

Lived Experiences of Mothers with Children Suffering from Down Syndrome at Mbarara Regional Referral Hospital, Uganda

Kyomukama Rhudovic¹, Josephine Gbobbo², Olayinka A. Onasoga²

¹Africa Centre of Excellence in Public Health and Toxicological Research of the University of Port Harcourt, Port Harcourt, Nigeria

²Department of Nursing, University of Ilorin, Ilorin, Nigeria

Email: kyomukamarhudovic@gmail.com

How to cite this paper: Rhudovic, K., Gbobbo, J., & Onasoga, O. A. (2026). Lived Experiences of Mothers with Children Suffering from Down Syndrome at Mbarara Regional Referral Hospital, Uganda. *Psychology*, 17, 903-916.
<https://doi.org/10.4236/psych.2026.179045>

Received: July 25, 2025

Accepted: September 27, 2026

Published: September 30, 2026

Copyright © 2026 by author(s) and Scientific Research Publishing Inc.
This work is licensed under the Creative Commons Attribution International License (CC BY 4.0).
<http://creativecommons.org/licenses/by/4.0/>



Open Access

Abstract

Globally, an estimated 1.6 to 5.4 million individuals live with Down Syndrome, with each mother's journey shaped by unique factors like culture, socioeconomic status, and resource access. This study explored the lived experiences of mothers with children diagnosed with Down Syndrome (DS) at Mbarara Regional Referral Hospital in Uganda, a facility serving over four million people in Western Uganda and neighboring regions. A cross-sectional phenomenological design was employed, which utilized a semi-structured, face-to-face interview guide conducted in March 2025 in English and Runyankole to capture the personal narratives of 15 mothers, selected via convenience sampling until data saturation was achieved. Data were collected from the hospital's paediatric neurological clinic and analyzed thematically, revealing five key themes: emotional experiences, social support and relationships, healthcare experiences, coping strategies and resilience, and hopes and fears for the future. Mothers described initial shock and grief that evolved into acceptance, bolstered by faith and family, yet tempered by persistent stigma and limited healthcare resources. Challenges included long wait times, inadequate equipment, and poor provider communication, while resilience emerged through spiritual beliefs and practical caregiving routines. Hopes centered on the children's health and inclusion, contrasted by fears of future care and societal rejection. This study highlighted the interplay of cultural resilience and systemic gaps, and offered novel insights into Ugandan mothers' realities compared to Western contexts. Findings underscored the need for enhanced healthcare training, formal support networks, and stigma reduction initiatives to support these mothers and their children effectively.

Keywords

Chromosome, Down Syndrome, Emotions, Intellectual Disability, Lived Experiences

1. Introduction

Down Syndrome (DS) is a genetic condition caused by the presence of an extra copy of chromosome 21, resulting in a total of three copies instead of the usual two (a condition known as trisomy 21) (Antonarakis et al., 2020). Individuals with Down Syndrome often exhibit flat facial features, eyes that slant upward, shorter necks, a prominent single crease in the palms, shorter height, and reduced muscle tone (Bamson & Mandah, 2024). In the late 1800s, Langford Down released a precise account of an individual affected by this condition. The onset of DS typically takes place during the prenatal stage, and it can be detected before birth using prenatal screening methods such as ultrasounds and maternal serum tests (He et al., 2021). A conclusive diagnosis is generally established through diagnostic procedures like amniocentesis or chorionic villus sampling (CVS), which examine fetal cells for chromosomal anomalies (Kats et al., 2024).

Around 1.6 to 5.4 million people worldwide have Down Syndrome (Kats et al., 2024). It is one of the most common genetic conditions, with a high prenatal mortality rate of 70% - 80% and affecting about 1 in every 800 to 1000 live births. DS is often associated with cognitive challenges and growth delays, making it one of the main reasons for these types of issues in children (Alrayes et al., 2024). More than half of babies born with DS also have congenital heart defects, and they are more likely to face thyroid issues, hearing problems, diabetes, obesity, leukemia, gastrointestinal issues, and sleep apnea. In developed countries, the help and resources available for families with children who have Down Syndrome have improved significantly over the past few decades (Noroozi et al., 2024). Better healthcare, early intervention, inclusive schools, and community support have improved life for these children and their families, leading to an average life expectancy of about 60 years (Tolouei Rakhshan et al., 2024). In the U.S., around 6000 babies are born with Down Syndrome each year, which means about one in 700 newborns is affected. In Europe, Down Syndrome is the most common aneuploidy, with about 10.1 live births for every 10,000 (Steffensen et al., 2024).

