

The Role and Perspectives of Caregivers in Childhood Antiretroviral Therapy (ART) Adherence: Results of a Cross-Sectional Study in Urban Cameroon

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Abstract

Background: In sub-Saharan Africa, including Cameroon, children living with HIV depend almost entirely on their primary caregivers for daily antiretroviral therapy (ART). Although ART has made HIV a manageable condition, adherence among young children remains low because of caregiver-related, child-related, social, and structural challenges. **Objective:** This study explored the roles, challenges, and perspectives of primary caregivers of children aged 0 - 9 years living with HIV in two urban hospitals in Bamenda, North-West Region, Cameroon. **Methods:** A descriptive cross-sectional study was conducted from July 2023 to December 2024. Sixty-four primary caregivers were conveniently sampled from Bamenda Regional Hospital (n = 40) and Nkwen Baptist Hospital (n = 20), and 60 completed a semi-structured questionnaire (response rate 94%). Data on their role and perspectives were collected through in-depth interviews (IDI) and analyzed using SPSS version 25 for the quantitative aspect and Thematic Analysis Process for the qualitative aspect to identify themes. The principles of the thematic analysis technique, such as coding of data, searching for themes, refining the themes, and reporting the findings, are relatable to other qualitative methods, such as discourse analysis. Thematic analysis is a method to analyze qualitative data. It involves the identification and reporting of patterns in a data set, which are then interpreted for their inherent meaning; these patterns can be found on the basis of

understanding the meaning of keywords used by caregivers. **Results:** Most (55%) of caregivers were female, 78% of respondents were biologically related to the child, and the child stayed with the child's parents, while 93% of caregivers used reminder systems that help them administer the child's medications and other care. Self-reported adherence was good, as $\geq 85\%$ of caregivers reported it, and compliance with doses was reported by 83% of caregivers of children. Primary caregivers played multiple roles, including administering medicines—notably by mothers, as reported in 38% of cases—providing nutritional and emotional support by 32% of respondents, and 68% of caregivers ensured linking children to clinic services. The main challenges faced by respondents were forgetfulness, reported by 57% of primary caregivers; lack of food, as 72% reported that drugs are not administered at times when food was insufficient; 23% had skipped doses because no food was available; 77% reported transport difficulties; 44% cited stigma/secretcy or never gave medicine in front of others; 40% of respondents reported child refusal due to pill burden, bad taste, or side effects. **Conclusion:** Primary caregivers of young children living with HIV in urban Cameroon are highly dedicated and perform essential roles far beyond giving medicines. However, household food insecurity, transport costs, stigma, and unsuitable drug formulations seriously threaten consistent adherence. Targeted, caregiver-centred interventions that provide food support, transport assistance, child-friendly formulations, and stigma-reduction strategies are urgently needed to sustain ART adherence and improve long-term outcomes for children living with HIV.

Keywords

Childhood HIV, Antiretroviral Therapy Adherence, Primary Caregivers, Roles, Perspectives, Urban Settings, Cameroon

1. Introduction

Human Immunodeficiency Virus (HIV) and acquired immunodeficiency syndrome (AIDS) remain global public health challenges, particularly in sub-Saharan Africa (SSA), where over 1.7 million children under 15 years live with HIV [1]-[5].

Antiretroviral therapy (ART) has transformed HIV from a fatal disease to a manageable chronic condition, enabling viral suppression, immune recovery, and reduced transmission risks. However, for children living with HIV (CLHIV), achieving optimal adherence—typically defined as $\geq 95\%$ intake—is essential for long-term health outcomes, yet it is often suboptimal due to developmental, social, and systemic factors [4] [6].

Childhood adherence to ART is particularly complex, as children depend heavily on caregivers for medication administration, monitoring, and emotional support [4] [7]. In children, adherence to daily oral ART is particularly challenging due to dependency on caregivers for pill administration, adherence monitoring, and providing emotional support to mitigate stigma and fatigue [8]. Primary care-

givers play a pivotal role in pediatric ART adherence, as young children depend entirely on them for medication dosing, side-effect monitoring, and ongoing emotional encouragement to sustain long-term therapy [9]. Primary caregivers have critical roles in increasing children's adherence to ART and are typically family members or close relatives who provide partial or full unpaid care to a dependent person who is unable to care for themselves, facilitating their well-being and assisting in various tasks and activities related to the person's health such as medication adherence, wound treatment, and equipment monitoring [5]. According to Yiryuo L., *et al.* [10], these informal carers bear more pressure due to the nature of children's reliance on them to meet their basic needs, and they are frequently overloaded and under-resourced. In the paediatric population, adherence is dependent on the motivation and commitment of the parent or caregiver [6]. In SSA, where the pediatric HIV burden is highest, adherence rates average 65% - 70% [11] [12], far below UNAIDS 95-95-95 targets [13]. Caregivers, often parents or relatives, face difficulties including knowledge gaps [14] [15], stigma [16]-[18], food insecurity [18]-[20], and logistical barriers [10] [21], which exacerbate non-adherence and increase risks of virological failure [22] [23], drug resistance [5] [15] [18] [24]-[26], and preventable child morbidity and mortality [5] [10] [25] [27]-[29].

Young children are often left behind when it comes to accessing the newest medicines approved in adults. Delays are primarily driven by the availability of child-friendly formulations, lack of dosing guidance, and relevant safety information. The problem is acute in Cameroon, where political instability in the Northwest Region, including Bamenda, disrupts healthcare access, and childhood HIV coverage remains low at approximately 35% [30]. High loss-to-follow-up (LTFU) rates (up to 58%) are linked to socioeconomic challenges [31], underscoring the need for caregiver-centered interventions. This study's relevance lies in addressing these gaps by analyzing caregivers' perspectives, informing tailored models for adherence in low-resource settings.

Caregivers bear primary responsibilities such as administering medications [10] [18] [32], ensuring timely refills [33]-[35], monitoring side effects [36], and providing nutritional [10] [37] and emotional support [10] [38]. However, they encounter difficulties like forgetfulness, busy schedules, stigma fears [39] leading to non-disclosure, and resource constraints. Children factors influencing adherence include age (younger children are more dependent), refusal due to pill burden or taste, lack of understanding of their condition, and side effects like nausea and vomiting [39]. Successes noted include high use of reminder systems (93%) and strong parental involvement, which correlate with better adherence.

In sub-Saharan Africa, where the burden of childhood HIV is the highest globally [40], primary caregivers play a pivotal role in facilitating access to and adherence to ART for children under their care. Yet, the factors that motivate and sustain primary caregivers' involvement in their children's ART regimen are not well understood. Existing research has primarily focused on adherence barriers [11]

[41], with limited exploration of the factors that facilitate primary caregivers' ability to consistently engage their children in sustainable HIV care.

This study aimed to address this gap by exploring the lived role and perspectives of primary caregivers of children living with HIV in Cameroon. The study seeks to understand the key challenges and motivational strategies that enable primary caregivers to maintain consistent retention in ART for their children, ultimately enhancing their long-term health and well-being [11] [23]. Identifying the factors that drive and sustain primary caregivers' motivation is crucial for developing targeted interventions to support adherence and retention in pediatric HIV care. Understanding these motivations, whether they stem from personal convictions, social influences, or the perceived necessity for medical care, can provide valuable insights into improving ART adherence. Furthermore, examining the behavioural strategies that primary caregivers implement can identify best practices and potential areas for intervention, ultimately contributing to more effective retention strategies within ART programs. These findings can be used to design more responsive and supportive programs to address the unique needs of caregivers, ultimately improving health outcomes and quality of life for children living with HIV in Cameroon and other LMICs and/or SSA countries.

2. Materials and Methods

2.1. Study Site, Design, and Study Participants

The study was conducted at Bamenda Regional Hospital, located in the Bamenda Health District, and Nkwen Baptist Hospital, located in the Bamenda III Health District, respectively, in the North West Region, Cameroon. The Bamenda Health District and the Bamenda III Health District in Cameroon, like many regions globally, face significant public health challenges, one of which is the management and treatment of HIV among various children living with HIV/AIDS. A retrospective review of data in the Bamenda Health Districts from December 2023 to April 2024 revealed 65 primary caregivers of children aged 0 - 9 years who were receiving ART. Out of this number, two (02) deaths have been recorded and two (02) were lost to follow-up, representing 6.7%.

