

## Research Article

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# A Qualitative Assessment of the Determinants of Adherence to Antiretroviral Therapy among Adolescents living with HIV in the Centre Region of Cameroon

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## Abstract

**Background:** Adherence to antiretroviral therapy (ART) is known to be challenging among adolescents living with HIV/AIDS, meanwhile it is the key to success for ART programmes. In Cameroon, although a few researchers have investigated on the quantitative aspects of adherence among adolescents, less is known about qualitative information. This study aimed at investigating the key factors that contribute to ART adherence for adolescents living with HIV in the Centre Region of Cameroon.

**Methods:** The study was conducted in the Centre Region of Cameroon. Adolescents on ART with disclosed status was recruited from health facilities. Six focus group discussion (FGD) sessions were conducted with 56 adolescents both girls and boys aged more than 15. In addition, 3 FGD with 34 parents/guardians and 10 individual in-depth interviews with health care providers were all conducted between the months of June and September 2018.

**Results:** A total of 56 adolescents, 34 parents and 10 health care providers were approached for participation. Results showed that a range of factors related to the individual, family, environment, medication and health system

levels determine the reasons for poor adherence to ART among adolescents living with HIV. In fact, most adolescents mentioned in this study that compliance with medicine intake is seen as a punishment or drudgery.

**Conclusion:** In supporting adherence to ART, it would be important to develop approaches that facilitate and help adolescents to adequately comply to medication intake like the creation of discussion groups through phone messages and WhatsApp for the sharing of experiences and for mutual support. A multi-sectorial approach would also be needed to address this issue.

**Keywords:** Qualitative research; HIV; AIDS; Adolescents; Adherence; Cameroon

**Abbreviations:** CAMPHIA-Cameroon Population Based HIV Impact Assessment; HIV-Human Immunodeficiency Virus; ART-Antiretroviral treatment; ALWHIV-Adolescents living with HIV; PLHIV-People living with HIV; AIDS-Acquires Immunodeficiency Syndrome

## **1. Introduction**

Of the estimated 36.3 million people living with HIV (PLHIV) worldwide, about 2.1 million of them are adolescents [1, 2] of whom the majority (1.7 million) live in sub-Saharan Africa (SSA) [3-5]. This number continues to grow, mainly due to ongoing mother-to-child transmission, increased survival as a result of antiretroviral therapy (ART), and sexual transmission among adolescents [3, 6]. While mortality in people living with HIV in all other age groups is decreasing, that of adolescents living with HIV is increasing [7]. In general, adherence for adolescents to chronic medication has been found to be lower compared with younger children or adults [2] mainly due to the transition process of this subgroup. This transition is a stage in life characterized by significant biological, physical, and psychosocial changes marking the beginning of adulthood. At this stage, adolescents experience changes that affect self-control. Because of the unique behavioral characteristics of adolescents, they may have worse adherence to ART [8] which would increase their risk of both morbidity and mortality [9] and poor adherence can result in negative health outcomes and treatment-resistant strains of the virus [7]. Suboptimal adherence may include missed or late doses, treatment interruptions and discontinuations, as well as sub-therapeutic or partial dosing, delayed diagnosis [3, 7], stigma [3], difficulties with disclosure, lack of awareness of sero status [3], denial of care by legal parents or guardians for a myriad of personal reasons such as fear of the child's parents, [4, 10, 11]. It is worth noting that poor adherence to antiretroviral therapy (ART), known as the footprint for therapeutic success, remains a major setback for adolescents receiving ART. In order to meet the third pillar of the UNAIDS 90-90-90 targets (90% of PLHIV know their status, 90% of those who know their status are on treatment, and 90% of those on treatment are virally suppressed) among adolescents living with HIV (ALHIV). It is essential to implement efficient measures for adherence assessment and to identify areas of specific interventions for the improved management and monitoring of adolescents receiving ART [12]. Therefore adherence should be one of the main concerns when providing antiretroviral treatment (ART), especially in resource limited settings.

In Cameroon, since the first cases of AIDS appeared in 1985, the Government has made response to HIV and AIDS a priority. The many efforts undertaken have made it possible to considerably reduce its prevalence over the past two decades, although the country still remains in a pandemic situation. As of 31 December 2018, 281 083 persons living with HIV are on treatment [13]. According to the results of the Cameroon Population-based HIV Impact Assessment (CAMPHIA) in 2018, the highest prevalence of HIV is in adolescents and youths (1.2%) with 2.0% among female and 0.4% among male [14]. With regard to Cameroon's 2018-2022 strategic plans, emphasis was placed on the care of young people and adolescents living with HIV [15]. In 2018, 34,566 adolescents living with HIV (ALHIV) aged 10 to 19 were expected to be identified, while as of 31 December of the same year, only 14,594 had been identified, or 42%. From those identified, 9,404 were placed on ART, making an ART coverage of 64% among adolescents [13]. Studies on adherence have been primarily focused on adults, few quantitative studies have assessed factors influencing adherence to ART among adolescents [16, 17]. To our knowledge, no qualitative study in Cameroon has addressed ART adherence in this specific age group of adolescent. Although health-care workers play a pivotal role in providing adherence support and are thus usually more informed through their interactions with the patients and their understanding of the health-care system, few studies have included them when assessing adherence. More information is needed in order to design appropriate interventions to improve or maintain sufficient ART adherence levels. The present study, therefore, aimed at investigating barriers to ART adherence in ALHIV in the Centre Region Cameroon, and interventions to address them.

