



Overcoming the Dilemma: The Plight of Parents of Children with Trisomy 21

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ABSTRACT

This qualitative research employing multiple case study determines challenges and coping mechanisms of parents of children with Trisomy 21. The informants were the parents of the students in one of the Special Education schools in the Municipality of Kabacan. Results showed that lack of support system, parents' lack of experiences, rumors from neighbors, financial problem, teased by classmates, health problem are the major challenges faced by the parents. They overcome it through cooperation, having the sense of optimism, going away from the gossipers, bringing the child to church, and acceptance. They shared some pieces of advice the importance of acceptance of child's condition, and kindness to the child,

INTRODUCTION

Children are said to be the gift from the Almighty God. They are the source of hope, inspiration, and happiness to parents. Parents do everything for their children. Aside from this, they wanted to give their children the best of life that they deserve. However, sometimes parents are facing the predicaments especially when they have children with disabilities.

Parenting is a tough yet a rewarding job especially with a child with disability (Steffensen et al., 2022). It can be surmised that mothers in general showed the spirit of resiliency in taking care of their children with disabilities. They looked life positively even in the midst of the quandary (Lee et al., 2022). Conversely, not all have the same views in life. Some of them experienced stigma and misunderstood by others. Social support has not been given to them (Tekola et al., 2022).

Mothers are most likely to quit and gave in to their job to give full time care to their children with disabilities (Szlamka et al., 2022). Even the COVID-19 pandemic caused detrimental effects to them especially to poor and surviving families (Mbazzi et al., 2022). In addition, parental distress was the significant predictor of poor parental adjustment which can be associated with depression, anxiety, and stress (Sandoval-Obando et al., 2022).

Prior to this, numerous studies relative to the plight of parents of children with disabilities have been explored. The study of Villamero (2014) made a constructivist study on the assessment of teachers for children with disabilities. For Agbon and Mina (2017), they discussed the participation of children with disabilities to school activities. On the contrary, none of these studies give concern on how parents overcoming the dilemma in the local setting especially in handling with a Trisomy 21 or down syndrome.

This study is timely and relevant since it will look into the different dimensions of strengths and vigor of parents in handling their children with down syndrome. Their views will be deepened as well as to give lessons to other parents who are in the same dilemma. To give light to educational practice, this study will pave the way of how teachers will understand their students with down syndrome and necessary measures and intervention will be observed.

Statement of the Problem

1. What challenges do parents face in handling their children with down syndrome?
2. How do parents with children with down syndrome cope with the challenges?
3. What inspiring words can they share to parents who have children with down syndrome?

METHODOLOGY

Research Design

I will utilize the qualitative-multiple case study research design. Qualitative research is defined as an approach in exploring the experiences of human lives (Smith & Dunworth, 2003). It is different from the quantitative where numbers are the bases for interpretation of the data (Dodgson, 2017). In this regard, qualitative research is concerned with the narratives, stories, words, and pictures. Sometimes, the interpretation is merely hermeneutics.

For Yin (2017), multiple-case study involves two or more cases across the same phenomena under investigation. The difference with the single case is the design itself; but they are within the same methodological approach especially in the data interpretation. Different cases will be bounded in order to make an inference of the general opinion (Houghton et al., 2015).

This study is qualitative since it will not seek any relationship with the variables. As such, there is no need to test it because only the experiences of the cases will be determined. Parents who have children with Down Syndrome or Trisomy 21 will be interviewed so that their challenges and coping mechanisms will be understood especially by those parents who are in the same dilemma.

Locale of the Study

This study will be explored in one of the SPED implementing schools in the Province of Cotabato. Since it will tackle sensitive issues about the identities of the parents as well as the learner, the locale of the study will be hidden to ensure that they will be protected to the highest level. More so, this is one of the biggest schools which caters students with disabilities like those with down syndrome or trisomy 21. The school has trained teachers who catered the needs of these learners.

Research Instrument

The following research instrument will be used in this study. I will first prepare the interview guide questions. Following this is the consent-to-participate form. I will also use the recorder especially in gathering the data.

Sampling Procedure

The sampling technique to be used in this study is the purposive sampling. It is a judgmental sampling technique wherein the researcher selects the sampling because of a purpose (Andrade, 2021). Hence, in this study, the informants will be selected using the criterion-based sampling (Campbel et al., 2020). The following criteria will be set for the selection:

1. Parents of a child with Trisomy 2/Down Syndrome;
2. The child is currently enrolled in one of the SPED schools; and
3. Both parents are hands-on caregivers on taking care of the child.

Data Gathering Procedure

The following procedures will be observed in this study. I will interview some SPED teachers in one of the schools in the Province of Cotabato about the presence of students with Down Syndrome/Trisomy 21. After this, the identification of the parents will be determined through the teachers. Initial talk with the parents will be done by the researcher to inform them about the purpose of the study.