The research objectives were to explore the roles, challenges, and perspectives of primary caregivers of children aged 0 - 9 years living with HIV in two urban hospitals in Bamenda, North-West Region, Cameroon. The two hospitals provide differentiated HIV care services for paediatric and adult populations separately, with places for counselling. The Bamenda Regional Hospital (BRH) has two HIV care centres: one for adults called the Day Hospital and the centre for paediatric clients that cares for children and adolescents aged 0 - 19 years. The Nkwen Baptist Hospital (NBH) has one HIV Treatment Centre that has two subunits and two groups of healthcare providers. The unit for adults provides care to adults only, while the unit for paediatric care provides care to children and adolescents aged 0 - 19 years, as well as adolescents or adults who are parents or caregivers of HIV-exposed children and who are also living with HIV. This study used an exploratory descriptive

approach with quantitative methods, based on the interpretivist paradigm. This means it focused on understanding the personal feelings, experiences, and meanings that primary caregivers assign to their role in helping children aged 0 - 9 years living with HIV adhere to their antiretroviral treatment (ART).

The interpretivist approach was chosen because it is ideal for exploring the unique, personal, and socially shaped realities of these caregivers. It prioritizes seeing the world through their eyes and understanding their behavior from their own perspectives.

The study targeted caregivers of CLHIV aged 0 - 9 years in Bamenda Regional Hospital (BRH) and Nkwen Baptist Hospital (NBH), Cameroon. A convenience sample of 64 caregivers was recruited, with 42 (66%) from BRH and 22 (34%) from NBH.

The inclusion criteria were that the person had to be a caregiver of a child living with HIV, the child had to have been taking ART medicine for at least 3 months, and the caregiver had to agree to take part and had to give their informed consent.

The exclusion criteria were anyone who did not want to participate or was unable to take part, for example, because of health, language, or other reasons.

A written consent that explained the purpose of the study was distributed to the study participants and the heads of the clinics. Also, the research principal investigator (PI) and research assistants (RAs) had to explain the purpose of the study to the caregivers before data collection. All these purposively selected primary caregivers consented to the study and were asked to sign the consent forms and went on to participate in the interview. For caregivers who could not read or write, the questionnaire was completed for them after interviewing these parents/caregivers who accompanied these children. However, primary caregivers who were literate were asked to complete the questionnaire in the presence of the research staff, assisted by a nurse who had already been trained for the purpose of this study.

2.2. Ethical Considerations

Approval to carry out this study was obtained from the Institutional Review Board (IRB) of The University of Bamenda (Ref: 2022/0704H/UBa/IRB) and the Cameroon Baptist Convention Institutional Review Board (Ref: IRB 202387). Administrative clearance was obtained from the Regional Delegate of Public Health for the North West Region (Ref No 292/ATT/NWR/RDPH/BRIGAD). Administrative authorisation was obtained from the Director of Bamenda Regional Hospital (REF No R005/MPH/RDPH/RHB/369) and the Nkwen Baptist Hospital (Ref. CBC/N-BH/Admin-L/24/05). Before being allowed to access the HIV treatment Centre of the Nkwen District Hospital to pilot the data collection instruments, administrative authorisation had to be obtained from the director of the (REF.NO.I 1/MPH/RDPH/NDH/195), as well as from the individual caregivers and staff of each paediatric HIV treatment Centre, before any data collection procedure started. All necessary efforts were made to guarantee patient confidentiality throughout the

study. The study sample was calculated according to Krejcie & Morgans [42] [43]; the required sample size for children was calculated using the formula for estimating a single population proportion for a cross-sectional survey.

$$n_o = \frac{Z^2 pq}{e^2}$$

Therefore,

$$n_o = \frac{(1.96)^2 (0.5)(0.5)}{(0.05)^2} = 385$$

Finite population

$$n_0 = \frac{n_o}{1 + \frac{n_o}{N}} = \frac{385}{1 + \frac{385}{720}} = \frac{385}{1.53} = \frac{385}{1.5} = 256$$

256 – 196 (children aged 10 - 19 years)

= 60 (CLHIV aged 0 - 9 years.)

Original sample size (n): 60

Anticipated non-response rate (d): 5% or 0.05

Adjusted sample size (M): $60/(1 - 0.06) = 60/0.94 = 64$

Where N (720) is the total number of children and adolescents, or the target population (444 CALHIV at BRH and 276 CALHIV at NBH), attending the two pediatric HIV treatment centres in the two hospitals, n_0 is the required minimum sample size, Z is a standard score corresponding to a 95% confidence level, and is thus equal to 1.96, p is the proportion of awareness, but the information is not available, so 50% (0.5) is assumed to obtain the possible maximum sample size. e is the margin of error and is taken to be 5% (0.05).

The sample size for N (720) children and adolescents living with HIV (CALHIV) was calculated to be 256; children living with HIV (CLHIV) was 60 and adolescents living with HIV (ALHIV) was 196. Since the ratio of respondents in BRH to the respondents in NBHC is 2:1, the same ratio is used to calculate the number of adolescents from each Paediatric Treatment Centre for HIV, which was 40 respondents from BRH and 20 respondents from NBHC, respectively.

2.3. Data Collection

A semi-structured questionnaire divided into sections (medication description, adherence measurement, reasons for non-adherence, barriers, and the way forward) was administered by primary caregivers of children taking care of children aged 0 - 9 years. The open-ended questions served as an in-depth interview and supplemented the quantitative data. Tools were in English, with Pidgin translations for non-readers. Data collection spanned July 2023 to December 2024.

An in-depth interview method was employed to collect the data by using a semi-structured interview form. The multiple choice and open-ended questions for the in-depth interview were developed by the research team based on the relevant literature. **Table 1** shows samples of the multiple choice and open-ended questions that were used to collect data from the in-depth interview (IDI).

Table 1. Sample Questions from the Semi-Structured Questionnaire considered as IDI.

25. Sometimes, a child does not take their medicines every day or at the same time every day because of difficulties for the caregiver. What may be problems for you as a caregiver in having the child take the medicines? (Tick all that apply car to you or the child's caregiver.)

- I had difficulty with reading instructions.
- I was afraid of side effects on the child.
- I did not understand the medication instructions.
- I thought other matters were more urgent.
- I thought treatment was completed.
- I was away from home (work, field, etc.)
- I was not always around with the child.
- I was discouraged or losing hope.
- I was taking alcohol or other drugs.
- There were frequent changes in caregivers.
- I did not want others to see.
- Caregiver being too busy and forgetting.
- I had trouble with timing or giving the doses on time.
- I was not aware of the child's status.
- I did not think the drugs were helping.
- I wanted to try another treatment or prayers.
- I thought the child needed a break from the medicines.
- None of the above.
- Other (specify) _____

26. Sometimes, children do not take their medicines because of difficulties within the community. What difficulties in the community caused your child to miss taking their medicines? Stop me when you hear a problem mentioned that applies to you:

- I was unable to explain why the child was taking medicines.
- I did not want the child to be seen taking medicine.
- I was being discouraged by neighbors, friends, and family.
- I feared discrimination and isolation.
- The child was in school and I did not want to remove them from school.
- Others did not believe medicines are needed.
- I did not receive help from neighbors/friends/family
- Other: (specify) _____
- Could not get to the clinic without others wondering.
- None of the above.

27. Sometimes, problems at the clinic make it difficult for families to give these medicines every day.

Have any of these things been a problem for you?

- The clinic staff did not explain well enough how to give or take the medicine or did not write instructions.
- The clinic staff seemed to have a negative or judgmental attitude about the medicines.
- The clinic staff made you feel harassed.
- There was no money to purchase medicine (if not offered at PTC).
- The medicine was not available in the pharmacy. **Which medicine?**
- ARVs
- Septrin
- Other (include antibiotics) (specify) _____

None of the above.

One of the authors, with prior experience in in-depth interviews (EBD), conducted the face-to-face interviews in the counseling room of the Paediatric HIV Treatment Centre with only the interviewer or Researcher Assistant, who is also the ward charge of the Centre and the participant present, then Research assistants continued the rest of the IDI. Privacy was ensured by assigning an anonymous ID.

2.4. Data Management and Analysis

Quantitative data were analyzed using SPSS version 25 and STATA. Descriptive statistics, frequencies, and percentages were presented in tables and charts. Bivariate analysis used Chi-square tests for associations ($p < 0.05$ significance). Roles were measured via self-report of 1-day, 5-day, and 1-week periods, with $\geq 85\%$ classified as good. The study assessed caregivers' performance in key roles supporting antiretroviral therapy (ART) adherence for children living with HIV. These roles included acting as medication administrators to ensure no doses were missed; providing monitoring and supervision by tracking schedules, watching for side effects, and ensuring correct dosing; offering emotional support through encouragement and help with illness-related stress; and serving as advocates and educators by attending appointments, collecting medications, communicating with providers, and promoting the child's needs in family and community settings.

Performance in these roles was measured through caregivers' self-reports of how well they fulfilled their responsibilities over four recall periods: the past 1 day, past 3 days, past 5 days, and past 1 week. For each period, caregivers reported their performance level as a percentage of the ideal, and a level of $\geq 85\%$ was classified as "good" for that period.

