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RESEARCH ARTICLE OPEN ACCESS

A phenomenological study of lived experiences of parents caring for children with Down syndrome in Iju, Lagos State, Nigeria

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Abstract
Objective: Caring for persons with Down Syndrome (DS) presents complex emotional, social, and practical challenges for families, particularly in resource-constrained settings. However, context-specific evidence on the lived experiences of parents in Nigeria remains limited. This study explored the lived experiences of parents caring for children with Down Syndrome in Iju, Lagos State, Nigeria.
Methods: A qualitative phenomenological design was employed. Eight participants (n = 8), comprising seven parents and one sibling, were purposively recruited through the Down Syndrome Foundation Nigeria (DSFN), Iju, Lagos State. Data were collected using in-depth semi-structured interviews and analysed using thematic analysis guided by phenomenological principles.
Results: Five interconnected themes emerged: emotional and psychological trajectory, multidimensional caregiving burden, adaptive coping strategies, navigating stigma and social visibility, and support systems and structural gaps. Parents described an initial period of shock followed by gradual acceptance and resilience. Financial strain, employment disruptions, and emotional fatigue were prominent challenges. Participants relied heavily on family, religious networks, and the DSFN for support, while perceiving limited formal governmental assistance.
Conclusion: Parenting persons with Down Syndrome in this setting is an emotionally demanding yet adaptive journey shaped by persistent caregiving pressures and uneven structural support. Strengthening formal support systems, expanding financial and psychosocial assistance, and addressing disability-related stigma are essential to improving family well-being.

Keywords: Down Syndrome, Caregivers, Qualitative Research, Phenomenology, Social Stigma, Nigeria

Plain English Summary

Caring for a child with Down Syndrome can be both meaningful and demanding for families. This study explored the everyday experiences of parents in Iju, Lagos State, Nigeria, who are raising children with Down Syndrome. We interviewed eight participants, including seven parents and one sibling involved in caregiving. Many parents described feeling shocked when they first learned of their child's condition, but

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over time, they developed acceptance and strength. Families reported major challenges, especially the high cost of therapy and special education, time pressures, and emotional strain linked to public misunderstanding.

Despite these difficulties, parents showed strong resilience. They coped by seeking information, engaging in personal stress-relieving activities, and relying heavily on relatives, religious communities, and the Down Syndrome Foundation Nigeria. However, participants consistently noted limited government support. Overall, the findings highlight the need for stronger financial, psychosocial, and community support systems to improve the well-being of families raising children with Down Syndrome in Nigeria.

Background

Down Syndrome (DS) remains one of the most common chromosomal conditions globally, characterised by an extra copy of chromosome 21 that alters physical development, cognitive functioning, and overall health trajectories (1, 2). Children with DS frequently present with distinctive physical features, varying degrees of intellectual disability, and a heightened risk of comorbid conditions such as congenital heart defects, hearing and vision impairments, and neurological or mental health challenges (2, 3). While advances in medical care and early intervention have improved survival and developmental outcomes for individuals with DS, these gains have simultaneously expanded the scope and duration of caregiving responsibilities borne by families.

For many parents, the birth or diagnosis of a child with DS marks a profound emotional turning point. Families often experience an initial period marked by shock, grief, and uncertainty as they reconcile expectations of a typically developing child with the realities of raising a child with special needs (1, 4). This experience has been conceptualised as ambiguous loss, an ongoing and fluctuating emotional process that may persist across the family life course (5). Although many families demonstrate resilience and eventually adapt (1), the pathway to adaptation is rarely linear. Parents must simultaneously process complex emotions while acquiring new caregiving skills and navigating unfamiliar health and social systems.

Beyond the emotional adjustment, the day-to-day management of a child with DS places sustained practical and psychological demands on caregivers. Parents are required to coordinate medical appointments, monitor developmental progress, seek specialised educational services, and mobilise financial and social resources over many years (1). This prolonged management role has been associated with elevated parenting stress and increased vulnerability to mental health difficulties, particularly among mothers (1). Significantly, caregiver well-being is shaped not only by the child's functional needs but also by the caregiver's socioeconomic context and the availability of social support.

