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Loss to Follow-up among Children and Adolescents Attending ART Clinics in the Context of Socio-Political Crises in the Northwest and Southwest Regions of Cameroon (2018-2021): The Caregiver's Perspectives

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Abstract

Background: Loss to Follow-Up (LTFU) among HIV positive children and adolescents greatly contributes to sub-optimal retention in HIV prevention and treatment program outcomes. This can be worse among conflict affected areas of the country. LTFU threatens efforts to ensure longevity and survival of children and adolescents living with HIV. In the context of the ongoing socio-political crises and instability in the Northwest and Southwest Regions of Cameroon, we investigated reasons for LTFU among children and adolescents enrolled on ART.

Methods: We conducted a qualitative study, nested within a larger cohort study (2018-2022) on assessing the incidence of LTFU among children and adolescents in two regions of Cameroon. The data collection was done from November 2021 to January 2022.We traced and interviewed 25caregivers of children and adolescent's LTFU. Recorded interviews were transcribed, translated and then analyzed using Atlas-ti Version 9.

Results: The following reasons were reported as the main contributing factors of LTFU: Socio-political crises/displacement, long distances/cost of transportation, lack of partner/family support, refusal/dating/marriage among adolescents, poverty/competitive life activities, stigma, shortage of ARVs/poor efficacy, alternative forms of health care and negative attitudes of healthcare providers.

Conclusion: Our study found multiple factors at personal, family, community and health system levels, which contribute to poor retention of children and adolescents in HIV care with the leading reason postulated being displacements and constant roadblocks due to the current sociopolitical crises. The impact of the socio-political crisis on HIV services therefore cannot be neglected.

Keywords: Loss to follow up; Children; Adolescents; Socio-political Crises; Cameroon

List of Abbreviations: LTFU: Loss to Follow Up; HIV: Human Immunodeficiency Virus; AIDS: Acquired Immune Deficiency syndrome; WHO: World Health Organization; ART: Antiretroviral therapy; ARV: Antiretroviral; CALHIV: Children and Adolescents Living with HIV

Introduction

Significant progress has been achieved in the global fight against HIV/AIDS in the last twenty years [1]. However, retention in care for children and adolescents living with HIV (CALHIV) remains a major operational challenge requiring innovation and creativity [2-4]. Following great success in the use of Antiretroviral Therapy (ART), larger numbers of children living with HIV are surviving into adolescence and adulthood. Adolescents, defined as persons aged 10-19 years, constitute a major driving force in the continued transmission of HIV globally, particularly in Sub-Saharan Africa (SSA) [5]. As of 2018, an estimated 1.6 million adolescents were living with HIV, with 80% in SSA [6]. Despite improved survival rate due to ART in children and adolescents, poor retention in this age group still constitutes a major challenge for most HIV programs [6].

Socio-political instability can hamper or affect disease prevention and control programs as well as the accessibility to the health facilities for services. Political instability may take the acute forms of armed conflict, violent regime change, or politically motivated assassinations. Ndokang LE, et al. [7] define government instability as "unforeseen and unexpected events such as the end of a government or of an electorate that occurs either legally or by force." Political instability may also manifest itself in the state's chronic inability to perform its

basic functions over a protracted period. One of the aspirations of the African Union's Agenda 2063 is good governance on the African continent and one of its stated goals is "healthy and well-nourished citizens" [8]. During times of conflict children and adolescents are most vulnerable and education, healthcare and their wellbeing is usually affected. Vulnerability has been further compounded by limited access to education for children due to a ban and attacks on schools by the armed groups [9]. In 2016, socio-political crises broke out in the two English speaking regions of Cameroon. The crisis further worsened from mid-2018 due to increased hostilities ahead of the presidential elections [10]. Movements were restricted in the two regions due to a curfew in the North-West, a "No Movement" declaration by non-state actors with an increase of both official and informal checkpoints on the roads [10]. As more children living with HIV age into adolescence or become newly infected with HIV during adolescence, poor adherence, retention, and transfer rates impede the progress made by global HIV programs [11]. Research to quantify longitudinal trends and determinants of retention in children and adolescents on ART is a critical foundation for developing targeted interventions [11]. These interventions will strengthen programs by improving adherence patterns, enhancing the transition process, and ensuring subsequent program retention [11-12]. Understanding the reasons for LTFU among children and adolescents, will provide critical information to design feasible, acceptable and effective interventions by HIV care programs for these CALHIV who are less likely to access and remain in health care compared to adult populations. Our study therefore employed a qualitative method to shed more light on perceptions of caregivers on the reasons of LTFU among CALHIV enrolled in care in the conflict affected Northwest and Southwest Regions of Cameroon.