## **2. Materials and Methods**

### **2.1 Study area and justification**

The study was conducted in the Centre Region of Cameroon. It hosts the country political capital Yaounde, with 30 health districts for a total of 3,724,000 inhabitants. The region also has reference paediatric health facilities, it also has the highest number of PLHIV on ART and the highest number of adolescence (25% national coverage) [18]. In the entire region, a total of 105 health facilities provide ART of which 99 had adolescent healthcare services in 2017. The Centre Region is serviced by a large number of hospitals and clinics and had the highest burden of HIV in 2016 (25%). It is also has more advanced adolescents living with HIV compared to other regions. The present socio-anthropological phase was held respectively in Yaounde in 5 health facilities, namely the Mother and Child Centre of the Chantal BIYA Foundation-Yaounde; the Yaounde Jamot Hospital, the Mbalmayo District Hospital, the Bikop Health Centre and the Health and Social Animation Centre of Nkoldongo, from the 8 health districts of the Centre Region of Cameroon.

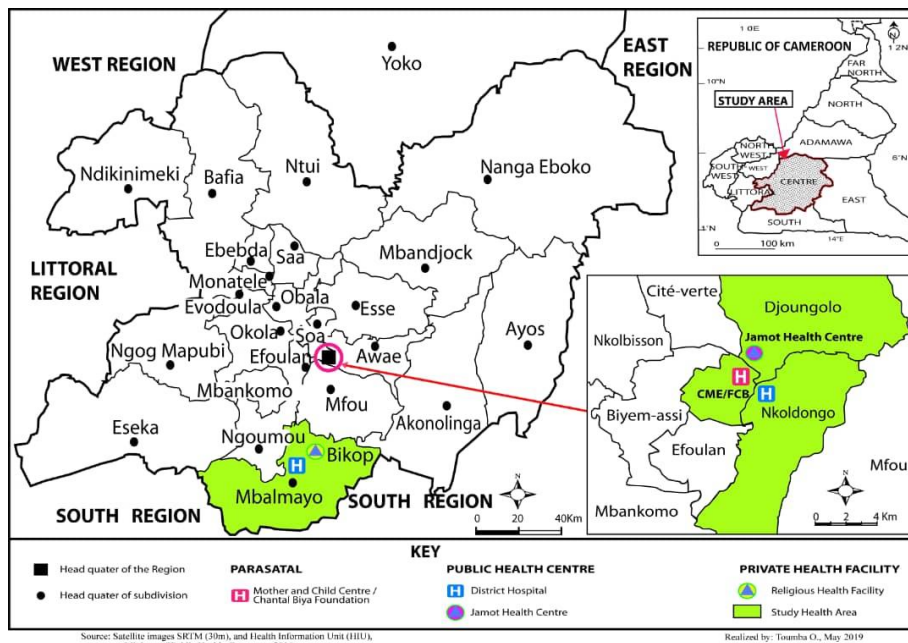


Figure 1: MAP of the Centre Region of Cameroon.

## 2.2 Study design

We conducted a qualitative research from July to September 2018. Purposive sampling was used to select adolescents. For the sake of saving the work done by the health staff from the health facilities that hosted our data collection, we discussed only with adolescents who are already aware of their status and are aged more than 15 years old, their guardians and their health care providers. The social ecological model was used to understand the factors related to adolescent adherence to ART and help identify areas most amenable to intervention. The organization of focus group discussions (FGDs), according to the various groups under study, was applied in rural and urban areas with adolescents of both sexes on the one hand, and parents on the other hand. In total, six FGD were conducted with fifty-six (56) adolescents (3FGD with girls and 3FGD with Boys); 4FGD with thirty-fourth (34) guardians and 10 in-depth interviews (IDIs) with 10 health care providers were conducted. These helped the researchers to explore the reasons for failure to adhere and what could help them (adolescents/caregivers) to maintain high levels of adherence. During selection, an attempt was made to have a representative number of people in rural and urban zones. This was to ensure that the views of adolescents, health care providers and guardians from these zones were captured comprehensively.

## 2.3 Inclusion criteria

The inclusion criteria were for the primary and secondary populations

### ✚ For adolescents

- Adolescents who were between the ages of 15-19;
- Adolescents who had been on treatment for at least 6 months in one of the health facility involved in this study;

- Adolescent who were receiving ART from any of the health facility in the study area;
- Adolescents who were aware of their status;
- Adolescents who accepted to participate and whose guardians gave permission to participate in this study.

**✚ For guardian**

- Guardians of adolescents living with HIV;
- Guardians who accepted to participate.

**✚ For health care workers**

- Should work in any of the health facilities involved in this study;
- Should be responsible for adolescents' healthcare in the health facilities involved (Medical doctor, nurse or psychosocial support);
- Should voluntarily accept to participate.