To determine the final overall classification of "good" adherence, the longest recall period or 1 week was prioritized as the primary measure because it provides a more reliable and representative view of typical behaviour patterns and reduces over-reporting bias. Shorter periods, especially 1 day, were more vulnerable to unusual daily events, while medium periods (3 or 5 days) fell in between. Shorter recalls were considered to have offered greater precision for recent events, which were easier to remember accurately, but longer ones better captured ongoing habits. The final "good" classification required strong performance across multiple periods, with the 1-week report serving as the main criterion of $\geq 85\%$ = good, supported by shorter periods for added detail, consistency checks, and validation.

Qualitative data underwent thematic analysis, with direct quotations incorporated.

Ethical clearance was obtained from the University of Bamenda Institutional Review Board, with administrative approvals from relevant authorities. Confidentiality was ensured through coding, voluntary participation, and secure data storage.

The perspectives were analyzed using the five-step thematic analysis method. At the beginning of the data analysis process, the principal investigator independently extracted responses for the open-ended questions and linked each to

the specific respondents. This was to assure methodological accuracy and ensure that the perspectives correctly represented the statements of the participants. Once the raw data were gathered, three researchers independently created their codes and themes by reading the raw data. Then, they came together and identified the similarities and differences between the themes and subthemes they determined through codes. The researchers used code meanings and code frequencies to assess data saturation. After 60 caregivers were interviewed, it was determined that there was no new code, the data had reached the sample size, it was decided that the data were sufficient, and no more interviews were held. These were shared with the researchers participating in the study (LLN, AMBS) for their opinions and recommendations, and the final revision was made. Each author provided final approval for the publication of this version and agreed to be considered accountable for all aspects of the work.

3. Results

3.1. Socio-Demographic Factors of Caregivers and Children

Table 2. Socio-demographic factors for caregivers and children living with HIV (N = 60).

| Variable | Frequency (N) | Percentage % |
|---|---------------|--------------|
| Health facility | | |
| BRH | 40 | 67 |
| NBH | 20 | 33 |
| Child age | | |
| <5 years | 35 | 58 |
| 5 - <10 years | 25 | 42 |
| Child gender | | |
| Female | 36 | 60 |
| Male | 24 | 40 |
| Caregiver's gender (N = 60) | | |
| Female | 33 | 55 |
| Male | 27 | 45 |
| Caregiver's level of education (N = 60) | | |
| No formal Education | 10 | 17 |
| Secondary Education | 17 | 28 |
| Tertiary Education | 33 | 55 |
| Caregiver's marital status (N = 60) | | |
| Married | 09 | 15 |
| Not married | 51 | 85 |
| Caregiver HIV Status | | |
| HIV positive | 44 | 73 |
| HIV negative | 15 | 25 |
| Unknown | 01 | 02 |

Sixty primary caregivers or parents participated in this study. **Table 2** summarizes data into key findings, identifies patterns, and highlights notable trends across the variables related to health facility, child demographics, caregiver knowledge, and medication practices. It addresses potential implications and suggests areas for further investigation where relevant. For the health facility, 40 (67%) of the caregivers attended BRH, 35 (58%) of the children were <5 years old and 25 (42%) were aged 5 - <10 years, 36 (60%) were female, and 33 (55%) had attained a tertiary level of education. **Table 2** shows the sociodemographic factors for caregivers and CLHIV.

3.2. Caregiver's Factors Related to ART and other Drugs Affecting Childhood Adherence

The analysis of caregivers' knowledge of ARV prescription shows that 32 (53%) of them could not name the drug, 45 (75%) could name the dose, 33 (55%) of them were male, and 51 (85%) of the caregivers were not. Other findings revealed that 44 (73%) of caregivers affirmed that the child was on other drugs and 33 (75%) of these could name other drugs that the child was taking, 37 (84%) could name the dose, and 32 (72%) of caregivers could give the time to take the drug. Five (8%) said the child was taking herbal/traditional drugs, and 15% confirmed their child takes herbal teas or is on traditional drug use, while 40% denied it. **Table 3** shows caregivers' factors related to knowledge of ART and other drugs.

Table 3. Factors associated with knowledge of ART and other drugs (N = 60).

| Variable | Frequency Percentage | |
|---|----------------------|-----|
| | (N) | (%) |
| Caregiver's knowledge of ARV prescription (N = 60) | | |
| Could you name the drug? | 26 | 43 |
| Could not name the drug. | 32 | 53 |
| Preferred not to say | 02 | 03 |
| Caregiver's knowledge of the dose of ARV (N = 60) | | |
| Could you name the dose of ARV? | 45 | 75 |
| Could not name the dose of ARV. | 10 | 17 |
| Preferred not to say | 05 | 08 |
| Child taking other drugs (N = 60) | | |
| Child on other drugs | 44 | 73 |
| Child not on other drugs. | 09 | 15 |
| Prefer not to say | 07 | 12 |
| Caregiver knowledge on other drugs (N = 44) | | |
| Could you name other drugs? | 33 | 75 |
| Could not name other drugs. | 10 | 22 |
| Prefer not to say | 01 | 03 |

Continued

| Caregivers' knowledge on the dose of other drugs (N = 44) | | |
|---|----|----|
| Could you name other drugs? | 37 | 84 |
| Could not name the other drug. | 05 | 11 |
| Preferred not to say | 02 | 05 |
| Caregiver knowledge of the time to take other drugs (N = 44) | | |
| Caregiver could give time to take the drug. | 32 | 72 |
| The caregiver couldn't find time to administer the drug. | 02 | 05 |
| Preferred not to say | 10 | 23 |
| Herbal teas or traditional drug taking (N = 60) | | |
| Child taking herbal drug | 05 | 08 |
| Child not taking herbal drugs. | 15 | 25 |
| Preferred not to say | 40 | 67 |
| Other medications from other consultants (N = 60) | | |
| Child taking other medication from other consultants | 09 | 15 |
| The child is not taking other drugs from other consultants. | 24 | 40 |
| Preferred not to say | 27 | 45 |

3.3. Roles and Involvement of Primary Caregivers of Children Living with HIV (N = 60)

The analysis of caregivers' emotional and psychological support to keep the child healthy revealed that 15 (25%) of the caregivers concentrate on the child's nutrition, and 9 (15%) of them concentrate on nutrition or give drugs on time, all in an effort to make the child stay healthy in spite of his status of living with HIV. The findings also indicate that 23 (38%) of primary caregivers revealed that mothers are the persons who often administer medicine to the child, and 49 (82%) of respondents revealed that other persons besides caregivers know the child's HIV-positive status. It was also reported by 32 (53%) of respondents that the child has been informed of his status, and 41 (68%) caregivers always link the child to care and advocate for needs. **Table 4** shows factors associated with the roles/involvement of primary caregivers.

Table 4. Factors associated with Roles/Involvement of primary caregivers (N = 60).

| Variable | Frequency (N) | Percentage (%) |
|--|---------------|----------------|
| Caregivers' Emotional & Psychological Support to make the child stay healthy (N = 60) | | |
| Remind the child to take medicine. | 02 | 03 |
| Vaccinate child against | 01 | 02 |
| Give fruits and a balanced diet. | 05 | 08 |

Continued

| | | |
|---|----|----|
| Concentrate on the child's nutrition | 15 | 25 |
| Concentrate on nutrition/give the drug on time | 09 | 15 |
| Balanced diet and encouragement | 19 | 32 |
| Preferred not to say | 09 | 15 |
| Primary Caregiver that Often Gives Child Medicine | | |
| Mother | 23 | 38 |
| Father | 03 | 05 |
| Child's Parents | 02 | 03 |
| Others | 32 | 54 |
| Disclosure of Child's HIV Positive Status to Others besides Caregiver | | |
| Others beside the caregiver know | 49 | 82 |
| Others besides the caregiver do not know. | 09 | 15 |
| Preferred not to say | 02 | 03 |
| Child's awareness of taking ARVs/Disclosure management: (N = 60) | | |
| Child knows/has been disclosed to | 32 | 53 |
| Child does not know/has not been disclosed to | 25 | 42 |
| Preferred not say | 03 | 05 |
| Advocacy and Linkage to Care | | |
| Caregiver always links child to care and advocates for the child's needs | 41 | 68 |
| Caregiver does not always link the child to care or advocate for the child's needs. | 19 | 32 |

3.4. Challenges Faced by Caregivers and Children Living with HIV (N = 60)

Table 5 revealed that 19 (40.4%) of primary caregivers faced the challenge of a child complaining of being tired of taking too many pills every day when not sick, children of 10 (21.3%) of the primary caregivers complained of big pill size/bad taste of the drug, and 4 (8.5%) of participants said children had problems with food/finance/school. Nineteen (32%) of caregivers reported that medicines ever made the child sick/ill or had side effects, and 34 (58%) of respondents had no problems giving medicines. Twenty (34%) of primary caregivers never give medication in front of people, while 4 (44%) of the 9 respondents who never gave medication in front of people said they do so for privacy. Moreover, 43 (72%) of the caregivers reported that there were times the child missed because the caregiver did not have enough food for the family, 14 (23.3%) said they had ever failed to give medicines because of no food, and 37 (62%) of the respondents ever had problems with the child taking medicines. Twenty-three (38%) of primary care-

givers reported that they faced challenges giving medicines because the child does not know why they take the drug, 32 (53%) of these caregivers were unemployed, and of the 28 (47%) of them who were employed, 28.6% had part-time employment and casual employment respectively, and 15% of the participants said others besides the caregiver do not know of the child's HIV-positive status. **Table 5** shows factors associated with challenges faced by caregivers and children.

