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Voices of Strength: Narrative of Resilience from Parents Having Trisomy 21 Child

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Abstract

This narrative inquiry dives into the resilience and strength of parents raising children with Trisomy 21. The metaphoric framework of building a house illustrates the progressive and complex experiences of parents with Trisomy 21 child. This study is based on eight purposively selected participants, initially grappling with shock and denial is akin to laying a foundation, followed by understanding genetic and societal implications as the house structure rises. Coping strategies and adapting to care needs represent building walls and installing a roof. Within this metaphorical house,

evolving acceptance and support networks shape family dynamics and social interactions. The narrative not only captures personal growth and deeper family bonds but also reflects broader societal shifts toward inclusion. This metaphor for home building not only builds up a narrative inquiry but also highlights the progressive development of resilience and deeper family bonds, which is illustrated by significant personal growth and societal shifts towards inclusion.

Keywords: Trisomy 21, Down Syndrome, Experience, Resilience, Parents

Introduction

As the world continues to revolve around, some individuals are still not aware of what parents have been through with a child who is diagnosed with Trisomy 21. Based on Makati Medical Center (2020), The most common chromosomal condition in the world is Down Syndrome, resulting in one case for every 1,000–1,100 births. One baby in every 800 babies born in the Philippines has Down syndrome. Down syndrome patients and their family may not live their best lives, but they can still lead fulfilling lives.

Trisomy 21, also called Down Syndrome, is a chromosomal condition caused by intellectual disability and can be distinguished by several other clinical findings. Babies only inherit 23 chromosomes from each mother and father, for a total of 46 chromosomes. However, Down Syndrome babies end up with three chromosome pairs in position 21 instead of regular pairs. This is due to abnormal cell division when sperm or egg cells develop (Marilyn *et al.*, 2020).

According to the American Pregnancy Association (2021), infants with Down Syndrome have estimated about 85% that survive for a year, while 50% of those will live longer than 50 years. Individuals are still found clueless about what every parent with a child with Down Syndrome experiences. Humanity is still oblivious that parents with Down syndrome child frequently encounter unique circumstances and feelings, such as grief, fear, and uncertainty. Raising a Trisomy 21 child has faced many difficulties and experiences, including the emotional and psychological health of the parents, financial problems, isolation from others by having a Trisomy 21 child, and in terms of education.

One of the most common neurodevelopment disorders in the country of the Philippines is Down syndrome (Trisomy 21, 2021). Raising a child with Trisomy 21 brings a great challenge to some parents who do not know how to handle this kind of situation. Parents raising Trisomy 21 might experience higher levels of stress and anxiety based on research. (Desimpelaere, *et al.* 2024). Having a family member who is suffering from mental and physical disabilities plays a massive role in raising them (Juandó-Prats *et al.*, 2021). Studies show that parents who are raising a child who has Down syndrome have more certain effects than obstructive effects. The parents' acceptance and understanding of their children's situation and condition is the reason for this. (Widyawati *et al.*, 2021).

The main experiences of parents were emotional burdens, discrimination, concerns about the future, and challenges related to health and education. Despite all of these, parents still find themselves with some strategies to overcome these challenges.

These are seeking support and help, understanding them, and accepting and adopting their optimistic attitudes (P. *et al.*, 2023). Parents with Trisomy 21 children show a higher level of parenting stress than those typically developing children. It was found that parent-child interaction with a trisomy 21 child has the highest percentage of clinical scores, 39.7%. Both internalizing and externalizing problems are correlated with maternal stress, as well as autistic symptoms (E. Fuca *et al.*, 2022) ^[17]. Parents who have a Down Syndrome Child mostly use an authoritative parenting style. On the other hand, some use a reasoning or induction style. Parents with Down syndrome children were described as having the most difficult experiences in their family life (L. De Clercq, *et al.*, 2022).

If a system member is not working correctly, the system will struggle. Research shows that raising a child with development a disability such as Down syndrome has few adverse effects and more positive effects on their parents as caregivers. Because of the parents' acceptance and understanding of their children's condition (Widyawati *et al.*, 2021). However, an older adult raising an adult with Trisomy 21 with epileptic seizures is a whole different life experience. It was also identified as a more robust and more dynamic source of support than organized religion in coping with stressors and life's challenges associated with raising a child with Down syndrome. It was rarely discussed how or what the father's perspective and feelings on having a child with Trisomy 21; the father and child bond is loving and happy, and fathers rarely mentioned financial stressors or their children's negative behaviors. Instead, many fathers reported children's speech problems among their children with Trisomy 21 (J. *et al.*, 2020).

This study looks to give a stage for these guardians to share their accounts and give knowledge about their encounters, which can be significant for clinical experts, teachers, and different guardians in comparative circumstances. It aims to identify common themes and strategies that parents employ to cope with challenges by examining these parents' stories of resilience. This can also help in growing better emotionally supportive mediation for families with kids who have Down Syndrome.

This study is significant because it provides support that helps parents when they encounter unique circumstances. It identifies the actions or methods of a parent to alleviate the problems faced and experienced by a parent with a child with trisomy 21. Through this, individuals can learn enough about what they have been through during their parent's journey.

Conducting this research aims to understand the feelings and experiences of a parent with a Trisomy 21 child. This study shows the resilience, love, and determination of parents and their children to provide inspiration and hope. This study can help the Noveletaños understand and be more careful in handling such situations or encountering children who have Trisomy 21, as well as the parents. Today, individuals need to open their minds and spread their minds to understand more about their parents' situation and what they have experienced having a one-of-a-kind child because every person is special and unique, and so are they.

