Indonesian Journal of Community and Special Needs Education 4(2) (2024) 111-124

Indonesian Journal of Community and Special Needs Education

Journal homepage: http://ejournal.upi.edu/index.php/IJCSNE/

The Financial Burden of Disability: Narratives of Filipino Families with Low Socioeconomic Status Raising Children with Disabilities

Olivia Cassandra P. Bondad, Inero V. Ancho, Rhea R. Bailey, Melissa P. Ferido, Daisy V. Pelegrina*

University of the Philippines Los Baños, College 4031, the Philippine

*Correspondence: E-mail: ivancho@up.edu.ph

ABSTRACT

Raising a child with a disability (CWD) often incurs additional costs for any family. However, when a family is situated within a low socioeconomic status, the financial burden can be even more pronounced. This prompted a phenomenological study to delve deeper into the lived experiences of such families, focusing on how disability exacerbates the family's finances. Utilizing semi-structured interviews, participants were able to narrate the unique challenges and barriers they faced in raising CWD within the context of limited financial resources. The emerging themes revealed multifaceted challenges, including caregiving tasks, parental stress, and hurtful remarks. Concerns about the future of the children and the caregiving responsibilities being placed on mothers were also highlighted. Additionally, families often face trade-offs between meeting the needs of other family members and those of the CWD due to financial constraints. Access to healthcare presents further barriers, particularly for low-income families. While some existing support programs offer relief, there is a notable absence of specific support for CWD families. The Head, meanwhile, also shared his plans for the person with the disability community.

ARTICLE INFO

Article History:
Submitted/Received 26 Mar 2024
First Revised 06 Jun 2024
Accepted 12 Aug 2024
First Available online 13 Aug 2024
Publication Date 01 Sep 2024

Keyword:
Barriers,
Children with disabilities,
Low socioeconomic status,
Programs.

1. INTRODUCTION

Raising a child is costly and can be overwhelming for any family. However, for a family raising a child with a disability (CWD), additional financial challenges may emerge as their needs are wide-ranging and determined by distinct features of the disability, the unique characteristics of each family member, and the overall uniqueness of the situation of the family they belong to (Vanegas & Abdelrahim, 2016). They must adjust to a lifestyle that caters to the child's needs who is disadvantaged in parts of their body, physically or mentally. Severe disablement from infancy may usually result in prolonged dependency. Hence, time and energy demand from parents would be continuous, and as a result, their capacity to earn may inevitably suffer, which can implicate the child's situation, considering financial demand and extra expenditures increase as children with special needs grow up.

Ghosh & Parish (2013) established that despite income status, families raising CWDs experience significant unmet needs in contrast with families without CWDs. Raising a child with special needs is three times more difficult and expensive than children without disabilities. For low-income families, forgoing necessary goods and services for their CWD due to inadequate financial resources may hinder and restrict them from maximizing their participation in society.

As families with low socioeconomic status face a double burden of raising CWDs, it is high time to uncover their personal stories and inquire whether the local government support they receive is adequate and appropriate. Thus, this study aims to answer these crucial questions: What are the general experiences of families with low socioeconomic status in raising a child with a disability? Particularly in the financial aspect, what are the difficulties encountered when raising a child with a disability? What are the available programs or services received from the local government to address these difficulties?

Aligned with the United Nations Sustainable Development Group to promote inclusivity and reducing inequality (UNSDG, nd), this study aims to fill existing gaps in disability research, particularly in developing countries like the Philippines, where such studies are insufficient and outdated (Nasir et al., 2019). By shedding light on the lived realities of CWDs and their families in a city in South Luzon, the study also intends to raise awareness and influence policy implementation related to better supporting this vulnerable sector of society.

