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Navigating Autism: A Phenomenological Exploration of Parental Resilience in Raising Children with Autism Spectrum Disorder in the Philippines

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Abstract

The increasing prevalence of Autism Spectrum Disorder (ASD) has generated growing concern regarding the well-being of parents who serve as primary caregivers. While numerous studies have documented the challenges associated with raising children with ASD, limited attention has been devoted to understanding how parents develop resilience within resource-constrained educational and social contexts. This study explored the lived experiences and resilience of parents raising children with ASD enrolled at Cauayan South Central School Resource Center Catering SNED-LWD, Philippines. Using a phenomenological research design, semi-structured interviews were conducted among twelve purposively selected parents until data saturation was achieved. Thematic analysis revealed five major themes: (1) From Denial to Acceptance, (2) Everyday Challenges and Adjustments, (3) Financial and Social Barriers, (4) Emotional and Psychological Resilience, and (5) The Strength of Adaptive Parenting. Findings demonstrate that resilience is a dynamic process characterized by emotional adaptation, family collaboration, coping flexibility, and persistent advocacy for children's developmental needs. Despite substantial challenges related to communication difficulties, behavioral management, financial burden, and social stigma, parents developed adaptive strategies that enabled them to sustain caregiving responsibilities while promoting their children's growth and well-being. The study highlights the importance of family-centered interventions, psychological support services, inclusive educational programs, and community awareness initiatives that strengthen parental resilience. Implications for special education practice, policy development, and family support programs are discussed.

Keywords: Autism Spectrum Disorder, parental resilience, phenomenology, special education, family adaptation, caregiving

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by persistent difficulties in social communication, social interaction, and repetitive patterns of behavior, interests, or activities. The growing prevalence of ASD worldwide has significantly increased the number of families navigating the complex realities of caregiving and developmental support. Although educational and therapeutic interventions primarily focus on children diagnosed with ASD, the experiences of parents remain equally critical because they serve as the primary agents of care, advocacy, and developmental facilitation.

Parents of children with ASD often encounter emotional distress, financial strain, social isolation, and psychological exhaustion. The demands associated with therapy appointments, educational planning, behavioral management, and future uncertainties create cumulative stress that influences family functioning and parental well-being. Nevertheless, many parents demonstrate remarkable resilience, enabling them to adapt positively despite persistent challenges.

Resilience refers to the dynamic process through which individuals successfully adapt to adversity, trauma, stress, and significant life challenges. Within the context of ASD parenting, resilience encompasses emotional regulation, adaptive coping, social support utilization, family cohesion, and positive meaning-making. Understanding how parents develop resilience is essential for designing interventions that support both families and children.

Guided by McCubbin and McCubbin's Resiliency Model of Family Stress, Adjustment, and Adaptation, this study explored the lived experiences of parents raising children with ASD. Specifically, it sought to understand the challenges they encounter, the coping mechanisms they employ, and the resilience processes that enable them to continue providing care despite substantial caregiving demands.

2. Theoretical Framework

This study was anchored on the Resiliency Model of Family Stress, Adjustment, and Adaptation developed by McCubbin and McCubbin (1993). The model explains how families respond to stressors through adaptation processes involving available resources, coping mechanisms, and family perceptions.

In the context of ASD parenting, the diagnosis serves as a significant family stressor that triggers emotional, social, financial, and psychological responses. Parents initially experience shock, denial, uncertainty, and distress. Through adaptive coping strategies, family support systems, and access to professional services, families gradually move toward acceptance and positive adaptation (bonadaptation). Conversely, inadequate support and ineffective coping may result in maladaptation.

The framework provides a valuable lens for understanding how parents transform adversity into resilience while maintaining family functioning and supporting their children's developmental needs.

3. Methodology

Methodology

Research Design

This study employed a qualitative phenomenological research design to explore and understand the lived experiences of parents raising children with Autism Spectrum Disorder (ASD). Phenomenology was deemed appropriate because it seeks to capture the essence of human experiences and the meanings individuals attach to significant life events. Specifically, the study focused on how parents perceive, interpret, and respond to the challenges and realities associated with raising a child with ASD. Through this approach, the researcher was able to gain deeper insights into the emotional, psychological, social, and practical dimensions of parenting children with ASD. The phenomenological design allowed participants to freely describe their experiences, providing rich and detailed narratives that illuminated the processes through which they developed resilience and adapted to their caregiving roles.