These challenges are often intensified in contexts marked by health inequities. People with disabilities and their families frequently encounter barriers such as limited access to quality healthcare, gaps in preventive services, and providers who may lack adequate training or confidence in disability care (1, 6). Such systemic constraints can erode trust in healthcare relationships and compound caregiver burden. However, the lived realities of these inequities vary across settings; local health systems, cultural expectations, and resource availability profoundly shape them.

Although existing scholarship has explored stress and coping among parents of children with developmental disabilities, much of the evidence is derived from high-income countries and quantitative designs that may overlook the nuanced meanings parents attach to their experiences. Stress and coping theory suggests that caregivers cognitively appraise demands and adopt varied coping strategies, problem-focused, emotion-focused, positive reframing, or religious and denial-based approaches, with differing implications for well-being (7, 8). Emerging studies also highlight the protective role of social support and active coping in fostering resilience (9, 10). However, there remains limited phenomenological evidence capturing how parents in resource-constrained settings actually live through, interpret, and negotiate the realities of raising a child with DS.

In Lagos State, Nigeria, where healthcare access, social services, and disability support structures remain uneven, parents of children with DS are likely to confront layered emotional, social, and systemic challenges. However, their voices are largely absent from the literature. Without context-specific insight into their lived experiences, coping pathways, and support needs, interventions risk being culturally misaligned or practically ineffective.

Therefore, the problem this study addresses is the insufficient contextualised understanding of the lived experiences of parents raising children with Down Syndrome in Lagos State, Nigeria. A phenomenological exploration is necessary to illuminate how these parents make meaning of diagnosis, navigate caregiving demands, access support, and sustain family functioning within their sociocultural and health system realities. Generating such evidence is essential for informing responsive clinical practice, family-centred policies, and support interventions that genuinely reflect the needs of affected families in this setting.

Materials and Methods

Research Design

The study adopted a qualitative phenomenological research design to explore and interpret the lived experiences of parents caring for children with Down Syndrome in Iju, Lagos State, Nigeria. A phenomenological approach is considered appropriate because the study seeks to understand how parents perceive, make meaning of, and navigate the realities associated with caring for a child with Down Syndrome within their sociocultural context.

Research Settings

The research setting is the Down Syndrome Foundation of Nigeria, Iju, Lagos State. The study was conducted in Lagos State, Nigeria, among parents of children with Down Syndrome, with access to participants facilitated through the Down Syndrome Foundation Nigeria (DSFN). Lagos State, Nigeria's most populous and socio-economically diverse urban centre, provided an appropriate context for examining the realities of families raising children with developmental disabilities within a complex health and social environment. The Down Syndrome Foundation Nigeria, established in 2001, is a non-governmental, not-for-profit organisation dedicated to supporting individuals with Down Syndrome and their families through advocacy, parent support, public awareness, and capacity-building initiatives. The foundation brings together parents and caregivers, making it a strategic and credible entry point for recruiting participants with relevant lived experiences. Conducting the study in Lagos State, in collaboration with DSFN, enabled the generation of contextually grounded insights into how parents navigate the emotional, social, and caregiving demands of raising a child with Down Syndrome in Nigeria.

Population

The sampling frame for the study consisted of 20 families registered with the Down Syndrome Foundation Nigeria (DSFN) in Iju, Lagos State, who were caring for children with Down syndrome. These families constituted the pool of eligible participants from which study participants were purposively recruited.

Inclusion Criteria

Participants were eligible for the study if they:

Were biological parents, adoptive parents, or primary family caregivers (including siblings with substantial caregiving responsibility) of a child diagnosed with Down Syndrome.

Had been providing care for the child for at least six (6) months before the study to ensure sufficient lived caregiving experience.

Were affiliated with or registered members of the Down Syndrome Foundation Nigeria (DSFN), Iju, Lagos State.

Were aged 18 years and above.

Were willing to participate and able to provide informed consent.

Exclusion Criteria

Participants were excluded if they:

Were caregivers of children with suspected but not medically confirmed Down Syndrome.

Were too emotionally distressed or medically unwell at the time of data collection to participate meaningfully in an in-depth interview.

