ISSN: 3116-3475
International Journal
of Education, Research, and Innovation Perspectives
Volume 2 Issue 8 (August 2026)

# Lived Experiences of Caregivers of Children with Autism: Implications for Clinical Practices

Ma. Esperanza M. Ordaneza
*Professional Schools, University of Mindanao, Davao City, Philippines*
*m.ordaneza.488456@umindanao.edu.ph*

Date Submitted:
**March 23, 2026**

Date Accepted:
**June 18, 2026**

Date Published:
**August 13, 2026**

DOI:
**10.5281/zenodo.21920984**

**ABSTRACT**

This study explored the lived experiences of caregivers supporting children with severe autism spectrum disorder during the transition from late childhood to early adolescence, with emphasis on caregiving demands, coping strategies, and support systems relevant to clinical practice. A qualitative phenomenological design was employed at the Rainbow Intervention Center of Autism Foundation, Inc. in Davao City. Ten purposively selected participants—center-based caregivers and teachers and caregivers of enrolled children—participated in individual in-depth interviews using a validated and pilot-tested interview guide. Data were transcribed, coded, and analyzed thematically until saturation. Three clusters of findings emerged. Caregiving was emotionally demanding and relationally intense, involving emotional strain and attachment, complex behavioral challenges, communication and social difficulties, and disrupted routines with caregiver fatigue. Participants sustained caregiving through emotional self-care, acceptance and meaning-making, structured behavior management, supportive relationships, and a sense of reward and purpose derived from children's progress. They also identified medical and health services, active family involvement, continuous educational and therapeutic support, safe community-based exposure, and financial or government assistance as essential. The findings support integrated, caregiver-inclusive clinical practices that protect caregiver well-being while strengthening continuity, safety, and developmental support during early adolescence.

**Keywords:** *autism spectrum disorder, severe autism, caregivers, phenomenology, early adolescence, clinical psychology*

## INTRODUCTION

Caregivers are central to the developmental, behavioral, and emotional support of children with autism spectrum disorder (ASD). The demands of care become especially intensive when children require substantial support in communication, self-care, behavior regulation, and safety. ASD is characterized by persistent differences in social communication and interaction together with restricted or repetitive patterns of behavior, and individuals requiring very substantial support may remain highly dependent on adults across daily routines (American Psychiatric Association, 2022; Posar & Visconti, 2023). Global reviews also document increasing identified autism prevalence as recognition and detection have expanded across settings (Zeidan et al., 2022). As children grow, physical maturation can increase the practical complexity of supervision while developmental changes introduce new concerns involving privacy, self-care, social expectations, and independence (Baker et al., 2021; Arslan et al., 2025).

Caregiving burden during this developmental transition extends beyond the number of tasks performed. Caregivers may experience persistent emotional strain, uncertainty, disrupted sleep, social restriction, and difficulty balancing care with personal and family responsibilities. Problem behaviors such as aggression, irritability, tantrums, social withdrawal, or noncompliance can intensify caregiver burden, particularly when

ISSN: 3116-3475
International Journal
of Education, Research, and Innovation Perspectives
Volume 2 Issue 8 (August 2026)

communication is limited and caregivers must interpret behavior as an expression of discomfort or need (Chua et al., 2023; van Niekerk et al., 2023). Qualitative evidence likewise shows that caregivers may experience isolation, stigma, and unmet service needs, while sustained caregiving can simultaneously generate strong attachment, purpose, and commitment (Azubuike et al., 2024; Ray et al., 2024).

The transition to adolescence is therefore a clinically important period. Developmental changes can alter routines, emotional regulation, self-care needs, and the level of assistance required from caregivers. At the same time, families and care providers must navigate service continuity, educational arrangements, behavioral support, and future independence. Existing research has documented changes in the autism behavioral phenotype during transition periods and the need for individualized supports as youth mature (Taylor & Seltzer, 2010). Yet much of the evidence on autism care has been generated outside low- and middle-income settings, limiting understanding of how sociocultural and service contexts shape caregiving experiences (Divan et al., 2024).

Within the Philippines, available studies have described emotional strain, changing family roles, early-intervention experiences, and barriers to services among families raising children with ASD (Leosala, 2023; Reyes & Domingo, 2025). However, less is known about how caregiving is experienced during early adolescence among children with severe ASD, particularly in intervention-center contexts where professional caregivers, teachers, and families share responsibility for daily care. This gap is important because clinical recommendations can only be sustained when caregiver capacity, resources, and support needs are considered alongside the child's developmental needs.