Research Setting

The study was conducted at the Cauayan South Central School Resource Center Catering SNED-LWD located in Cauayan City, Philippines. The institution serves as a specialized educational center that provides educational services and support programs for learners with disabilities, including children diagnosed with Autism Spectrum Disorder. The school was selected as the research locale because it accommodates a significant number of learners with ASD and actively collaborates with parents in implementing educational and developmental interventions. As a resource center for special needs education, the institution provides an appropriate context for examining the experiences of parents who are directly involved in supporting the growth, development, and education of children with ASD. The setting offered a valuable environment for understanding the realities, challenges, and resilience mechanisms of parents within a specialized educational framework.

Participants of the Study

The participants of the study consisted of twelve (12) parents of children clinically diagnosed with Autism Spectrum

Disorder and enrolled in the special education program of Cauayan South Central School Resource Center Catering SNED-LWD. Participants were selected through purposive sampling, a non-probability sampling technique commonly used in qualitative research to identify individuals who possess firsthand knowledge and direct experience relevant to the phenomenon under investigation. To qualify for participation, individuals had to be the parent or primary caregiver of a child diagnosed with ASD, directly involved in the child's daily care, developmental support, and educational activities, and willing to voluntarily participate in the study. The researcher continued participant recruitment and data collection until thematic saturation was achieved, indicating that no new significant information or themes emerged from subsequent interviews. The selected participants provided rich and meaningful accounts of their experiences, allowing for a comprehensive exploration of parental resilience in raising children with ASD.

Data Collection Procedure

Data were gathered through semi-structured individual interviews, which enabled participants to openly share their experiences, thoughts, feelings, and perceptions regarding raising a child with Autism Spectrum Disorder. The semi-structured format provided a balance between consistency and flexibility, allowing the researcher to explore predetermined topics while also probing for additional details when necessary. Interview questions focused on understanding the participants' challenges, coping mechanisms, adaptation processes, emotional experiences, support systems, and perceptions of resilience. Prior to data collection, informed consent was secured from all participants, and ethical considerations regarding confidentiality, anonymity, and voluntary participation were strictly observed. The interviews were conducted in a comfortable and private setting to encourage openness and honesty. With participants' permission, all interviews were audio-recorded to ensure the accuracy and completeness of the data. The recordings were subsequently transcribed verbatim to facilitate a detailed and systematic analysis of the participants' narratives.

Data Analysis

The data gathered from the interviews were analyzed using thematic analysis, a widely recognized qualitative analytical method that enables researchers to identify, analyze, and interpret recurring patterns of meaning within textual data. The analysis began with data familiarization, wherein the researcher repeatedly read and reviewed the interview transcripts to gain a comprehensive understanding of the participants' experiences. This was followed by the coding process, during which significant statements, phrases, and ideas relevant to parental resilience were identified and assigned initial codes. Similar codes were then grouped into broader categories, which were subsequently examined to generate overarching themes that reflected common experiences and perspectives among the participants. The themes were continuously reviewed, refined, and validated to ensure that they accurately represented the participants' narratives and aligned with the objectives of the study. Through this rigorous analytical process, meaningful insights were generated regarding the resilience, challenges, coping strategies, and adaptive experiences of parents raising children with Autism Spectrum Disorder.

4. Findings and Discussion

Findings and Discussion

Theme 1: From Denial to Acceptance

One of the most profound experiences shared by parents was the emotional journey they underwent upon learning that their child had Autism Spectrum Disorder (ASD). The diagnosis represented not merely a medical label but a life-altering event that challenged their expectations, dreams, and perceptions of parenthood. Most participants initially experienced shock, confusion, sadness, anxiety, and denial before gradually moving toward acceptance.

Subtheme 1.1: Limited Understanding and Initial Confusion

Many parents admitted that they had little or no prior knowledge about autism. The unfamiliarity of the condition intensified their fears and uncertainty.

One participant shared:

"Nuong hindi pa po na diagnose si Ethan na Autism hindi ko po alam wala po akong idea ano yung spectrum or autism, di talaga ako familiar kung ano talaga yung spectrum at may mga different level pa pala ang autism." (P11)

Similarly, another parent narrated:

"Nung una, hindi naman ako masyadong familiar. Nanonood lang po ako sa YouTube at nagsesearch para maintindihan kung ano ang autism." (P3)

These responses suggest that lack of awareness significantly contributes to parental distress immediately after diagnosis. Consistent with Shilubane and Mazibuko (2020), inadequate knowledge regarding ASD often delays parental acceptance and creates barriers to accessing early intervention services.

Subtheme 1.2: Emotional Shock, Sadness, and Denial

Upon confirmation of the diagnosis, parents described overwhelming emotional reactions.