Sampling Frame and Recruitment

Participants were recruited through the Down Syndrome Foundation Nigeria (DSFN), Iju branch, which maintains a verified register of families of individuals with Down Syndrome who receive ongoing support services. Confirmation of diagnosis was based on medical documentation submitted to DSFN at the time of family registration. These documents typically include paediatric or specialist medical reports and, where available, chromosomal diagnostic confirmation records maintained in the Foundation's registration files. The existence of this documentation ensured that the DSFN registry served as a reliable sampling frame, as all families listed had previously established clinical diagnoses.

During routine support meetings and organisational communications, DSFN staff informed eligible caregivers about the study. Individuals who expressed interest permitted their contact details to be shared with the research team. The researchers then contacted these caregivers, provided detailed information about the study, responded to questions, and obtained written informed consent before enrolment. Recruitment took place between 4 and 11 April 2025, while interviews were conducted from 14 to 24 April 2025. Using purposive sampling, eight participants were enrolled: seven parents and one adult sibling who had assumed substantial day-to-day caregiving responsibilities within the household. The sibling participant was retained in the sample because of their sustained caregiving role, which offered additional insight into the broader dynamics of family caregiving.

The final sample size was guided by the principle of information power together with the concept of thematic saturation in phenomenological research. Data collection and preliminary analysis occurred concurrently. After the seventh interview, no substantially new experiential insights or codes were identified. One additional interview was conducted to confirm thematic redundancy. Following team discussions of the developing codebook and analytic memos, recruitment was concluded at eight participants, as the dataset was considered sufficiently rich to support a meaningful phenomenological interpretation.

Instrument for Data Collection

Data were generated through in-depth, face-to-face interviews using a researcher-developed semi-structured interview guide. The guide was designed to elicit rich, first-person accounts of the lived experiences of parents raising children with Down Syndrome within the community context of Iju, Lagos State, Nigeria. The semi-structured format allowed flexible probing while ensuring consistent coverage of key domains. All information obtained from participants was treated as strictly confidential.

Interviews were conducted by ACCC (RN, PhD), a Senior Lecturer and Nurse researcher trained in qualitative methods, with support from ADP (RN, BNSc), a trained research assistant. The researchers had no prior relationship with the Down Syndrome Foundation Nigeria (DSFN) or with any participants before recruitment. To minimise the influence of pre-existing assumptions, ACCC engaged in ongoing reflexive practice throughout the study. Presuppositions were documented before interviews, reflexive field notes were maintained during data collection, and conscious bracketing was applied during analysis. Interpretations were periodically reviewed within the research team to ensure that findings remained grounded in participants' lived experiences. The interview guide comprised two sections. Section A captured socio-demographic characteristics, including age, gender, relationship, and years of caregiving experience. Section B contained open-ended questions exploring parents' emotional, social, and psychological experiences; the challenges encountered; coping strategies; the influence of cultural and societal attitudes; and the availability and perceived impact of support systems within their communities.

To enhance content validity, experts in qualitative research and child health reviewed the guide for clarity, relevance, and cultural appropriateness. One pilot interview was conducted with a parent outside the study sample, and minor refinements were made to improve question flow and comprehension. Interviews were conducted at locations convenient and comfortable for participants and were audio-recorded with permission. Each interview lasted approximately 47 minutes. All interviews were conducted in English, which participants understood adequately. Credibility was strengthened through prolonged engagement, iterative probing, and real-time member checking during interviews, where key points were summarised and confirmed with participants. These procedures supported the generation of rich and trustworthy data consistent with phenomenological inquiry.

Enhancing Trustworthiness of the Study

The rigour of this phenomenological study was guided by Lincoln and Guba's criteria of credibility, dependability, confirmability, and transferability (11). These strategies were integrated throughout the research process to strengthen the integrity of the findings.

Credibility

Credibility was enhanced through in-depth, face-to-face interviews that enabled detailed exploration of parents' lived experiences. Probing questions elicited clarification and depth, while member checking during interviews allowed participants to verify the accuracy of their accounts. Expert review and pilot testing of the interview guide further improved clarity and contextual relevance.

Dependability

Dependability was supported through a transparent audit trail documenting recruitment via DSFN, interview procedures, transcription processes, and analytic decisions. The semi-structured interview guide promoted consistency across interviews while preserving phenomenological depth.

Confirmability

Reflexive practice was maintained throughout the study to minimise researcher bias. Audio-recorded interviews were transcribed verbatim to preserve participants' meanings, and analytic interpretations were grounded firmly in participants' narratives.