Objectives of the Study

This study aims to share and let individuals know the resilience of parents having a trisomy 21 child. It also seeks to examine the relationship between the two variables and

their effects. Specifically, it aims to (1) determine the portraits of resilience and strength merged from the experiences of parents raising children with Trisomy 21; (2) describe the moment they learned about their child's diagnosis of Trisomy 21 and what the impact of understanding of parenthood; (3) determine the significant moments or turning points do parents recount in their resilience while raising a child with Trisomy 21; (4) describe how parents express their dreams and aspirations for their child with Trisomy 21 and how these influence their parenting decisions and actions; and (4) determine the ways do parents' intersect with broader societal narratives and discourses regarding disability, inclusion, and acceptance.

Materials and Methods

This follows a qualitative approach and a narrative interview. According to Steven Tenny *et al.* (2022), qualitative research probes and provides a profound understanding of the actual world problems. Also, the qualitative one gathers the participants' experiences, perceptions, and behaviors. Moreover, a narrative interview is a technique that allows the subject to express their perspective 'off the cuff' about a particular topic, part of their daily life, or even their whole story. Of life (Shossain, 2020). This research method design was chosen because it is related to what the researchers want to study and because it is suitable for the research on the experiences of parents who have a child with trisomy 21. This can be a great help in understanding the parents' situation with a Trisomy 21 child.

The process of gathering data is essential to research. To make the study more accessible and our findings more significant, researchers must ensure they understand this critical phase. Researchers will use a one-on-one interview, which is an interview to meet certain people to exchange information and thoughts via the questions and answers portion. Communication is an element of this exchange and leads to a common understanding of the subject (Chauhan *et al.*, 2020). With the parents who have Trisomy 21 children. Several studies were conducted to understand the experiences and obstacles that parents of children with trisomy 21 have had. Lee (2021) ^[26] carefully examined the available research to acquire knowledge about the perspectives of the parents of children with Down syndrome.

Gathering and analyzing data involves researching problems, providing answers, evaluating findings, and identifying trends and opportunities. Researchers use this strategy to make things easier, making it a unique way to generate ideas like this. After making questionnaires, the researcher will formally write a letter to the Noveleta Senior High School superintendent requesting to conduct the study. The researchers will also formally write a letter of request to Noveleta Elementary School's principal and convey a letter of request to interview the parents of children with trisomy 21. To gather the data or information, researchers will conduct a one-on-one interview with parents of trisomy 21 children. This will allow the researcher to easily understand and comprehend the parents' situation. The researchers will record the parents' statements with their permission. This will allow the researcher to understand and comprehend the parents' situation quickly. This only looks at a specific population: Parents of

young students with trisomy 21 at Noveleta Elementary School. The parents of children with trisomy 21 live in Noveleta, Cavite. The researchers selected the parents for the study. To collect their personal stories, experiences, and information, a sample of eight (8) participating parents. Selected using a technique called the purposive technique. According to the Dovetail Publication Group (2023). Purposive sampling may be a technique utilized in qualitative investigations to choose particular groups of individuals. After the researchers conducted all the interviews, they compiled all the interviewees' statements and transcribed all the parents' statements using decoding.

Results and Discussion

This presents the result and discussion of data gathered from the preceding study which aimed to understand better and understand their experience. This chapter will show each parent's trial and how they overcame it as a parent. The data found in this chapter were arranged according to the theme of the research.

Theme 1: Foundation Laid: Setting the Groundwork for Understanding

This theme aims to show the parents' emotions and the challenges facing a life on how to raise a child with Trisomy 21. The denial stage and the eventual acceptance of parents that have a child with Trisomy 21. And the parents' shock and adjustment to learning that their child is diagnosed with Trisomy 21 and how should they raise a child with Trisomy 21. The goal of this theme is to understand carefully and with an open mind the experiences of parents. Here you can see their ways of understanding and dealing with the trials that pass through them (Delisle, 2021) ^[14].

Parental Emotions and Challenges. For parents, the birth of a new baby is generally considered an honor. However, when a child is born with a disability like Down syndrome, it can add to a parent's stress level, which can harm or affect their quality of life. Having a child with a chronic disability is a challenging experience for a parent (Eddoudi, *et al.*, 2023). It is inevitable for a parent to face many trials especially when they are raising a special child. Some parents cannot help but be emotional when it comes to their children. It's like when the child you've been waiting for a long time, you don't know is a special and unique child.

Denial and eventual acceptance of having a child with Down syndrome. A test for a parent is not easy acceptance of their child, especially if it is a special child. We can't deny the fact that there are parents who find it difficult to accept a child if we know that when they were in the womb, they took care of it completely. It must be considered that these outcomes of parents' emotions and challenges are influenced by numerous factors beyond the household, including the level of parental involvement. It includes the strength of each child's support enforcement, expanding access to affordable childcare, and enhancing education (Rees, *et al.*, 2023). This study involves various factors or reasons influencing the parents' emotions. One of these factors is its denial stage. Anastacia stated,

“noong inalabas siya pina ano ng doctora pero ayaw niya yong bata sakto umiiyak yong pero ayaw niya tingnan yong bata kasi nagulat siya pero ilang ano lang tinignan na niya, unica hija kasi siya. Hindi sya matignan ng mama nya ng ilang oras, kasi hindi nya inexpect nag anon.”

It is shown here in this situation that he is one of the parents who find it difficult to accept that his child has Trisomy 21. To the point that it's hard for him to look at it because of the shock that his son has this condition. But even if that's the case, you won't deny that they accept their child because somehow it belongs to them, it's their blood and it's their child. Even if you don't accept it, you will accept it because it is still your child (Juvini, *et al.*, 2022) ^[22].

Emotional struggles and sacrifices made by parents. Despite accepting that our child is different from other children, parents still cannot avoid struggling with their emotional well-being while raising their child. They also made sacrifices to push themselves to accept their child. It is on their part as a parent to make or plan ways of how they would raise their child if they knew it was different (McWorther, *et al.*, 2022) ^[29]. Krystyn shares her thoughts,

“Oo, noong Nakita ko pero sa katawan nya hindi, yun lang, yun doon ko sya Nakita. Noong pagtingin ko ng ganyan sa kanya, ay napaiyak ako “Ay Diyos ko! Yung anak ko down syndrome.”