In developing countries, Down Syndrome can be particularly difficult to manage, mostly because many people are not aware of it and medical resources are lacking (Noroozi et al., 2024). In Eastern China, it is the most common birth defect, occurring in about 30.7% of all births (Wang et al., 2022). In India, 1 out of every 830 children is affected, which means around 23,000 to 29,000 children are born each year with it, and only about 44% survive. Each mother's story is unique and can change significantly based on factors such as culture, finances, access to care, and the individual needs of the child. The situation surrounding Down Syn-

drome in these areas has been inconsistent, shaped by various social and economic factors, slow technological advancements, and often, minimal support from the government (Ko et al., 2021). Understanding these personal experiences provides a better understanding of the challenges families face and their resilience in coping with these difficulties.

In sub-Saharan Africa, people with disabilities experience stigma and discrimination manifested through negative perceptions from family and community members, derogatory names, and misconceptions about the origins of disabilities. This leads to diminished self-worth, feelings of depression, and the social isolation of individuals with disabilities (Gboyega et al., 2024). The exact prevalence of Down Syndrome (DS) in African populations is not well established due to inaccuracies in many studies related to its incidence and prevalence. This inaccuracy arises when significant factors like socioeconomic, cultural, educational, genetic, racial, and environmental aspects of various African populations are overlooked, thereby compromising the reliability of the information (Sifir, 2024). In Ethiopia, the arrival of a child with Down Syndrome brings significant physical and emotional impacts on parents, particularly mothers, such as difficulty in accepting the birth of a child with a disability, changes in their lifestyle, dynamics within family relationships, concerns about the child's uncertain future, access to essential services, and acceptance by society and the community (Sifir, 2024).

In Nigeria, as in many other low- and middle-income countries, children with Down syndrome and their families face unique challenges related to healthcare, education, social stigma, and access to support services. The physical and mental obstacles can hinder parents and families from coming to terms with these circumstances, often resulting in a sense of shock, particularly for mothers. Additionally, this situation leads to significant mood swings, as many families find themselves needing extra income to cover the costs of additional therapy (Suza et al., 2020). Mothers often experience greater fatigue compared to fathers, as they devote more time to caring for the child.

In Uganda, Down syndrome is linked to adverse perceptions within the community, challenges in accessing therapy, a higher occurrence of unstable physical and mental health in mothers, and rejection from both community members and some family relatives. Additionally, there is a shortage of facilities that cater specifically to individuals with disabilities (Peters et al., 2024). The condition induces emotions such as sadness, anger, difficulty in accepting the situation, and anxiety, which create challenges for mothers who are living with and caring for the children (Peters et al., 2024). Consequently, it was essential to thoroughly investigate the experiences of mothers who have children with Down syndrome. Mbarara Regional Referral Hospital serves as a critical healthcare provider in the southwestern region of Uganda, catering to a diverse population with varied socio-economic backgrounds and healthcare needs (Peters et al., 2024). Although Down syndrome greatly affects families, there is a lack of local studies that specifically examine the experiences of mothers. Existing literature predominantly reflects

perspectives from high-income countries, which may not fully capture the socio-cultural contexts and challenges faced by mothers in Uganda. Gaining insight into the experiences of mothers who have children with Down syndrome at Mbarara Regional Referral Hospital was crucial.

Purpose of the study

The purpose of this study was to explore the lived experiences of mothers with children suffering from Down syndrome at Mbarara Regional Referral Hospital, Uganda.

Objectives

- 1) To explore the experiences of mothers with children suffering from Down syndrome at Mbarara Regional Referral Hospital, Uganda.
- 2) To explore the social and cultural-related experiences of mothers with children suffering from Down syndrome at Mbarara Regional Referral Hospital, Uganda.

