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# Parental Grief and Coping Strategies in Parents of Children with Autism Spectrum Disorder

## Duelo parental y afrontamiento en madres y padres de infantes con trastorno del espectro autista

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**Abstract:**

This study analyzes the grieving experiences and coping strategies used by mothers and fathers of children diagnosed with autism spectrum disorder (ASD). A total of 19 parents (16 mothers and 3 fathers), whose children were between 3 and 7 years old, participated. The Texas Revised Inventory of Grief, the Parental Attitude toward Disability Questionnaire, the Coping Strategies Questionnaire (CAE) and semi-structured interviews were applied. Findings show a predominance of emotional reactions (grief) during the first year after diagnosis, with acceptance in later stages. The most frequently used coping strategies were problem-focused coping and positive reappraisal. The study concludes that psychoeducational programs are needed to promote adaptive coping and family well-being.

***Keywords:***

*Autism, Coping, Grief, Parents*

**Resumen:**

Este estudio analiza las experiencias de duelo y las estrategias de afrontamiento empleadas por madres y padres de niños diagnosticados con trastorno del espectro autista (TEA). Participaron 19 progenitores (16 madres y 3 padres) con hijos entre 3 y 7 años. Se aplicó el Inventario de Texas Revisado de Duelo, el Cuestionario sobre la Actitud Parental ante la Discapacidad, el Cuestionario de Afrontamiento del Estrés y entrevistas semiestructuradas. Los resultados muestran predominio en reacciones emocionales que indican la presencia de duelo durante el primer año tras el diagnóstico, y aceptación en etapas posteriores. Las estrategias de afrontamiento más frecuentes fueron la focalización en la resolución de problemas y la reevaluación positiva. Se concluye la necesidad de programas psicoeducativos para fomentar el afrontamiento adaptativo y el bienestar familiar.

***Palabras Clave**:*
*Afrontamiento, Autismo, Duelo, Padres*

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## INTRODUCTION

Approximately one in every 100 children receives a diagnosis of Autism Spectrum Disorder (ASD), the figure varies across studies and countries (World Health Organization, 2023). In the United States, for example, prevalence is reported at 80 cases per 10,000 children, ranking eighth worldwide, behind countries such as Qatar, Canada, and Colombia (Statista Research Department, 2022). In Latin America, precise epidemiological data are lacking, but prevalence is assumed to be similar to global estimates, given that autism is not determined by socioeconomic, cultural, or ethnic factors (Sputnik Mundo, 2020). In Mexico, there are also no official statistics; however, a study conducted by Autism Speaks and the Mexican Autism Clinic (CLIMA) estimated that one in every 115 children presents ASD (Teletón México, 2024).

ASD is defined by the WHO (2021) as a group of conditions characterized by alterations in social interaction, communication, and the presence of restricted and repetitive interests or behaviors. Its manifestations are heterogeneous: some individuals speak fluently, others rely on alternative communication systems; some have intellectual disability and require significant support, whereas others may lead independent lives (Autism Speaks, 2025). Currently, a social and scientific movement emphasizes that autism should not be understood as a disease or disorder, but rather as a condition within neurodiversity, conceptualized as a natural variation in neurological and cognitive functioning (Milton, 2012). This perspective seeks to reduce stigma and promote a deeper understanding of each person's needs and strengths.

The grieving process is understood as a set of phases in which an individual experiences disruptions to daily life following the loss of an object, event, condition, or significant person, leading to distress and intense emotional reactions. Among the various types of grief, ambiguous loss refers to situations in which no physical loss occurs; instead, the loss emerges from recognizing that a significant person will not be present in the daily life of the family or surrounding individuals with whom an emotional bond exists or is desired. As a result, there is no "closure" to the grieving process; rather, it involves ongoing changes depending on the circumstances (Boss, 2017).

An ASD diagnosis affects not only the child's life but also that of parents and relatives, who often experience a grieving process triggered by the loss of the idealized child. This grief is not associated with death but with the need to reconstruct expectations, which may evoke feelings of denial, anger, guilt, and hopelessness before reaching acceptance (Neimeyer, 2019; Worden, 2013). Worden distinguishes between adaptive grief, which allows progress toward resolution, and complicated or pathological grief, in which the individual remains trapped in maladaptive behaviors or prolonged suffering.

