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The Role of Culture in the Lived Experiences of Parents Raising Children with Autism Spectrum Disorder: A Phenomenological Study

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Abstract: This phenomenological study explored how culture shapes the lived experiences of parents raising children with autism spectrum disorder (ASD) in Benguet Province, Philippines. It examined parents' caregiving experiences, cultural influences, coping and meaning-making processes, and sources of support and resilience. Using an interpretive phenomenological approach, eight parents were purposively selected based on established eligibility criteria. Data were collected through semi-structured interviews and analyzed using Braun and Clarke's reflexive thematic analysis. The findings revealed six themes: reconstructing meaning after ASD diagnosis; culture as a foundation of caregiving and family responsibility; negotiating cultural expectations and community understanding; spirituality and meaning making in the caregiving journey; building resilience through support networks; and culturally responsive support needs. Participants described initial emotional struggles, including fear, uncertainty, and self-blame, followed by gradual acceptance and a deeper understanding of their children's needs. Cultural practices such as *binnadang*, family involvement, and spirituality provided emotional encouragement, practical assistance, and strength in navigating caregiving challenges. However, community misconceptions, stigma, and limited access to accessible and affordable services remained significant concerns. The findings highlight culture as both a source of support and a context in which caregiving challenges are experienced. The study underscores the importance of culturally responsive, family-centered, and inclusive support systems and proposes the Culturally Responsive Parent Support Framework (CRPSF) as a potential basis for strengthening family, school, healthcare, and community collaboration in supporting parents and children with ASD.

Keywords: Autism Spectrum Disorder; caregiving; culture; lived experiences; parental resilience

INTRODUCTION

ASD is a complex neurodevelopmental condition that affects how people communicate, interact socially, behave, and participate in daily activities. It not only affects the individual but also shapes the roles and responsibilities of parents and families (Essel et al., 2026). Globally, parents raising children with ASD deal with a range of challenges—emotional, psychological, social, and financial—as they manage diagnoses, caregiving, educational needs, and find support services (Essel et al., 2026; Wang et al., 2025). Parenting a child with ASD is not only about medical or developmental issues; it is deeply influenced by cultural beliefs, family values, religious practices, traditions, and community ties, all of which affect how parents understand and respond to their child's needs (Essel et al., 2026; Wang et al., 2025).

This intersectional experience is closely linked with the United Nations Sustainable Development Goals (SDGs). Take SDG 3 (Good Health and Well-being), for instance. It is all about promoting the overall physical and mental health of children with ASD and their caregivers by ensuring that they have access to proper health services and family-centered support (Essel et al., 2026). SDG 4 (Quality Education) emphasizes the need for inclusive, fair, and accessible educational opportunities that cater

to the learning needs of children with ASD. It highlights the importance of systems that recognize diverse needs (Essel et al., 2026). Lastly, SDG 10 (Reduced Inequalities) focuses on breaking down discrimination, social exclusion, and the barriers that often prevent children with disabilities and their families from accessing services and opportunities (Wang et al., 2025). Therefore, holistic support frameworks go beyond clinical interventions. They include inclusive education systems, accessible community services, and family-centered approaches that respect the cultural contexts of caregiving. Developing responsive support systems means acknowledging and respecting families' beliefs, values, traditions, and lived experiences to effectively meet their unique challenges and build resilience (Essel et al., 2026; Wang et al., 2025).

In the Philippines and nearby regions, caregiving is tied to family bonds, religious beliefs, spirituality, and community involvement. These elements play a significant role in how families make decisions and support children with ASD (Essel et al., 2026). Filipino parents of children with ASD face a number of challenges, such as social misconceptions, limited awareness, financial pressures, and difficulty accessing professional services and inclusive education (Essel et al., 2026). However, extended family networks and community involvement are crucial. They offer emotional support, practical help, and shared caregiving duties, showing that support is a collective effort (Essel et al., 2026). In places such as the Cordillera Administrative Region and Benguet Province, cultural traditions, family ties, and community practices, such as Binnadang—which is all about mutual help and cooperation—shape everyday caregiving and social support (Essel et al., 2026). Spirituality, family values, and community relationships give parents strength, hope, acceptance, and resilience as they navigate caregiving. However, cultural expectations and misconceptions about disabilities can also lead to social judgment and emotional stress (Essel et al., 2026).