Accordingly, this study explored the lived experiences of caregivers supporting children with severe ASD during the transition to early adolescence. It examined how caregiving affected emotions, behavior, and life routines; identified coping strategies used to sustain care; and elicited caregivers' insights regarding medical, family, educational, therapeutic, community, and financial supports needed during this developmental period. The study sought to translate these lived experiences into implications for caregiver-inclusive clinical practice without separating the well-being of the caregiver from the continuity and quality of care provided to the child.

## Literature Review

### *Autism Spectrum Disorder and the Transition to Early Adolescence*

Autism spectrum disorder is heterogeneous in severity, communication, sensory processing, adaptive functioning, and support requirements. For children with severe ASD, the transition to early adolescence may heighten the caregiving implications of communication limitations, behavioral rigidity, and dependence in daily living. Adolescence also brings physical and social changes that can make established routines more difficult to maintain. Research on adaptive functioning shows that daily living skills remain a major intervention priority for autistic adolescents because limited independence can extend caregiver involvement into toileting, hygiene, meals, mobility, and other routines (Baker et al., 2021). Puberty may create additional self-care and privacy needs that require repeated, concrete teaching and caregiver support (Arslan et al., 2025).

Transition periods can also alter behavioral presentation and service requirements. Taylor and Seltzer (2010) documented developmental changes in autism-related behavior during the transition to adulthood, while Samadi and Samadi (2020) emphasized the breadth of caregiving demands across the lifespan. These changes are clinically relevant because caregivers must adapt strategies as physical size, emotional regulation, communication patterns, and expectations for independence change. A developmentally sensitive approach therefore requires continuity between behavioral intervention, communication support, medical monitoring, and practical life-skills training rather than treating adolescence as merely an extension of childhood services.

### *Caregiver Burden, Emotional Strain, and Family Well-Being*

Caregiver burden reflects both objective demands and the subjective meaning attached to those demands. Zarit et al. (1980) conceptualized burden as the caregiver's appraisal of how caregiving affects emotional, social, and personal functioning. This perspective is highly relevant to severe ASD because constant supervision, challenging behavior, disrupted sleep, and uncertainty can accumulate over time. Studies of caregivers of children

ISSN: 3116-3475
International Journal
of Education, Research, and Innovation Perspectives
Volume 2 Issue 8 (August 2026)

with ASD consistently identify emotional exhaustion, psychological strain, and role disruption, particularly when behavior problems are severe or services are limited (Chua et al., 2023; van Niekerk et al., 2023).

The caregiving experience is not uniformly negative. Attachment, affection, and a sense of contribution may coexist with exhaustion and grief. Recent work has shown that caregivers can experience both substantial stress and meaning derived from the child's development and from their caregiving identity (Manohar et al., 2025). This duality is important for clinical practice because caregiver support should neither romanticize resilience nor reduce caregiving to burden alone. Instead, service systems should recognize both vulnerability and strengths, monitor caregiver mental health, and preserve opportunities for recovery, connection, and positive meaning while the child's support needs remain high.

***Coping, Resilience, and Meaning-Making in Autism Caregiving***

The Stress-Appraisal Coping model explains stress as a dynamic interaction between perceived demands and perceived coping resources rather than as a direct consequence of the event itself (Lazarus & Folkman, 1984). Caregivers continuously evaluate whether a behavior, health concern, or disruption can be managed and what resources are available. In autism caregiving, coping may therefore involve emotion-focused strategies such as acceptance, reframing, and temporary withdrawal, as well as problem-focused strategies such as structured routines, behavioral plans, and help-seeking. Sumbane (2024) similarly identified varied coping strategies among caregivers of children with autism, illustrating the importance of flexibility rather than reliance on a single coping style.

Resource availability further shapes adaptation. Hobfoll's (1989) Conservation of Resources theory proposes that stress increases when valued resources—time, energy, sleep, finances, social support, or access to services—are threatened or depleted. For caregivers of children with severe ASD, repeated sleep disruption, crisis management, medical expenses, and limited respite may produce cumulative resource loss. Conversely, caregiver training, peer support, consistent routines, and accessible services can preserve or restore resources. This perspective complements evidence that parent- and caregiver-mediated interventions can improve confidence and support more sustainable management when caregivers receive structured coaching and feedback (Bradshaw et al., 2022).

