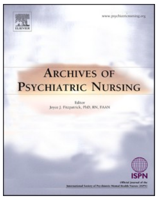
Archives of Psychiatric Nursing 56 (2025) 151864

Contents lists available at ScienceDirect

Archives of Psychiatric Nursing

journal homepage: www.elsevier.com/locate/apnu



Experiences and coping strategies of parents with children diagnosed with autism spectrum disorder in early care with emphasis on social skills and family cultural values: A qualitative study

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ARTICLE INFO

Keywords:
Parents experiences
Coping strategies
Autism spectrum disorder
Social skills
Early care

ABSTRACT

Parents of children diagnosed with autism spectrum disorder (ASD) often experience a grieving process upon receiving the diagnosis. In Spain, early care centers focus on providing care to this population. However, little is known about parents' experiences during this process, the daily challenges they face due to their children's social skills deficits, and how their context and values influence this process. The aim of this study was to explore and describe the experiences of parents of children diagnosed with ASD in early care services, focusing on their children's social skills and the family's cultural values. For this purpose, a semi-structured interview was conducted with 17 parents and a qualitative thematic analysis was made based on the principles of Gadamer's hermeneutic phenomenology. Three main themes could be identified: the emotional process of the parents upon receiving the diagnosis, the unanticipated obstacles and coping strategies they use, and the role of cultural family values that maintain the family dynamics. Part of the findings emphasize the need for greater parental mental health care, the social difficulties faced by both parents and their children, and the importance of support networks and parental values in raising their children.

Introduction

According to the Diagnostic and Statistical Manual of Mental Disorders DSM-5, autism spectrum disorder (ASD) is a neurodevelopmental disorder diagnosed by an individual who presents persistent deficits in social environments and shows a restricted and repetitive pattern of behavior, interests or activities (American Psychiatric Association, 2013). It is estimated that one in every 160 children presents this disorder (World Health Organization, 2023), however, in Spain, specifically in the autonomous community of Andalucia, 1 in 70 children has been diagnosed with some level of autism spectrum disorder (Villegas-Lirola, 2023), which makes them a relevant health issue to be addressed in this particular population.

Children diagnosed with this disorder often struggle with understanding and expressing emotions, both their own and those of others. Researchers have examined the socioemotional understanding of children with ASD, finding that they may have difficulties in recognizing and expressing emotions, which can impact their decision-making (McKown et al., 2013). Additionally, emotional self-awareness tends to be lower in individuals with ASD compared to those without the disorder, potentially affecting their ability to navigate social interactions effectively (Huggins et al., 2021). Emotional functioning, including emotion control, recognition, and vocabulary, is typically diminished in young children with ASD, leading to increased behavioral challenges (Li et al., 2020), all of the above contribute to deficits in social skills, which in turn increase the risk of peer rejection, social isolation and academic problems (Williams White et al., 2007). These difficulties pose significant lifelong challenges for individuals with ASD and their parents (Ghanouni & Quirke, 2023).

Part of the difficulties presented by children diagnosed with ASD are sensory features, as they may have atypical responses to sensory stimuli (Kirby et al., 2022), these sensory features can be classified into three groups: sensory reactivity (hypo- or hyper-reactivity) and unusual sensory interests, sensory perception and sensory integration (Schaaf &

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https://doi.org/10.1016/j.apnu.2025.151864
Received 9 October 2024; Received in revised form 25 November 2024; Accepted 26 March 2025

Lane, 2015). It is estimated that approximately 74 % of children diagnosed with ASD present at least one of these sensory characteristics (Kirby et al., 2022). Sensory features have been found to be related to behavioral problems, such as internalizing and externalizing problems, social functioning, adaptive behavior, attention, emotional states, hyperactivity, sleep and feeding problems (Kirby et al., 2022; Tseng et al., 2011; Zhai et al., 2023).

Another important aspect that has gained interest is the relationship between ASD and social anxiety, since a high comorbidity has been observed in these disorders (Montaser et al., 2023). Social anxiety disorder is a marked fear or anxiety about one or more social situations in which the individual is exposed to possible scrutiny by others characterized by avoidance to social situations that affect functioning areas. In children, the fear or anxiety may be expressed by crying, tantrums, freezing, clinging, shrinking, or failing to speak (American Psychiatric Association, 2013). Some studies suggest that social anxiety is related to sensory features, due to the high presence of both in children diagnosed with ASD, not only because both are present but also because hypersensitivity to sensory stimuli causes more anxiety in them as they are bombarded by the signals they receive around them (Liew et al., 2015; Pickard et al., 2020). Some evidence suggests that there is a bidirectional relationship between social skills and social anxiety, with direct consequences on individuals' daily lives. Social anxiety can affect their social skills, leading them to avoid social interactions, while social interactions can simultaneously trigger symptoms of social anxiety (Beidel et al., 2014; Chiu et al., 2021; She et al., 2023). However, the difficulties of having a diagnosis of ASD are not only for children and adolescents with ASD, but also for their parents or primary caregivers.