The study encompasses three primary objectives: first, to narrate the experiences faced by low-income families in raising CWDs; second, to analyze how the disability of a child contributes to the financial burden in the family; and third, to identify available social programs and services specific for PWDs, children with disabilities, or families of PWDs offered by the city in Southern Luzon based from the narratives of low-income families raising children with disability. This research aims to deepen the understanding of how low socioeconomic status interacts with disabilities, potentially contributing to developing theories related to family dynamics and resource management. Through qualitative inquiry, it seeks to uncover nuanced challenges within these families, providing valuable data to inform future research methodologies and interventions. The study's findings are expected to benefit various stakeholders, including families, educators, healthcare professionals, policy-makers and implementers, and researchers, contributing to a more inclusive environment for families raising CWDs in a city in Southern Luzon.

2. METHODS

A phenomenological qualitative approach was employed to delve deeply into the unique lived experiences of families with CWDs in a city in Southern Luzon. Calamba City. This approach prioritized understanding the participants' subjective perceptions by facilitating in-depth, semi-structured interviews, making a pre-hypothesis unnecessary.

2.1. Participants of the Study

The ten participants were purposively selected based on recommendations from PWD volunteers of the community. Criteria for selecting participants were as follows: belonging to a family with a monthly income of no more than Php 22 000, being a registered resident of a city in Southern Luzon, and raising a child possessing a PWD card. In one case where the primary caregiver was unavailable, the secondary caregiver was considered the participant on their behalf. Additionally, the PDAO Head of the city was interviewed.

The participants were diverse. Eight are mothers, mostly housewives. In one case, a grandmother is the primary caregiver, and another is an uncle, a secondary caregiver. Their ages ranged from 27 and 62 years. One participant has multiple children with disabilities, and another has a grandparent-type family. All participants' monthly family income does not exceed Php 15000. Orthopedic and intellectual disabilities are most common among the children. Moreover, their ages range from four to 32 years. The largest family size is seven, while most have a family size of five.

2.2. Data Collection Procedure

Letters were sent to the leaders seeking permission to conduct the study and assistance in identifying participants. Moreover, participants signed informed consent forms before the interviews, which lasted at least 40 minutes and were conducted face-to-face in their residences. These were recorded via a smartphone's audio recorder to ensure accuracy, and questions were posed in Filipino for better understanding and narrative sharing.

2.3. Data Analysis

Interpretative Phenomenological Approach (IPA) is particularly utilized for studying complex subjects like disability. The approach involves analyzing participants' narratives directly rather than preexisting notions and theories (Smith & Osborn, 2015). By systematically identifying significant statements, coding them, and deriving themes following Creswell's recommended procedure, we captured the essence of participants' experiences. Verbatim quotations were provided to illustrate the participants' experiences, addressing the 'what' and 'how' of their lived phenomena. This method facilitated a deep exploration of data, revealing its phenomenological significance and impact on the participants' lives.

2.4. Ethical Considerations

We obtained permission from the community and organization leaders for data gathering. Participants were briefed on the study's purpose and nature before interviews, through an informed consent form process. Interviews were conducted sensitively, ensuring emotional well-being by maintaining distance from CWDs during questioning. Confidentiality was maintained, with no sharing of voice recordings or photos without explicit consent from the participants.

3. RESULTS AND DISCUSSION

Having a CWD has revealed multifaceted experiences for these families, encompassing a diverse range of challenges and adaptations unique to their circumstances. Such experiences necessitate adjustments and patience, as they navigate a family dynamic that deviates from the 'norm'. Moreover, families, specifically caregivers, often must exhibit patience as they grapple with understanding the needs of a child with a specific and severe type of disability, while also witnessing discrimination the CWDs endure. Furthermore, family members, specifically the parents, must make adjustments in their role within the child's life. These experiences are significantly dependent on factors such as socioeconomic status, the presence of a support system, and the type and severity of the children's disabilities (**Table 1**).

Table 1. Emerging themes describing the experiences faced by the family.