2. Methodology

This study employed a cross-sectional phenomenological descriptive approach, utilizing qualitative data collection methods to investigate the experiences of mothers with children diagnosed with Down syndrome. This study targeted mothers of children who were diagnosed with Down syndrome seeking medical care at Mbarara Regional Referral Hospital. The sample size in the qualitative study was determined by saturation attained from a homogeneous population. Therefore, the sample size depended on information saturation during interviews, which was obtained after interviewing 15 participants. The research utilized a convenience sampling method to choose participants for the study. This enabled the researcher to choose participants who were accessible and contributed to the achievement of study goals. A semi-structured interview guide containing open-ended questions was created to facilitate the discussions. Among the questions were prompts related to mothers' emotions concerning raising a child with Down syndrome, their daily routines, and the challenges encountered while caring for the affected children, among other topics. In March 2025, in-depth interviews were carried out in person to gather information from participants. The data were collected in both English and Runyankore languages. It was recorded using notebooks and audio recordings. The researcher contacted suitable participants via the managers of the hospital or ward and provided an informed consent form to fill out. This form contained comprehensive details regarding the study's procedures. After obtaining consent, each participant was interviewed individually by the researcher, who is proficient in both English and the Runyankore language. The interviews were conducted in both English and the local dialect. Taking place in a private room within the Hospital, the interviews lasted approximately 50 minutes. Each session was audio-recorded with separate consent, and a notebook was used by a trained research assistant to note specific aspects of the interviews. Following the interviews, the recordings were transferred to a computer and securely backed

up with a password. The researcher then transcribed all recordings verbatim to maintain the fidelity of both content and intention. Experienced translators fluent in both Runyankore and English were tasked with translating the transcribed documents into English. After translation, the researcher listened to the original interviews while comparing them to the English translations to verify accuracy. Once the researcher confirmed the translated English versions were accurate, the documents were then prepared for analysis. Data obtained through the digital audio recorder, field notes, and transcriptions were maintained in a confidential manner and utilized exclusively for the specified purpose. All physical documents gathered were securely locked away in filing cabinets, granting access solely to the researcher. Electronic records were saved in files protected by passwords. The researcher retained both physical and digital records for a duration of five years, after which all materials will be disposed off.

The collected data underwent analysis utilizing the thematic analysis approach. This process consisted of six stages, including:

- 1) Becoming familiar with the data (pre-coding tasks). This step involved transcribing audio recordings and noting any significant meanings and patterns throughout the dataset, as well as reading and re-reading the transcripts and making notes on potential codes to develop.

- 2) Creating the initial codes (open coding tasks). A series of initial codes was generated to capture the patterns and meanings within the data. A codebook was established to organize these codes, followed by a thorough review of the data to pinpoint intriguing excerpts and assign the relevant codes.

- 3) Identifying themes (grouping of initial codes). All excerpts linked to a specific code were organized together.

- 4) Evaluating possible themes (organizing selective codes). The codes were categorized into potential themes. These themes highlighted trends and patterns observed in the data, with some codes consolidated to form sub-themes.

- 5) Defining and labeling themes (final examination). Each theme was made distinct, ensuring it was supported by adequate data. Similar themes were combined, while those without enough supporting data were eliminated.

- 6) Compiling the report. The concluding step involved drafting the report, taking into account the themes to effectively express the validity of the analysis.

3. Results and Discussion

3.1. Results and Analysis

The study investigated the lived experiences of mothers of children with Down syndrome at Mbarara Regional Referral Hospital in Uganda. Fifteen mothers of children with Down syndrome who were receiving hospital care were involved. Five major themes emerged from the thematic analysis of semi-structured interview data: healthcare experiences, coping mechanisms and resilience, emotional experiences, social support and relationships, and future hopes and fears. There were subthemes within each theme.

Background information

Maternal Background: The mothers' ages ranged from 22 to 46 years, with the majority (roughly 10) being between 28 and 38 years old. This indicates that the mothers were a mix of younger and middle-aged individuals. Different family structures were represented by the fact that two mothers were single, five lived in extended family settings with grandparents or in-laws, and roughly half (8 mothers) lived in nuclear households with their husbands and children, with an average of 3 - 5 family members. Three were unemployed and dependent on family support, three worked in low-paying jobs (such as shop assistants or cleaners), and the majority (9) were subsistence farmers or petty traders with modest incomes. The resource limitations influencing their experiences providing care were highlighted by this socioeconomic profile.

Age of the children and time of Diagnosis: With a median age of roughly 4 years, the children with DS ranged from 6 months to 13 years. The timing of the diagnoses varied: three children were identified later (between three and five years old), frequently following multiple medical visits; five children were diagnosed between six months and two years old as developmental delays became apparent; and seven children were diagnosed at birth based on physical characteristics that were readily apparent and frequently confirmed within weeks at the hospital. Some mothers experience delays in diagnosis due to a lack of early screening and awareness, which exacerbates their emotional and practical difficulties.

Theme 1: Emotional Experiences

Mothers' psychological journey from the time of diagnosis to their continued daily lives was captured in emotional experiences. This theme emphasizes the initial shock and developing fortitude that defined their emotional terrain.