There are some instances in which the parents are shocked to see that they are bearing a child with Trisomy 21. Parents struggle to accept the diagnosis that lets them lead on the answer of how to raise a child with Trisomy 21. Parents, especially mothers who are most likely to take care of children, were dealing with health conditions, and handling a child with Trisomy 21 was a difficult task to deal with (AlShatti, *et al.*, 2021) ^[2].

Shock and adjustment to the diagnosis. Parents with better adjustment might have fewer difficulties with the reason that they can cope up with their child. They have better parenting behaviors that can handle a child (Rudolph, 2022). As what Krystyn said in her previous statement, she can't really avoid it because with all her children, only her youngest child is different. The moment she knew that her son was a special child, her shock was there but hidden in that motive was raising the child properly. So, when Oddete stated that,

“Wala naman, inaano lang namin na kung ano yung trato sa mga kapatid nya ganon din sa kanya.”

What she said in this situation is that even though his son is different from his siblings, he treats him like a normal child, but he still can't take care of his son. A parent raising a child with trisomy 21 faces challenges related to the child's intellectual, health, and psychosocial developmental disabilities. Every family experience higher level of stress, higher financial burdens, and greater caregiving needs (Desimpelaere, *et al.*, 2023) ^[15].

Challenges in coping and adapting to the situation. One of the challenges of the parents is to think of the right coping strategies that they know they can use in raising their special child. This is a test, but if you don't think of a proper coping mechanism, you will be the one who will have difficulty raising a unique child (Inguglia, *et al.*, 2022) ^[20]. Merlia stated,

“Ang mahirap alagaan daw, siyempre, kase hindi naman ako ganon kagamay mag-alaga ng ganito, pero kahit papaano napalaki ko naman sya ng ayos.”

Both Parents were informed of the illness during pregnancy and some were informed after encountering a hard time facing the fact that they have a child with trisomy 21. However, parents who wondered why their child had to be a child with Trisomy 21 felt an instant regret for hoping that the medical diagnosis was a false alarm. Those who learned prenatally spoke of similar shock and sadness, which were followed by a slow assimilation of the information (Clark, *et al.*, 2020)^[13]. But despite those parents that can still accept them and have a life with them. Some parents chose not to have a life with their Trisomy 21 child. As Anikka stated,

“Lumipas ang araw, tinawagan ako ng hospital iniwanan nga yung bata. Noong nanganak iniwanan sa ospital yan. Ayaw din ng nanay, parang kinakahiya nya din yung anak nya.”

Annika pointed out that the child's real mother can never accept him. It seems that some of the parents have accepted that their children were diagnosed with Trisomy 21. The remaining parents found it difficult to accept that their child was diagnosed with Trisomy 21. Parents who have difficulties accepting their child, people can't blame them because they have personal reasons, as much as they want to accept it there are still regrets that they are the ones at fault that's why their child was diagnosed with Trisomy 21 (Rasendrakumar, *et al.*, 2021)^[36].

Theme 2: Framework Erected: Constructing Understanding and Acceptance

The purpose of this theme is to construct an understanding and acceptance of parents with their Trisomy 21 child. This theme will explore and understand the genetic implications and different types of Trisomy 21. Acceptance might be the easy yet hardest part if you know your child has Trisomy 21. It might look easy, but in reality, acceptance is not just about accepting a person but accepting its whole existence including the special one. Understanding, on the other hand, will not only revolve around understanding the person's situation but the whole experience too.

Genetic Factors and Disability. Genetic factors can help disabilities to develop. While disability is a genetic condition that is hereditary or runs in a family. One of the examples is Trisomy 21, which can be either hereditary or caused by a parent without her knowing that it can affect the baby (Baker, *et al.*, 2021)^[6].

Understanding the genetic causes of Down syndrome (Trisomy 21). This chromosomal form and type of condition are now known as Down syndrome or Trisomy 21. Although every form of support that should be provided to affected children and their families is widely adopted, there is still a gap in access to proper health and other types of support services (Bull, 2020)^[8]. There are still some parents who are unaware that they are having a child, and because of their actions, it affects the child itself. Genevieve stated that,

“So, nung mga time na malaman ko na siya, yung totoo, nasa six months na siya, sa tiyan ko. So, may mga chemical-chemical, alam mo naman, pag sa laundry, hindi naman basta ano yun, may chlorine, may mga ozalic sila, something mga ganon-ganon, maraming ano. So, maihigop mo yun, kasi hindi ka

naman nagfe-face mask nung mga at that time yun na pinakaano ko siya.”

In this situation, the mother does not know that there is a child inside her. She only found out that she was pregnant when she was about 6 months old, but at that time she was working at a resort laundry and there were possibilities that the chemicals she came into contact with would affect the child. Maybe because of the stress he was facing at that time because he was also sending his two children to school (Glick, *et al.*, 2021)^[18].

Exploring the impact of genetic defects on disability. The possibility for development and socialization with people or children with Down syndrome is slowly appreciated. Patients differ significantly in their physical characteristics; intellectual disability tends to be moderate but can be severe or mild, and social functioning is often better than with memory impairment (Bull, 2020)^[8]. Some parents learned that their child might have Trisomy 21 from an ultrasound technician, nurse, or obstetrician. Those parents felt happy and blessed despite having a child with Trisomy 21, parents came up with resources about this Syndrome and shared the great news with others (Clark, *et al.*, 2020)^[13]. As Corrine stated,

“ang down syndrome is nasa tatay ko sakin talaga yong genetic ang dugo ng down syndrome dahil yun nga hindi namin tinukso sinabihan na nagsisi ako sayo hindi, hindi ganun, tinanggap namin siya na kasama namin niyakap naming.”