***Support Systems, Service Continuity, and Clinical Practice***

Caregiving outcomes are strongly influenced by the surrounding service system. Support is needed not only within the family but across health, education, therapy, and community settings. Clinical continuity becomes especially important during adolescence because medical concerns, behavioral changes, communication needs, and preparation for independence occur simultaneously. Scattoni et al. (2023) highlighted persistent gaps in pathways of care for autistic individuals, while Cheng and Lai (2023) emphasized the protective role of social support in reducing family stress. These findings suggest that caregiver competence is most sustainable when individual coping is reinforced by accessible, coordinated services.

In the Philippine context, culturally responsive and family-centered supports are particularly important because access to specialized services and financial resources can vary widely. Local qualitative studies have already documented service barriers and the emotional demands encountered by Filipino families of children with ASD (Leosala, 2023; Reyes & Domingo, 2025). The present study extends this discussion to early adolescence and foregrounds the interaction between caregiver well-being and continuity of care. Support systems that address medical access, family participation, functional education, therapy, community inclusion, and financial assistance may reduce avoidable interruptions while helping caregivers sustain safe and developmentally appropriate care.

ISSN: 3116-3475
International Journal
of Education, Research, and Innovation Perspectives
Volume 2 Issue 8 (August 2026)

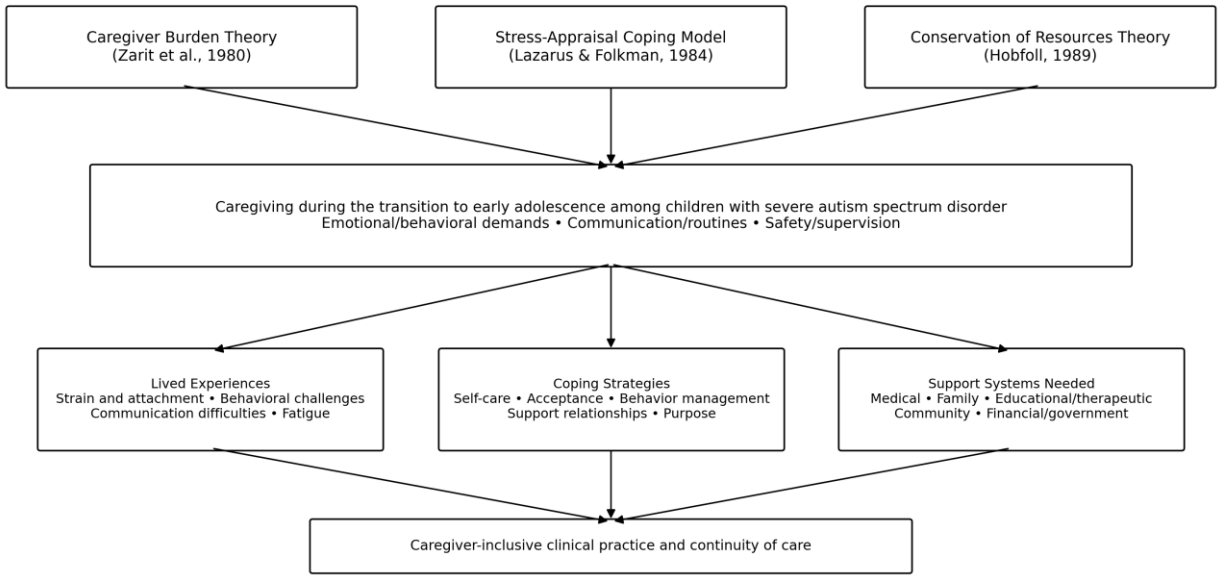


*Figure 1. Conceptual framework of caregiver experiences during the transition to early adolescence.*

## METHODS

### Research Design

The study employed a qualitative phenomenological design to describe the essence and meaning of caregivers lived experiences while supporting children with severe ASD during the transition from late childhood to early adolescence. Phenomenology was appropriate because the inquiry centered on how participants interpreted emotional burden, behavior-related demands, coping, and support needs in everyday caregiving contexts (Moustakas, 1994; Creswell & Poth, 2018). The researcher served as the primary instrument for interviewing, field-note documentation, transcription, coding, theme development, and interpretation, while maintaining reflexive awareness throughout the process.

