was prepared with guiding questions that were reviewed by the expert judges, obtaining

adequate agreement for its use. A pilot interview was also used to verify the structure of the interview (Martínez, 2004), which led to certain questions being rephrased (in the areas of perception and strategies), to develop a more fluid interview format. Following the above, the interview guide was modified, finding the questions suitable for application and aiming for fluid communication that would allow for in-depth information to be gathered (Table 2).

The field notes generated during the interviews were also considered. They included what corresponded to the non-verbal language from the participants as well as paralinguistic elements and impressions during the interview process.

Table 2
Guiding questions regarding the psychosocial adaptation of parents of children diagnosed with ASD

Guiding categories	Examples of interview questions
Stressor	Before diagnosis, what did you know about autism spectrum disorder?
	What were the behaviors that caught your attention and caused you to take your child to a specialist?
Social support	What kind of changes emerged in the family dynamics?
	How have your friends reacted to the diagnosis?
Perception	How did you feel when you noticed the first signs?
	What kind of help do you think you needed?
Strategies	After the diagnosis, did you seek any kind of guidance for yourself?
	How have you handled it?

Procedure and data analysis

To conduct this study, the ethical criteria outlined in the Declaration of Helsinki were considered. First, a group of parents with children diagnosed with ASD was contacted via social networks. Next, the purpose of the study was explained to them and, subsequently, those who agreed and signed the informed consent were interviewed through video calls. It is worth mentioning that only one session was held with each of the participants. Each interview lasted approximately 40 minutes and was performed by the main author of the study, and pseudonyms provided by the interviewees were used in the analysis. After the data was collected, they were transcribed literally and later returned to the participants so that they could provide feedback, thereby contributing to the accuracy of the study (Mertens, 2015).

A thematic content analysis was conducted, using a hybrid coding approach, both inductive and deductive

(Fereday & Muir-Cochrane, 2006; Swains, 2018), which was supplemented as outlined by Braun and Clarke (2013). In this sense, the stages after the analysis were as follows: construction of an initial codebook, familiarization with data by transcribing the interviews, a test of the relevance of the initial codes, code generation considering the specific characteristics found in the interviews and codebook application, followed by a search for themes by comparing categories and codes, thematic review, where constant patterns in the interviews were analyzed and finally, report preparation (Braun & Clarke, 2013; Fereday & Muir-Cochrane, 2006;). The authors of this study participated in the coding and were in charge of the evaluation of its consensus. The process was carried out with the ATLAS.ti 7.5 software. As tactics to generate meaning, we searched for patterns or representativeness in the interviews, as well as for the frequencies and density (relationships) of the codes (Miles et al., 2014).

RESULTS AND DISCUSSION

Based on the analysis, five categories were found concerning the psychosocial adaptation process in parents of children diagnosed with ASD (Table 3).

The first category found is a *stressor*, which refers to a new situation that arises and generates stress and imbalance both at the emotional and family levels. It is made up of *knowledge of the subject* before diagnosis in which most of the interviewed parents did not know what ASD was; therefore, they showed difficulties in understanding what was happening with their child, leading to an adaptive transition toward it, which is consistent with that mentioned in various extant studies. Sumalavia-Casuso (2019) and Zúñiga and Asturias (2015) mention that failing to understand what is happening with their child generates high levels of stress. "I thought, why me? I was pretty shocked to understand the situation and deal with it; one year I even forgot that I had a husband and children" (Jenny, 49 years old).

Furthermore, in terms of *recognizing the situation*, the parents, despite noticing behaviors that are not in line with what was expected in their child's development, were struggling since they were intrigued and anguished due to not knowing how to act initially when faced with this new situation- This is consistent with that pointed out by Krakovich et al. (2016), Bonis (2016) and Miranda et al. (2019), who point out that most parents show high levels of stress in the first years of diagnosis due to the specific care they require and their ignorance of how to address their child's behavior.