The way how parents navigate this process is closely linked to their coping strategies, understood as cognitive and behavioral efforts to manage stressful situations (Clínica Universidad de Navarra, 2020). Such strategies are dynamic responses aimed at adaptation; several may be used simultaneously, depending on how the stressful situation is perceived (Camacho et al., 2024), although not all strategies achieve this adaptive goal. Coping may be oriented toward problem solving, active emotional processing—considered more effective—or avoidant coping, which is generally less adaptive (Worden, 2013). Recent studies show that the use of adaptive resources, such as social support and positive reappraisal, is associated with greater psychological well-being among caregivers of children with ASD, whereas maladaptive strategies correlate with higher stress and lower quality of life (Durán et al., 2016; Romero et al., 2020). Fernández et al. (2016) reported the presence of active grief associated with denial, fear, guilt, anger, and sadness among mothers and fathers, identifying both mechanisms that facilitate grief resolution and obstacles linked to the developmental and social adaptation challenges faced by their children. Similar emotions were documented by Uzátegui-Gamarra and Malvaceda-Espinoza (2023) in the psychosocial adaptation process of parents navigating the complexities of raising children with ASD.

In Latin America and Mexico, literature on grief and coping among parents of children with ASD remains limited. Some studies describe negative emotions related to the lack of information and resources (Sumalavia, 2019), the protective and sacrificial role of mothers (Estrada-Quispe, 2020), or the resilience that emerges despite stigma and adversity (Reddy et al., 2019). More recently, Aguirre-Aguilar (2022) identified a direct relationship between parental stress and coping strategies among parents of children with ASD enrolled in a special education institution.

In this context, examining how parents experience grief and coping following the diagnosis and care of a child with ASD is crucial, because these processes directly influence family dynamics and the child's development (Higgings et al., 2022; Uzátegui-Gamarra & Malvaceda-Espinoza, 2023).

Given the investigations cited before, the objective of this study is to describe the principal emotional reactions and characteristics of the grieving process, and to identify the coping strategies used by parents when facing stressful situations associated with supporting a son or daughter with ASD who have attended the services of a child–youth neurodevelopment and learning psychology center in the city of Tepic, Nayarit, Mexico.

## METHODS

To reach the objective, a mixed-methods research design with a descriptive scope was employed, specifically a QUAL–quan sequential explanatory approach (Pereira, 2011). The qualitative phase enabled an exploration of parents' experiences and the meanings they attributed to them, whereas the quantitative phase

allowed for the objective measurement of the presence of active grief as well as coping strategies.

The sample consisted of 19 parents (16 mothers and 3 fathers) of children diagnosed with Autism Spectrum Disorder (ASD). Participants' ages ranged from 27 to 45 years (M = 34.2, SD = 5.8).

A non-probabilistic, purposeful convenience sampling strategy was used, as the study involved parents who regularly attended the selected center. Inclusion criteria were: being the parent of a minor with an ASD diagnosis confirmed by a specialist; being of legal age; and voluntarily agreeing to participate through informed consent. Parents who did not regularly attend the center or who had insufficient reading–writing skills to comprehend the psychometric instruments were excluded. Table 1 presents the sociodemographic characteristics of the participants.

**Table 1**
*Sociodemographic characteristics of the participants.*

| **Participants:** | N= 19 16 women (84%) 3 males (16%) | | | | |
|---|---|---|---|---|---|
| *Age:* | F | % | *Occupation:* | F | % |
| 25 a 30 | 3 | 15.7 | Home | 7 | 33.8 |
| 31 a 35 | 4 | 21 | Employed | 2 | 10.5 |
| 36 a 40 | 9 | 47.3 | Professional | 5 | 26.3 |
| 41 a 45 | 3 | 15.7 | Non-professional trades | 5 | 26.3 |
| *Age of child with ASD:* | | | *Marital Status* | | |
| 3 years | 5 | 26.3 | Single | 4 | 21.1 |
| 4 years | 6 | 31.6 | Married | 11 | 57.9 |
| 5 years | 3 | 15.8 | Common-law union | 3 | 15.8 |
| 6 years | 4 | 21.1 | | | |
| 7 years | 1 | 5.3 | | | |
| Religion: | | | | | |
| Catholic | 13 | 68.4 | | | |
| Christian | 2 | 10.5 | | | |
| Non-practicing | 3 | 15.7 | | | |
| No religion | 1 | 5.2 | | | |

