

Denying to Embracing: A Mother's Path to Acceptance, Love, and Resilience in Raising a Child with Down Syndrome



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ABSTRACT. Down Syndrome is one of the most common neurodevelopmental disorders in the Philippines, presenting significant challenges for families. This qualitative study explores the experiences of five mothers raising children with Down Syndrome, revealing their initial struggles with denial, managing expectations, behavioral issues, caregiver fatigue, and anxieties about the future. However, the study finds that these mothers ultimately learn to accept their child's condition, embrace their role, and find strength in love and faith. This research emphasizes the need for increased public awareness and support for families affected by Down Syndrome. It also recommends that future research incorporates diverse perspectives from fathers, siblings, and families from various backgrounds to gain a more comprehensive understanding of the challenges and coping mechanisms associated with raising a child with Down Syndrome.

1.0. Introduction

Down Syndrome is known to be caused by trisomy 21, a third copy of chromosome 21 (Bull, 2020). Down Syndrome (DS) is one of the most prevalent causes of intellectual disability (Nelson Goff et al., 2016). Children with Down Syndrome tend to have mild-to-moderate intellectual disabilities and have decreased cognitive abilities (Mazurek & Wyka, 2015). According to DSM-5-TR (2022), intellectual disability is a neurodevelopmental disorder that affects a child's ability to function in conceptual, social, and practical areas of daily life. Although parents of children with intellectual disabilities share the same love and joy for their children, they are more likely to experience stress, anxiety, and depression (Machalick et al., 2015).

A Malaysian study found that mothers of children with Down Syndrome experience high levels of parenting stress (Isa et al., 2016). Many mothers reported increased caregiving responsibilities, role changes, and greater time demands (Choi & Riper, 2017). They noted that caring for a child with Down Syndrome requires significant time and effort, limiting their ability to engage in extracurricular activities or pursue

employment opportunities (Choi & Riper, 2016). However, Sijeeni (2016) highlighted that a child with Down Syndrome can strengthen family bonds, promote clarity of thought, teach unconditional love, and foster appreciation for diversity.

In the Philippines, a study found that some parents initially tried to ignore their child's Down Syndrome diagnosis but were unable to avoid their responsibilities, leading to feelings of despair and social anxiety (Masanda & Masanda, 2018). Additionally, mothers faced challenges related to medical needs and the financial burden of providing for a child with Down Syndrome (Tanganim et al., 2017). While parents acknowledged the difficulties, especially regarding medical and behavioral issues, they also valued the experience, noting that their close bond with their child gave their lives purpose and positively impacted their worldview (de Castro-Hamoy et al., 2022). Furthermore, Retuerma (2019) found that, despite challenges, fathers viewed their children as a blessing, strengthening the family bond instead of creating conflict.

In Negros Island Region, interactions with parents of children with Down Syndrome diagnosed with moderate intellectual disability revealed limited knowledge about the developmental care and academic learning needs of these children. The researcher was inspired to conduct

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the study based on these caregiving experiences. Supporting this, Hinggo et al. (2022) found that despite their lack of knowledge, parents made efforts to support their children's academic progress and maintain their motivation to learn.

Several studies worldwide have explored the experiences of parents raising children with intellectual disabilities. Badu (2016) found that in Ghana's Ashanti Region, parents faced mental strain, social stigma, financial difficulties, and marital issues. Maritska et al. (2018) observed that while most parents are hopeful about their children's work prospects, they hold opposing views on the educational needs of children with Down syndrome. In the national context, Cabbeh et al. (2015) emphasized the importance of pre-vocational education for children with intellectual disabilities to help them live independently. However, there is a limited focus on the experiences of mothers raising children with Down Syndrome diagnosed with moderate intellectual disabilities through qualitative research. Hence, this is the research gap this study would like to fill.

Thus, this study aimed to explore and describe the experiences of mothers raising children with Down Syndrome in Negros Island Region.

2.0. Methodology

Research design. This study employed a descriptive phenomenological research design, focusing on understanding a person's experiences in the world (Neubauer et al., 2019). The research aimed to identify key themes as participants navigated their experiences, exploring the essence of those lived experiences (Creswell & Poth, 2016). The phenomenological approach was chosen to explore the "why" and "how" of mothers raising children with Down Syndrome, particularly those diagnosed with moderate intellectual disability. Interviews were conducted to gather insights into their experiences, and ethical guidelines were strictly followed throughout the study.

Participants and sampling technique. The study participants were mothers raising children with Down Syndrome attending public elementary schools. A purposive sampling method was used to select participants based on specific criteria, ensuring a fair selection. Purposive sampling, a nonrandom technique, involves choosing participants for their relevant characteristics without needing underlying hypotheses or specific participant numbers (Etikan et al., 2016). The inclusion criteria required mothers of children with Down Syndrome, diagnosed with moderate intellectual disability, attending public elementary schools for the 2023-2024 school year. Additionally, the mother must reside with the child to affirm parental responsibility. The researcher obtained a medical certificate to verify

the child's condition while maintaining the privacy and anonymity of the participants.