Corrine already accepted that she would have a Trisomy 21 child someday. Her father was also diagnosed with Trisomy 21, but she never expected that it would be her. Nonetheless, they accepted her child and embraced that her child was unique and special.

Different types and variations of Trisomy 21. Down syndrome is usually caused by an error in cell division called “nondisjunction.” This results in a nondisjunction from the results of an embryo with three copies of chromosome 21 instead of the usual two chromosomes. The pair of the 21 chromosomes are either the sperm or the egg that failed to separate. When the embryo develops, the extra chromosome is replicated in every cell of the body. This type of Down syndrome usually appears in 95% of some cases. On the other hand, there are also 46 chromosomes some containing 47 and, in this cell, there is an extra chromosome 21. This is called mosaicism, the least common form of Down syndrome and only appears in 2% of cases of Down syndrome. The total number of chromosomes in the cell remains at 46, but an additional full or partial copy of chromosome 21 is attached to another chromosome, usually chromosome 14, in translocation, which accounts for about 3% of cases of Down Syndrome (Facts about Down syndrome, 2021). There are different types of Down syndrome, they may be identical in their appearance but they do still have differences. Genevieve explained,

“Meron siyang mild Down syndrome sa category ng anak niyo, sa 5 pataas na, sa 5 pababa siya. Kasi ang history ng cardiotyping niya is, yun nga yung trisomy 21, na nakalagay.”

Her child had mild Down syndrome, which will fall into the nondisjunction type of Down syndrome. Anneliese also stated,

“pero iba yung ano niya hyper siya kasi ang mga down syndrome maraming klase yan. Mayroong hypertension May 3 fourth, eh yong klasmeyt niya naka upo kalang sa baby bus eh nasa likod namin biglang hihilahin ang buhok mo.”

There are also some cases in which a child with Trisomy 21 can be aggressive. This explains that if the child is not yet to be disciplined it will cause difficulties to the parents and the people around them. According to Hyun Seung Kim, *et al.* (2023) [24], not all parents can bear handling a child, especially if that parent is single and if that parent had a child with Trisomy 21. Single-parent families in this kind of situation should have more or greater attention given that they need proper facilities, care, and help. Imagine a two-parent family that still found a little difficult when handling a child with Trisomy 21, what else if that is a single-parent family that faces greater challenges in life? Taking care of it alone and raising it alone.

Theme 3: Walls Raised: Coping Strategies and Adaptation

The purpose of this theme is to show the coping strategies and adaptation of parents in raising a Trisomy 21 child. This will discuss how they adapt and cope with their kids' needs and wants.

Coping and Adaption Strategies. Studies on parenting children who have Trisomy 21 and other intellectual disabilities have encountered many different types of stress and coping techniques, yet studies have shown that raising such kids may also be rewarding despite its challenges and tribulations. Furthermore, a little research always shows the mother's side despite the side of the father. To close this gap researchers, ask some parents what parenting styles they do in their everyday lives. Child positive attributes and behavior, parents always give sight on what is the child's attributes and behavior so that parents can monitor what parenting style they'll use to adjust (Sheldon, *et al.*, 2020) [38]. Some parents expose their children as coping strategies, this helps the parent and also the child to adapt to their surroundings. Anastacia stated,

“kapag meron kaming bisita siya ang entertainment naming. kasi ano naman siya eh lumaki naman siyang hindi namin tinatago, yong iba tinatago pero siya hindi, hindi naman namin siya ikinahihiya yong iba kinakahiya kami hindi...”

It helps the child to enhance their social skills as the parents try to associate the child with other people. Anastacia also added that,

“kung ano gusto niya mama nagugutom nako yung ano gusto ko french fries gusto ko jollibee siya ang masusunod, wala akong ma utusan ito nalang french fries magluluto ako, ayaw ko niyan gusto ko jollibee ayaw ko ng palengke, minsan nga dinadaya ko yong sa jollibee minsan di ko tinatapon yung french fries, pag nagluluto ako dun ko nilalagay,”

There are times when some children with Down syndrome have a hard time communicating with people, especially if

they want to express the things they want and need. But there are also that a child needs to limit its spoiledness. It will affect its development if the parents will not discipline their child. In addition, a parent also needs to be understanding to be able to communicate well.

“wala, kailangan molang alagahan kasi kong hindi ka matiyaga talo ka inis talo ka niyan, kasi hindi ka mananalo sa kanila yong mommy at kapatid niya ganun din, kaya dapat-pag aralan mo, eh kasi nga minsan mahahalata mo laging nakasimangot”

Research suggests that there is a wide range of opportunities for parents to satisfy their needs. However, there are unique difficulties and barriers to the parent-child bond while raising a kid with Trisomy 21, personal freedom for the reason that you need to take care of your child always, and professional ambitions there are many sacrifices to make as a parent, but the child needs to sacrifice that not all the wishes and ambitions you want to achieve with that child will come true (Desimpelaere, *et al.*, 2023) [15]. Even though they are special they do still need to have freedom and most importantly to be treated normally. Genevieve stated,

“hindi naman actually, kasi nung mga time na ano, wala naman kasi eni-expose ko siya sa iba hindi naman, hindi naman ako naka ano sakaniya na dapat ganito oh, mas inaano panga siya eh binibigyan ng attention na sinasabi na special”

Genevieve let her child be exposed to other kids. Even though her child is special in their compound the child is treated normally and has the freedom to freely play with kids without any judgment, in fact, kids in their compound like the idea of playing with the child. Positive Discipline is a type of parenting program that emphasizes a style of parenting that is certain like an authoritative parenting style. Even though Trisomy 21 children need special needs, we can't deny the fact that parents still need to treat them properly, employing proper care that parents should not spoil them to the point. Positive discipline can help the parents on how to handle a child with disabilities such as Trisomy 21, not only that this will make a great impact on the child so that the child can know his/her limits in doing such things (Caroll, 2021) [10]. Positive parenting style is a must, so that children can know their limits, Krystyn stated,

“Tsaka ano, pag tinititigan ko lang siya, pag galit na ako, tahimik na siya. Alam niya na ako, kasi, ay, galit na ako. Pag sinabi mong tama na, yan lang. Sabi ko kase yung ganyan kailangan disiplinahan yan. Kailangan talaga ng disiplina, kahit sabihin mong ganyan sila, meron silang kinakatakutan.”

