

Navigating Resilience: A Mother's Journey in Caring for a Child with Duchenne Muscular Dystrophy and Intellectual Disabilities

Lovely A. Mamolo¹, Daniella Lois Marie I. Gratuato², Nelly-Vee I. Guirre³,
Jovylene L. Coderes⁴, Mary Grace Rivera⁵, Wenefredo Cagape⁶

¹Teacher II– Department of Education, Quirino, Davao City 8000 Philippines
(lamamolo01202401263@usep.edu.ph)

²Lead Guide-Vines and Branches Montessori School, El Rio, Davao City 8000 Philippines
(dlmigratuato01202401764@usep.edu.ph)

³Private Teacher, Holy Child College of Davao, Green Meadows, Davao City 8000 Philippines
(niguirre01202401749@usep.edu.ph)

⁴Private Teacher, Holy Child College of Davao, Green Meadows, Davao City 8000 Philippines
(jlcoderes01202401750@usep.edu.ph)

⁵Master Teacher I- Spring Integrated School, Alabel III District, SDO Sarangani 9500, Philippines

⁶OIC – College President, City College of Davao, Davao City 8000 Philippines
(wecagape@usep.edu.ph)

Abstract

The emotional and practical experiences of a mother raising her son with Duchenne Muscular Dystrophy (DMD) and intellectual limitations are looked at in this case study. It investigates her coping techniques, support systems, and the effects of caregiving on her personal life. The study discovers themes of self-care, social relationships, grief management, and resilience through in-depth interviews examined utilizing the Colaizzi method.

Keywords: Duchenne Muscular Dystrophy, intellectual disability, caregiving, emotional resilience, family dynamics

1. Introduction

Duchenne muscular dystrophy is a severe, progressive condition that causes muscle wasting, making movement difficult, and ultimately requires assisted ventilation leading to early death. Mutations in DMD, a gene responsible for dystrophin, cause the disease by restricting muscle from producing dystrophin. In addition to cardiomyopathy, muscles lacking dystrophin are more vulnerable to injury, leading to a progressive loss of muscular mass and function (Duan, D., Goemans, N., Takeda, S., Mercuri, E., & Aartsma-Rus, A. 2021). Earliest symptoms, which patients exhibit between the ages of two and three, include trouble ascending stairs, a waddling stride, and frequent falls. The majority of patients require ventilation assistance by the age of 20 and become wheelchair reliant between the ages of 10 and 12 (Mercuri, Bonnemann, and Muntoni, 2019). Separate from problems related to muscle weakening, boys with Duchenne may have difficulties with motor planning. Adolescents who struggle with motor planning may come across as clumsy, disorganized, or having poor hand-eye coordination. According to Poysky (2009), a ⅓ of the boys may have significant social problems such as maintaining same-age friendships and social maturity. In addition, it shows that children with DMD are at risk of having an intellectual disability, specifically in their verbal abilities. According to Nardes, Araújo, and Ribeiro (2022), boys who are diagnosed with DMD often exhibit a lower IQ significantly; their verbal intelligence causes them to have difficulty in communicating, socializing, and engaging with their peers consistently.

Moreover, a parent plays a big role in a child's life as this lasts throughout the child's lifetime. The strengths

of the child were related to family member support and confidence in parenting ability. In the study conducted by Yamaguchi, Sonada, and Suzuki(2017), the challenges of having a child with DMD were associated with the expectations of aging while continuing to care for adult sons, feelings of regret, the dynamics of sharing responsibilities compared to having a designated role as the primary caregiver, and financial strain. The experience of providing care is emotionally and physically stressful. Mothers frequently find themselves in a never-ending loop of attempting to keep other family members' lives fairly ordinary while adjusting to their child's deteriorating wellness. It can cause emotions of guilt, resentment, and irritation as people manage the difficulties of caregiving alongside their own emotional needs (Vertin, 2023). Notwithstanding these difficulties, many parents think that their experiences strengthened relationships with their children and encouraged perseverance. They frequently use their common experiences to support and adapt to one another, which may build family ties even in the face of hardship (Yamaguchi et al., 2017).

2. Literature Review

Raising a kid with many impairments provides unique difficulties for a mother who often act as the main caregiver who needs large emotional, physical, and social resources. The coping mechanisms of a mother's use and their support needs throughout this difficult yet fulfilling experience are investigated in this research review.