## **2.4 Exclusion criteria**

**✚ Adolescents**

- Adolescents who did not know their status;
- Adolescents who were less than 15 years old; Adolescents who refused to participate or/and whose guardian had not given permission to participate.

**✚ Guardians**

- Guardian who did not give their consent;
- Guardian who did not have an adolescent living with HIV.

**✚ Health care providers**

- Who not in charge of adolescents living with HIV;
- Who refuse to participate.

## **2.5 Procedure**

Adolescents and guardians were identified and selected during their visit to the health facilities. The consent and assent forms were given to them and they were required to sign after informed consent. So they indicated their agreement to participate voluntarily in the research study. Then the appointment was taken for the FGD. Health care providers were selected from the health facilities and submitted to a structured interview. Concerning adolescents, the FGDs were stratified by clinic and gender. In-depth interviews were conducted for the professionals and FGDs for both guardians and adolescents in a private space located at the hospital involved. Individual in-depth interviews were conducted with a physician, a nurse, a psychologist staff and a peer counselor. The professionals were selected

because of their experience in working with adolescents receiving ART for HIV and information they had regarding ART adherence in this population.

## **2.6 Data collection**

As mentioned above, FGDs was used for adolescents and guardians and in-depth interviews were used for the health care providers. For the FGDs, 8-12 participants were selected per a group and each group had a moderator and a secretary, and lasted for one hour and 30 mins. For health care providers responsible for adolescents, we recorded their opinions following an elaborated guide for a period of 60 minutes each, and audio-recorded. The semi structured FGD interview guide questions covered the level of knowledge and participant perceptions about adherence, and adherence barriers and facilitators.

## **2.7 Data management and analysis process**

Interview topics included experiences with adolescents on long-term treatment with either declining adherence or persistent poor adherence. All the recordings were transcribed verbatim from audio recordings into Microsoft word documents. After that, all transcripts in French were translated into English. Analyses of transcripts were done using a computer based analysis called Atlas-ti software. Also, a team approach was used to analyze these data. First, an analysis plan was developed based on study objectives in order to identify key themes. Then we generated a coding scheme (Adolescents living with HIV=ALHIV; Girls=G and Boys=B, Mbalmayo District Hospital=MB-HD Mother-Child Centre of the Chantal BIYA Foundation=FCB; Yaoundé Jamot Hospital=HJY; Bikop Health Centre =BIK and Health and Social Animation Centre of Nkoldongo=CASS.NK) after reading a few transcripts. A general thematic analysis was then conducted focusing on similarities and differences of perspectives between different groups of respondents. Information was analyzed to capture the different perspectives of the different actors. We ruined reports for each theme and used them in writing the results.

## **2.8 Ethical and administrative considerations**

Ethical Clearance for the study was obtained both from the Regional Delegation of Public Health of the Centre region-CE02243N°/CRERSHC/2017 and the Institutional Review Board of the Faculty of Health Sciences of the University of Buea-2018/024/UB/SG/IRB/FHS. An administrative authorization was also obtained from the Regional Delegation of Public Health, Centre region-1902/L/MINSANTE/SG/DRSPC. A written consent was obtained from each guardian as well as an assent from each participant. For the purposes of confidentiality and privacy, data were managed using specific identifiers and stored in a password-protected computer.

## **3. Results**

### **3.1 Socio demographic characteristics of participants**

A total of 56 adolescents, 34 parents and 10 health workers were approached for participation. The target population of adolescents were aged between 15 and 19, and were mostly at the secondary level of education. A few of them were from primary school. The organization of focus group discussions (FGDs) according to the various groups under study took effect in rural and urban areas with adolescents of both sexes on one hand, with parents and health

workers on the other hand. Parents were divided into two categories: legitimate parents, a category which included participants living with HIV and healthy participants and legal parents or guardians. According to the data, only 3 parents were living with HIV.

### **3.2 Knowledge about HIV/AIDS**

The majority of respondents had a sound knowledge of HIV and the role of ART. The definition of the disease and the role of ART were different from one respondent to another. The following quotes are some of the responses of some of the participants from both urban and rural areas.

*“.....A virus that cannot be cured, we can stop it from being active, it can be weakened with antiretroviral. For it to be known, tests are carried out to assess the level of the viral load. A low level of the viral load (VL) means that the infected person cannot transmit the virus to another person, and a high level of the VL means that the infected person can transmit the virus to another person”*(MB.HD-FGD-ALHIV-G-NUMBER-1).

*“.....Okay, HIV is a disease that cannot be cured so, to continue to be alive, we should take our medicine”*(CASS.NK-FGD-ALHIV-G-NUMBER-1).

*“.....HIV is AIDS virus; it is the immunodeficiency virus that is contracted when using contaminated objects, from mother to child and that attracts opportunistic diseases through sexual intercourse and blood transfusion”* (BIK-FGD-ALHIV-B-NUMBER-5).

*“....It is a disease that is contracted in many ways: from the mother to the child and through sexual intercourse, for examples. It is advisable to take medicines to be healthy. If one does not take their medicines, their body will be weak and opened to various diseases”*(MB.HD-FGD-ALHIV-G-NUMBER-2).