With a little word from her, her child listens very well. Every child like them has something to be afraid of, if they do not fear any it can cause difficulties in raising them. Parents with trisomy 21 children typically experience a range of emotions while seeking to take care of and develop her/his children's needs to meet the physical and social demands of that child. Bad parenting style can affect the process of a child's development and growth, especially since some children can develop independence in such an

early stage until adulthood (Subu, *et al.*, 2024)^[42]. Based on Annika,

“Once na Nakita ko o may nagsumbong saakin na nanakit yan, pinapalo ko. Sa pwet ah, hindi kung saan, para alam nya na mali yung ginawa nya. Kasi once na hind mo pinalo yan, alam Nyang tama yung ginagawa nya.”

It may be aggressive parenting but this is considered as a disciplined parenting style, that Annika does to her Down syndrome child. The intervention that was helpful among children with Trisomy 21 was Applied Behavioral Therapy, where our understanding of how behavior works in real situations, there are two goals in this therapy to increase the helpful effects and to decrease the harmful effects on the children (Spinazzi, *et al.*, 2023)^[40]. Therapy is also needed in raising a Down syndrome child, this can help them to develop their social and communication skills. As Corrine stated,

“kailangan mong e therapy yan, na therapy naman siya at dati naman siyang nag sasalita eh dati 2 years old, 3 years old na karga ko lang siya dati ko siya na therapy sa PGH, ang therapy kasi kailangan t-tuturuan mo rin sila, speech therapy tsaka therapy parehas lang yan kay langan tuturuan din sa school”

Even though they have a school for someone like them, it is also important that every child needs to go once in a therapy session.

Theme 4: Roof Installed: Providing Continuous Care and Development

The purpose of this theme is to discuss the provided care and development of children with Trisomy 21. This will show the required and important care of children who have Down syndrome. The therapy and developmental progress of the child, and the discipline and teaching towards the child. Childcare is one of the important things that parents need to do because this is where what they call development comes into play. As time continues to run, parents need to be able to maintain child care for a child, especially a child diagnosed with Trisomy 21. Children with Trisomy 21 need thorough care because there are times when they don't know what to do. When they do this, they will develop (Kuehne, *et al.*, 2020)^[25].

Child care and Development. The global community has played a significant role in the progress of saving children's lives. On the other hand, these advancements are failing to help all children, especially children with disabilities. The impact of biological and psychosocial factors on the development of the brain and the effects of early intervention on the development of the brain have been the focus of most research on early childhood development. Yet studies typically exclude children with disabilities, so relatively little is known about which interventions are effective for this high-risk group (Smythe, *et al.*, 2020). Child care plays a significant role in raising and taking care of children. Development is the progress they make while raising the child.

Intensive and continuous care is required for a child with Down syndrome. Raising a child with disabilities can significantly alter a family's daily routine and situation.

Parents' important role is not just to take care of them but also to accept them whole despite having special needs. They are the only ones that can nurture their capabilities and strength (Nejad, *et al.*, 2020)^[32]. It is also important to have intensive and continuous care for them, it helps them to develop easily. Annika stated that,

“Okay lang, ano lang nilalagay ko sya kung saan ako pupunta, lagi syang kasama pag ako nasa bahay nandon lang sya nanonood ng tv, pag sinabi kong nak, maliligo na tayo at tayo'y magtitinda na, oh ayan na ang damit mo, pagkatapos ko sa kanyang maligo, magsusuot nay an ng damit. Okay lang hindi naman sya mahirap alagaan. Oo nakikinig! Hindi kumpara noong maliit sya, hirap na hirap ako. Kasi kahit saan ako magpunta karga ko sya.”

Development is the progress they make while raising the child. Merliah said,

“ano sya alaga sa sakit sya yun, sipunin ubuhin yun lang naman yun wala namang ano, kaso mo nga lang syempre down syndrome sya hindi ko alam kung pano gagawin takbo agad kami sa doctor sa hospital ayoko kasi ng ano eh na medyo natatakot ako para sa kanya eh.”

From the two statements above, it is shown how important it is to give attention to a child with Trisomy 21. Besides needing to take care of them, they also need enough attention that they need. They need special care because that is the way not only to be cared for but also to be understood. Assessing and monitoring the child's therapy and developmental progress. There are remarkable medical treatments for those with intellectual disabilities associated with Down syndrome. However, some discoveries can greatly improve the quality of life of a patient (Mundakel, 2022). This study presents and illustrates the actions taken by a parent with their child with trisomy 21. Corrine explains,

“saakin talaga magkakaroon yan kaya yung down syndrome hindi napo ako maapektuhan kasi meron sa side ng tatay ko pero actually ang down syndrome may trabaho sila sa ibang bansa naka taposn din kasi ang down syndrome kailangan mong e therapy yan, na therapy naman siya at dati naman siyang nag sasalita eh dati 2 years old, 3 years old na karga ko lang siya dati ko siya na therapy sa PGH,”

She said that he would not be surprised and that when his daughter was young, he had him undergo therapy at PGH. Parenting a child with special needs can have a great impact on the life and situation of a family and the important role of parents is not only to value but also to accept the whole despite having special needs.