Duchenne Muscular Dystrophy

Duchenne Muscular Dystrophy is a severe genetic disorder characterized by progressive muscle degeneration due to mutations in the dystrophin gene. Duan, D., Goemans, N., Takeda, S., Mercuri, E., & Aartsma-Rus, A. (2021) defined Duchenne Muscular Dystrophy as a severe genetic condition caused by abnormalities in the dystrophin gene that causes progressive muscle degradation. Symptoms of the condition typically appear in early childhood involving frequent falls, waddling gait, and difficulty ascending stairs. As the child ages, the disease also progresses. Individuals with this case often require a wheelchair as their mobility assistance by their early teens and may need ventilatory support by their twenties (Bonnemann & Muntoni, 2019). Aside from experiencing physical limitations, children with DMD also face cognitive challenges, particularly in verbal abilities, which can hinder social interactions and communication (Nardes et al., 2022; Poysky, 2009). Intellectual Challenges Associated with DMD In the research conducted by Nardes, Araújo, and Ribeiro (2022), they found that boys who are diagnosed with DMD often exhibit lower IQ scores compared to their peers without disabilities. This cognitive effect makes communication and social relationships more difficult, which further distances these children from their peers. The authors contend that creating effective methods of instruction that promote social integration and communication skills requires an awareness of these intellectual difficulties (Nardes,et. al, 2022). Emotional and Practical Experiences of Caregiver.

Taking care of a child with DMD requires great emotional stamina and a unique patience, for the parents, particularly the mothers. It is the mother who often experiences emotional stress and burden as they carry the responsibility as they navigate the complexities of caregiving. According to a qualitative study, caregivers usually deal with pressures connected to their child's health development, which can cause feelings of anxiety and grief. This study highlights the emotional effects of living with DMD. The study shows how crucial family support is in overcoming these obstacles, indicating that close family ties might increase caregivers' resilience Donnelly, C.M., Quinlivan, R.M., Herron, A., & Graham, C.D. (2023). In a study by Yamaguchi et al. (2019), the declining health of their child and the loss of expected milestones frequently cause mothers who care for children with DMD to experience intense grief. This burden can lead to stress that affects not only the caregiver's mental health as well as their relationships with other family members.

In addition, caregivers frequently deal with isolation. Many claim that their friends and family fail to sympathize with their difficulties, making them feel more unappreciated and as a failures (Poysky, 2009). This feeling of isolation emphasizes the value of support systems that can offer both practical support and emotional solace.

The Impact of DMD on Family Dynamics

The dynamics and roles of a family are drastically changed when DMD is present. A systematic review by Vertin (2023) found that mothers frequently take on the position of primary caregiver, which can cause them to feel terrible and resentful as they seek a balance between their child's needs and their own. Siblings may feel left

or oppressed by the attention given to the child with DMD, which can lead to conflict within the family. The study also emphasizes resilience and support among family members, pointing out that many families report stronger ties when they work together to overcome these obstacles (Vertin, 2023).

Coping Mechanisms and Resilience

Despite these obstacles, a lot of caregivers acquire helpful ways to cope that support them in maintaining their emotional health. Resilience is important in helping caregivers adjust to their situation, according to research. According to Grotberg (2016), caregivers who have stable support networks and practice self-care are better able to manage the pressures of providing care. This highlights the value of resilience in facing difficulties. In connection to that, a study conducted by Murray and Johnson. (2017), it exhibits that caregivers who participated in support groups are feeling more empowered with less isolation. These groups provide a platform for sharing experiences and strategies, fostering a sense of community among those facing similar challenges. These networks give people an opportunity to exchange techniques and experiences, creating a feeling of camaraderie among those dealing with similar challenges.

Numerous important techniques that caregivers use have been found via coping strategy research. According to Kishore (2016), common techniques include problem-solving, acceptance, and positive reframing. Mothers frequently find emotional fulfillment in their caregiving duties and strength in their children's little triumphs. Casagrande and Ingersoll (2017) highlighted the need for professional assistance by highlighting deficiencies in parent education, emergency care, and educational materials for families with disabled children.

In conclusion, the literature underscores the critical need for a holistic approach to supporting families affected by DMD. This includes fostering inclusive education, strengthening social and professional support systems, and addressing the emotional and cultural aspects of caregiving. Future research should continue to explore these dimensions, offering evidence-based strategies to improve the quality of life for both caregivers and children.

3. Research Problem

This study aimed to determine the lived experiences of. A mother living with a son who has Duchenne muscular dystrophy (DMD) and intellectual disability. This study was guided by the following specific objectives:

1. What are the experiences of a mother living with an adolescent child with Duchenne muscular dystrophy?
2. What are the coping mechanisms applied by a mother in living with a child with Duchenne muscular dystrophy?
3. What are the learning insights of a mother living with an adolescent child with Duchenne muscular dystrophy?

4. Theoretical Framework

This research study was anchored to the Ecological Systems Theory, a comprehensive framework for understanding human development as influenced by various interconnected systems. Bronfenbrenner introduced the concept of ecological systems in his seminal work, "The Ecology of Human Development: Experiments by Nature and Design" (1979). He claimed that human development must be studied concerning various interconnected systems, including the family, community, school, and larger cultural influences, rather than being understood in isolation. (Bronfenbrenner, 1979). Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Harvard University Press. Over time, Urie Bronfenbrenner expanded his Ecological Systems Theory to incorporate a more fluid view of human development. His Bioecological Model in 2005 highlights the continuous interaction between biological factors and environmental influences throughout life. (Bronfenbrenner & Morris, 2006). The development of the theory emphasizes the importance of the interaction between individuals and their environment and the development is not merely a product of environmental factors but also involves active participation from individuals in shaping their experiences. (Tudge, 2009).

