

Nurturing Teenagers with Special Needs: As a Basis for Government Intervention Programs

A B S T R A C T

Background

Compared to parents of average children, parents of teenagers with special needs (ASD) experience higher stress levels and endure various health issues.

Aim

This study aimed to look at parents' experiences of nurturing teenagers with special needs (ASD) autism spectrum disorder in San Fernando, La Union, The Philippines.

Methods

This was a descriptive research study. The study employed a mixed methods approach to explore (in-depth) parents' experiences using both a questionnaire and an oral interview. Data were obtained from 8 parents of children with autism who were chosen using the purposive strategy. Three specialists in the profession evaluated both the questionnaire and the interview guide. The information gathered was examined using frequencies count, percentages, and themes. Following the questionnaire, researchers conducted a face-to-face interview to explain the goal of the inquiry by an interview methodology expressly created for that reason. The parents' exact body movements, gestures, and facial expressions were also studied.

Results

The results found that most of the teenagers' parents were female (62.5%), most of the respondents were within the 31– 35-year age group (37.5%), and three were separated from their spouses (37.5%). Most of the parents had a college graduate degree (50%). The four major themes were derived from nurturing teenagers with special needs: as a basis for government intervention programs through intelligent transcription, revealed the Parental/Guardian Involvement, Challenges of Parents/Caregivers, Coping Mechanisms of Parents, and Special Road.

Conclusions

This article revealed that parents' both fathers and mothers of teenagers with special needs (ASD), were female (62.5%), most of the respondents were within the 31– 35-year age group (37.5%), and three were separated from their spouse (37.5%). Most of the parents had a college graduate degree (50%). It implies that the parents and teachers of teenagers with ASD were knowledgeable and educated enough that they could nurture and care for their wards. Even without adequate support from the government and community, they still developed a coping strategy that helps them to nurture their teenagers.

Keywords: Autism spectrum disorder, Nurturing teenagers, Family support, Government intervention program, special road.

1. INTRODUCTION

Education is critical to the prosperity of a country. If a country does not have proper education, it may be left behind by other countries that support education [1]. Many factors affect the education system. Culture, technology, and economic matters impact the education system. The regulations made by the government affect how the education system works in a country. Education is essential in human life. And as time goes by, the method of schooling changes dynamically to meet the needs of human beings [2].

Special needs are a phrase that covers a wide range of illnesses, ranging from those who resolve swiftly to those who will be a long-term commitment burden for the rest of one's life and from very moderate to profound. Teenagers with special needs may have a variety of developmental delays, medical issues, psychological disorders, and congenital conditions. These specific requirements necessitate modifications so that teenagers can realize their full potential [3].

ASD is a developmental disorder that lasts a lifetime and is characterized by significant challenges in community interaction, communication, specialized and repeated interests, and behaviors. The word "spectrum" is used because the span and stringency of the problems people with ASD experience vary widely [4]. Autism spectrum disorder (ASD) is diagnosed in children at a younger age [5].

In the United States, there has been a significant rise in the number of children reported having specific special needs (ASD) within the last two decades since the U.S. Department of Education first recognized it as a disability in 1991 [6]. This is mainly due to the increase in public awareness and education of ASD and the development of better diagnostic protocols, leading to an increased need to help those children and their parents. The Centers for Disease Control and Prevention (CDC) is a federal agency that works to prevent disease and estimates that one out of every 68 children in the United States have one specific need (ASD). Boys are four and a half times more likely than females to have autism. When you investigate ASD's history, it's evident that it's a relatively recent disorder with many unknowns [6].

It's been proven that caring for a teenager with a developmental handicap causes more stress than caring for a youngster with typical development [7]. The birth of a disabled child produces tension in the family, particularly among parents, impacting the parents' quality of life. It is more difficult for parents of children with impairments, such as those diagnosed with autism spectrum disorder, to care for them than for parents of typical children. Given that chronic stress has been linked to various physical and mental health issues, parents of healthy or normal children have claimed that their children with ASD had poorer health and more ailments than their healthy or normal children. [8].