My son used to do flapping; since he was born, he had these stereotypical movements, he could not sleep well either; he had always dealt with sleep problems. There were also times when his behavior changed and he used to bite; he lost his speech, besides a series of things that if you put him next to a regular child, you realized that they were completely different (Fernanda, 40 years old).

Table 3
Categories and subcategories created

Categories	Subcategories
Stressor	Knowledge of the subject
	Recognizing the situation
Support received	Family and spousal support
	Social support
Perception	Self-analysis
	Changes in family dynamics
	Changes on a personal level
Expectations	Prejudices
	Realistic (Level of severity of the diagnosis)
Strategies	Seeking support
	Sense of belonging
	Taking control
	Situational adjustment

According to the above, both knowledge of the subject, as well as recognizing the situation, lead to understanding and managing the stress generated both at an emotional (personal) and family level in different ways. Both have been pointed out by several authors (Bonis, 2016; Krakovich et al., 2016; Miranda et al., 2019; Sumalavia-Casuso, 2019; Zúñiga & Asturias, 2015;) who indicate that parents take time to adapt during the early years and when managing difficult behavior-related situations.

The second category — *support received* — encompasses the human resources that provide support to the person, including *family support*, where the relationship with the parent of the child and other children, if any, is mentioned. At this point, most of the mothers stated that their husbands found it difficult to accept their child's diagnosis, which coincides with what Aguilar-Villota et al. (2017) indicated; in this sense, it refers to the fact that mothers “adapted” more quickly as they were the main caregivers of their children. This particular aspect reflects the position and traditional roles assumed by mothers, who primarily refer to themselves as the individuals responsible for the home. This explains their rapid adaptation, unlike fathers. “We had to change everything; I had to dedicate myself 100% to D because before it was the three of them. I left home early and did not get back until late; I did not see my other children” (Carla, 41 years old).

In line with the above, the support received from a spouse is important because it facilitates adaptation to the situation, which is reflected in the study conducted by Krakovich et al. (2016) and Sumalavia-Casuso (2019) who emphasize the support from their partner, as both are responsible for the child's education and care, thus requiring much more time and attention. “A lot of support from both my husband and my eldest daughter, I feel really supported [...] we have always been with them and, above all, support each other in the therapies; for me, that's what helped us the most” (Berta, 42 years old).

However, there is the *social support* received by the parents' friends and external family (who do not live with them). With this type of support, the importance of social support provided by external family members is clear. As mentioned by the parents, they usually give up their social life and focus on the child, so the few friendships they maintain are of great importance. “As parents, in social terms, we may not be able to go out with friends; we can't have fun just like everyone else, because it's more arduous to care for them” (Guadalupe, 40 years old).

The third category considered is *perception*, which refers to how the new situation is processed and interpreted. This in turn includes *self-analysis* in which both the feelings and actions taken in response to the diagnosis are analyzed. In this regard, parents report going through a “natural grieving process” after their child's diagnosis, as mentioned in the research by Aguilar-Villota et al. (2017). At this point, mothers indicate that they recover sooner than fathers, as they tend to be more involved in parenting. “You feel like your dreams fade away. My wife and I broke down, especially because he is our only son and we had many dreams and ideas [...] it is a battle, as they say; it lasted about 15 days” (Pedro, 50 years old).

The former is linked to *changes in family dynamics* that encompass the process of transformation that the family experienced both at personal, social, and family levels since they have to modify their routines according to the child's needs. In this sense, the participants indicate that their routine had to become adjusted to their child's routine, changing their professional and social lifestyle. In this regard, parents initially experienced feelings of sadness, confusion, and frustration linked to expectations about their child and family, since many households suffer changes in family dynamics that end up affecting them (Aguilar-Villota et al., 2018; Albarracín et al., 2014; Pozo, 2010; Zúñiga & Asturias, 2015). “My husband took it better than me; he had to, because I felt bad and I needed to be strong to be able to

keep my body and soul together. Not once did he collapse in front of me” (Guadalupe, 40 years old).