Concerning guardians, many of them showed understanding of the nature of the virus as seen in some responses below.

*“....A virus that has no cure so far. It is acquired sexually, by blood transmission from mother to child or by soiled objects. This virus is inactive and sleeps with the taking of antiretroviral medication. In addition, knowledge of t statusis obtained by screening, and later on treatment if the level of the viral load is not good or is high”*(MB.HD-FGD-GUARDIAN-NUMBER-4).

But two guardians said that only God can cure the disease as presented below.

*“....I think that the medication cannot treat a patient. Only God can treat a person who is suffering from the disease.”*(MB.HD-FGD-GUARDIAN-NUMBER-2).

*“....Only God can cure every kind of diseases.”*(FCB-FGD- GUARDIAN-NUMBER-1).

The majority of our respondents have a sound knowledge of HIV and the role of ART. The definition of the disease and the role of ART, as varied as it could be, are different from one respondent to another. Indeed, for one another and whether we are in an urban or a rural area; the following quotes were the responses of the participants:

*“.....A virus that cannot be cured, we can stop it from being active, it can be weakened with antiretroviral. For it to be known, tests are carried out to assess the level of the viral load. A low level of the viral load (VL) means that the infected person cannot transmit the virus to another person, and a high level of the VL means that the infected person can transmit the virus to another person”*(MB.HD-FGD-ALHIV-G-NUMBER-1).

*“.....OK, HIV is a disease that cannot be cured so, to continue to be alive, we should take our medicines”*(CASS.NK-FGD-ALHIV-G-NUMBER-1).

*“.....HIV is AIDS virus; it is the immunodeficiency virus that is contracted when using contaminated objects, from mother to child and that attracts opportunistic diseases through sexual intercourse and blood transfusion”* (BIK-FGD-ALHIV-B-NUMBER-5).

*“...It is a disease that is contracted in many ways: from the mother to the child and through sexual intercourse, for example. It is advisable to take medicines to be healthy. If one does not take their medicines, their body will be weak and open to various diseases”* (MB.HD-FGD-ALHIV-G-NUMBER-2).

Concerning guardians, many of them are fed up with this situation. As regard morbidity, they recognize that this is a virus.

*“.....A virus that has no cure so far. It is acquired sexually, by blood transmission from mother to child, by soiled objects. This virus is so far inactive, asleep when taking antiretroviral. In addition, the knowledge of the status passes by screening, test and later on one is under treatment if the level of the viral load is not good or is high”*(MB.HD-FGD-GUARDIAN-NUMBER-4).

But two guardians said only God can cure the disease as written bellow.

*“.... For me, I thing even that the medication cannot treat a patient, God only can treat the person who is suffering from this disease”* (MB.HD-FGD-GUARDIAN-NUMBER-2).

*“....Only God can cure every kind of diseases”* (FCB-FGD- GUARDIAN-NUMBER-1).

### **3.3 Knowledge about ARVs**

As regards ARVs role, both adolescents and guardians all agreed that ARVs are used for stabilizing and making the virus inactive in order to stop their multiplication and help the virus carriers not to be sick. The responses were as follows.

*“..... It is advisable to take medicines to be healthy. If one does not take their medicines, their body will be weak and opened to various diseases.”* (MB.HD-FGD-ALHIV-G-NUMBER-2).

*“...its role, as my friends said, is to calm down, deaden or to reduce the power of the virus.”* (FCB-FGD-ALHIV-G-NUMBER-3).

*“....According to me, I would say that these drugs really improve health because they stop the development of the virus and consequently enable a person to lead a normal life like that of every healthy person”* (FCB-FGD-GUARDIAN-NUMBER-6).

*“...Antiretroviral ensures that the disease does not develop”* (CASS.NK-FGD-GUARDIAN-NUMBER-2).



### **3.4 Sharing information relating to the status**

For adolescents, this knowledge is also part of the management process. But often, according to the context, we checked if they disclosed their status to the people around them. There were various answers. Ninety-five per cent (95%) of adolescents shared the information only with their immediate associations, that is to say, their close family members. Although parents seem to accept children's status, the fear of disclosing it is real given the stigma attached by the overall perception of the population about the disease: "*disease of shame*." The quote below supports the point.

*"...It's not easy to talk to people about their status. I'm sure my daughter already knows her status but she is still waiting for me to tell her. The questions she always asks me make me think that she is already aware of her status."*(CASS.NK-FGD-GUARDIAN-NUMBER-7).

We also noticed that some adolescents faced psychological problems related to ill-treatment, rejection and felt the need to be loved and supported. One adolescent for example said.

*"...I am worried about my future and wonder if I will one day have a boyfriend, get married and have children ... how will I tell my friend that I am HIV positive? Will he stay with me? He will run away"* (HJY-FGD-ALHIV-B-NUMBER-2).

Some of adolescents pointed during the interviews to the fact that they informed others about their status. The responses are as follows.

*"...My friend knows my status but our friendship has not changed. He says that since we are not lovers, it is not possible to transmit the virus. Well, he treats me well and everyone loves me in my family, in my neighborhood and everywhere. I am like a star. I am called to every activity in the neighbourhood, everyone loves me"* (FCB-FGD-ALHIV-G-NUMBER-11).

