CHALLENGES OF PARENTS/CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

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ABSTRACT: *Parents and caregivers of children with Autism Spectrum Disorder (ASD) face diverse challenges that influence their well-being and family functioning. This study explored the lived experiences of parents and caregivers of children with ASD and developed a Support and Coping Model grounded in their experiences. Using a qualitative phenomenological research design, in-depth semi-structured interviews were conducted with parents and caregivers of children diagnosed with ASD. Data were analyzed using thematic analysis. Four major themes emerged: general challenges, coping strategies, support networks, and long-term outcomes. Findings revealed that participants experienced communication and behavioral difficulties, emotional distress, financial burden, caregiving adjustments, and social stigma. Despite these challenges, parents demonstrated resilience through patience, acceptance, faith, practical problem-solving, and lifestyle adjustments. Family members, educators, healthcare professionals, and religious communities served as primary sources of support, although participants expressed the need for more accessible services and stronger community awareness. Parents also hoped for their children's independence, meaningful education, and social inclusion while expressing concerns about lifelong care and future security. The findings support Lazarus and Folkman's Transactional Model of Stress and Coping, emphasizing the dynamic interaction among caregiving demands, coping resources, and support systems. Based on these findings, a Support and Coping Model was developed to guide family-centered interventions, enhance caregiver resilience, and inform policies and programs that improve the quality of life of families raising children with Autism Spectrum Disorder.*

Keywords: Autism Spectrum Disorder, parents, caregivers, phenomenology, coping strategies, support systems.

1. INTRODUCTION

Autism Spectrum Disorder (ASD) is a complex developmental condition that affects individuals across various domains, including social interaction, communication, and behavior. As the prevalence of ASD continues to rise globally, understanding the unique challenges faced by parents of children with this disorder has become a crucial area of research. Parents of children with ASD often experience a combination of emotional, social, financial, and educational challenges that can significantly impact their daily lives and well-being. These challenges are not only shaped by the child's symptoms but also by the broader societal and cultural context in which the family resides.

Theories of autism, such as the Theory of Mind (ToM) proposed by Simon Baron-Cohen [1], suggest that individuals with ASD struggle with understanding and interpreting the mental states of others, which contributes to difficulties in social interaction and communication. This cognitive gap can lead to significant emotional challenges for parents, such as feelings of frustration, isolation, and anxiety, as they navigate their child's complex needs. Similarly, Uta Frith's Weak Central Coherence Theory [2] highlights how individuals with ASD tend to focus on details rather than the broader context, which might make it harder for parents to connect with their child's experiences or find effective interventions.

Another key theory, the Executive Dysfunction Theory, proposed by Tony Attwood [3], suggests that individuals with ASD face challenges in higher-order cognitive functions such as planning, flexibility, and attention. This dysfunction often extends to parents, who must adapt their strategies to manage daily routines, caregiving responsibilities, and academic requirements. The Empathizing-Systemizing Theory, also introduced by Baron-Cohen [1], further explains that children with ASD might excel in logical or technical tasks but struggle with emotional empathy. This imbalance can create additional emotional burdens for parents, who may feel that they lack the necessary support to help their child navigate social and emotional landscapes.

The Social Motivation Theory, proposed by Chevallier and colleagues [4], suggests that children with ASD often show reduced interest in social interaction and rewards from social engagement. Parents, in turn, must cope with the emotional strain of advocating for their child's social inclusion and addressing social stigma. This theory connects closely with the Sensory Sensitivity Model, proposed by Olga Bogdashina [5], which suggests that heightened or diminished sensory sensitivities in children with ASD can lead to behavioral issues that are difficult for parents to manage, especially when navigating public spaces or family gatherings.

In understanding how parents cope with these challenges, the Cognitive Theory of Autism, discussed by Elizabeth Hill [6], emphasizes that difficulties in processing social information can extend beyond the child's behavior, affecting the family dynamic. Moreover, theories related to self-regulation and mirror neuron dysfunction, proposed by Giacomo Rizzolatti

and colleagues [7], further underscore the emotional and behavioral complexities of ASD, providing a basis for understanding why certain coping strategies might be more effective than others.

Given the multifaceted nature of ASD, this study aims to explore the specific challenges parents face in managing the emotional, social, and financial burdens associated with raising a child with ASD. By examining the coping strategies adopted by parents, as well as the support systems available to them, this research seeks to provide a deeper understanding of the lived experiences of families affected by ASD and offer insights into potential avenues for improving support and interventions.

Parents of children with Autism Spectrum Disorder (ASD) often face unique and multifaceted challenges in managing their children's developmental needs. These challenges encompass emotional, social, financial, and educational aspects. This study seeks to understand the specific difficulties parents experience and how these challenges impact their daily lives, decision-making, and coping strategies in Dumaguete City.

This study aims to explore the lived experiences of parents of children with Autism Spectrum Disorder (ASD) in Dumaguete City, focusing on four key areas.

1. It seeks to describe the general challenges that parents encounter in raising and caring for their children with ASD, encompassing emotional, social, financial, and educational aspects.
2. It aims to identify the coping strategies that parents employ to manage these challenges and maintain their well-being.
3. It endeavors to examine the role of support networks, including family, friends, healthcare providers, and community organizations, in assisting parents of children with ASD.
4. It seeks to explore the parents' perceptions of the long-term outcomes for their children and families, including hopes, expectations, and future plans.