Materials and Methods

Study design and study sites

This was a qualitative sub-study nested within a cohort study to explore the reasons of LTFU in CALHIV conducted in selected hospitals in the Northwest and Southwest Regions of Cameroon. Study sites constituted five (5) ART treatment centers (three in the NW and two in the SW) serving a large population, in the two regions of Cameroon.

Study population and inclusion criteria

This study included caregivers whose children and adolescents were LTFU and also those who resumed ART after documented LTFU between January 2018 and December 2021. LTFU was considered if the ART status assessed by both the Health care workers and research team, if a child or adolescent is not on any prescribed ART after 90 days and if they either later returned to the clinic for ART resumption after 90days within the study period or still could not be traced during the study period (Figure 1).

Sample size and selection of study participants

The total sample size for this study was 25 caregivers whose children and adolescents were LTFU. A multistage sampling method was done to recruit study participants. Five healthcare facilities were purposefully selected from the treatment centers in the Northwest and Southwest Regions of Cameroon. A list of enrolled children and adolescents who were LTFU at the selected facilities was established from ART registers and an existing electronic database. In order to balance selection of caregivers of children and adolescents, CALHIV were grouped into 0-10years and 11-19years and caregivers randomly selected to include each of the age groups. Bias was further minimised by selecting caregivers of CALHIV from each of the 0-4years, 5-9years, 10-14years, 15-19years age categories. Selection was done to ensure that at least a caregiver with child or adolescent in each of the age categories is represented in the study. A maximum of five children and adolescents who were LTFU in each facility were randomly selected and their caregivers interviewed.

Data collection (In-depth interviews among caregivers)

Data collection was conducted from November 2021 to January 2022 and caregivers who could not be traced were excluded from the study. The data collection team comprised of trained research assistants who were community volunteers (expert clients) with extensive knowledge on paediatric HIV/management. Firstly, the research assistants together with the principal investigators checked the health facility records such as ART registers, individual files and electronic data base, triangulating data in the three sources to verify whether the identified children and adolescents were indeed LTFU. Thereafter the research team initiated the process of tracing the caregivers of children and adolescents, with the assistance of paediatric nurses and other community volunteers (expert clients). Caregivers were reached both in person by the team and also through telephone calls and eligible caregivers were assessed whether they were willing to participate in the follow-up interviews. If they expressed willingness, a suitable location void of distraction where they can freely express themselves was agreed upon for the interview guided by the choice of the caregiver. Where the caregiver was found in a hard to reach area and could not be seen physically, a telephone interview was conducted. The interviews were held at any location, either at the health facility or in the community, and through phone calls in privacy as the clients deemed that their identity and confidentiality could be safeguarded. On average, an interview took about 30-45 minutes. Written consent was obtained to conduct and audio-record the interviews from the caregivers seen physically while those reached on the phone gave a verbal consent for participation and audio recording. Questions were asked beginning from the general to very specific questions following an interview guide. Study participants were given non-leading open ended questions concerning adherence to ART and barriers to clinic visits for ART refills. Participants were further probed with questions based on main reasons for ART attrition for their children and adolescents Responses were recorded in audio tapes until saturation was reached i.e no new concept emerged from the individual interviews.

Data analyses

Data collected in audio tapes was transcribed word-verbatim into a Microsoft word document by one of the study team members with experience in transcription. Transcripts and each level of analysis were crosschecked by another team member for consistency and to ensure trustworthiness.

All the transcripts were uploaded and analyzed using computerized qualitative data analysis software, Atlas-ti version 9. Transcribed data coded as well as thematic analysis were done and reviewed by two authors for validity. Data analysis was conducted using the inductive method of content analysis [13] based on emerging categories (socio-political, family, economic, personal, shortage of ARVs (health system) and alternative forms of healthcare). Thereafter, subcategories (subthemes) under the major categories were also developed based on previous themes. The transcripts were coded according to these categories. The frequency of the themes was entered into excel and percentages of occurrence as per respondents analyzed. Final interpretations were supported by quotes from in-depth interviews to illustrate specific findings within each particular theme. Descriptive statistics was used to summarize the caregiver's socio-demographic data and their HIV sero-status.