Themes	Description	Subthemes
1. Lived realities, living in uncertainties	This refers to the day-to-day experiences, challenges, and uncertainties faced by families and CWDs.	1.1. Depending on caregivers 1.2. Navigating sibling dynamics 1.3. Persisting discrimination 1.4. Bearing parental and caregiving stress 1.5. Lingering worries for the child's future
2. Usual family roles, unique challenges	This refers to how traditional family dynamics intersect with the unique circumstances brought by raising CWD.	2.1. Mothers as primary caregivers and fathers as the primary providers 2.2. Loss of freedom and control 2.3. Prioritizing childcare over work

3.1. Lived Realities, Living in Uncertainties

Families are the most intimately involved in the lives of children with disabilities. Understanding the unique challenges these families face is crucial for developing support systems that ensure their well-being and foster an inclusive society. Exploring this theme revealed several subthemes: daily caregiving, sibling dynamics, experiences of discrimination, the stresses of parenting and caregiving, and concerns about the future of CWDs.

Extensive assistance is provided by caregivers of children with visual and orthopedic disabilities, such as feeding, bathing, and constant supervision, due to the children's limited ability to perform essential tasks independently. Primary caregivers are often unable to leave their homes to ensure the safety and immediate needs of children are met. They also adjust their daily activities around the children's schedules. For instance, children's sleeping time is utilized to complete household chores.

I feed her and bathe her. Because of her condition, I need to take care of her. I can not leave her on her own. (Participant 2)

I carry him and feed him. My attention is mainly on him—carrying, feeding, and taking him out for a stroll. Even though he has a wheelchair, he does not want to use it. Thus, I really can not do anything; I'm just at home. (Participant 3)

In the morning, I take advantage of her still being asleep to clean whatever needs cleaning and wash the dishes. I also cook rice. Thus, I can feed her when she wakes up. Sometimes, we only go out in front of our house, but I have to keep a close eye on her because she tends to disappear if no one is watching her. (Participant 7)

Conversely, caregivers of children with less severe disabilities report routines comparable to those of other children, indicating that caregiving responsibilities vary significantly based on the severity of the child's disability.

It is similar to other kids. He just eats after he wakes up, then plays. He comes back here when he feels fatigued. When he is called to prepare for school, he gets ready. The only thing we need to be cautious of is ensuring he takes his medicine and does not go far without a chaperone. (Participant 6)

The presence of a disability in one sibling significantly shifts sibling dynamics, impacting how other children engage and interact with their sibling with a disability. Often, the assignment of responsibilities limits the other child to interact with friends, or engage in their interests, causing them to feel annoyed and jealous towards the sibling with disability (Kao et al., 2012). Participant 7 reported that her eldest child feels jealous of the sibling with a disability due to perceived preferential treatment towards the sibling with a disability.

Sometimes she tells me that her sibling always gets understanding, while she gets scolded over the slightest mistake. She also feels like we do not treat her as our child. (Participant 7)

On the contrary, Participants 1, 3, and 5 observed no signs of jealousy among their children. In some cases, families with other children aside from their CWD express concerns over balancing the needs of all children to avoid jealousy among siblings. With this, constant reassurance and discussions help siblings understand and support their disabled sibling, leading to better cooperation within the family, as evidenced by Participant 4's experience.

I treat them equally, even though I give her more attention. I just ask for their understanding and assure them that I do not favor anyone over the other. (Participant 1)
She is the defender of her siblings. I love all my children equally; I do not have any favorites just because two of them have disabilities. It does not have to be that way. I see them all equally. However, I explained to her, 'You see the baby's condition, you see his state.' which is why I dedicate more time to him. (Participant 3)
There is no jealousy. She is the one who takes care of him. We always remind her to look after him since his situation is different. (Participant 4)
There is no jealousy among them because I always tell her older sister and my youngest that I treat them all the same. I do not favor anyone among them; I simply ask them to understand their brother, to understand him...when it comes to anything- utilities or food- they're all treated equally. (Participant 5)

Verbal bullying, often involving teasing about their disability, is a common form of discrimination experienced by CWDs. Participants recounted instances where even adults insulted these children. Responses to such situations varied: some parents reacted assertively through physical actions or rebuttals, while others took a more passive approach by ignoring the remarks. Participant 3 encourages her daughter to make others realize their privilege of being 'normal', promoting an assertive yet compassionate response.