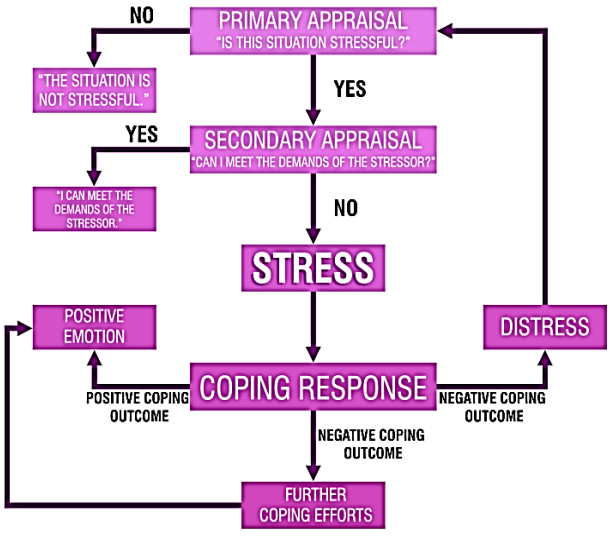

Fig.

2. THEORETICAL FRAMEWORK OF THE STUDY

This study is anchored on Lazarus and Folkman's Transactional Model of Stress and Coping [8], which explains how individuals evaluate and respond to stressful life situations. The theory posits that coping is a dynamic process involving continuous interaction between the individual and their environment. It emphasizes that stress is not merely a stimulus or a response but a transaction shaped by a person's appraisal of the situation and the coping strategies they employ.

According to the model, when individuals face a potential stressor, they first engage in primary appraisal, assessing whether the situation poses a threat, a challenge, or is irrelevant to their well-being. In the context of this study, parents of children with Autism Spectrum Disorder (ASD) appraise the general challenges they face, including emotional strains, social stigma, financial demands, and educational barriers, as stressors affecting their lives.

Following this, secondary appraisal occurs, where individuals evaluate the resources available to manage the stressor. This aligns with the study's focus on coping strategies, which may be problem-focused such as seeking therapy and adjusting routines, or emotion-focused such as practicing self-care and reframing perspectives.

The model also recognizes the crucial role of social support systems in moderating stress. For parents of children with ASD, support networks comprising family, friends, healthcare providers, and community organizations serve as important buffers that enhance coping effectiveness and resilience.

Finally, the model includes the concept of reappraisal, where individuals reassess their situation after implementing coping strategies, leading to potential adaptation and positive change. This relates to the study's interest in long-term outcomes, as parents reflect on their hopes, expectations, and future plans for their child and family.

3. REVIEW OF RELATED LITERATURE

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by persistent deficits in social communication and interaction, accompanied by restricted and repetitive patterns of behavior, interests, or activities. The lifelong nature of ASD requires continuous support not only for affected individuals but also for their families, particularly parents who serve as the primary caregivers. The responsibilities associated with caregiving often extend beyond meeting the child's developmental and educational needs, encompassing emotional, financial, psychological, and social demands. Consequently, a growing body of literature has focused on understanding the experiences of parents and caregivers of children with ASD, highlighting the complex interplay between caregiving challenges, coping strategies, support systems, and family quality of life.

Challenges Experienced by Parents of Children with Autism Spectrum Disorder

Parents of children with ASD encounter multifaceted challenges beginning from the period of diagnosis and continuing throughout the child's developmental journey. Emotional distress is often among the earliest responses

following diagnosis, with parents commonly reporting feelings of shock, denial, sadness, frustration, and uncertainty about the future. Through qualitative interviews, Topan *et al*. [9] found that parents initially experienced disbelief and emotional devastation upon learning of their child's diagnosis, followed by concerns regarding caregiving responsibilities and societal reactions. Similarly, Carvalho et *al. [*10] reported that families experienced frustration, pain, and emotional exhaustion during the early stages of adjustment before gradually developing acceptance and stronger emotional attachment to their children.

These emotional challenges frequently coexist with psychological burdens. Phetoe *et al*. [11], in their rapid review, synthesized evidence showing that parents experience grief, anxiety, emotional fatigue, altered family dynamics, and parenting stress both before and after diagnosis. Likewise, Bonjibon et al. described parents' journeys as emotionally complex, involving fear, confusion, guilt, resilience, and eventual advocacy for their children. Parents emphasized that despite numerous obstacles, their experiences also fostered personal growth and strengthened family relationships.

Financial burden represents another significant challenge consistently documented in the literature. Families often incur considerable expenses related to therapy, medical consultations, educational services, transportation, and assistive interventions. Blackwell [12] demonstrated that families raising children with ASD face numerous hidden household costs extending beyond formal healthcare expenses. These additional expenditures are compounded by inadequate public support services and employment barriers experienced by caregivers. Similarly, Begum and Mamin [13] concluded that autism substantially affects the financial stability of families while simultaneously altering family routines and lifestyles.

Financial challenges became even more evident during the COVID-19 pandemic. Gagat-Matula [14] found that children from lower-income households exhibited lower quality of life and relied more heavily on maladaptive emotion-focused coping strategies than children from families with moderate financial resources. The findings emphasized that financial security significantly influences both children's adjustment and family well-being during periods of crisis.

Apart from financial concerns, parents frequently encounter educational and community-related challenges. Carrera et al. [15] conducted a meta-analysis involving parents from diverse cultural settings and reported that mainstream schools often lacked sufficient understanding of the educational and developmental needs of children with ASD. Parents expressed frustration regarding limited collaboration between schools and families, inadequate accommodations, and insufficient teacher awareness. Likewise, Chaidi and Drigas [16] emphasized that parental involvement in children's education is critical for successful developmental outcomes and that parent education programs strengthen parents' ability to participate effectively in educational planning.