Currently, it is well-established that parenting can be an experience of happiness and joy that brings meaning to life (Nelson et al., 2014), however, dealing with an ASD diagnosis in their children could significantly impact in their family life (Aysel et al., 2019), in some studies parents reported felling sad, anxious, worried about the future, a feeling of loss, frustration, powerlessness and stress, typically after receiving the diagnosis and during the adaptation process (Fernańdez-Alcántara et al., 2016; Malhi et al., 2022; Wai Chau & Furness, 2023). Furthermore parents may experience intense and constant suffering and pain, due to the impact that the responsibility of caring for a child with these characteristics has on all aspects of their lives (Bravo-Benítez et al., 2019) the lack of information they have on the subject also generates fear and frustration (Lockwood Estrin et al., 2021), it has also been documented that parents go through a grieving process upon receiving the diagnosis, as they experience a sense of loss of the expectations of the "ideal child" that they had previously developed (Fernańdez-Alcántara et al., 2016), in this particular case, six stages of grief process that parents of children diagnosed with ASD go through have been described due to the peculiarities of this disorder and the needs that parents must cover, first the uncertainty of dealing with the unpleasant unknown, then being hurt and broken inside, followed by isolation and concealment as a consequence of the pressure caused by ignorance, then trying to look for the cause, searching for a cure and realizing that there is none, finally comes the phase of rupture or blossoming (Mihandoust et al., 2021).

Another aspect that can influence the entire process that parents go through from the time they receive their child's diagnosis until they adapt to their new reality is the culture and the context in which the parents are immersed (Papadopoulos, 2021) and their beliefs and values are subjected to scrutiny that generally entails changes in their personal plans, their roles as parents and family, and their outlook on life (King et al., 2006). Among these values, familism denotes attitudes towards support and commitment to family members across generations, emphasizing attachment, loyalty, and family obligations that take precedence over individual interests (Cahill et al., 2021; Sabogal et al., 1987). Another value is traditional gender roles, which entail an unequal distribution of power and rights between men and women; specifically, within the family, husbands are seen as the breadwinners and decision-makers, while women are responsible for housework and childcare (Hoffman & Kloska, 1995). Additionally, religion remains an important traditional value in the world that provides behavioral influences such as moral norms and role models (De Andrés-Sánchez et al., 2023) and finally competition and independence, which are values that are part of more individualistic cultures but are increasingly being adopted in Western countries and also influence the way parents view life and the way they raise their children and encourage them to be more self-sufficient (Goncalo & Krause, 2010; Tamis-LeMonda et al., 2008).

Currently, in some parts of the world, including Spain, there are early care programs, which can be effective tools to help parents to better manage the various situations they face. Early care is the set of interventions aimed at the child population from 0 to 6 years of age, the family and the environment, which aims to respond to the temporary or permanent needs of children with developmental disorders or at risk of suffering them. These interventions must be focused on the globality of the child and must be planned by a team of professionals with multidisciplinary orientations (GAT, 2005). For approximately thirty years, Spain has been working on this issue, making laws so that children and their families receive the attention they need, creating early care centers, which have shown great effectiveness in improving the quality of life of their users (Quirós Pérez, 2009). The early care model considers the child as the main agent of its development, makes a change in the educational model, the attention is linked to the first diagnostic evaluation, the family plays a leading role in the interventions, which are carried out in natural environments with meaningful activities led by professionals working multidisciplinary (Gutiez Cuevas, 2005; Robles-Bello & Sánchez-Teruel, 2021). In early intervention programs, the principal aim is to work with families to provide them with the necessary information, support and advice, so that they can adapt to the new situation and maintain adequate emotional relationships with their children. In addition, the aim is to enrich the child's environment by providing adequate stimuli in all aspects to favour his or her development. The relationship between parents and children is fostered, avoiding inadequate interactive styles, and the child's progress is maximized to achieve independence in the different areas of development. Intervention strategies are used in a natural context and through the child's routine situations, avoiding overly artificial formulas. A preventive action is also carried out, since these programs make it possible to slow down the progressive deterioration of developmental levels and prevent children from presenting more serious alterations in the different developmental aspects. This preventive facet extends to the entire family environment, by establishing from the outset appropriate behaviors that are more adapted to reality (GAT, 2005; Robles-Bello & Sánchez-Teruel, 2013).

This qualitative study aims to explore and describe the experiences of parents of children diagnosed with ASD in early intervention services in Spain. It also aims to learn about parents' perceptions regarding social aspects they observe in their children, especially those related to social skills. Finally, we aim to learn how family values such as familism, religion, traditional gender roles, competence and independence may be related to parents' experiences.

Method

Study design

This study used a qualitative approach through a semi-structured interview and a thematic analysis, following the principles of Gadamer's phenomenological hermeneutics, which is based on understanding the meaning of experiences through dialogue and interpretation, influenced by the interpreter's historical, cultural, and personal context (De La Maza, 2005). We decided to use a qualitative approach because the objective of the research was to understand the experiences and coping strategies of parents in early intervention centers. Therefore, we determined that conducting interviews with each parent would allow us to gain a closer understanding of the phenomenon and all the factors involved in the specific and complex family and social dynamics addressed in this study (Busetto et al., 2020). All participants agreed to conduct the interview for approximately 50 min, in person, in an environment where they would not be interrupted and could express their ideas. All interviews were recorded with the consent of the participants and for practical research purposes.

