LIFE EXPERIENCES OF PARENTS RAISING CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER

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ABSTRACT

Parents raising children diagnosed with autism spectrum disorder (ASD) face unique challenges that impact their emotional, social, and financial well-being. This study aims to explore and understand the diverse experiences of these parents in Dupax del Sur, Nueva Vizcaya. Using a descriptive-qualitative approach, the research involved semi-structured interviews with purposively selected parents, which were analyzed using thematic analysis. The findings revealed that parents experience significant emotional distress, social stigma, and financial strain. They reported feelings of confusion and anxiety upon diagnosis, followed by a gradual adaptation as they developed coping strategies. Support systems, including family, healthcare providers, and community networks, play a critical role in their adjustment. However, limited awareness of ASD in the community intensified parents' struggles, emphasizing the need for public education and targeted support. The study highlights the importance of strengthening community-based support services, enhancing public awareness of ASD, and ensuring access to affordable interventions for affected families. These insights contribute to a better understanding of parental experiences and inform the development of comprehensive support programs for families of children with ASD.

Keywords: Autism spectrum disorder, challenges, enhanced awareness, parents' lived experiences, support service

INTRODUCTION

Parenting is an inherently challenging journey that demands great patience and unconditional love. However, raising a child with autism introduces an additional layer of complexity, necessitating heightened understanding, advocacy, and unparalleled commitment from parents. Moreover, despite the significance of Autism Spectrum Disorder (ASD) research for public health, there is a noticeable gap in understanding the experiences of parents raising children with ASD. Hence, this study addresses the gap in understanding the experiences of parents raising children with ASD, emphasizing the crucial role of ASD research in public health. The primary objective is to comprehensively explore the daily challenges and life experiences faced by parents navigating the complexities of raising children on the autism spectrum.

ASD affects individuals across diverse demographics, with a global prevalence of 1 in 100 children (World Health Organization, 2023). In the United States, the CDC reported a prevalence of 1 in 36 children in 2020, a notable increase from 1 in 150 in 2000. Data from the US Centers for Disease Control and Prevention (CDC) places the average number of people with autism at 1 to 2 percent of the world's total population. In the Philippines, Senate President Miguel Zubiri (2023) stated that ASD cases have been steadily rising over the past decade, with CHR data indicating approximately 1.2 million or 1 in every 100 Filipinos having autism (Torregoza, 2023).

According to the study conducted by Tye et al. (2019), individuals with ASD are commonly affected by medical and/or psychiatric comorbidities such as epilepsy, sleep problems, gastrointestinal (GI) dysfunction, and immune dysfunction. The presence of comorbid medical conditions in ASD highlights the vast heterogeneity within the disorder. Moreover, a systematic review study of Bougeard *et al.,* (2021) highlighted the prevalence of nine comorbidities commonly found in children and adolescents with ASD i.e. Attention-Deficit/Hyperactive Disorder [ADHD] (0.0-86%), anxiety (0.0-82.2%), depressive disorders (0.0-38.6%), epilepsy/seizures (2.8-43.75%), GI syndromes (0.0-49%), hearing impairment (0.0-87.8%), sleep disorders (6.4-72.5%), and visual impairment (0.0-15.3%).

Additionally, contrary to societal perceptions framing ASD as a medical condition, the UK's National Health Service (2022) asserts that autism is not an illness and does not adhere to conventional medical classifications. This perspective reframes the narrative surrounding ASD, emphasizing that it extends beyond a mere medical condition. Unlike many illnesses, ASD lacks universally prescribed treatments or a definitive "cure," highlighting the intricate and multifaceted nature of the disorder. This recognition prompts a shift in perspective, encouraging a more comprehensive understanding of ASD that goes beyond traditional medical frameworks. Unfortunately, diagnosing ASD lacks a definitive medical test, relying on developmental history and behavior assessment by professionals. Detection can occur as early as 18 months, with a reliable diagnosis possible by age 2. However, many receive diagnoses later, hindering timely support. Early diagnosis is crucial for timely intervention and optimal development, a process that involves multiple steps (CDC, 2023).