Social stigma also contributes significantly to parental stress. Studies conducted by Topan *et al.* [9], Carvalho *et al*. [10], and Rıfat *et al*. [17] consistently revealed that negative public attitudes, lack of awareness, and limited community acceptance often isolate families and increase emotional strain. Parents frequently reported feeling judged in public settings, leading some families to withdraw from social participation.

Family Quality of Life among Families of Children with ASD

Family Quality of Life (FQoL) has emerged as a central concept in understanding the overall well-being of families raising children with ASD. Rather than focusing solely on the child's functioning, FQoL examines how autism influences family relationships, emotional well-being, financial stability, social participation, and access to support services.

Losada-Puente *et al*. [18] compared families of children with ASD and those with other developmental disabilities and found that although both groups shared common concerns, families of children with ASD exhibited significantly greater unmet needs. Large discrepancies existed between the importance parents placed on various aspects of family life and their satisfaction with available resources, suggesting substantial gaps in existing support systems. Furthermore, the age of the child influenced changing family priorities, emphasizing the need for individualized and family-centered interventions.

Similarly, Kasem *et al*. [19] found that parents of children with ASD in Jordan reported significantly poorer quality of life across all measured domains compared with parents of typically developing children. Variables such as educational attainment, employment status, living conditions, and gender significantly influenced parental quality of life, suggesting that socioeconomic factors moderate caregiving experiences.

Begum and Mamin [13] likewise concluded that autism affects every family member, including parents and siblings, resulting in modifications of family roles, daily routines, social interactions, and financial priorities. These findings reinforce the perspective that ASD should be viewed as a family-centered rather than solely an individual condition.

Coping Strategies Employed by Parents

Despite the substantial challenges they encounter, parents develop various coping mechanisms that enable them to adapt to caregiving demands. Lazarus and Folkman's Transactional Theory of Stress and Coping provides an appropriate framework for understanding these adaptive processes.

A systematic review by Bakar et al. [20] identified several recurring coping strategies among parents of children with ASD. These included seeking information about autism, maintaining hope, developing empowerment, supporting other families, and actively searching for appropriate services. As parents gained greater understanding of ASD, they became more confident advocates for their children and increasingly participated in peer support networks.

Similarly, Phetoe *et al.* [11] identified information seeking, meaning-making, reliance on support systems, and social isolation as common psychosocial coping strategies. Parents often alternated between problem-focused coping, such as seeking interventions and professional assistance, and emotion-focused coping, including acceptance and positive reframing.

Bonjibon *et al.* further demonstrated that parents relied heavily on emotional support from family members and close friends while simultaneously advocating for greater inclusion within their communities. Likewise, Carvalho *et al*. [10] observed that although caregiving initially generated negative emotions, daily interaction with their children eventually became rewarding as parents developed resilience and deeper emotional connections.

Research examining structured interventions has also demonstrated positive outcomes. Deb *et al.* [21], through a systematic review and meta-analysis, found that parent-training interventions produced mild to moderate improvements in child outcomes while reducing parental stress. Although intervention approaches varied considerably, parent-focused programs consistently showed beneficial effects.

Similarly, Zygopoulou *et al*. [22] reviewed interventions specifically targeting parents of preschool children with ASD and reported improvements in parental well-being, reduced stress, and enhanced psychological functioning across most intervention types. Although methodological differences prevented direct comparisons, the overall findings strongly support continued investment in parent-focused support programs.

Family Empowerment and Support Systems

Social support remains one of the strongest protective factors influencing parental adaptation. Vosough Matin and Sari [23] found that structured family education programs significantly improved parents' perceptions of empowerment, self-determination, and competence in managing their children's developmental needs. Although parental participation in educational activities was initially low, family education substantially strengthened parents' confidence and involvement.

Chaidi and Drigas [16] likewise emphasized that parent education programs enable parents to implement effective intervention strategies and become active participants in their children's educational development. These findings highlight the importance of empowering parents not merely as caregivers but also as educational partners.

Khara *et al*. [24] further examined family needs from both parents' and specialists' perspectives. Specialists identified needs related to knowledge, caregiving skills, attitudes, financial assistance, educational services, mental health support, and family functioning, whereas parents primarily emphasized information, support services, and financial assistance. Although considerable overlap existed between both perspectives, important differences suggested the need for stronger collaboration among families, professionals, and policymakers.

Social support systems also emerged as critical determinants of successful coping. Carvalho *et al*. [10], Bonjibon et al., Phetoe *et al.* [11], and Rıfat *et al.* [17] consistently demonstrated that support received from family members, healthcare professionals, schools, community organizations, and peer groups substantially reduced caregiver burden and enhanced resilience. Conversely, inadequate services and fragmented support systems intensified parental stress.

Long-Term Concerns and Transition to Adulthood

Parental concerns extend well beyond childhood. Havens [25] explored the lived experiences of parents whose children with ASD were transitioning into adulthood. Parents described inadequate transition planning, limited employment opportunities, insufficient postsecondary educational supports, and continued dependence of their adult children. These findings illustrate that caregiving responsibilities often continue indefinitely, reinforcing the importance of long-term support services across the lifespan.

Similarly, Rıfat *et al*. [17] identified persistent concerns regarding financial sustainability, mental health, family conflict, and future caregiving responsibilities. Parents emphasized the necessity of community-based services and professional support, particularly for mothers who frequently assume primary caregiving roles.

