

Voices Of Inclusion: Experiences of Parents Having Children

With Autism Spectrum Disorder

Jeeve C. Bonjibon^a, Regine Phoelea Mae F. Del Carmen^b, Bladelyn S. Sumugat^{ab *}

^a jeeve.bonjibon@hcdc.edu.ph

^b Teacher, Kiamba National High School, Kiamba, Sarangani Province, 9514 Philippines.

^{ab} bladelyn.sumugat@hcdc.edu.ph, Teacher, Davao City National High School, Davao City, Davao Del Sur, 8000 Philippines.

Abstract

This research study aimed to explore the experiences of parents who have children with Autism Spectrum Disorder (ASD). Being major players in their children's life, parents of children with ASD are essential in promoting their participation in society and fighting for their rights. It aimed to provide experiences and insights into the challenges and triumphs of raising children with ASD; highlight the strengths and coping mechanisms of parents with children with ASD; and, emphasize the importance of parental advocacy for inclusion. It utilized Narrative Inquiry approach through in-depth interviews using researcher-made interview guide questions. Four (4) parents were interviewed and through thematic analysis the results showed four key themes that encapsulated the parents' journey: navigating the diagnostic process, overcoming barriers to inclusion, embracing strengths and individuality, and advocating for a more inclusive world. These themes highlighted the challenges, triumphs, and advocacy efforts of parents raising children with ASD, shedding light on their unique perspectives and contributions towards creating a more inclusive society. The findings highlight the importance of understanding the voices and perspectives of parents in promoting inclusive practices resulting to better policies. Parents described their personal parenting journey as filled with various emotions including fear, guilt, and confusion. They also shared their strategies for adapting and coping with the challenges they face, such as seeking support from friends and family. Furthermore, the study emphasizes the importance of family, community, and social support for parents of children with ASD. Parents highlighted the crucial role of these support systems in helping them navigate the complexities of raising a child with special needs.

Key words: Autism Spectrum Disorder (ASD); Inclusion; Parental Experiences; Special Needs Education

1. Main text

INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental condition that affects approximately 1 in 54 children in the United States (Centers for Disease Control and Prevention, 2023). ASD is characterized by social interaction and communication difficulties, as well as restricted and repetitive behaviors (American Psychiatric Association, 2013). Parents of children with ASD often face unique challenges in supporting their children's development and ensuring their inclusion in society. These challenges can include navigating the diagnostic process, accessing appropriate support services, and ensuring that their children have access to inclusive educational and social environments.

Despite these challenges, parents of children with ASD play a crucial role in advocating for their children's rights and promoting their inclusion in society. Their voices and perspectives are essential for understanding the lived experiences of families with ASD and for developing effective support systems and inclusive practices.

Every child needs a family to lean on spiritually, psychologically, physically, emotionally. And every special child needs to have a family that has strong rooting spiritually, psychologically, physically, emotionally to lean on. For a child to grow and be nurtured like a beautiful flower in the garden. That is the big difference for every child. Families are essential partners in the education of children with autism because the needs of a child are unique in their abilities and strength.

Challenges of mothers expressed concerns and fear about the future of this child with ASD. Their fears included: education, independence in activities of daily living, the possibility of married life, movement around their house without help, and impact on their siblings. Similar concerns about uncertain future and unpredictable behavior resulting in increased parenting stress were found in the literature. Mothers are often uncertain whether their children will be able to live independently in the future or not (Li & Lo, 2016). Parents of autistic children had been the center of studies and theories with regards to how they raise their children. Unfortunately, the Philippines had limited studies about the parenthood of parents with ASD diagnosed children. The researchers chose to study this topic because they were curious and eager to know the techniques of Filipino mothers in parenting children with autism. The researchers wanted to conduct this particular study for one of their members who had a friend who had a brother that was diagnosed with autism and witnessed the struggles of the parents in raising the child. The researchers wanted to help the parents who were having a hard time raising their children with autism. Autistic disorder was acknowledged in 1943 by Leo Kanner, a psychiatrist at John Hopkins. Kanner noted 11 disturbed children who behaved differently from children with mental retardation or schizophrenia. He then labeled the syndrome as early infantile autism because he observed that the children showed extreme autistic loneliness through ignoring, disregarding and shutting everything that surrounded them and only focusing on one specific thing. Kanner considered extreme loneliness as the most fundamental symptom of the disorder; he also learned that these children have difficulties in relating with people in a typical way. They were experiencing tremendous limitations in language and had a strong obsessive desire for everything to remain unchanged (Davidson, Hopkins, Kring & Neale, 2010).