One parent explained:

“At first when the doctor told us that Jaden has this kind of disability, I was shocked emotionally, spiritually, and mentally. I don't know what to say and I don't know what to do.” (P7)

Another participant stated:

“Of course I was devastated. I didn't think that I would be having a child with autism.” (P8)

Likewise, another parent shared:

“Syempre nalungkot ako nung nalaman ko may ganoon pala na sakit ang anak ko.” (P9)

Several participants openly acknowledged experiencing denial.

“Nung una dahil nga denial ako, hindi ko matanggap.” (P1)

“Mahirap tanggapin yung sitwasyon niya.” (P2)

These narratives reveal that denial functioned as an emotional defense mechanism. According to Abella et al. (2024), denial is a common psychological response among parents confronted with unexpected developmental diagnoses, providing temporary protection from emotional distress while they process the reality of the situation.

Subtheme 1.3: Acceptance through Support and Learning

Over time, parents gradually accepted their child's condition through increased knowledge, professional interventions, and emotional support from family members.

One participant narrated:

“Mahirap po nung una, pero buti nalang po yung partner ko ay very understandable. Nagtulungan po kami.” (P3)

Another parent explained:

“Instead of complaining regarding his situation, we thought of the best things to do for him. Nagpa-assessment kami at sumailalim siya sa therapy.” (P6)

These experiences demonstrate that acceptance emerged not from the disappearance of challenges but from a deeper understanding of ASD and a commitment to supporting the child. This finding aligns with Uysal et al. (2024), who emphasized that parental acceptance develops through education, support systems, and adaptive coping.

The movement from denial to acceptance reflects the adjustment phase of McCubbin and McCubbin's Family Resilience Model, wherein families begin reorganizing resources and coping strategies following a significant stressor.

Theme 2: Everyday Challenges and Adjustments

Even after reaching acceptance, parents continued to face daily struggles associated with caregiving. These challenges involved communication barriers, behavioral management, sensory issues, and educational support.

Subtheme 2.1: Communication Difficulties

Communication emerged as one of the most difficult aspects of caregiving.

One parent explained:

“Pag meron siyang gusto hindi niya po masasabi. Kinukuha lang niya ang kamay namin at itinuturo niya ang gusto niya.” (P3)

Another participant shared:

“Very challenging dahil nonverbal po si Jeruiel. Kapag may sakit siya hindi namin alam kung saan masakit dahil hindi niya masabi.” (P10)

The inability of children to verbally express needs generated significant anxiety among parents. Similar findings were reported by Salomone et al. (2019), who found that communication deficits are among the strongest predictors of parental stress among caregivers of children with ASD.

Subtheme 2.2: Managing Daily Routines

Parents also experienced difficulties teaching self-care and daily living skills.

One participant stated:

“Mahirap maituro sa kanya ang daily routine katulad ng pagpunta sa bathroom. Kailangan ulit-ulitin araw-araw.” (P1)

Another parent explained:

“Nagpiprint ako ng daily activities niya. Gumagamit ako ng pictures at smiley faces para masundan niya ang routine.” (P11)

These responses highlight the extensive effort required to establish consistency and independence among children with ASD. Structured routines became an essential coping mechanism for both parents and children.

Subtheme 2.3: Educational Challenges

Parents expressed concern regarding their children's educational needs.

“Sa educational needs niya po nahihirapan po kaming turuan siya.” (P4)

“Nahihirapan po kaming turuan siya lalo na kapag hindi siya interesado.” (P5)

The findings indicate that many parents assume dual roles as caregivers and home educators. This reflects previous studies emphasizing the importance of parent-mediated interventions in supporting developmental progress

among children with ASD.

Discussion

The findings reveal that resilience extends beyond emotional endurance. It also involves practical adaptability, resourcefulness, and continuous learning. Parents actively modified routines, environments, and communication approaches to meet the developmental needs of their children.

Theme 3: Financial and Social Barriers

The financial and social realities of raising a child with ASD emerged as major stressors that shaped parental experiences.

Subtheme 3.1: Financial Burden of Therapy and Medical Care

Several parents reported difficulties sustaining therapy and medical expenses.

One participant stated:

“Wala naman kaming pera para sa therapy at sa pag-check up.” (P5)

Another parent explained:

“Yung gamot niya umaabot minsan ng dalawang libo isang linggo kaya doon kami nahihirapan.” (P2)

A single mother shared:

“Nag-resign ako sa trabaho para maalagaan siya. Ang hirap kasi wala nang pumapasok na income pero tuloy pa rin ang gastos sa therapy.” (P11)

These narratives demonstrate the substantial economic burden associated with ASD caregiving. Similar findings were reported by Anderson et al. (2020), who identified therapy costs and lost employment opportunities as significant contributors to parental stress.