Table 5. Factors associated with challenges faced by caregivers and children.

| Variable | Frequency Percentage | |
|--|----------------------|------|
| | (N) | (%) |
| Child-Related Factors: (N = 47) | | |
| Refusal to take | 04 | 08.5 |
| Why take drugs when not sick? | 03 | 06.4 |
| Tired of taking too many pills every day when not sick. | 19 | 40.4 |
| Large pill size/poor taste of drug | 10 | 21.3 |
| No problem | 05 | 10.6 |
| Problems with food/finance/school | 04 | 08.5 |
| Preferred not to say | 02 | 04.3 |
| Medicines have ever made the child sick or ill /Side Effects (N = 60) | | |
| Medicines have ever made the child sick/ill. | 19 | 32 |
| Medicines never made the child sick/ill. | 38 | 63 |
| Preferred not to say | 03 | 05 |
| Caregiver Burden and Psychosocial Issues (N = 60) | | |
| Problems giving medicines | 23 | 39 |
| No problems giving medicines. | 34 | 58 |
| Preferred not to say | 03 | 03 |
| Not giving medicine in front of people (N = 60) | | |
| Never give medication in front of people. | 20 | 34 |
| Ever give in front of people? | 38 | 63 |
| Preferred not to say | 02 | 03 |
| Reasons for not telling others that the child takes medicine (N = 09) | | |
| Privacy | 02 | 22 |
| I do not want others to know. | 04 | 44 |
| Preferred not to say | 03 | 33 |
| Times child ARV because caregiver does not have enough food for family (N = 60) | | |
| At times, there is not enough food. | 43 | 72 |
| No time when there is not enough food | 17 | 28 |

Continued

| Caregiver never gave child medicines because there was no food (N = 60) | | |
|---|----|------|
| Ever failed to give medicines because there was no food? | 14 | 23.3 |
| Never failed to give the child medicines because of lack of food. | 44 | 73.3 |
| Preferred not to say | 02 | 03.7 |
| Challenges with getting the child to take medicines (N = 60) | | |
| Ever have problems with a child taking medicines? | 37 | 62 |
| Never have problems with a child taking medicines. | 20 | 33 |
| Preferred not to say | 03 | 05 |
| Had challenges giving medicines because the child does not know why to take the drug (N = 60). | | |
| Problems giving medicines | 23 | 38 |
| No problems with giving medicines | 34 | 57 |
| Preferred not to say | 03 | 05 |
| Employment Status | | |
| Employed | 28 | 47 |
| Not employed | 32 | 53 |
| Type of employment (N = 28) | | |
| Full-time employment | 12 | 42.9 |
| Part-time employment | 08 | 28.6 |
| Casual employment | 08 | 28.6 |
| Disclosure of Child's Status to Others besides Caregiver | | |
| Others beside the caregiver know | 49 | 82 |
| Others besides the caregiver do not know. | 09 | 15 |
| Preferred not to say | 02 | 03 |

3.5. Challenges Associated with Transport (N = 60)

From **Table 6**, which presents challenges primary caregivers faced that are related to transport, it can be deduced that 22 (36.7%) of primary caregivers took more than one hour to travel to the Paediatric HIV Treatment Centre, 14 (23.3%) spent more than 1000 FCFA as one-way transport cost to reach the Centre, 46 (77%) of the participants had difficulties with transport, with 10 (22%) of caregivers who had difficulties with transport experiencing these difficulties many times, and 18 (39%) of them expressing a lack of money and time to enable them to travel to the paediatric treatment centre. **Table 6** shows challenges caregivers faced that are associated with transport.

Table 6. Challenges associated with transport.

| Variable | Frequency (N) | Percentage % |
|---|---------------|--------------|
| Distance in time to travel to clinic (N = 60) | | |
| 0 - 30 minutes | 13 | 21.7 |
| 31 mins - 1 hr | 25 | 41.7 |
| >1 hr | 22 | 36.7 |
| Transport to come (one way) to the clinic (N = 60) | | |
| <300 FCFA | 08 | 13.3 |
| 300 - 500 FCFA | 21 | 35 |
| >500 - 1000 FCFA | 17 | 28.3 |
| >1000 FCFA | 14 | 23.3 |
| Difficulties with Transport (N = 60) | | |
| Have difficulties with transport. | 46 | 77 |
| No difficulties with transport or not | 14 | 23 |
| Frequency of difficulties with transport (N = 46) | | |
| Many times | 10 | 22 |
| Sometimes | 25 | 54 |
| Occasionally | 11 | 24 |
| Kind of problem (N = 45) | | |
| Lack of money | 15 | 33 |
| Lack of means | 07 | 15 |
| Lack of time | 06 | 13 |
| Lack of money/time | 18 | 39 |

3.6. Perspectives of Primary Caregivers on Roles and Challenges in ART Adherence

Caregivers' perspectives, as captured in responses to the open-ended questions, revealed a mix of dedication, frustration, and practical concerns. While there are no direct verbatim quotes, the data reflect their voiced experiences through survey responses. These include emotional support and adherence, medication administration challenges, child resistance and side effects, logistical barriers, and support networks.

Emotional support and adherence: Caregivers view their role as holistic, emphasizing nutrition and encouragement. One perspective is seen in 32%, who said they provide a “*balanced diet and encouragement*” R10, R11, R12, R14, to keep the child healthy, showing a belief in combining medical adherence with positive reinforcement. Another 25% focused solely on “*concentrate on child's nutrition,*” R13, R19, R20, R50, indicating they see food as key to making ART tolerable and effective. See **Table 4**, which shows factors associated with the roles/involvement of primary caregivers.

Medication administration challenges: Perspectives highlight stigma and secrecy. For example, 44% of those not telling others cited “*I do not want others to*

know,” R47, R48, reflecting fears of judgment or isolation. On assessing perspectives on problems hindering adherence, 30% mentioned “*having to take medicines*” and 22% of them feared “*discrimination and isolation*,” R43, R46, R47, R48, R49, R50, R51, R52, R53, suggesting caregivers feel burdened by constant justification and social risks. See **Table 5** for factors associated with challenges faced by caregivers and children.

Child resistance and side effects: Caregivers express concern over the child’s understanding and well-being. 40.4% noted the child being “*tired of taking too many pills every day when not sick*,” R7, R11, R16, R20, R23, R25, R36, R42, R47, R48, R53, and in worries causing non-adherence, 23% highlighted the child “*asking why taking medicines*,” R8, R9, R11, R25, R29, R42, R43, R46, R55, R56, R60, indicating caregivers perceive a need for better age-appropriate explanations. Additionally, 15% pointed to medicines being “*too bitter*” R6, R16, R36, R42, R43, R46, R47, R48, R51, R52, R53, or causing refusal, showing frustration with drug formulations. See **Table 5** that shows factors associated with challenges faced by caregivers and children.

Logistical barriers: Perspectives on transport and resources are pragmatic and highlight inequities. In the family difficulties graph, 27% each cited “*no money for transport to clinic*” and “*no transport to clinic available*,” R7, R11, R16, R20, R28, R36, R43, R47, R48, R50, R51, R52, R53 while 18% mentioned “*too little/no food to give with medicine*.” R3, R5, R8, R11, R12, R16, R17, R22, R24, R25, R30, R49 This reflects caregivers’ view that external factors like poverty and infrastructure undermine their efforts, with 13% in clinic problems noting “*no money to purchase medicine*” R6, R16, R17, R26, R47, R48, if not free. See **Table 6:** that shows Challenges Associated with transport.

Support networks: Caregivers’ living situations influence adherence, with 78% reporting that the child is staying with the child’s parents and 38% saying the child stays with a spouse. However, 12% in hindrances mentioned being “*discouraged by neighbors/friends/family*,” R1, R11, R28, R29, R40, R53, and 7% felt a lack of help from them, suggesting mixed perspectives—family can provide support but also add pressure or disbelief in the need for medicines (7%) of the caregivers.

Overall, caregivers appear committed but overwhelmed, often prioritizing privacy and basic needs while advocating for better clinic support and child-friendly drugs to improve ART adherence. These insights underscore the need for targeted interventions to ease their burdens.