In the same vein, the preparation of the interview guide questions will be done. This will be checked and validated by the pool of experts. The contents will be thoroughly checked to ensure that these would not disparage the parents and may hamper the flow of the interview.

The informants will be the one who will set the date and time of the interview. Prior to this, they will be asked to affix their signature on the consent-to-participate form. The interview will last for 1 hour or more depending on the stories to be shared by the informants.

When the interview is done, I will transcribe the recorded data. Responses in their mother tongue will be translated to English. Then, the data will be brought to the data analyst for the identification of emergent themes. Discussion of each theme will be done with the support of the narrations of the stories of each informant. To validate the findings, I will return to them and ask them on the veracity and authenticity of the data as well as the interpretation. As an expression of gratitude, I will give them token for the time and effort they spent.

Data Analysis

Thematic analysis is the process of identifying and analyzing qualitative data which means that repeated patterns from the responses of the informants will be interpreted (Braun & Clarke, 2006). Codes will be interpreted based on the responses. The data will be analyze using the MAXQDA (Guetterman et al., 2015).

RESULTS AND DISCUSSIONS

Challenges of Parents in Handling Children with Down Syndrome

The first research question determines the challenges of parents in handling children with down syndrome.

Lack of Support System. It cannot be denied, that handling a child with down syndrome is such a great challenge for parents. Without the support system it is difficult for them to survive especially that they need people who would have to help them. This considers the situation of the child who is different

to those who are considered as “normal” by the society. In the same vein, this entails that parents without getting any support from people who surround them could hardly handle to overcome the challenges that lie ahead of them. Similarly, this explains that family members should have the first to understand the situation of the child.

One of the informants narrated that:

“Sobrang hirap namin siyang pinalaki. Nangangailangan kasi siya ng dobleng pag-aalaga. Kahit na ang mga simpleng bagay ay mahirap ituro sa kaniya. Dapat laging may umaalalay sa kaniya lalo na kapag kumakain, naliligo at nagbibihis.” (She was raised with a lot of difficulties. She requires twice as much love and care. Even the simple things are challenging to teach her. She should always have something to support her especially when eating, bathing and getting dressed). Informant 1

In the same manner, support system has been an issue from one of the parents. For example, the husband had the hesitations of accepting the situation of his child. As confirmed on the interview:

“Noong una hindi ko matanggap, namoblema talaga ako pati asawa ko. Hindi ko alam paano ko tatanggapin yong kalagayan ng anak ko, dahil alam ko ang pagkakaroon ng anak na may down syndrome ay hindi madali kasi may condition siyang kakaiba. Nadepress ako. Palagi ako umiiyak.” (At first I’m really frustrated also my husband. I do not know how to deal with this problem. It really bothered me, because having a child with a down syndrome is not easy. I was depressed. I’m always cried). Informant 2

Raising a child with Down syndrome can be emotionally and psychologically demanding. Without a support system, parents may feel overwhelmed, isolated, and stressed, which can impact their well-being and ability to provide effective care (Dabrowska & Pisula, 2010). Parents often need information and guidance on how to support the specific needs of their child with Down syndrome. A lack of support can result in a shortage of resources, information, and guidance, making it more difficult for parents to navigate the challenges associated with the condition (De Clercq et al., 2019).

Parents’ Lack of Experiences. One of the challenges being faced by the parents is the lack of experiences in handling a child with down syndrome. May it be the first case in the family; thus, it could be understood that these parents do not have the first-hand experience in handling the child and in providing their needs. Further, without proper knowledge of the condition of the child will lead the parents to complicate the situation.

“Naging problema yong pag-aalaga sa kaniya kasi ang hirap niyang alagaan lalo na noong baby pa siya, dapat dobleng pag-aalaga ang gagawin. Naging problema din yong tingin ng mga tao sa kaniya. Binubully siya ng mga kalaro niya, kaya halos ang kalaro lang niya yong mga pinsan niya. Iniiwas namin siya sa mga matataong lugar kasi siya yong sentro ng tingin.” Tinutukso siya ng baliw, o mongoloid.” (It was a problem for me to take care of her, she was hard to take care of especially when she was a baby. She needs doble caring. People treatment of her also became a problem. She was always experiencing bullying with her playmates, so most of her friends are her cousins. We avoid her from crowded places because people often look at her. She was said to be abnormal). Informant 5

Parents may not be familiar with the typical developmental milestones for children with Down syndrome as stated by Onnivello et al. (2023). This lack of knowledge can make it challenging to gauge their child’s progress and know what to expect in terms of cognitive, motor, and social development. Parenting a child with Down syndrome may require different approaches and techniques. Parents who lack experience may struggle to find effective strategies for communication, discipline, and fostering independence that are tailored to their child’s unique needs (Steffensen et al., 2022).