Transferability

Transferability was supported through a rich, contextual description of the study setting, participants, and procedures. By clearly situating the study in Iju, Lagos State, among parents affiliated with DSFN, sufficient detail was provided for readers to judge the applicability of the findings to similar contexts.

Procedures Used to Minimise Distress During Interviews

Given the sensitive nature of caregiving experiences, several measures were implemented to minimise emotional distress. Interviews took place in quiet, private spaces within the Down Syndrome Foundation Nigeria to promote comfort and openness. At the start of each session, participants were reminded that participation was voluntary and that they could pause, skip any question, or withdraw at any time without consequence. Throughout the interviews, ACCC remained attentive to verbal and non-verbal signs of discomfort. When distress was observed, the interview was gently paused, and supportive reassurance was provided, proceeding only with the participant's consent. At the end of each interview, participants were debriefed and reminded of available support services through DSFN, including counselling guidance and peer-support resources. No participant required formal referral or discontinued participation due to distress.

Method of Data Analysis

Data were analysed using an inductive reflexive thematic approach informed by phenomenological principles to illuminate the meanings embedded in parents' lived experiences of raising children with Down Syndrome in Iju, Lagos State, Nigeria. The analytic process was iterative, interpretive, and firmly grounded in participants' narratives to capture both shared experiential patterns and the deeper essence of caregiving.

All interviews were audio-recorded and transcribed verbatim. The research team immersed themselves in the data through repeated reading of the transcripts alongside reflective memo-writing to develop a holistic understanding of participants' accounts. Analysis followed the reflexive thematic analysis procedures described by Braun and Clarke (12), while maintaining sensitivity to participants' subjective meanings.

The analytic process unfolded in six interconnected phases. First, the researchers familiarised themselves with the dataset through repeated reading and reflexive engagement with the transcripts. Second, initial inductive codes were generated line-by-line to capture significant statements and meaning units relevant to caregivers' experiences. Third, related codes were clustered into potential themes representing patterned meanings across the dataset. Fourth, emerging themes were reviewed against both the coded extracts and the full dataset to ensure internal coherence and clear distinctions between themes. Fifth, themes were refined, defined, and named to reflect their underlying experiential significance. Finally, the authors developed a coherent narrative account supported by verbatim participant quotations to preserve participants' voices.

ACCC led the coding process, while ADP and OF independently reviewed the transcripts and contributed to refining the coding framework to enhance analytic rigour. Coding was iterative rather than strictly independent; early transcripts were coded line-by-line, and the evolving codebook was progressively refined as additional interviews were analysed. Regular analytic meetings were held among ACCC, OF, ADP, and IN to compare interpretations and resolve differences through consensus, with constant reference to the original transcripts to ensure fidelity to participants' intended meanings.

Coding and data management were conducted manually using Microsoft Word and Excel. Reflexive memo-writing and a detailed audit trail were maintained throughout to document analytic decisions and enhance transparency.

Exemplar of code-to-theme development:

Participant quote: "I made Google my best friend… that is how I began to heal."

Initial code: information-seeking to manage uncertainty

Category: self-education as coping

Final theme: adaptive coping and meaning-making strategies

Real-time member checking was conducted during interviews, whereby key points were summarised by the interviewer and confirmed or clarified by participants. Participants were informed that they could request access to their interview transcripts; however, none requested transcript review after the interviews. This study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) 32-item checklist. The completed checklist is provided as Supplementary File 1.

Results

Sociodemographic Characteristics

From Table 1 below, a total of 8 participants were included, comprising 7 parents and 1 sibling directly involved in the care of children with Down Syndrome. The sample was predominantly female (n = 7), with one male participant. Participants were distributed across early- to late-adult age groups (mean 40.9 ± 7.5 years). Caregiving experience ranged from 4 to 18 years (mean 9.9 ± 4.7 years), indicating substantial exposure to long-term caregiving demands.

The details of the demographic characteristics and interview excerpts are shown in Supplementary File 2.