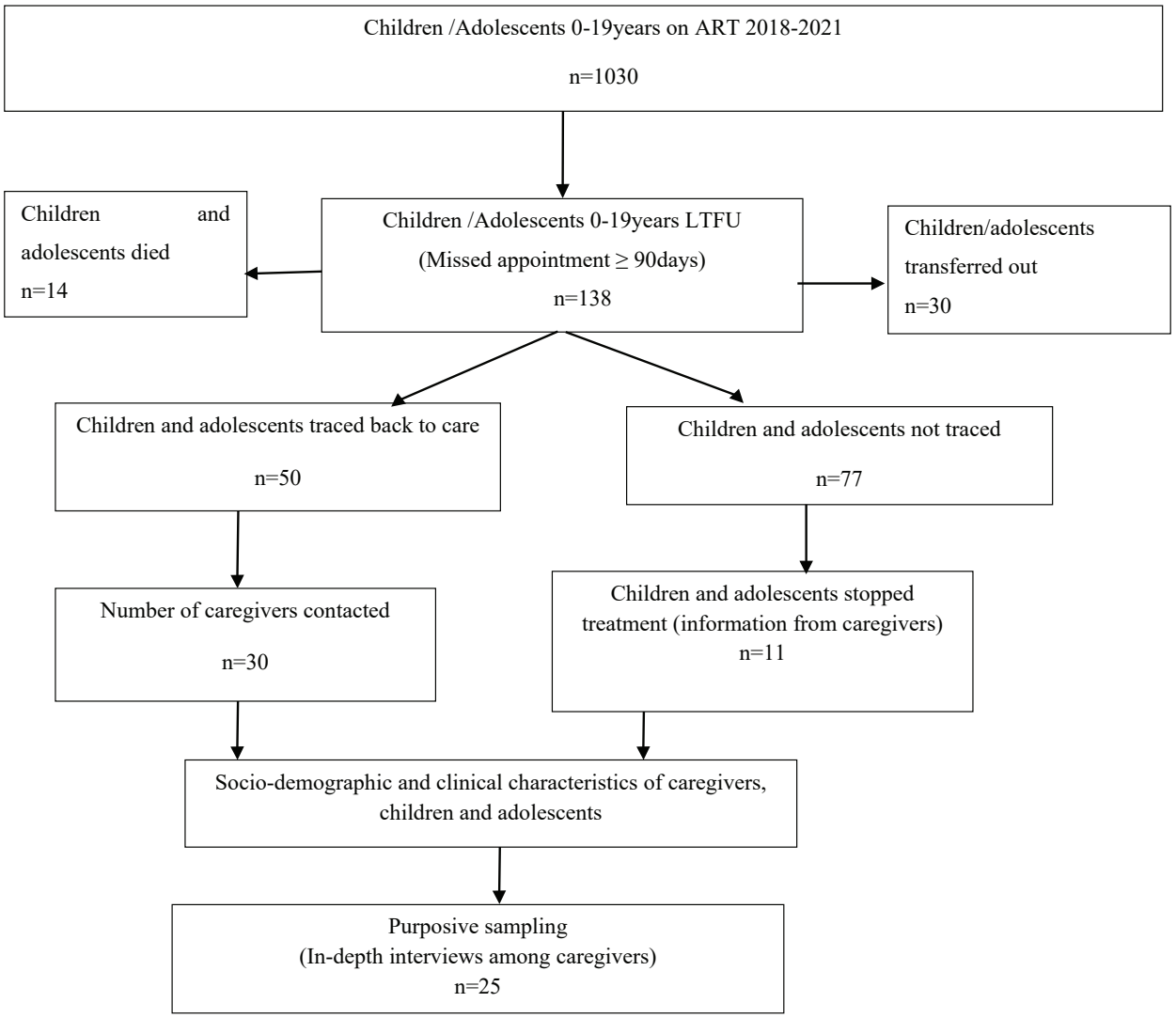

Figure 1: Flow diagram showing tracing of children and adolescents LTFU and the recruitment of caregivers.

Ethical considerations

Ethical authorization was obtained from the Cameroon Baptist Convention Health Services Institutional Review Board (CBCHS-IRB 2021-42), while administrative authorization was obtained from the different health facilities involved in the study. We obtained written and verbal consent from the caregivers of children and adolescents LTFU for the qualitative study and ensured respect of their privacy and confidentiality.

Results

Socio-demographic characteristics of Caregivers enrolled for in-depth interview

A total of 25caregivers of children/adolescent who were LTFU at any time in the cohort from January 2018-December 2021were interviewed.

The median age for the caregivers was 35 years and age range of 21-70 years. Thirteen participants had attained primary school education (13), fourteen of them live in the rural areas (14) and eleven of them survived on subsistence farming (11). Fifteen of the care givers were equally living with HIV (Table 1).

Reasons for Loss to follow-up among children and adolescents; (Caregivers perspectives)

Results from the integrated content analysis identified socio-political crises/displacement, long distances/cost of transportation, lack of partner/family support, refusal/dating/marriage among adolescents, stigma, poverty/competitive life activities, shortage of ARVs/poor efficacy, alternative forms of health care and attitudes of healthcare providers as reasons for poor retention in CALHIV.