Research instrument. The researcher used an unstructured, in-depth individual interview. The researcher used open-ended questions to ask only broad questions to the participants, allowing them to express their opinions freely (Creswell & Creswell, 2018). To explore and glean the "why" and "how" of the lived experiences of mothers raising children with Down Syndrome diagnosed with moderate intellectual disability. Their experiences during the phenomenon were the focus of the study, so only questions about their experiences were asked.

Data collection and analysis. To conduct the study with mothers of children with Down Syndrome and moderate intellectual disability, the researcher submitted a letter of intent to the Schools Division Superintendent in a component city in the Negros Island Region to obtain demographic information. Participants were selected based on inclusion criteria and were informed of ethical considerations. They signed an informed consent form voluntarily, with attention to privacy and health safety. The interviews took place in quiet, undisturbed settings, lasting 45 to 60 minutes. The researcher explained the study's goals, the significance of the data, and the confidentiality of the project. The researcher employed bracketing to remove personal biases and focus on understanding the participants' lived experiences (Brue & Brue, 2016). Probing questions were used to gather further details when responses seemed incomplete or unclear. Data saturation was achieved when responses became repetitive, indicating no new insights emerged (Creswell & Creswell, 2018). The researcher allowed participants to express themselves freely without interruption, recording verbal and non-verbal responses in their native Cebuano language. The data analysis followed Creswell and Creswell's (2018) five-step process: organizing and preparing the data, reviewing all the data, coding the data, generating descriptions and themes, and presenting the findings with supporting descriptions and themes.

Ethics concern: The researcher follows the ethical guidelines of the Philippine Health Research Ethics Board (PHREB), ensuring respect for persons, beneficence, and justice to maintain the study's ethical integrity. The welfare of the participants was prioritized, ensuring their voluntary participation and the freedom to withdraw at any time without consequences. They were given an informed consent form explained in their native language, confirming that they understood the study's terms before signing. The researcher ensured participants' privacy by using pseudonyms and adhering to the Data Privacy Act of 2012, with all identifying information protected. All raw data was securely stored

and later properly disposed of to maintain confidentiality.

3.0. Results and Discussion

Profile of the Participants

Tessa is 54 years old and has three children. Fifteen-year-old daughter Stephanie, her youngest child, has been diagnosed with Down Syndrome. She works at their restaurant and grocery shop, a family business. Her daughter is officially enrolled in a public elementary school, specifically the SPED department. She fetches up every day despite her hectic schedule and health condition. She is residing in the same house as her daughter and personally taking care of her. When I first met her, she had a stern, strict appearance, but as we welcomed each other, she broke into a wide smile. Despite being a reserved woman, she volunteered to share her experiences raising a child with Down Syndrome.

Anna, who is 56 years old, is a mother of three. Her youngest daughter, Jela, twelve, receives a diagnosis of Down Syndrome. She holds a college degree and has previous experience as a sales representative. She is currently caring for her youngest child, assuming full responsibility, and living a housewife lifestyle. Her husband provides for their needs. I went to their house on the day of the interview. She seemed to be amiable and very willing to share her experiences. After being briefed, she signed the consent form. Anna answered all my questions honestly and with openness during the interview. I ended the conversation by thanking her for her time.

Mylene, a proud mother of five, is 67 years old. Tina, her youngest daughter, is twenty-seven years old and has Down Syndrome. She is a former private employee and a college graduate. She is, nevertheless, currently retired. As her older children have left for overseas, she is currently caring for her youngest daughter at home. Following her husband's passing, she became a widow and enjoyed sewing as a pastime. Their means of subsistence include their children's remittances, her retirement payment, and her husband's pension as a public nurse. I interviewed in their house. I walked up to her, and she was quite welcoming. She has shared a great deal about her experiences as a mother. She indicated her points with hand gestures and maintained eye contact throughout the interview. She chuckled a lot during the interview as she talked about Tina and her home situation. With no hesitation, she responds to the inquiries.

Jessa is 50 years old and has two sons. Paolo, her youngest child, is eleven years old, and he has Down Syndrome. She stays at home and takes care of her child full-time. In previous years, she made a living by selling

food at their home, but these days, she depends on her husband's salary. We had a quick introduction; she signed the consent form. The interview took place at their residence. She opens fully about her experiences as a mother. She maintained eye contact and answered my questions honestly, which helped us stay connected throughout the interview.

Rita is 41 years old with three children. Her eldest daughter, Jen, her sixteen-year-old daughter, has Down Syndrome. Having completed her college education, she has been employed as a sales representative at an appliance retailer. The couple earns a living together since her spouse works for the government. She is in full parental responsibility and is assisted by her mother in caring for her daughter. I am cordially welcomed into her home by her entire family. I interviewed them at their house. She answers me openly and without hesitation to share her experiences without any reservations.

