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# Raising Autistic Children in Rural Greece: Parental Interpretations and Challenges

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#### **Abstract**

Autism Spectrum Disorder (ASD) presents unique challenges not only for individuals diagnosed but also for their families. While research on autism parenting has expanded globally, there remains limited understanding of how cultural and geographical context, especially in rural, non-Western settings—influence parental experiences. This study explores how parents in rural northern Greece perceive, experience, and navigate the realities of raising a child with autism, within the broader context of cultural values, stigma, and systemic limitations. A qualitative, phenomenological approach was employed. Seven parents (four mothers, three fathers) of autistic children aged 10–15 participated in semi-structured, face-to-face interviews. Data were analysed thematically using NVivo software. Four key themes emerged: (1) evolving parental understanding of autism, (2) emotional and practical impact on daily life, (3) inconsistent and often misleading sources of information, and (4) fragmented support systems. Participants highlighted a lack of state support, stigma in local communities, and reliance on informal networks. Findings underscore the urgent need for culturally sensitive, decentralised autism services in Greece. Parents demonstrate resilience but require structured, long-term support to sustain their caregiving roles and their own well-being.

Keywords: Autism; Greece; Rural parenting; Lived experience; Support systems

#### Lav Abstract

Raising a child with autism can be a deeply rewarding but also challenging experience, especially for families living in rural areas with limited access to support. This study looks at the lives of seven parents in northern Greece who are raising autistic children. It focuses on how they understand autism, how it affects their daily lives, where they get their information, and what types of help they can or cannot access. The parents in this study shared powerful personal stories. Many first noticed something different in their child's behaviour—such as avoiding eye contact or not speaking—but didn't know what it meant. When they finally received a diagnosis, they felt both relief and fear. Some said they had never even heard of autism before. Most had to search for information on their own, often turning to the internet or other parents. Unfortunately, this information was not always reliable or easy to understand. Living in rural areas made things harder. Parents talked about feeling judged by others, struggling to find therapists or teachers trained in autism, and facing long travel distances just to get help. Despite all this, they showed strength and determination. Some found comfort in local parent groups, while others leaned on family members—though not always without conflict. This study shows how much families can do on their own—but also how much more support they need. It calls for better services, more accurate and accessible information in Greek, and more understanding from the wider community. Above all, it gives a voice to parents who are doing their best to care for their children, often in difficult circumstances. By sharing their stories, these parents help us all learn how to build a more inclusive and supportive society for autistic people and their families.

## Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition characterised by differences in social communication, behaviour, and sensory processing. As its global prevalence continues to rise [1], so too does the need to understand how autism is experienced not only by individuals on the spectrum but also by their families, particularly their parents, who often bear the greatest caregiving responsibilities.

Research has consistently shown that parents of autistic children face elevated levels of stress, emotional strain, and social isolation [2,3]. Yet the way these challenges are interpreted, negotiated, and supported varies widely depending on cultural, social, and geographic context.

In Greece, a country with a rich but complex socio-cultural fabric and ongoing economic constraints, the experiences of

parents raising children with autism are shaped by a combination of familial traditions, religious values, public health limitations, and societal attitudes toward disability. While some studies have begun to explore autism in the Greek context [4,5], most research has focused on urban centres, leaving the experiences of families in rural regions significantly underexplored. Rural Greek families often have fewer resources, less access to specialised services, and more entrenched societal stigma, all of which influence how they perceive and respond to their child's diagnosis.

International literature recognises the multifaceted impact of autism on family life, encompassing not only psychological strain but also economic hardship and disrupted social dynamics [6,7]. Mothers, in particular, frequently report feelings of guilt, exhaustion, and emotional burnout [8]. In the Greek context, these emotional experiences are further influenced by strong cultural expectations surrounding motherhood, family honour, and religious interpretations of suffering and difference [9,10]. Moreover, stigma remains a significant issue in many Greek communities, often leading to concealment, withdrawal from public life, and delayed access to diagnosis and support [11,12].