On the other side are *expectations*, which refer to the ideas about children and their families. These can be based on *prejudices* or be *realistic*. Due to not having enough information initially, parents often do not think about the fact that, with therapies and early intervention, their children can improve.

Regarding the expectations based on realistic elements, the parents mentioned that their hopes also depend on the degree of severity of the diagnosis. Thus, in the case of the participants, their children were diagnosed at an average age of four to five years old, which allowed them to have higher expectations for their children. Although the ultimate goal is the same—to provide them with skills so they can better adapt to the world and try to be independent within their capabilities — this is consistent with that indicated by Sumalavia-Casuso (2019) and Ekas et al. (2015).

I knew it was for life; at that time, there was no talk of early intervention like now. If he had had everything there is now... I expected to get as much as I can out of him so that he can be a little bit more independent than what I saw since his affectation is quite deep or moderate (Paula, 52 years old).

In this regard, it is important to contextualize this result, indicating that these expectations also depend on their economic capacity, since their stimulation with more appropriate therapies depends on this factor.

We have been at the Ann Sullivan [treatment center] for 8 years. We were lucky enough to make the right decision and take our son there, although this was not financially overwhelming, we were sure that it was the best place we could access that we know about (Pedro, 50 years old).

Finally, in the *strategies* category, the efforts to face problems that exceed a person’s resources are considered. These include *searching for support*, which occurs when parents seek some type of counseling or therapy at the couple or family levels. As indicated in different studies (Dardas & Ahmad, 2015; Magaña et al., 2017; Pozo, 2010), seeking support from professionals provides greater peace of mind, just as handling information allows for better adaptation, helping to change their way of thinking and acting.

I also had psychological therapy and, well, the psychologist understood me well. She told me: “You can get more information here; you can visit this page. I recommend

that you read a lot because you will also have to help him with the therapies”. So, I did (Ana, 35 years old).

Whereas there is a *sense of belonging* to a social group where they identify with other parents who experience similar situations, and mothers tend to resort to groups on social networks to share their experiences. This aligns with that stated by Albarracín et al. (2014) who point out the tendency of parents to join a religion as a result of the diagnosis. “I follow Facebook pages like “I am autistic,” in addition to groups of mothers with children with autism in Miraflores. There is also a group where they told me that I could undergo therapies with other mothers out there, but it is very far from me” (Ana, 35 years old).

There is also *take control* of the new reality, based on activities or workshops around ASD, which allows them to feel more control over the situation. Having a lot of information allows parents to feel like it is no longer an unknown situation, helping them to know how to act or react to certain episodes: “I guide parents; we have done activities and take the children to the Mirabus. We mostly focus on the use of Facebook to guide and defend the rights of people with disabilities” (Fernanda, 40 years old).

Finally, there is the *situational adjustment* strategy, referring to the fact that most of the parents have adapted to their child’s diagnosis and, to do so, they have had to change their routines and lifestyles. “Let’s say... on a scale from 1 to 10, I am at a 7 or 8. I have already calmed down; I do not consider autism as a problem, I just see it like: “He is my son; he has the diagnosis; he is autistic; he is like that” (Guadalupe, 40 years old).

According to the above, the psychosocial adaptation of parents with children with ASD is associated with a process that entails various emotions such as fear, sadness, anger, frustration, resignation, and resilience, not always experienced in the same order, giving way to a series of actions carried out with the aim of more appropriately providing the society with skills. The stressor destabilizes the family dynamics due to misinformation, which is counteracted by the support received by the family. This helps them to adapt better, together with the economic factor that will allow them to take their child to different types of therapy, which is reflected in their development. On the other hand, parents tend to adopt strategies that are within their reach to facilitate adaptation, such as group and individual activities.