Thematic Insights

To set aside her biases and beliefs about the lived experiences of mothers raising public elementary children with Down Syndrome, the researcher employed phenomenological bracketing prior to the data analysis. For the researcher to acknowledge and understand the viewpoints of the participants, the researcher bracketed biases. Throughout the research process, the researcher made sure that their personal experiences with this population were limited and that they were not familiar with any mothers raising children with Down Syndrome to maintain an open mind to new information from the participant's experiences.

The researcher used the five steps outlined by Creswell and Creswell (2018) to identify relevant information from each participant's data after interviewing the five (5) participants and transcribing their verbatim. Composite descriptions that derived the essence of the phenomenon were developed. The descriptions contextualized "why" and "how" they experienced the phenomena.

Challenges in raising a child with Down Syndrome

Mothers openly and willingly shared their experiences of raising a child with Down Syndrome, often expressing struggles with denial and the initial emotional impact of their child's condition. Common challenges include dealing with reality, handling expectations, dealing with misbehavior, caregiving exhaustion, teaching the child to walk, and worrying over the future care of their child.

Denial with reality. Denial is the initial stage of grief, where mothers initially struggle to accept their child's disability, often refusing to acknowledge it. As revealed by the participants:

Yes, I wept because I found it hard to accept her condition. (Anna, Personal Communication, April 9, 2024)

Yes, it was difficult. I had mixed emotions when I first learned of his situation, and it was hard to accept. (Jessa, Personal Communication, April 9, 2024)

Because she is my first child, it was really difficult. (Rita, Personal Communication, May 19, 2024)

The responses indicate the phenomenon of denial and the emotional turmoil that mothers experience when confronted with the reality of their child's condition. As Korkow-Moradi et al. (2017) noted, mothers often face emotions like sadness, fear, anger, grief, and guilt, which are tied to their self-reflection and questioning of the situation.

Handling expectations. It arises as they struggle with the disappointment of not having a "normal" child, leading to overwhelming questions about how their child was born with Down Syndrome despite their best efforts during pregnancy and their family's genetic history.

What happened to this child? Why is she in this state? You may, at times, encounter depression. (Anna, Personal Communication, May 7, 2024)

I struggle to accept this, wondering why it is happening. I never expected him to be this way, especially since it is not in our family genes, not even on my husband's side. (Jessa, Personal Communication, April 9, 2024)

I often wonder, "Why does she look like this?" as I gaze at her. It made me think deeply, and I cried a lot. Why did God give us this child, especially when I had a normal pregnancy? (Rita, Personal Communication, May 19, 2024)

The responses suggest that mothers often face a struggle in handling expectations of their child having Down Syndrome, feeling overwhelmed by the disparity between their expectations and reality. As noted by Behrani and Shah (2016) and Kantekin (2023), they experience a range of emotions, including guilt, sorrow, and confusion, questioning how the condition could have occurred despite their efforts to ensure a healthy pregnancy. Based on the responses, participants feel heartbroken and question why they were given a child with Down Syndrome, sometimes blaming themselves or God for their circumstances, as seen in the study by Karaca and Konuk Şener (2021), which highlights feelings of punishment and deep grief over their situation.

Dealing with misbehavior. Individuals with Down Syndrome often struggle with expressing themselves, leading to tantrums when their needs and desires are unclear. The mothers in this study faced challenges in disciplining their children and trying various strategies to manage aggressive behaviors and other unusual actions.

Yes, I hit her since she would probably do it again. She has to be disciplined by me. She started to feel shy while she was sitting. She has stopped hitting people currently. (Anna, Personal Communication, April 9, 2024)

I simply leave him alone when he throws tantrums. Whenever he wanted something and could not have it, he would have tantrums. He will become enraged, but he will not harm anyone. He would often speak. At times, when he is playing, he is talking. (Jessa, Personal Communication, April 9, 2024)

It is very hard to manage. But we treat her as a normal child. When she throws tantrums, we do not get angry because if we do, she will become worse. (Rita, Personal Communication, April 10, 2024)

Mothers in this study struggle with managing their child's misbehavior, especially during tantrums, as observed in similar research by Mona and Rehab (2019) and Patel et al. (2018), highlighting the challenges of caregiving and behavioral difficulties in children with Down Syndrome. Participants shared common strategies, including allowing tantrums to run their course and emphasizing the importance of discipline while recognizing that their emotional responses could impact their child's behavior and emotional development.

Caregiving exhaustion. Participants noted the physical and emotional toll of managing their children's daily needs and school responsibilities. Mothers described the challenge of balancing home care, overseeing school activities, and assisting with routines, hygiene, and meal planning, all while remaining attentive to their children's well-being.