Being a parent or family member of an autistic person comes with its own set of difficulties and heartbreaks. Bullying and exclusion are just a few of the issues that many people experience. Sustainable development can only be attained if the needs of the most vulnerable people in society are met. National and municipal governments have made tremendous progress toward implementing the UN Convention on the Rights of Persons with Disabilities [9].

Parents of non-disabled children, when compared to parents of children with autism spectrum disorder (ASD), exhibit more significant levels of stress and lower physical health [10]. The parenting stress experienced by parents of a child affected by ASD appears to pose a greater risk to the parents' psychological and health-related quality of life [11].

Despite the prevalent research on autism, few studies have investigated this disorder's effect on the child's parents. Autism, at its very core, makes intimate familial relationships extremely difficult to develop. A condition inherently changes the parent-child relationship: communication is impeded or impossible; intimacy can be a challenge, and a child's self-injurious behaviors may make a parent feel frightened and helpless. Parents of autistic teenagers are more stressed than regular parents [12].

The department of education (DepEd) Order No. 32, [13] demands a holistic approach and a stronger partnership among schools, households, and communities. Parents and teachers who nurture their children, help them with their homework, and provide tutoring using resources provided by the teachers do a better job of nurturing their children than those whose parents do not help them. Parents and caregivers must recognize their contribution to the success of their children's education, nurturing, and upbringing.

promotes the rights and well-being of children. It is a basic human right that cannot be compromised. Children should be able to continue their education even in times of crisis, such as the COVID-19 epidemic, according to a former DepEd Undersecretary, "but we must put in place children's safety, which is important, and ensure that they have a safe and inclusive learning environment."

Hence, this study aims to investigate in-depth the experiences of parents of teenagers with special needs, as a Basis for Government Intervention Programs.

2. MATERIALS AND METHODS

The study used a mixed-method research design. According to this method, mixed methods research is a study that involves both qualitative and quantitative methodologies. It enables people to create and associate their own subjective and intersubjective meanings as they interact with the world around them. The study used a phenomenology approach to qualitative research to extract information from fathers and mothers using an interview guide. The information gathered was submitted to thematic analysis using a semi-structured interview guide. A questionnaire was used to induce reliable answers from the fathers and mothers, including demographic profiles: age, gender, civil status, and highest educational attainment. The participants in this study included fathers and mothers or the guidance of children diagnosed with one

particular need (ASD). Tables were created from the data collected from the questionnaires as frequencies and were analyzed using percentages. Parents have at least one child diagnosed with a specific condition (ASD) enrolled in a Special Education (SPED) school in the City of San Fernando, La Union. The sampling technique used for this study was the purposive sampling technique. All eight (8) parents interested in voluntary participation in this study and having a child diagnosed with special needs (ASD) in the City of San Fernando, La Union, were used for this study.

3. RESULTS AND DISCUSSION

The study results revealed the distribution of the respondents according to the demographic profile along the age, gender, civil status and highest educational attainments of both fathers and mothers of the teenagers with special needs (ASD). The demographic data of the respondents revealed that most were female 5 (62.5%) of the 31 – 35 years age group 3 (37.5%), separated 3 (37.5%), And most of the parents had a college graduate 4 (50%) (Table 1).

Table 1: Distribution of respondents by Age, gender, civil status and HEA of the parents

Age	Frequency (f)	Percentage (%)
26 -30	2	25
31 – 35	3	37.5
36 – 40	1	12.5
41 -45		-
45 – 50	1	12.5
51 – 55		-
55 – above	1	12.5
Total	8	100%
Gender		
Male	3	37.5
Female	5	62.5
Total	8	100
Civil Status		
Single Parents	2	25
Married	2	25
Separated	3	37.5
Widow	1	12.5
Total	8	100
Highest Education Attainment		
Doctorate Graduate	1	12.5
Master Graduate	0	-
College Graduate	4	50
Tech Vocational Graduate	2	25
High School Graduate	1	12.5
Total	8	100