Participants

Using a convenience sampling approach, the parents were contacted through associations with early care centers in southern Spain, in each association, we contacted the personnel in charge of the psychology area, who were responsible for sharing information with the parents and selecting the parents who were more suitable for the study, since some of them, due to their jobs, lack of time or difficulty in talking about their child's diagnosis, showed less openness. Later, we explained to all the parents the importance of participating in the research and the informed consent so that they could be sure that all the information provided was anonymous and that the necessary ethical standards were met. Finally, 21 parents were selected, 4 of them did not finish the interview or did not make it to the interview because they did not show up for the session, so they had to be eliminated, the invitation included an explanation of the study, and all parents who were interested in participating in the research were contacted personally to arrange the day, time and place for the interview. The inclusion criteria were: being a parent of a child diagnosed with ASD, being of legal age, speaking Spanish, and that their child has received or is receiving early intervention because of the ASD diagnosis. A total of 17 parents met the inclusion criteria, 14 females and 3 males.

Trustworthiness

The trustworthiness of this study was maintained from study design to data analysis and presentation through the criteria established by Morse (2015) for validity and reliability by developing an inter-rater coding system, developing the codes separately and then analyzing them together to determine similarities and discrepancies, and then including the codes that were consistent enough to be included.

Data collection

Ethical approval for the research was obtained from the ethics committee of the University of [blinded for review]. Interviews were conducted at participating associations in southern Spain. Participants provided informed consent before the semi-structured interviews, which covered sociodemographic information and various topics related to their child's diagnosis. The interviews were individual, private, lasted about 50 min on average, and were recorded, below is the general structure that was followed in each of the interviews, considering that each case is particular and it is a semi-structured interview, there were some questions that were added when it was considered that more information was needed on a particular topic (see Table 1). They concluded when parents had answered all questions and no new relevant information was provided. The interviews were later transcribed and analyzed using ATLAS.ti software (ATLAS.ti Scientific Software Development GmbH, 2024).

Data analysis

The interviews were transcribed and analyzed using the thematic analysis model by Braun and Clarke (2021), which involves six phases: 1) familiarization with the data through reading and re-reading; 2) generation of initial codes to label relevant information; 3) identification of themes through inductive analysis; 4) reviewing and refining themes; 5) defining and naming themes to align with research questions; and 6) writing the report, where themes and sub-themes are linked to the analysis and theoretical framework.

Table 1
Summary interview.

Interview Phase	Interview Topic	Content
Introduction	Information and ethical aspects	The participants were explained the objective of the research, all the ethical aspects, emphasizing that the interview would be recorded for practical purposes and that if at any time they no longer wished to participate they could withdraw without giving any explanation.
Beginning	Sociodemographic data	Participants were asked about their dates of birth, marital status, place of residence, educational level, socioeconomic status, number of children and ages of their children.
Development	Diagnosis	parents were asked what diagnosis their children had, when they had received it, how they had taken the news, and how they were doing with the diagnosis.
	Social difficulties	Questions were asked about the difficulties they observed in their children's social interactions, whether they have friends, whether they like to play with other children, and how they handle their emotions.
	Family cultural values	Parents were asked what they consider to be their obligations to their family, how close they are, if religion is an important part of their lives, and how they motivate their children to be independent and achieve their goals.
Closure	Final question	Parents were asked if there was anything else they wanted to add that they considered important to mention.
	Appreciation	Every participant was thanked for their participation and help.

Note: this table presents the content of the interviews, the main topics and the order in which they were conducted.

Community involvement

In this study, healthcare professionals working in early intervention centers in southern Spain collaborated by sharing the research information with parents. They also provided suggestions on how to approach the topic with the parents, as some had only recently received their child's diagnosis. Additionally, the parents interviewed contributed by sharing their perspectives and discussing topics that provided us with insights and added depth to the analysis.

Results

Here we present the results of semi-structured interviews conducted with 17 fathers and mothers of children diagnosed with ASD who have been cared for in early childhood centers in southern Spain. The age range was from 28 to 51, all of them are married or cohabiting and have medium-low to medium income, in Table 2 all sociodemographic data are presented. Through the process of analyzing the semi-structured interviews, it was observed that the participants coincided in several of their answers when describing their perceptions regarding the diagnosis of ASD in their children and how the early care has been from that moment on. The following themes emerged as the most relevant when analyzing the parents' experiences (see Table 3): 1) the diagnosis, 2) challenges, and 3) family values. In the presentation of the results, some quotes from the parents' interviews are added to support the results.

Three main themes emerged, the first one is (1) the emotional process that parents go through when their children are diagnosed with ASD, the second one is (2) the unforeseen obstacles and coping strategies

Table 2
Sociodemographic information.