I was reported to the barangay because I beat her up severely. (Participant 1)
He is teased by his playmates. But I tell him to shrug it off. (Participant 8)
I tell my daughter to tell them they're lucky because they're complete… (Participant 3)

Raising a CWD requires parents to cope with many changing demands, leading to heightened stress (Isa et al., 2016). Most participants reported high-stress levels, particularly those with children with intellectual disabilities (specifically Participants 5 and 7), due to difficulties in understanding their non-verbal children's needs. Participant 5, a mother of a child with intellectual disability, also expressed experiencing depression, primary caregivers of such children, often mothers, encounter significant challenges to their mental well-being.

It is overwhelming. Sometimes I just end up crying, I do not know what to do anymore. I often feel so depressed, asking myself, 'What did I do? Why is my child like this? Why this, why that?' It is so depressing- mentally, and emotionally- I feel like it is my fault because he turned out this way. (Participant 5)
People like them are hard to understand, especially when they're having tantrums, or when they want something and we struggle to comprehend their needs right away. (Participant 7)

Some participants cited worry over their child's delicate condition and being restricted from doing some activities to avoid triggering their illnesses as a major stress, aligning with Vanegas and Abdelrahim's (2016) findings on the impact of severe child conditions on parental stress.

It is so stressful. Extremely stressful, especially during times when he is constantly having epilepsy attacks. (Participant 6)
When I am unable to attend to him, my headaches. It is also the same when he gets sick. When he cries and has an asthma attack, his stomach swells out then returns to normal afterwards. (Participant 8)

Financial stress related to disability-related costs was significant to Participants 3 and 9 (McCann *et al*., 2015).

The stress comes from the household expenses and the needs of my children for the week. (Participant 3)
My concern is that I want him to start studying, but the teacher said we need to get his eyes checked first. We have to buy glasses before he can begin studying. However, they're too expensive, very expensive. (Participant 9)

This unique stress, encompassing emotional and financial aspects, is consistent with Mount and Dillon (2014), who noted feelings of incompetence and the need to constantly accommodate a child's needs as stress contributors. Conversely, Participant 4 did not consider caregiving stressful, preferring it over raising a 'normal child,' supporting Mbatha & Mokwena's (2023) suggestion that stress levels should not be generalized among families of CWDs.

Having a special child is better than having a normal one because he listens to me. I can ask him to do something, and he does it instantly... But his older sister? If you ask her to do something, she'll cry and run away. I get more stressed over the normal one than the special one. I have never been stressed over my special child. (Participant 4)

Parents of CWDs, as well as those in parental roles, commonly share concerns about their children's future independence. This worry spans across various types of disabilities. Additionally, participants express anxiety regarding the future caregiving arrangements for the CWDs, highlighting these significant familial concerns.

We fear what will happen if we're not around anymore. How will he sustain his lifestyle once we're gone? There are things he can not do compared to normal people. (Participant 6)

3.2. Usual Family Roles, Unique Challenges

Family roles can be influenced by disability, shaping how responsibilities are distributed within the family unit. In families with CWDs, roles often adapt to accommodate their needs. This dynamic reveals three subthemes: mothers as the primary caregivers and fathers as the primary providers, loss of freedom or control, and prioritizing childcare over work.

Caregiving responsibilities for CWDs are often assigned to women, particularly mothers, due to societal expectations of their nurturing capabilities. This traditional gender role reinforces the prioritization of family and caregiving duties over personal aspirations and career pursuits. Some participants acknowledged not discussing family roles with their partners, reflecting a presumption that caregiving for children with disabilities is solely a mother's responsibility while earning income is seen as the father's domain.

...I know I am in charge of taking care of the kids, and he is in charge of work. He is a man, so I am the one responsible for attending to our child. (Participant 2)

Participants 3, 5, and 7 described instances of compromise and cooperation in caregiving roles within their families, despite initial discussions. These adjustments were influenced by health issues and external factors like the pandemic. However, these adjustments towards role reversal only lasted for a short while, as mothers were perceived to possess greater knowledge and capability in managing their children's needs effectively.