Parents raising children with autism spectrum disorder (ASD) in Benguet Province go through caregiving in a setting that is shaped by their unique cultural, family, and community backgrounds. They deal with understanding and accepting their children's developmental conditions while adjusting family roles and handling daily caregiving tasks. This adjustment means that they draw strength and resilience not only from family ties but also from spirituality, cultural traditions, and community practices—key elements in how they find meaning and cope with challenges (Md Salim et al., 2026; Wang et al., 2025). Their caregiving journey is marked by acceptance, patience, shared responsibility, and understanding within family and community networks, which act as important support systems during tough times (Guo et al., 2026; Hayes et al., 2022). Even with culturally rooted support systems like mutual assistance practices similar to Binnadang, parents still encounter social misconceptions, limited awareness about ASD, and difficulties accessing services, similar to issues seen in other non-Western settings (Md Salim et al., 2026; Ng & Ng, 2022). The current literature shows a gap in research when it comes to deeply exploring how these cultural values and community practices are linked to caregiving experiences in rural parts of the Philippines, especially in Benguet Province, where phenomenological studies are rare. Most previous research has focused on Western or urban populations and leans heavily on quantitative methods, which do not provide much insight into the culturally embedded personal meanings parents attach to their caregiving journey (Md Salim et al., 2026; Zeng & Chohan, 2026).

Focusing on an interpretive phenomenological approach that considers biological parents as the main caregivers can shed light on how local culture— such as spirituality, family dynamics, and community values—affects resilience, coping strategies, and how caregiving is viewed in Benguet. These culturally rich stories can help create family support systems that are sensitive to the specific social and cultural situations these parents face (Guo et al., 2026; Wang et al., 2025). This kind of focused research could really bridge some important gaps by offering detailed insights needed to design interventions that not only respect but also make use of Indigenous cultural strengths, while tackling the challenges these families encounter.

STATEMENT OF THE PROBLEM

This phenomenological study explores how culture shapes the lived experiences of parents raising children with autism spectrum disorder (ASD) in Benguet Province. Specifically, it seeks to answer the

following questions:

1. What are the lived experiences of parents in Benguet Province raising children with autism spectrum disorder within their cultural context?
2. How do cultural beliefs, values, traditions, and community practices influence parents' perceptions and day-to-day caregiving experiences?
3. How do parents interpret and respond to the emotional and psychological challenges of raising a child with ASD through culturally influenced coping and meaning-making processes?
4. What cultural and community-based resources, support systems and practices do parents identify as contributing to their resilience and helping them navigate the challenges of raising a child with ASD?

METHODOLOGY

This study employed a qualitative phenomenological research design, specifically an interpretive (hermeneutic) phenomenological approach, to explore the lived experiences of parents raising children with autism spectrum disorder (ASD) in Benguet Province, Philippines. This approach enabled the researchers to examine how parents interpret and make sense of their caregiving experiences within their cultural, familial, and community contexts.

The study involved eight participants who were selected through purposive sampling based on their direct experiences as parents and primary caregivers of children diagnosed with ASD. The participants were biological mothers or fathers who lived in the same household as their children, had at least two years of caregiving experience, and had resided in the selected communities of La Trinidad and Buguias, Benguet, for at least two continuous years. The study focused on parents of children aged 5–18 years with a documented ASD diagnosis issued by a licensed medical professional at least two years before data collection, with the children classified under ASD Levels 1 or 2.

Data were collected using a researcher-developed semi-structured interview guide consisting of open-ended questions that aligned with the research objectives. The interview questions explored participants lived experiences of raising a child with ASD, particularly their cultural beliefs and practices, family relationships, caregiving responsibilities, spirituality, coping strategies, challenges encountered, and sources of support in this regard. The open-ended nature of the questions allowed the participants to describe their experiences, perceptions, and interpretations in their own words.