### Research Locale

The study was conducted at the Rainbow Intervention Center of Autism Foundation, Inc. in Davao City. The center provided a setting in which participants were directly involved in the daily care, teaching, and intervention of children with severe ASD aged approximately 10 to 13 years. This context allowed the inquiry to focus on caregiving experiences during a developmental period in which behavioral, communication, self-care, and supervision needs were changing.

### Participants and Sampling Technique

Purposive non-random sampling was used to recruit ten participants whose experience was directly relevant to the phenomenon. Eight participants were center-based caregivers and teachers involved in intervention services, while two were caregivers of children enrolled in the center. Seven participants were female and three were male. Roles included a supervising head who also functioned as caregiver and teacher, live-in caregivers, and caregiver-teachers. Their caregiving experience ranged from approximately one year and three months to 20 years. Eligibility required being at least 18 years old, having at least one year of practical experience with children with severe ASD, working with children aged 10 to 13, and willingness to participate in an in-depth interview. Data collection continued until thematic saturation was reached.

ISSN: 3116-3475
International Journal
of Education, Research, and Innovation Perspectives
Volume 2 Issue 8 (August 2026)

### Research Instrument

Data were collected using a validated semi-structured interview guide that was partly adapted from related qualitative literature and partly developed by the researcher. The guide contained an orientation and consent section, a demographic profile, and open-ended questions aligned with the study objectives, supported by probing questions. The instrument was reviewed by the research adviser and five expert validators with backgrounds in qualitative research, psychology, special education, and clinical or developmental practice. A pilot test involving five individuals from the same center who were not part of the final sample led to minor revisions in wording, sequencing, and technical terminology before the actual interviews.

### Data Gathering Procedure

After institutional permission was secured, the researcher coordinated with the center's executive director to identify eligible participants. Participants received a pre-interview orientation describing the study purpose, voluntary participation, confidentiality, possible emotional risks, and their right to decline or withdraw. Those who agreed signed informed consent forms. Individual interviews were scheduled at convenient times and conducted in settings that protected privacy. With permission, interviews were audio-recorded and supplemented by field notes. Recordings were transcribed, checked for accuracy, and organized for analysis.

### Data Analysis

Thematic analysis was conducted through familiarization with the transcripts, identification of meaningful statements, generation of initial codes, clustering of related meanings, development and refinement of themes, and synthesis of the essential descriptions of experience (Castleberry & Nolen, 2018). Coding and theme development were repeatedly checked against participants' accounts to preserve context and meaning. Credibility was strengthened through accurate transcription, sustained engagement with the data, member checking with selected participants, and review of emerging interpretations by the research adviser. Transferability was supported through contextual description, dependability through documentation of procedures, and confirmability through verbatim evidence, an audit trail, and reflexive notes consistent with qualitative trustworthiness principles (Lincoln & Guba, 1985).

### Ethical Consideration

Ethical clearance was obtained from the University of Mindanao Ethics Review Committee under Protocol No. UMERC-2025-166. Participants were informed of the study in understandable language, participation was voluntary, and signed consent was obtained before interviews. Anonymous participant codes were used in transcripts and reports, and research data were stored securely in accordance with privacy requirements. The researcher sought to minimize deception, fabrication, and undue influence, while respecting participants' dignity and emotional safety throughout the qualitative process (Mohd Arifin, 2018).

## RESULTS AND DISCUSSION

### Lived Experiences of Caregivers During the Transition to Early Adolescence

Four themes described the lived experiences of caregivers: emotional strain and attachment, complex behavioral challenges, communication and social difficulties, and disrupted routines with caregiver fatigue. Participants described the transition as emotionally demanding because physical maturation and changing behavior increased supervision needs while strong relationships with the children deepened attachment. Emotional overload, fear of not being able to continue, grief after separation or loss, and simultaneous feelings of joy and fulfillment illustrated how burden and attachment coexisted. These accounts are consistent with evidence that caregivers of autistic children experience substantial psychological strain, especially when support needs remain intensive (van Niekerk et al., 2023; Lam et al., 2025).