3.7. Reasons for Missed Dose

According to **Figure 1**, which displays six common reasons for a person or caregiver to miss a dose of medication, 34 (57%) complained it was due to forgetfulness, 30 (50%) were too busy, 29 (48%) cited caregiver problems keeping to the time of giving medicines, 20 (34%) did not want to give in the presence of other people, 13 (22%) had no food, and 4 (9%) reported refusal by the child to take.

Figure 1 shows the reasons for missed dose.



Figure 1. Reasons for missed doses.

3.8. Worries about Medicines: Worries That Caused the Child Not to Take Medicines

An analysis of the data on Figure 1 reveals the following distribution of worries that caused children not to take medicines as follows: 30% of respondents cited “*Forgot to take medicine*”, 23% of respondents reported that their children asked why they were taking the medicines, some were tired of taking the medicines, and were playing or at school or work. Twenty-two percent of respondents indicated that they felt better, 17% of respondents said they did not understand the medication instructions, 15% of respondents said the children find medicines “*too bitter*” and refused to take medicine, 12% of respondents indicated that their child felt ill or was vomiting after taking the drug, 8% of caregivers said their child does not want others to see the medicines, 7% of respondents cited “*Has problems with 1 formulation (tablets, liquids)*” and “*Believes medicine does not help*”, 5% of respondents cited other worries such as complaining bitter but will still end up taking the drug, while 3% of respondents said their child cannot take without food. Figure 2 shows worries that caused the child not to take medications.

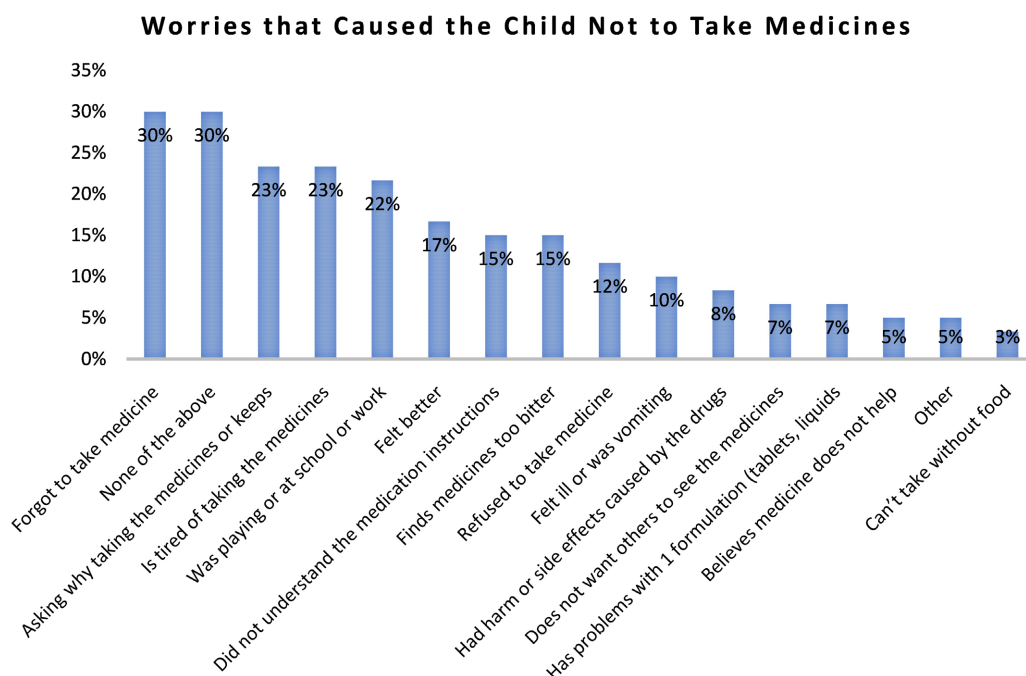


Figure 2. Worries that caused the child not to take medications.

3.9. Problems Medication Administration Challenges

Figure 3 on problems that hinder caregivers in having a child take medicines shows that 58% reported that they faced none of the problems listed that hinder caregivers in having a child take medicines, 30% of caregivers feared discrimination and isolation and that hindered them in having a child take medicines, 22% of the respondents indicated that the child was in school and they did not want the child to be removed from school, 18% of respondents did not want the child to be seen taking medicines, 15% of caregivers could not get to the clinic without others wondering, 12% said they were being discouraged by neighbors/friends/family, 7% of respondents said they did not receive help from neighbors/friends/family, and equally others did not believe medicines are needed while 2% of caregivers were unable to explain why the child was taking medicines. **Figure 3** shows problems in the community that hinder caregivers in having a child take medicines.

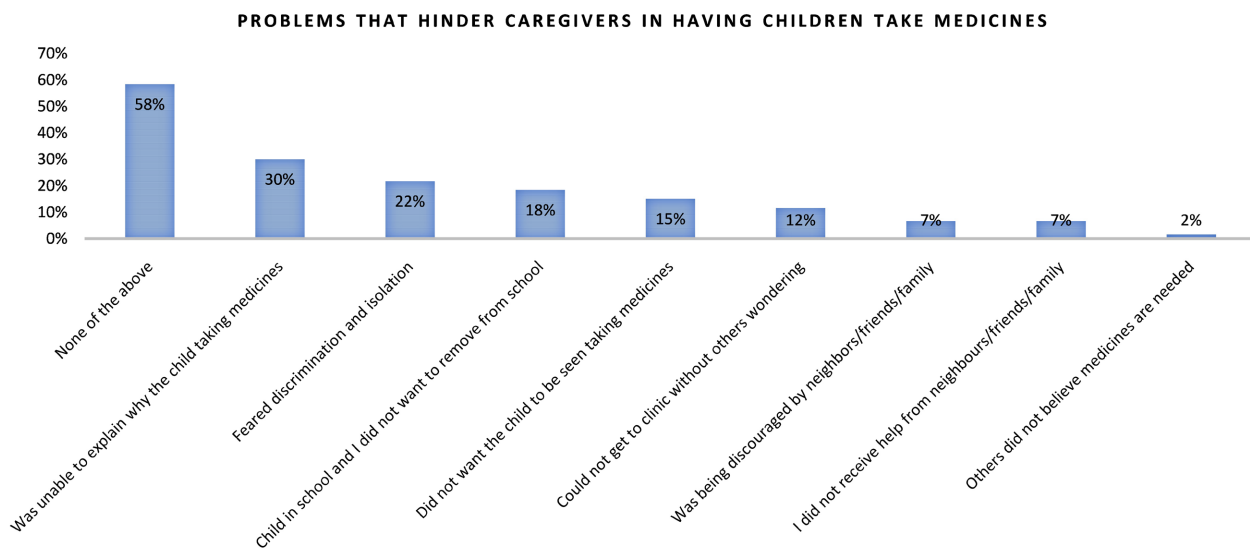


Figure 3. Problems in the community that hinder caregivers in having children take medicines.

3.10. Clinic Problems That Made It Difficult for Families to Give the Child Medication

As seen in **Figure 4**, which displays clinic problems that made it difficult for families to give child medication, 71% of respondents reported they had no problem, 16% complained that the staff made them feel harassed, 13% reported that the staff did not explain well enough and equally had no money to purchase medicine respectively, 9% reported that the medicine was not available in the pharmacy, 4% complained that the staff seemed to have a negative/judgmental attitude, while 2% of the caregivers reported other problems, which include the stock-out of antibiotics for opportunistic infections. **Figure 4** shows problems at the level of the

clinic that made it difficult for families to give the child's medication.

Clinic Problems That Made It Difficult for Families to Give the Child Medication

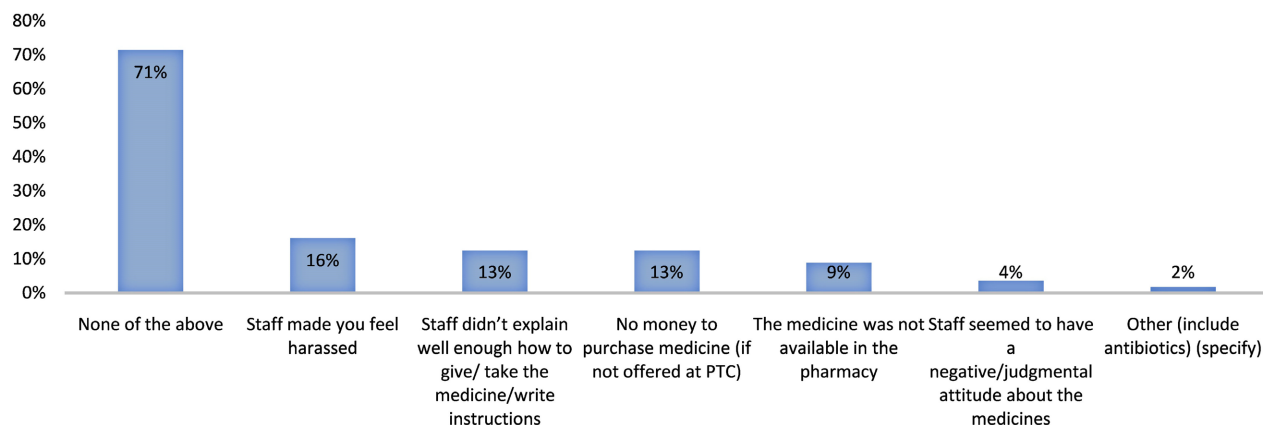


Figure 4. Clinic problems that made it difficult for families to give child's medication.