While legislation in Greece formally guarantees support for individuals with developmental disabilities—such as Law 3699/2008 mandating inclusive education— implementation is uneven, particularly in rural areas. Families outside major cities frequently report difficulty accessing diagnosis, therapy, and educational accommodations [13]. In response, parents often turn to informal support networks, local associations, and the internet for guidance—though the quality and consistency of such information can vary greatly [14,15].

This study addresses the gap in culturally and geographically situated autism research by exploring the lived experiences of parents in a rural northern Greek province. Through a qualitative design using semi-structured interviews, the research investigates four interrelated questions: (1) How do Greek parents understand and interpret autism? (2) How has autism affected them in their role as parents? (3) What sources of information do they rely on? and (4) What forms of support have they accessed, and how effective have these been?

#### **Methods**

## Study design

This study employed a qualitative, phenomenological research design to explore the lived experiences of parents raising children with autism in rural Greece. Phenomenology is particularly well-suited to this inquiry, as it seeks to understand how individuals make meaning of their personal experiences in specific social and cultural contexts [16]. The aim was not to generalize but to capture the depth and complexity of parental perspectives in a region where autism remains under-discussed and under-researched.

## Participants and sampling

Participants were recruited through a local parent association for families of children with autism in a rural northern Greek province. Purposive sampling was used to select individuals who met specific inclusion criteria: (1) they were the legal guardians of a child formally diagnosed with autism by a public educational or medical authority in Greece; (2) their child had been diagnosed at least four years prior to the interview; and (3) they resided outside major urban centres, specifically in areas defined as rural by Greek administrative standards. Seven parents participated in the study four mothers and three fathers. The age of their children ranged from 10 to 15 years. While the sample size was small, it aligns with best practices in qualitative research, where depth and richness of data are prioritized over breadth [17,18].

#### **Data collection**

Data were gathered through semi-structured, face-to-face interviews conducted in Greek, allowing participants to express themselves in their native language and in a manner that felt natural and comfortable. Interviews were guided by a flexible question schedule covering four key thematic areas: (1) parental understanding of autism, (2) the impact of autism on daily life and identity, (3) sources of information, and (4) the role and effectiveness of support systems.

Each interview lasted approximately 60 to 90 minutes and was audio-recorded with the participant's consent. A pilot interview was conducted prior to the main study to refine the question format, improve clarity, and assess emotional sensitivity. The final interview guide consisted of 13 open-ended questions designed to elicit in-depth narratives while allowing room for emergent themes.

## Data analysis

Interviews were transcribed verbatim and translated from Greek to English by the researcher. While care was taken to preserve the meaning and emotional tone of the original dialogue, some limitations due to linguistic and cultural translation were acknowledged. Translation was conducted in consultation with native speakers to reduce potential distortion, especially for idiomatic expressions or emotionally charged responses.

Thematic analysis was employed to interpret the data, following Braun and Clarke's (2006) [19], six-phase approach: familiarisation, coding, theme identification, theme review, theme definition, and reporting. NVivo software was used to assist with data organisation and coding. Four main thematic categories emerged: (1) parental understanding of autism, (2) the emotional and practical impact of autism, (3) the pathways and barriers to acquiring information, and (4) formal and informal support systems.

## **Ethical considerations**

The study received ethical approval from the University of South Wales' ethics committee. All participants were provided

with an information sheet and consent form outlining the purpose of the study, their right to withdraw at any time, and the measures taken to ensure confidentiality. Pseudonyms were used in all transcripts and reports to protect participant identities. Interview recordings and transcripts were stored on a password-protected, encrypted drive accessible only to the researcher.

Given the potentially sensitive nature of the discussions, particular care was taken during the interviews to ensure emotional safety. Participants were reminded that they could skip any question or terminate the interview at any point. In cases where participants became visibly emotional, the interview pace was adjusted, and information about counselling services was offered.