Interview	Relationship with the child	Child age	Age	Marital status	Education	Occupation	Place of residence
1	Mother	4.5	28	Free union	Secondary school	Housewife	Urban
2	Mother	4.6	39	Married	Secondary school	Professional caregiver	Urban
3	Father	4.6	41	Married	Graduated	Municipal gardener	Urban
4	Mother	7.5	45	Married	Secondary school	Housewife	Urban
5	Mother	12. 17 and 20	51	Married	Truncated degree	Housewife	Urban
6	Mother	3.9	44	Married	Degree	Housewife	Urban
7	Mother	4.6	35	Married	Secondary school	Housewife	Rural
8	Mother	4.2	40	Married	Adm. degree	Administrative	Rural
9	Mother	3.8	37	Married	Secondary school	Elderly caregiver	Rural
10	Mother	11.5	43	Married	PhD	Projects inspector	Urban
11	Mother	14.9	49	Married	Business degree	Housewife	Rural
12	Father	14.9	51	Married	Informatic engineer	Informatic supporter	Rural
13	Mother	2.5	43	Free union	Degree	Housewife	Rural
14	Father	2.5	38	Free union	Meddle school	Business manager	Rural
15	Mother	4.1	38	Married	Secondary school	Waitress	Urban
16	Mother	6.3	47	Free union	Primary school	Housewife	Rural
17	Mother	6.1	35	Free union	Secondary school	Housewife	Rural

Note: this table presents the sociodemographic data of all interviewees such as marital status, educational level, occupation, and place of residence.

and the third one is (3) the importance of cultural family values in maintaining the family dynamics, which allow to understand what is the experience of parents when their children are diagnosed with ASD and what happens during the whole process until the whole family is able to live with their new reality.

Emotional process of parents when their child is diagnosed with ASD

This section discusses the emotional process that parents go through when their children are diagnosed with ASD, how it is surprising for them to receive this diagnosis which also implies going through a grieving process, how it is difficult for them to understand what is happening due to the lack of information or the misconceptions that exist about this disorder and how early care services are focused on the care of children but leave aside the mental health care of parents.

Grieving as the first step of unexpected news

In this section, parents described their experience upon receiving the diagnosis of ASD about their children, many of them agree that it is unexpected news despite having detected some symptoms previously, however they keep the hope that it is something temporary or that it is not the diagnosis of a lifelong disorder, they talk about how their ideas and expectations change from knowing that it is a definitive diagnosis and everything that goes through their mind.

“I did spend a week… because the whole idea that you have falls away… that vision and those things that we thought about no longer” (2), “We had the idea of one thing and then you find something like this and it kind of breaks the schemes and you don’t expect it at all” (3).

Additionally, they described the emotional impact of receiving a diagnosis, emphasizing the distress associated with it. They discussed the various emotions that accompany sadness, including concerns about the future, the ability of their children to care for themselves and integrate socially, and frustration at the difficulties they face and the lack of knowledge about how to help them or improve the situation.

“It was a very painful thing, I have gone through a grieving process, I have had a very bad time because you are all the time thinking about what is going to happen to her, in fact when she has a problem or whatever I still get very upset when I see her suffering and I cannot do anything” (5).

Furthermore, parents also mentioned that part of the pain and fear they experience is because they were facing an unknown situation, which caused them a lot of emotional discomfort. They had many questions in their minds that they did not know how to answer, and as time went on, this turned into continuous anguish that led to the development of mental health problems that they also had to deal with.

“It is very painful, it is very painful because you are facing something unknown… I had a hard time, I had to resort to taking an antidepressant treatment and the truth is that for a while I had some pretty pronounced anxiety attacks, but I prefer to know than not to know” (11).

The initiation of interventions in early intervention centers could focus on providing support to parents after receiving the diagnosis, as for some, it is profoundly distressing information that they may find difficult to process. This can lead to other negative consequences for family dynamics, the couple’s relationship, and their social environment (Alimohamadi et al., 2024).

Lack of information and misconceptions about ASD

About this topic, parents narrated that when they received the diagnosis of autism it was the first time they heard this term, they had a total ignorance of the subject and therefore did not have the tools to face the situation, as time went by, although they have learned they have realized that in their environment the same thing does not happen, since their own extended family sometimes does not understand what happens to their children, their friends do not know how to react and even at school sometimes teachers do not know what strategies to use to assist their students diagnosed with ASD.

“In the first school we went to, the truth is that it didn’t go well, because, although they knew it was ASD, they didn’t know how to treat it, how to handle it…and with society, there are times when people don’t know, they don’t know about it, so they see something strange and immediately give an opinion “ (4).

Additionally, they mentioned not only the lack of information regarding the characteristics of the disorder itself, as the parents were empirically able to recognize the symptoms their children displayed even if they didn’t know the disorder by name, but also the lack of information about what needs to be done or what tools are needed to help their children improve their skills. They also needed guidance on how they, as parents, could help their children to improve.

“The only thing that worries me about autism is not knowing what tools my daughter needs, as long as I know all the tools she needs, whether it is the shadow teacher or this or that, all I ask is that they inform me and tell me what she needs, and that way I’m happy” (9).

A need we identified is the implementation of psychoeducational courses or workshops aimed at increasing awareness about ASD among parents, educators, healthcare professionals, and the general population (Morsa et al., 2022). The lack of knowledge among all involved parties hinders and delays the opportunities to implement programs already structured for addressing neurodevelopmental issues from the moment they are identified (Dillenburger et al., 2013).

Table 3
Themes, sub-themes and units of meaning.