Rumors from Neighbors. Parents as always would always have to make it sure that they have to side with their children no matter what. Hearing negative comments from neighbors about the condition of their child could have an emotional impact to them. They are the first people who could feel the burden and pain upon hearing negativities. At the end of the day, these parents are parents who would have the sense of acceptance of the condition of their children. These neighbors who do not have the proper education about the condition of the child could complicate the situation.

“Nagkaroon kami ng problema noong ipinanganak ko siya. Una, pinagtsismisan kami ng mga kapitbahay sinabi nilang abnormal ang anak ko. Pangalawa, problema sa financial dahil simula ng ipinanganak ko siya hindi na ako nakapagtrabaho. Wala kaming maiwanan sa bata eh! na maaaring mgbantay sa kaniya. Hirap din ipagkatiwala sa iba dahil sa kalagayan niya at sobrang hina ng physical development niya yong mga kaedad niyang mga bata nagtatakbuhan na. Samantala yong anak ko hindi pa halos makalakad.” (We had a real problem when I birth to her. First, the neighbor’s gossiped about us, they said my son is an abnormal. Second is about financial problem because since I gave birth to her I haven’t been able to work. We can’t leave anything to the child. We also don’t want to let others watch over her because of his condition. Even her physical body is weak. Those kids her age used to run but she could barely stand-up). Informant 3

Rumors and misconceptions may lead to social isolation, as parents may feel judged or stigmatized. This isolation can impact both the parents' and the child's ability to engage with the community. In addition, rumors can have a significant emotional impact on parents, causing stress, anxiety, and feelings of inadequacy. It can be emotionally taxing to feel judged or scrutinized by those in the community (Prizeman, et al., 2023).

Financial Problem. A child with a down syndrome condition needs to have a close monitoring by the medical doctors. It can be noted that their condition is different from those children who were born normally or without any problems both in physical and mental aspects. In addition, this confirms that parents who do not have the financial capability could not even bring the child to the medical doctor especially to the one who is specializing the condition of the child.

The parent expressed the burden she experienced especially on the finances. She articulated that:

“ Ang kondisyon ng aking anak ay sobrang nakaapekto sa akin at sa buong pamilya. Nagkaroon kami ng problema sa pera dahil maliban sa kondisyon niyang down syndrome mahina din ang puso ng bata. ” (The condition of my son affects my life. The whole family was suffered from severe financial problems. All our savings have been exhausted, because except for his down syndrome condition, his heart is also weak). Informant 2

Children with down syndrome may require regular medical check-ups, specialist consultations, and potentially surgeries. These medical expenses can strain a family's budget (Brosnan et al., 2021). Parents may need occasional respite care or support services which may have associated costs.

Teased by classmates. As the child grows, he/she is surrounded by children of his/her same age. Parents usually send their children to school in order for them to get acquainted with and in to make them feel that they are not different from other children. However, along the way there are children who could not understand them. They were treated differently, as such, they were victims of bullying at school. As parents, this could have a big impact to them since the only purpose that they have is to give their child the experiences of becoming part of the society and be accepted of who he/she is.

“Iyakin siya noong baby pa siya, palaging nga siyang umiiyak. Ang liit niya tapos ang tagal niyang nakapaglakad. Nawawalan ako noon ng pag-asa tuwing nakikita ko yong kalagayan ng anak ko. Noong anim na taon na siya pinasok ko siya sa paaralan bilang kinder pero hindi naging magandangtrato ng mga klasmets niya sa kaniya, tinutukso siya. Kaya pinahinto ko na lang siya. Namoblema ako ng husto sa anak ko. Ang gusto lang sana naming maging normal din yong mga galaw niya, yong pagsasalita niya pero mahirap tagala siya turuan. ” (When she was a baby, she always cried. She was very small and she's been able to walk for a long time. I was losing my hope every time I saw my daughter's condition. When she was 6 years old, I enrolled her in kindergarten class, but her classmates did not treat well and teased her. So, I decided to just stop schooling. I had lots of problem with my child. I just want her to learn to become normal, her movement, speaking but it's really hard to teach). Informant 4

This problem had been shared by Informant 7. She stated that:

“ Ang naging problema talaga namin yong tingin ng tao sa kaniya. Madalas siyang tuksuhin. ” (The way people treated her was a really problem). Informant 7

Teasing can negatively impact the self-esteem and confidence of the child with Down syndrome. It may lead to feelings of isolation and a sense of not fitting in with peers. In the same vein, persistent teasing may result in social isolation, as the child may withdraw from social activities to avoid negative interactions (Gee, 2012).

Health Problem. A child with down syndrome is different with children who were born and healthy and normally. Usually, they have a weak immune system considering that the number of their chromosomes is different. It is a challenge for parents to bring their child to the doctor every now and then. A child needs the close monitoring by the medical doctor. Aside from that, the child has to undergo therapy in order for them to learn how to speak and walk.