Table 1. Demographic Characteristics of Participants (N = 8)

Variable	Category	n (%) / Summary
Age (years)	Mean ± SD	40.9 ± 7.5
	Range	29–52
Age group	29–38	3 (37.5)
	39–48	3 (37.5)
	49–52	2 (25.0)
Gender	Female	7 (87.5)
	Male	1 (12.5)
Relationship to child	Mother	6 (75.0)
	Father	1 (12.5)
	Sibling caregiver	1 (12.5)
Years caregiving	Mean ± SD	9.9 ± 4.7
	Range	4–18

SD = Standard Deviation; N = 8; % = Percentage.

Experiences of Parents of Children with Down Syndrome

Analysis of the in-depth interviews revealed a coherent experiential pattern in how parents navigated the realities of raising children with Down Syndrome. Five interrelated themes emerged: the emotional trajectory of parenting, the multidimensional burden of caregiving, adaptive coping processes, sociocultural negotiations, and the role of support systems in a context of limited formal assistance.

Emotional and Psychological Trajectory of Parenting a Child with Down Syndrome

Participants described parenting as an evolving emotional journey that began with intense disruption and gradually transitioned into adaptation and resilience. This trajectory unfolded through four interconnected processes.

Initial shock

For most parents, the moment of diagnosis triggered profound emotional upheaval. The news often contradicted prior expectations of a typically developing child, leading to disbelief and distress. One mother recalled the intensity of this moment: "I screamed, 'No, this can't be my child!" (Participant A, Mother, 37 years). This reaction illustrates the depth of the initial psychological rupture experienced by parents.

Gradual acceptance and meaning-making

Over time, participants described moving toward acceptance through deliberate efforts to understand the condition. Information seeking—particularly through online resources—served as both a practical and emotional coping pathway. As one participant explained: "I made Google my best friend… That is how I began to heal" (Participant B, Mother, 45 years). Acceptance, therefore, emerged as an active, meaning-making process rather than a passive adjustment.

Emerging resilience

Despite persistent challenges, parents demonstrated growing emotional strength. Resilience was expressed as continued forward movement rather than the absence of difficulty. One participant noted: "It is not easy, but we move. We keep going" (Participant F, Mother, 52 years). This finding reflects sustained perseverance in the face of ongoing caregiving demands.

Assumption of sibling responsibility

The experience of Down Syndrome extended beyond parents to siblings, who in some cases assumed expanded caregiving roles. One participant described this shift vividly: "I was not just a sister — I became her second mother" (Participant C, Sister, 29 years). This finding highlights how the condition reshaped family dynamics and redistributed emotional labour within the household.

Multidimensional Burden of Caregiving

Parents reported that caregiving imposed cumulative pressures affecting financial stability, employment, and emotional well-being. The parents experienced these burdens as persistent and interwoven.

Financial strain from therapy and education costs

The cost of therapies and specialised schooling emerged as a significant source of stress. Many parents described the financial demands as overwhelming and challenging to sustain in the long term. One participant stated: "You need to be rich to afford the therapies and special schools" (Participant D, Mother, 40 years). This finding underscores the heavy economic load associated with caring for a child with Down Syndrome.

Time conflicts and career disruption

Frequent medical and therapy appointments created significant time pressures that interfered with employment. Some parents reported losing jobs or reducing work commitments due to caregiving responsibilities. One of the participants shared: "I lost my job because of the therapy appointments" (Participant E, Father, 48 years). This finding demonstrates how caregiving demands directly affected household economic security.

Emotional fatigue and social exhaustion

Beyond practical challenges, parents described cumulative emotional strain. The need to repeatedly explain their child's condition in public spaces was experienced by the parents as draining and isolating. One participant reflected: "I had to explain her difference everywhere we went" (Participant G, Mother, 34 years). This finding highlights the often invisible emotional labour embedded in daily parenting.

Adaptive Coping and Meaning-Making Strategies

In response to ongoing pressures, parents employed multiple coping strategies that combined personal agency with relational support.

Information seeking and self-education

Many participants actively sought knowledge about Down syndrome to reduce uncertainty and improve caregiving confidence. One participant noted: "I Googled everything. That is how I started understanding her" (Participant A, Mother, 37 years). This finding indicates that self-education served both as a practical tool and an emotional stabiliser.