In this present study, the demographic data of the respondents revealed that five were female (62.5%), most of the respondents were within the 31– 35-year age group (37.5%), and three were separated from their spouses (37.5%). Most of the parents had a college graduate degree (50%). It implies that the parents and teachers of teenagers with ASD were knowledgeable and educated enough that they could nurture and care for their wards. The parents of these teenagers may have had the opportunity to read or listen to their children's teachers' teaching and encouragement. This agrees with Horowitz [16], who noted that parents who finished college degrees could efficiently work and make sure that their children were also knowledgeable about health and what was happening around them, knowing fully well that their children were their future. In the same vein, Muhammed [17] pointed out that the role of parents is vital in developing and nurturing children in the way they should grow among their peers. Teenagers with educated parents demonstrated a higher level of knowledge and practice if their parents influenced their understanding and nurtured them in putting what they learned at school and home into practice.

Some of the Themes derived from this Study

The analysis of the transcribed responses of the participants, done through intelligent transcription, revealed the *Parental/Guardian Involvement, Challenges of Parents/Caregivers in nurturing Children with ASD, Coping Mechanisms of Parents, and Special Road*. We present salient quotes.

To nurture and train children with special needs (ASD). This also gives parents a better understanding of the types of support and potential interventions that they may require from schools and governments towards support for teenagers with special needs (ASD) at this time of the pandemic crisis.

Involvement of Parents/Guardians in Home Schooling

Parental/Guardian Involvement

The department of education (DepEd) Order No. 32, [13] demands a holistic approach and a stronger partnership among schools, households, and communities. Parents who nurture their children, assist with their homework, and provide tutoring using resources supplied by educators tend to do better in school than children whose parents do not have time to nurture or assist in their homework. Parents must understand their importance in the success of the process of education and in the nurturing of their children. It is necessary for parents to be aware of the impact of the pandemic on teenagers' academic performance and well-being.

Furthermore, Shourbagi [18] stressed the importance of parents and guidance's involvement in the nurturing of their children, as their participation in teaching their children had been linked to increased parental boldness, higher interest in and pleasure with parenting, as well as a greater interest in their own education. This, in turn, prepares them to be ideal teachers and parents for their children.

Challenges of Parents/Caregivers in Home Schooling Children with ASD

Unwrapping Transitional Difficulties

Many families face unique challenges in nurturing and assisting their teenagers during home assignments or household chores. It may be difficult to consider the role of parents in raising a child to the level of attending school, but Kidd [19] found that parents, particularly mothers, can provide their children with an education suited to how they learn. She further discussed that mothers could also control their teenagers' environment to enable learning to occur.

The disruptions caused by the health crisis cause significant changes in the routines of teenagers with autism. The transition from studying in a four-walled classroom to confinement in their own homes, with their parents acting as both the teacher and a classmate, is a significant change in their daily school routine. Transitional difficulties in rules and authority, schedules and procedures, behavior management, and parental worry and stress fall under this domain. Applying rules and routines helps them engage more successfully in activities and prevents problem behavior. As a result, imposing rules and exercising authority can be difficult for parents because their children are already accustomed to attending school with the teacher exercising authority and enforcing rules during the learning process. The teenager's association with their teachers in school as educators was broken and interrupted during the transition. Thus, reinforcement is inconceivable, specifically in scheduling activities and implementing procedures, which eventually poses another struggle in nurturing teenagers with ASD. The National Autistic Society [20] described a meltdown as a strong reaction to a tumultuous circumstance. It occurs when a person is utterly overwhelmed by their current circumstance and loses control of their actions for a brief period of time. This loss of control can be expressed verbally (shouting, screaming, crying), physically (kicking, lashing out, biting), or both ways. A teenager with ASD may communicate their emotions of overload in a variety of ways, including meltdowns. They may even refuse to interact, retreating from or avoiding difficult circumstances entirely.