Socio-political crises/displacement

A total of eighteen respondents said the ongoing crises coupled with frequent roadblocks, schools not functioning for them to send their children, frequent gun shots with resultant displacements into bushes, neighbouring villages and towns were their main reasons for not bringing their children to the health facility for ARVs as seen in some interview sessions below:

Table 1: Socio-demographic characteristics of caregivers.

Variable (Caregiver)	N=25 n (%)
Age	
Range	21-70
Median	35
Age categories(years)	
21-30	8(32.0)
31-40	9(36.0)
41-50	3(12.0)
51-60	3(12.0)
60+	2(8.0%)
Level of Education	
No formal education	1(4.0%)
Primary	13(52.0)
Secondary	10(44.0)
Tertiary	3(12.0)
Location	
Urban	7(28.0)
Semi-Urban	4(16.0)
Rural	14(56.0)
Source of Income	
Business	6(24.0)
Farming	11(44.0)
Nursing	2(8.0)
Unemployed	2(8.0)
Others	4(16.0)
HIV status	
Positive	15(60.0)
Negative	6(24.0)
Unknown	4(16.0)

"My adolescent son was afraid during this crisis because there were gun shots everywhere, and we were leaving just besides the road. He ran away from Kumbo for a while and he was away for 6months without taking his medication. Hahahahahaha he was afraid of the gun shots and the military men. He was sick and his condition was not good and he came back to Kumbo and is now living with me even in the midst of the crisis……" (Caregiver #10, LTFU Health facility 3)

"……..the main reason is the crisis, as this crisis started it has been so challenging to bring the child to the hospital. The roads are always blocked by those boys; this makes it difficult for me to come" (Caregiver #14, LTFU Health facility 2)

"…..due to this crisis roads were always blocked with schools not functioning and because of this constant road blockage he stayed for three months without medication, I didn't bring him to the hospital on time based on the date given to us at the hospital. …" (Caregiver #23, LTFU Health facility 4).

Long distances/cost of transportation

Fifteen of the respondents complained of long distances and very high transportation fares which have further increased as a result of the crisis, although most of the times they do not even have to come to the clinic with their children. Some participants reported that they cannot afford to pay the high cost of transportation fare which prevents them from coming to the health facility. Some participants mentioned that they trek for very long distances passing through very bad roads with the children on their backs to come to the clinic. This prevented some of them from coming to the health facility and some relocated to other clinics without notifying their host clinics. Worst still, some of the clients got re-initiated on ART as new clients in the new clinics because they did not disclose that they had been on ART.

"…….my main reason for not coming to the hospital is because of the high transport cost. I leave at Ntieh village and just to come to the hospital I have to pay 8,000FCFA (17USD) to come to the health facility talk less of going back. So for some time now he has not been on treatment…. …." (Caregiver #8, LTFU Health facility 5).

"…..due to very high transport fare, I was no longer bringing the child to the hospital during her rendez-vous days. We normally leave small Babanki to Mbingo hospital and I will spend about 6.000 frs. What the hospital refunded as transport fare was never sufficient to cater for the complete fare for both of us. So we could not come to the hospital always because we live inside Babanki very far from the hospital…" (Caregiver #11, LTFU Health facility 4).

Lack of partner/family support

Twelve caregivers expressed lack of support from their spouses and family members as the reason for poor retention in their children. They said they are the only ones taking care of the children without external moral, psychological or financial support from their spouses and families. This sometimes weighs too much on them and also affects their constant bringing of the children to the clinic:

"…. I am the only one taking care of this child but it's not easy at all, I feel isolated and abandoned by them (husband and siblings) and this has really affected the child because sometimes you struggle to make sure the child eats, goes to school and takes medication at the hospital and no one to help you…".(Caregiver #14, LTFU Health facility 3).

"This child is my late brother's child and the mother came and left him here with me and went away. I don't even know where the mother went to. She did not even tell me about the child's condition, she just kept him with the medications and left. His mother does not even call me again and no one in the family sends money or even calls to find out about the child. Sometimes I struggle to make sure the child keeps taking his medication. I am a widow, I work my farms for food and also sell some to take care of these children. ……" (Caregiver #5, LTFU Health facility 1).

Refusal/dating/marriage among adolescents

Eleven participants reported that their adolescent girls left the home to get married and deliberately refused to take their medications. They further reported that their adolescent children did not disclose their status to their partners for fear of losing their partners and as such did not take their medications regularly. Others reported that their adolescent children deliberately refused asking why they are constantly taking medications.