ISSN: 3116-3475
International Journal
of Education, Research, and Innovation Perspectives
Volume 2 Issue 8 (August 2026)

Table 1. *Lived experiences of caregivers supporting children with severe ASD during early adolescence*

| Emerging Theme | Core Ideas |
|---|---|
| Emotional Strain and Attachment | Emotional overload and fear of not being able to continue; mixed joy, discouragement, and fulfillment; grief after loss or separation; deep emotional bond and empathy; painful adjustment to caregiver rotation. |
| Complex Behavioral Challenges | Puberty-related sexual behaviors and body awareness; aggression, tantrums, and self-injury; boundary-testing; day-to-day unpredictability; seizures and safety risks. |
| Communication and Social Difficulties | Non-verbal or minimally verbal communication; behavior used to express needs and emotions; difficulty communicating toileting, hunger, or discomfort; limited social-rule awareness; slow but meaningful communication gains. |
| Disrupted Routines and Caregiver Fatigue | Irregular sleep and exhaustion; bedwetting and toileting burden; rigidity and resistance to change; continued close supervision of bathing, eating, drinking, and other self-care. |

Behavioral challenges became more complex as participants managed aggression, self-injury, puberty-related sexual behavior, boundary-testing, seizures, and rapidly changing responses to familiar strategies. The stress generated by these behaviors reflected not only their severity but the caregivers' need to assess risk and respond immediately. Caregivers also described communication as interpretive work: when speech was minimal, changes in behavior signaled pain, hunger, toileting needs, anxiety, or frustration. Such experiences support clinical approaches that combine individualized communication support with behavior management rather than treating challenging behavior as isolated misconduct (Posar & Visconti, 2023).

Disrupted sleep, nighttime supervision, toileting demands, and persistent dependence in self-care contributed to physical and emotional fatigue. These conditions demonstrate how caregiving burden accumulates through repeated demands that reduce opportunities for recovery. Yet participants also emphasized meaningful progress, such as name recognition, greetings, self-care gains, or improved independence. The co-occurrence of exhaustion and reward illustrates why caregiver well-being should be addressed as part of the clinical care plan rather than as a secondary outcome. Screening for distress, structured respite, sleep-focused support, and developmentally appropriate self-care training may help protect both caregiver sustainability and child safety.

**Coping Strategies Used by Caregivers**

Five themes characterized coping: emotional self-care, acceptance and meaning-making, behavior management strategies, support systems and relationships, and finding reward and personal purpose. Participants intentionally created emotional boundaries after demanding caregiving periods, used exercise or leisure for stress release, and temporarily stepped away when emotions were high. These practices reflect appraisal-based coping in which caregivers recognized emotional overload and deliberately restored regulation before re-engaging with care. Sumbane (2024) similarly described varied coping responses among autism caregivers, emphasizing the importance of adaptive strategies tailored to the caregiving situation.

Table 2. *Coping strategies used by caregivers*

| Emerging Theme | Core Ideas |
|---|---|
| Emotional Self-Care | Letting go after work and creating emotional boundaries; hobbies and restorative activities; taking brief space when emotions are high. |
| Acceptance and Meaning-Making | Viewing caregiving as a chosen path or calling; accepting the child's condition; reframing difficult behavior with understanding; growth in patience, compassion, and caregiver identity. |
| Behavior Management Strategies | Consistent routines, chores, and physical activity; teaching functional life skills; firm but caring discipline; individualized, assessment-based strategies. |
| Support Systems and Relationships | Relying on coworkers and teamwork during crises; partnering with families; drawing strength from appreciation; relationship-building through shared activities. |

ISSN: 3116-3475
International Journal
of Education, Research, and Innovation Perspectives
Volume 2 Issue 8 (August 2026)

| | |
|---|---|
| Reward and Personal Purpose | Seeing progress and independence as a primary reward; valuing small developmental gains; personal fulfillment and purpose in contributing to the child's future. |

Acceptance reduced blame and helped participants reinterpret difficult behavior as part of the child's developmental and neurological condition rather than intentional opposition. Meaning-making also strengthened commitment: caregivers described their work as purposeful and reported that patience and compassion developed through long-term experience. These patterns align with the Stress-Appraisal Coping model, in which appraisal influences emotional response and the selection of coping strategies (Lazarus & Folkman, 1984). They also echo qualitative evidence showing that caregivers sustain themselves through reframing and meaning during adolescence (Manohar et al., 2025).

Practical coping relied on consistent routines, life-skills instruction, firm but caring boundaries, teamwork, and individualized behavior strategies. Participants also derived motivation from small developmental gains and from family recognition. These resources can buffer subjective burden by increasing perceived competence and restoring emotional energy. Caregiver-mediated intervention research likewise supports structured coaching and feedback as ways to strengthen caregiver confidence and maintain intervention consistency (Bradshaw et al., 2022). The findings therefore support combined clinical approaches in which emotional self-regulation, behavioral competence, peer support, and strengths-based progress monitoring are addressed together.