Yes, I must rise. Since I have to feed her, I must prepare the rice and viand. I also find it difficult when she refuses to take a bath because she thinks the water is too cold. Just give her a bath; I will make her do it. She would listen to music after I bathed her, after which I would feed her and get her dressed for school. (Anna, Personal Communication, May 7, 2024)

No, I do not consider giving up since he would be so pitiful if I did. He will be really pitiful. Who is going to look after him? Therefore, I unwind when I am feeling exhausted. I rest for a while. However, I never claim that I will give up because he will be miserable. (Jessa, Personal Communication, May 28, 2024)

Yes, I get tired, especially when I do my very best to help her routine, but she is not cooperating. (Rita, Personal Communication, May 19, 2024)

The responses show that mothers of children with Down Syndrome experience caregiving exhaustion as primary caregivers responsible for addressing their child's unique needs. Similar to Subu et al. (2024) in India, this study reveals that mothers invest considerable time and energy in meeting their child's physical, social, and educational needs, often navigating complex emotions while ensuring the best possible support for their daily routines. Mothers of children with Down Syndrome are more likely to experience fatigue than fathers (Albedeiwi et al., 2022).

Stretching patience. As mothers struggled to maintain composure while managing their child's challenging behavior, sometimes feeling frustrated and unable to prevent physical reactions during tantrums.

You do require it, yes. It is vital that you have a long-term patience strategy. Make sure there is no tension for them. (Anna, Personal Communication, May 7, 2024)

There are moments when I lack true control. I cannot take it anymore. However, on occasion, when I am in a good mood, I can be more patient; however, when I am under stress, my patience truly gets shorter). (Jessa, Personal Communication, May 28, 2024)

Yes, Ma'am, it requires long patience to deal with and understand her. (Rita, Personal Communication, May 19, 2024)

The responses highlighted that mothers raising children with Down Syndrome often stretch their patience, especially when addressing behavioral issues, teaching daily routines, and supporting their child's development. Like the study by Desimpelaere et al. (2024), the mothers emphasized the importance of patience in fostering a supportive environment, even during developmental stagnation or regression, to avoid frustration in their parenting journey.

Teaching the child to walk. Mothers express concern and fatigue over their child's delays, dedicating considerable time and effort, including using

unconventional methods like covering their child's feet with sand at the shoreline to encourage walking.

We visit the coast. We covered her lower limbs with sand. Then, we let her walk on the shore. She could walk by the time she was two and ½ years old. We believed that our mobility had been lost. She did, but it is not something she can do well. When she walks, she resembles a swing. That is not normal. (Anna, Personal Communication, April 9, 2024)

At 2 years old, she cannot walk yet. Her legs are extremely delicate, feeling almost boneless. I massage her legs, knees, and feet, then take her to the beach to bury her legs in the sand every morning as advised. (Jessa, Personal Communication, May 28, 2024)

I was advised to massage her legs from thighs to feet, including her knees, which worked well. We also buried her legs in the sand during seaside dips, which helped her learn to walk. (Rita, Personal Communication, April 10, 2024)

The responses showed that mothers dedicate significant time to teaching their child with Down Syndrome to walk, using methods like massages and sensory activities (Cetin et al., 2017). Despite concerns about delays, they remain hopeful and committed, reflecting a strong belief in their child's potential to walk (Alghamdi et al., 2021).

Worrying over the future. Highlights mothers' deep anxiety about their child's future, particularly their fear of not being able to care for them later in life, often expressing concerns about who will take responsibility for their child after their passing, with many entrusting their siblings to take on this role.

We will tell her siblings to care for their youngest after we are gone. (Anna, Personal Communication, May 7, 2024)

I sometimes feel depressed thinking about it, wondering what he will do when his father and I are gone. What worries me is who will take care of him then. I asked his older brother to look after him when we were no longer around. (Jessa, Personal Communication, April 9, 2024)

That is all. I have instructed her siblings to treat her as the youngest and care for her. I explain that her development is delayed. (Rita, Personal Communication, April 10, 2024)

The mothers expressed deep worry about their children's future, particularly their well-being after they are gone, with hopes that siblings will take on caregiving

responsibilities (Marshak et al., 2019). However, concerns about siblings' spouses potentially not fully supporting the child add to their anxiety about long-term care and acceptance.

Learning and Growing Experience in Raising a Child with Down Syndrome

The experience reveals that resilience helps mothers overcome challenges by accepting their child's condition, leading to personal growth and fulfillment. As mothers deepen their faith and embrace the reality of their situation, they focus on nurturing their children's independence and preparing them for a future where they can thrive.

Embracing the reality. Raising a child with Down Syndrome brings both challenges and rewards, and mothers feel compelled to embrace their child as no one else will. After accepting their child's condition, they find happiness and fulfillment in family life, focusing on small joys and celebrating their child's accomplishments despite the difficulties.