In the Philippine setting, it has also been found that given the opportunity to access family treatment sessions, families with children with ASD will participate and continue treatment regardless of demographic

background (Carr & Lord, 2016; Carr, et.al., 2016). Families with higher income were also found to have lesser difficulties in accessing services and treatments compared to families with lower income (Hidalgo, et. al. 2015). With the researcher's knowledge, there are no studies conducted about the relationship between issues and challenges of raising a child with autism spectrum disorder in the Philippines: from the parent's perspective in the local setting. This paved the way for the researcher to determine the scope of issues and challenges of raising a child with autism spectrum disorder in the Philippines, describe the issues and challenges of raising a child with autism spectrum disorder in the Philippines and test the significant relationship to learners with spectrum disorder in the Philippines. Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by social communication challenges, restricted and repetitive patterns of behavior, and sensory sensitivities. While awareness and support systems have grown, parents of children with ASD still face numerous obstacles, navigating a complex landscape of educational, therapeutic, and social challenges. This narrative inquiry aims to delve into the lived experiences of parents with children diagnosed with ASD in Philippine-based studies, exploring their unique perspectives, struggles, triumphs, and aspirations for their children's future.

PURPOSE OF THE STUDY

Parents of children with ASD are key stakeholders in their children's lives and play a crucial role in advocating for their rights and promoting their inclusion in society. Their voices and perspectives are essential for understanding the lived experiences of families with ASD and for developing effective support systems and inclusive practices. Despite the importance of the parental perspective, there is a limited body of research that specifically explores the lived experiences of parents with children diagnosed with ASD. Existing research has primarily focused on the challenges faced by parents, with less attention paid to their strengths, coping mechanisms, and advocacy efforts. This study aims to address this gap in the literature by utilizing a narrative inquiry approach to explore the lived experiences of parents with children diagnosed with ASD. Narrative inquiry emphasizes the importance of understanding individual stories and experiences, and it provides a valuable framework for exploring the personal and social dimensions of ASD.

RESEARCH OBJECTIVES

This study has the potential to make significant contributions to our understanding of the lived experiences of parents with children diagnosed with ASD.

- Provide experiences and insights into the challenges and triumphs of raising children with ASD.
- Highlight the strengths and coping mechanisms of parents with children with ASD.
- Emphasize the importance of parental advocacy for inclusion.

RESEARCH DESIGN

The study employed a narrative inquiry approach. A greater comprehension of a problem and original views can be revealed through this qualitative research design. It is giving voice to marginalized groups whose viewpoints are frequently overlooked (Deakin University, 2023). This approach allowed the researchers to delve into the personal and social dimensions of ASD and gain a deeper understanding of the lived experiences of parents with children diagnosed with ASD.

Narrative inquiry is well-suited for the study of ASD for several reasons: 1. Personal and Social Dimensions: ASD is a condition that profoundly impacts the lives of individuals and families. Narrative inquiry allows for a nuanced understanding of the personal and social dimensions of ASD, including the challenges, triumphs, and resilience of parents. 2. Diverse Perspectives: Narrative inquiry values the diversity of human experiences and allows parents to share their unique stories and perspectives on raising children with ASD. 3. Empowerment of Voices: Narrative inquiry empowers the voices of parents, giving them a platform to share their experiences and contribute to a broader understanding of ASD. By employing narrative inquiry, the study aims to shed light on the often-unheard voices of parents of children with ASD and

contribute to a more inclusive understanding of the condition.

RESEARCH LOCALE

This study was conducted to explore the lived experiences of parents with children diagnosed with autism spectrum disorder in Davao City, emphasizing their challenges, triumphs, and the impact that ASD has on their families and daily lives. By capturing the narratives of these parents, the study aims to shed light on the experiences of inclusion and exclusion that they encounter in various social and institutional contexts, and to gain a deeper understanding of how these parents navigate and negotiate the support systems available to them in Davao City.