**Support Systems Needed During the Transition to Early Adolescence**

Caregivers identified five interdependent support domains: medical support and health services, emotional support and family involvement, educational and therapeutic support, community-based exposure and programs, and financial or government assistance. Medical access was considered essential because some adolescents required continuous medication, seizure monitoring, developmental assessment, and autism-sensitive hospital care. Participants emphasized that interruptions in medication or medical management could intensify safety and behavioral concerns, reinforcing the need for coordinated health and behavioral services during adolescence.

Table 3. *Support systems identified as necessary for children with severe ASD and their caregivers*

| Emerging Theme | Core Ideas |
|---|---|
| Medical Support and Health Services | Reliable medication and seizure management; affordable medicines and hospital care; developmental assessment; autism-sensitive clinical and emergency handling. |
| Emotional Support and Family Involvement | Consistent parental presence and reassurance; affection and emotional connection; shared caregiving roles; stronger family participation to reduce distress. |
| Educational and Therapeutic Support | Specialized and functional education; continuous therapy and intervention; routines and independence training; early and sustained skill development. |
| Community-Based Exposure and Programs | Supported community outings; structured activities that build confidence; awareness efforts that reduce stigma and bullying; safe group participation. |
| Financial and Government Assistance | Financial support for therapy, medication, and education; agency assistance; expanded and sustained government programs to prevent interruption of essential care. |

Family involvement was viewed as more than financial provision. Participants emphasized affection, presence, reassurance, and shared responsibility, particularly when center-based caregivers filled emotional roles during prolonged periods of care. Educational and therapeutic continuity was also viewed as essential, with functional education and life-skills training serving both developmental goals and future transition preparation. These findings align with evidence that gaps in autism services can disrupt continuity and place additional pressure on families and caregivers (Scattoni et al., 2023).

Community exposure was perceived as a means of developing confidence, social familiarity, and tolerance for new environments while simultaneously reducing stigma through public awareness. Financial assistance,

ISSN: 3116-3475
International Journal
of Education, Research, and Innovation Perspectives
Volume 2 Issue 8 (August 2026)

however, remained a foundational concern because therapy, medication, specialized education, and clinical follow-up depended on the family's ability to sustain costs. From a Conservation of Resources perspective, these supports function as external resources that protect caregivers from cumulative depletion (Hobfoll, 1989). The findings therefore point to an ecological approach in which clinical care is coordinated with family support, education, community inclusion, and social protection rather than relying solely on individual caregiver resilience.

**Implications for Clinical Practice**

The findings indicate that caregiver well-being should be integrated into autism clinical care during early adolescence. Clinical psychologists and intervention teams may incorporate routine screening for caregiver stress, sleep disruption, grief, and emotional exhaustion; provide psychoeducation on behavior and puberty-related concerns; and establish referral pathways for counseling, respite, or crisis support when burden threatens continuity of care. Caregivers also need practical training in de-escalation, seizure recognition, safety planning, privacy and sexual-behavior guidance, and communication strategies so that crisis management does not depend on trial and error.

Care continuity should extend across home, school, intervention center, and health services. Shared communication plans, visual or augmentative communication supports, documented behavior-meaning profiles, consistent routines, and functional life-skills goals can reduce ambiguity and lessen the cognitive load placed on caregivers. Family participation and caregiver-team coordination should be treated as active components of intervention. Community organizations and public agencies can further contribute through inclusive programs, awareness initiatives, accessible therapy and medication, disability support, and financial assistance. In this model, caregiver support is not separate from child intervention; it is a condition for safe, consistent, and sustainable care.

**Methodological Limitations**

The findings should be interpreted within the boundaries of the study. The ten participants were recruited from a single autism intervention center in Davao City, limiting transferability to other caregiving settings and regions. Data were based on self-reported lived experiences and may therefore reflect memory, emotional, or social-desirability influences. Most participants were center-based caregivers or teachers, so the perspectives of parents, siblings, therapists, healthcare professionals, and other stakeholders were not equally represented. Although reflexivity, member checking, and an audit trail were used to strengthen trustworthiness, qualitative interpretation necessarily involved researcher judgment. The findings are therefore intended for contextual transfer rather than statistical generalization.