Themes	Sub-Themes	Units of meaning
Emotional process of parents when their child is diagnosed with ASD	Grieving as the first step of unexpected news	Expectations, grief, sadness, worry about the future, frustration, fear of the unknown, acceptance, underlying issues
	Lack of information and misconceptions about ASD	Symptoms, institutional support, personal and practical tools, societal ignorance, stereotypes, and prejudices
	Mental health care for primary caregivers on the back burner	Infrequent or non-existent attention, lack of an integrative system, failures in the healthcare system, lack of sensitivity, perception of inaccessibility to services
Unanticipated obstacles and coping strategies	Stigmatization as a vehicle for social isolation	Taboo, lack of support, minimizing the situation, bullying, isolation, incomprehension, denial, indifference, loneliness, mistreatment, lack of empathy
	The challenges of social interaction	Emotional changes, frustration, lack of language, hypersensitivity to stimuli, social anxiety
	The use of resilience as a coping strategy in the face of adversity	Willingness, participation, fear, acceptance, faith, prevention, help, pride, integration, perseverance, opportunities
The role of cultural family values in maintaining family dynamics	Involvement of family and friends in the development of children with ASD	Support networks, experiences, empathy, taboo, lack of knowledge, prejudice, understanding, distancing
	The influence of traditional values on family dynamics	Mothers in charge of the home and parenting, fathers more present, maintenance of gender roles, Catholicism as the predominant religion, religion as a tradition and not as a practice
	Values as tools for parenting of children with ASD	Support, help, freedom, confidence, stimulation, motivation, contact with the environment, practical resources such as stories or pictograms

Note: this table presents the themes, sub-themes, and units of meaning that were found during the interviews following the methodology proposed by (Braun & Clarke, 2021).

Mental health care for primary caregivers on the back burner

Another common aspect on which the parents agreed is that, although their children have received multidisciplinary support since the assessment to diagnose ASD and have continuous support both in the school area and therapies to improve different aspects of their development depending on their needs, for them, the attention is minimal from the professionals, not receiving the support they need to assimilate the diagnosis and go through the grieving process and neither support to take care of their mental health as primary caregivers, considering that most of their attention and time is focused on their children with ASD. Although early intervention centers are intended to provide comprehensive care for the entire family, the general perception and experience of parents is that they have not received any direct professional support for themselves. This represents a potential area for improvement in these services, as the well-being of parents is essential to the developmental process of their children (Newland, 2015).

"We always go with the therapy, if we have doubts and we have some things, but it is true that personally it does not help"(16).

Another important aspect to mention in this section is that it is not only about the lack of attention to the mental health of the parents, but also the lack of tact or sensitivity that some healthcare professionals have shown in delivering the news or in monitoring not only the emotional state of the children during sessions but also that of the parents. Since the parents are with the children all the time, the well-being of the parents becomes a crucial factor in the children's improvement. It is also acknowledged that part of this lack of attention is not due to the healthcare professionals themselves, but rather to a malfunction in the healthcare system.

"They don't give you any psychological support, they just told me: look, your daughter has this and that's it and go home, without even knowing what you have to do" (1).

Unanticipated obstacles and coping strategies

Regarding to this topic, parents talked about how having a child diagnosed with ASD can represent a great challenge every day, since they encounter new situations in which they do not know how to act, what strategies to use or how to help their children in a moment of crisis, in addition, they talked about how the environment can also be a determining factor that greatly influences how they deal with these new events and the decisions they make. In this section, three sub-themes were identified related to the challenges faced by parents, the first is the use of stigmatization as a vehicle for social isolation, the challenges of social interaction and the use of resilience as a coping strategy in the face of adversity.

Stigmatization as a vehicle for social isolation

From their experiences, parents have noticed that the lack of knowledge can often be linked to stigmatization. From the lack of information about ASD unrealistic ideas arise and lack of empathy for not understanding that for these children it is more difficult to adapt to social environments, as sometimes they do not have the necessary skills to interact with others in a flattering way, they do not know how to express their emotions and can feel very overwhelmed by all the stimuli they receive from the outside. Because of all this, it is constantly easier for social groups not to include them and simply ignore them and their families, so sometimes parents simply prefer not to talk about it or stop attending reunions with friends and family because they feel misunderstood.

"We have received more support from friends than from the family, the family is more indifferent, like a taboo subject, that is, sometimes they even ask me more about my daughter who does not have any condition than about my son who does" (14).

It was also identified that generational differences are a determining factor in stigmatization, as several parents mentioned that although they receive support from their own parents (the grandparents of the children diagnosed with ASD), they often do not fully understand what is happening. They tend to minimize or deny it by saying that nothing is wrong, which makes it very challenging for both the children and their parents to overcome and learn to deal with these situations.

"My mother is 82 years old… she grew up in a post-war period and then went through a dictatorship... she comes from a situation that let's say she had to live through quite hard…she says that nothing happens to the child, that there are worse things" (6).

Not only do parents receive these types of comments from family and friends directly when their children are young, but they also face other challenges as their children grow older. For example, their children may experience bullying for being "different" or having more difficulties adapting, which can in turn lead to their social circle, family connections, and support networks shrinking, making it more difficult to confront new challenges.