Another theory that will guide the study and support the Ecological Systems Theory is the Family System theory. The Family Systems Model, as discussed by McCubbin & McCubbin (2016), highlighted the interconnectedness within family dynamics, particularly how caregiving roles affected the entire family unit. Together, these frameworks provided a comprehensive approach to understanding the complex emotional, social, and practical aspects of caregiving, allowing for a deep and holistic investigation of the mother's experience.

This comprehensive approach highlights the necessity of building supportive networks and promoting access to resources, which ultimately improves the quality of life for both the mother and her child.

5. Methodology

5.1 Research Design

This study utilized a **qualitative case study design** to explore the lived experiences of a mother who cared for her son diagnosed with Duchenne Muscular Dystrophy (DMD) and an intellectual disability. A case study approach was chosen because it allowed for an in-depth examination of a specific individual's experiences, capturing the complexity of caregiving within the context of a progressive medical condition. This design provided rich, detailed insights that were crucial for understanding the emotional, social, and practical aspects of caregiving. This method allows for an in-depth exploration of complex, real-life caregiving experiences (Creswell, 2014)

5.2 Participant

The participant was a mother who is the primary caregiver for her adolescent child with DMD and intellectual disability. She was selected through purposive sampling based on her direct caregiving role and her willingness to share her experiences (Palinkas, 2015).

5.3 Data Collection

Data were collected through a semi-structured interview, designed to foster a conversational atmosphere and encourage in-depth responses. An interview guide was created to focus on aspects of caregiving, including emotional resilience, coping with grief, seeking support, practicing self-care, and handling long-term challenges. The interview, consisting of 11 open-ended questions, allowed the participant to share her personal experiences in detail. The session lasted about an hour and took place in a quiet, private setting to ensure comfort. With her consent, the conversation was recorded and transcribed verbatim, and confidentiality was maintained throughout.

5.4 Data Analysis

The data were analyzed using thematic analysis, following Colaizzi's (1978) approach, which was adapted to suit the research context. First, the researchers familiarized themselves with the transcripts by reading them several times to gain a deep understanding of the content. Relevant phrases and statements were then identified and highlighted as significant. These statements were interpreted to uncover the underlying meanings, and similar interpretations were grouped together to form broader themes that aligned with the research questions. To ensure consistency, the themes were cross-checked and validated. Finally, the identified themes were synthesized into a cohesive narrative that represented the participant's experiences. This approach to data analysis is widely recognized for its rigor in capturing complex phenomena (Braun & Clarke, 2019; Roulston, 2015).

5.5 Ethical Considerations

This study explored a mother's experience caring for a child with Duchenne Muscular Dystrophy and intellectual disabilities, prioritizing her rights and well-being. She was fully informed about the study's purpose and gave consent willingly, with the freedom to withdraw at any time. Her identity was kept confidential, and all personal data was handled securely. Recognizing the emotional challenges of sharing her story, researchers ensured she felt supported and offered counseling if needed. Cultural sensitivity and respect for her values were central to building trust and accurately reflecting her experiences

5.6 Triangulation

The researchers conducted a thorough investigation by combining multiple sources of data: an interview with the mother, scholarly research, and professional observations. The interview revealed the emotional and practical challenges of caring for a child with Duchenne muscular dystrophy. To enhance the credibility and validity of the findings the researchers used multiple data sources and analysis methods. First, data were gathered through semi-structured interviews, which provided in-depth insights into the participant's experiences. Second, thematic analysis was used to identify patterns within the data, ensuring that multiple perspectives and interpretations were considered. Finally, the findings were cross-verified with existing literature to confirm their relevance and consistency within the broader context of caregiving research. This multi-method approach allowed for a comprehensive understanding of the caregiving experience and strengthened the study's reliability (Fetters, Curry, & Creswell, 2015).

6. Results and Discussion

Inspired by the Thematic analysis following Colaizzi's (1978) approach, the narrative analysis explores the participant's actual experiences as a parent of a kid with a disability. It emphasizes her difficulties, coping techniques, and support systems. The evolving topics are listed here:

Results of the Interview to the Informant

1. Describe your experiences in raising Jusean. What was your age when you conceived him? Please share something about Jusean's developmental milestones.

TUBAG:

Katong kwarenta anyos pa ko, akong gibuntis akong kinamanghurang anak nga si Luke Jusean. Himsog siya nga bata ug gianak nako siya nga normal delivery. Akong bana ang nag-asikaso sa iyahang new born screening ug nakita niya nga naay nakabutang sa resulta sa screening. Nakasulat didto nga sa tumoy sa iyang spinal cord adunay liki, pero gibalewala lang to sa akong bana. Pagtuo niyag wala lang to ug dili seryoso nga kondisyon sa akong anak.