"……my daughter left the house since one year ago at 17 years, and she is nowhere to be found. I only heard where she was after some months. But before leaving the house she was no longer taking her medications she had started going out with men and did not want them to know about her status. We even tried to convince her and she said we should allow her to live her life, I just hope that she will come back to her senses and continue taking her medications again…". (Caregiver #19, LTFU Health facility 1)."

The father of a female adolescent declared with much pain and regret how her daughter ran away from home to marry a man and has since then discontinued treatment because she never wanted to disclose her HIV status as seen below;

"…my daughter ran away from the house, as she started dating men, she did not want to hear anything from me again (father of an adolescent girl). Her mother is of late and I am now living with her step mum. My daughter doesnot want to listen to me at all because she told me about the first guy who wants to marry her but I said she should bring him to me, she was angry and left, I called her and asked about her medications she said, I should forget about it…" (Caregiver #28, LTFU Health facility 4)."

"…. She is 16years and she is not taking her medications again. She abandoned us and ran away from the house when I was not around and till today, we do not know where she is….no I don't have her telephone contact, she does not even have one. Before she left the house, she deliberately refused taking her medications asking questions like why me?". (Caregiver #25, LTFU Health facility 3)."

Stigma

Qualitative findings showed that nine caregivers complained of themselves as well as their adolescents feeling stigmatized both from other family members and from the community. Some of them had not disclosed their children's status to them neither to their families nor to friends because they will speak negatively about them. Some complained of people in the community pointing fingers at them as they pass by. Most often they do not come by themselves to collect their drugs as they either send a nurse working at the hospital or their peers to come and collect the ARVs for them. Others decided to go to very distant hospitals where they will not be seen or known and this has affected their retention in care.

"……my son refused to come to the hospital by himself to collect his medications for a while, I am not around. He said his friends or classmates might see him since everyone knows that this particular section of the hospital is for those suffering from the disease. So I have this friend who is a nurse who now brings his medications at home" caregiver LTFU Health facility 3)."

"…..yes, I no longer live in that quarter because people always mocked at me and said funny things about me in the quarter where I lived before, so I had to transfer with my child and come here because nobody knows me here……."(Caregiver #5, LTFU Health facility 1).

Poverty/competitive life activities

A total of ten caregivers especially the relatives of orphaned children and adolescents reported that they were not able to provide basic needs for their children, talk less of an additional child who needs to constantly visit the hospital which they see as an additional burden on them. Some were peasant farmers who rely on their farms to feed their children. Sometimes they don't have enough to eat and this affects retention in care for the child. At the time of this interview, two of the caregivers requested for money to start small businesses so that they can feed their children and also take them to the hospital. Some also complained of being occupied with their farm work and businesses and when they appoint someone else to bring the child to the clinic they don't do and the child ends up missing his or her appointments as seen below:

"……I depend on my farms to take care of them and sometimes to get three square meals a day is not easy, talk less of taking child X every month to the hospital for his medications..…. sister please can you people look for money and give me to start a small business so that I can take care of them because it's not easy at all…" (Caregiver #20, LTFU Health facility 4)."

"This child was staying with my brother when she was not taking her treatment again. He refused to take responsibility to take the child to the hospital, He never wanted anything to disturb him because he is a busy business man who travels a lot. And because of this the child went for some months without medication. I had to go and take the child and she is with me here at Kumbo because I am not that busy and will be taking her to the hospital during her appointment days" (Caregiver #18, LTFU Health facility 3).".

"…she was leaving with my mother (her grandmother) in Kikia. She was so busy with her farm and was not taking her to the hospital often and my daughter's condition was bad. I was called to come and take her and now she is with me and taking her medications…." (Caregiver #24, LTFU Health facility 5).

Shortage of ARVs/Poor efficacy

Four participants reported shortages of ARVs and inefficacy of the ARVs their children were taking as the main reason why they stopped coming to the health facility with their children and had to go elsewhere where their children could be helped.

"I left because the medication was not working again. The child's condition was not improving even though I was following up with his medications, within one week I am back again at the hospital with the child. So I had to leave because things were getting worst for my son, he was constantly growing thinner and thinner despite the fact that he was on ARV. My friend directed me to a catholic hospital in Dschang and his medication was changed to a new one and he is fine now....the old medication was not working so I had to leave……" (Caregiver #16, LTFU Health facility 4).

"……. you will come to the hospital they will tell you the old medication the child has been taking is no longer available and sometime they will give another. Last time they gave us medications just for 2 weeks instead of complete one month that the medications were not available. I cannot be paying transport just to collect drugs for two weeks when I know I will still come back just in two weeks again……I had to relocate where I can be having her medications always…" (Caregiver #22, LTFU Health facility 5).