"From what we have been told (our daughter) sometimes she does not feel very understood, she feels a little lonely and perhaps alien to all the interests of the rest, sometimes she is treated terribly. Last year she did experience an episode of bullying" (15).

One of the main issues stemming from a lack of awareness about ASD is that it leads to other problems such as stigmatization, social rejection, discrimination, and bullying—not only for the diagnosed children but also for their families (Turnock et al., 2022). As expressed by some parents, they have even experienced rejection from their own families and society at large. This highlights the need to equip both parents and children with tools to identify and navigate these situations, minimizing their impact as much as possible (Aylward et al., 2021).

The challenges of social interaction

In this part parents shared their experiences of how they communicate with their children if they cannot talk, how they handle their emotional and social problems, considering that the daily life of parents of children with ASD can be more complex than that of parents with neurotypical children, from being able to communicate to trying to understand what is happening to them, in addition to the constant worry about their future, parents face challenges they may not have imagined.

"This is like a roller coaster, sometimes she is more focused, other times she is less focused…there are days she is more receptive, other days she is not, but well, teenagers also have that roller coaster of emotions and she more so because she can already identify many emotions, but she doesn't understand" (12).

Some of the difficulties that parents also described were those related to language, since one of the main problems faced by children diagnosed with ASD and their parents is the establishment of communication, often their limited language or total lack of it makes it very difficult for parents to understand the needs of their children, sometimes they make use of some tools such as pictograms and with them they are able to communicate, however for other people in their social environment it is still difficult to understand them, then this can generate frustration.

"He likes to be with the children… what happens is that he doesn't have language, he can't communicate…when he is a little bit sick or something, like you don't know until… he is not able to say it hurts here, so until it is bad, bad at all you don't know what is wrong with him, then he is a little more nervous, more unregulated" (4).

The use of resilience as a coping strategy in the face of adversity

Parents talked about how they faced and accepted the diagnosis over time, many mentioned that, after going through the grieving process, reach a point of acceptance of their family situation, adapt to their new reality and decide to start working together with their children to help them develop and adapt in the best way, show willingness to take them to therapy and get involved as much as possible in all activities. Although accepting the diagnosis has not been easy and they have gone through moments of uncertainty, fear of what they face and what may happen in the future, they have shown the ability to overcome the diagnosis and work on helping their children to get better and give them everything in their power to develop as well as possible.

"There is fear of all kinds, but I didn't stop, I didn't stop much and I said well, let's get down to work, that if this comes to nothing, God forbid, but if there is something, whatever it is, we are already taking measures against it, the sooner we start, the better" (6).

Another important aspect of the acceptance of the diagnosis and the resilience of the parents has been expressed by feeling fortunate to have all the support they need, realizing that they are in a context that allows them to get everything they need for their children and not being ashamed of who they are and what they have, but on the contrary, making ASD visible to generate more awareness.

"I see him as a child who has been given every opportunity since he was very young, we have worked a lot with him, I see that he is very well integrated in school and academically he is doing very well.… I'm very well with the diagnosis, because I also say it wherever I go, for me there is no secret and people know that I'm working in the association and everything and I kind of championed ASD" (10).

Despite the many challenges faced by parents of children diagnosed with autism, it was also observed during the interviews that they possess certain skills, such as resilience, to cope with daily adversities. One strategy that early intervention centers could implement is resilience training, as it would help parents strengthen and further develop this ability, turning it into one of their primary tools. Previous research has shown that resilience is directly linked to mental health, well-being, secure attachments, and positive emotions (Rutten et al., 2013).

The role of cultural family values in maintaining family dynamics

Finally, another very important aspect that was identified during the interviews is the importance of the support networks that parents have, both institutional and personal, family and friends can play a very important role in the well-being or discomfort of the whole family. It was also possible to identify that all families belong to very traditional structures, seem to be very united and maintain certain values such as mutual support, interdependence and emotional closeness, values that in turn have been transmitted to their children and that shape their way of upbringing. Three sub-themes unfold here that are the family and friends involvement in the development of children with ASD, the influence of traditional values on family dynamics and the values as tools for parenting children with ASD.

Involvement of family and friends in the development of children with ASD

During the interview, the participants emphasized the great support they have received from people close to them and how this has helped them to cope better with their child's ASD diagnosis. In some cases the extended family has not been present to support them, however, their friends have been the support network, in other cases it has been the opposite and many of them agreed that they have found great support in other parents of children with ASD, because according to their experiences they feel that they are the only ones who can really be empathetic because they can really understand what they have to go through day after day and that makes them feel that they are not alone as they express in the following fragments.

"My family, my mother and my mother-in-law is that people don't find out… we have much more support from the people here, the parents of the association that we know who are friends that we have all the kids and maybe one day we have a training session and then you go for a beer, that kind of support is much more than that of the family" (17).

A very important aspect of the support mentioned by the parents is related to empathy, they have felt that their extended families do not accept and do not fully understand what is happening to their children, sometimes they minimize it or blame them because they perceive that they are not doing a good job as parents, however, with other parents who also have children with ASD they have felt understood and supported, they feel they do not have to explain what is happening as with their relatives because they also live it and that has helped them to generate empathy and a support network to feel that they are not the only ones going through the same situation.