Parenting children with ASD is significantly more challenging than raising typically developing children, especially in regions where support resources are scarce (Ilias et al., 2018). This aligns with findings from global research, which consistently report heightened parenting stress among parents of children with ASD. Additionally, caregiving responsibilities are typically divided along traditional gender norms, with mothers bearing the brunt of caregiving duties and experiencing higher levels of stress and isolation. Caregiving for a child with ASD can predispose parents to depression, anxiety, and other psychosomatic disorders, affecting family functioning (Dunn et al., 2019). When an intellectual disability coexists, it further complicates the parent-child relationship and heightens emotional strain (Marshall et al., 2018).

By shedding light on the multifaceted aspects of caregiving and the unique demands it entails, the research aims to provide valuable insights that benefit parents, affected children, healthcare professionals, the community, and future researchers. Moreover, the study seeks to establish a foundational framework for ongoing research in this critical area, contributing to a deeper understanding of the parental journey in raising children with ASD. Ultimately, through this study, the researchers aim to create and conduct an evidence-based healthcare education towards the parents, caregivers, and significant others of children with ASD, as well as members of the community particularly healthcare workers and SPED teachers/instructors, to improve the quality of life of the children, their parents, significant others and to further the knowledge of the healthcare providers of the community.

In essence, the results of this study provided essential insights to support parents of children with ASD, aiming to improve their well-being by addressing their unique challenges and offering resources. For children with ASD, the study advocates for better outcomes and enhanced family support, while raising awareness and advocating for necessary community resources. Healthcare professionals and students can use these findings to understand better and connect with ASD families, particularly in Nueva Vizcaya, thereby promoting compassionate care. The study also aims to reduce stigma in the community by fostering understanding and creating a supportive environment for individuals with ASD. Academically, the research established a foundational platform for further studies, guiding future research and informing practices that benefit ASD families and the community as a whole.

Statement of the Objectives

This 12-month research study aimed to explore and thoroughly understand the diverse perspectives, lived experiences, and challenges faced by parents in raising children diagnosed with ASD. The study aimed to identify key themes and patterns that emerged from these experiences to inform support strategies and interventions. Specifically, it aimed to achieve the following:

1. Identify the early signs observed by parents that prompted suspicions about their child's unique needs.
2. Determine the factors that motivate parents to seek medical attention for their child.
3. Explore parents' emotional reactions upon receiving their child's ASD diagnosis.
4. Examine the length of time it took for parents to come to terms with their child's condition.
5. Investigate parents' initial expectations about the impact of raising a child with ASD on their daily lives and how these expectations have aligned with their experiences.

METHODOLOGY

This study aimed to explore the lived experiences, perceptions, and challenges faced by parents raising children diagnosed with Autism Spectrum Disorder (ASD) through a descriptive-qualitative design conducted in Dupax del Sur, Nueva Vizcaya. The research employed purposive typical case sampling and snowball sampling methods to include a total of 10 biological parents of children with ASD, ensuring data saturation was achieved by the point at which no new themes emerged. Participants were required to be first-time parents with an official ASD diagnosis for their child, and recruitment was facilitated through collaboration with barangay health centers and targeted outreach via online platforms. A semi-structured interview protocol comprising five validated guide questions was used, and interviews were conducted in a comfortable setting, with participants' consent obtained for audio recording. Data collection persisted until saturation was reached, followed by thematic analysis to identify recurring themes, while ensuring the credibility of findings through reflexivity and an audit trail.

Ethical approval was secured from the Saint Mary's University Research Ethics Board, and informed consent processes were emphasized to highlight the voluntary nature of participation and confidentiality protections. Support services were made available for participants experiencing emotional distress, and they were reassured of their right to withdraw from the study without any repercussions. The study aimed to yield valuable insights into the challenges parents face, thereby contributing to community building and understanding, while acknowledging the potential for emotional discomfort during the interview process. The findings were subsequently disseminated to participants, community health workers, and family members through health education sessions and the distribution of informative materials.