## CONCLUSION

Caregiving for children with severe autism spectrum disorder during the transition to early adolescence was experienced as emotionally demanding, physically tiring, and deeply relational. Participants confronted complex behavior, communication limitations, disrupted routines, safety concerns, and continuing dependence in self-care while simultaneously developing strong attachment to the children. Their experiences showed that burden was cumulative and could threaten caregiver well-being, yet caregiving also generated meaning, fulfillment, and renewed motivation when progress was observed.

Caregivers sustained their roles through emotional self-care, acceptance, structured behavior management, supportive relationships, and a sense of purpose. However, these personal strategies were not sufficient on their own. Sustainable care depended on reliable medical services, family participation, continuous education and therapy, safe community inclusion, and financial or government support. The study therefore contributes a caregiver-centered understanding of early adolescent transition in severe autism and underscores that the quality and continuity of clinical care are inseparable from the emotional, practical, and resource needs of caregivers.

ISSN: 3116-3475
International Journal
of Education, Research, and Innovation Perspectives
Volume 2 Issue 8 (August 2026)

## Recommendation

Clinical psychologists, intervention centers, and healthcare providers should institutionalize caregiver-inclusive services that combine mental-health screening, stress-management support, respite or recovery planning, crisis and safety training, behavior-management coaching, communication support, and guidance on puberty-related concerns. Caregiver distress, sleep disruption, and perceived inability to continue should be treated as clinically relevant indicators because they may affect the safety and continuity of care.

Families, schools, and intervention teams should strengthen coordinated care through shared routines, consistent communication plans, functional life-skills goals, and regular discussion of the child's progress and changing support needs. Community organizations and disability advocates should expand autism-awareness and supported participation activities that reduce stigma while giving adolescents safe opportunities to practice social and adaptive skills. Government and social-service agencies should continue strengthening access to affordable medication, developmental and mental-health services, therapy, special-needs education, caregiver assistance, and financial support so that essential care is not interrupted by resource constraints.

Future research should include larger and more diverse samples across multiple intervention centers, schools, clinics, and communities and should examine the perspectives of parents, siblings, therapists, clinical psychologists, and social workers. Longitudinal and mixed-methods studies may clarify how caregiver burden, coping, resilience, and support needs change from late childhood through adolescence and adulthood, while intervention studies can evaluate the effectiveness of caregiver-centered counseling, psychoeducation, respite, and behavior-management programs.

## References

American Psychiatric Association. (2022). Diagnostic and statistical manual of mental disorders (5th ed., text rev.). American Psychiatric Association Publishing. https://doi.org/10.1176/appi.books.9780890425787

Arslan, R., Yanık, D., & Pekşen Akça, R. (2025). Investigation of menstrual hygiene and self-care skills of adolescent girls with autism spectrum disorder: Mother views. Journal of Autism and Developmental Disorders, 55, 3530–3538. https://doi.org/10.1007/s10803-024-06446-8

Azubuike, A. O., Azubuike, P. C., Onyekachi, E. L., Enyam, M. O., Akinreni, T., Abuo, J., & Adai, G. S. (2024). Experiences and unmet needs among caregivers of children living with autism spectrum disorder in Nigeria: A qualitative study using the socio-ecological model. Discover Social Science and Health, 4, Article 77. https://doi.org/10.1007/s44155-024-00141-w

Baker, E., Stavropoulos, K. K., Baker, B. L., & Blacher, J. (2021). Daily living skills in adolescents with autism spectrum disorder: Implications for intervention and independence. Research in Autism Spectrum Disorders, 83, 101761. https://doi.org/10.1016/j.rasd.2021.101761

Bradshaw, J., Wolfe, K., Hock, R., & Scopano, L. (2022). Advances in supporting parents in interventions for autism spectrum disorder. Pediatric Clinics of North America, 69(4), 645–656. https://doi.org/10.1016/j.pcl.2022.04.002

Castleberry, A., & Nolen, A. (2018). Thematic analysis of qualitative research data: Is it as easy as it sounds? Currents in Pharmacy Teaching and Learning, 10(6), 807–815. https://doi.org/10.1016/j.cptl.2018.03.019

Cheng, A. W., & Lai, C. Y. (2023). Parental stress in families of children with special educational needs: A systematic review. Frontiers in Psychiatry, 14, 1198302. https://doi.org/10.3389/fpsyt.2023.1198302

Chua, S. Y., Abd Rahman, F. N., & Ratnasingam, S. (2023). Problem behaviours and caregiver burden among children with autism spectrum disorder in Kuching, Sarawak. Frontiers in Psychiatry, 14, 1244164. https://doi.org/10.3389/fpsyt.2023.1244164

Creswell, J. W., & Poth, C. N. (2018). Qualitative inquiry and research design: Choosing among five approaches (4th ed.). Sage.