Sub-theme 1.1: Initial Emotional Reactions

For mothers, receiving a DS diagnosis is frequently a life-changing and turbulent event. The first news triggered a wave of strong emotions at Mbarara Regional Referral Hospital. Mothers expressed shock, sadness, and anxiety, which were frequently exacerbated by their ignorance of DS. These reactions might be made worse by the hectic and occasionally impersonal hospital setting, which leaves mothers to process the diagnosis with little help right away. These early reactions were also impacted by cultural beliefs that added layers of guilt or confusion, such as attributing disabilities to supernatural causes. Their own statements below reflected the emotional beginning of their journey as carers.

"... My world seemed to fall apart when I learned that my child had Down syndrome, and I sobbed for days. I was troubled" (p. 6)

"... At first, I had no idea what Down syndrome was, so I was shocked and perplexed." (p. 3)

"... My first thought was, 'How am I going to handle this?' I was terrified of what lay ahead for her." (p. 10)

"... I couldn't stop asking myself, 'Why me?' It was a mixture of sadness and anger." (p. 2)

"... I thought I was alone and that no one could relate to what I was going

through..." (p. 5)

Sub-theme 1.2: Evolving Emotions

Mothers' emotional reactions changed over time as they adjusted to their role as mothers and the condition of their child. This sub-theme illustrates a transition from hopelessness to acceptance, as well as occasional pride and thankfulness. The process was not linear; mothers fluctuated between vulnerability and resilience in response to their child's developmental milestones, social criticism, and coping strategies. According to their own words below, maintaining emotional strength in the face of ongoing difficulties required the capacity to find joy in little victories, such as a child's smile or developmental milestone.

"... I'm attempting to manage since we are receiving health services. My child is now my joy, and I have come to love her for who she is." (p. 7)

"... Even though I still get sad sometimes, I become stronger every day." (p. 9)

"... I'm proud to be her mother now, but I used to feel embarrassed." (p. 11)

"... His smile makes the difficult days worthwhile." (p. 14)

"... I've come to terms with the fact that it's simply life and not a punishment." (p. 15)

Theme 2: Social Support and Relationships

With an emphasis on the support or lack thereof—from friends, family, and the larger community, this theme captured the interpersonal dynamics that influenced mothers' experiences. Mothers' capacity to manage DS was greatly impacted by social networks.

Sub-theme 2.1: Family and Community Support

Mothers relied on the support of their families and communities, but it was also a variable factor. In certain situations, spouses and close relatives offered both emotional and practical support, which lessened the strain of providing care. In addition, neighbors and church groups provided practical assistance, such as food or company. Support was patchy, though; some moms experienced rejection or condemnation from family members who saw DS as a stigma or a form of divine retribution. Support groups, which were frequently unofficial and started through hospital connections, became an essential resource because they provided empathy and a common understanding that family members alone could not always offer.

"... No, my child's DS hasn't caused me to face discrimination." (p. 7)

"... My spouse has been my pillar of support; he assists me with everything." (p. 14)

"... After the diagnosis, some family members stopped coming to see us because they believe it to be a curse." (p. 11)

"... Sometimes, when I'm too exhausted to cook, my neighbor brings food." (p. 2)

"... At the hospital and even at church, I joined a group of mothers who have a unique understanding of me." (p. 6)

"... Friends simply avoid the subject because they do not know how to discuss

it." (p. 3)

Sub-theme 2.2: Stigma and Societal Attitudes

In Uganda, stigma is still a major problem that stems from ingrained cultural views about disability. Discrimination against mothers was common and could take many forms, from covert exclusion to overt animosity, such as disparaging remarks or blame-shifting. Isolation grew as DS was misunderstood as a curse or the result of maternal misconduct. Public places like marketplaces and places of worship become places of condemnation where mothers' self-esteem is undermined by looks and rumors. This sub-theme emphasized the conflict between mothers' attempts to defend their children's dignity and societal attitudes.

"... I feel so small when people in the market stare at us."

"... I will always remember the pain I felt when someone told me that my child was useless."

"... They call it witchcraft in my village, and I no longer even dispute it."

"... I wish they would just accept her, but the church prays for her recovery."

"... It is exhausting that some people believe I did something wrong to deserve this." (p. 5)

Theme 3: Healthcare Experiences

Mothers' encounters with Mbarara Regional Referral Hospital, a significant public institution in southwest Uganda, were reflected in their healthcare experiences. This theme highlighted the healthcare system's advantages and disadvantages, which were crucial for managing DS.