Parenting stress refers to the perceived stress of the parent in reaction to the demands of parenting the child, and Fadare et al. [21] suggest that the child's difficult behaviors contribute to the parent's negative mood via decreases in parenting self-efficacy. Since mothers of children with ASD experience higher levels of stress than mothers of typical children, their increases in parenting stress may reduce parenting self-efficacy, which might lead to increases in anxiety and depression.

Coping Mechanisms of Parents

Acceptance

According to the APA Dictionary of Psychology [22], acceptance is a favorable attitude toward an idea, situation, person, or group. Acceptance occurs when an individual acknowledges and accepts a situation or scenario. It's usually used to

express acceptance and consent to an unfavorable circumstance. The Kubler-Ross model's last stage is acceptance, also known as the five stages of grief (denial, anger, bargaining, depression, acceptance). Parents pointed out that their new responsibility during this "new normal" of education left them with no choice but to accept and acknowledge this current role of being teachers to their teenagers at home. Preparing themselves, attending to their child's nurturing through sitting and learning with the child manifests their acceptance of the concept of homeschooling. Acceptance is a key trait in achieving happiness, according to research.

Positive Disposition

Having a positive disposition means having an optimistic outlook and attitude towards life despite experiencing adversities. The parents were faced with the challenge of having multifaceted roles, including homeschooling their children, and they have a look at it from a different perspective; during the nurturing challenges, the parents tried to figure out how to become positive, stay calm, and move forward. Being parents to teenagers with ASD includes many challenges, but it's how they rise to overcome these challenges with strength and positivity.

Time Management

For parents wrestling with the demands of everyday life, time management proves to be a real struggle. The additional responsibility of nurturing and educating a teenager with ASD who has unique and special needs can be a huge task that requires a significant amount of time for parenting. According to the article "What is Time Management?" [23], the process of preparing and planning how to do something and divide your time is called time management, known as time management among specific activities. It discusses how good time management allows you to work smarter and accomplish more in less time, even when time is limited, and pressure is high. Failing to manage your time damages your effectiveness and causes stress. Parenting is hard work and learning and keeping control of their time make their personal life and family life run smoothly.

Parnell [24] pointed out that having good time management in nurturing will give parents total and complete control over their child's environment, education, and social experiences. This will also allow the child to avoid and minimize sensory triggers, as a teenager with ASD thrives on routine and structure. Time management and structuring activities that work for the family's schedule will help the child, and other family members do their best with the learning plan provided by the school while being safe in the confinement of their homes. More importantly, time management enables parents to increase their family time and spend more time watching their wards grow and learn. Nurturing jobs for parents is more about creating safety, belonging, and acceptance than they are about academics.

Support from Family Members

The "new normal" in education has shifted toward parents nurturing their children, which necessitates a significant amount of time. This also calls for help and assistance from other members of the family. It is of importance to gain support and assistance throughout the home education process. Getting support from your family gives you time for other things that need to be accomplished and empowers you to be able to navigate the challenges of family life.

Moreover, many parents/guardians, in their quest to cope with the situation where they find themselves responsible for teaching and educating their teenager, adopt a style of consulting and connecting with the teachers in school and special therapists. This is the adaptive coping method of seeking social support as highlighted by Lai and Oei [25] in their studies. Going back to teachers and therapists to discuss their concerns about their teenager enlightens them and they can acquire additional learning and information on how to manage the nurturing process. This will ensure parents and teachers have an improved educational outcome for their children with ASD.

Parent-School Partnership

Families are involved in meaningful and culturally relevant activities by schools and other community agencies and organizations in relevant ways through family-school-community partnerships, which are a shared duty and reciprocal process. Families take the initiative to support their children's development and learning actively. Institutions and community groups also make an effort to listen to parents, support them, and provide them with the resources they require to be active participants in their children's education [26]. Parents are the first educators of their teenagers, and they continue to have an impact on their children's education and development throughout their school years and beyond afterward. Schools bear the important responsibility of nurturing and teaching future generations, and families rely on schools to lay the educational groundwork for their children's future. That is the importance of parents and schools working together in a partnership. The Parent-School Partnership refers to the collaborative relationships and activities between parents or families and the school.