Normally, children with down syndrome have been diagnosed with a heart disease.

“ Bukod sa pagiging espesyal niya dahil sa kalagayan niyang may down syndrome may sakit din siya sa puso. ” (Apart from her condition with down syndrome she also have heart disease). Informant 6

For Pfitzer et al. (2018), many children with Down syndrome are born with congenital heart defects. These may require surgical intervention and ongoing cardiac care. As well, they may be more prone to respiratory infections and conditions like sleep apnea. Similarly, hearing loss and vision impairments are more common in individuals with Down syndrome.

Overcoming the Challenges in Handling a Child with Down Syndrome

The second research question answers the strategies used by parents in overcoming the challenges in handling a child with down syndrome. There are five emergent themes extracted from their responses.

Cooperation. Parents hope is to allow the child to grow healthy and be treated not as different but as special that everybody understands the situation. Since it is difficult for them at first to accept the situation, however, they came into the realizations that they need to cooperate in order to give the child the life that he/she deserves. Cooperation in the family will truly strengthen their commitment to pursue their dreams and goals for the child. Indeed, they have the sources of strength to make themselves more focus for the child's overall well-being.

In line with this, the statement of the informant confirmed by saying that:

“Unang- una syempre nakatulog ang pagdarasal, pangalawa yong pagtutulungan ng bawat miyembro ng pamilya. Nagtulungan kaming lahat sa pag-aalaga sa bata. ” (First, of course prayer helped. Second, are the concerns from the family members. We helped each other to taking care my daughter). Informant 1

The emotional and practical support parents receive from a community network is vital. Building a strong support network through cooperation with other parents of children with Down syndrome shows a sense of belonging and shared experiences. Support groups, workshops, and community events provide spaces for mutual assistance, reducing feelings of isolation and overwhelm (Spalletta, 2021).

Sense of Optimism. Even in the middle of the difficulties and challenges brought by having a child with a down syndrome, parents still remain steadfast and optimistic. This means that they looked into the positive side of life and never allow negativities to ruin their commitment in giving the child the best

of them. Acceptance paves the way for optimism since they could not bring back the time and could no longer change the flow of life. All they have to do is to follow where the water flows and learn how to wrestle the tides.

“Nakayanan namin ang mga problema dahil sa positibo naming pagtanggap sa kalagayan ng aming anak. Dahan-dahan din naming natanggap ang katotohanan at walang sinumang makakatanggap sa kaniya kung hindi kami na sarli niyang pamilya. Simula noon nag-isip na kami kung paano naming siya mapapalaki ng maayos at gawing normal ang buhay niya.” We overcome this problem by positively accepting our son’s condition. We slowly accepted the truth that no one can accept his condition except his own family. Since then, we begin to think how we could grow him properly and make his life normal). Informant 2

Optimism involves maintaining a positive mindset despite the difficulties that may arise. Parents of children with Down syndrome often encounter unexpected medical issues and developmental delays. Nurturing a sense of optimism allows parents to approach these challenges with hope and resilience, focusing on the child’s strengths and celebrating small victories along the way (Axelsson et al., 2014).

Going away from the Gossipers. These gossipers are those who could not understand the situation of the child. They are the neighbors whose views about down syndrome is very limited. For the parents, they left the place so that they could have the sense of solace and peace. They went to a place where the child is treated so well and not being teased because of his/her situation. Meanwhile, these gossipers do not have the business to meddle with the condition of the child.

To ease the pain brought by the gossipers, they preferred to leave and settle to their loved ones where they could have the peace of mind.

“Para makaiwas sa mga pinagsasabi ng mga tao umalis muna kami sa bahay namin. Nagstay muna kami sa bahay ng kapatid ko sa ibang lugar. Naging aktibo kami ng asawa ko sa simbahan. Palagi ko talagang pinagdarasal ang anak ko.” (To avoid gossip neighbours we left our home. We stayed at my sister’s house somewhere else. Were always going to church. I’m always praying with my son). Informant 3

Gossip can be detrimental to parents already facing the intricate challenges of raising a child with Down syndrome. Negative rumors and misinformation not only perpetuate societal stigmas but also contribute to feelings of isolation, judgment, and inadequacy for parents navigating this unique parenting journey (Van Riper, 2007). Stepping away from gossip is a transformative process that allows parents to liberate themselves from the negative energy and judgments of others. By consciously choosing not to engage with gossipers, parents reclaim control over their narrative and create a space where their child can be celebrated for their uniqueness rather than subjected to misinformed opinions.

Bringing the Child to Church. Parents brought their children to the church. The purpose of this is to illuminate the child of how God has made him even in a different form. Love and acceptance can be felt inside the corridor of the church. More importantly, parents received prayers from the leaders as well as members to continue being the best of themselves in rearing the child.