I already accept it. I am now okay. I have already moved on, unlike the previous years when I was ashamed of her condition. Of course, some people look at her and would sometimes ridicule her condition. (Anna, Personal Communication, May 7, 2024)

There are people who gave me advice that helped me to accept the reality that I do not have control over it. So, I just accept it. I accept it. (Jessa, Personal Communication, May 28, 2024)

Yes, but I already accepted it. I just really cried. (Rita, Personal Communication, April 10, 2024)

The mothers in this study shared their initial struggles with acceptance, which gradually evolved as they embraced their children over time, similar to Kong's (2016) findings on mothers' paths to acceptance. The study of Masanda and Masanda (2018) also revealed that while acceptance was more difficult when the children were younger, stress decreased as the children grew, making the condition feel less overwhelming over time. Although the process was unclear, key moments helped them reassess their lives and ultimately accept their circumstances, focusing on the love and joy their child brings.

Loving the child. Raising a child with Down syndrome can be challenging, but many mothers find comfort in the deep love they share with their children. They cherish the affectionate gestures of their child and value having them at home, especially since their other children are married or working.

Yes, since we would be alone without her. She offers us consolation. Without her presence, we would feel really lonely. (Anna, Personal Communication, April 9, 2024)

After a short period, I will simply walk away, and she will come to me and give me lots of kisses. (Tessa, Personal Communication, April 10, 2024)

I am grateful that she is caring and not mischievous. (Rita, Personal Communication, May 19, 2024)

Participants in this study expressed deep love for their children with Down Syndrome, appreciating the affection and joy they bring, which aligns with Frizell's (2021) finding that parents cherish their children regardless of disabilities. Mitchell et al. (2015) discovered that mothers of children with Down Syndrome exhibited more loving, caring, sensitive, and affirming interactions. Additionally, the children's gestures of love, such as hugs and "I love you" declarations, reinforce the strong emotional bond, as noted by Murphy et al. (2017).

Growing in faith. The belief held by mothers included the notion that prayer might bestow their children better health and development in the future. Mothers find greater serenity in their lives and the lives of their children when they pray. Their comprehension of God's purpose for them and the children they raise is also deepened.

I believe she is a gift from God, so I accepted her and prayed for protection from any severe abnormalities. (Anna, Personal Communication, April 9, 2024)

Eventually, I accepted it, realizing God gave us this child for a reason. It is not in our genes, but He has a purpose for him. (Jessa, Personal Communication, April 9, 2024)

I just pray that everything will be all right. (Rita, Personal Communication, May 19, 2024)

Mothers in this study expressed strong faith, believing their child with Down Syndrome was given to them by God for a purpose, which is consistent with Asgarova's (2019) finding that religion helps mothers cope with their child's diagnosis. Additionally, their constant prayers for their child's development reflect a deepening faith, as noted by Counselman-Carpenter (2017), who found that the birth of a child with special needs often strengthens spiritual beliefs. The study showed that some mother's spirituality and religious

practices helped them find acceptance and provided helpful coping strategies (Gotay & Nishimura, 2024).

Nurturing independence. Mothers of children with Down Syndrome focus on teaching their children life skills to ensure they can live independently when their parents are no longer around. Driven by the desire to provide a better future, they work to equip their child with the necessary skills for survival and a higher quality of life.

Yes, so I can train her. I assigned her to wash our underwear, bra, and handkerchief. (Mylene, Personal Communication, June 18, 2024).

I teach him household chores, like refilling the pitchers and putting them in the fridge. He sweeps and washes dishes, taking on tasks to help him become more independent. (Jessa, Personal Communication, April 9, 2024)

I taught her how to bathe and cook rice, though she used it a lot during practice. I also showed her how to wash clothes, but she is lazy about it and only does her underwear. Sweeping the floor tires her, but it is part of her routine. After I bathe, she asks if I have put on deodorant, which she does, too. (Rita, Personal Communication, May 19, 2024)

The participants in this study focus on nurturing their child's independence by encouraging them to perform tasks like cleaning, cooking, and personal hygiene, aligning with the goals of mothers in Wahyuni et al. (2022) and Noroozi et al. (2024), who emphasize fostering self-reliance in children with Down Syndrome. The study's findings are consistent with Salsabila (2023), who emphasizes that parents play a vital role in nurturing their children's independence by equipping them with the knowledge and skills to complete tasks or activities independently. This approach mirrors the vision of a mother in Nadarajan and Haq's (2019) study, who aims for her child to manage daily activities independently in the future.

Synthesis. This qualitative research examines the emotional journey of mothers raising children with Down Syndrome, focusing on their transition from denial to acceptance and the challenges they face. In the beginning, these mothers experience emotions like denial, sadness, fear, and guilt as they come to terms with their child's disability. The emotional burden of guilt and confusion intensifies, creating a sense of loss and uncertainty.