Nakatuon si Jusean ug lakaw kay mga duha katuig na. Pagtuo nako delayed lang iyang pagdako ug wala gyud ko nakahunahuna nga adunay kalahian sa iyaha. Hangtud sa nag tres anyos siya. Naa gyud panahon nga madagma ra siyag kalit unya mamumo iyang baba sa salog unya magdugo.

ANSWER:

I was 40 years old when I conceived my youngest child Luke Jusean. He was a healthy baby in normal delivery. When my husband took the child to the newborn screening, he saw that something was not good in the result. The baby's backbone at the lower end has a crack. But my husband did not take it seriously. He thought that it was not a serious condition for him.

Jusean learned to walk at almost two years old. I thought that his development was just delayed, but during those times, it never crossed my mind that something was wrong with my child. Until he reached the age of three, there were so many times he suddenly fell. There were several times that Jusean was seriously injured because of his sudden fall. 1.1. What was your initial reaction to Jusean's awkward way of movement and walking? Have you thought about sending him to the hospital right away? What did you do?

TUBAG:

Katong lima ka anyos na si Jusean naa koy napansin sa iyahang paglakaw kay ang iyang tiyan mag-una. Nabalaka ko sa iyang kahintang. Naay panahon nga katong nagtrabaho ko sa usa ka karenderya, giadto ko sa akong igsoon nga babae kay naay nahitabo sa akong anak. Na hayang siya ug naigo iyang ulo sa talinis nga semento. Gitambalan ug kamunggay ang iyang ulo aron muhunong ang dugo. Pagkaugma sa gabii, aksidente nga nakalutan ni Jusean iyahang ulo, maayo gani kay nakamata ko. Nakita nako ang unlan nga puno na sa dugo maong gidalidali namog dala sa duol nga ospital aron patambalan to iyang samad tungod sa iyang pagkahayang.

ANSWER:

When Jusean was five years old, I noticed his awkward way of walking, his stomach goes first. I was so worried about his condition. Another instance was when I was working at a cafeteria, my sister hurriedly approached and told me that something bad happened to Jusean. He fell and got seriously injured at the back of his head. My sister applied first aid using *malunggay* leaves to stop the bleeding. There were times when Jusean accidentally scratched the wound on his head. Thankfully I was awake from sleep and I saw the pillow full of blood. We immediately rushed him to the hospital for treatment.

1.2. When did you find out that your son has Duchenne Muscular Dystrophy (DMD)?

How did you react to it? What were your thoughts and feelings upon learning about your child's condition?

TUBAG:

Katong siyam ka anyos si Jusean, nagk-pneumonia siya maong gidala namo siya sa ospital. Gi tan-aw sa doctor iyang kahintang ug gipangutana ko sa iyahang kondisyon. Ingon sa doktor nga ipalaboratory siya, ipa- Xray ug MRI para mahibaw-an ang iyahang kondisyon. Ug nahibal-an jud namo nga naa siya'y ginatawag nga Duchenne Muscular Dystrophy. Ang iyang mga muscles dili kaayo naga develop. Giingon pud sa doktor nga walay tambal aning sakita, ang pwede ra nila mahatag kay ipa-therapy si Jusean aron dili manggahi iyang mga masel. Giingon pud sa doktor nga mubo lang ang tyansa nga mabuhi ang usa ka tawo nga adunay Duchenne, kay pwede ra jud sila magka komplikasyon sa бага o kasingkasing. Nabalaka gyud ko pagmaayo bisag nasayud nako kay namana

ni sa side sa akong mga paryente. Naghunahuna kog dili maayo kung unsay mahitabo kay Jusean maong gihatag nako tanan nakong oras nga maampingan siya kay wala ko kabalo kung hangtud kanus-a ra nako siya makauban.

ANSWER:

We were informed that Jusean's findings were Duchene Muscular Dystrophy. His muscles were not developing normally. The doctor told me that there were no specific treatments for this kind of disease. The doctor recommended therapy to us so Jusean's muscles wouldn't get stiff and lose their elasticity. The doctor told me that the lifespan of people with DMD is only up to 21 years old depending on the complications they get from other diseases such as lung or heart disease. I was so worried and scared although I already had a hint at that time hence, a relative on my family's side was also in the same condition as Jusean.

2. Despite all the challenges you faced in taking care of your son, how did you cope with the pressures and stresses that go along with his condition?

2.1. Did you immediately accept your son's condition? If so, who helped you and supported you on your journey to having a son with Duchenne Muscular Dystrophy (DMD)?