Alternative forms of health care

Three respondents reported seeking care from traditional and religious sources claiming their children are now okay and do not need to come to the ART clinic again for their medications as seen below:

"….my daughter is fine. I have not seen her with any fever, rashes or anything for two years now. God has intervened in the matter. It's been long about two years now and she is fine with no medications. You know that God works when we pray for certain situations it can change. Her health is fine, she is healed and she is not on treatment again….."(Caregiver #1, LTFU Health facility 1)."

"…… I gave her some herbs and supplements that we got from the herbalist he said we should take it first for some time and let him follow up the child……. I think it's helping the child….." (Caregiver #13, LTFU Health facility 2).

Attitudes of healthcare providers

Two caregivers complained of the attitudes of the healthcare providers towards them when they lastly visited the health facility were

not willing to go there again. Below is an excerpt from the integrated content analysis:

"….If not that the other lady that is working with her(hospital staff) came to my house I will not have set my feet again at the hospital with my child, I was planning to go somewhere else,,,the way she spoke to me as if I am a child, I was not around that's why I did not bring the child to the hospital then she started speaking any how…."(Caregiver #3, LTFU Health facility 1).

Discussions

Loss to follow up in children and adolescents is a serious challenge affecting the fight against HIV and impacts children and adolescent transitioning to adulthood. This was a qualitative sub-study nested within a cohort study to explore the reasons of LTFU in CALHIV. Opinions of care givers were sampled and the main recurrent themes for the reasons of poor retention are discussed below;

Socio-political crises/displacement

The socio-political crisis which started in November 2016 in the Northwest and Southwest Regions of Cameroon has recorded over 4,000 people killed already, over 500,000 internally displaced and at least 40,000 externally displaced into neighbouring Nigeria [9]. Our findings show that caregivers of CALHIV could not access health facilities for care due to the frequent road blocks emanating from the sociopolitical crises in the two regions of the country. This tallies with reports by the Cameroon Relief Web which the crisis has led to disruption of movement, dysfunction of many health facilities and numerous ghost towns [9]. This indeed led to the drop in health facility visits and retention in care for children and adolescents on lifelong ARVs as observed from this study. Similarly report in Ukraine showed crises-related disruption in treatment for PLWHIV with continued attacks on health facilities and difficulties in transporting medication were both impacting the availability of health services [14]. Our findings were congruent with those of Mann M, et al. 2014 [12] which showed that socio-political crises in resource limited settings lead to treatment interruptions, limited supply and subsequent drug resistance among people living with HIV/AIDS. Humanitarian emergencies and conflicts disrupt normal social and economic structures and activities and often involve mass displacement. The breakdown of social cohesion, lack of income, shortage of food, sexual violence, increased drug use and the disruption of health, education and infrastructure that characterize complex emergencies all contribute to putting populations affected by these crises at greater risk of HIV. These also present challenges for those already living with the virus accessing ART [12]. Health systems are also put under strain in emergencies and during outbreaks of conflict [11]. This can hamper the treatment and prevention of HIV. Healthcare staff may find it harder to do their jobs and access facilities [11]. This could be due to a range of factors including safety, access to facilities and non-payment of wages [11]. Similarly, patients had difficulties accessing healthcare facilities [11]. Other study has shown a decline in health system utilization as of 2018 in the Southwest region of Cameroon as a result of the armed conflict [15]. The negative health effects of this conflict are considerable, in addition to impacting schooling for children, there has been the degradation of essential infrastructure including roads, health facilities with resultant disruption of treatment in CALHIV.

Long distances/cost of transportation

Distance to the health facility was posed as barriers or causes of treatment interruptions for children and adolescents. Distance is a notable challenge that makes compliance difficult to achieve. Caregivers complained about the distance they have to cover, and sometimes through dangerous and muddy roads with their children on their backs just for them to access the treatment center for follow up visits. Our findings were consistent with other studies [16,17], which showed that long distances contributed to poor retention in children and adolescents on ART.A study in Uganda [17] also show that distance to health facility also contributed to LTFU among children and adolescents. Our study was however contrary to that obtained in Malawi [16] were caregivers used US$0.66 to US$2.65 one-way transport fare which was lower than the 8,000FCFA(14.0USD) to 20000FCFA(35.0USD) one-way transportation cost obtained in our study. In these conflicts affected zones with an upsurge in transportation fare calls for an increase in transport subsidies for CALHIV in order to retain them in care.