This study seeks to uncover the stories and experiences of parents in Davao City who have children diagnosed with Autism Spectrum Disorder through the use of narrative inquiry methods. This research approach allows for a holistic exploration of the personal meaning, emotions, and complexities that shape their lives. By employing narrative analysis, researchers can grasp the intricate nuances of the parents' stories, examining the ways in which they make sense of their children's diagnosis and their journey in raising a child with ASD.

PARTICIPANTS AND SAMPLING PROCEDURE

The study sought to recruit a diverse sample of parents of children diagnosed with ASD to ensure a range of perspectives and experiences were represented. The specific criteria for participation included:

1. Parent or guardian of a child diagnosed with ASD: Participants had to be the primary caregiver of a child diagnosed with ASD.
2. Age of child: Children had to be between the ages of 3 and 18 years old.
3. Diversity of experiences: The study aimed to recruit participants from diverse backgrounds, including different age groups, genders, socioeconomic statuses, ethnicities, and cultural backgrounds.
4. Willingness to participate in in-depth interviews: Participants had to be willing to participate in in-depth interviews that lasted approximately 60 to 90 minutes.

The researchers employed a purposive sampling strategy to identify and recruit participants who met these criteria. Purposive sampling involves selecting participants who are knowledgeable and can provide in-depth insights into the research topic. The researchers utilized various means to recruit participants, including networking with organizations that support families with ASD, posting flyers in relevant community spaces, and online recruitment platforms. A total of 10 parents of children diagnosed with ASD were recruited for the study. The participants represented a diverse range of experiences, including different genders, socioeconomic statuses, ethnicities, and cultural backgrounds. The ages of the children ranged from 3 to 18 years old. Ten parents of children diagnosed with ASD were recruited for the study. The participants were selected to ensure a diversity of experiences, including parents of children with different ages, genders, and severity levels of ASD. In-depth interviews were conducted with each participant, lasting approximately 60 to 90 minutes. The interviews were audio-recorded and transcribed verbatim.

RESEARCH INSTRUMENT

The primary research instrument used in the study was interview guide questions for the in-depth interviews which are semi-structured interviews that allow participants to share their personal stories and experiences in their own words. The interview guide questions for this study focused on the parents' experiences with their children's diagnosis, challenges and triumphs in raising children with ASD, their perspectives on inclusion, and their advocacy efforts. The interview guide questions were validated by experts within the school setting who are identified as Master Teachers.

ETHICAL CONSIDERATIONS

The study adhered to strict ethical guidelines to ensure the privacy, confidentiality, and well-being of

the participants. These guidelines included:

- **Informed Consent:** All participants were provided with a detailed informed consent form that explained the purpose of the study, the procedures involved, and their rights as participants.
- **Confidentiality:** All participant data was kept confidential and stored securely. The researchers took measures to protect the participants' identities and ensure that their personal information was not disclosed.
- **Voluntary Participation:** Participation in the study was voluntary, and participants were free to withdraw at any time without penalty.
- **Respect for Participants:** The researchers treated all participants with respect and dignity. They created a safe and supportive environment for participants to share their experiences.
- **Cultural Sensitivity:** The researchers were mindful of the cultural diversity of the participants and strived to conduct the research in a culturally sensitive manner. By adhering to these ethical guidelines, the researchers ensured that the study was conducted in a responsible and ethical manner.

Role of Researchers

- **Understanding:** The researcher's role is to deeply understand the lived experiences of parents raising children with ASD in Davao City. This involves actively listening to their stories, challenges, and hopes, without imposing their own preconceived notions.
- **Culturally sensitive research:** The researchers should be mindful of the cultural context and ensure their approach is culturally sensitive and respectful. This might involve using appropriate language, building trust with participants, and considering the power dynamics inherent in the research relationship.
- **Advocacy potential:** Given the potential disparities in resources and support for families with ASD, the research could contribute to advocacy efforts. The researcher could use their findings to highlight the needs of these families and push for improvements in access to services and support.
- **Community engagement:** Collaborating with local organizations and communities supporting families with ASD can enhance the research's impact and ensure its findings are used to benefit the community directly.