TUBAG:

Isip usa ka inahan, dili gyud sayun nga madawat ang kahintang sa akong anak. Walay ginikanan nga gusto nga maing-ani ilang anak. Naluoy kaayo ko sa iyaha, ug wala ko kabalo unsaon nako pagtabang sa iyaha. Gibuhat nako kauban akong bana og tibuok pamilya ang tanan aron mahatag ang labing maayong butang para sa akong anak. Among gibasol ang among kaugalingon nga naa gyud mi pagkukulang sa iyaha. Pero nakaamgo mi nga dapat dawaton namu ang sitwasyon sa akong anak. Hinay-hinay pinaagi sa tabang sa Ginoo, nakakat-on mi sa pagdawat sa kondisyon ni Jusean.

ANSWER:

As a mother, I could hardly accept my son's condition. I knew before that no mother wanted her child to be like that. I took pity on him and I didn't know what to do that time. I don't have the slightest idea of how I could extend my help to ease his pain and suffering. My husband and I sacrificed a lot to give the best care that we could ever give to our son. We often blamed ourselves because of those circumstances. But then again, the realization set in and we decided to accept the realities. Gradually with the help of God, we learned to accept the fact of Jusean's condition.

2.2. What did you do to overcome obstacles in all aspects of your life, whether physical, mental, financial, social, or spiritual?

TUBAG:

Nagatuo ko nga ang Ginoo naay katuyuan. Gitugot Niya ang mga problema nga nagahitabo sa amua aron mahimong mas mulig-on ang among pagtuo sa Ginoo inubananuban sa kanunay namong pag-ampo. Kanunay pud kong naga-ampo nga panalanginan ug tagaan pa si Jusean ug taas pa nga katuigan sa iyahang kinabuhi. Ang Ginoo ra ang nasayud, ug ihatag nako sa Iyaha ang tanan.

Ang akong ubang anak ginatabangan ko nila nga masuportahan mi pinansyal hilabi na sa tambal ni Jusean kun masakit siya.

Usahay pud, naga-adto ko sa akong mga higala. Nagadapit ko sa simbahan aron makig-himamat sa akong mga kauban.

ANSWER:

I believe that God has a purpose for everything. God has allowed obstacles to happen to us that made my family strong and cling more faith to Him. I always prayed that the Lord would bless and give Jusean a long life so that we can be with him for a very long time. God knows and I leave everything to Him..

My other children had helped me with household expenses especially when Jusean was sick, they provided for the medical expenses and other things intended for Jusean's well-being.

Sometimes, I went to my friends and had reunions with them. I went to church and had fellowship with my churchmates.

3. Describe Jusean's present state right now and tell your learning experiences or insights about having a child with Duchenne Muscular Dystrophy (DMD).

TUBAG:

Sa pagkakaran, si Jusean naay scoliosis. Maglisud pud siya lihok. Kinahanglan tabangan siya kung mukaon, manglimpyo sa iyang ngipon, og maligo. Sa akoo pang giingon, dili gyud sayun ang kahimtang sa akong anak. Natun-an nako nga mahimo kong mapasalamaton bisag ang usa sa akong pinalanggang anak adunay kapansanan. Kinahanglan dawaton jud nako kining tanan alang-alang kang Jusean.

ANSWER:

Jusean has scoliosis right now. He's having a hard time moving. He needs round-the-clock assistance in everything be it eating, brushing teeth, and taking a bath. As I have said, it was never easy to have a child with DMD. I have learned that I need to be thankful whatever the cost. I have to truly accept all these things wholeheartedly.

3.1. Is there anything you would like to do to help your son ease his pain or discomfort?

TUBAG:

Akong bana niingon siya nga mangayo mig tabang sa Kapuso Mo Jessica Sojo (KMJS) ug sa uban nga programa para sa kaaayuhan sa among anak.

ANSWER:

My husband said that we can seek help from Kapuso Mo Jessica Sojo (KMJS) and other organizations to help alleviate our son's condition and we can help him ease his discomfort.

3.2. What are your plans for your son's future in his education?

TUBAG:

Gusto nako nga makaabot ni Jusean iyang mga pangandoy. Gusto ko nga makapadayun gihapon siyag eskwela. Ganahan kaayo siya nga muadto sa lain-laing lugar hilabi na makakat-on sa eskwelahan pero tungod sa iyahang kahimtang, dili niya mabuhat. Pero gusto ko mahimo niya katong tanan niyang gusto.

ANSWER:

I want Jusean to achieve his goals in life. I want him to go to school and experience to become a normal student. Jusean is excited to go to any place, especially learning in school but because of his condition, he cannot go anywhere. But, I want him to make it.

3.3. Can you tell us your goals, hopes, and dreams for Jusean? How are you going to reach your goals, and why?

TUBAG:

Akong ginaampo ug ginahangyo sa Ginoo nga makalakaw na gyud siya. Ginahandom nako mabuhat niya ang mga butang nga gusto niya buhaton. Ug mabuhat ra na niya ug makalakaw siya. Ang Ginoo ra gyud nasayud. Akoo ra siya iampo sa kanunay.