4. SIGNIFICANCE OF THE STUDY

This study is significant as it provides a deeper understanding of the challenges faced by parents of children with Autism Spectrum Disorder (ASD) and highlights the coping strategies they adopt in response to these challenges. The findings of this research have implications for various stakeholders:

Parents of Children with ASD

This study offers parents an opportunity to see their experiences reflected in research, fostering a sense of community and shared understanding. By identifying common struggles and effective coping mechanisms, the research can empower parents to adopt strategies that may improve their well-being and caregiving approaches.

Students with ASD

The findings of this study can indirectly benefit students with ASD by promoting more effective parental support, which is crucial for their development and learning. Understanding the challenges their parents face can lead to interventions that not only support families but also enhance the educational, emotional, and social outcomes of students with ASD. A well-supported parent is better equipped to advocate for their child, access appropriate services, and provide an environment that fosters growth, independence, and inclusion.

Healthcare Professionals and Therapists

Insights from this study can guide healthcare providers in developing more targeted interventions and support programs tailored to the specific emotional, financial, and social challenges of parents. This understanding can improve the delivery of counseling, therapy, and medical support for both parents and their children.

Educators and School Administrators

The research highlights the importance of accessible and adequate educational resources for children with ASD. By understanding parental concerns, educators and school administrators can better design inclusive learning environments and support systems that cater to the diverse needs of children with ASD and their families.

Policymakers and Advocacy Groups

The study can inform policymakers in crafting legislation and programs that address the financial and social burdens of families with children on the autism spectrum. Advocacy

groups can use the findings to strengthen campaigns aimed at reducing social stigma and increasing public awareness about ASD.

Researchers

For researchers, this study contributes to the growing body of literature on ASD by focusing on the lived experiences of parents. It offers a foundation for future studies to explore related topics, such as the effectiveness of various support systems and interventions for families.

Community and Society

By shedding light on the societal and cultural factors influencing the experiences of families affected by ASD, the study promotes greater understanding and inclusivity within communities. This can lead to more supportive environments that recognize and address the unique needs of these families.

Ultimately, the study aims to enhance the quality of life for families with children diagnosed with ASD by advocating for evidence-based interventions and fostering a more empathetic and informed society.

5. METHODOLOGY

This study employed a qualitative research design utilizing a phenomenological approach to explore the lived experiences of parents of children with Autism Spectrum Disorder (ASD). The phenomenological method was deemed appropriate as it seeks to understand and interpret the meanings that individuals attach to their personal experiences. The participants consisted of parents of children diagnosed with ASD who were enrolled at the West City Exceptional Child Learning Center in Dumaguete City.

Data were collected through semi-structured interviews, which served as the primary method of gathering information. An interview guide was developed based on the research questions to ensure consistency while allowing flexibility for participants to share their unique perspectives. All interviews were conducted in a private and comfortable setting to promote openness and comfort. With the consent of the participants, the interviews were audio-recorded to ensure accurate transcription and analysis.

The data gathered were analyzed using the thematic analysis method, which involved identifying, analyzing, and interpreting recurring patterns and themes emerging from the participants' narratives. Informed consent was obtained from all participants prior to data collection. They were fully informed about the purpose of the study, the voluntary nature of their participation, and their right to withdraw at any point without penalty. Confidentiality was maintained by anonymizing all data and securely storing both audio recordings and transcripts. Throughout the study, sensitivity to the emotional well-being of the participants was prioritized to ensure that the research process remained respectful and ethical.

Scope and Limitation of the Study

This study explores the challenges faced by parents of children with Autism Spectrum Disorder (ASD) and the coping strategies they adopt in managing these challenges. The research focuses on understanding specific aspects such as emotional struggles, financial burdens, social stigma, access to educational resources, and the role of support systems. The study also examines how the severity of the child's condition and the availability of support networks influence parental experiences.

The research is qualitative in nature and involves collecting data through interviews or focus group discussions with parents of children diagnosed with ASD in Dumaguete City. It aims to provide a detailed and contextualized understanding of their experiences, coping mechanisms, and perceptions. The study emphasizes the lived experiences of parents to offer insights that can inform interventions, policies, and programs to better support families with children on the autism spectrum.

Geographic and Demographic Coverage

The study is limited to parents whose children with Autism studying in West City Exceptional Child Learning Center in Dumaguete City. As such, findings may not fully capture the experiences of parents in different cultural, economic, or social contexts.

Sample Size

Given the qualitative nature of the research, the sample size is relatively small, which may limit the generalizability of the findings. The focus on in-depth exploration means that broad statistical trends cannot be derived.

Subjectivity of Responses

The study relies on self-reported data, which may be influenced by the participants' subjective perspectives, emotions, or memory biases. The findings reflect personal experiences rather than objective measures of challenges or coping strategies.

Focus on Parents

The study specifically examines the perspectives of parents and does not directly explore the experiences of children with ASD or other family members, such as siblings, who may also be impacted.

Variability in ASD Severity

The diverse manifestations and severity of ASD may lead to a wide range of experiences among participants. This variability could limit the ability to draw universal conclusions applicable to all families with children on the autism spectrum.

Time Constraints

The data collection and analysis are conducted within a limited timeframe, which may restrict the depth of exploration or the inclusion of longitudinal perspectives on parental challenges and coping strategies.

Despite these limitations, the study aims to provide valuable insights into the multifaceted experiences of parents raising children with ASD and contribute to the development of more effective support systems and policies.

6. RESULTS AND DISCUSSION

The interview transcripts were analyzed thematically according to the four major areas of inquiry: general challenges, coping strategies, support networks, and long-term outcomes. Repeated ideas and experiences were coded, compared, and clustered into broader themes. Because several interviews were originally conducted in Cebuano or mixed Cebuano-English and were machine-transcribed, selected statements were lightly edited or translated for

clarity while preserving the participants' intended meanings. The analysis generated four overarching thematic domains and twelve interconnected themes.