"I have sought more to unburden myself with the families who have children with ASD than with my immediate family, who have always seen it as a minor problem, they didn't really understand what it was, however, with my friend, if the child becomes dysregulated or something, I don't have to give her any explanation" (10).

Another key aspect we identified is the support networks available to parents to assist them or their children on days when coping with challenges becomes more difficult. In some cases, these support networks consist of their own families, while in others, they include friends or other parents going through similar situations. The importance of having support networks lies in providing families with the reassurance that they are not alone and that there are people around them they can turn to when needed (Benson, 2012).

The influence of traditional values on family dynamics

In the family structure of all the participants it was observed that they maintain a traditional form, where the mother is in charge of the housework and raising the children, although it is also true that some parents are quite involved, especially in relation to therapies and in the improvement of their children. They mentioned that they usually go everywhere together, both to therapies and other activities since it is difficult for one person to take care of their child alone, so it seems that having the diagnosis of ASD and all the activities that it entails has influenced the existence of more family cohesion. Here are the most significant responses on this point.

"Basically, from Monday to Friday I (do everything at home) and on the weekend her father has been here at home, this week he has been doing homework all week and I have spent more time for example cooking, doing things around the house because I was no longer alone with the two children" (7).

It was also observed that all the families are believers of the Catholic religion, however, they are not practicing, and religion is not part of their basic value system. Although Catholicism is the most practiced religion in Spain, the parents agreed that they do not practice it, it is maintained as part of the country's tradition and the celebrations of the religion are followed, but on a day-to-day basis it does not seem to be part of their value system.

"The truth is that we are Catholics, but we don't practice it, it's just more like tradition, we don't really practice it, we respect it a lot and we like it, but we don't practice it" (13).

A recurring pattern observed in most interviews is that both the nuclear and extended family play a pivotal role in the dynamics surrounding children diagnosed with autism. Most families maintain a traditional structure, with clearly defined roles and assigned responsibilities. As evidenced by the significant disparity between the number of mothers (14) and fathers (3) who participated in this study, mothers predominantly take on direct caregiving roles. Another initiative that early intervention centers could consider is promoting active fatherhood, encouraging fathers to become more involved. This could also yield benefits for the overall well-being of the family (Bowles et al., 2022).

Values as tools for parenting of children with ASD

Finally, parents talked about how they motivate their children to be more independent and to achieve their goals. Their answers were focused on being the support their children need and helping them in everything within their reach so that they can be as self-sufficient as possible. They also mentioned that although sometimes it is difficult to stand back and let them make their own mistakes, they know that it is part of their growth and the skills they must learn, they understand that it is very important to motivate them and find the best strategies to do so. The values most frequently mentioned by parents were trust, motivation, freedom and help. A key strategy that could be implemented in interventions is focusing on identifying the most important values within each family, helping parents become aware of these values and leveraging them as effective tools for their children's education.

"I think that stimulating her and taking her to the park every day... I don't know, making her life more enjoyable, stimulating her, I think that is a good way for her to have those resources so that at some point she can reach her goals" (9).

Discussion

The aim of this study was to explore and describe the experiences of parents of children diagnosed with ASD in early intervention services in Spain, considering the social skills of their children, the coping strategies they implement and the family cultural values.

Through the analysis of the interviews, 3 main themes were identified that parents talked about according to the experiences they have had since receiving the diagnosis of ASD in their children. In the first theme, they talked about the emotional process that parents go through when they begin to notice some signs or that something is not quite right with their children, the hardest emotional moment when they receive the diagnosis and all the challenges they face. It could be observed that parents go through a grieving process, which begins with the unexpected news of the diagnosis, which is accompanied by sadness, anxiety and frustration, parents expressed feeling very affected by the news and worried about the future of their child, they had to say goodbye to the idea they had about their "ideal" child and accept their new reality, a process that has been previously described and documented in this particular population (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016; Mihandoust et al., 2021).

It was also possible to identify that part of the concern expressed by parents was related to their lack of knowledge or misconceptions they had about ASD, some mentioned that this was the first time they had heard about autism, which caused them more uncertainty not knowing what would happen to their children or if it was a condition that at some point would be removed (Lockwood Estrin et al., 2021). In addition to this, despite the fact that early care centers are based on comprehensive care for the family, the reality is that parents do not receive psychological support before, during or after receiving the diagnosis, so it was observed that there is no care for their mental health, which is left to drift and can cause other underlying problems.

After having received the diagnosis and having gone through the whole grieving process and being able to accept their new reality, parents are faced with many obstacles that they had not thought they could have before, in this second issue we identified about the challenges that parents face, the first of them is the stigmatization they receive from society, since like them, the general population does not have much information about ASD, so it is still seen as very taboo. Parents have had to face isolation from their own families of origin, they have not received enough support as their families do not understand what is happening and prefer to remain oblivious to it, they have also faced stigmatization in their children's schools and bullying, which becomes an underlying problem to deal with and for which they sometimes do not have enough emotional resources (King et al., 2006).