As such she revealed that the church helped her a lot in overcoming the situation.

“Nakatulong lang sa akin maam yong pagpray. Tuwing Linggo nagsisimba kami dala ko po yong bata. Pinagpray ko po talaga maam na sana buksan ng panginoon ang isip ko at matanggap ko ang anak ko. Bigyan ako ng lakas para maalagaan ko ng maayos ang bata. Hanggang sa dahan dahan po natanggap ko po ang kalagayan niya.” (My prayer helped me maam. Every week we go to church, I bring my daughter, I really praying ma’am that my the Lord will open my mind so that I can accept the condition of my daughter. I’m always praying God will give me strength to take care my daughter. Until, I slowly accepted my child’s condition). Informant 4

The process of bringing a child with Down syndrome to church begins with a commitment to creating inclusive spaces. Churches play a vital role in nurturing a welcoming environment that embraces diversity. Congregations that prioritize inclusivity lay the foundation for a transformative experience for both the child and their family. The church community can become a pillar of support for families raising children with Down syndrome. Providing resources, organizing support groups, and offering a listening ear create a network of understanding within the church. This support system becomes an essential component in overcoming the day-to-day challenges that families may encounter (Broussard, 2018).

Acceptance. Acceptance is the antidote to the problem. Having it will allow parents to know their children’s hidden talents and skills. It does not mean that having the child with a down syndrome is a punishment, but it is a gift that they need to celebrate with. As they look into the face of the child, they can see the rays of hope that they have to be strong enough to walk hand with their child.

The power of acceptance was reiterated from the interview.

“Nakinig ako sa advised ng mga magulang at mga kaibigan ko. Sabi nila tanggapin mo kasi anak mo yan” (I listened to the advice of my parents and friends. They say accept your daughter’s condition because she is your child. I followed their pieces of advice). Informant 5

In the same vein, an informant also provide the idea on the importance of acceptance of her child’s condition.

“Maliit pa lang ang anak ko tinanggapko na ang itsura niya at kalagayan niya. Magulang ako kaya ako ang dapat unang nakakaintindi sa anak ko.” (I already accepted his appearance and condition. I am a parent so I should be the first to accept my child). Informant 7

As well,

“Sa tingin ko ang nakatulong sa amin ng malaki ay yong positibong pagtanggap namin sa kalagayan ng anak ko.” (I think what helped us a lot was our acceptance of my son’s condition. The pieces of advice from our relatives and close friends also helped). Informant 2

Acceptance often begins with an acknowledgment of the initial struggle that parents may face when they learn about their child's Down syndrome diagnosis. It is natural to experience a range of emotions, including grief, uncertainty, and fear. The transformative process of acceptance starts with allowing space for these emotions and gradually moving towards a place of understanding and love. Acceptance flourishes in an environment of support. Parents actively seek and build a support network comprising family members, friends, and other parents of children with Down syndrome. This network becomes a source of strength, guidance, and shared experiences, fostering a sense of community that transcends challenges (Solomon, 2012).

Advice to Other Parents with a Down Syndrome Child

The third research question aims to determine the pieces of advice of parents to other parents of a child with down syndrome.

Acceptance of Child's Condition. It can be noted that acceptance is a crucial step for parents with a down syndrome child. To make it happen, they always have to remember that everything happens for a reason. The child's presence is never a punishment nor a downfall on the part of the parents but it serves as a gift. They have been blessed with a child who is considered as special because it is within the hands of special parents.

Acceptance has been the word of mouth of the informants. As shared:

"Ang maipapayo ko lang sa kapwa ko may ganitong parehong kalagayan ng anak ay tanggapin ang anak nila ng buong-buo. Mahalin at alagaan ang anak at ang pinakamahalaga maging matatag sa situasyon." (The only thing I can advise to my other parents who have the same condition of the child is to accept the child completely. Love the child and take care of it and the important the most important is being strong for the situation). Informant 1

This is also the pieces of advice of Informant 2 to parents who are in the same situation.

"Ang masasabi ko lang sa mga magulang na may ganito ring situasyon ang anak ay tanggapin nila yong anak nila ng buong puso. Bigyan sila ng walang hanggang pagmamahal, alagaan nila ng maayos at higit sa lahat suportahan nila kung anuman ang gustong gawin ng anak nila na nakakabuti para sa kanila." (All I can say to all parents who have the same dilemma is accept your child with all your heart. Give them unconditional love and take care of them properly and most of all support what they love to do).

Acceptance helps reduce stigma associated with Down syndrome. When society accepts and embraces individuals with Down syndrome, it challenges stereotypes and contributes to a more inclusive and understanding community (Eifert & Forsyth, 2005).