*"...Yes, I shared it with my family and also my friend who is my classmate and in my neighborhood"* (FCB-FGD-ALHIV-B-NUMBER-1).

*"...Yes, my best female friend and my best male friend in addition to my family"* (CASS.NK-FGD-ALHIV-G-NUMBER-8).

### **3.5 Support strategies that assist adolescents to take their medication properly**

Adolescents and their guardians received various forms of support. Notwithstanding, some adolescents took the responsibility of assisting themselves in taking medication by the use of a clock. The responses are as follows.

*"...I have an alarm that I use. It rings every day at 8pm, which is the time I take my medication"* (FCB-FGD-ALHIV-G-NUMBER-4).

*"...For me, I always use my phone, it is what reminds me to take my drugs on time"* (FCB-FGD-ALHIV-B-NUMBER-3).

*"...I bought a clock for my daughter to remind her to take her drugs. But sometimes, she ignores the alarm when it rings and when I ask her if she took the medication, she says yes"* (HJY-FGD- GUARDIAN-NUMBER-3).

It was also discovered that a few adolescents did not use any support to take their medication and their responses are presented below.

*“...I know that if I do not take my medication, I will be sick, so I just remember to take it every day” (CASS.NK-FGD-ALHIV-G-NUMBER-1).*

*“...If one does not take their medicines, their body will be weak and opened to various diseases.”(MB.HD-FGD-ALHIV-G-NUMBER-2).*

*“...Before, it was my grandmother who reminded me to take my medication, but in the past two years, since I got to know my status, I've been taking them every day. I simply remember” (BIK-FGD-ALHIV-G-NUMBER-1).*

Some participants indicated that they received their support from their family members. The examples below support this point.

*“...My Aunt used to remind me every day” (FCB-FGD-ALHIV-G-NUMBER-7).*

*“...My mother reminds me every evening. Sometimes, she is the one who administers the medication to me” (HJY-FGD- GUARDIAN-NUMBER-9).*

*“At home, his elder sister and I give him the medicine otherwise he will not take them as prescribed by the doctor” (CASS.NK-FGD- GUARDIAN-NUMBER-7).*

*“...My daughter complies with her drug intake time because I have adjusted my phone alarm to her drug intake time and I remind her five minutes before. This enables her to always take her drugs on time” (CASS.NK-FGD-GUARDIAN-NUMBER-6).*

*“...Given that I am also on treatment, we all take drugs at the same time. And if she goes out with her friends, I always make sure that she takes her drugs with her in case she will be out beyond her drug intake time. When time comes, I call her to remind her to take her drugs” (FCB-FGD-GUARDIAN-NUMBER-11).*

It was also realized from the data that some of the adolescents were supported by the health care system within the health facilities that they were enrolled. The responses were as follows:

*“...The nurse at the health facility that I always go to collect medication advises me to take it every day at the prescribed hours” (FCB-FGD-ALHIV-G-NUMBER-2).*

*“... Sometimes, we are called to come to the health facilities for counseling and advised to always take our medication” (FCB-FGD-ALHIV-B-NUMBER-8).*

*“...We reinforce adherence at each ARVs refill. We ask adolescents to respect their daily medication intake and the time for the intake” (FCB-IDI-NUMBER-1).*

*“... We carry out Patients Therapeutic Education (PTE) at every appointment in a presence of the psychologist. We later organize encounters with all our adolescents to talk about a particular issue” (BIK-IDI-NUMBER-2).*

One participant did not say anything about the support they used to take their medication and another expressed neglect as shown below.

*“...When I remember, I take it, and if I forget, I do not take it” (FCB-FGD-ALHIV-B-NUMBER-6).*

*“... I experience lack of care from family with whom I stay with because my mother and my father died of the same disease” (MB.HD-FGD- ALHIV-G-NUMBER-3).*

### **3.6 Factors that influence adherence to ART**

The study that was conducted showed that there are many factors that influence adherence to ART. The findings indicated that these factors were at the level of individual, medication, family and health care management.

**3.6.1 Individual factors (ART experiences/negative emotions related to ART):** Most of the adolescents indicated in the study that they see compliance with medicine intake as punishment or drudgery. Indeed, for these adolescents, there is a great need for psychological support in taking medicines, and especially on how they understand the experience of the health condition and the pain which is deep for many of them. The data below supports this.

*“...I do not often take my medicines because I ask myself whether I am the only person who suffers from the disease” (FCB-FGD-ALHIV-NUMBER-7).*

*“.....Same for me, same for me, that's one of the reasons we sometimes do not take our medicines. But, well! We often still get back to take medication because it is for our good” (BIK-FGD- ALHIV-G-NUMBER-7).*

*“....I do not know if the medicines make me sicker or heal me, I'm confused, I don't understand (shrugging and shaking the head at the same time)” (MB.HD-FGD-ALHIV-G-NUMBER-5).*

*«....It puts us out of society, we feel rejected, and we conclude that life is unfair to us. It makes us feel bad when we take it” (BIK-FGD-ALHIV-B-NUMBER-7).*

For some adolescents, they did not take the drugs because they were infected at infancy by their mothers, and thought it was unfair to them. The quotes below support the point.