From **Figure 5**, which presents data on family difficulties related to medicines, 27% complained that they had no money for transport to the clinic or no transport to the clinic was available, 18% of caregivers said they had too little or no food to give with medicine and suffered pouring (vomiting) of medicines, 17% of respondents ran out of medicine before the clinic appointment, 15% of participants said they needed to hide medicines, 13% of caregivers said they had no clean water to use with medicines, and 12% of participants said that the family refused medication.

Family Difficulties Related to Medicines

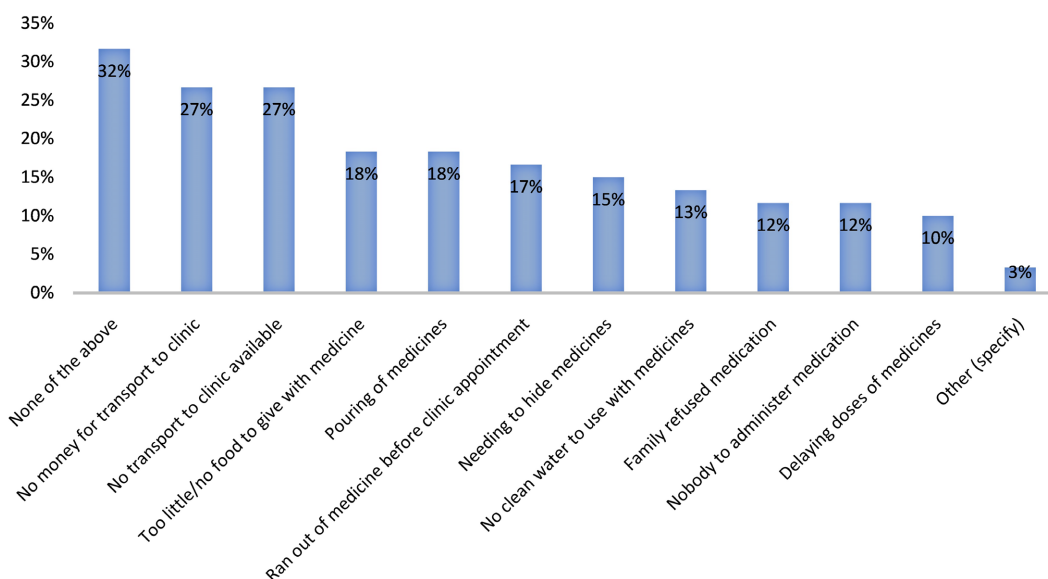


Figure 5. Family difficulties related to medicines.

Figure 5 shows family difficulties faced by participants that were related to medicines.

3.11. Person Caregiver and Child Stay With

From **Figure 6** on whom the caregiver and child stay with, it is seen that 78% of the respondents reported they stay with the child's parents, 38% and 37% of caregivers reported staying with the caregiver's spouse and the caregiver's partner respectively, 20% of respondents reported staying with the child's grandparents, 15% of the caregivers said they stayed with friends, and 12% said they stayed with other children. Seven percent of caregivers reported they and the child stayed with the child's uncle/aunt/cousins, while 2% of the respondents respectively said they were staying alone and with other persons such as an adopted mother. **Figure 6** shows the persons with whom the caregiver and child stay.

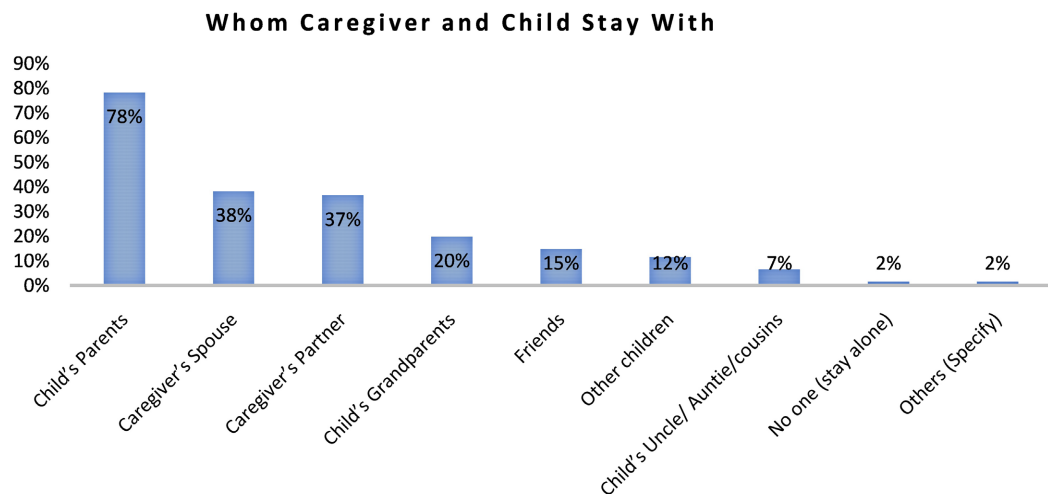


Figure 6. Person, caregiver, and child stay with.

3.12. Other Persons in the Household Taking Medicines

From **Figure 7**, which presents who else, besides the child, is also taking medicines, 78% of the caregivers reported that the child's parents are taking medicines alongside the child, 38% of the respondents revealed that the caregiver's spouse is also taking medicines, 37% of the respondents indicated that the caregiver's partner is also taking medicines, 20% of participants reported that the child's grandparents are also taking the medicines, 15% of caregivers indicated that friends of the child are also taking ARVs, and 12% reported that other children or siblings of the child are also taking medicines. Seven percent of respondents reported that the child's uncle/aunt/cousins are also taking medicines, 2% of caregivers stay with no one (stay alone) and would not know the other persons who take the medicine, while another 2% reported other persons taking medicines such as an adopted father. **Figure 7** shows other persons who also take medicines or ARVs.

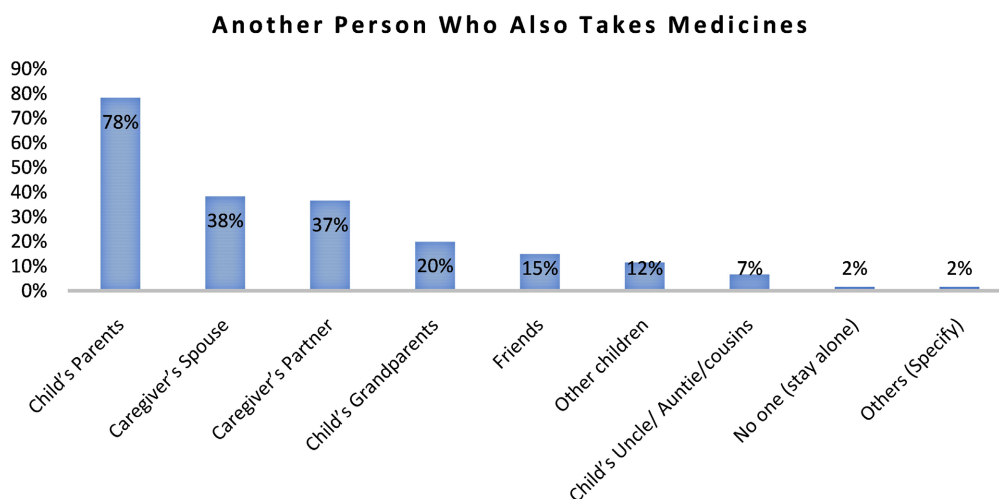


Figure 7. Another person who also takes medicine.

3.13. Association between Adherence to ART and Some Adherence Factors

According to **Table 7** presenting the association between adherence to ART and some adherence factors, with statistical analysis using Chi-square (X^2) tests and corresponding p-values, the primary caregiver involvement showed 51.2% good adherence (21/41) and 48.8% poor adherence (20/41), which is deemed maximum involvement, while 36.8% good adherence (7/19) and 63.2% poor adherence (12/19) is deemed minimum involvement. $X^2 = 0.578$, $p = 0.447$ is not statistically significant. Concerning child age <5 years, 51.4% had good adherence (18/35) and 48.6% poor adherence (17/35).

For the children 5 - < 10 years: 40.0% had good adherence (10/25), 60.0% had poor adherence (15/25).

$X^2 = 0.768$, $p = 0.381$, implying the age difference is not statistically significant.

For caregiver gender: male: 45.5% good adherence (15/33), 54.5% poor adherence (18/33).