GENERAL CHALLENGES ENCOUNTERED BY PARENTS AND CAREGIVERS

Theme 1. Communication and behavioral difficulties complicate everyday caregiving

One of the most prominent challenges concerned the children's limited communication, nonverbal behavior, tantrums, hyperactivity, sensory reactions, and difficulty expressing pain or discomfort. Parents described communication as a fundamental concern because they could not always determine what their children wanted, felt, or needed. One father directly identified "communication" as the primary challenge. He explained that when his child became ill, the child could not describe the pain, making medication and caregiving more difficult.

Other caregivers described children becoming distressed when routines were disrupted, gadgets were removed, they were awakened early, or they entered crowded and unfamiliar environments. One mother explained that her child's tantrums were particularly difficult at home and in public places with many people. The family sometimes had to move the child to another area to calm him and reduce disturbance to the father's online work. Another parent recalled difficulty managing the child in shopping centers because the child became highly interested in objects and had difficulty controlling impulses.

These findings demonstrate that caregiving stress is not generated solely by the diagnostic label but by the continuous demand to anticipate triggers, interpret behavior, and adjust the environment. Topan *et al*. [9] similarly found that parents experienced major difficulties in childcare, behavioral management, and understanding their children's needs. Carvalho et al. [10] also reported that family members struggled with the children's communication and behavior, particularly during the early stages of adjustment. Phetoe *et al*. [11] described such experiences as multidimensional because behavioral concerns interact with parents' emotional, social, and practical responsibilities.

From the perspective of Lazarus and Folkman's Transactional Model of Stress and Coping, these behaviors represent recurring stressors that parents appraise according to their perceived severity and available resources. When caregivers feel uncertain about what the child needs or lack adequate skills and support, the situation is more likely to be perceived as threatening or overwhelming.

Theme 2. Caregiving requires substantial adjustments in routines, work, and family life

The participants repeatedly described how caring for a child with ASD reshaped their daily lives. Parents had to organize their schedules around school, therapy, medical consultations, feeding, transportation, and behavioral episodes. Several participants reduced their employment, worked part-time, became full-time caregivers, or relied on a spouse as the primary income earner.

One mother explained that she had shifted from full-time work to part-time employment because she wanted to remain a hands-on parent. She described time management as difficult because caregiving involved schoolwork, therapy, household tasks, and the child's tantrums, all of which affected her financially, mentally, and emotionally. Another participant described being a stay-at-home father while his wife worked because he was responsible for caring for their children. A working parent also reported having limited time for friends because her daily routine revolved around work, school, and therapy.

Caregiving also affected marital and household relationships. One mother recounted that her child's noise and tantrums sometimes interfered with her husband's online employment, resulting in tension between the couple. However, other participants described adaptation over time, indicating that routines gradually became more manageable as the family learned to accommodate the child.

These experiences support Begum and Mamin's [13] conclusion that autism persistently modifies the lifestyle of every family member. Blackwell [12] likewise found that parents' employment experiences were shaped by childcare demands, school schedules, inadequate services, and the need to personally coordinate support. Carrera *et al.* [15] further emphasized that parents frequently carry the responsibility of connecting home, school, and therapeutic services when institutional coordination is limited.

Theme 3. Emotional experiences move from shock and denial toward acceptance

Many parents described an emotional process beginning with uncertainty, pain, disbelief, or denial and gradually progressing toward acceptance. One father explained that although his wife first noticed the child's lack of eye contact and response to his name, he initially denied that anything was different. Over time, professional consultation and everyday experience helped him accept the child's condition. Another mother acknowledged that there were periods when she found it difficult to accept her child's condition, but she later identified acceptance as the most important advice she could give to other parents. She stated that parents must be open to their child's needs because continued denial delays appropriate support.

Some participants portrayed parenting as difficult yet meaningful. One mother described the experience as a struggle but emphasized that she had learned to handle it through patience and calmness. Others framed the child as a blessing rather than a burden and emphasized unconditional care.

These accounts closely parallel Carvalho *et al.* [10], who found that families initially experienced frustration and pain but later described affection, dedication, and rewarding interactions. Topan *et al*. [9] also documented shock, sadness, and difficulty accepting the diagnosis. Bakar *et al.* [20] found that fear and despair were recurrent challenges in parents' narratives, while hope and empowerment developed as parents gained understanding and experience.

The movement from denial to acceptance can be interpreted as reappraisal within the Transactional Model of Stress and Coping. As parents gain knowledge, observe the child's progress, and identify available resources, they reassess the condition and develop more adaptive meanings.

Theme 4. Financial pressure limits access to therapy and specialized services

Financial hardship emerged as one of the most serious and persistent challenges. Parents identified occupational therapy, speech therapy, medical consultations, transportation, school requirements, and hospitalization as costly. Some families discontinued therapy because they could no longer afford it.

One father stated that therapy had stopped because it was expensive. Another reported that occupational therapy cost approximately 750 pesos per hour, aside from speech therapy and other services, and described the financial burden as one of the heaviest aspects of caregiving. A mother similarly emphasized that private therapy and hospital-based services were beyond the means of many parents and appealed for greater government support.

Financial difficulty was intensified when a caregiver could not maintain regular employment. Participants who were unemployed, working part-time, or dependent on one family income had fewer options for continuous therapy. Some parents therefore relied on home-based activities, school services, or advice from teachers and developmental specialists.