Approaches to discipline and teaching tailored for children with special needs. But in all this everything must have a limit. Because not all time can be given to the child, it will result in us spoiling the child which can make the parent's routine difficult. Coregulation between parents and children, to support the growing regulatory capacity of children. It is the process by which parents and children regulate each

other through their goal-oriented behavior and expressed influence (Lobo, *et al.*, 2020)^[27]. Krystyn stated,

“Pag sinabi mong tama na, yan lang. Sabi ko kase yung ganyan kailangan disiplinahin yan. Kailangan talaga ng disiplina, kahit sabihin mong ganyan sila, meron silang kinakatakutan.”

Explanation of the statement that when he says that it is right, he immediately follows and this also shows a parent disciplining the child with Down syndrome.

Theme 5: Interior Design: Family Dynamics and Support Networks

The purpose of this theme is to focus on how family dynamic has a great role in supporting their child's development. This will show the arrangement and support networks of the family. Also, the roles of each relative in providing assistance and acceptance to the child and parent. The financial struggles and assistance they receive from the government.

Family and Social Dynamics. The focus of this thesis is family dynamics. The literature is intended to evaluate whether Federal Judges are taking into account factors such as family dynamics. Several historical studies, compared to recent literature, will be used to assess family dynamics and relations (Haneen, 2023). The family must help one another in raising a unique child by this they can learn and understand the child's situation.

Living arrangements and support networks within the family. Having trisomy 21 or having a family member have this condition it's difficult to put through with them at first but over time we get thoughts and information around this circumstance and presently can cherish and support them. It can help people's perspective to understand more about having a Trisomy 21 child. Some things can't be avoided, for instance, the parent's thoughts, behavior, and emotions, parents may usually experience things that they might think were the right thing to do but are not. Child's challenging behavior, some children with Trisomy 21 can experience mood swings and changing behaviors. Institutional and systemic issues as well as people's bad attitude towards the child (Sheldon, *et al.*, 2020)^[38]. Merliah explained,

“Sa kamag anak don sya sa ate ko kasi nawili sa aircon so 8 months palang kasi ate ko balibasa namatay ang anak nyang babae, hinahanap hanap nya yung anak nya nawili sa anak ko pero ganon pa man hindi naman nakakalimutan ni eric na kami ang magulang nya, pero lagi sya kinukuha ng ate ko pero mag kapit bahay lang naman kami mag kadikit kumbaga duplex ang bahay naming”.

Role of relatives in providing assistance and acceptance. The importance of family relationship in offering assistance, bolstering, and appreciation to the part with trisomy 21 has an enthusiastic impact on the whole family, it keeps up warmth and reinforces the affiliation of each one which brings around progressing adaptability and joined together improvement.

“Kaya sabi noong si principal, pinatawag ako sabi noong teacher ay ma ano yan, special yan, down syndrome yan, hindi nyo ba alam. Sabi noong

principal namin, wala sa istura nya na down syndrome sya. Talagang ipinilit nya sa principal na tanggalin, pinull-out ko sya”.

Tending to the condition of each one can be battled for but usually there are individuals who cannot fight since of their condition with the assistance of their family there will be information and addressing the condition of their family part, trisomy 21 is the condition that most to other individuals it is made fun of.

Financial strains and government assistance for special needs care. Every family experience higher level of stress, higher financial burdens, and greater caregiving needs. The 'Down syndrome advantage' implies that these families only experience fewer adverse effects but have a high positive adaptation (Desimpelaere *et al.*, 2023)^[15]. Raising a Trisomy 21 child, needs a financially stable life, because of its therapy and other healthcare needs. Geneveive shares,

“ahh sa government yun na meron syang id nakaka discount sa gamot sa mga pagkain sa mga groceries yun na nag kakaroon kami ng discount dahil sa kanyang id”.

The straightforward offer of assistance and support of the government includes an enormous effect not as it were on the child's condition of trisomy 21 but also on his family who have offered assistance to move forward with the condition of the disabled.

Theme 6: Exterior Finishing: Shifting Societal Perspectives

The purpose of this theme is to discuss how society accepts the child who has Trisomy 21 and the parent who is raising a child with Trisomy 21. This will tackle the discrimination and stigma that they experience. How the society changes its perspective towards parents who are raising Trisomy 21 and legal frameworks or rights for individuals with special needs.

Society and Acceptance. The benefits and difficulties faced by fathers of children with Down syndrome discovered that they saw the creation of a close, caring relationship as one of the benefits of raising children with Down syndrome youngsters. Furthermore, they paid little attention to negative elements like money problems or four bad habits. (Sheldon, *et al.*, 2020)^[38]. Society still discriminates against people that they know that different from them. Not only the child is hurt but also the parent who shares the same feelings they had for their child. But on the other hand, despite the negative effects, there are still people who understand and accept them wholeheartedly.

Experiencing societal stigma, discrimination, and acceptance. There are still people who no matter what we do to intensify a person's situation, cannot avoid judging. People are already discriminating against children with trisomy 21 and at the same time, other parents are also receiving judgmental eyes. Parents saw the eyes of people, asking “Why is your child like that?” (Metzner, *et al.*, 2022)^[30]. But despite all this, there are still people who are ready to accept and appreciate a special child.

“tas sa awa naman ng panginoon dito naman sa eskinita namin mahal si rhem tanggap nila kung anong meron kaming anak kung бага mas minamahal

nila si rhem, mga kapitbahay namin tanggap si rhem wala akong nakikitang panghuhusga “.

Within the time I've lived in the world, discrimination has been uncontrolled in normal people or with conditions, but what else when you have trisomy 21, what alteration and flow in life do they have to be done, in this encounter, there's an associated acceptance of what condition there is it feels way better.