*“...I do not take the medication because I did not personally contract the disease, my father and my mother died of it, so, it is better that I also die” (MB.HD-FGD- ALHIV-G-NUMBER-4).*

*“....It is very difficult to suffer from something that you are not really the cause of” (FCB-FGD-ALHIV-B-NUMBER-5).*

*“...I am tired of taking the medication which I started since I was one year old” (FCB-FGD -ALHIV-G-NUMBER-5).*

A few of the adolescents did not take medication because of forgetfulness, as seen below.

*“...I forget to take the medicines because of tiredness and forgetfulness” (HJY-FGD-ALHIV-B-NUMBER-7).*

*“...I used to forget at the beginning, but now it's OK, I take it every day” (CASS.NK-FGD-ALHIV-G-NUMBER-4).*

**3.6.2 Medication and regimen factors:** The ARV medication is taken once a day, every day, especially since there are a lot of side effects. Some adolescents desire the possibility of taking only one dose per week while on the contrary, some do not recognize the importance of the medicine intake. Also, many adolescents in examination classes do not comply with medicine intake because of the side effects. The reactions to medication intake are as follows.

*“...If we reduce the medicine intake to one time per month, it would be less painful” (FCB-FGD-ALHIV-NUMBER-2).*

*"....Strange side effects, hallucinations, strange behaviour with everyone, violence, dizziness, palpitation. Me, I decided not to take anymore, here like this! Hum! Clapping hands"* (CASS.NK-FGD-ALHIV-G-NUMBER-1).

*"...After taking medicines, we are dizzy, we have nausea, stomach ache and some mates even have breathing problems"* (FCB-FGD-ALHIV-B-NUMBER-6).

Others participants had the following to say:

*"...I don't take it every day because some time when I take it without food, I vomit it"* (FCB-FGD-ALHIV-B-NUMBER-5).

*".... I wish the daily drug consumption is reduced to once a week or once a month and why not reach the point of healing.... It stigmatizes both children and families"*(FCB-FGD- GUARDIAN-NUMBER-8).

*"...I do not take medication when I am writing examinations, because I am afraid to wake up late. It causes fatigue"* (CASS.NK-FGD-ALHIV-G-NUMBER-7).

*"...I spent two years without taking my medicines after the death of my parents, on their will, the ticket they forgot to write that. It was only later when I talked about it to my elder sister that I was taken back to the hospital"* (CR-FCB-FGD-ALHIV-G-NUMBER-12).

All the responses above depict adolescents' experiences which suggest the causes of non-compliance to medicine intake. All these answers depict adolescents' lifestyles which can lead to non-compliance with medicine intake. In addition, they show us that they live the same way other adolescents do, a life beyond the reality that always catches up to them with the obligation to comply with medicine intake at the prescribed time.

**3.6.3 Social and family factors:** Participants pointed to some family and environmental factors that could contribute to poor adherence on ART such as the death of a biological parent or the lack of support for some parents or guardians. Some responses are presented below.

*".... I do not know exactly what to say. When my daughter was alive, her son readily took medication. Since she passed away, he does not want to take it"* (FCB-FGD- GUARDIAN-NUMBER-4).

With respect to alternative or traditional medicines, the adolescents said that they had heard about alternative or traditional medicines that could cure HIV. However, at their level, they did not take such medication apart from two of them. The quotes below present the data of the two participants on alternative medication.

*"...My dad's friend told me about a plant that cures the virus. It is a reddish plant with pictures of it on Facebook and I always use it"* (FCB-FGD-ALHIV-B-NUMBER-4).

*"...I have heard about traditional medicines and I take some.... My aunt took traditional medicines and recovered from HIV"*(BIK-FGD-ALHIV-B-NUMBER-4).

Regarding alternative and traditional treatments, parents and guardians were aware of them and believed that they were able to cure HIV. Nevertheless at their level, they did not take those medicines and could not encourage adolescents to do so until they are made official. They had the following to say.

*“....There are too many charlatans and liars whose aim is to make money and get rich no matter what they say and do” (HJY-FGD-GUARDIAN-NUMBER-6).*

It was found in the study that some guardians and parents used prayers to manage the disease, although most of the respondents unanimously acknowledged that they have never used this means. The responses are presented below.

*“....Only God can do a miracle. We remain hopeful and only pray” (HJY-FGD-ALHIV-B-NUMBER-3).*

*“.... With faith, we must confess healing and not doubt, because if we do, God will not answer our prayers” (MB.HD-FGD-GUARDIAN-NUMBER-5).*

The lack of economic resources causing the lack of food was observed as a common barrier to ART adherence. It was discovered that some adolescents did not take their drugs every day because of lack of food as seen below.

*“....I think the government is doing much for patients: giving ARV medicines; they do much for us. If in addition to that they give food, it would be too heavy for them” (MB.HD-FGD-ALHIV-G-NUMBER-1).*

*“....Sometimes, my daughter does not take her medicines because of the lack of food. He will say he cannot take the drug with an empty stomach” (HJY-FGD- GUARDIAN-NUMBER-6).*

Some participants did not take medication doses whenever there were guests in their house. Their responses were as follows.