Nota: Own elaboration. F= frequency

The sessions were conducted in a private office at the care center, under adequate lighting and ventilation, which ensured participants' comfort and confidentiality.

A semi-structured interview designed specifically for this study was used to explore the experiences and emotions of parents of children with ASD, as well as the adjustments made in their daily lives and the coping strategies they employed, for the qualitative phase. The open-ended questions were organized into the dimensions: sociodemographic background, reconciliation and support in caregiving, diagnostic process, initial adaptation, knowledge about ASD, concerns about the future, and coping strategies.

For the quantitative phase, the Texas Revised Inventory of Grief (TRIG; Faschingbauer, Zisook, & De Vaul, 1987) was used. This is a 21-item self-administered questionnaire with a 5-point Likert scale that assesses grief intensity through two subscales: (a) past feelings and (b) present feelings. The original version reports Cronbach's alpha reliability coefficients ranging from .75 to .86. The Spanish adaptation by García et al. (2005) demonstrated adequate factorial validity and internal consistency. In the Mexican population, Fernández-Ávalos et al. (2023) applied the scale to parents of neurodiverse children, confirming its sociocultural relevance and reporting satisfactory reliability coefficients ($\alpha > .80$). For the present study, the first eight items—comprising the past feelings subscale—used a cutoff score of 14 or higher to indicate the presence of grief, whereas a score of 23 or higher on the present feelings subscale (13 items) indicated prolonged grief, following the criteria used by Miranda (2020), given the sociocultural similarities of the population and the focus on parents of neurodiverse children.

Additionally, the "Parental Attitude Toward Disability" questionnaire developed by Fernández and Oliva (2012) was administered. This is a 19-item self-administered instrument with a 4-point Likert response format that identifies the adjustment stage in which parents find themselves regarding their child's disability: shock phase, reaction phase (rejection or overprotection), or adaptation phase. The original study reported Cronbach's alpha reliability of .782 and content validity established through expert review. The scale has demonstrated usefulness in subsequent studies with parents of children with disabilities in Mexico, confirming its consistency in identifying adjustment stages.

The Coping with Stress Questionnaire (CAE; Sandín & Chorot, 2003) was also used. It consists of 42 Likert-type items (0 = never to 4 = almost always) that assess seven coping styles: problem solving, negative self-focus, positive reappraisal, open emotional expression, avoidance, seeking social support, and religion. In the original validation, Cronbach's alpha coefficients ranged from .64 to .92 (mean = .79), supporting good reliability; the instrument was validated in Mexico by González and Landero (2007).

All participants signed an informed consent form—after reading it—which was developed in accordance with the General Health Law (Government of Mexico, 2014) and the ethical guidelines for psychological research established by the Ethical Code of Psychologists (APA, 2017). The form included an explanation of

the study objectives, voluntary participation, data confidentiality, and the participants' right to withdraw at any time.

Paper-and-pencil questionnaires and coded answer sheets were used for the quantitative phase instruments, along with a digital recorder for the interviews and a computer with IBM SPSS v.25 for descriptive statistical analysis. The interviews, which lasted approximately 45 to 60 minutes, were transcribed and analyzed through double-entry tables by dimensions, followed by content analysis.

Data collection occurred across two individual sessions: the first consisted of administering the semi-structured interview, and the second involved the application of the questionnaires.

