Supplementary File 2

Study: A Phenomenological Study of Lived Experiences of Parents Caring for Children with Down Syndrome in Iju, Lagos State, Nigeria.

SOCIODEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

Participant	Gender	Relationship	Age (years)	Years of Caregiving Experience
A	Female	Mother	37	6
B	Female	Mother	45	10
C	Female	Sister	29	15
D	Female	Mother	40	7
E	Male	Father	48	11
F	Female	Mother	52	18
G	Female	Mother	34	4
H	Female	Mother	42	8

TRANSCRIPT EXCERPTS

Extended De-identified Interview Excerpts Supporting Thematic Analysis

Article title: A Phenomenological Study of Lived Experiences of Parents Caring for Children with Down Syndrome in Iju, Lagos State, Nigeria.

Purpose of this file: This supplementary document provides extended verbatim excerpts from participant interviews to strengthen analytic transparency and illustrate how the themes and subthemes were grounded in participants' narratives. All excerpts have been carefully de-identified. Participant labels include only role and age to protect confidentiality. Minor punctuation adjustments were made for readability without altering meaning.

THEME 1: Emotional and Psychological Trajectory of Parenting

Participants described an emotionally disruptive beginning following diagnosis, followed by gradual adjustment and resilience over time.

Sub-theme: Initial shock

Participant A, mother, 37 years: “I screamed, ‘No, this can’t be my child!’ At that moment, I was confused and overwhelmed because nothing during the pregnancy had prepared me for what the doctor was saying. I kept asking questions in my head and wondering how I would cope.”

Sub-theme: Gradual acceptance and meaning-making

Participant B, mother, 45 years: “I made Google my best friend… that is how I began to heal. I spent many nights reading and trying to understand what Down syndrome really meant. The more I learned, the more my fear started reducing.”

Sub-theme: Emerging resilience

Participant F, mother, 52 years: “It is not easy, but we move. We keep going. With time, I realised that crying every day would not help my child, so I started focusing on what I could do to support her growth.”

Sub-theme: Expanded sibling responsibility

Participant C, sister-caregiver, 29 years: “I was not just a sister — I became her second mother. There were many times my parents were tired or busy, so I stepped in to help with their routines and appointments.”

THEME 2: Multidimensional Burden of Caregiving

Caregivers consistently highlighted the financial, occupational, and emotional pressures associated with long-term care.

Sub-theme: Financial strain

Participant D, mother, 40 years: “You need to be rich to afford the therapies and special schools. Every session costs money, and it is something you cannot ignore because you want your child to improve.”

Sub-theme: Time conflicts and employment disruption

Participant E, father, 48 years: “I lost my job because of the therapy appointments. I was always asking for time off, and eventually it became difficult to balance work and my child’s needs.”

Sub-theme: Emotional fatigue and social exhaustion
Participant G, mother, 34 years: “I had to explain her differences everywhere we went. Sometimes you just want to move freely without answering many questions, but people keep staring or asking.”

THEME 3: Adaptive Coping and Meaning-Making Strategies

Participants described multiple coping pathways that combined personal effort with relational and spiritual support.
Sub-theme: Information seeking and self-education
Participant A, mother, 37 years: “I Googled everything. That is how I started understanding her. I joined online groups and read articles because I did not want to remain in ignorance.”
Sub-theme: Personal emotional regulation
Participant C, sister-caregiver, 29 years: “I cook, I create content—it keeps me sane. Those little activities help me clear my head when the caregiving becomes overwhelming.”
Sub-theme: Family support
Participant H, mother, 42 years: “Her grandmother helped me for two years. Without that support, managing hospital visits and daily care would have been much harder for me.”
Sub-theme: Religious support
Participant F, mother, 52 years: “My church never treated her differently—we were accepted. That acceptance gave me strength during the early difficult period.”

THEME 4: Navigating Stigma and Social Visibility

Accounts revealed persistent stigma alongside intentional efforts by some caregivers to resist negative societal narratives.
Sub-theme: Cultural blame narratives
Participant B, mother, 45 years: “A doctor said I was the cause after reading my palm. That statement really hurt me because I was already emotionally vulnerable at the time.”
Sub-theme: Experiences of social rejection
Participant C, sister-caregiver, 29 years: “People tend to distance themselves from her and act like being around her was contagious. You notice the body language, and it can be very discouraging.”
Sub-theme: Advocacy and intentional openness
Participant D, mother, 40 years: “I carry this advocacy like a calling—I do not hide my child. I want people to see her and understand that she deserves to be included.”

THEME 5: Support Systems and Structural Gaps

Support from family networks and the Down Syndrome Foundation Nigeria (DSFN) was frequently described as helpful, while formal governmental support was perceived as limited.
Sub-theme: Institutional support through DSFN
Participant G, mother, 34 years: “The DSF carried me through my darkest days. They provided resources for me to cope and support my child when I was still trying to understand everything.”
Sub-theme: Informal family support
Participant C, sister-caregiver, 29 years: “I always had to explain things for her—at home, church, school. It became part of my daily routine as we tried to support her.”
Sub-theme: Perceived lack of government support
Participant G, mother, 34 years: “There is nothing from the government—not even health insurance. Most of the responsibility is left to the family.”