#### Results

The thematic analysis of interviews with seven parents revealed four central, interwoven themes that reflect their lived experiences raising autistic children in rural Greece: (1) Parental Understanding of Autism, (2) Impact on Daily Life and Emotional Well-being, (3) Sources of Information, and (4) Support Systems. These findings illustrate a nuanced portrait of parental resilience, cultural tension, emotional vulnerability, and adaptive learning within a socio-political landscape often unequipped to meet their needs.

## Parental understanding of autism

Parents described their first encounters with autism not through clinical definitions, but through lived confusion and daily observations. Many had not heard of autism prior to their child's diagnosis, or associated it with outdated or negative stereotypes. Early signs such as a lack of eye contact, speech delays, repetitive behaviours, or resistance to physical affection were often misattributed to shyness, hearing problems, or "just being different." Anna, a mother of a 13-year-old boy, explained: "He didn't talk, avoided hugs, stared at things. We thought maybe it was a phase. The word 'autism' never crossed our minds." Diagnosis brought a mixture of validation and devastation. For most, it offered clarity—an answer to years of questions. But it also marked the beginning of an emotionally taxing journey. Parents had to quickly reframe their understanding of their child and begin navigating a system that often offered little guidance. Hermes, a father of a 12-year-old son, described it as follows: "When the diagnosis came, it was like hearing a foreign word. It helped, yes, but also scared us. We didn't know what the future would look like." Most parents reported learning about autism not from professionals, but from their own attempts to make sense of the behaviours they observed. Their interpretations evolved over time, informed by personal reflection, exposure to other families, and (in some cases) educational seminars. However, in the early stages, this lack of understanding often delayed access to appropriate support. Furthermore, cultural and religious lenses significantly influenced how parents made sense of the

diagnosis. Some interpreted autism as a "test" or burden given by God, while others struggled with internalised shame due to societal misconceptions. Ioli stated: "My aunt told me maybe it was because I worked too much when I was pregnant. I started blaming myself.". Such reflections underscore the interplay between personal meaning-making and collective cultural narratives, which shaped how these parents approached not only autism, but also themselves and their identities as caregivers.

#### Impact on daily life and emotional well-being

The emotional toll of raising a child with autism in a rural Greek setting was a dominant theme. Participants spoke at length about feelings of exhaustion, isolation, uncertainty, and emotional vulnerability. The rhythms of everyday life were altered dramatically. Ordinary tasks shopping, schooling, socializing—became logistical and emotional challenges. Eva, whose son is 15, stated: "Even going to the supermarket feels like preparing for battle. I watch every move, every sound, always afraid of a meltdown".

Daily life was described as rigidly structured. Many parents reported adhering to strict routines to avoid distress in their children, but this often-left little space for spontaneity or personal well-being. Several participants noted feeling "trapped" in their own homes, with social isolation stemming both from caregiving demands and societal judgment. Rania stated: "We don't go out anymore. He doesn't like it, and people stare. Some think I've done something wrong to raise a child like this.". Emotional fatigue was compounded by limited institutional support. Parents repeatedly mentioned how mental health services were either absent, too far away, or too expensive. As a result, they became the primary emotional regulators in their families, often without professional help. Despite these difficulties, parents also described unexpected moments of joy and resilience. Several spoke about how their child had transformed their outlook on life, teaching them patience, empathy, and strength. Alexander stated: "He taught me to appreciate small things—like when he looks at me and smiles. Those moments carry me through.". At the same time, long-term concerns loomed large. Nearly all participants worried about the future—particularly what would happen to their child when they were no longer able to provide care. Paulos declared: "Who will look after him when I'm gone? This thought keeps me awake at night.". This blend of daily endurance, emotional highs and lows, and long-term anxiety formed a common emotional landscape across the interviews.