The interviews were conducted in a private and comfortable location mutually agreed upon by the researcher and participants, with each session lasting approximately 45–90 min. Participants were allowed to express themselves in Ilocano, Filipino, English, or a combination of these languages to facilitate meaningful and authentic responses to the questions. With their permission, the interviews were audio recorded and transcribed verbatim. Reflexive field notes were maintained to document relevant observations, contextual information, and reflections throughout the data collection process.

The collected narratives were analyzed using Braun and Clarke's Reflexive Thematic Analysis, following six recursive phases: familiarization with the data, generation of initial codes, construction of initial themes, review and refinement of themes, definition and naming of themes, and production of the final report. This analytical approach facilitated the identification and interpretation of patterns of meaning across participants' accounts, providing an understanding of how cultural contexts, family relationships, spirituality, caregiving experiences, and support systems were reflected in the lived experiences of parents raising children with ASD.

RESULTS AND DISCUSSION

Profile of Participants

The study involved eight parents of children diagnosed with autism spectrum disorder (ASD) in Benguet Province, Philippines. The participants comprised six mothers and two fathers who served as the primary caregivers of their children. The children were between 6 and 15 years old at the time of the study, and their ages at diagnosis ranged from 2 to 5 years. Participant codes (AP1–AP8) were used to protect the participants' identities.

Table 1. Profile of Participants

Participant	Relationship to Child	Child's Age	Age at Diagnosis
AP1	Mother	10 years	2 years, 8 months
AP2	Mother	12 years	5 years, 3 months
AP3	Mother	9 years	3 years, 6 months
AP4	Father	11 years	4 years
AP5	Father	8 years	3 years
AP6	Mother	6 years	2 years
AP7	Mother	12 years	4 years
AP8	Mother	15 years	5 years

Emergent Themes

The analysis of the participants' narratives revealed six major themes concerning the lived experiences of parents raising children with ASD: These themes reflected their emotional responses following diagnosis, cultural and family influences, experiences with community expectations, spirituality, resilience, and perceived support needs.

Table 2. Emergent Themes and Subthemes the Role of Culture in the Lived Experiences of Parents Raising Children with Autism Spectrum Disorder

Emergent Themes	Subthemes
1. Reconstructing Meaning After ASD Diagnosis	Initial emotional responses; movement toward acceptance; redefining expectations
2. Culture as a Foundation of Caregiving and Family Responsibility	*Binnadang* and collective caregiving; family involvement in decision-making
3. Negotiating Cultural Expectations and Community Understanding	Stigma and misconceptions; balancing acceptance and social expectations
4. Spirituality and Meaning-Making in the Caregiving Journey	Prayer as strength; faith-based acceptance and hope
5. Building Resilience Through Support Networks	Family support; parent-to-parent connection; personal growth
6. Culturally Responsive Support Needs	Awareness programs; accessible services; inclusive community support

Parents raising kids with autism spectrum disorder (ASD) often deal with a mix of emotional, social, and cultural challenges that really shape their caregiving journey. All over the world, caregivers go through a tough emotional process when they first receive the diagnosis. It starts with grief and slowly moves toward acceptance, all influenced by cultural and family values that affect how they understand and respond to their child's needs (Galán-Vera et al., 2025; Malhi et al., 2022). In places like China and Spain, parents say that getting the diagnosis means they have to rethink their expectations and adjust how their family works. Support networks, including social and community resources, become super important for building resilience and coping (Han & Gao, 2025; Wang et al., 2025). Caregivers often face hurdles such as stigma, social isolation, financial stress, and limited access to specialized services, which make their caregiving roles and emotional well-being even more challenging (Dira et al., 2024; Malhi et al., 2022). The cultural backdrop plays a big role in how parents make sense of things, where spirituality and faith might be sources of strength, and family values keep their caregiving efforts and resilience going strong (Galán-Vera et al., 2025; Mohamed et al., 2026). Parents also stress the need for culturally responsive support systems that include mental health care, inclusive education, and community awareness to fill service gaps and boost family functioning (Dira et al., 2024; Han & Gao, 2025; Sousamli et al., 2026). This overview highlights how culture, social support, and coping strategies play key roles in shaping the experiences of parents raising children with ASD in different global and cultural settings.