*“....It feels difficult to take my drug at home when there are visitors” (BIK-FGD- ALHIV-G-NUMBER-2).*

**3.6.4 Health system factors:** Health care providers' characteristics could affect adolescence adherence to ART. The interviews showed that participants generally strictly followed appointments in some health facilities but not in others. There are some health facilities that are negatively outstanding because their patients fail to respect appointments. The responses below explain.

*“.....The lack of social, psychological and sometimes family support could contribute to this type of behaviour. In addition, the resignation of some parents from their support mission is also another factor of the failure to respect appointments” (FCB-IDI-NUMBER-2).*

Some of the health facilities visited had developed strategies to help adolescents on ART to take their drugs, but some health workers indicated the issue of lack of psychosocial support, untrained staff and finance to do home visits to support ART adherence as seen below.

*“....I think untrained staff on the individual management of adolescents relates to poor adherence” (HJY-IDI-NUMBER-1).*

*“....We have to be trained on how to help adolescents to take their medication and the government has to develop adolescents support forums of information, education and communication” (CASS.NK-IDI-NUMBER-1).*

Some elements were mentioned by health workers to have negative influences on adherence to ART like the poor quality of services, lack of therapeutic education and information about HIV, non-compliance to appointments, the lack of the active involvement of some adolescents, poor supervision, lack of moral and social support, and the transition from adolescence to a poorly prepared adult life. According to parents, the staff members at the health

facilities take time to listen to their children and guide them through counseling. However, the recurrent problem they faced was the very long wait for the results of some medical examinations. Parents, however, request the setting up of a virtual exchange platform to improve health services.

*“...If one facility is charged or far from the refilling medication stock, patients should be able to know where to go for medicine supply without difficulty. In other words, the system has to be computerized”* (CASS-NK-FGD-GUARDIAN-NUMBER 5).

### **3.7 Strategies for optimal adherence**

The adolescents and Parents/Caregivers who participated in the study suggested that to support adherence to medicine intake, it would be important to develop approaches that facilitate and help people to adequately comply with medicine intake. The management process of adolescents so far suffers from a lack of consideration in research and approaches that take into account their needs and requirements. The group, as we have seen above, faces many problems in their social and sexual lives. Moreover, adolescents dread the future because it is uncertain. They believe that there is still much to do base on what is experienced in HFs and in the cities with the stigma and rejection of people living with HIV. The study s gave us the opportunity to realize that people living with HIV are often left out during recruitments and some competitive entrance examinations into training schools. The situation also contributes to the deterioration of the living conditions of patients. The following examples are given to depict their opinions.

*“...I think that in order to help, it would be better for the government to provide work for them or their relatives. I suggest that the State provides work for people living with HIV to enable them to cope in society”* (HJY-FGD-ALHIV-B-NUMBER-5).

This approach suggested above is more likely to be used for adolescents from low income level families who sometimes lack food to be physically and socially balanced. Participants in the study also suggested that in supporting adherence to medicine intake, it would be important to develop approaches that facilitate and help people to adequately comply with medicine intake. Examples are presented under the subtopics below.

#### **3.7.1 Use of text message/ call /creation of discussion groups through SMS, WhatsApp for sharing experience and mutual support:**

Some participants proposed the telephone telephone medium and social media as tools to improve adherence as seen below: This approach is more likely to be used for adolescents from low or very-low income families who sometimes lack food to be physically and socially balanced.

*“...The creation of discussion groups through WhatsApp could allow adolescents to share their experiences and support each other away from the interference of the general public. This strategy could also act as a reminder for various appointments for medicines intake, medical examinations and counseling sessions. This option could also help those concerned to come up with research techniques and solutions to problems encountered such as loneliness, anxiety, grief and stress”* (HJY-IDI-NUMBER-1).

*“...I think the government should set up a system that will allow telephone communication companies like Orange or MTN to remind ALHIV of their medication intake every day at the relevant times”* (FCB-IDI-NUMBER-1).

**3.7.2 Setting up counseling sessions:** Participants in the study held that counseling sessions could help ALWHIV to properly interact with each other and with health personnel in order to get out of the stress and confinement caused by the disease.

*“...These sessions help us a lot because it provides the opportunity for me to freely talk about my experiences together with my girlfriend” (BIK-FGD-ALHIV-B-NUMBER-2).*

*“...It frees us from pressure and it helps us to forget that we are ill” (CASS.NK-FGD-ALHIV-G-NUMBER-4).*

For others adolescents, they will be like to be counseled by their peers. This will help them to better communicate and improve their adherence. The quotes below support this point:

*“...Yes, nurses give us advice, but I think that we want young people like us to advise us too, because with them, we can talk to them” (FCB-FGD-ALHIV-G-NUMBER-4).*

*“...That's true; because with young people like me, I can easily be open” (HJY-FGD-ALHIV-B-NUMBER-3).*

**3.7.3 Health system support and follow up:** Parents/caregivers expressed gratitude to the State for what has been done so far by the health care system although they believe that there is still much to be done based on what is experienced in health facilities by patient and the stigma and rejection of people living with HIV in the society. Parents who took part in this study had the following to say.