My partner and I practice give and take. If he does not have work, I work. I offer laundry services, and I also sell whatever I can, even fish. If he is unable to work, he is responsible at the house and vice versa… My husband is quite slim. He is unlike other husbands who can work in any environment... (Participant 3)
We discussed it. During the pandemic, he lost his job and I worked to support the family. I told him, 'You stay at home, and I will work. Currently, he is the one working because he does not know how to handle our son... sometimes our son has a seizure while I am away, and my husband does not know how to respond and manage the situation. Unlike me, I have been taking care of him since he was only months old. When his hair strands on his body stand, like he is getting goosebumps, it is a sign he is about to have a seizure. (Participant 5)
Sometimes I tell him I can work if it gets tiring. Any job will do as long as it is honest work. However, he prefers working over being a stay-at-home dad because he finds it difficult to care for our daughter. I am the only one who is patient with our daughter. There is no one else who is willing to put in as much effort as I am. (Participant 7)

Four participants expressed frustration over their lack of agency and desire to contribute financially to their families, hindered by their roles as primary caregivers for CWDs. This sentiment reflects a common experience among mothers, who often assume caregiving responsibilities, limiting their ability to engage in income-generating activities (Ghazawy et al., 2020; Oti-Boadi, 2017).

…If only things were normal, I would be able to work and contribute. We would not be struggling like this- almost all our earnings go to bills, and nothing is left. Perhaps if things were normal, we could save up a bit because we both have jobs. (Participant 5)

Motherhood profoundly alters women's priorities, shifting their focus towards unwavering dedication to their child's wellbeing. Across different cases, mothers prioritize caregiving responsibilities over other pursuits, reflecting their deep commitment to meeting their children's needs. Some have chosen to stop their business operations, resign from work, postpone thoughts of finding a job, or balance caregiving with sideline jobs. These mothers express a desire to work but are constrained by their children's needs, reflecting the economic challenges and indirect costs of caregiving reported by Ghazawy et al. (2020).

I tried a stay-out job before. We have service. However, I resigned within three months because I felt uncomfortable being away from home. Whenever I receive updates like, 'Mom, she had an episode earlier,' I become fearful, so I decided to stop working. (Participant 1)
... I used to run a small barbecue grilling business, but I stopped because I felt like I was neglecting them. Ariella would skip meals when I was busy. She often ends up having breakfast or lunch late, as she is still asleep when I am already busy taking care of things. (Participant 2)
Sometimes I consider working, but I also think about my child. Yes, my siblings are there to take care of him, but it is different when he is under his parents' care... because he is quite mischievous. Even my father gave up...] (Participant 4)
This year I started PC. Personal Collection. I sell products from Personal Collection. I only sell my products when someone is watching over my child… (Participant 7)

Analyzing the financial challenges faced by families raising CWDs revealed two primary themes: the complexities of needs prioritizations, and accessing essential services, such as healthcare. These encompass subthemes highlighting the intricacies of managing finances, navigating unique expenses, and barriers to healthcare access, including financial constraints, inaccessible healthcare facilities, and disparities in healthcare quality. Additionally, the nature of the child's disability significantly impacts these challenges (**Table 2**).

Table 2. Financial challenges and issues encountered by the family

Themes	Description	Subthemes
1. Resource allocation	This refers to the complexities of needs prioritization within families raising CWDs	1.1. Challenges in managing family's financial resources 1.2. Expenses associated with disability
2. Inability to access healthcare	This refers to the various factors influencing the healthcare access of CWDs.	2.1. Lack of financial resources 2.2. Inaccessible healthcare facilities 2.3. Public vs. private: healthcare quality 2.4. Nature of the child's disability

3.3. Resource Allocation

Ranking needs according to their significance and identifying those that are truly essential to purchase or provide is something experienced by families with insufficient financial resources. This can lead to delayed or absent care for crucial disability-related interventions (Ghosh & Parish, 2013), inadvertently neglecting necessary items and potentially impacting the child's development progress or exacerbating their condition.