## RESULTS

Regarding sociodemographic characteristics, it is noteworthy that the majority of participants were women (84.2%). In terms of family dynamics, it was observed that mothers were typically the primary caregivers for two reasons: firstly, because they directly assumed this role while their partners provided for the family's finances (n = 8; 67%), and secondly, because several children were raised by single mothers (n = 4; 33%). The majority were married (57.9%) and resided in Tepic (89.5%). Nearly half were between 36 and 40 years old (47.4%). Regarding religion, Catholicism predominated (68.4%). The total age of the participants ranged from 27 to 43 years, with varying levels of education and diverse occupations.

Presence/Absence of Current Grief

The data shows, on the Past Feelings subscale of the Texas Grief Inventory, that the item with the highest average score was item 2 ("After my son's diagnosis, I had trouble concentrating at work"), reflecting that the main impact on their life after receiving the diagnosis was in the workplace. The overall mean for the subscale was 21.0 (SD = 8.6), indicating a high level of past grief.

On the Present Feelings subscale, the highest-scoring item was item 13 ("Sometimes I'm overcome with the need for my son to be like other children"), showing a desire for normalization in their child's development. The overall mean for the instrument was 28.3 (SD = 13.5), suggesting that the grief persists in the present.

In terms of frequency, 15 parents (78.9%) showed indicators of grief in the past, and 11 participants (57.9%) in the present still experience emotions and feelings associated with unresolved grief (see Table 2).

**Table 2**

*Descriptive statistics of instruments used to identify the presence of grief, parental attitude and type of coping of parents of children with ASD*

| Instrument | Mean | Standard Deviation | F | % |
|---|---|---|---|---|
| Texas Revised Inventory of Grief | | | | |
| Past Grief | 21.05 | 8.66 | 15 | 78.94 |
| Present Grief | 28.36 | 13.56 | 11 | 57.89 |
| Disability Parental Attitude | | | | |
| Positive | 19.21 | 2.65 | 12 | 63.15 |
| Negative | 40.63 | 6.79 | 7 | 36.84 |
| Coping | | | | |
| Positive | 49.47 | 12.39 | 16 | 84.21 |
| Negative | 22.52 | 8.00 | 3 | 15.78 |

Regarding the Disability Parental Attitude, the item with the highest negative score answered with the "Strongly disagree" option was 18 ("I avoid being around other people when I am with my child because I feel ashamed"), which is associated with feelings of shame towards their children. Among the positive items, the "Strongly agree" option predominated, was 24 ("I maintain a positive and optimistic attitude towards my child's situation, in relation to their abilities and limitations"), with an overall mean of 40.6, indicating favorable adaptive attitudes.

For the adjustment phases, the majority of parents were in the adaptation stage (63.1%), followed by the shock stage (31.5%), and, to a lesser extent, the reaction stage (5.2%), which involves overprotective or rejecting behaviors. These last two stages are considered to be ongoing. However, the reaction stage is considered non-integrated, meaning there is difficulty in accepting the diagnosis and prognosis of their child. Table 3 reviews the frequency of the adjustment phase according to the age at which the diagnosis was made, finding that, in relation to the number of cases, mothers and fathers of infants between 2 and 3 years of age received the news of the diagnosis with greater distress and even emotional shock, and in all cases they are gradually using strategies to achieve adaptation.

**Table 3**

*Attitudinal adjustment and reaction of parents according to the child's age at diagnosis.*

| Age | 0-1 year old | | 2-3 years old | | 4-6 years old | |
|---|---|---|---|---|---|---|
| *Phase of Adjustment* | Fr | % | Fr | % | Fr | % |
| Shock | - | - | 3 | 15.7 | 3 | 15.7 |
| Reaction | - | - | - | - | 1 | 05.2 |
| Adaptation | 1 | 05.2 | 4 | 21.0 | 7 | 36.8 |

| Age | 0-1 year old | | 2-3 years old | | 4-6 years old | |
|---|---|---|---|---|---|---|
| Total: | 1 | 05.2 | 7 | 36.8 | 11 | 57.8 |

*Coping with Stress Questionnaire (CSQ) Results*

Among the negative items, the one with the highest score was item 39 ("I struggled and vented by expressing my feelings"), reflecting intense emotional expressions. In contrast, item 36 ("I carefully considered the steps to take to address the problem") had the highest score for positive coping, demonstrating planning and problem-solving skills.