Shifting perspectives on Down syndrome and disabilities. Being open to surprises means that whatever the outcome they will still accept and learn from how to guide a child with Trisomy 21. The lived experiences of the parents have a great role in helping to develop their child's capacities and capabilities. Reflecting on this attitude can be a sole lesson to encourage parents, educators, and healthcare professionals to make the most of qualities and to enhance the relationship with their children who have Trisomy 21 (Spinazzi, et al., 2023)^[40]. Despite the parents' denial stage, they still embrace their child's uniqueness from others. Merliah stated,

“nag aaral sya sa sped nung una sa ladislaw sya, eh ngayon ay hindi ko na maihatid doon kasi nga ano nalalayuan na ako pero matagal kami 2011 sa lagis na ako kami nag-start eh 2011 hanggang 2019 nag-ano kami tapos dito sa ano tumigil ako dito sa noong matapos na yung pandemic dito na kami lumipat sa noveleta”

I moreover saw changes after understanding and understanding the word trisomy 21, in living, in playing, in talking, and in learning that individuals with this condition ought to be given uncommon treatment which they have a great viewpoint in this condition.

Legal frameworks and rights for individuals with disabilities. Republic Act 11650 is a law that states all public schools nationwide are required to provide learners with special needs with a free basic and quality education. It is also required that all municipalities must have at least one Learning Resource Center (ILRC), (Learning Resource Center, 2022). This stated that all special people including children with Down syndrome have the right to have enough assistance and help from schools and municipalities. Corrine stated,

“tsaka dapat sabi sakin sa PGH sa assessment na wag itago actually ngayon kasi may batas na tayo na bawal pintasan ang bata kapag may naririnig ka ng pangpipintas na masakit para sayo pwede mo silang e DSWD i papulis kasi meron na tayong batas para sa mga down syndrome kasi nga napag aralan sa PGH, may bowsi na sila sa korte kasi wala naman silang isip tayo yung may isip “.

A legal concept of a right enshrined in law that goes a long way to respect, care for and protect people with disabilities, helps give everyone legal rights, and is a sign of a balance of well-being and quality of life.

Theme 7: Utilities Connected: Navigating Healthcare and Medical Challenges

The purpose of this theme is to know and understand a parent's experiences in supporting a parent with their child

with Down syndrome. And also, to know the difficulties of a parent.

Healthcare and Therapy. When a child with Down syndrome is sure to receive care from a group of health professionals but not limited to doctors, speech therapists, physical therapists, physical therapists, and occupational therapists the professionals who interact with the children with Down syndrome should provide comfort and encouragement, (MidlinePlus, 2024).

Barriers to accessing healthcare and therapeutic interventions. When it comes to healthcare for children with Trisomy 21, parents face many barriers. One thing here, is the are no enough money to support the children's therapy (Skaar, 2021)^[39]. This study shows that many of our countrymen who have children with disabilities do not receive assistance from the government. Annika said,

“Ang gobyerno namimili, inilapit ko nay an pero namimili sila ng tutulongan. Wala, sa Rosario namimili ng tutulongan kung sino pa yung naroroon yun pa ang natutulongan. Matagal ko ng...”

It is explained here that there are governments that help but it is only selected even if you are from there the chance of being selected is small. And also, another parent testified to this statement that the government's help did not reach either. Merliah stated,

“May pwd sya pero hindi naman nagagamit, sa mahabang taon wala naming tumutulong o nakatanggap kaming”

This statement explains that even if you have a PWD assistant, you may not be able to get help from the government. In addition, there is a parent who has explained that due to a lack of finances, it is difficult to provide for the needs of his child. Began to explain,

“oo kasi syempre hindi naman ganun ako sa pinansyal eh yong totally yun talaga kasi alam ko marami siyang need na hindi kanaman na”

Managing serious illnesses and complications associated with Down syndrome. Down syndrome disease has various associated diseases. According to NIH (2023) in addition to intellectual disabilities, children with Down syndrome are at high risk for several diseases or health problems such as heart defects, infections, blood disorders, hypotonia and mental health and emotional problems. And also this causes children with Down syndrome to stop learning. Corrine stated,

“mayron siyang condition na high sa dugo sa potassium na pneumonia siya after nito tapos na hospital ng mahigit isang buwan ang condition niya ngayon ay hindi na makalakad dahil sa kanyang potassium bumaba ang potassium niya kaya umano ang kanyang condition hindi siya maka school ngayon dahil bawal pa siya ma expose sa mga kaklase dahil may ubo sipon ng hindi siya makaawa ng ganun, alam yan ni maam jay tapos dati siyang nag-aaral sa ladislaw six years siya sa ladislaw bago kami nailipat ng noveleta elementary school”

This statement explains the various illnesses of his son and the reason for taking a break from studying. And also Krystyn shared the same statement,

“2008 nag open heart surgery sya, sa heart center doon sya tumigil. Tumigil sya noong pumasok”

Krystyn explained that his son had open heart surgery and this was the reason for his son to stop studying. Moreover, there was a parent who shared that his child had various diseases. Annika stated,

“Sari-saring sakit daw, andon yun nag-close open yung ilong. Andon ang broncho, okay lang” This statement explains the various illnesses that his son had.

Importance of medical advice and specialized care. Furthermore, other parents listen and follow the advice of a doctor and even a quack doctor. Medical advice is a tremendous asset in your life's journey to optimal health and wellness (Mind and body counseling associate, 2023). Corrine stated,

“ginawa ko nag pacheck out ako binigyan ako ng doctor ng pampakapit ilang months din yun kasi nga malalaglag sya, ayun after”

This statement explain became the doctor's advice so that his child could hold on and live, and also other parents also follow the doctor's advice and others follow the advice of a quack doctor, Krystyn stated.

“meron isang matanda ang nagsabi Nakita sya, Neng sabi nya yung damo nyo pag umaga, iupo nyo, iupo nyo sya. Tapos yun nga masahe, massage daw, massage. E wala naman masamang mag-ano try, walang masama doon diba? Ginawa naming yun, siguro mga 4 to 5 nag-umpisa na sya mag gabay gabay. Saktong 5 years, lumakad sya”

This statement explains that even qualified doctors are helpful because their advice can work. And also Annika testified to this,

“Ang ginawa ko naghanap ako ng manghihilot, sa isang lingo tatlong beses sya hinihilot, yun unti-unti sya lumalaki.”