Subtheme 3.2: Social Stigma and Misunderstanding

Parents also encountered judgment and misunderstanding from relatives and community members.

One parent narrated:

“May mga kamag-anak kami na nagtatanong kung bakit kami nagkaroon ng ganitong anak.” (P3)

Another participant shared:

“Hindi maintindihan ng ibang tao ang kalagayan ng anak ko lalo na kapag nagpapakita siya ng ibang behavior.” (P5)

Similarly:

“We became distant to those who didn't understand our situation.” (P8)

These experiences indicate that stigma remains a persistent challenge for families raising children with ASD. Social misunderstanding often contributes to isolation and reduced support networks.

Discussion

The findings demonstrate that resilience is influenced not only by personal factors but also by socioeconomic conditions and community acceptance. Financial assistance programs, public awareness campaigns, and inclusive community initiatives are necessary to reduce barriers faced by families.

Theme 4: Emotional and Psychological Resilience

Despite numerous challenges, parents demonstrated remarkable emotional strength and psychological growth.

Subtheme 4.1: Developing Inner Strength

One participant reflected:

“Nagka-anxiety attack ako dati pero natutunan kong maging mas matatag. Okay lang umiyak pero bawal sumuko.” (P11)

Another parent stated:

“Mas magiging matatag pa po ako para sa aking anak. Hindi po ako mapapagod sa kanya.” (P3)

These responses suggest that adversity became a catalyst for personal growth rather than defeat.

Subtheme 4.2: Cultivating Patience and Optimism

Parents repeatedly emphasized patience as an essential quality.

“Kapag may anak kang spectrum, bawal mapatid ang pasensya.” (P11)

“I adapt and become flexible because my child needs me.” (P5)

The narratives reveal how parents consciously maintained optimism despite uncertainty. Rather than focusing on limitations, they celebrated small developmental gains and continued supporting their children.

Discussion

The findings support contemporary resilience theory, which views resilience as a dynamic developmental process rather than a fixed personality trait. Parents transformed emotional pain into strength, demonstrating perseverance, hope, and commitment.

Theme 5: The Strength of Adaptive Parenting

The final theme illustrates how parents transformed their experiences into proactive caregiving strategies.

Subtheme 5.1: Seeking Support

Parents actively sought assistance from therapists, teachers, healthcare professionals, and support networks.

“Nagpa-assessment kami at sumailalim siya sa therapy.” (P6)

“Malaking tulong ang support ng asawa ko.” (P3)

Subtheme 5.2: Advocacy and Active Involvement

Several parents became advocates for their children.

“Pinilit kong ipaliwanag sa kanila ang kalagayan ng anak ko para maintindihan nila.” (P10)

Parents increasingly viewed themselves as active participants in their child’s development rather than passive observers of their challenges.

Subtheme 5.3: Spirituality and Hope

Many participants drew strength from faith and prayer.

“Nagdadasal na lang kami na ma-overcome namin ang sitwasyon.” (P2)

Spirituality provided emotional comfort and a sense of purpose during difficult periods.

Discussion

Adaptive parenting emerged as the highest manifestation of resilience. Through advocacy, collaboration, spirituality, and active engagement, parents continually adjusted their expectations and strategies to support their children’s growth. This finding strongly reflects McCubbin and McCubbin’s concept of bonadaptation, wherein families achieve positive adjustment despite ongoing adversity.

5. Implications

The findings have significant implications for educational institutions, policymakers, healthcare professionals, and family support organizations.

Schools should implement parent education programs focusing on ASD awareness, behavior management, communication strategies, and emotional support. Mental health services should be integrated into special education programs to address parental stress and psychological well-being.

Government agencies should expand financial assistance programs, subsidized therapy services, and inclusive educational resources. Community awareness campaigns are also necessary to reduce stigma and promote acceptance of individuals with ASD and their families.

6. Conclusion

The resilience of parents raising children with Autism Spectrum Disorder is characterized by a dynamic process of adaptation, perseverance, and personal transformation. While parents encounter substantial emotional, social, financial, and practical challenges, they develop resilience through acceptance, adaptive coping, family collaboration, and sustained commitment to their children’s development.

Resilience is not a fixed characteristic but an evolving process shaped by experiences, support systems, and access to resources. Strengthening these support systems is essential for enhancing parental well-being and improving outcomes for children with ASD.

The study highlights the necessity of family-centered interventions that recognize parents as critical partners in the developmental journey of children with Autism Spectrum Disorder.

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