Be kind to the Child. It is never the fault of the child with a condition called down syndrome. Therefore, parents and those who surround the child should have the compassionate heart to understand. They should never be the source of pain as well as the downfall, but instead they have to act as the support system until the child could see the true essence of his/her existence in this abode. Nonetheless, teachers at school should have to ignite into the hearts of their learners to love their classmates regardless of their situations in life.

Kindness to the child will help the parents to become the best version of themselves.

"Para sa mga magulang na may anak na may ganitong kalagayan maging mabait po tayo sa ating mga anak. Mahalin natin sila kasi sila ay grasyang bigay ng Diyos sa atin alagaan natin sila at huwag ikahiya." (For parents with children in this situation be kind to the child. We love them because they are a grace from God. Let's take care of them and not be ashamed). Informant 3

Love is also one of the secrets of overcoming it.

"Ang masasabi ko lang sa mga magulang na may ganitong kalagayan ang anak ay huwag mawalan ng pag-asa. Mahalin nila ang kanilang anak, gabayan, turuan at huwag pabayaan." (What I can advise parents whose child has this condition is not to lose hope. They should love their child, guide them and don't neglect them). Informant 5

Kindness creates a comfortable and safe space for communication. Children with Down syndrome may experience delays in language development, and a patient and understanding approach encourages them to express themselves more confidently. Positive interactions, supportive environments, and understanding show a sense of belonging and happiness as mentioned by Byleveldt, (2013).

IMPLICATIONS FOR PRACTICE, IMPLICATIONS FOR FUTURE RESEARCH, AND CONCLUDING REMARKS

Implications for Practice

Parenting is the most important profession. They can see the different aspects of how to raise a child. It taught them different lessons that would make them the best parents. Although, there will be a lot of challenges that may hamper their ways, they already have the capacity to overcome it because life teaches them to be strong enough to overcome it.

The case of down syndrome for others is an obligation and a challenge knowing the situation of the child. Cases may differ from child to child depending on the severity. In turn, challenges and coping among parents may differ as well. The only thing they have in common is the acceptance and the love they have shown to their child.

Similarly, having a child with down syndrome had caused so much trouble. There were those neighbors who caused them so much pain. These are the people who have no knowledge at all of the condition of the child and how would it become a parent of the child.

Although the school should have been the place for learning and respect, however, it became one of the avenues for parents to struggle for the acceptance of their child. There are learners who could not understand the situation of their classmates. Thus, for teachers, it is crucial for them to educate well the children on the presence of a down syndrome in the class.

Foremost, schools should have teachers who specialize in special education. They are trained to develop the skills and capabilities of these children to live like a normal life. In addition, they know well the strategies as well as the attitudes of these children who have this kind of condition. Finally, these children are special enough because they too have special roles in the society.

Implications for Future Research

This study has the biggest implications for research. Based on the findings of the study, there are still a lot of rooms to look into. For example, there could be a similar study involving the neighbors of the child of what really is their perspective of the condition of the child. In this regard, people could be able to understand their views and eventually they should be educated well on the condition of the child.

In the same vein, this study has enormous contribution to psychology as well as in the world of human behavior. By understanding humans in general this can create a room for research especially in leading people to have the compassion towards children within this condition. They have to understand that every child is special in their own aspects regardless of their conditions.

Conversely, a quantitative study will be explored by using the themes as the dimensions of the variables. By creating a model for acceptance and tolerance, then it could help parents to have the sense of hope and solace especially when they are facing the most challenging moments of their lives.

Furthermore, future researchers may have to deepen their understanding on the cases of bullying among children with down syndromes at school and how do schools mitigate this. As well, this will look into the special roles of the parents' association and the students' association in carrying out programs that would help children with down syndrome be respected and accepted in its highest form. This study will pave the way for the creation of policy which will surely make the school a safe haven for everyone.

Concluding Remarks

This study has taught me three most important lessons in life. First, having a down syndrome child is not a punishment, instead, it is a gift from God. They are humans who were born with special looks, features, and needs. They are no different to us because they breath the same air, they eat the same food, and they speak the same language.

Second, a child with down syndrome needed utmost care not only by parents but also by teachers. As a teacher, I made it sure that bullying in my class has no room. Every learner has to make it sure that they have to value respect, love, acceptance, as well as being humane in all aspects of life.

Third, this study opens my mind that I have to fully understand parents with a child with down syndrome. It is my role to talk with them and try to comfort them on their lowest levels of their lives. Support system makes a greater impact as they cope with different challenges.

Henceforth, I conducted this study because I saw in the eyes of every child the meaning of hope. They gave me the reasons to climb the mountains and becoming victorious in my own battle. As a mother, I can truly say that we too have the special role in this world to inculcate in them the true value of love.