***The*** mean score for negative strategies was 22.5, while for positive strategies it reached 49.4, indicating a predominance of adaptive coping. In terms of frequency, 16 parents (84.2%) primarily used positive strategies, and 3 (15.8%) used negative strategies (see Table 4***).***

**Table 4.**

*Copping Styles (CS) Prevailing in Parents*

| *Style* | *F* | *%* |
|---|---|---|
| *Focused on Problem Solving (FPS): Positive CS* | *10* | *52.6* |
| *Negative Self Focus (NSF): Negative CS* | *1* | *05.2* |
| *Positive Reevaluation (PRE): CS Positive* | *3* | *15.7* |
| *Open Emotional Expression (OEE): CS Negative* | *1* | *05.2* |
| *Avoidance (AVD): CS Negative* | *1* | *05.2* |
| *Seeking Social Support (SSS): CS Positive* | *1* | *05.2* |
| *Religion (RLG): CS Positive* | *2* | *10.5* |
| *Total:* | *19* | *100.0* |

*Note: CS: Coping Style, F: Frequency*

*Qualitative results of the semi-structured interview*

The analysis of the interviews allowed the identification of four central categories that reflect parents' experiences in relation to the ASD diagnosis:

1. *Initial Emotional Impact.* Participants reported that the moment of receiving the diagnosis was marked by feelings of sadness, denial, and disorientation. Immediate reactions included crying, hopelessness, and guilt. One mother stated, "When they gave me the diagnosis, I walked out and burst into tears; I couldn't believe it" (Case 3). These responses reveal that the onset of the process was characterized by an emotional grief that affected daily life and perceptions of the immediate future.
2. *Adjustment and Adaptation Process***.** Over time, parents described changes in their understanding and support of their children. Most reported learning to recognize that certain behaviors were not "tantrums" but rather part of the condition. This shift promoted the development of greater patience and more effective educational strategies. One mother noted, "I became more patient because I used to think it was due to tantrums, and now I understand it is part of how he learns" (Case 6). This category highlights the transition toward a more understanding and functional attitude within family dynamics.
3. *Concerns About the Future.* Narratives showed persistent concern regarding their children's autonomy and future, particularly in relation to communication, social inclusion, and the possibility of becoming self-sufficient in adulthood. One mother expressed, "I worry that he may never develop language, and this will limit him when I am no longer here" (Case 5). This category reflects the ongoing uncertainty that accompanies parents and their desire to ensure a dignified and secure future for their children.
4. *Coping Strategies.* Parents described a variety of ways to address the emotional and practical demands associated with the diagnosis. Among the most frequently mentioned strategies were seeking psychological support, participating in mutual aid networks, religious faith, and creating spaces for self-care. One participant stated, "Psychological therapy, self-help groups, and getting closer to God have helped me move forward" (Case 2). These strategies function as protective resources that promote emotional balance and family resilience.

Overall, the qualitative findings indicate that the ASD diagnosis triggers an emotional grief process, followed by a progressive adjustment involving attitudes of understanding and adaptation. Nevertheless, uncertainty about the children's future persists. The coping strategies identified suggest that the combination of professional, spiritual, and community support contributes to parental resilience.

## DISCUSSION

The present study aimed to describe the characteristics of the grief and coping processes experienced by mothers and fathers of children with Autism Spectrum Disorder (ASD). The findings show that mothers are primarily responsible for providing care and accompaniment to their children, either because they are single mothers (33%) or because fathers assume the role of financial providers (67%). This finding is consistent with Fernández et al. (2014), who also reported greater maternal involvement (64%) compared to fathers (36%).

However, while Fernández et al. (2014) indicate that this situation may be interpreted as a form of cultural violence against women—by assuming that only mothers can and should fulfill this role—several participants in this study reported receiving spousal support in caring for their child. This result aligns with the findings of Nieto-Olazabal et al. (2022), who describe that mothers perceive their partners' involvement as a fundamental emotional support in coping with the acceptance of the diagnosis.