## **Sources of information**

Accessing accurate, timely, and understandable information was one of the most significant hurdles faced by the parents. The majority first turned to the internet after noticing atypical behaviours, searching for terms like "speech delay" or "avoids eye

contact." This early exploration often led them down contradictory paths. Ioli stated: "One website said it's vaccines. Another said it's parenting. I didn't know what to think.". While the internet offered initial insights, it also sowed confusion and fear, particularly when it exposed parents to pseudoscientific claims or miracle-cure narratives. Participants expressed frustration over the lack of structured, evidence-based information in Greek. Eva declared: "I found helpful articles but they were all in English. Translating them was hard, and I kept wondering if I was doing things right.". Only after receiving an official diagnosis did some parents gain access to more credible information—through public seminars, special education staff, or local associations. However, these resources were described as limited in scope and frequency, often requiring travel to urban centres like Thessaloniki. Grandparents, extended family, and neighbours were also sources of information—though not always reliable. Cultural narratives about parenting, discipline, or divine punishment were sometimes shared as "advice," which parents found confusing or hurtful. In the absence of robust professional support, parents became self-taught experts, relying heavily on trial and error, peer learning, and the lived experience of caring for their child.

#### Support systems

The fourth major theme was the inconsistent and often inadequate nature of support systems available to families. Participants described support as "patchy," "slow," or "invisible." Government assistance was seen as minimal and unreliable, particularly in rural regions where infrastructure was weak. Hermes declared: "The school promised parallel support. A year passed, and we're still waiting.". Parents voiced frustration with the gap between official policy and lived reality. While national laws mandate inclusive education and therapeutic access, implementation varied dramatically depending on location, school resources, and staff training. Financial support was another major concern. Most therapies—speech, occupational, behavioural—were only partially subsidized or not at all. Several parents reported having to pause interventions due to cost, with long-term consequences for their child's development. Also, Anna stated: "We had to stop ABA [Applied Behaviour Analysis]. It was too expensive. No one explained if there were free alternatives.". Psychological support for parents themselves was largely absent. Only one participant had regular access to a psychologist. Others coped through informal means—faith, journaling, conversations with other parents, or, in some cases, emotional withdrawal. One of the more consistent sources of strength came from local associations. These spaces provided both emotional solidarity and practical knowledge. However, their reach was limited, especially in more isolated villages. The role of grandparents emerged again as both a supportive and contested presence. Some were described as indispensable in caregiving; others clashed with parents over their interpretations of autism and child-rearing. Alexander declared: "My father thinks my son just needs discipline. He doesn't accept the diagnosis. It hurts.". Religious beliefs also

played a dual role. For some, faith was a source of comfort and endurance. For others, it reinforced feelings of guilt or

passive acceptance of suffering. Finally, many participants drew comparisons with other countries, often through online communities. They perceived countries like the UK, Sweden, or the Netherlands as offering more humane and organised systems for autism care. Rania declared: "If we lived in another country, maybe things would be different. Maybe easier."

## Discussion

This study set out to explore the lived experiences of rural Greek parents raising children with autism. Through in-depth qualitative interviews, four interconnected themes emerged: parental understanding of autism, emotional and practical impact on daily life, access to information, and the role of support systems. These findings both confirm and extend existing literature on autism parenting, particularly within culturally and geographically specific contexts. The findings confirm that many parents first encounter autism through confusion and uncertainty, rather than informed clinical pathways—a trend documented in both global [2,20] and Greek literature [4,9]. In rural Greece, where autism remains under-recognised, parents often notice behavioural differences long before a diagnosis is offered. This lag in identification reflects not only limited awareness but also insufficient early screening protocols in non-urban settings.

As in other studies, diagnosis brought both clarity and emotional upheaval [6,7]. In the Greek context, however, this process was complicated by deeply held cultural and religious beliefs. Some participants described autism through the lens of personal failure, divine punishment, or familial shame—echoing earlier findings by Kourkoutas (2010) and Sinodinou (2007) [10,11], who noted the significant influence of Orthodox Christian values and collectivist family structures on parental perceptions.