References

- Abbasi, S. S. (2016). Evaluation of quality of life in mothers of children with Down syndrome. *Pract Clin Psychol* ;4:81–8.
- Abdelall, G. (2021). The effectiveness of acceptance and commitment therapy to reduce social stigma among mothers of children with Down syndrome. *Journal of Studies in Social Work Issue* 55.
- Andrade, C. (2021). The inconvenient truth about convenience and purposive samples. *Indian Journal of Psychological Medicine*, 43(1), 86-88.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Bray, L. C. (2017). Parent-to-parent peer support for parents of children with a disability: a mixed method study. *Patient Educ Couns* ;100:1537–43.
- Camara, M., Bacigalupe, G., & Padilla, P. (2017). The role of social support in adolescents: are you helping me or stressing me out? *International Journal of Adolescence and Youth*, 22(2), 123–136.
- Campbell, S., Greenwood, M., Prior, S., Shearer, T., Walkem, K., Young, S., ... & Walker, K. (2020). Purposive sampling: complex or simple? Research case examples. *Journal of research in Nursing*, 25(8), 652-661.
- Canfield, M. A., Honein, M. A., Yuskiv, N., Xing, J., Mai, C. T., Collins, J. S., ... & Kirby, R. S. (2006). National estimates and race/ethnic-specific variation of selected birth defects in the United States, 1999–2001. *Birth Defects Research Part A: Clinical and Molecular Teratology*, 76(11), 747-756.
- Carothers, A. D., Hecht, C. A., & Hook, E. B. (1999). International variation in reported livebirth prevalence rates of Down syndrome, adjusted for maternal age. *Journal of medical genetics*, 36(5), 386-393.

- Chen, J. (2005). Relation of academic support from parents, teachers, and peers to Hong Kong adolescents' academic achievement: the mediating role of academic engagement. *Genetic, Social, and General Psychology Monographs*, 131(2), 77–127.
- Cohen, S., Underwood, L. G., & Gottlieb, B. H. (Eds.). (2000). *Social support measurement and intervention: a guide for health and social scientists*. New York: Oxford University Press.
- Dabrowska-Zimakowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of intellectual disability research : JIDR*. 54. 266-80. 10.1111/j.1365-2788.2010.0125.
- Dempsey, I. K. (2009). Parent stress, parenting competence and family-centered support to young children with an intellectual or developmental disability. *Res Dev Disabil* ;30:558–66.
- Dodgson, J. E. (2017). About research: Qualitative methodologies. *Journal of Human Lactation*, 33(2), 355-358.
- Duckman, R. H. (2014). Visual status of children with Down syndrome. *Optom Vis Perf*, 2, 240-243.
- Kiefer, S. M., Alley, K. M., & Ellerbrock, C. R. (2015). Teacher and peer support for young adolescents' motivation, engagement, and school belonging. *RMLE Online*, 38(8), 1–18.
- Gashmard, R. A. (2020). Coping strategies adopted by Iranian families of children with Down syndrome: A qualitative study. *Medicine (Baltimore)*. 2020 Jul 10;99(28):e20753. doi: 10.1097/MD.0000000000020753.
- Gholami, J. F. (2018). Systematic review on social support of parent/parents of disabled children. *Arch Rehabil* ;19:126–41.
- Ghosh, S., & Dey, S. K. (2013). Risk factors for Down Syndrome birth: Understanding the causes from genetics and epidemiology. *Down Syndr*.
- Glasson, E. J., Sullivan, S. G., Hussain, R., Petterson, B. A., Montgomery, P. D., & Bittles, A. H. (2002). The changing survival profile of people with Down's syndrome: implications for genetic counselling. *Clinical genetics*, 62(5), 390-393.
- Guetterman, T., Creswell, J. W., & Kuckartz, U. (2015). Using joint displays and MAXQDA software to represent the results of mixed methods research. *Use of visual displays in research and testing: Coding, interpreting, and reporting data*, 145-175.
- Hassold, T. (2007). AUTHOR QUERIES-TO BE ANSWERED BY THE CORRESPONDING AUTHOR. *Human Molecular Genetics*, 16(1-5).
- Houghton, C., Murphy, K., Shaw, D., & Casey, D. (2015). Qualitative case study data analysis: An example from practice. *Nurse researcher*, 22(5).
- Jaramillo, S., Moreno, S., & Rodríguez, V. (2016). Emotional Burden in Parents of Children with Trisomy 21: Descriptive Study in a Colombian Population. *Propiedades psicométricas de la Escala de Ideología de Género en adolescentes colombianos. Universitas Psychologica*, 14(1), xx-xx. <http://dx.doi.org/10.1>.
- Kashi, A. S. (2015). The effect of “Kashi practices” on the improvement of psycho motor skills in people with Down syndrome. *Iran Rehabil J* ;13:13–21.
- Kiefer, S. M., Alley, K. M., & Ellerbrock, C. R. (2015). Teacher and peer support for young adolescents' motivation, engagement, and school belonging. *RMLE Online*, 38(8), 1–18.
- King, G. B. (2009). Belief systems of families of children with autism spectrum disorders or Down syndrome. *Focus Autism Other Dev Disabil* ;24:50–64.
- Lara, E., & de los Pinos, C. (2017). Families with a disabled member: impact and family education. *Procedia Soc Behav Sci* ;237:418–25. .
- Lee, A., Yeh, V. J. H., Knafl, K. A., & Van Riper, M. (2022). Perceived experiences of Korean immigrant mothers raising children with disabilities in the United States. *Journal of Transcultural Nursing*, 33(2), 219-227.
- Malecki, C. K., & Demaray, M. K. (2003). What type of support do they need?
Investigating student adjustment as related to emotional, informational, appraisal, and instrumental support. *School Psychology Quarterly*, 18(3), 231–252.
- Mbazzi, F. B., Nalugya, R., Kawesa, E., Nimusiima, C., King, R., Van Hove, G., & Seeley, J. (2022). The impact of COVID-19 measures on children with disabilities and their families in Uganda. *Disability & Society*, 37(7), 1173-1196.
- Morris, J. K., Wald, N. J., & Watt, H. C. (1999). Fetal loss in Down syndrome pregnancies. *Prenatal Diagnosis: Published in Affiliation With the International Society for Prenatal Diagnosis*, 19(2), 142-145.
- Murthy, S. K., Malhotra, A. K., Mani, S., Shara, M. E. A., Al-Rowaished, E. E. M., Naveed, S., ... & AlAli, M. T. (2007). Incidence of Down syndrome in Dubai, UAE. *Medical Principles and Practice*, 16(1), 25-28.