Divan, G., Chiang, C.-H., Villalobos, M., Bakare, M., & Hoekstra, R. A. (2024). Shifting the centre of gravity: Towards a truly global representation in autism research. Autism, 28(1), 3–5. https://doi.org/10.1177/13623613231214644

Hobfoll, S. E. (1989). Conservation of resources: A new attempt at conceptualizing stress. American Psychologist, 44(3), 513–524. https://doi.org/10.1037/0003-066X.44.3.513

Lam, X. R., Cheng, L. J., Leo, C. S., Toh, Z. A., & He, H.-G. (2025). Global prevalence of depression in caregivers of children with autism: A systematic review and meta-analysis. Journal of Pediatric Nursing, 80, e74–e85. https://doi.org/10.1016/j.pedn.2024.11.020

Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. Springer Publishing Company.

Leosala, L. (2023). Meeting the needs of children with autism spectrum disorder: Early intervention experiences of Filipino parents. Psychology and Education: A Multidisciplinary Journal, 11(4). https://doi.org/10.5281/zenodo.8191312

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Sage Publications.

Manohar, H., Kommu, J. V., Kishore, M. T., Jacob, P., & Jayarajan, D. (2025). Experiences of parenting an autistic individual during adolescence and emerging adulthood in the Indian context: An interpretative phenomenological analysis. Indian Journal of Psychological Medicine, 47(3), 230–237. https://doi.org/10.1177/02537176241238417

Mohd Arifin, S. R. (2018). Ethical considerations in qualitative study. International Journal of Care Scholars, 1(2), 30–33. https://doi.org/10.31436/ijcs.v1i2.82

Moustakas, C. (1994). Phenomenological research methods. Sage Publications. https://doi.org/10.4135/9781412995658

Posar, A., & Visconti, P. (2023). Autism spectrum disorder in 2023: A challenge still open. Turkish Archives of Pediatrics, 58(6), 566–571. https://doi.org/10.5152/TurkArchPediatr.2023.23194

Ray, A., Alphonsa, K. K., & Chandran, S. (2024). Lived-in experience among caregivers of autistic children: A qualitative study from South India. Journal of Indian Association for Child and Adolescent Mental Health, 20(4), 338–343. https://doi.org/10.1177/09731342241258583

Reyes, B. F., & Domingo, P. G. (2025). A phenomenological study of the lived experiences of families of children with autism in the Philippines. Ho Chi Minh City Open University Journal of Science - Social Sciences, 15(1), 137–151. https://doi.org/10.46223/HCMCOUJS.soci.en.15.1.3235.2025

Samadi, H., & Samadi, S. A. (2020). Understanding different aspects of caregiving for individuals with autism spectrum disorders (ASDs): A narrative review of literature. Brain Sciences, 10(8), 557. https://doi.org/10.3390/brainsci10080557

Scattoni, M. L., Shih, A., & Schendel, D. (2023). Editorial: Pathway of care and gaps in services for children and adults with autism spectrum disorder. Frontiers in Psychiatry, 14, 1186061. https://doi.org/10.3389/fpsyt.2023.1186061

Sumbane, G. O. (2024). Coping strategies adopted by caregivers of children with autism in the Limpopo Province, South Africa. African Journal of Disability, 13, a1384. https://doi.org/10.4102/ajod.v13i0.1384

Taylor, J. L., & Seltzer, M. M. (2010). Changes in the autism behavioral phenotype during the transition to adulthood. Journal of Autism and Developmental Disorders, 40(12), 1431–1446. https://doi.org/10.1007/s10803-010-1005-z

van Niekerk, K., Stancheva, V., & Smith, C. (2023). Caregiver burden among caregivers of children with autism spectrum disorder. South African Journal of Psychiatry, 29, a2079. https://doi.org/10.4102/sajpsychiatry.v29i0.2079

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. The Gerontologist, 20(6), 649–655. https://doi.org/10.1093/geront/20.6.649

Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. Autism Research, 15(5), 778–790. https://doi.org/10.1002/aur.2696