Mothers of children with Down Syndrome face numerous difficulties, particularly in dealing with misbehavior and stretching patience. Their caregiving responsibilities often lead to exhaustion, yet they remain

committed to providing a loving and nurturing environment. Their dedication to their child's growth and resilience in managing emotional demands highlight their strength in overcoming adversity.

4.0. Conclusion

Mothers raising children with Down Syndrome often face initial denial, struggling to reconcile the reality of their child's condition with their expectations. Acceptance becomes a gradual process, not about giving up, but recognizing and appreciating their child for who they are. This shift allows them to face challenges with clarity, setting aside previous dreams for new, more realistic ones and focusing on their child's potential and needs.

These mothers demonstrate that the love between a mother and child is profound and instinctual, often conveyed through simple acts like hugs and kisses that speak volumes without words. Their love is distinctive, characterized by a deep sense of gratitude for a child who will remain with them, unlike other children who eventually leave home. This devotion is unwavering, with mothers knowing no one else could offer the same level of love. Raising a child with Down Syndrome requires immense resilience, as these mothers face difficulties with strength, transforming obstacles into opportunities for growth and ensuring their child's needs are met with unshakeable commitment. True resilience lies not in avoiding struggles but in finding strength and purpose through them, embracing the journey with love and acceptance.

5.0. Limitations of the Findings

Given the study's limited scope and the small sample of only five mothers who serve as the primary caregivers for children with Down Syndrome, the results are not definitive. This limitation prevents a comprehensive understanding of the diverse experiences within this population in a broader context.

6.0. Practical Value of the Paper

The results of this study play a crucial role in enhancing public awareness among mothers raising children with Down Syndrome. By shedding light on the distinct challenges and experiences these mothers encounter, the research can encourage other mothers within the community to develop initiatives that promote better caregiving and understanding for their children. The practical implications of this study also extend to assisting other mothers who are beginning their journey, enabling them to adapt more effectively to their new circumstances and the challenges they encounter. Additionally, the involvement of family members in supporting these mothers can create a stronger network of assistance, fostering a sense of solidarity. This

heightened awareness can contribute to building a more inclusive environment where mothers feel empowered and receive the necessary support throughout their journey.

7.0. Directions for Future Research

The limited research on the experiences of mothers raising children with Down Syndrome highlights the need for further studies in this area. This study serves as an essential starting point for future research focused on the lived experiences of these mothers. It offers a framework for researchers who are interested in exploring additional challenges faced by mothers or both parents, whether they are raising children with Down Syndrome or other disabilities. By building on the findings of this study, scholars can delve deeper into the emotional landscapes and daily struggles of families, contributing to a broader understanding of their needs.

Looking ahead, future research could enhance the knowledge base by including a wider range of participants, such as fathers and siblings, and examining families in different geographic locations beyond Negros Island. Researchers may also consider employing various methodologies, including quantitative approaches, to gather diverse insights. By expanding the scope and depth of the research, future studies can better address the limitations of the current findings, ultimately enriching public awareness and support for families navigating the complexities of raising children with disabilities.

8.0. Declaration of Conflict of Interest

The researchers declare that no conflicts of interest are associated with this study or its publication and that no financial or personal relationships have influenced its content or findings.