Sub-theme 3.1: Access to Services

Due to resource constraints that are common in low-income environments, access to healthcare services was a major concern. Though they pointed out lengthy wait times, a lack of specialized equipment, and the cost of therapies, mothers appreciated the hospital's efforts. Advanced interventions, which required travel or private funding beyond the means of most families, were frequently inaccessible, even though basic care was available. Mothers' caregiving responsibilities were further burdened by this sub-theme, which emphasized the disparity between need and provision.

"... Health professionals have been providing my child with high-quality, specialized care services ever since we began receiving care at Mbarara. However, transportation to come for review can occasionally be an issue." (p. 7)

"... The doctors at Mbarara Hospital make an effort, but there is insufficient equipment."

"... It was annoying that we had to wait for months to see a specialist."

"... The therapies they suggest are too expensive and too far away for me to afford."

"... They gave us some basic advice, but nobody ever gets back to us."

"... I feel like my child isn't a priority because of how crowded the hospital is." (p. 7)

Sub-theme 3.2: Communication with Healthcare Providers

While crucial, effective communication with healthcare providers was not always consistent. While some mothers felt dismissed or misinformed, others valued the kind staff members who provided explanations. Due to time constraints, technical jargon, and language barriers, mothers were unable to understand their child's condition or future needs. Good encounters, such as recommendations for support groups, were notable exceptions, indicating room for development through education and compassion.

"... I still do not fully understand the doctor's explanation of Down syndrome."

"... While some nurses are nice, others make it seem as if I'm to blame."

"... They speak too quickly, leaving me with more questions than answers."

"... I wish they had told me what to anticipate regarding her development."

"... The best assistance I received came from a nurse who recommended a support group." (p. 8)

Theme 4: Coping Strategies and Resilience

This theme arose from the ways in which mothers use both tangible and intangible resources to manage the demands of raising a child with Down syndrome. Adversity and cultural strengths helped to create resilience, which became a defining characteristic.

Sub-theme 4.1: Practical Strategies

It took creativity and perseverance to provide care on a daily basis. In order to meet their child's specific needs, such as feeding issues brought on by the oral-motor difficulties typical of Down syndrome, mothers created customized routines. Dressing and bathing became time-consuming tasks that frequently required trial and error to teach fundamental skills. Mothers adapted to limited access to professional support by relying on family involvement or improvisation in resource-constrained environments. This demonstrated their proactive approach to problem-solving in the face of limitations.

"... I do what the health care workers tell me to do."

"... He chokes if I feed him quickly, so I get up early to feed him slowly."

"... Although it takes time, she is learning how to dress herself thanks to my instruction."

"... I follow a schedule because it makes us both feel more at ease."

"... I have to stay up all night when she's sick; it's exhausting but necessary."

"... It's now a family endeavor, so I ask my older children to assist. When I'm in the shamba for cultivation, my older kids assist with childcare." (p. 9)

Sub-theme 4.2: Cultural and Spiritual Coping

Spiritual and cultural beliefs were a significant source of fortitude. In order to promote acceptance and a sense of purpose, mothers presented DS as a divine test or blessing. When practical solutions failed, community rituals, scripture, and prayer provided emotional comfort and reduced stress. This sub-theme highlighted the ways in which caregiving and faith interacted, setting Ugandan experiences apart from secular coping strategies.

"... Every day I pray, and God gives me the strength to keep going."

“... I cling to our pastor’s statement that she is a blessing.”

“... I can’t give up on her; we take care of our own in our culture.”

“... I’ll pass this test, which I think is a test from God.”

“... When I’m feeling overwhelmed, I find that reading the Bible helps me relax.” (p. 8)

Theme 5: Hopes and Fears for the Future

In a society with little support for people with disabilities, this theme reflected mothers’ forward-looking viewpoints and struck a balance between optimism and concern about their child’s future.

Sub-theme 5.1: Hopes

Mothers had hopes for their kids’ socialization, growth, and well-being. Despite obstacles, they dreamed of achievements like education, friendships, or better communication, motivated by love and willpower. These aspirations were tempered by reasonable expectations that were influenced by their circumstances and reflected a desire for acceptance and normalcy. The importance of societal change was highlighted by the emergence of community inclusion as a recurring goal.

“... One day, I hope, he will be able to attend school and make friends.”

“... The only thing that matters to me is that my child is happy.”

“... I hope that she will learn to speak more.”

“... As he matures, I hope society will embrace him.”