Female: 48.5% good adherence (13/27), 51.9% poor adherence (14/27), while $X^2 = 0.043$, $p = 0.835$, meaning gender is not statistically significant.

Concerning whether someone besides the caregiver knows the child is on ARV, those for whom someone knows had 51.0% good adherence (25/49) and 49.0% poor adherence (24/49). Those for whom someone does not know had 33.3% good adherence (3/9) and 66.7% poor adherence (6/9), with $X^2 = 2.620$ and $p = 0.106$, which is not statistically significant.

For the child's knowledge of taking ARV, the "Child knows" group had 37.5% good adherence (12/32), and 62.5% poor adherence (20/32). The "Child doesn't know" group had 60.0% good adherence (15/25), and 40.0% poor adherence.

For difficulties with transport to clinic, those who encountered difficulties had 43.5% good adherence (20/46) and 56.5% poor adherence (26/46). Those who en-

countered no difficulties: 57.1% good adherence (8/14), 42.9% poor adherence (6/14). $X^2 = 0.350$, $p = 0.370$, which is not statistically significant. **Table 7** shows the association between adherence to ART and some adherence factors.

Table 7. Association between Adherence to ART and some adherence factors.

| Variable | Good ART adherence N (%) | Poor ART Adherence | X^2 | p-value |
|--|--------------------------|--------------------|--------------|--------------|
| Primary caregiver Involvement | | | | |
| Maximum involvement | 21 (51.2%) | 20 (48.8%) | 0.578 | 0.447 |
| Minimum involvement | 7 (36.8%) | 12 (63.2%) | | |
| Child age | | | | |
| <5 years | 18 (51.4%) | 17 (48.6%) | 0.768 | 0.381 |
| 5 - <10 years | 10 (40.0%) | 15 (60.0%) | | |
| Caregiver gender | | | | |
| Male | 15 (45.5%) | 18 (54.5%) | 0.043 | 0.835 |
| Female | 13 (48.5%) | 14 (51.9%) | | |
| Someone besides caregiver Knowledge of child on ARV | | | | |
| Someone knows | 25 (51.0%) | 24 (49.0%) | 2.620 | 0.106 |
| Someone doesn't know | 3 (33.3%) | 6 (66.7%) | | |
| Child's knowledge of taking ARVs | | | | |
| Child knows | 12 (37.5%) | 20 (62.5%) | 3.101 | 0.214 |
| Child doesn't know | 15 (60.0%) | 10 (40.0%) | | |
| Difficulties with transportation to the clinic | | | | |
| Difficulties with transport | 20 (43.5%) | 26 (50.5%) | 0.350 | 0.370 |
| No difficulties with transport. | 8 (57.1%) | 6 (42.9%) | | |

4. Discussion

The findings from this study underscore the pivotal roles played by primary caregivers in facilitating antiretroviral therapy (ART) adherence among children living with HIV (CLHIV) in an urban setting in Cameroon, while also highlighting the multifaceted challenges these primary caregivers encounter and their nuanced perspectives on these experiences. By exploring these elements through a descriptive cross-sectional design involving 60 caregivers from Bamenda Regional Hospital and Nkwen Baptist Hospital, the study provides valuable insights into the caregiver-child dyad in a low-resource context marked by political instability and socioeconomic constraints.

4.1. Roles of Primary Caregivers

Primary caregivers in this study emerged as central figures in the management of childhood HIV, with roles extending beyond mere medication administration to encompass emotional support, advocacy, and coordination of healthcare services.

A striking 93% of caregivers reported using reminder systems, with reports of 50% of them using phones or 13% using alarm clocks to ensure timely ART dosing, aligning with their maximal involvement in 68% of cases. This involvement included 38% of mothers administering medications and 54% of other relatives monitoring side effects and providing nutritional support, as evidenced by reports of 32% of respondents emphasizing balanced diets and encouragement. These roles reflect the definition of primary caregivers as unpaid family members or relatives who facilitate well-being through tasks like adherence support, as articulated in the introduction drawing from Yiryuo *et al.* (2024) [10].

These findings align with a study by Attigah *et al.* (2025) [24] in Ghana that also described caregivers' roles as motivational and behavioral strategists, focusing on reminders and emotional encouragement to enhance retention in ART, much like the 93% reminder usage here. Both studies highlight caregivers as advocates linking children to services, with 68% of primary caregivers in this study always facilitating clinic access, akin to Attigah's emphasis on navigating healthcare systems. The current study's findings also align with those of another study in the SSA context by Yiryuo *et al.* (2024) [10] in Ghana, that reported caregivers' overburdened yet committed roles in emotional nurturing and medication monitoring, mirroring the holistic approach reported by the current study, where 25% of primary caregivers prioritized nutrition alone. These alignments underscore a regional pattern in sub-Saharan Africa where caregivers compensate for systemic gaps, such as limited paediatric formulations, by integrating medical and psychosocial support. These similarities show a common trend across sub-Saharan Africa whereby caregivers make up for weaknesses in the health system, like the lack of child-friendly medicines or limited paediatric formulations, by combining medical care with emotional support or by integrating medical and psychosocial support.

However, differences arise in the scope and intensity of roles. In contrast to this study's urban Cameroonian focus, where 85% of caregivers were knowledgeable about dosing but only 47% could name drugs, a study by Nasuuna *et al.* (2019) [23] in Uganda reported higher knowledge levels of over 80% of primary caregivers for drug naming, possibly due to more robust counseling programs. This discrepancy may stem from Cameroon's sociopolitical instability in the Northwest Region, as noted by Nshomwezi *et al.* (2023) [44] [45], which disrupts education and training. Additionally, while Lahai *et al.* (2020) [32] in Sierra Leone emphasized caregivers' roles in disclosure similar to the 53% child disclosure in this current study, their study reported lower emotional support integration, focusing more on logistical tasks. This suggests, in the context of our study, that caregivers' roles are more emotionally intensive due to stigma reported by 30% of participants, differing from settings with stronger community support networks.

This may be because, in our study, caregivers had to provide more emotional support because 30% of them faced stigma. This finding differs from that reported by Kamphuis AEM *et al.* (2024) [4], with stronger community help; for example,

community health workers (CHWs) from the same villages were used to support caregivers, and the community assisted CHWs with transport to clinics, food parcels, group counselling for caregivers, and teaching kids why they take medicine. The current study also differs from a Ugandan study by Izudi J. *et al.* (2024) [46], in which young people living with HIV (aged 18 - 24) who were trained as Community Adolescent Treatment Supporters (CATS) visited homes, reminded kids to take medicine, provided emotional support, and linked families to clinics. As a result, caregivers felt less alone, stigma was reduced, and adherence improved because the community was actively involved. The findings of 30% of caregivers having reported stigma in the community moreover, differ from those of qualitative findings involving caregivers of children living with HIV by Pius *et al.* (2021) [45], who reported several interpersonal, health worker, and health system-level factors that influence ART adherence and VL suppression.

Furthermore, the study found that 73% of children were on additional drugs, with 75% of caregivers demonstrating high knowledge of naming these additional drugs, a finding that aligns with a study carried out in South Sudan by Tong *et al.* (2020) [36] on monitoring polypharmacy but differs from an Ethiopian study by Gemechu *et al.* (2023) [25], where caregiver knowledge gaps led to poorer adherence. This shows that caregivers in Cameroon are very good at adapting and finding solutions, and this strength may also come from the helpful education and support they receive at the BRH and NBH paediatric treatment centres.

Overall, these roles position caregivers as indispensable in achieving UNAIDS 95-95-95 targets, yet they reveal a need for tailored training to bridge knowledge disparities.

4.2. Challenges Faced by Primary Caregivers

The challenges identified in this study encompass forgetfulness reported by 57% of caregivers, food insecurity reported by 72% of participants, transport barriers complained of by 77% of the caregivers, and stigma reported by 30% of them. These aforementioned challenges threaten sustainable ART adherence, despite self-reported good adherence by 83% of the caregivers. Child-related factors, such as pill refusal reported by 8.5% of respondents due to taste or size as reported by 21.3%, side effects as revealed by 32% of them reporting illness after taking medications, and the compounded caregiver burdens reported by 62% of the caregivers who were revealed to be struggling to administer drugs. Logistical issues, including travel times over 31 minutes for 78.4% and costs exceeding 300 FCFA for 86.6%, reflect broader resource constraints in SSA.

The primary caregivers in our study cited challenges such as food insecurity, which negatively affected 23.3% of them and was the reason for which the child missed doses of ARVs. Transport challenges were also cited by 27% of the respondents, who said they had no money for clinic visits, similar to this study's 17% poor adherence.

... akin to this study's 17% poor adherence. These findings have evident simi-

larities with those of a study carried out in Malawi by Phiri *et al.* (2025) [18], which cited challenges of food insecurity and transport, linking them to viral non-suppression in children under 9.