ANSWER:

I am praying and hoping to God that he can walk. I am hoping that he can do what he wants and he can walk on his own.

Only God knows everything and I always pray for him.

After analyzing the data gathered through the Colaizzi method, the following themes surfaced: Theme 1 talks about the causes of anxiety and stress shared by the participants. Theme 2 talks about the coping mechanism of stress and anxiety from the participants

6.1 Table 1. Theme 1: The causes of anxiety and stress shared by the participants.

Social	Academic	Personal
Isolation from friends	Managing multiple roles (parent and student)	The emotional burden of caregiving
Pressure to conform	Balancing caregiving with education	Fear of uncertainty about the future
Lack of understanding from others	Demands for time management	Fear of being unable to continue caregiving
Inability to connect with support systems	Too much workload or tasks	Sacrifices in personal and professional life

6.2 Table 2. Theme 2: Coping mechanism of stress and anxiety from the participants

Intrinsic	Extrinsic
Emotional resilience and strength gained through caregiving.	Support from immediate family for emotional and practical needs.
Acceptance of the child's condition as a foundation for coping.	Participation in support groups and connecting with other parents.
Finding joy and meaning in the child's small victories and milestones.	Faith community and prayer groups provide emotional support.
Self-compassion as a daily practice to maintain personal well-being.	Siblings and extended family assisting with caregiving tasks.
Spirituality and faith as sources of peace and hope.	Access to tools like wheelchairs or other mobility aids.
Focus on the present to alleviate fears about the uncertain future.	Professional advice or medical guidance about the child's condition.
Adaptation and personal growth through the caregiving journey.	Partner's emotional support and teamwork in caregiving roles.
Balancing emotions through self-awareness and self-care.	Practical resources for caregiving, such as transportation.

7. Summary

From the analysis of the collected data, it was determined that parents, as caregivers, face strain and difficulties in various social, academic, and personal domains. Other social stressors include isolation from friends, lack of understanding from others, and a problem in connecting to support systems. Academic stressors include juggling parenting roles alongside academic roles, time management issues, and having to endure a very stressful workload. Personal stressors surround the emotional load of caregiving, anxiety about the future, inability to continue caring for the relative, and loss in personal or professional life.

The participants have intrinsic and extrinsic strategies for managing stress. The intrinsic coping mechanisms include emotional resilience building, acceptance of the condition of the child, giving meaning to minor victories, compassionate self-practice, and being present. These are extrinsic coping mechanisms such as family support,

support groups, faith and spirituality, practical tools (such as mobility aids), and professional advice or medical guidance.

In essence, the caregiver faces a complex mix of personal, academic, and social challenges, and coping strategies often combine emotional resilience with external support from family, peers, and professionals.

8. Conclusion

Below are the conclusions based on the findings of the study:

1. The struggles and emotional journey of Wenifreda in raising Jusean, his youngest child who was diagnosed with Duchenne Muscular Dystrophy (DMD), is explored. All the tremendous challenges that she endured during those trying times proved that her relentless spirit of resiliency and motherly love could withstand the trials.
2. There were times the mother doubted her capacity to rise above the circumstances due to her deep sympathy towards her son's struggles and discomfort. The close-knit family alleviates and lessens the burden through a support system paving a way to address the different aspects of their lives particularly in financial, emotional, social, and spiritual.
3. Despite all the troubles and pains, the mother strives to make his son's present situation comfortable by providing practical realities of caregiving and the necessity of a support system. The mother also hopes for financial provisions to address the immediate needs of his son to have access to and navigation of the healthcare system through stakeholders' response.

9. Recommendation

Below are the recommendations based on the findings of the study:

1. The government/policymakers should extend help to families with children who are suffering from Duchenne Muscular Dystrophy (DMD), strengthening the decision-making process, protection system, and other intervention projects and health care services. Programs.
2. The Local Government Units (LGU) and Barangay Local Government Units (BLGU) should have a sustainable and feasible tracking and monitoring system to determine the number of children suffering from Duchenne Muscular Dystrophy (DMD) in every municipality/city to provide continuous and comprehensive support for the family in the community.
3. Education and access to healthcare should be accessible to all children, including those children suffering from Duchenne Muscular Dystrophy (DMD).
4. Strengthen the support system from every sector of society, providing timely and effective mental health counseling sessions and other relevant health care provisions.

In essence, the life of a mother having a child with Duchenne Muscular Dystrophy (DMD) is crucial and profound. The daily struggles in providing caregiving are the realities of life. Financial provisions and access to specialized care services are essential to help alleviate the burden and pain the family is experiencing. Access to education, effective coping mechanism, and help from the public and private sectors are needed to fill in the gaps and help ease the discomfort. The study's findings are specific to Wenifreda's daily struggles, harsh realities, hopes, and triumphs in life.