REFERENCES

- Albedeiwi, M. S., Alshammari, S. N., & Aluzeib, A. A. (2022). Emotional burden and copying styles in parents of children with Down Syndrome. *Journal of University Studies for Inclusive Research*, 8(19), 3812-37. <https://usrij.com/wp-content>
- Alghamdi, S., Banakhar, M., Badr, H., & Alsulami, S. (2021). Physical activity among children with down syndrome: maternal perception. *International Journal of Qualitative Studies on Health and Well-Being*, 16(1). <https://doi.org/10.1080/17482631.2021.1932701>
- Asgarova, S. (2019). Mothers' experiences of continuing their pregnancy after prenatally receiving a diagnosis of Down syndrome. <https://dx.doi.org/10.14288/1.0384570>
- Badu, E. (2016). Experiences of parents of children with intellectual disabilities in the Ashanti Region of Ghana. *Journal of Social Inclusion*, 7(1). <https://doi.org/10.36251/josi.100>
- Behrani, P., & Shah, P. (2016). The coping patterns of fathers and mothers of children with disability: A comparative study. *Indian Journal of Health and well-being*, 7(5), 535.
- Brue, K. L., & Brue, S. A. (2016). Experiences and outcomes of a women's leadership development program: A phenomenological investigation. *Journal of Leadership Education*, 15(3). <https://doi.org/10.12806/V15/I3/R2>
- Bull, M. J. (2020). Down syndrome. *New England Journal of Medicine*, 382(24), 2344-2352. <https://doi.org/10.1056/nejmra1706537>
- Cabbeh, K. D., Villafuerte, B. J. A., Ruiz, J. K. O., & Adanza, J. (2015). Lived experiences of parents of children with intellectual disability undergoing pre-vocational education. In *Proceedings of the DLSU Research Congress*, 3(1-15). <https://www.dlsu.edu.ph/wp-content/uploads/pdf>
- Cetin, S. Y., Calik, B. B., Taspinar, F., & Aslan, U. B. (2017). The effect of functional independence level and age's on the quality of life of mother's with Down syndrome children. *Curr Pediatr Res*, 21(4), 652-657. <https://d1wqtxts1xzle7.cloudfront.net/112981754>
- Choi, H., & Van Riper, M. (2016). Maternal perceptions to open-ended questions about life with down syndrome in Korea. *The Qualitative Report*, 21(2), 288. <https://doi.org/10.46743/2160-3715/2016.2221>
- Choi, H., & Van Riper, M. (2017). Adaptation in families of children with down syndrome in East Asian countries: An integrative review. *Journal of Advanced Nursing*, 73(8), 1792-1806. <https://doi.org/10.1111/jan.13235>
- Counselman-Carpenter, E. A. (2017). The presence of posttraumatic growth (PTG) in mothers whose children are born unexpectedly with down syndrome. *Journal of Intellectual & Developmental Disability*, 42(4), 351-363. <https://doi.org/10.3109/13668250.2016.1247207>
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, Quantitative, and Mixed methods approaches (5th Ed.)*. Los Angeles: Sage Publications.
- Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches (4th Ed.)*. Los Angeles: Sage Publications, Inc. ISBN: 978-1-5063-3020-4
- de Castro-Hamoy, L. G., Tumalak, M. A. J. R., Cagayan, M. S. F. S., Sy, P. A., Mira, N. R. C., & Laurino, M. Y. (2022). Attitudes of Filipino parents of children with Down syndrome on noninvasive prenatal testing. *Journal of Community Genetics*, 13(4), 411-425. <https://doi.org/10.1007/s12687-022-00597-w>
- Desimpelaere, E. N., De Clercq, L. E., Soenens, B., Prinzie, P., & De Pauw, S. S. (2024). Parenting a child with down syndrome: A qualitative study on parents' experiences and behaviors from a self-determination theory perspective. *Journal of Pediatric Nursing*, 74, e14-e27. <https://doi.org/10.1016/j.pedn.2023.10.021>
- Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied*