RESULTS AND DISCUSSION

SECTION 1. Early signs observed by parents

Parents often serve as the first observers of developmental differences in their children, particularly noting social communication deficits, such as speech delays, limited eye contact, and social withdrawal. These behaviors become more evident as children grow and social interactions increase. Additionally, parents reported behavioral challenges like hyperactivity and impulsivity, which can lead to difficulties in structured environments such as classrooms.

Observations of frequent tantrums, especially during routine changes, and motor delays were also significant concerns. These findings align with existing research indicating that early impulsivity and emotional regulation issues can predict future behavioral disorders. The early identification of such symptoms is vital for timely intervention, which can improve long-term developmental outcomes. Consequently, healthcare providers need to educate parents about developmental milestones, empowering them to recognize these signs early and seek appropriate support, thereby enhancing children's integration into social settings.

Research supports these parental observations, highlighting that early signs of autism spectrum disorder (ASD) often manifest through atypical social interactions, repetitive behaviors, and communication delays (Zeidan et al., 2022). Rakap (2023) emphasized that early detection, followed by timely intervention, significantly improves developmental outcomes. Furthermore, Çelik et al. (2020) stressed the importance of community awareness, particularly among parents and teachers, in recognizing early indicators of ASD.

Furthermore, although the majority of parents emphasized these signs, they are not confined solely to these observations. Some parents also reported behavioral challenges, including hyperactivity and frequent tantrums. Some parents describe their children as more impulsive than their peers, which can lead to difficulties in structured environments such as classrooms. P1 expressed, "You can hardly stop him, always running, can't stay still even for a moment. Others report frequent temper tantrums, particularly during routine changes or unfamiliar social settings. Motor difficulties, such as delayed walking, are also noted by parents, reflecting potential developmental concerns. These observations are crucial as they provide early insights that guide parents towards seeking professional advice.

SECTION 2. Factors that prompted parents to seek medical attention

Parents' decisions to seek medical intervention for their children are largely influenced by their recognition of developmental delays and behavioral differences, particularly when they are aware of typical developmental milestones. Comparative awareness, especially among parents with older children or those familiar with childhood development, often catalyzes seeking help. For instance, one parent noted their concern when observing that their child was silent while peers were speaking. The study found that parents who are attentive to developmental norms are significantly more likely to pursue early intervention, aligning with research indicating that such awareness is crucial for timely action. The presence of strong familial support systems also enhances early identification and intervention.

Parental concerns are further heightened by the emotional and practical implications of their child's behavior. Many parents report feeling a sense of urgency to understand their child's condition, especially when behaviors begin to interfere with daily life or social interactions. Lau et al. (2021) found that parents who are attentive to developmental milestones are twice as likely to seek early intervention. Similarly, Constantino et al. (2020) emphasized the importance of family support in early identification. Çelik et al. (2020) also noted that early intervention guided by parental concerns yields better outcomes for children with ASD.

These findings emphasize the importance of informed and observant parenting in facilitating early detection of developmental concerns. Consequently, healthcare professionals should actively engage parents during routine check-ups and prioritize early screening when concerns are raised, thereby increasing the likelihood of effective therapeutic interventions for developmental delays.

SECTION 3. Parents' initial reaction upon receiving their child's diagnosis

Receiving a diagnosis of ASD for their child often triggers intense emotional distress in parents, characterized by feelings of confusion, sadness, anxiety, and disbelief due to unmet expectations of typical development. This emotional turmoil can impede parents' ability to process information and make informed decisions about their child's care. Many parents reported shock and difficulty accepting the diagnosis, particularly when they lacked familiarity with the condition, echoing findings from previous studies that highlighted heightened psychological distress and anxiety stemming from an unclear diagnostic process and cultural stigma. However, obtaining a formal diagnosis can transform this uncertainty into clarity, offering emotional relief and enabling proactive caregiving. Parents who initially felt anxious often reported a sense of relief upon understanding the root of their child's behavior, which validated their concerns and empowered them to support their child effectively. This shift from distress to acceptance is significant, as it fosters adaptive coping mechanisms and encourages early intervention. Healthcare professionals, especially nurses, play a crucial role in facilitating this transition by providing clear information, emotional support, and resources, thereby helping to alleviate the emotional burden parents experience during the diagnostic journey.