Regarding emotional reactions associated with the grief process, participants reported feelings of sadness, crying, frustration, guilt, anger, and denial upon receiving the diagnosis—reactions that correspond to a normal initial grief response, as described by Worden (2013), who identifies these same emotions as characteristic of loss-related situations. Similarly, Sumalavia (2019) and Estrada-Quispe (2020) reported the presence of stress, uncertainty, and perceptions of the diagnosis as a grief and acceptance process mediated by professional and family support. In this study, 78.9% of parents reported having experienced grief in the past, while 57.8% continued to manifest it at the time of data collection, confirming the persistence of the process. Estrada-Quispe (2020) also documented that the mothers experience feelings of denial and guilt, followed by eventual acceptance. These findings suggest that although parental grief is a dynamic process, it may extend over time and reactivate at different stages of the child's development.

With respect to parental attitude phases, most participants were situated in the Adaptation stage (63.1%), while 31.5% remained in Shock and 5.2% in Reaction. These results resemble those reported by Fernández et al. (2014), who found that most parents eventually reach the adaptation phase after an initial period of impact. Likewise, Arteta et al. (2019) argue that parental grief involves a process of readjusting expectations about their children, a phenomenon also observed in this study.

Mothers identified areas of opportunity in the caregiving process, such as developing greater patience, following therapeutic recommendations, updating their knowledge of ASD, and applying behavioral strategies at home. Estrada-Quispe (2020) reported similar findings, noting that these actions promote emotional closeness with their children and contribute to improvements in language and behavior.

Regarding coping strategies, results showed that the predominant style was positive coping, particularly problem-focused coping (52.6%), followed by positive reappraisal (15.7%). Only 15.7% of participants relied on negative coping styles such as negative self-focus, avoidance, or open emotional expression.

This finding contrasts with Aguirre-Aguilar (2022), who reported a higher prevalence of negative coping (21%) among parents of children with ASD. In this regard, the results of the present study align more closely with those of Durán et al. (2016), who argue that the use of adaptive strategies (such as social support and positive reappraisal) is associated with better quality of life, as well as with the findings of Higgings et al. (2023).

Differences with previous studies may be explained by cultural and familial factors. In this study, several participants emphasized the importance of faith and support networks, which may have fostered more positive and resilient coping.

Consistent with previous research (Sumalavia, 2019; Estrada-Quispe, 2020), participating parents expressed concerns about their children's future regarding autonomy, social inclusion, language acquisition, access to education, employment opportunities, and long-term care. These concerns reflect the constant uncertainty associated with the neurodevelopmental condition of ASD and represent a central theme in the parental experience.

This study has several limitations that must be considered. First, the sample size was small (19 participants), which restricts the generalization of the findings. Additionally, convenience sampling was used, which may limit representativeness. Another aspect to highlight is the predominance of mothers in the sample, which makes it difficult to systematically compare the experiences of fathers. Finally, the study used a cross-sectional design, which prevents the observation of changes over time.

Based on these limitations, it is recommended that future research include larger and more diverse samples, incorporate greater participation from fathers, and employ longitudinal designs to track the evolution of grief and coping strategies at different stages of the child's development. It is also necessary to explore psychological and psychoeducational interventions that strengthen parents' positive coping strategies, considering the role of cultural, religious, and community factors in the adaptation and coping process.

## CONCLUSION

This study aimed to describe the characteristics of the grief and coping process in parents of children diagnosed with ASD. The findings showed that most participants experience phases of grief, both at the time of receiving the diagnosis and in the present, even years after beginning to care for children with ASD, to reach the adaptation stage. It was observed that the most frequently used coping strategy was focusing on problem-solving, while negative strategies—such as self-focus, open emotional expression, and avoidance—were less common.

The main contribution of this work is to demonstrate that parental grief in the face of ASD does not end with the initial acceptance of the diagnosis, but rather is reactivated at different points in the child's development, forcing caregivers to develop new coping strategies. These results underscore the need to strengthen psychoeducational strategies and support networks that promote family resilience and the psychological well-being of parents.

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