At the same time, parents also constructed alternative, often more empowering interpretations of autism. Many viewed their children as teachers of patience, resilience, or unconditional love, resonating with recent literature on parental growth and meaning-making in the context of disability [21,22]. This shift in framing—from deficit to difference—suggests that cultural narratives are not static but negotiable, even within traditionally conservative environments. The study reinforces existing knowledge on the emotional and practical demands placed on parents of autistic children, particularly mothers [8]. Participants described their lives as structured around routines, shaped by fear of public scrutiny, and constrained by exhaustion. In contrast to some urban-based studies, however, the rural context introduced additional burdens: geographical isolation, lack of specialised services, and limited access to inclusive education.

Importantly, this study highlights the "invisible labour" parents perform not only as caregivers but also as therapists, advocates, teachers, and emotional buffers. This aligns with Gena's (2002)

[23], observations about the multifaceted roles assumed by Greek mothers, who often navigate their child's developmental journey without adequate institutional scaffolding. The emotional toll of this labour was palpable in participants' narratives. Many spoke of feeling trapped, anxious, or chronically fatigued—descriptions consistent with the concept of "chronic sorrow" [24]. At the same time, the resilience evident in these accounts supports arguments by Gray (1998) and Altiere and von Kluge (2009) that families adapt over time, developing unique strengths in response to chronic adversity [25,26].

A striking finding was the fragmented and often misleading nature of parents' initial information sources.

The internet, while accessible, was described as both a lifeline and a minefield—offering unfiltered content that oscillated between helpful and harmful. This corroborates research by Goddard, Lehr, and Lapadat (2000) [27], on the internet's double-edged role in autism parenting. In rural Greece, the absence of formal information pathways was particularly problematic. Without proactive guidance from professionals, many parents were left to interpret autism independently—often encountering pseudoscientific claims, outdated perspectives, or anecdotal advice. This lack of clear, accessible, and culturally relevant information increases the risk of confusion and delay in effective intervention.

Language barriers further compounded the issue. Much of the high-quality literature and online content is in English, leaving Greek-speaking parents dependent on translated or locally generated materials, which are often scarce or overly clinical. The need for accurate, plain-language, and contextually tailored information—delivered early and continuously—is critical. While Greek legislation, particularly Law 3699/2008 [28], mandates inclusive education and therapeutic support for children with disabilities, implementation remains inconsistent—especially in rural regions. Participants' experiences confirm previous findings by Drosinou-Korea (2017) and Moutavelis et al. (2015) [13,29], who describe a policy- practice gap exacerbated by economic austerity, administrative inefficiency, and staffing shortages. One clear example of this gap is the parallel support model, which theoretically allows children to receive specialised instruction alongside mainstream schooling. Despite being guaranteed by law, several parents in this study reported long delays or complete absence of such support, echoing concerns raised by Mavropalias and Anastasiou (2016) [30].

Financial burden was another central concern. Therapeutic interventions—particularly speech therapy, occupational therapy, and behavioural programs—were often only partially subsidised or not at all. In a country still grappling with the effects of the 2008 economic crisis, these costs proved prohibitive for many families, reinforcing health inequities between urban and rural populations. Psychological support for parents was almost universally absent. This finding is especially troubling given the

high emotional toll documented in this and other studies. The lack of accessible counselling services or caregiver respite programs underscores the urgent need for family-centred policy approaches. One partial remedy came in the form of local parent associations, which emerged as vital nodes of support. These associations offered not only practical advice but also emotional solidarity—a space where parents could feel heard and understood. However, their reach was limited, and their reliance on volunteer efforts made sustainability an ongoing concern.

A culturally unique feature of this study was the central role of grandparents. In some cases, they were sources of strength, contributing caregiving support and family cohesion. In others, they were sources of tension, bringing outdated views or attributing autism to supernatural or moral causes. This dual influence reflects broader Greek cultural dynamics, where extended family networks play a central but sometimes conflicting role in health and caregiving decisions [31].