CONCLUSIONS

Evidence shows that the psychosocial adaptation of parents to their child’s ASD diagnosis leads to experiencing various emotions such as feelings of guilt, sadness, frustration, and anger, among others, until reaching acceptance, giving way to a series of actions taken to provide their child with

skills for greater adjustment to society, so that they can function as naturally as possible.

Although the initial situation, as a stressor, destabilizes the family dynamics due to the care provided to the child with ASD, causing uncertainty and intrigue as a result of

misinformation (severity of the diagnosis), the perceived family support is a substantial element that facilitates both individual and group adaptation. At this point, social networks are a fundamental part of this process since they ease that process.

One of the implications of the study is that it will serve as a reference for future research or as reference material for relevant professionals; also, other parents could turn to

scientific journals in search of reliable information. Finally, one of the limitations of this study was the small group of participants, in addition to the difficulty in accessing more fathers in the study sample, as they showed little willingness to participate. The findings of this study should be considered for similar contexts that allow us to better understand the process of psychosocial adaptation of parents concerning their children.

REFERENCES

- Aguilar-Villota, M., Heredia, J. Pesantez, C. & Villavicencio, C. (2018). Diferencias del duelo y afrontamiento de los padres de niños con trastornos del espectro autista [Differences in bereavement and coping from parents of children on the autism spectrum]. *Conference Proceedings UTMACH*, 2(2), 17 - 26. encr.pw/KktMR
- Albarracín, A., Hernández, L., & Jaimes, M. (2014) Estrategias de afrontamiento y características sociodemográficas en padres de hijos con trastornos del espectro autista [Coping strategies and sociodemographic characteristics in parents of children with autism spectrum disorders]. *Revista Virtual Universidad Católica del Norte*, (42), 111 - 126. 11nq.com/uj5pR
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed.). American Psychiatric Association.
- Barroilhet-Diez, S., Forjaz, M., & Garrido, E. (2005). Conceptos, teorías y factores psicosociales en la adaptación al cáncer [Concepts, theories, and psychosocial factors in adaptation to cancer]. *Actas Españolas de Psiquiatría*, 33(6), 390 - 397.
- Bohórquez, D., Alonso, R., Canal, R., Martín, M., García, P., Guisuraga, Z., Martínez, A., Herráez, M. & Herráez, L. (2008). *Un niño con autismo en la familia. Guía básica para familias que han recibido un diagnóstico de autismo para su hijo o hija* [A child with autism in the family. A basic guide for families who have received a diagnosis of autism for their son or daughter]. Publicaciones del INICIO
- Bonis, S. (2016). Stress and Parents of Children with Autism: A Review of Literature. *Issues Ment Health Nurs*, 37(3), 153–163. doi:10.3109/01612840.2015.1116030
- Braun, V., & Clarke, V. (2013). *Successful qualitative Research*. SAGE.
- Brinkmann, S. (2013) *Qualitative Interviewing. Understanding qualitative research*. New York: Oxford University Press.
- Colic, M., Dababnah, S., Garbarino, N. & Betz, G. (2019). Parental experiences raising children with autism spectrum disorder in Eastern Europe: a scoping review. *International Journal of Developmental Disabilities*. <https://doi.org/10.1080/20473869.2019.1688931>