Theme 1. Reconstructing Meaning After ASD Diagnosis

Participants described the diagnosis of ASD as an emotionally challenging experience, characterized by

fear, confusion, sadness, and self-blame. During the initial period, some parents struggled to understand the condition and expressed concerns about their children's future, education, independence, and social relationships.

Participant AP1 recalled the emotional experience of receiving a diagnosis:

"I was also blaming myself, asking myself, maybe I did not take care of my child. I also asked questions if why this happening to my child is?" (AP1)

Over time, participants described gradually developing a better understanding of ASD and accepting their children's individual abilities and developmental needs. Their accounts reflected a shift from uncertainty to patience, understanding, and acceptance.

Theme 2. Culture as a Foundation of Caregiving and Family Responsibility

Family relationships and cultural values emerged as important sources of support in the participants' caregiving experiences. In particular, the cultural practice of *binnadang*, which participants described as helping one another, reflected shared responsibility in caring for children with ASD.

Participant AP1 explained this as follows:

"In our culture, we have what we call binnadang, in which we help each other. I remember when I had to work because our caregiver bid us goodbye. Our relatives took turn in caring for my children so that I can work." (AP1)

Participants also described their family members as sources of emotional encouragement, childcare assistance, and practical support. These experiences show that caregiving responsibilities are often shared among parents, relatives, and other family members.

Theme 3. Negotiating Cultural Expectations and Community Understanding

Participants reported experiences of community misunderstanding, insensitive comments, and misconceptions about ASD. Some encountered individuals who interpreted their children's behaviors as signs of poor discipline or being spoiled. These experiences sometimes caused emotional distress and placed additional pressure on parents.

Participant AP1 shared:

"Sometimes people will say something about my child's behavior. I heard a man say, 'Spoiled siguro.' They think I do not discipline my child." (AP1)

Despite these experiences, parents described learning to prioritize their children's developmental progress rather than conforming to other people's expectations. Some also expressed the need to promote greater awareness and understanding of ASD within their communities.

Theme 4. Spirituality and Meaning-Making in the Caregiving Journey

Spirituality and religious beliefs were identified as sources of strength, hope, and emotional support for the participants. Participants described prayer and faith as ways of managing uncertainty and sustaining their commitment to care.

Participant AP1 stated:

"*Even I sometimes felt giving up, still I pray a lot. I pray for patience, good health and wisdom to understand him and guide him." (AP1)*

Beyond providing emotional strength, participants described how raising a child with ASD influenced their understanding of parenting, patience, and personal growth. They learned to appreciate their children's progress and recognize individual differences in development.

Theme 5. Building Resilience Through Support Networks

Participants described resilience as developing through their experiences, family relationships, and ongoing efforts to support their children. Family members provided practical assistance and emotional encouragement, helping parents manage their caregiving responsibilities and feelings of isolation.

Participant AP4 shared:

"*My family helps us a lot. When we are tired, they remind us that we are not alone in this journey." (AP4)*

Participants also described personal growth, particularly in terms of developing patience, understanding, and acceptance. Their experiences highlighted how support networks and changing perspectives helped them continue their caregiving journeys.

Theme 6. Culturally Responsive Support Needs

Although participants recognized the importance of family and cultural support, they also identified the need for stronger community-based and formal support services in the field. Their accounts emphasized the importance of autism awareness, accessible interventions, affordable services, and coordinated assistance from schools, healthcare providers, and local government units (LGUs).

Participant AP2 expressed the need for greater community awareness and organized support:

"Parents' support groups, awareness programs, information campaigns about autism, and more understanding from the community would help." (AP2)

Participants also emphasized the importance of affordable interventions and accessible assistance for families, particularly those living outside urban centers.