Religion also played a dual role—sometimes providing meaning and comfort, other times reinforcing guilt or resignation. Some participants drew strength from their faith, seeing their situation as part of a divine plan. Others described how religious interpretations from their social circle led them to question their parenting or feel stigmatised. These findings align with previous work by Kourkoutas (2010) and the Greek Orthodox Archdiocese (2017) [10,32], which highlight the ambivalent relationship between faith, disability, and social identity in Greek society.

While many of the challenges described by participants are common to parents of autistic children worldwide, the rural setting added layers of complexity. Distance from urban centres restricted access to diagnosis, therapies, and inclusive education. Parents frequently had to travel long distances to attend seminars or medical appointments, often at significant financial and emotional cost. Moreover, smaller communities were described as more judgmental, with stigma and gossip acting as strong deterrents to seeking support. This finding echoes Hoogsteen's et al., [33], observations in rural Canada and suggests that geographic isolation is not only logistical but also deeply social and psychological.

## Limitations

While this study offers valuable insights into the lived experiences of rural Greek parents raising children with autism, several limitations must be acknowledged. First, the sample size was small (n=7), as is typical in phenomenological qualitative research. While the aim was to explore depth rather than achieve generalisability, the limited number of participants—drawn from a single rural province—means that findings may not fully represent the diversity of parental experiences across Greece or other rural areas with different socio-cultural dynamics. Second, all interviews were conducted in Greek and later translated into English by the researcher. Despite careful attention to accuracy

and cultural nuance, some meaning may have been lost or altered in translation—particularly emotionally charged expressions or idiomatic language. This introduces the potential for interpretive distortion. Third, gender representation among participants was slightly skewed toward mothers (four mothers, three fathers). While this reflects the caregiving realities observed in many families, it may also reinforce gendered patterns in who feels entitled or willing to speak on these issues. The study could benefit from broader inclusion of fathers, grandparents, or siblings in future research. Fourth, participant recruitment was facilitated through a local parent association. While this provided access to engaged and willing participants, it may have biased the sample toward families who are already connected to informal support networks. Parents without such affiliations—who may be more isolated or overwhelmed—were not captured in this study. Lastly, this research was conducted during a specific socio-economic period in Greece marked by continued austerity and post-crisis recovery. The findings are therefore shaped by contemporary political and financial conditions, which may evolve and affect future parenting experiences differently.

#### Conclusion

The findings of this study reaffirm existing international literature on the stress and stigma experienced by parents of autistic children, while offering new insight into how these experiences are shaped by Greek cultural norms, economic austerity, religious beliefs, and rural isolation. Despite the systemic challenges, participants displayed considerable agency. They navigated gaps in service provision by becoming self-taught experts, leaned on family and peer networks for support, and reframed autism through more personal and sometimes spiritual lenses. At the same time, the lack of consistent professional guidance, accessible therapies, and inclusive educational options limited their capacity to fully support their children's development.

The implications of this study are both immediate and long-term. Policymakers and service providers must recognise the need for decentralised, culturally sensitive, and sustainably funded autism support structures—particularly in rural regions. Information must be made accessible in clear, accurate, and native-language formats, and parent mental health must be addressed as a key area of concern, not a secondary consideration. Furthermore, the findings highlight the importance of moving beyond a purely clinical or individualised understanding of autism toward one that acknowledges the socio-cultural and structural contexts in which families live. Autism cannot be fully understood in isolation from the economic, religious, and educational systems that either support or constrain families.

This study's strength lies in its in-depth, narrative approach and its focus on an underrepresented population. While it does not claim generalisability, it offers a valuable, grounded contribution to both Greek and international discussions on autism and family life.

Future research should build on these findings by including a more diverse range of voices—fathers, siblings, educators—and by exploring longitudinal experiences across different life stages. Greater attention should also be given to how stigma, religion, and rurality interact in shaping both challenges and coping strategies among families. Ultimately, understanding autism in Greece—or anywhere—requires listening carefully to those who live it every day. The parents in this study, through their honesty and resilience, challenge simplistic narratives and call for a more inclusive, compassionate, and responsive social framework.

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