- Corcoran, J., Berry, A., & Hill, S. (2015). The lived experience of US parents of children with autism spectrum disorders: A systematic review and meta-synthesis. *Journal of Intellectual Disabilities*, 19(4), 356–266. <https://pubmed.ncbi.nlm.nih.gov/25819433/>
- Creswell, J., y Poth, C. N. (2018). *Qualitative inquiry and Research design: Choosing among five approaches* (4th ed.). SAGE.
- Dardas, L., & Ahmad, M. (2015). Coping Strategies as Mediators and Moderators between Stress and Quality of Life among Parents of Children with Autistic Disorder. *Stress and Health*, 31, 5–12. doi: 10.1002/smi.2513
- Drogomyretska, K., Fox, R. & Colbert, D. (2020). Brief Report: Stress and Perceived Social Support in Parents of Children with ASD. *Journal of Autism and Developmental Disorders*, 50, 4176–4182. <https://doi.org/10.1007/s10803-020-04455-x>
- Ekas, N., Timmons, L., Pruitt, M., Ghilain, C. & Alessandri, M. (2015). The Power of Positivity: Predictors of Relationship Satisfaction for Parents of Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 45, 1997–2007. <https://doi.org/10.1007/s10803-015-2362-4>
- Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., y Kyngäs, H. (2014). Qualitative Content Analysis: A Focus on Trustworthiness. *SAGE Open*, 4(1), 1–10. <https://doi.org/10.1177/2158244014522633>
- Fachao, A., Menéndez, M. & González L. (2013). Apoyo social: Mecanismos y modelos de influencia sobre la enfermedad crónica [Social support: mechanisms and models of influence on the chronic disease]. *Cadernos de Atención Primaria*, 19, 118 - 123
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International journal of qualitative methods*, 5(1), 80-92. <https://doi.org/10.1177/160940690600500107>
- Guevara, Y., & González, E. (2012). Las familias ante la discapacidad [Families dealing with disability]. *Revista Electrónica de Psicología Iztacala*. 15(3), 1023–1050. encr.pw/z7jY5
- Grau, C. & Espada, M. (2012). Percepciones de los padres de niños enfermos de cáncer sobre los cambios en las relaciones familiares [Perceptions of parents of children with cancer on changes in family relationships]. *Psicooncología*, 9(1), 125 - 136. https://doi.org/10.5209/rev_PSIC.2012.v9.n1.39142
- Hesamzadeh, A., Dalvandi, A., Maddah, S., Khoshknab, M. & Ahmadi, F. (2015). Family Adaptation to Stroke: A Metasynthesis of Qualitative Research based on Double ABCX Model. *Asian Nursing Research*, 9(3), 177–184. <https://doi.org/10.1016/j.anr.2015.03.005>
- Krakovich, T., McGrew, Yue, Y. & Ruble L. (2016). Stress in Parents of Children with Autism Spectrum Disorder: An Exploration of Demands and Resources. *Journal of Autism and Developmental Disorders*, 46, 2042-2053. <https://doi.org/10.1007/s10803-016-2728-2>
- Magaña, S., López, K. & Machalicek, W. (2017). Parents taking action: a psycho-educational intervention for latino parents of children with autism spectrum disorder. *Family Process*, 56, 59-74. <https://doi.org/10.1111/famp.12169>
- Martínez, M. (2004) *Ciencia y Arte en la Metodología cualitativa* [Science and Art in Qualitative Methodology]. Trillas.
- McCubbin, H. I.; Olson, D. H. & Patterson, J. M. (1983) Beyond Family crisis: Family Adaptation. *International Journal of Mass Emergencies and Disasters*, 1(1): 73-94
- Mertens, D. (2015). *Research and evaluation in education and psychology: integrating diversity with quantitative, qualitative, and mixed methods*. SAGE.
- Miles, M., Huberman, M., & Saldaña, J. (2014). *Qualitative Data Analysis. A Methods Sourcebook* (3rd.). SAGE.