SECTION 4. Length of time it took for parents to come to terms with their child's condition

While many parents exhibited signs of early acceptance regarding their child's ASD, influenced by emotional preparedness, prior awareness, and a practical mindset, some struggled to come to terms with the diagnosis. Participants like Echo expressed immediate acceptance and actively sought guidance on caring for their child. This swift acceptance aligns with findings from Ting and Chu (2021), who indicated that parents who receive early education about developmental disorders demonstrate lower emotional resistance upon diagnosis, and with Reyes et al. (2022), who highlighted that Filipino parents who recognize early developmental red flags tend to accept their child's condition more readily. However, not all parents experience quick acceptance; some, like Hera, expressed confusion and difficulty in understanding their child's diagnosis, reflecting the stages of denial outlined in Kübler-Ross's (1969) grief model. Research from Lee et al. (2020) and Cheng et al. (2018) supports this notion, revealing that psychological resistance often precedes acceptance, particularly when parents' expectations of "normal" development are challenged. These findings underscore the significance of empathetic support during the acceptance process, as parents navigate their emotional responses. Consequently, healthcare professionals, particularly nurses, can play a vital role in fostering a supportive environment and encouraging peer connections to assist parents through their emotional journey.

SECTION 5. Parents' initial expectations about the impact of raising a child with asd and alignment with their experiences

Upon receiving an ASD diagnosis for their child, parents often face emotional and practical challenges, particularly concerns about lifelong dependency. Initially, parents express worries about their child's future, as exemplified by Calliope's anxiety over her daughter's ability to study as she grows up. However, many parents, including Aphrodite and Echo, report a shift in perspective as they observe their child's progress through consistent therapy. This evolving outlook reflects the concept of adaptive resilience, where parents adjust their expectations based on their child's development and available support. Research by McStay et al. (2021) supports this notion, indicating that parental expectations can evolve positively as they become more familiar with their child's abilities and the benefits of ongoing therapy. Nonetheless, the initial emotional strain highlights the need for mental health support and counseling services to help parents cope with feelings of uncertainty and fear. Nurses are pivotal in this process, providing ongoing education and resources to empower parents, facilitate their adjustment, and promote resilience, ultimately ensuring the well-being of both the child and family.

CONCLUSION AND RECOMMENDATIONS

Conclusion

This study highlights the multifaceted journey of parents raising children with autism spectrum disorder (ASD) in Dupax del Sur, Nueva Vizcaya, revealing that early recognition, often by parents and teachers, is a critical factor in initiating diagnosis and intervention. Observable signs such as speech delays, emotional dysregulation, and lack of social responsiveness were central in prompting concern, especially when compared to typical developmental milestones. External influences, including teacher guidance and family support, also played pivotal roles in decision-making.

Emotional responses to the diagnosis varied, with some parents experiencing immediate acceptance while others struggled with prolonged denial and confusion. These differences underline the psychological toll of caregiving and the importance of sustained emotional support. Moreover, the unpredictable nature of ASD-related behaviors contributed to parental exhaustion and social isolation, further emphasizing the need for comprehensive support systems.

The findings collectively stress the significance of early detection, timely intervention, and community education. Healthcare professionals, especially nurses, must provide empathetic, accessible, and family-centered care to guide parents through the diagnostic and adjustment process.

Recommendations

1. Encourage active information-seeking and training about Autism Spectrum Disorder (ASD) to understand their child's needs and behaviors better. Foster a supportive home environment that promotes patience, acceptance, and structured routines.

2. Prioritize the development of structured, community-based systems that promote early detection and comprehensive intervention for families raising children with ASD. Strengthen intersectoral collaboration between the Department of Health, Department of Education, and local government units to ensure integrated child development monitoring and cohesive support services.

3. Equip healthcare providers, especially nurses, midwives, and community health workers, with clinical knowledge and skills in communication, emotional support, and family-centered care.

4. Implement inclusive education programs by training teachers to handle children with ASD and adapting curricula to accommodate diverse learning needs.

5. Expand the scope of similar studies to include a larger and more diverse group of participants across various geographical areas.

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