Personal emotional regulation through hobbies and outlets

Parents described engaging in personal activities to manage stress and maintain psychological balance. A participant explained: "I cook, I create content—it keeps me sane" (Participant C, Sister, 29 years). Such outlets served as important mechanisms for emotional regulation within demanding caregiving routines.

Reliance on family support

Extended family members played a significant role in sustaining caregiving. Practical assistance from relatives reduced parental burden and provided continuity of care. One of the participants reported that: "Her grandmother helped me for two years" (Participant H, Mother, 42 years). This result reflects the centrality of kinship networks in the caregiving ecosystem.

Reliance on religious support

Faith communities also emerged as meaningful sources of emotional reassurance and social acceptance. One participant stated: "My church never treated her differently—we were accepted" (Participant F, Mother, 52 years). Religious inclusion, therefore, functioned as an important buffer against broader societal pressures.

Navigating Stigma and Social Visibility

Cultural beliefs and community reactions to disability profoundly shaped parents' experiences. Participants described both stigmatising encounters and intentional resistance through advocacy.

Cultural stigma and blame narratives

Some parents encountered harmful cultural interpretations that attributed responsibility for the child's condition to the family, particularly mothers. A participant recounted: "A doctor said I was the cause after reading my palm" (Participant B, Mother, 45 years). Such experiences intensified emotional distress and reinforced feelings of marginalisation.

Experiences of social rejection

Participants also described subtle and overt forms of discrimination in everyday interactions. One of the participants noted: "People tend to distance themselves from her, and act like being around her is contagious" (Participant C, Sister, 29 years).

These responses heightened social vigilance and increased the emotional burden on parents.

Advocacy and intentional openness

In response to stigma, some parents adopted an advocacy-oriented identity characterised by openness and refusal to conceal their child. One of the participants stated: “I carry this advocacy like a calling—I do not hide my child” (Participant D, Mother, 40 years). This finding reflects identity reconstruction and active resistance to societal stigma towards children with Down Syndrome.

Support Systems and Structural Gaps

Support structures played a mixed but influential role in parents’ experiences, offering important resources while also revealing significant systemic shortcomings.

Institutional support through the Down Syndrome Foundation

The Down Syndrome Foundation Nigeria was widely recognised as a vital source of emotional support and practical assistance. One participant reflected: “The DSF carried me through my darkest days. They provided resources for me to be able to cope and support my child adequately” (Participant G, Mother, 34 years). This result highlights the foundation’s role as a key support anchor for families, caregivers, and educators to enhance support for persons with Down Syndrome and intellectual disabilities.

Informal family and sibling support

Within households, siblings and extended relatives contributed meaningfully to daily caregiving tasks. One of the participants explained: “I always had to explain things for her—at home, church, school” (Participant C, Sister, 29 years). Informal family involvement, therefore, functioned as an essential support layer.

Lack of government support

Despite the presence of informal and non-governmental supports, participants consistently emphasised the absence of meaningful state assistance. One of the participants lamented, “The government does not care about children with Down syndrome. There is nothing from the government—not even health insurance” (Participant G, Mother, 34 years). This perceived structural gap intensified reliance on family, faith, and civil society resources.

Discussion

This phenomenological study explored the lived experiences of parents caring for children with Down syndrome in Iju, Lagos State, Nigeria. The findings reveal a complex and evolving parenting journey characterised by initial psychological disruption, sustained caregiving burden, active coping efforts, ongoing negotiation with sociocultural stigma, and heavy reliance on informal and non-governmental support systems.

The findings demonstrate that the diagnosis of Down Syndrome represents a profound emotional turning point for parents, often marked by shock and distress. This pattern is consistent with family adaptation literature, indicating that the birth or diagnosis of a child with Down Syndrome constitutes a major family stressor requiring psychological adjustment. Evidence shows that families commonly experience increased stress but may gradually adapt over time (1). Notably, the present study illustrates how acceptance emerged through active meaning-making, particularly via information seeking. This finding supports stress-and-coping perspectives that conceptualise the presence of a child with Down Syndrome as a stressor that families can accommodate through adaptive processes (13).

Over time, parents in this study demonstrated resilience despite ongoing pressures. This finding aligns with Nurmalita’s work, which shows that many families can “endure, survive, and even thrive” while raising a child with Down Syndrome (14). The inclusion of one adult sibling who had assumed sustained primary caregiving responsibilities provided additional insight into family-level caregiving dynamics. While the study primarily reflects parental perspectives, the sibling participant’s account highlighted how caregiving responsibilities may extend across family members, reinforcing the collective nature of caregiving within many Nigerian households (15).