“... I hope he has a long and healthy life.” (p. 5)

Sub-theme 5.2: Fears

Fears focused on vulnerability and uncertainty, especially with regard to long-term care and social rejection. Mothers were concerned about their child’s protection, independence, and decline in health after their own passing. In addition to financial instability and stigma, there were significant social and educational obstacles. This sub-theme highlighted the conflict between individual dedication and structural shortcomings.

“... I’m afraid of what will happen to him after I’m gone. I worry that, in the future, other people might separate my child from me.”

“... What happens if she never gains her independence? That worries me.”

“... I worry that because he is unique, people will treat him badly.”

“... I’m not sure how we will handle education; it seems unattainable.”

“... As he gets older, I fear his health will deteriorate.” (Who said this)

3.2. Discussion of Findings

The results shed light on the diverse experiences of mothers at Mbarara Regional Referral Hospital, highlighting both general trends and subtleties unique to the setting. Convergence, divergence, and contextual influences were highlighted when comparing the results of this study with pertinent studies from the literature review.

The results showed that mothers of children with Down syndrome in Uganda faced a complex interplay of emotions, social dynamics, and systemic challenges. The initial shock, grief, and confusion that Ugandan mothers reported were in

line with the feelings of disappointment, sadness, and anger that mothers expressed after receiving a diagnosis in Desimpelaere et al. (2024) in Belgium and Kammes et al. (2022) in the USA. Similar to Kammes et al.'s discovery of mothers' ignorance of DS, the Ugandan context, however, intensified these responses because of a lack of prior knowledge of the condition. The cultural perspective of Ugandan mothers, who saw DS as a possible curse, added guilt, a nuance less evident in Western studies than in Grane et al. (2023) in Ireland, where initial resistance gave way to patience. In contrast to Mengoni et al., this indicated a lack of resource awareness.

The shift from hopelessness to pride and acceptance was similar to that of Jönsson et al. (2022) in Sweden, where mothers expressed steadfast thankfulness in the face of adversity. As opposed to the protracted depression reported by Kammes et al. (2022), Ugandan mothers' faster acceptance might be the result of their cultural resilience. Due to a lack of therapeutic resources, Ugandan mothers placed more emphasis on celebrating small victories than Desimpelaere et al. (2024), who emphasized and encouraged independence as a coping mechanism. This resilience was influenced by faith-based acceptance rather than secular adaptation, which was consistent with Grane et al.'s (2023) sincerity.

Although Ugandan mothers reported spousal support, Huiracocha et al. (2017) found that caregiving burden strained relationships in Ecuador—a pattern similar to the variable family support seen in Uganda. In contrast to the structured systems in high-resource settings, Uganda lacked formal support networks. However, its informal, hospital-based support groups were similar to the peer support described by Mengoni et al. (2023) in the UK, with the latter's organic community assistance (such as neighbors sharing food) adding a distinctive collectivist element.

While stigma in Uganda associated with moral failings or witchcraft was consistent with the environmental challenges identified by Duranovic et al. (2017), it surpassed the subtle rejection in Grane et al. (2023). Ugandan stigma was culturally based, exacerbating isolation beyond Western experiences, in contrast to Kammes et al.'s (2022) emphasis on medical misunderstanding. Duranovic et al. (2017) highlighted integration success in Croatia, which was a far-off possibility in Uganda, where public opinion (such as market stares) mirrored but outperformed Iran's struggles related to fatigue.

The lack of resources at Mbarara Hospital stood in stark contrast to the UK's Mengoni et al. (2023) specialist support, where professional assistance was provided to meet feeding goals. Huiracocha et al. (2017) mentioned the caregiving burden in Ecuador, and Ugandan mothers' struggles with therapy access and equipment shortages were similar, but overcrowding was a unique obstacle in Uganda's public hospitals. In contrast to Duranovic et al.'s (2017) emphasis on educational integration, Ugandan healthcare showed a low-resource disparity by prioritizing basic care over developmental support.

Ugandan poor communication, characterized by jargon and a lack of follow-

up, deviated from the trusted support model proposed by Mengoni et al. (2023). While Ugandan mothers experienced additional dismissive attitudes that were not present in Jönsson et al.'s (2022) Swedish context, it was more in line with Kammes et al.'s (2022) call for medical understanding of maternal needs. Systemic limitations restricted consistency, although positive exceptions (such as referrals to support groups) indicated possible alignment with Grane et al.'s (2023) patience-building interactions.