- National Institute of Child Health and Human Development (2002). Report to the NACHHD Council. Washington, DC: U.S. Department of Health and Human Services, National Institutes of Health, Carter KC, Early conjectures that Down Syndrome is caused by chromosomal nondisjunction. *Bulletin of the History of Medicine*.528-63.
- Potter, H. (1991). Review and hypothesis: Alzheimer disease and Down syndrome -chromosome 21 nondisjunction may underlie both disorders. *American journal of human genetics*, 48(6), 1192.
- Pyhältö, K. (2018). Function of supervisory and researcher community support in PhD and post- PhD trajectories. In E. Bizer, L. Frick, M. Fourie-Malherbe, & K. Pyhältö (Eds.), *Spaces, journeys and new horizons for postgraduate supervision* (pp. 205–222). (Studies into Higher Education; No. 5)). Stellenbosch: African Sun Media.
- Sandoval-Obando, E., Alcaide, M., Salazar-Muñoz, M., Peña-Troncoso, S., Hernández-Mosqueira, C., & Gimenez-Serrano, S. (2022). Raising children in risk neighborhoods from Chile: Examining the relationship between parenting stress and parental adjustment. *International journal of environmental research and public health*, 19(1), 45.
- Sherman, S. L., Allen, E. G., Bean, L. H., & Freeman, S. B. (2007). Epidemiology of Down syndrome. *Mental retardation and developmental disabilities research reviews*, 13(3), 221-227.
- Smith, L. H. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *J Autism Dev Disord* ;40:167–78.
- Smith, J., & Dunworth, F. (2003). Qualitative methodology. *Handbook of developmental psychology*, 603-621.
- Szlamka, Z., Tekola, B., Hoekstra, R., & Hanlon, C. (2022). The role of advocacy and empowerment in shaping service development for families raising children with developmental disabilities. *Health Expectations*, 25(4), 1882-1891.
- Steffensen, E. H., Rosvig, L. H., Santoro, S., Pedersen, L. H., Vogel, I., & Lou, S. (2022). Parenting a child with Down syndrome: A qualitative study of everyday practices in Danish families. *Journal of Genetic Counseling*, 31(3), 758-770.
- Tekola, B., Kinfu, M., Girma Bayouh, F., Hanlon, C., & Hoekstra, R. A. (2022). The experiences of parents raising children with developmental disabilities in Ethiopia. *Autism*, 13623613221105085.
- Upadyaya, K., & Salmela-Aro, K. (2013). Development of school engagement in association with academic success and well-being in varying social contexts: a review of empirical research. *European Psychologist*, 18(2), 136–147.
- Villamero Jr, R. (2014). *Teachers' assessment strategies for children with disabilities: A constructivist study in regular primary schools in Negros Oriental, Philippines* (Master's thesis).
- Wahab, A. A., Bener, A., & Teebi, A. S. (2006). The incidence patterns of Down syndrome in Qatar. *Clinical genetics*, 69(4), 360-362.
- Yin, R. K. (2017). *Case study research and applications: Design and methods*. Sage.