Parents in this study described caregiving as financially, occupationally, and emotionally demanding. The high cost of therapy and specialised education emerged as a dominant stressor. Existing literature confirms that caring for a child with Down Syndrome often involves lifelong and resource-intensive care needs that affect multiple aspects of family life (1).

The reported employment disruptions further illustrate how caregiving responsibilities can constrain parental economic participation. Previous studies on families of children with disabilities similarly note that caregiving demands can negatively affect professional productivity and economic stability (1, 16). Beyond material pressures, parents described emotional fatigue associated with repeated social explanations of their child’s condition. This finding contributes to the literature by highlighting the less visible emotional labour embedded in caregiving, extending beyond the traditionally measured financial and physical burdens (1, 17).

Despite substantial challenges, parents demonstrated notable agency in managing caregiving demands. Information seeking emerged as a key coping strategy, consistent with evidence that families actively mobilise coping resources to adapt to the presence of a child with Down Syndrome (13). Participants also reported using hobbies and personal activities to regulate emotional stress. These findings align with evidence that caregivers’ engagement in meaningful leisure is linked to perceived quality of life and well-being, even though caregiving demands often restrict such participation (1, 18). Family and religious networks functioned as critical protective resources. The firm reliance on extended family observed in this study reflects broader evidence that family cohesion and social support play important roles in adaptation among families of children with Down Syndrome (1).

A central contribution of this study is its illumination of the sociocultural environment surrounding Down Syndrome. Participants’ accounts of blame-oriented beliefs and social avoidance indicate the persistence of disability-related stigma. Prior psychosocial research has documented stigma experiences among mothers of children with Down Syndrome, emphasising its emotional and social consequences (1, 19). Notably, some parents in this study responded to stigma by adopting advocacy-oriented identities characterised by openness and refusal to conceal their child. This finding supports the family adaptation literature, which suggests that parents may reconstruct meaning and develop strength-based identities over time (13). These insights underscore the need for community-level disability education and stigma-reduction interventions within the Nigerian context.

Support structures in this study functioned as both enablers and constraints. The Down Syndrome Foundation Nigeria emerged as a critical lifeline, reinforcing evidence that parent support organisations play an important role in helping families adapt to the demands of Down Syndrome (1, 13). Informal family and sibling support also featured prominently, consistent with research showing that family system variables strongly influence adaptation outcomes in families of individuals with Down Syndrome (1, 13). However, participants repeatedly emphasised the absence of meaningful governmental assistance. This finding mirrors broader evidence that families caring for children with disabilities in resource-constrained settings often rely heavily on informal support due to limited state provision (20, 21). Participants’ perceptions of limited governmental assistance are noteworthy when considered alongside Nigeria’s policy landscape. The Discrimination Against Persons with Disabilities (Prohibition) Act of 2018 provides a legal framework for protecting the rights and welfare of persons with disabilities, including provisions related to healthcare access, education, and social inclusion (22). However, participants’ accounts suggest that the practical translation of these policy commitments into accessible family-level support remains uneven. Similar implementation gaps have been noted in disability scholarship within Nigeria, where legislative progress has not always been matched by adequate service delivery and funding mechanisms.

These findings highlight the need for strengthened operationalisation of existing disability policies, including improved financial protection for therapy services, expanded inclusive education support, and structured caregiver assistance programmes. Bridging the gap between policy intent and lived family experience may significantly reduce the caregiving burden reported by parents in this study.

Conclusion

This study shows that raising a child with Down Syndrome in Lagos State is an emotionally demanding yet adaptive journey for parents. Participants described an initial period of shock that gradually gave way to acceptance and resilience as families adjusted to the realities of caregiving. However, this adjustment occurred alongside significant and persistent burdens, including high therapy and education costs, employment disruptions, and ongoing emotional fatigue linked to social scrutiny. Parents did not remain passive in the face of these challenges. They actively sought information, engaged in personal stress-relieving activities, and relied heavily on family members, religious communities, and the Down Syndrome Foundation Nigeria for support. At the same time, experiences of stigma and the perceived absence of meaningful government assistance increased the caregiving burden and reinforced reliance on informal networks. Strengthening formal support systems, expanding financial and psychosocial assistance, and addressing disability-related stigma are essential steps toward improving outcomes for families raising children with Down Syndrome in this setting.