Although they lacked expert advice, Ugandan mothers' feeding difficulties-related routines (such as slow feeding and family assistance) mirrored those of Mengoni et al. (2023). This was similar to Duranovic et al. (2017) emphasis on teaching daily habits, but it lacked Croatia's institutional backing. Ugandan strategies put survival above development, reflecting resource scarcity similar to Huiracocha et al.'s (2017) time-intensive care, in contrast to Desimpelaere et al.'s (2024) independence focus.

In Uganda, spiritual coping was very similar to that of Gashmard et al. (2020) in Iran, where prayer was a stress reliever and DS was a divine test. In contrast, Uganda's faith-driven acceptance is highlighted by Jönsson et al. (2022) or Grane et al. (2023), who discussed secular resilience. Contrary to Mengoni et al.'s (2023) reliance on peer-professional support, Ugandan mothers' cultural obligation to care reflected weariness but was supported by religious serenity, a special strength. Hopes for happiness and education were in line with Duranovic et al.'s (2017) integration goals, but unlike Croatia, Uganda's resource constraints made these aspirational rather than realistic. Although this optimism lacked Sweden's institutional support, it echoed the gratitude expressed by Jönsson et al. (2022). The Ugandan hopes were more expansive than Mengoni et al.'s (2023) feeding goals, reflecting societal inclusion desires over particular milestones. Fears of abandonment were more in line with caregiving challenges than Grane et al.'s (2023) adjustment focus. In contrast to Duranovic et al.'s (2017) favored integration, Ugandan fears were exacerbated by socioeconomic vulnerability, as opposed to Desimpelaere et al.'s (2024) concern about independence. The depression context presented by Kammes et al. (2022) was different because Ugandan concerns were grounded in systemic flaws and pragmatism.

4. Conclusion

At Mbarara Regional Referral Hospital in Uganda, mothers faced a difficult environment characterized by emotional development, inconsistent social support, and inadequate medical care. Cultural beliefs strengthened their resilience, but structural obstacles prevented them from providing their children with optimal care and inclusion.

5. Recommendations

To the Government of Uganda

Healthcare Improvement: Increase access to specialized care at regional hos-

pitals and improve DS training for medical staff.

Support Networks: Create official support groups for mothers to promote emotional support and peer group learning.

To the Hospital

Public Awareness: Start initiatives to lessen stigma and encourage DS acceptance in Ugandan communities.

Policy Support: Encourage the provision of educational materials and subsidized therapies for children with Down syndrome.

Follow-Up Care: Establish routine follow-up procedures to ensure moms are informed and encouraged.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

References

- Alrayes, N., Issa, N. M., Alghubayshi, O. Y., Al-Amaa, J. Y., Alsabban, A. H., Al Shaer, D. S. et al. (2024). Quality of Life in Children with Down Syndrome and Its Association with Parent and Child Demographic Characteristics: Parent-Reported Measures. *Molecular Genetics & Genomic Medicine*, 12, e2337. <https://doi.org/10.1002/mgg3.2337>
- Antonarakis, S. E., Skotko, B. G., Rafii, M. S., Strydom, A., Pape, S. E., Bianchi, D. W. et al. (2020). Down Syndrome. *Nature Reviews Disease Primers*, 6, Article No. 9. <https://doi.org/10.1038/s41572-019-0143-7>
- Bamson, M., & Mandah, S. O. (2024). Dietary Habits and Impact of Good Nutrition in Children with Down Syndrome in Rivers State, Nigeria. *Nigeria Journal of Home Economics*, 12, 137-143. <https://doi.org/10.61868/njhe.v12i10.324>
- Desimpelaere, E. N., De Clercq, L. E., Soenens, B., Prinzie, P., & De Pauw, S. S. W. (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>
- Duranovic, M., Klasnic, I., & Opic, V. (2017). A Child with Down Syndrome—Challenge for Families, Kindergartens and Schools. *New Trends and Issues Proceedings on Humanities and Social Sciences*, 3, 32-41. <https://doi.org/10.18844/prosoc.v3i5.2002>
- Gashmard, R., Ahmadi, F., & Kermanshahi, S. M. K. (2020). Coping Strategies Adopted by Iranian Families of Children with Down Syndrome: A Qualitative Study. *Medicine*, 99, e20753. <https://doi.org/10.1097/md.00000000000020753>
- Gboyega, V., Martinez, R. M., Aderemi-Ige, T. J. et al. (2024). *Disability Inclusion in Nigeria: A Rapid Assessment*. World Bank. <https://documents.worldbank.org/en/publication/documents-reports/documentdetail/780571593336878236/Disability-Inclusion-in-Nigeria-A-Rapid-Assessment>
- Grane, F. M., Lynn, F., Balfe, J., Molloy, E., & Marsh, L. (2023). Down Syndrome: Parental Experiences of a Postnatal Diagnosis. *Journal of Intellectual Disabilities*, 27, 1032-1044. <https://doi.org/10.1177/17446295221106151>
- He, F., Wang, W., Zhong, K., Yuan, S., Du, Y., & Wang, Z. (2021). Analysis of External Quality Assessment of Maternal Serum Prenatal Screening for Down Syndrome in the First Trimester in China. *Clinical Laboratory*, 67, No. 6. <https://doi.org/10.7754/clin.lab.2020.201004>