Lack of partner/family support

Our study shows that some caregivers especially mothers of these children and adolescents had no support or minimal support from their spouses or other family members which made it very challenging to cope with an HIV-infected child/adolescent and continuity on services rendered at the treatment center. This was apparent in single mothers or those with more children to carter for by themselves. Some spouses and relatives failed to provide physical, moral, and psychological support which they said could have been a source of strength and support to maintain their children in care. Lack of partner support was mostly reported by mothers whose husbands do not provide the support to ensure continuity in care for their children. Other studies [18-20] showed lack of partner support as associated with poor retention in care for children and adolescents.

Refusal/dating/marriage among adolescents

Some caregivers complained that their adolescent girls refused to take their medications for fear of losing their partners should they be aware of their status.

Some care givers complained of dating and marriage among their adolescents who do not want to disclose their status to their partners as a reason for poor adherence. Adolescence is a stage of transition from childhood to adulthood, associated with specific challenges (including puberty) and vulnerability (such as early sexual debut, HIV, and STI acquisition [21]). Similar study in Uganda [21] showed that some adolescent boys of caregivers choose to have pleasure with girls than receive ART with a risk of their HIV status being discovered. Non-disclosure to partners is a hindrance to adherence and retention in care among adolescents. Deliberate refusal may also be linked to psychosocial issues, as some caregivers complained of their adolescents asking question like why should it be them taking medications. Adolescent clinics may need to intensify adolescent monitoring to better guide those entering into dating or marital relationships. Trained peer mentors can also assist with their psychosocial needs as well as revealing their status to their partners and the possibility raising children who are not infected with the virus.

Stigma

Stigma was another reason for missed appointment and poor retention as obtained from our study. Our findings were consistent with previous findings in a systematic review in SSA [19], Uganda [21] and Ethopia [22]. This highlights the need to intensify interventions to reduce HIV-related stigma and discrimination in all domestic and social circles. In Cameroon, despite diverse efforts put in place by the Cameroon health system to combat HIV-related stigma and discrimination, HIV-related stigma and discrimination remains a

significant obstacle to the fight against HIV/AIDS and the adherence to HIV/AIDS [23]. Furthermore, stigma and discrimination serve as a barrier to proper care, support and treatment for PLHIV. Fear of stigmatization keeps them from seeking and receiving adequate treatment. Stigma and discrimination leads to psychological distress, which further undermines the state of health and general well-being of PLHIV [23]. Some caregivers reported that their adolescents do not want to be seen at the health facility. There is need for the reinforcement and monitoring of adolescent support groups to ensure the distress of stigma is dealt with and they can feel free to live in the society like any of their peers. There is need for sensitization against community stigmatization and discrimination of PLHIV to improve retention in care among children and adolescents.

Poverty/competitive life activities

In our study, caregivers complained of not having sufficient means to cater for the needs and feeding of the children which has affected the continuity in care for their children. Our findings were in line with that obtained in Malawi [16] where household poverty characterized by food shortage was reported as an important factor associated with poor ART adherence and LTFU. This was consistent with previous findings in Mozambique [24].This obviates the need for targeting social safety needs of HIV-affected families as a short-term solution and strengthening of economic empowerment programs as a long-term strategy for many HIV programs in Cameroon. Malawi has recently introduced a social cash-transfer program targeting vulnerable households, including those affected by HIV [25]. This can serve as a best practice and could be rolled out in our context in the NW and SW targeting vulnerable households affected by HIV and the crisis. Such programs will require proper monitoring to examine whether it leads to a positive impact on ART adherence and retention in HIV care for children and adolescents in such households. Similar study shows busy work schedule with resultant missed appointment as reason for poor retention [26]. Caregivers may be so busy with business or jobs as a means of livelihood or to take care of their children and this busy schedule prevents them from bringing children to the health facilities. Health facility staff could link their clients who live in the same communities who will pick up regimens for each other as well and do frequent home visits or targeted home dispensation to prevent treatment interruptions and subsequent LTFU.

Shortage of ARVs/poor efficacy

In our study, shortage of ARVs was cited by some caregivers as reasons for poor retention in children and adolescents. This discourages them as many of them who live in distant areas with high cost of transport cannot come just after two (2) weeks for refill just because the ARVs were out of stock or not available at the time. Our findings also show poor retention linked with continuous deterioration of the health condition of some children despite continues ART intake with resultant relocation to other health facilities without notifying the host health facility. They might be experiencing ART resistance or taking suboptimal regimens which might have caused these parents to seek help elsewhere. There is need for proper monitoring, ensure availability of optimal regimens and timely ART optimization to prevent treatment failure. Similar findings associated with shortage of commodities including ARVs in Malawi [16] were reasons for poor retention and treatment failure. Issues of adherence and right doses of drugs for the right weight might have created resistance leading to the impression of drugs not working.