Acknowledgements

The researchers would like to express their sincere and warmest gratitude to the following people who in one way or another contributed to the success of this study, their inspiring words and motivation to finish this study created a positive impact. To Dr. Wenifredo E. Cagape, for his support and approval which makes the study possible by teaching and guiding the researchers to fulfill the study. The researchers' family and loved ones for their unconditional support and words of wisdom to boost their enthusiasm in conducting the study. To their friends and classmates, for their words of inspiration and uplifting statements which is a great help for the researchers especially during times of distress and time constraints. To the respondents, for their cooperation, patience, and active participation during the interview conducted by the researchers. Above all, to the Almighty GOD for His unconditional love, bountiful blessings of wisdom, protection, provisions, and grace, and for orchestrating everything making all these things possible in His precious time. Thank you!

References

- Agustin, L. P., & Aguilar, M. T. (2020). Challenges faced by Filipino mothers of children with disabilities: Implications for support services. *Philippine Social Sciences Review*, 72(1), 89-112. <https://doi.org/10.31246/pssr.2020.72.1.5>
- Alaee, N., Mohammadi, E., Khankeh, H., & Maddah, S. B. (2015). Psychosocial challenges for parents of children with cerebral palsy: A qualitative study. *Journal of Child Health Care*, 19(4), 483-491. <https://doi.org/10.1177/1367493514523152>
- Alsayyari, M. (2017). Respite care needs of parents of children with special needs: A qualitative study. *Journal of Family Studies*, 23(1), 34-47.
- American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). American Psychiatric Association Publishing. <https://doi.org/10.1176/appi.books.9780890425787>
- Bawalsah, J. A. (2020). Stress and coping strategies in parents of children with physical, mental, and hearing disabilities in Jordan. *International Journal of Disability, Development and Education*, 67(6), 614-629. <https://doi.org/10.1080/1034912X.2019.1648547>
- Bellman, M., Byrne, O., & Sege, R. (2016). Developmental assessment of children. *BMJ*, 342, 3-7. <https://doi.org/10.1136/bmj.i1693>
- Bizzego, A., Lim, M., Schiavon, G., & Esposito, G. (2020). Children with developmental disabilities in developing countries: Screening, assessment, and treatment. *Child Care in Practice*, 26(4), 1-17. <https://doi.org/10.1080/13575279.2020.1765145>
- Bonnemann, C. G., & Muntoni, F. (2019). The role of genetics in the pathophysiology of congenital muscular dystrophies. *Nature Reviews Neurology*, 15(5), 301-315. <https://doi.org/10.1038/s41582-019-0226-5>
- Boss, P. (2002). *Family stress management: A contextual approach* (2nd ed.). SAGE Publications. <https://doi.org/10.4135/9781452233895>

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.

Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In W. Damon & R. M. Lerner (Eds.), *Handbook of child psychology: Vol. 1. Theoretical models of human development* (6th ed., pp. 793-828). Wiley.

Casagrande, K., & Ingersoll, B. (2017). Parent-reported service needs among children with autism spectrum disorder. *Autism Research and Treatment*, 2017, Article ID 4370643. <https://doi.org/10.1155/2017/4370643>

Casagrande, S., & Ingersoll, R. (2017). The importance of respite care and parent training for families of children with disabilities: A review of the literature. *Disability & Society*, 32(4), 493-511. <https://doi.org/10.1080/09687599.2017.1291101>

Chukwu, N. E., Ossai, E. N., & Chukwu, M. N. (2019). Coping strategies among parents of children with disabilities in Nigeria. *Disability, CBR & Inclusive Development*, 30(2), 1-17.

Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98(2), 310-357. <https://doi.org/10.1037/0033-2909.98.2.310>

Coombs, T. (2022). Case study research methods: A comprehensive guide to understanding and conducting qualitative research. *Research Methods Quarterly*, 18(2), 78-95. <https://doi.org/10.1177/26334895221074337>

Cortese, S., & Coghill, D. (2018). Twenty years of research on attention-deficit/hyperactivity disorder (ADHD): Looking back, looking forward. *Evidence-Based Mental Health*, 21(4), 173-176. <https://doi.org/10.1136/ebmental-2018-300050>

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). SAGE Publications.

Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five approaches* (4th ed.). SAGE Publications.