- Huiracocha, L., Almeida, C., Huiracocha, K., Arteaga, J., Arteaga, A., & Blume, S. (2017). Parenting Children with Down Syndrome: Societal Influences. *Journal of Child Health Care, 21*, 488-497. <https://doi.org/10.1177/1367493517727131>
- Jönsson, L., Olsson Tyby, C., Hullfors, S., & Lundqvist, P. (2022). Mothers of Children with Down Syndrome: A Qualitative Study of Experiences of Breastfeeding and Breastfeeding Support. *Scandinavian Journal of Caring Sciences, 36*, 1156-1164. <https://doi.org/10.1111/scs.13088>
- Kammes, R. R., Lachmar, E. M., Douglas, S. N., & Schultheiss, H. (2022). "Life-Altering": A Qualitative Analysis of Social Media Birth Stories from Mothers of Children with Down Syndrome. *Journal of Intellectual Disabilities, 26*, 919-937. <https://doi.org/10.1177/17446295211025960>
- Kats, D. J., Donelan, K., Banerjee, S., de Graaf, G., Skladzien, E., Hooper, B. T. et al. (2024). Results of Inaugural International Down Syndrome Societal Services and Supports Survey. *Genetics in Medicine, 26*, Article 101114. <https://doi.org/10.1016/j.gim.2024.101114>
- Ko, K. M. M., Linn, K., Aye, A. M. M., Saw, M. T., & Aung, P. P. (2021). Health Status of Children with Down Syndrome in Myanmar. In *Abstracts* (pp. A4.2-A5). BMJ Publishing Group Ltd. <https://doi.org/10.1136/bmjpo-2021-rcpch.8>
- Mengoni, S. E., Smith, B., Wythe, H., & Rogers, S. L. (2023). Experiences of Feeding Young Children with Down Syndrome: Parents' and Health Professionals' Perspectives. *International Journal of Developmental Disabilities, 71*, 545-553. <https://doi.org/10.1080/20473869.2023.2269321>
- 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*, 1-15. <https://doi.org/10.1155/2024/9992595>
- Peters, K., Moses, O., Olive, K., Dorah, N., Lydia, K., & Stella, K. (2024). In Hospital Experiences of Mothers of Children with Major External Birth Defects during Hospitalisation at a Tertiary Hospital in South Western Uganda. *International Journal of Innovative Science and Research Technology, 9*, 1730-1736. <https://doi.org/10.38124/ijisrt/ijisrt24feb1520>
- Sifir, C. K. (2024). Impact of down Syndrome among Families Who Have Children with Down Syndrome and Have Follow-Up for Their Children at Black Lion Hospital in 2019. *Clinical Trials and Bioavailability Research, 3*, 1-13. <https://doi.org/10.58489/2836-5836/012>
- Steffensen, E. H., Santoro, S. L., Pedersen, L. H., Vogel, I., & Lou, S. (2024). Encounters with Public and Professional Understandings of Down Syndrome: A Qualitative Study of Parents' Experiences. *Journal of Applied Research in Intellectual Disabilities, 37*, e13221. <https://doi.org/10.1111/jar.13221>
- Suza, D. E., Napitupulu, M. A., & Hariati, H. (2020). Experiences of Mothers of Children with Down Syndrome. *Family Medicine & Primary Care Review, 22*, 338-342. <https://doi.org/10.5114/fmpcr.2020.100445>
- Tolouei Rakhshan, S., Byford, S., Razimoghdam, M., Moradi, F., & Soltani, S. (2024). Determinants of Healthcare Costs in Individuals with Down Syndrome: A Systematic Review. *Health Science Reports, 9*, e72297.
- Wang, Q. Q., He, C. Y., Mei, J., & Xu, Y. L. (2022). Epidemiology of Birth Defects in Eastern China and the Associated Risk Factors. *Medical Science Monitor: International Medical Journal of Experimental and Clinical Research, 28*, e933782-1-e933782-8.