Alternative forms of health care

Seeking alternative forms of healthcare with religious leaders and traditional healers was another reason for poor retention in children and adolescents. Retention Prior visit to a traditional healer and visit of prayer institutions were linked with poor retention. This decision to seek alternative care appeared to be influenced by religious teachings and traditional beliefs. This finding suggests the need for continued community sensitization about HIV and its treatment and engagement with key community stakeholders in health care, including traditional and religious leaders in a collaborative manner to maximize the strengths of each sector for proper follow up of children and adolescents on ART. Approaches or decisions that may interrupt care and subsequent LTFU should be discouraged through policy regulations and proper patient counselling. Our findings were in line with that obtained in Malawi [11,18]were seeking alternative healthcare was associated with LTFU.

Attitudes of healthcare providers

Negative attitude of health care workers towards caregivers are similar to findings from the studies in Kenya and Garbon which revealed that mothers of children were being scolded at by health workers for missed appointments which caused them to shy away from treatment centres [27,28]. Furthermore, due to the negative attitudes of some healthcare workers who scold at caregivers for not respecting appointments or for other reasons also contributed to poor retention in them [28]. Another study has shown that increased workload leads to burn-out and subsequent poor attitude from health care workers [28]. Our findings suggest the need for HIV service staff to be user-friendly in the facilities especially towards adolescents who may require friendly special attention/care. The WHO Health report [5] recommends development and implementation of national quality standards and monitoring systems as a key step in transforming how health systems respond to adolescent health. [23].

Other studies mentioned reasons for LTFU being forget fullness by caregivers [23], client (caregiver) mobility [29], waiting times at the health facility [23] side effects of ARVs and perceived good health, which was not the case with our study.

From our study, treatment interruptions were mostly associated with socio-political conflict. Findings from this study may warrant the putting in place strategies for caregivers who find their children in situations of unplanned conflict related interruptions. Such strategies should take into account the regimen prior to interruption, medication half-life, replacement therapy options, close monitoring, and perhaps, if feasible, resistance testing three months after resumption of care and close monitoring thereafter. An additional strategy should include implementation of contingency treatment plans in the Northwest and Southwest Regions addressing factors like consistent drug supplies, improved patient follow-up, and education for health care providers, implementation of viral load monitoring and resistance testing, and availability of multiple treatment regimens. In particular, relief agencies would benefit from an increased focus on identifying HIV positive victims especially children and adolescents for intensive follow up during this crisis. Parent concerns for transport and access to clinics including road conditions and transport safety, as well as water and food safety and availability, must also be addressed to ensure continuity in care for CALHIV.

Limitation of this Study

Some caregivers whose children and adolescents were loss to follow-up could not be traced for interviews or back in care due to absence of or wrong location and phone numbers. Lastly, information was obtained from only five healthcare facilities in the two conflicts

affected regions of the country. However, efforts were made to ensure regional representation by involving health facilities per region that receive large numbers of children and adolescents for ART and care.

Conclusions

Retention in care is very vital in CALHIV for smooth transition into adolescent and adulthood respectively. Qualitative data revealed a complex interplay between socio-political crises, facility-level, community level and client based-level barriers associated with poor retention for children and adolescents in HIV programs. This study is similar to other studies by portraying some reasons for poor retention in CALHIV, it is however unique by identifying the effect of ongoing socio-political crises on HIV care programs as a major factor for poor retention which might be missed, undermined in most HIV programs in the conflict affected regions of Cameroon. Planned multisectorial collaboration is warranted to put in place interventions to address socio-political, health facility, community and personal level barriers of adherence in CALHIV.

Education of caregivers and adolescents, provider awareness and preparedness will greatly improve retention in CALHIV. Policy makers and politicians in Cameroon can directly impact the lives of HIV-infected patients including children and adolescents by avoiding conflicts and their consequences. Perhaps increased awareness of this long-term and often overlooked consequence on the health outcome of CALHIV will provide opportunity for re-consideration in similar future circumstances. Given the severity of the potential effects discussed here, it would be advantageous for political leaders to begin a pre-emptive discourse on prevention of violence, while treatment programs put in place a contingency plan for HIV patient's especially vulnerable groups like children and adolescents amidst this crisis and preparedness measures for patient management during conflicts.

Competing Interests

The authors declare no conflicts of interest. No financial gain is promised upon publication of this work.

Authors' Contributions

CWA participated in the conception, data collection, data analysis, drafting of the manuscript, correction and proof reading for scientific content. EMK participated in the design of data collection instruments, supervision of data collection, review of analysis, manuscript writing and proof reading for scientific content. PMT participated in the supervision of the research process from data collection to manuscript development, read and corrected the manuscript for scientific content. All authors read and approved the final copy of the manuscript.

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