Adequate financial resources enable families to meet necessities, but low socioeconomic status can lead to direct trade-offs. Participants 6 and 8 exemplify differing prioritization strategies: one prioritizes medicine for the child with a disability, while the other prioritizes food and school allowances.

We prioritize his medicine because missing his medication is not an option, and then we address our own needs afterward. (Participant 6).
With the amount my spouse earns, we can not prioritize his maintenance [colostomy bag] as part of our immediate necessities. Our budget covers only essential food items like rice and viand, as well as our eldest's allowance. We purchase his maintenance supplies in subsequent weeks. (Participant 8)

The dilemma between prioritization of necessities over other essential medical items or vice versa underscores the challenges of managing both everyday expenses and the additional costs associated with disability care. These challenges stem from a combination of factors, including differences in income level, income stability, and the prescribed frequency of providing for disability-related needs (Palmer et al., 2015). Additionally, these may also intersect with family size given that having a larger family typically leads to overall higher expenses. Based on the sociodemographic profile of participants, Participant 8 displays the highest number of family members, totalling 7.

Participants 2 and 10 manage their finances by working within their means, considering factors such as family size, income, and their children's disabilities. This adaptive approach showcases their resourcefulness in handling their financial limitations, within their specific constraints.

…Honestly, our income is insufficient, but we make do with what we have. We do not have any other choice but to make it work. (Participant 2)
It is enough. We just stretch the money to make ends meet… For example, I use the first 15 days' salary to pay for electricity and buy food essentials like rice and viand. Then, with the next 15 days' salary, I budget for water, WiFi, rice, and viand. (Participant 10)

Despite a minimum wage of Php 520 per day in Calabarzon, some families earn less and face financial instability, leading them to borrow money to cover basic needs. This borrowing, often from informal sources like relatives and friends, can trap families in a cycle of debt.

Debt is something we sometimes manage to pay off, and sometimes we can't; that's just how it goes. Right now, we have borrowed money to cover the electricity bill. Meanwhile, the billing period for water has not yet started. (Participant 4)
He works at a construction site and usually comes home later. However, when it rains, he does not have any work. Honestly, his salary does not suffice. When his salary comes, we pay our debts, but then we end up borrowing again, and this cycle continues. (Participant 5)

Meanwhile, Participant 3, with two children with disabilities, engages in sideline work like offering her laundry services to supplement the household income, while others may not allocate specific funds for their children's needs due to financial constraints.

I need to take on some laundry when the budget falls short. I take on any work I can earn from, but

only if I can do it from home. I keep an eye on him while doing the laundry because I have to. I do not have a choice… Monthly, I set aside Php 1500 for his needs. My monthly budget for his diapers is 36 pieces. One diaper costs Php 12. Usually, he uses two in a day. (Participant 3)

Participants discussed the additional costs of raising CWDs, highlighting how expenses vary depending on the type and severity of the condition (Mitra et al., 2017). For example, Participant 5's son requires therapy that is unaffordable due to biweekly therapy sessions and transportation costs, leading the participant to use social media for therapy guidance. Parent-implemented interventions, effective for intellectual disabilities, are hindered by financial constraints, impeding the child's progress (Lequia *et al*., 2013).

The doctor recommended therapy for his tongue. While searching on my cellphone, I found that such therapies are expensive, costing around Php 2000 or more per session, plus transportation costs. With two sessions required and additional transportation expenses, we can not afford it because even before we receive my husband's salary, we already have nothing left… I know I can not afford it so I did the 'therapy' myself. I tried to pull his tongue, but he cried. I do not know how to do it. I do not even know if I can call it therapy. (Participant 5)

Participants 4 and 5 noted that children with intellectual disabilities often cannot comprehend financial limitations, leading to frustration when their desires cannot be met.