In addition to this, they face the difficulty of understanding their own children because they are not able to express what they need, they also face social situations in which their children prefer not to interact with others or find it very difficult to do so (Huggins et al., 2021), they may react in a random and hypersensitive manner to different stimuli (Kirby et al., 2022), they may manifest social anxiety when they are in specific situations that alter or deregulate their emotional state (Liew et al., 2015; Pickard et al., 2020), making it difficult to return to a state of calm. This makes it difficult for parents to have a frequent social interaction with family and friends; however, some parents stated that with parents who also have children diagnosed with ASD this social situation becomes easier, because they are the only ones capable of understanding the situation that the other parent is going through. Thus, it has been possible to identify that parent groups can be a determining factor for the well-being of families acting as support networks. It was also possible to identify that parents showed an attitude of participation, acceptance, helping each other, integration and even pride in the diagnosis, they are able to see the opportunities instead of seeing the obstacles and show willingness to get involved, to learn more about the subject and to help their children, showing a great capacity for resilience in the face of adversity.

Finally, in the last topic it was possible to identify that the context in which the family is found is very important for the development of the children as well as for the ability of the parents to cope with everything that comes with having a child diagnosed with ASD. In this case, the participation and importance of family and friends were taken into account. Parents mentioned that since receiving the diagnosis of their children they have had many experiences, some of them pleasant and some of them unpleasant (Papadopoulos, 2021), there were parents who felt understood and supported by their own families of origin, who have supported them emotionally and economically, however, their friends have not had the same response, in other cases the opposite is true, their friends have become their new family, since their family does not accept the situation or does not understand it or simply prefers to distance themselves. In general, it can be said that parents feel supported by the people who have remained close to them since they know that this is not an easy situation, they have people they consider their family and the support and understanding they receive from them makes them feel that they are not alone (Cahill et al., 2021; Sabogal et al., 1987).

Another very important aspect of the family that could be observed is that all of them are immersed in a traditional dynamic in which the fathers are the providers and the mothers are the housewives, however, in some cases there is a greater involvement of the fathers, and there are also some working mothers. Although the norm continues to be the traditional model (Hoffman & Kloska, 1995), since Spain is a very religious country, it was observed that most families keep Catholicism as their religion in a more traditional than practical way, since they do not inculcate religious values in their children and they do not practice them either (De Andrés-Sánchez et al., 2023). Finally, it could be observed that parents, despite knowing that their children have some difficulties to develop certain skills, use their values as tools to educate their children and to make them as self-sufficient as possible, many of them mentioned that they try to motivate them, stimulate them with different activities every day, give them the freedom to make mistakes and to learn from their mistakes and support them in what they need, for them the most important thing is that their children are as independent and happy as possible (Goncalo & Krause, 2010; Tamis-LeMonda et al., 2008).

We think that the findings observed could contribute to improving the quality of early intervention services in southern Spain. Notably, we identified important areas, such as the mental health of parents, that are not being directly addressed but could yield substantial benefits if actively incorporated into the intervention programs of these centers. Additionally, we identified very specific needs, such as psychoeducation on autism, to provide parents with a deeper understanding and better tools for interacting with their children.

On the other hand, we also observed strengths that could be further developed, such as resilience and family values. If these particular aspects were identified and actively considered in the centers, they could potentially benefit family dynamics. Moreover, fostering support networks within the community could help develop a sense of belonging and inclusion (Sánchez-Teruel & Robles-Bello, 2014).

Finally, some limitations of this study include the number of participants. Although we obtained fairly consistent responses and reached data saturation during the interviews, we acknowledge that there may be other perspectives we did not have the opportunity to hear and, therefore, could not consider. Additionally, by focusing solely on the population in southern Spain, we recognize the difficulty of generalizing the results to other countries or even other regions within the same country, given the diverse realities experienced. However, we believe that this type of approach could inspire other researchers to replicate the study in different populations. Comparing results could then help identify the extent of variations that exist.

In conclusion, it can be said that parents of children diagnosed with ASD go through a grieving process which is very difficult emotionally, however, early care programs in Spain provide children with interdisciplinary support to develop their skills effectively, although these programs have some details to improve, as they do not directly address the mental health of the parents, which is a determining factor for the well-being of the children, since if their parents are not well, they cannot be the optimal caregivers that their children need. It was also possible to determine that there are several social problems that affect both parents and children, many of them experience hypersensitivity to stimuli, which hinders their ability to thrive in social environments, for others, it is very difficult to live with other people, when they are forced to do so they may present high levels of social anxiety, since as it is well known children with ASD have deficits in their social skills. Therefore, it is more difficult for them to integrate into social groups both at school and in other contexts, making it easier for them to suffer discrimination or social isolation, this phenomenon is also experienced by parents with their own families or friends when they learn about the diagnosis of ASD in their children, because in the general population there is not much knowledge about the subject.

CRediT authorship contribution statement

Ingrid Zugey Galán-Vera: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **María Auxiliadora Robles-Bello:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Aziz Sarhani-Robles:** Writing – review & editing, Writing – original draft, Visualization, Validation, Methodology, Conceptualization. **Nieves Valencia-Naranjo:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Funding

This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Sklodowska-Curie grant agreement No 101034319 and from the University of Jaen (Spain).

Declaration of competing interest

There are no conflicts of interest.

Acknowledgments

Would like to thank all the families and institutions that opened their doors so that we could write this paper. Their participation is invaluable.

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