Special Road

The experience of having a teenager with special needs (ASD) on the autism spectrum greatly affects the lives of most parents. Prior to the pandemic, parents' daily routines included doing housework, going to work, tending to family needs, and driving their children to school. With the emergency health crisis, parents have now taken on the role of educators, guiding their teenagers through learning modules given by schools and online classes. According to the United Nations report, "the COVID-19 pandemic has created the largest disruption of the education system in history, affecting nearly 1.6 billion learners in more than 190 countries as well as all continents. School and other learning space closures have touched 94 percent of the world's student population, with up to 99 percent in poor and middle-income countries and lower middle-income countries [28]. For the parents of teenagers with special needs, particularly ASD, finding a solution to the "new normal" education is a positive way of focusing on the child instead of dwelling on the challenging situation. Filipino parents' unique approach to surviving this new learning modality has given them a fresh perspective. Parents have become hands-on and have direct involvement in educating their children, and this has become an opportunity for them to monitor their children's progress.

Essential Learning methods

Staying at home and not attending school creates a uniquely stressful situation for teenagers with special needs and their families. It is noted that teenagers with impairments, such as autism, who rely on structure and regular routines, may be particularly affected by interruption. Though structured home education is difficult in the transitional period, Cahapay [29] noted that parents have jointly expressed the importance of any sort of education taking place in their homes to the development of their children. Learning at home can be tailored to the needs of teenagers and family conditions. So, learning activities are more focused. This is supported by Feeney [30], who reported that many parents of children with special needs are considering home education as an alternative to traditional schooling. Furthermore, he claims that home education is beneficial for children with special needs (ASD) and will offer students the finest possible learning environment. Narzisi [31] added that home-based learning would maximize a child's potential early on without having to adhere to the usual time standards set by schools. As in the case of teenager with autism, who work and learn at their own pace [29]. Some people may think that teenagers with special needs should not be given duties and responsibilities at home, but UNESCO [32] indicates that it is important to note that the duties you entrust to them and the work they take up can contribute to molding them and helping them develop identities of their own. As simple as keeping their things safe, secure, clean, and cleaning the dining tables after having dinner can be assigned as responsible tasks. This would help them develop a sense of responsibility. Small roles could also be given in each of the tasks performed by the elderly, as this would increase the confidence level of the child and help in the formation of an identity. This is supported by the Theory of the Hierarchy of Needs of Abraham Maslow, which offers a framework for how humans can thrive. When basic needs are met, self-actualization occurs, according to the theory. The love, warmth, and care provided by parents have made children respond positively, hence, making both parents and teenagers thrive and develop a sense of belongingness and a sense of being loved, therefore making the home education experience a special road.

4. CONCLUSIONS

In this article, it was revealed that parents' both fathers and mothers of teenagers with special needs (ASD) were female (62.5%), most of the respondents were within the 31–35-year age group (37.5%), and three were separated from their spouse (37.5%). Most of the parents had a college graduate degree (50%). It implies that the parents and teachers of teenagers with ASD were knowledgeable and educated enough that they could nurture and care for their wards. Even without the adequate supports from the government and community, they still developed a coping strategy that help them to nurture their teenagers.

The researchers then suggest and recommended that governments and NGOs, should support the parents of teenagers with special need (ASD) by giving adequate supports and educate them with adequate training and support that will enable them to know that the teenagers are normal in their own ways.

5. LIMITATIONS

In comparison to prior research investigations, the current study included several drawbacks, such as a larger proportion of parents participating in this study.

Consent: Written and verbal consent was obtained from the principal and parents of teenagers with special needs (ASD).

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