CONCLUSION

This study revealed that the lived experiences of parents raising children with autism spectrum disorder (ASD) in Benguet Province are deeply shaped by cultural beliefs, family relationships, spirituality, community expectations, and shared caregiving practices. The findings showed that parents experienced emotional challenges following their children's diagnosis, gradually developed acceptance and understanding, and redefined their expectations as they navigated their caregiving journey. Cultural values, particularly *binnadang* and collective family responsibility, provided practical and emotional support, while spirituality and faith served as sources of hope, strength, and perseverance for the participants. However, parents also encountered social misconceptions, stigma, and limited access to appropriate support services, highlighting the need for greater awareness of autism and community understanding. The participants' experiences further demonstrated that resilience develops not only through individual adaptation but also through supportive family relationships and meaningful community connections. These findings emphasize the importance of culturally responsive, family centered, and inclusive support systems that recognize the cultural realities and caregiving needs of parents raising children with ASD. Strengthening collaboration among families, schools, healthcare providers, community organizations, and local government units may contribute to more accessible, compassionate, and culturally sensitive support for families in Benguet Province and similar communities in the future.

RECOMMENDATIONS

Based on the findings of this study, the following recommendations are proposed. Families raising children with ASD may be encouraged to strengthen family involvement and shared caregiving practices to promote emotional support, cooperation, and resilience. Community leaders, local government units, and organizations may develop autism awareness and advocacy programs that address misconceptions, stigma, and discrimination while promoting understanding, acceptance, and inclusion. Schools, healthcare providers, and service institutions may strengthen collaboration in providing accessible, affordable, and family-centered services that respond to the developmental and caregiving needs of children with ASD and their parents. Parent support groups and community-based networks may also be established or strengthened to provide opportunities for sharing experiences, practical assistance, emotional encouragement, and culturally meaningful coping strategies. Furthermore, support programs may recognize and respect the cultural beliefs, traditions, spirituality, and collective values of families in Benguet while ensuring that these are integrated with appropriate educational, therapeutic, and psychosocial services. Finally, the Culturally Responsive Parent Support Framework (CRPSF) developed from the study's findings may serve as a basis for designing, implementing, and evaluating culturally sensitive interventions and support initiatives for families raising children with ASD.

LIMITATIONS OF THE STUDY

This study was limited to eight parents raising children with ASD in selected communities in La Trinidad and Buguias, Benguet Province, Philippines. The purposive selection of participants and the

localized setting allowed for an in-depth exploration of culturally situated caregiving experiences; however, the findings may not reflect the experiences of parents from other geographic, cultural, or socioeconomic contexts. The study also focused exclusively on biological parents who served as primary caregivers of children with ASD classified under Levels 1 and 2, thereby excluding the experiences of other caregivers and families whose children may have different support needs. Furthermore, the findings were based on participants' self-reported experiences gathered through interviews, which may have been influenced by individual perceptions, personal interpretations, and contextual circumstances. Despite these limitations, the study provides meaningful insights into the cultural, familial, spiritual, and community dimensions of caregiving and offers a contextually grounded understanding of the experiences of parents raising children with ASD in Benguet Province.

FUTURE RESEARCH DIRECTIONS

Future research may explore the lived experiences of parents raising children with ASD across other provinces, Indigenous communities, and diverse cultural settings in the Philippines to provide broader perspectives on the influence of culture on caregiving. Studies involving larger and more diverse groups of participants, including fathers, grandparents, siblings, extended family members, and other primary caregivers, may further deepen the understanding of family-centered caregiving and support systems. Researchers may also investigate the role of spirituality, collective caregiving practices, community participation, and culturally rooted traditions in promoting parental resilience and well-being. Further research may examine the accessibility, affordability, and effectiveness of educational, therapeutic, healthcare, and community-based services for families raising children with ASD. In addition, the Culturally Responsive Parent Support Framework (CRPSF) proposed from the findings may be subjected to further development, validation, pilot implementation, and evaluation to determine its feasibility, effectiveness, and potential application in supporting families within Benguet Province and other culturally diverse communities.

ETHICS STATEMENT

This study adhered to the ethical principles of conducting research involving human participants. Permission was obtained from the concerned authorities, and informed consent was obtained from all participants prior to data collection. Participation was voluntary, and the participants were informed of their right to withdraw from the study at any time without penalty. Confidentiality and anonymity were maintained through the use of participant codes instead of real names of the participants. Interview data were handled with care and used exclusively for research. This study respected the privacy, dignity, and personal experiences of all participants throughout the research process.

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AI DISCLOSURE STATEMENT

The research, data collection, analysis of findings, and development of conclusions for this study were all carried out without the use of artificial intelligence (AI) tools.