These findings are consistent with Blackwell [12], who demonstrated that the expenses of raising children on the autism spectrum include not only direct service costs but also hidden costs, lost employment, transportation, and inadequate public provision. Khara *et al.* [24] likewise identified financial assistance as a central need from both parents' and specialists' perspectives. Rıfat *et al.* [17] reported that financial burden, caregiving demands, and reduced work opportunities were strongly interconnected. Kasem *et al*. [19] further found that employment status and living conditions significantly affected the quality of life of parents of children with ASD.

Gagat-Matula [14] showed that lower financial status was associated with poorer family and child quality of life and less constructive coping. Thus, financial pressure is not merely an economic concern; it also restricts treatment access, increases parental stress, and affects the family's capacity to plan for the future.

Theme 5. Stigma, misunderstanding, and bullying create social vulnerability

Participants described negative public reactions, judgment, misunderstanding, and bullying. Some caregivers had to explain autism to relatives, neighbors, and community members who interpreted the child's behavior as poor discipline. One father noted that older community members initially misunderstood the child's behavior, requiring the family to educate them about autism. Another parent expressed concern that her son had been bullied and prayed that he would eventually be accepted and included.

Some parents limited social participation because crowded places could trigger tantrums or because they feared judgment from other people. Others remained protective because they did not want their child to feel rejected or alone. One mother explicitly associated the family's difficulties with stigma and the lack of acceptance surrounding her child's condition.

These findings support Topan *et al.* [9], who found that parents were distressed by the gaze and judgment of others. Bakar *et al*. [20] likewise identified stigmatization and social barriers as major themes in autism parenting narratives. Rıfat *et al.* [17] reported community-related difficulties, while Carrera *et al*. [15] found that parents frequently encountered limited awareness of ASD even within mainstream educational settings.

The participants' experiences indicate that public misunderstanding increases caregiving strain by forcing parents to manage both the child's needs and society's reactions. Social acceptance and autism awareness are therefore essential components of family support.

COPING STRATEGIES USED BY PARENTS AND CAREGIVERS

Theme 6. Patience, Acceptance, And Emotional Self-Regulation Are Central Coping Resources

Patience was the most frequently emphasized personal resource. Participants repeatedly stated that they had learned to remain calm, avoid reacting impulsively, and understand that progress requires time. One mother explained, "I just have to be patient. I have to be calm." A father advised other parents to "take time" because raising a child with ASD requires patience, love, and continued learning. A guardian similarly described patience as the most important requirement of caregiving.

Acceptance was closely connected to patience. Parents described acceptance as recognizing the child's condition without blame, remaining open to the child's needs, and continuing to provide care despite uncertainty. One participant stated that her son was not a burden and advised other parents not to blame themselves or their children.

These coping responses reflect emotion-focused coping because parents regulate their emotional reactions and reinterpret their caregiving responsibilities. Bakar et al. [20] similarly identified hope, meaning, empowerment, and support for others as important adaptive responses. Carvalho *et al.* [10] found that daily learning transformed initial emotional pain into affection and dedication. Acceptance therefore did not mean passivity; rather, it allowed parents to respond more constructively to the child's needs.

Theme 7. Faith and prayer provide meaning, comfort, and endurance

Religious faith emerged as a significant coping mechanism. Several participants reported praying when faced with difficulties, trusting God with their children's future, and receiving emotional comfort from church teachings and religious leaders. One mother stated that she always prayed when challenges arose. Another described prayer as her first response to hardship and viewed acceptance as part of trusting God's purpose. She explained that her church leader comforted her and helped her understand that her experiences had meaning.

Faith appeared to support meaning-making, reduce fear, and sustain hope when families had limited control over finances, health, and the child's future. This finding corresponds with Phetoe *et al*. [11], who identified meaning-making as an important psychosocial coping strategy. It also aligns with Bakar *et al*. [20], whose review showed that parents often

maintain hope and develop empowerment through personally meaningful interpretations of their experiences.

Within Lazarus and Folkman's model, faith may function as an emotion-focused strategy that changes the meaning attached to stress. It can also encourage persistence in problem-focused actions by helping parents remain hopeful and engaged.

Theme 8. Parents use practical adjustments and child-centered strategies

Parents did not rely solely on emotional coping. They also made practical changes, including modifying routines, separating the child from overstimulating environments, changing therapists, monitoring interventions, adjusting meals, reducing gadget use, engaging the child in physical activities, and reorganizing employment schedules.

One parent adjusted the child's diet by providing foods the child would willingly eat. Another consulted a developmental pediatrician and discontinued a therapy arrangement after observing that it was negatively affecting the child, demonstrating active parental monitoring and advocacy. A working parent incorporated walking, jogging, and other physical activities into her routine with the child. A father reserved time during days off for family activities and intentionally strengthened his connection with the child through play, conversation, and affection.

These strategies constitute problem-focused coping because parents acted directly on the source of difficulty. Chaidi and Drigas [16] emphasized that parents can learn and implement educational and behavioral strategies when given appropriate training. Deb *et al*. [21] similarly found that parent-training interventions produced positive, though variable, effects on children and parents. Zygopoulou *et al.* [22] reported that parent-focused interventions generally improved parental well-being and reduced distress.

Theme 9. Self-care is present but often limited and informal

Self-care practices included bathing, eating preferred foods, spending time at the beach, exercising, resting, dating one's spouse, or temporarily stepping away from stressful situations. One mother stated that she took a bath to calm herself. Another identified food as a source of comfort. One participant went to the beach or pool when stressed, while another father scheduled occasional dates with his wife and protected family time during days off.