- Ministerio de la Mujer y Poblaciones Vulnerables (2020, April 02). Conadis realiza seguimiento al plan nacional de personas con Trastorno del Espectro Autista TEA para promover su inclusión social. encr.pw/1hg6a
- Miranda, A., Mira, A., Berenguer, C., Rosello, B. & Baixauli, I. (2019). Parenting stress in mothers of children with autism without intellectual disability. Mediation of behavioral problems and coping strategies. *Front. Psychol*, 10: 464 <https://doi.org/10.3389/fpsyg.2019.00464>
- National Institute of Statistics and Informatics. (2020). *Mapa de pobreza monetaria provincial y distrital 2018* [Provincial and district monetary poverty map 2018]. INEI.
- Paynter, J., Riley, E., Beamish, W., Davies, M., & Milford, T. (2013). The double ABCX model of family adaptation in families of a child with an autism spectrum disorder attending an Australian early intervention service. *Research in Autism Spectrum Disorders* 7(10), 1183–1195. <https://doi.org/10.1016/j.rasd.2013.07.006>
- Pozo, P. (2010). *Adaptación psicológica en madres y padres de personas con trastornos del espectro autista: un estudio multidimensional* [Psychological adjustment in mothers and fathers of people with autism spectrum disorders: a multidimensional study]. [Doctoral thesis, National University of Distance Education]. <http://e-spacio.uned.es/fez/view/tesisuned:Psicologia-Mppozo>
- Rabba, A.; Dissanayake, C. & Barbaro, J. (2019) Parents' experiences of an early autism diagnosis: Insights into their needs. *Research in Autism Spectrum Disorders*, 66. <https://doi.org/10.1016/j.rasd.2019.101415>
- Robinson, O. C. (2014). Sampling in Interview-Based Qualitative Research: A Theoretical and Practical Guide. *Qualitative Research in Psychology*, 11(1), 25–41. <https://doi.org/10.1080/14780887.2013.801543>
- Rogge, N. & Janssen, J. (2019) The Economic Costs of Autism Spectrum Disorder: A Literature Review. *Journal of Autism and Developmental Disorders*, 49, 2873–2900. <https://doi.org/10.1007/s10803-019-04014-z>
- Rubio, E. (2015) *La adaptación de las familias con hijos/as con síndrome de Down, una aproximación desde el Modelo Doble ABCX* [The adaptation of families with children with Down syndrome, an approach from the ABCX Dual Model]. [Doctoral thesis, Comillas Pontifical University]. Repositorio Comillas. <https://repositorio.comillas.edu/xmlui/handle/11531/6576>
- Sumalavia-Casuso, M. (2019). *Proceso de adaptación de padres y madres de hijos diagnosticados dentro del Trastorno del Espectro Autista* [Tesis de grado, Universidad Peruana de Ciencias Aplicadas]. <https://doi.org/10.19083/tesis/625079> (link quebrado) encr.pw/CtvH8
- Swain, J. (2018). A Hybrid Approach to Thematic Analysis in Qualitative Research: Using a Practical Example. In *SAGE Research Methods Cases*. <https://doi.org/10.4135/9781526435477>
- Uljarević, U., Carrington, S. & Leekam, S. (2016). Brief Report: Effects of Sensory Sensitivity and Intolerance of Uncertainty on Anxiety in Mothers of Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 46, 315-319. <https://doi.org/10.1007/s10803-015-2557-8>
- Unique Digital Platform of the Peruvian State (2020). *Conadis realiza seguimiento al plan nacional de personas con Trastorno del Espectro Autista TEA para promover su inclusión social* [Conadis follows up on the national plan for people with Autism Spectrum Disorder (ASD) to promote their social inclusion]. Retrieved from <https://www.gob.pe/institucion/mimp/noticias/111784-mimp-conadis-realiza-seguimiento-al-plan-nacional-de-personas-con-trastorno-del-espectro-autista-para-promover-su-inclusion-social>
- Vera, J., Barrientos, P. & Hurtado, M. (2011, November, 7-11). *Apoyo parental, cohesión y adaptabilidad: recursos familiares frente a la discapacidad* [Parental support, cohesion, and adaptability: family resources in the face of disability] [Conference Session]. XI National Conference on Educational Research. Mexico.
- World Health Organization (2022, March 30). *Autism spectrum disorder*. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>
- Zúñiga, A., & Asturias, A. (2015). El proceso de duelo en padres de niños autista [The grieving process in parents of autistic children]. [Graduate thesis, San Carlos de Guatemala University]. Repositorio USAC <http://www.repositorio.usac.edu.gt/id/eprint/4388>