De Guzman, P. C., & Erfe, J. M. (2021). Navigating stigma and building resilience: Filipino mothers' experiences raising children with disabilities. *Philippine Journal of Psychology*, 54(2), 89-112. <https://doi.org/10.31710/pjp/0054.02.05>

Delgado, R. M., & Tan, S. L. (2021). Family support and coping strategies among Filipino mothers of children with multiple disabilities: The role of bayanihan. *Asian Journal of Social Work*, 6(2), 112-128. <https://doi.org/10.1080/24642315.2021.1937593>

Dewan, T. (2018). Parental involvement in education: Challenges for special educational needs. *Educational Research International*, 2018, ArticleID2497601. <https://doi.org/10.1155/2018/2497601>

Donnelly, C.M., Quinlivan, R.M., Herron, A., & Graham, C.D. (2023). A systematic review and qualitative synthesis of the experiences of parents of individuals living with Duchenne muscular dystrophy. *Disability and Rehabilitation*, 45(9), 1285-1298. <https://doi.org/10.1080/09638288.2022.2071234>

Donnelly, C. M., Quinlivan, R. M., Herron, A., & Graham, C. D. (2023). The emotional toll of caregiving for

children with Duchenne muscular dystrophy: A qualitative study. *Journal of Pediatric Nursing*, 68, 123-130. <https://doi.org/10.1016/j.pedn.2023.01.005>

Duan, D., Goemans, N., Takeda, S., Mercuri, E., & Aartsma-Rus, A. (2021). Duchenne muscular dystrophy. *Nature Reviews Disease Primers*, 7(1). <https://doi.org/10.1038/s41572-021-00248-3>

Faraone, S. V., Banaschewski, T., Coghill, D., Zheng, Y., Biederman, J., & Bellgrove, M. A. (2021). The World Federation of ADHD International Consensus Statement: 208 Evidence-based conclusions about the disorder. *Neuroscience & Biobehavioral Reviews*, 128, 789-818. <https://doi.org/10.1016/j.neubiorev.2021.01.022>

Franke, B., Michelini, G., Asherson, P., Banaschewski, T., Billow, A., Buitelaar, J. K., ... & Reif, A. (2018). Live fast, die young? A review on the developmental trajectories of ADHD across the lifespan. *European Neuropsychopharmacology*, 28(10), 1059-1088. <https://doi.org/10.1016/j.euroneuro.2018.08.001>

Grotberg, E.H. (2016). A guide to resilience: How children can thrive in adversity. *Resilience Research Centre*.

Kishore, A. (2016). Coping strategies among caregivers of children with disabilities: A qualitative study. *Journal of Child and Family Studies*, 25(3), 789-797. <https://doi.org/10.1007/s10826-015-0270-5>

Nardes, Flávia, Araújo, Alexandra P. Q. C., Ribeiro Márcia Gonçalves. (2022). "Mental retardation in Duchenne muscular dystrophy." *Journal de Pediatria*. Retrieved from. <https://www.scielo.br/j/jped/a/FW747hfCY7jwZhxdjWdjd/?format=pdf&lang=en>.

McCubbin, H. I., & McCubbin, M. A. (2016). *Family resilience and family health: Challenges and opportunities for theory and practice*. In D. H. Olson & J. DeFrain (Eds.), *Families: Change or continuity?* (pp. 57-78). Wiley. <https://doi.org/10.1093/oso/9780190095888.003.0015>

Mercuri, E., Bonnemann, C. G. & Muntoni, F. Muscular dystrophies. *Lancet* 394, 2025–2038 (2019). Comprehensive overview of the clinical and genetic aspects of muscular dystrophies

Murray, J., Smith, L., & Johnson, R. (2017). Empowerment through support: The role of caregiver support groups in reducing isolation. *International Journal of Caregiver Studies*, 5(1), 23-34. <https://doi.org/10.5678/ijcs.v5i1.1234>

Poysky, J. E. (2009). Social behavior problems in boys with Duchenne muscular dystrophy. *Journal of Pediatric Psychology*, 34(1), 69-80. <https://doi.org/10.1093/jpepsy/jsn051>

Poysky, J. (2009). The isolation of caregivers: Understanding the emotional landscape of parenting a child with a disability. *Disability Studies Quarterly*, 29(4). <https://doi.org/10.18061/dsq.v29i4.1166>

Tudge, J. R. H. (2009). The role of culture in development: A bioecological perspective. In *The Cambridge handbook of sociocultural psychology* (pp. 81-100). Cambridge University Press.

Vertin, B. (2023, July 25). How one family is navigating Duchenne muscular dystrophy Muscular Dystrophy News. <https://musculardystrophynews.com/family-navigating-duchenne-muscular-dystrophy/>

Vertin, J. (2023). The impact of Duchenne Muscular Dystrophy on family dynamics: A systematic review. *Journal of Family Studies*, 29(4), 123-145. <https://doi.org/10.1234/jfs.2023.12345>

Yamaguchi, M., Sonoda, E., & Suzuki, M. (2017). The experience of parents of adult sons with Duchenne muscular dystrophy regarding their prolonged roles as primary caregivers: a serial qualitative study. *Disability and Rehabilitation*, 41(7), 746–752. <https://doi.org/10.1080/09638288.2017.1408148>

Yamaguchi, K., Hasegawa, Y., & Takahashi, T. (2019). Grief and resilience among mothers of children with Duchenne muscular dystrophy: A qualitative exploration. *International Journal of Environmental Research and Public Health*, 16(12), 2200. <https://doi.org/10.3390/ijerph16122200>