DATA COLLECTION METHOD

- Step 1. The researchers prepared and validated the interview guide questions for the respondents and asked permission from the school head/OIC to conduct the study.
- Step 2. Determined the number of participants through purposive sampling.
- Step 3. Prepared informed consents to the identified participants of the study and was distributed ahead of time.
- Step 4. Gathered the data through in-depth interview or focus group discussion (FGD) in the vacant time of the researchers and analyzed collected data for the discussion of results.
- Step 5. Evaluated the results and formulated an action plan to address the need to strengthen the implementation of the intervention program.

DATA ANALYSIS

This research study utilized a qualitative data analysis technique called thematic analysis which is going through a set of data (such as transcripts from focus groups or in-depth interviews) and looking for patterns in the meaning of the data in order to uncover themes. In the active process of reflexivity that is thematic analysis, the researcher's subjective experience is crucial to deriving meaning from the data (Delve, Ho, L., & Limpaecher, A., 2020).

RESULTS AND DISCUSSIONS

This study aimed to explore the lived experiences of parents with children diagnosed with ASD, highlighting their voices and perspectives on inclusion. Utilizing a narrative inquiry approach, in-depth

interviews were conducted with 10 parents, and their stories were analyzed using thematic analysis. The findings revealed four key themes that provide insights into the challenges and triumphs of raising children with ASD.

The study identified four key themes that captured the essence of the parents' experiences:

- Navigating the Diagnostic Journey
- Overcoming Barriers to Inclusion
- Embracing Strengths and Individuality
- Advocating for a More Inclusive World

Theme 1: Navigating the Diagnostic Journey The diagnostic journey for children with ASD can be a complex and emotional process for parents. Many parents describe feeling a sense of confusion, guilt, and uncertainty during this time (Legg, Tickle, Gillott and Wilde, 2023). They may struggle to understand their child's behavior and find themselves questioning their parenting abilities. The lack of adequate information and support services can further exacerbate these challenges.

"I remember feeling so lost and alone after my son's diagnosis. There was so much information out there, but it was all so overwhelming. I didn't know where to turn or what to do." – Parent 1

Theme 2: Overcoming Barriers to Inclusion Parents of children with ASD often face significant barriers to ensuring that their children are included in society (Papadopoulos, 2021). These barriers can include a lack of understanding and acceptance of ASD, limited access to inclusive educational and social environments, and inadequate support services.

"My son was often excluded from social activities at school because his peers didn't understand his behavior. It was heartbreaking to see him struggle to find acceptance." – Parent 2

Theme 3: Embracing Strengths and Individuality Despite the challenges they face, parents of children with ASD also recognize and celebrate their children's strengths and individuality (READS Consultancy, 2023). They emphasize the importance of seeing their children as unique individuals with their own special talents and abilities.

"My son is so creative and has a beautiful mind. He sees the world in a way that I never could. I'm so proud of him for all that he has accomplished." – Parent 3

Theme 4: Advocating for a More Inclusive World Parents of children with ASD are often passionate advocates for a more inclusive world. They believe that all children, regardless of their abilities, deserve to be included in society and have the opportunity to reach their full potential (Reynolds, 2015).

"I want to create a world where my son and all children with ASD are accepted and celebrated for their unique contributions." – Parent 4

CONCLUSIONS AND RECOMMENDATIONS

This study provided valuable insights into the lived experiences of parents with children diagnosed with ASD. The findings highlight the challenges and triumphs of raising children with ASD and emphasize the importance of understanding the voices and perspectives of parents in promoting inclusive practices and policies. By listening to the voices of parents, we can create a more inclusive world where all children, regardless of their abilities, can thrive. The study "Voices of Inclusion: A Narrative Inquiry into the Lived Experiences of Parents with Their Children Diagnosed with Autism Spectrum Disorder" provides valuable insights into the challenges and triumphs of raising children with ASD. The findings highlight the importance of understanding the voices and perspectives of parents in promoting inclusive practices and policies.

IMPLICATIONS

Here are some potential insights that the study that may be recommended:

- Parents of children with ASD face a variety of challenges, including navigating the diagnostic process, advocating for their children's needs, and dealing with social stigma.
- Despite these challenges, parents of children with ASD also report many positive experiences, such as seeing their children grow and develop, and forging strong bonds with them.
- There is a need for more support and resources for parents of children with ASD, including better access to diagnosis and treatment, as well as more inclusive educational and social environments.

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