Yes, it is tough. He can not afford to go hungry. (Participant 4)
There are times when he wants something and you just can not refuse. When he asks for it, I feel frustrated with myself because it is such a simple thing, and yet, why can not I give it to my child? Like that. What he is asking for is not even expensive. There are times when he wants this or that, which I can not provide because it is costly. (Participant 5)

3.4. Inability to Access Healthcare

Healthcare for children with disabilities often requires specialized care, including continuous check-ups, therapy, assistive devices, and medications. However, access to this essential care is frequently hindered by various barriers. Theme 2 of the narrative explores these barriers, which include financial constraints, inaccessible healthcare facilities, poor healthcare quality, and the children's specific medical conditions. The interviews highlighted these intersecting factors as significant challenges to obtaining necessary healthcare for children with disabilities.

Finances play a crucial role in accessing adequate healthcare for children with disabilities (CWDs), enabling families to cover diverse medical expenses. However, most participants cited a lack of financial resources as the main barrier to receiving necessary healthcare. Participants 5 and 9 mentioned that, despite past medical consultations, they can no longer afford the costly recommended treatments and interventions.

It was suggested that he undergo therapy. I want him to receive therapy, but my question is, how can I manage to have him undergo therapy if I can not even afford the transportation fare? (Participant 5)

Now, what he needs are eyeglasses. But we do not have the means to buy them. When we had a check-up at CMC, the eyeglasses were priced at Php 29,000. We have already spent a lot; the check-up alone costs over Php 2,000, and that's in addition to the amount we need to pay for the glasses, which we can not afford. (Participant 9)

Six participants highlighted geographical barriers, particularly distance and transportation, as significant obstacles to accessing healthcare for their children with disabilities (CWDs). They noted that healthcare facilities are far from their homes, adding transportation expenses and requiring time off work, which strains their finances further. Participant 5 mentioned better access to hospitals when they lived in Metro Manila.

We used to have check-ups in Parañaque when we lived there, but after we relocated, transportation became an issue because it is far away. Now, we just have them wherever it is possible. (Participant 5)

The concentration of healthcare workers in urban areas exacerbates disparities across regions, like NCR and BARMM (Collado,2019), with outmigration worsening local shortages (Alibudbud, 2023). Participants 6 and 8 described seeking care wherever available or managing their child's health needs themselves due to the unavailability of specialized care.

Participant 2, prioritizes the quality of healthcare when choosing a hospital and prefers a private hospital for her daughter's ophthalmology consultations. This preference intersects with financial issues, as private healthcare often involves higher costs for consultations and procedures. Despite the financial strain, families opt for private healthcare due to perceived advantages such as immediate attention, better equipment, a wider range of specialists, and reduced waiting times, as identified by Vergunst et al. (2015). However, the affordability of private healthcare remains a significant concern for low-income families.

In public hospitals, it is the same – we still have to wait in line. And we're unsure if the check-up she'll undergo will be comprehensive. We want her to receive thorough attention and diagnosis, which is why I'm keen on having her undergo a check-up with a specialist… heard that the consultation costs around Php 1500 now. Before, it was only Php 800, excluding the cost of medicines. We felt like we were not getting enough attention in public hospitals. Thus, we opted to take her to a private one. (Participant 2)

The child's medical condition itself can impede access to healthcare, requiring specific treatments only after meeting certain developmental criteria. This can delay interventions, creating significant barriers. There were instances when an epilepsy treatment was halted due to the incompletion of an initial step, leading to reliance on costly long-term medication. This study underscores that such conditions necessitate careful consideration before administering treatments, compounded by financial implications that may prevent caregivers from working for an extended period and leading to lost earnings.

I only had my son checked up once. The doctor told me he needed to be of the right age before I brought him back for consultation. (Participant 3)

As far as I know, they attempted an MRI once, but it failed because the child needed sedation, which could not be administered, leaving everyone feeling sorry for the child. As a result, they decided not to proceed with the MRI. Currently, they have not been able to take him to the hospital due to these circumstances. Right now, their focus is solely on his maintenance. (Participant 6).