However, some parents admitted that they had little or no time for themselves. One caregiver said, "I don't have time to take care of myself," indicating that self-care was frequently sacrificed to meet the child's needs. This suggests that although parents recognize the importance of emotional recovery, their self-care is often unstructured and dependent on available time and resources.

Zygopoulou *et al*. [22] emphasized that parents of young children with ASD experience elevated stress, anxiety, and psychological distress and therefore require interventions directed specifically at parental well-being. Kasem et al. [19] also showed that parents of children with ASD experience poorer quality of life across multiple domains. Structured respite care, counseling, and parent wellness programs may therefore strengthen parents' capacity to sustain caregiving.

SUPPORT NETWORKS AVAILABLE TO PARENTS AND CAREGIVERS

Theme 10. Immediate family members are the primary source of support

Parents most commonly turned to spouses, siblings, parents, and other close relatives. Support included childcare, financial assistance, listening, transportation, and helping during medical emergencies. One mother identified her sister as an important source of help. Another reported that relatives and family members were generally supportive and willing to assist. A father identified his wife and parents as his main sources of support and advice.

However, support was uneven. Some participants said they had few people to talk to, distrusted friends, lived far from relatives, or felt that family members were judgmental. One mother stated that her parents were geographically distant, leaving her dependent on her husband's family and church acquaintances. Another father described relatives as judgmental and indicated that he had no dependable person with whom to share his concerns.

These contrasting experiences show that the presence of relatives does not automatically guarantee effective support. The usefulness of support depends on acceptance, understanding, availability, and the family's ability to respond to the child's specific needs. Carvalho *et al.* [10] stressed the importance of including both the child and family in multidisciplinary support networks. Phetoe *et al.* [11] likewise identified support systems as central to family coping.

Theme 11. Professional and community support is valuable but fragmented

Teachers, therapists, developmental pediatricians, church members, and specialized schools were identified as important sources of help. Parents appreciated professionals who explained the child's condition, taught strategies, monitored progress, or referred them to appropriate services.

Nevertheless, access to professional help was inconsistent. Participants described expensive private therapy, limited government programs, uncertainty about where to seek assistance, and negative experiences with some service providers. One mother changed therapists after consulting a developmental pediatrician because she believed the previous arrangement had distressed her child. Another participant requested more special education programs and parent seminars. Parents also called for government-supported therapy because private services were financially inaccessible.

These findings closely align with Khara *et al*. [24], who found that families needed information, services, support, financial assistance, education, and mental health resources. Vosough Matin and Sari [23] demonstrated that structured family education programs significantly improve parental empowerment. Chaidi and Drigas [16] likewise emphasized that parent participation is strengthened when families receive practical education and guidance.

Theme 12. Parent groups and online communities remain underused

Only a few participants reported meaningful involvement in online groups or parent communities. Several explicitly stated

that they were not members of any group, did not like online interaction, lacked a cellphone, preferred face-to-face communication, or believed that online groups might simply repeat similar problems.

The limited use of peer groups suggests a gap in available support. Parents may benefit from shared experiences, but barriers such as digital access, discomfort with disclosure, language, mistrust, and preference for personal interaction must be considered. A parent-support program should therefore not rely exclusively on online delivery. Face-to-face groups, school-based parent circles, and community seminars may be more appropriate for some families.

Bonjibon et al. emphasized that family, community, and social support help parents manage the complexities of raising children with ASD. Bakar *et al*. [20] also found that parents gained empowerment not only by seeking support but by supporting other parents. Thus, peer networks may transform isolated caregivers into informed and active advocates.

PERCEPTIONS OF LONG-TERM OUTCOMES

Theme 13. Parents hope for independence, education, and meaningful participation

The dominant hope was that children would eventually become independent, complete their education, work, communicate effectively, and function safely in society. One father stated that his main hope was for his child to become independent and capable of working. Other parents hoped for improvement in communication, behavior, academic skills, social interaction, and daily functioning.

The desire for independence reflects parents' awareness that they may not always be present to provide care. It also shows that their aspirations extend beyond symptom reduction toward inclusion, dignity, and meaningful participation. Carrera *et al*. [15] emphasized that inclusive schooling can support learning and social development when the child's individual needs are recognized. Chaidi and Drigas [16] similarly noted that parental involvement contributes to long-term educational and developmental outcomes.

Theme 14. The future is accompanied by fear, uncertainty, and concerns about lifelong dependence

Alongside hope, participants expressed fear that their children might be bullied, mistreated, remain dependent, fail to obtain employment, or lack someone to care for them in adulthood. Parents also worried about what would happen if they became ill or died.

One father identified bullying as his major fear. Another mother worried that she might eventually become unable to recover physically or emotionally enough to continue providing care. Some participants admitted that they were not financially or practically prepared for the future and were managing life one day at a time.

Havens [25] similarly found that parents of young adults with ASD faced inadequate transition planning, limited employment and postsecondary opportunities, and continued dependence. Begum and Mamin [13] noted that autism produces long-term effects across the family, while Losada-Puente et al. [18] found that family needs change according to the child's age. These findings indicate that support must continue beyond early intervention and schooling.

Theme 15. Families seek accessible programs, trained teachers, and stronger public commitment

Parents recommended affordable or free therapy, parent education, autism seminars, specialized learning programs, trained and patient teachers, inclusive schools, anti-bullying initiatives, and sustained government assistance. One participant directly requested additional special-needs educational programs and seminars for parents. Another asked the government to develop a clearer plan for affordable therapy services. A caregiver emphasized that teachers should be patient and recognize that children with developmental needs remain learners who require understanding.