Limitations of the Study

This study should be interpreted in light of several limitations.

First, the sample size was small (n = 8). While this is consistent with phenomenological inquiry, which prioritises depth over breadth, it may have limited the range of experiences captured. Although data saturation was achieved, the findings are not intended for statistical generalisation. Rather, their transferability is most appropriate to contexts with similar sociocultural and support environments.

Second, participants were recruited through a single support organisation—the Down Syndrome Foundation Nigeria (DSFN). Families affiliated with structured support networks may have greater access to information, peer connection, and coping resources than families who are not similarly connected. Consequently, the narratives presented in this study may reflect relatively more supported or resource-aware families, potentially underrepresenting the realities of more socially isolated or underserved caregivers. Future research would benefit from recruiting through multiple community entry points to broaden experiential diversity.

Third, the sample was predominantly female, with mothers constituting the majority of participants. Although this pattern mirrors the gendered distribution of caregiving in many settings, the limited inclusion of fathers may have narrowed the range of perspectives captured. Fathers may interpret and manage caregiving demands differently, particularly in relation to financial responsibility, emotional expression, and help-seeking behaviours. Purposeful inclusion of more fathers in future studies would strengthen gender balance and enrich family-level understanding.

Fourth, confirmation of Down Syndrome diagnosis relied on the DSFN registry and parental report rather than independent verification of medical records. While the Foundation maintains a structured registration process that provides reasonable assurance of prior diagnosis, the absence of direct clinical record triangulation introduces a small degree of classification uncertainty.

Fifth, the use of self-reported interviews raises the possibility of social desirability bias. Participants connected to the Foundation may have been inclined to emphasise adaptive or socially acceptable coping narratives. Efforts such as rapport building, reassurance of confidentiality, and the use of open-ended questioning were employed to minimise this risk, although it cannot be entirely excluded.

Finally, interviews were conducted in English. Although participants were able to communicate effectively in the language, the use of English may have constrained the full expression of culturally nuanced meanings for some respondents, with the possibility that subtle experiential details were simplified in translation to formal interview discourse.

Notwithstanding these limitations, the study offers rich, contextually grounded insight into the lived experiences of parents raising children with Down Syndrome in Lagos State. These considerations should be borne in mind when interpreting the scope and applicability of the findings.

List of Abbreviations

vDS:	Down Syndrome
DSFN:	Down Syndrome Foundation Nigeria
NIH:	National Institutes of Health

Declarations

Ethical Considerations and consent to participate

Research governance and administrative permission for this study were granted on 3 April 2025 by the Down Syndrome Foundation Nigeria (DSFN), Iju, Lagos State, which acted as the recruitment gatekeeper. DSFN reviewed the protocol to confirm that the study aligned with ethical principles for research involving human participants. Given the qualitative design, the minimal risk involved, and the use of an established community organisation as the authorised gatekeeper for recruitment, the study was considered exempt from formal institutional review. All participants gave written informed consent, with separate consent for audio recording. Interviews were conducted by an experienced qualitative researcher (ACCC) with no clinical relationship to participants, and reflexive notes were kept throughout to bracket preconceptions. Signed consent forms, audio recordings, and verbatim transcripts are stored securely on a password-protected institutional computer accessible only to the research team, and all materials will be retained for a minimum of five years in line with institutional research governance requirements.

Consent for Publication

All the authors gave consent for the publication of the work.

Availability of Data

De-identified interview transcripts and the analytic coding framework are available from the corresponding author upon reasonable request. Access is subject to participant confidentiality protections and approval from the Down Syndrome Foundation Nigeria (DSFN) and relevant institutional governance requirements.

Conflict of Interests

The authors have no conflict of interest to declare.

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Author Contributions

ACCC, OF, ADP, IN: Study conception and design and Data analysis and interpretation
ACCC, ADP: Data collection
ACCC, OF, AAQ, AET: Drafting of the article
OF, ACCC, IN: Critical revision of the article

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