And on the other hand some parents rely on or use therapy for their child. Geneveive said,

“Ang therapy kasi kailangan t-tuturuan mo rin sila, speech therapy tsaka therapy parehas lang yan kay langan tuturuan din sa school”

He said that therapy and speech therapy are the same and that children should be taught in school. But on the other hand, the doctor advises that even if therapy is not given, they will still talk. Annika stated,

“Pina-doctor ko nga sya, sabi ng doctor. Hindi na kailangan ipa-therapy yan, magsasalita yan. Kase ngayon naman, nag-sasalita na sya”

She said that the doctor advised her that there is no need for therapy because she will speak on her own.

Theme 8: Home Complete: Personal Growth and Strong Parental Bond

The purpose of this theme is to understand the personal growth of a parent raising a child with trisomy 21

Personal growth and development. Every mother of children with Down syndrome goes through certain emotional processes, but they appear to be more resilient and this also reflects the importance and difficulty of motherhood for women from different cultures, it describes how personal growth occurs in mothers of children with Down syndrome (Gokgoz, et al 2022). This study shows the love and acceptance of a parent for his child, Corrine stated,

“tinanggap lang namin ng talagang buong buong kung ano sya”

This statement explains the wholehearted acceptance of a parent to his child. And also other parents also have the same acceptance of their child. Merliah explain,

“Tanggap naming si princess buong pamilya at di naming ikinahihiya sa totoo lang kayang kaya nya makipagsabayan sa tiktok sa sayawan”

She said that she is not ashamed of his son and that his whole family loves him and that his son dances well. There is suffering that grandparents experience after birth and there is also a perceived need to work more on self-determination in people with disabilities that prevent grandparents from caring with siblings with Down syndrome (Gómez, et al. 2021). This study shows the bonding between a child and a parent. Geneveive explains,

“Sabi ko next time na lang kapag may pera na ako kasi wala tayong pera nak “okay” kasi sanay siya sa mama ko, mama ko kasi panay sila jollibee sa akin kasi kahit panganay ko sinasabi ko sa kanila “next time kapag may pera ako” basta ang bonding namin palengke, school tapos kalimitan sa bahay nasanay siya sa bahay”

She said that when a child wants Jollibee, he tells him that it's next time because he doesn't have enough money and he also says that the only bonding between him and his daughter is at the market, school, and home. People with Down syndrome have unique learning needs and abilities, however, the landscape of education student with genetic conditions is often fraught with ambiguity, which can also pose significant challenges for educators and parents (Positive Action, 2023). This study shows the teaching and guidance of a parent to his child. Geneveive stated,

“tinuturuan ang ganiyang case kasi ng bata tinuturuan sila kong ano nyung kakayahan nila kasi halimbawa nag wawalis ako gusto niya mag walis ayahan mo siya okaya na kikita sayo nag tutupi ka nagtutupi din siya ayahan mo siya ganun para matutu sila tapos tuwing nakikita niya papa niya nagtutupi ng kumot kahit hindi yan maayus”

This statement says that she teaches and lets her daughter learn to do household chores. And also other parents say the same statement who are also taught the right thing to do. Krystyn explains,

“nong una nahihirapan ako kasi pinapakita “mama oh” ang tawag niya dati “wawa” kasi nuon nong meron pako nuon sabi niya mama ano yan?”

She said at first he had a bit of a hard time teaching because the child didn't know what he was doing.

Here we better understand what kind of upbringing they had, what challenges they faced in raising a child with special needs, what kind of healthcare a child with trisomy 21 needs, what their ways to raise their child is fine, and what is the discrimination and judgment they have experienced from people in raising a child with trisomy 21. This is more difficult not only for people to understand but also to accept and treat it as no different from them. Especially for parents who until now have had a hard time raising their child with trisomy 21.

Conclusion

In conclusion, our research entitled "Voice of Strength: Narratives of Resilience from Parents of Trisomy 21 Children" shows the beauty of our research and the amazing stories of parents who have shown unparalleled resilience in dealing with care for their children with a disability called down syndrome and this study aims to inform, comprehend, establish the status, validate, and support Parents in their varied hardships and experiences related to this condition. These words describe the resilience, resistance, and unparalleled love that parents have for their children with special treatment. Reiterate our points of support by conducting interviews that validate our assertions and reveal the most in-depth questions we have written. We may utilize these interviews as both justifications and proof for our statements. Due to trisomy being a rare disability, we had trouble locating the respondent for our thesis. Therefore, the findings of this study highlight the importance of providing support and resources for families having children with trisomy 21, as well as recognizing and celebrating the resilience of these parents. Overall, our study highlights the remarkable resilience of parents who face the challenges of raising children with trisomy 21 and the need for greater understanding and support from society in total. As a result, we stepped up our search efforts until we found the pieces we required to address our research questions of the response.

Recommendations

This study revealed Voice of Strength: Narratives of Resilience from Parents of Trisomy 21. Therefore, recommendations are presented here. Conduct in-depth interviews with parents of those with trisomy 21 to uncover their narratives in more detail. Using open-ended questions to encourage participants to share their experiences. Due to the difficulty in finding participants for this study, it is recommended to further expand the sample size and the scope of the study. This study is recommended for professionals such as pediatricians and therapists to assess perceptions and offer practical recommendations for supporting parents and families affected by trisomy 21. This research is recommended especially to government agencies

to understand the problems faced by parents especially when it comes to finances so that the government can provide adequate assistance to parents with trisomy 21 children. It is worth recommending this research because it can lead to more knowledge and improved support services and raise awareness among each other. The future researcher can conduct a parallel study using other variables such as quantitative or mixed methods to further study the perspective and experiences of parents and to convey to others the voice of a parent.

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