These recommendations support Vosough Matin and Sari's [23] finding that family education improves empowerment and participation. Deb *et al*. [21] and Zygopoulou *et al.* [22] likewise demonstrated the potential value of structured parent interventions, although both emphasized the need for better-designed and more consistent programs. Khara *et al.* [24] concluded that a shared understanding among parents, professionals, and policymakers is necessary to adequately address family needs.

7. CONCLUSIONS

This study explored the lived experiences of parents and caregivers of children with Autism Spectrum Disorder (ASD) and revealed that caregiving is a multifaceted and lifelong responsibility shaped by emotional, behavioral, financial, social, and developmental challenges. The findings demonstrate that parents navigate complex caregiving demands that extend beyond managing their children's symptoms to include restructuring family routines, balancing employment and caregiving responsibilities, addressing financial constraints, coping with social stigma, and preparing for an uncertain future. These interconnected challenges significantly influence parental well-being and overall family functioning, underscoring that autism affects the family as a whole rather than the diagnosed child alone.

Despite these difficulties, the participants demonstrated remarkable resilience through various adaptive coping strategies. Acceptance, patience, faith, emotional regulation, and practical problem-solving emerged as essential mechanisms that enabled parents to adjust to the demands of caregiving. Parents also relied on support from spouses, immediate family members, healthcare professionals, educators, and religious communities, although the availability and adequacy of these support systems varied considerably. The findings suggest that while personal resilience plays a vital role in adaptation, effective coping is strengthened when supported by responsive family relationships, accessible professional services, and an understanding community.

The study further highlights that parents' aspirations extend beyond managing present challenges toward securing meaningful futures for their children. Their hopes for independence, education, social acceptance, and productive adulthood are accompanied by concerns regarding lifelong dependence, financial sustainability, limited services, and societal acceptance. These long-term concerns illustrate that caregiving responsibilities continue across the lifespan and

require continuous support beyond early intervention and formal schooling.

Overall, the findings affirm the Transactional Model of Stress and Coping proposed by Lazarus and Folkman, demonstrating that parents continuously appraise caregiving demands and mobilize available personal, familial, spiritual, and social resources to adapt to ongoing stressors. The dynamic interaction between caregiving challenges, coping strategies, support networks, and future aspirations reflects a continuous process of adaptation rather than a fixed experience. This study therefore contributes to the growing body of literature by providing an in-depth understanding of the lived experiences of Filipino parents and caregivers of children with ASD. More importantly, the emergent themes provide an empirical foundation for the development of a contextually grounded Support and Coping Model that reflects the realities, strengths, and evolving needs of families raising children with Autism Spectrum Disorder.

8. RECOMMENDATIONS

The Department of Education (DepEd), through Special Education (SPED) centers and inclusive education programs, may strengthen parent education initiatives by conducting regular seminars, workshops, and training sessions on Autism Spectrum Disorder (ASD). These programs should focus on communication strategies, behavior management, home-based interventions, emotional well-being, and transition planning to equip parents with practical knowledge and caregiving skills.

The Department of Health (DOH), in collaboration with local government units and healthcare institutions, may improve access to affordable developmental services by expanding community-based therapy programs, developmental screening, counseling services, and mental health support for both children with ASD and their caregivers. Financial assistance or subsidy programs for therapy, assessment, and medical consultations may also be considered to reduce the economic burden experienced by families.

The Local Government Units (LGUs), through their Persons with Disability Affairs Offices (PDAO) and Social Welfare and Development Offices (MSWDO/CSWDO), may establish community-based parent support groups where parents can regularly meet, share experiences, receive peer support, and access professional guidance. Such initiatives may reduce caregiver isolation while strengthening resilience and social connectedness within the community.

Schools and educational institutions may strengthen collaborative partnerships with parents by maintaining consistent communication, involving families in individualized educational planning, and promoting inclusive educational practices. Teachers and school personnel may also be provided with continuous professional development on autism awareness, inclusive instructional strategies, positive behavior support, and effective collaboration with families.

Healthcare professionals, therapists, psychologists, guidance counselors, and social workers may adopt a more family-centered approach in delivering services by recognizing parents as active partners in intervention planning. Comprehensive family assessments, caregiver counseling, stress management programs, and regular follow-up support may further enhance parents' coping capacity and psychological well-being.

Community organizations, faith-based institutions, and non-government organizations (NGOs) may collaborate in promoting autism awareness campaigns to reduce stigma, misconceptions, and discrimination toward children with ASD and their families. Increasing public understanding may foster greater acceptance, inclusion, and social participation within communities.

Parents and caregivers may continue strengthening adaptive coping strategies by maintaining open communication within the family, participating in available parent support networks, seeking professional guidance when necessary, and prioritizing their own physical, emotional, and mental well-being. Recognizing self-care as an essential component of caregiving may enable parents to provide more consistent and effective support to their children.

The Commission on Higher Education (CHED) and higher education institutions offering teacher education, psychology, nursing, social work, and allied health programs may incorporate more comprehensive coursework and field experiences related to autism, family-centered care, and inclusive education. Such preparation may increase the competence of future professionals who will serve children with ASD and their families.

The proposed Support and Coping Model developed from this study may be utilized as a conceptual framework by educators, healthcare providers, social workers, and policymakers in designing intervention programs, caregiver education, and community support services tailored to the needs of parents and caregivers of children with ASD. The model may also serve as a guide for developing evidence-based family support initiatives that promote resilience, empowerment, and improved quality of life.

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