4. CONCLUSION

Raising CWD presents unique challenges for families, particularly those with low socioeconomic status, as it adds financial burden and emotional stress. These families must manage additional caregiving tasks, face discrimination, and worry about the future independence of CWDs. Financial strain often forces parents, typically mothers, to prioritize caregiving over careers. The costs associated with raising CWDs vary based on the type and severity of their conditions, influencing how families manage their finances according to their specific circumstances and family size. Accessibility to healthcare is also a common issue. Therefore, addressing these challenges requires systemic intervention, with local governments playing a crucial role, and involving families in developing new initiatives is essential and valuable for effective support.

Future researchers should consider using the Ecological Systems Theory by Urie Bronfenbrenner as an additional theoretical foundation to better understand the role of subsystems in special needs provision. Longitudinal studies can track changes in financial resources over time, evaluate the effectiveness of programs, and examine the long-term impacts of disability on families' finances. Creating parent-support groups can reduce parental stress by providing a community for shared experiences and advocacy, raising disability awareness, and disseminating valuable information about resources and existing available programs. Additionally, training parents in managing intellectual disabilities and providing early childhood education at the barangay level is recommended.

5. AUTHORS' NOTE

The authors declare that there is no conflict of interest regarding the publication of this article. Authors confirmed that the paper was free of plagiarism.

6. REFERENCES

Alibudbud, R. (2023). Addressing the burnout and shortage of nurses in the Philippines. *SAGE Open Nursing*, *9*, 23779608231195737.

Collado, Z. C. (2019). Challenges in public health facilities and services: evidence from a geographically isolated and disadvantaged area in the Philippines. *Journal of Global Health Reports*, *3*, e2019059.

Ghazawy, E. R., Mohammed, E. S., Mahfouz, E. M., and Abdelrehim, M. G. (2020). Determinants of caregiver burden of persons with disabilities in a rural district in Egypt. *BMC Public Health*, *20*, 1-10.

Ghosh, S., and Parish, S. (2013). Prevalence and economic well-being of families raising multiple children with disabilities. *Children and Youth Services Review*, *35*(9), 1431-1439.

Lequia, J., Machalicek, W., and Lyons, G. (2013). Parent education intervention results in decreased challenging behavior and improved task engagement for students with disabilities during academic tasks. *Behavioral Interventions*, *28*(4), 322-343.

Machalicek, W., and Lyons, G. (2013). Parent education intervention results in decreased challenging behavior and improved task engagement for students with disabil- ities during academic tasks. Behavioral Interventions, 28, 322–343.

Mbatha, N. L., and Mokwena, K. E. (2023). Parental stress in raising a child with developmental disabilities in a rural community in South Africa. *International Journal of Environmental Research and Public Health*, *20*(5), 3969.

McCann, D., Bull, R., and Winzenberg, T. (2015). Sleep deprivation in parents caring for children with complex needs at home: a mixed methods systematic review. *Journal of Family Nursing*, *21*(1), 86-118.

Mitra, S., Palmer, M., Kim, H., Mont, D., and Groce, N. (2017). Extra costs of living with a disability: A review and agenda for research. *Disability and Health Journal*, *10*(4), 475-484.

Nasir, M. N. A., Efendi, A. N. A. E., and Hussain, R. B. M. (2019). Assessing the Situation of Disability Research in the Philippines: An Exploratory Study. *e-BANGI*, *16*(8), 1-11.

Oti-Boadi, M. (2017). Exploring the lived experiences of mothers of children with intellectual disability in Ghana. *Sage Open*, *7*(4), 2158244017745578.

Palmer, M., Groce, N., Mont, D., Nguyen, O. H., and Mitra, S. (2015). The economic lives of people with disabilities in Vietnam. *PloS One*, *10*(7), e0133623.

Smith, J. A., and Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain*, *9*(1), 41-42.

Vanegas, S. B., and Abdelrahim, R. (2016). Characterizing the systems of support for families of children with disabilities: A review of the literature. *Journal of Family Social Work*, *19*(4), 286-327.