- Statistics, 5(1), 1-4.
<https://doi.org/10.11648/j.ajtas.20160501.11>
- Frizell, C. (2021). Learning disability imagined differently: an evaluation of interviews with parents about discovering that their child has down's syndrome. *Disability & Society*, 36(10), 1574-1593.
<https://doi.org/10.1080/09687599.2020.1816904>
- Gotay, S., & Nishimura, N. (2024). Exploring spirituality and religiosity among mothers of adult children with down syndrome. *International Journal of Developmental Disabilities*, 1-11.
<https://doi.org/10.1080/20473869.2024.2440036>
- Hinggo, J., Naparan, J., & Naparan, G. (2022). Parent's engagement in the learning needs of learners with down syndrome in the new normal education. *International Journal of Theory and Application in Elementary and Secondary School Education*, 4(2).
<https://doi.org/10.31098/ijtaese.v4i2.1041>
- Isa, S. N. I., Ishak, I., Ab Rahman, A., Saat, N. Z. M., Din, N. C., Lubis, S. H., & Ismail, M. F. M. (2016). Health and quality of life among the caregivers of children with disabilities: A review of literature. *Asian journal of psychiatry*, 23, 71-77.
<https://dx.doi.org/doi:10.1016/j.ajp.2016.07.007>
- Kantekin, P. E. (2023). A Qualitative study on the experiences of mothers having a child with down syndrome. <https://hdl.handle.net/11511/105523>
- Karaca, A., & Konuk Şener, D. (2021). Spirituality as a coping method for mothers of children with Developmental disabilities. *International Journal of Developmental Disabilities*, 1-9. <https://doi.org/10.1080/20473869.2019.1603730>
- Kong, H. (2016). Finding peace in life's unexpected journey: The process of grieving and identity transformation for mothers of children with down syndrome. <https://hdl.handle.net/11244/34679>
- Korkow-Moradi, H., Kim, H. J., & Springer, N. P. (2017). Common factors contributing to the adjustment process of mothers of children diagnosed with down syndrome: A qualitative study. *Journal of Family Psychotherapy*, 28(3), 193-204.
<https://doi.org/10.1080/08975353.2017.1291238>
- Machalick, W., Lang, R., & Raulston, T. J. (2015). Training parents of children with intellectual disabilities: Trends, issues, and future directions. *Current Developmental Disorders Reports*, pp. 2, 110-118. <https://doi.org/10.1007/s40474-015-0048-4>
- Maritska, Z., Abdurrahman, F., Pranajaya, B., Parisa, N., Syifa, S., Triwani, T. (2018). Down syndrome: Through the eyes of the parents. *JKK*, (5) 3, 138-142
<https://doi.org/10.32539/JKK.V5I3.6316>
- Marshak, L. E., Lasinsky, E. E., & Williams, C. (2019). Listening to fathers: Personal impacts of raising children with down syndrome. *Journal of Intellectual Disabilities*, 23(3), 310-326.
<https://doi.org/10.1177/1744629518801112>
- Masanda, C. M. P., & Masanda, A. B. (2018). Raising kids with down syndrome: Experiences of selected parents in the Philippines. *International Journal of Science and Research (IJSR)*, 8(2), 2112-2117.
<https://doi.org/10.21275/ART20195774>
- Mazurek, D., & Wyka, J. (2015). Down syndrome-genetic and nutritional aspects of accompanying disorders. *Roczniki Państwowego Zakładu Higieny*, 66(3).
- Mitchell, D. B., Hauser-Cram, P., & Crossman, M. K. (2015). Relationship dimensions of the 'Down syndrome advantage'. *Journal of Intellectual Disability Research*, 59(6), 506-518. <https://doi.org/10.1111/jir.12153>
- Mona, M. B., & Rehab, E. M. (2019). Relationship between parent stress, psychological well-being, and coping strategies among parents with down syndrome children. *Journal of Nursing and Health Science*, 8(6), 1-18. <https://doi.org/10.9790/1959-0806075774>
- Murphy, N., Epstein, A., Leonard, H., Davis, E., Reddihough, D., Whitehouse, A., ... & Downs, J. (2017). Qualitative analysis of parental observations on quality of life in Australian children with Down syndrome. *Journal of Developmental & Behavioral Pediatrics*, 38(2), 161-168.
<https://doi.org/10.1097/DBP.0000000000000385>
- Nadarajan, D., & Haq, F. S. (2019). A study of lived experiences of parents of children with down syndrome on activities of daily living. *Asia Pacific Journal of Business, Humanities and Education*, 4(1), 31-70.
- Nelson Goff, B. S., Monk, J. K., Malone, J., Staats, N., Tanner, A., & Springer, N. P. (2016). Comparing parents of children with down syndrome at different life span stages. *Journal of Marriage and Family*, 78(4), 1131-1148. <https://doi.org/10.1111/jomf.12312>
- Neubauer, B. E., Witkop, C. T., & Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education*, 8, 90-97. <https://doi.org/10.1007/s40037-019-0509-2>
- Noroozi, F., Farrar, Z., Gharibi, T., & Gashmard, R. (2024). Family self-support in managing down syndrome children: A qualitative study. *The Scientific World Journal*, 2024(1), 9992595.
<https://doi.org/10.1155/2024/9992595>
- Patel, L., Wolter-Warmerdam, K., Leifer, N., & Hickey, F. (2018). Behavioral characteristics of individuals with down syndrome. *Journal of Mental Health Research in Intellectual Disabilities*, 11(3), 221-246.
<https://doi.org/10.1080/19315864.2018.1481473>
- Retuerma, S. F. N. (2019). A single case Phenomenological study of a father of a child diagnosed with down syndrome. <https://www.researchgate.net/profile/Syra-Retuerma/publication>
- Salsabila, D. (2023). Communication patterns of parents in building independence of down syndrome children descriptive qualitative study on parental communication patterns in building independence of down syndrome children in Bekasi Regency.
<https://doi.org/10.37010/lit.v5i1.1174>
- Sijeeni, A. S. M. (2016). Understanding the experiences of mothers caring for children with down syndrome in Saudi Arabia .
<https://eprints.qut.edu.au/98052/1/Amal%20Salem%20M>

- Subu, M. A., Lubis, E., Mustikowati, T., Marianna, S., Dewi, A., Dewi, S. H., ... & Al Yateem, N. (2024). Listening to the voices of mothers in Indonesia: Qualitative content analysis of experiences in parenting children with Down Syndrome. *Journal of Pediatric Nursing*. <https://doi.org/10.1016/j.pedn.2024.02.028>
- Tanganim, V., Barrantes, J. K., Villafranca, M., & Cusi, K. (2017). Sa ugoy ng duyan: Mothers raising a child with down syndrome. *JPAIR Multidisciplinary Research*, 30(1), 153-166. <https://doi.org/10.7719/jpair.v30i1.559>
- Wahyuni, S., Purnamasari, A., Said, F. M., & Nambiar, N. (2022). Effectiveness of occupational therapy on improving eating independence in school-age children with down syndrome at Kendari Autism Service Center, Indonesia. *Malaysian Journal of Medicine and Health Sciences*, 187, 104-7. https://medic.upm.edu.my/upload/dokumen/2022012610185421_1182.

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