The current study's finding that 23.3% of caregivers skipped doses due to lack of food aligns with the finding by Owens *et al.* (2024) [20] in the U.S. context, though not in SSA, that echoed food insecurity's impact on adherence, emphasizing its universal effect in exacerbating caregiver stress. In Ethiopia, Wondifraw *et al.* (2025) [15] found that non-adherence rates of 35% - 40% were due to forgetfulness and stigma, which is similar to the forgetfulness cited by 57% of caregivers and secrecy cited by 34% of the respondents said to be due to stigma or fears in this current study. These similarities point to systemic issues in low- and middle-income countries (LMICs), where economic vulnerabilities amplify adherence barriers, as per Magura *et al.* (2025)'s [12] scoping review on SSA ART adherence.

The findings in the current study showed that the drug formulation issues were less emphasized, suggesting they may not be as prominent a challenge in this setting. On the other hand, in the Kenyan study by Finocchario-Kessler *et al.* (2025) [39], caregiver difficulties mainly focused on issues with paediatric HIV medications, such as their bitter taste, which often led to children refusing to take the medicine, for example, by spitting it out, vomiting, or running away, and this was a major barrier to ART adherence by children. The current study also found that 15% of primary caregivers reported herbal use, considered to be much lower and likely because of urban access to formal healthcare services in Bamenda, which made it easier to get standard treatments without turning to alternatives. This finding differs from the finding of a rural Kenyan study context carried out by Finocchario-Kessler *et al.* (2025) [39], which found that caregivers relied more heavily on herbal or traditional alternatives for treating children, especially during clinic stockouts when formal HIV medications were unavailable.

Moreover, in this study, clinic unavailability was reported by only 9% of the primary caregivers, which is lower than in rural Kenyan settings, further reducing the need for herbal options.

The current study in Cameroon found that 44% of caregivers reported non-disclosure, which was slightly lower and driven more by general privacy concerns rather than extreme stigma. This suggests Cameroonian caregivers face stigma that is still widespread but less severe, possibly influenced by cultural norms that are more accepting or less openly discriminatory.

This finding differs from a study by Finocchario-Kessler *et al.* (2025) in Kenya [39] where 50% of cases involved non-disclosure due to intense stigma, in which caregivers avoided sharing the child's HIV status because of fear of discrimination or social rejection.

The current study, non-disclosure reported by 44% of caregivers, was slightly lower and driven more by general privacy concerns rather than extreme stigma. This may be because Cameroonian caregivers face stigma that is still widespread

but less severe, possibly influenced by cultural norms that are more accepting or less openly discriminatory.

The findings of the current study Cameroon show that 70% of primary caregivers faced transport challenges for clinic visits, but the barriers were more complex, as 39% of caregivers cited a combination of lack of money and time constraints. This reflects Bamenda's urban layout, where clinics are closer, but ongoing instability, for example, the conflict-related disruptions, affects infrastructure, making even short trips unreliable [45].

Similar transport challenges were reported by Yiryuo *et al.* (2024) [10] in Ghana and affected 77% of caregivers, but their main issue was physical distance to clinics, with less emphasis on other factors like cost or time, as in the case of the current study.

These differences show how local factors like urban access, cultural attitudes, and infrastructure stability shape HIV care challenges beyond just general barriers such as food or transport.

Psychosocial burdens, such as struggling with child non-understanding, were reported by 38% of primary caregivers, aligning with Nabunya *et al.* (2023) [17] on parenting stress in Uganda, but differing in magnitude, as the Ugandan study caregivers reported higher mental health impacts, possibly due to less facility support than in Cameroon's hospitals. Water and hygiene issues were reported by 75% of participants in the current study not boiling water, differing from Chongwo *et al.* (2025) [19] in Kenya, where food insecurity dominated without hygiene emphasis. These challenges collectively underscore the need for integrated interventions, as non-adherence risks virological failure [22] and resistance [24].

4.3. Perspectives of Primary Caregivers

Caregivers' perspectives in this study revealed a blend of commitment and frustration, viewing their roles as holistic yet hindered by external factors. Open responses highlighted dedication to nutrition; 32% of primary caregivers cited a balanced diet and encouragement, and 44% of them cited secrecy for privacy, while 40.4% of the respondents talked of being tired of pills, and 27% cited no transport money, expressing concerns over child resistance and logistical inequities. Overall, they perceived adherence as achievable with support, advocating for child-friendly drugs and clinic improvements.

These findings align with those of qualitative studies, such as a Tanzanian study by Msoka *et al.* (2025) [16], that captured caregivers' views on disclosure and stigma, similar to 82% of participants sharing status beyond themselves in the current study, and emphasized emotional reinforcement for adherence. Atanuriba *et al.* (2021) [11] in Ghana matched the perspectives on nutritional integration as key to tolerance, with primary caregivers seeing food as motivational, like the 25% of primary caregivers focusing on child nutrition. Like the current study, the study by Sensoy *et al.* (2025) [41] in Türkiye, though non-SSA, shared frustrations with

pill burden and side effects, viewing better formulations as essential, aligning with the 21.3% of primary caregivers who reported that their child had complaints about bad taste.

This study's urban sample, like the study by Pantelic *et al.* (2024) [48], highlighted privacy over community networks, possibly due to higher stigma in conflict zones.

The current study, unlike the Ugandan study by Nasuuna *et al.* (2019), [23] where caregivers perceived social support as facilitative, had mixed feelings, with 12% of the participants discouraged by family.

The current study is similar to a Zambian study by Mzyece and Munalula (2025) [49] in that both advocate for decentralized services, but differ in that this study emphasizes transport and food, while the Zambian study focused on viral load access barriers. The current study had perspectives on support networks, with 78% of the primary caregivers living with parents, in contrast to a Ugandan study by Mengesha *et al.* (2020) [50], where orphan caregivers felt more isolated, suggesting familial structures in Cameroon provide resilience despite burdens.

These insights inform primary caregiver-centered models, as per Kamphuis *et al.* (2024) [4], emphasizing motivations arising from personal convictions and necessities.

4.4. Limitations of the Study

This study has several limitations. The convenience sampling of 60 caregivers from two urban hospitals may limit generalizability to rural or other Cameroonian regions, potentially introducing selection bias toward more accessible participants. Self-reported adherence of 83% considered as good risks social desirability bias, as pill counts and viral load data were not comprehensively verified, differing from studies like Rivas C., *et al.* (2024) [51] using cohorts. The cross-sectional design precludes causality, unlike longitudinal approaches in Hunziker & Blankenagel (2021) [47]. Qualitative data, while thematic, lacked verbatim quotes, reducing depth compared to Yiryuo *et al.* [10]. Political instability may have affected participation, and the focus on 0 - 9-year-olds excludes adolescent perspectives. Finally, no significant associations ($p > 0.05$) between adherence and factors like age or gender may stem from the small sample size, limiting statistical power. Despite these barriers, caregivers showed strong commitment, emphasizing balanced diet, encouragement, and privacy protection. No statistically significant associations were found between adherence and child age, caregiver gender, or transport problems (all $p > 0.05$), probably because of the small sample size.

5. Conclusion

In conclusion, primary caregivers in urban Cameroon are essential in driving ART adherence for CLHIV through multifaceted roles, yet they face substantial challenges from food insecurity, transport, and stigma, shaping perspectives of dedication amid frustration. Comparisons with SSA studies reveal shared barriers but

contextual differences, emphasizing the need for integrated support to sustain adherence and meet global targets. By addressing these, health outcomes for CLHIV can improve, transforming HIV management in resource-limited settings.

6. Suggestions for Further Research

Future studies should adopt longitudinal designs to track adherence trajectories and causal factors, incorporating viral load outcomes as in Phiri *et al.* (2025) [18]. Larger, multi-site samples including rural areas could enhance generalizability, with mixed-methods approaches capturing verbatim caregiver voices, for example, per Attigah *et al.* (2025) [24]. Interventions testing decentralized services or nutrition programs, informed by this study's recommendations, warrant evaluation. Exploring adolescent caregivers or male perspectives, underrepresented here, and integrating mental health assessments [17] could deepen understanding. Finally, comparative studies across SSA countries could identify scalable best practices for caregiver support.

Ethical Approval

Approved by the Institutional Review Board of the University of Bamenda (Ref: 2022/0704H/UBa/IRB).

Approved by the Cameroon Baptist Convention Institutional Review Board (Ref: IRB 202387).

Authors' Contributions

EBD, LLN, AL, and AMBS conceptualized the study. EBD, LLN, AL, and AMBS developed the methodology. Formal analysis was conducted by EBD, LLN, and AMBS. The original draft was prepared by EBD, LLN, AL, and AMBS.

All authors reviewed and approved the final manuscript.

Conflicts of Interest

The authors declare no competing interests.

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