*“...The State must set up mechanisms that will solve this problem, for example, at the last competitive entrance examination into the Advanced School of Police (PLHA), some candidates who wrote and passed the first part of the examination were rejected during medical examination when examiners discovered their seropositivity”(FCB-FGD-GUARDIAN-NUMBER-5).*

*“...I think the State is doing too much for patients through the ARVs, medicine that they give us. If in addition to that we are given food again, that would be too much for the government. However, I think the State could at least help people living with HIV to get jobs” (HJY-FGD-GUARDIAN-NUMBER-6).*

*“...In competitive entrance examinations into training schools and recruitments, PLHIV are always side-lined. It is not normal. Are they not human beings or can they not work as “normal” people? How can we earn a living without working? With all the demands like medical tests and daily life problems such as renting, electricity and water bills, clothing, other bills and food, how do we cope?” (MB.HD-FGD-GUARDIAN-NUMBER-3).*

*“In addition to ART, travel expenses for the collection of ARVs from health facilities should be covered” (FCB-FGD- GUARDIAN-NUMBER-6).*

Others held that therapeutic education for parents and guardians should be strengthened.

*“..... We should not focus only on education of adolescents, but we also have to schedule therapeutic education for parents” (MB.HD-IDI-NUMBER-1).*

## **4. Discussion**

This study provides information on adherence to ART for adolescents and the support needed to improve ART adherence.

### **4.1 Knowledge about HIV and ARV**

It was discovered that most adolescents and guardians knew the definition of HIV and the role of ARV. As regards to morbidity, they recognized that it as a virus and all agreed that ARVs are used for controlling and making the virus inactive in order to stop their multiplication and help virus carriers not to be sick. This finding are confirmed by a study conducted in Botswana in 2012 where most of adolescents responded that this is a virus and all agree that ARVs are used for stabilizing and making the virus inactive in order to stop their multiplication and help virus carriers not to be sick [16, 19].

### **4.2 Factors that influence adherence to ART**

Adolescents, guardians and health workers mentioned a variety of factors that detrimental to ART adherence.

**4.2.1 Personal/individual related factors:** Adolescents pointed out during the research that they faced challenges with adherence to the medication because of their lifestyle. They showed they could hardly keep up with the obligation to take medication at prescribed times. The finding is related to another study related to barriers to ART among Peruvian adolescents in 2018 [20, 21]. Also, most adolescents revealed that they shared their status only with immediate relations, that is to say, close family (parents) and friends. Adolescents feared that they would be discriminated against or abandoned by family and peers if their HIV status was known. The findings are supported by a qualitative study conducted in Rwanda where the fear of disclosing HIV status is real given the stigma surrounding the overall perception of the disease [22]. Keeping HIV status secret can generate substantial barriers to adherence as was discovered by a qualitative assessment of barriers to ART for adolescents living with HIV in Kenya [23] and Brazil [19]. In contrast, a study found that the disclosure of a child's HIV status to family and the community might help reduce stress and mobilize support for adherence [24]. As regards to alternative or traditional medicines, adolescents said they had heard about alternative or traditional medicines that could cure HIV. It was also found that few adolescents do not use any support to take their medication.

**4.2.2 Medication related factors:** Side effects were also reported as a barrier to adherence in adolescent patients in this research. Previous studies identified forgetfulness as a major contributor to non-adherence [21, 25]. Most of the adolescents pointed out during the FGD that the medication is cumbersome because it is taken once a day and every day, especially since there are a lot of side effects after intake. Similarly, studies conducted in Kenya and Rwanda also showed that other barriers to adherence include the pill burden (quantity, size, taste, side effects), medication fatigue, and lack of planning to bring medication on journeys away from home [9, 20, 23].

**4.2.3 Social, family and environmental related factors:** Participants also stated some family and environmental factors that contributed to poor adherence to ART such as the death of biological parent and the lack of support from



some parents and guardians. These findings are supported by other studies which showed that adolescents who lost their parents did not take their medication as expected [21, 26]. The lack of economic resources causing the lack of food was a common observation barrier to ART adherence. It was also indicated that some adolescents did not take their drug every day because of lack of food. Our data corroborate many of the findings from similar studies in other countries [21]. Adolescents and their guardians experienced various forms of support which helped them to adhere to their treatment. The findings indicated that some adolescents took the responsibility themselves to take their medication. They had developed multiple strategies to enhance ART adherence by using the clock or phone. The results of the present study are similar to studies that were respectively conducted in Maseu [21] and Peru [20] where adolescents always use their phone or clock as adherence support against forgetfulness. Other adolescents said that they received their support in their family which revealed that adolescents always used their phones or clocks as adherence support for forgetfulness. Other adolescents said that they received support from their families.

Regarding alternative or traditional treatments, adolescents and guardians expressed awareness of the potency in curing HIV. Nevertheless, some did not take those kinds of medicines and did not encourage intake because they were not official. However, five (both adolescents and guardians) agreed to be consumers of traditional medicines to cure HIV. Unfortunately, the consumption of traditional medicines may prevent adolescents from being observed during their treatment.

Regarding the management of the disease through prayers and churches, all respondents unanimously acknowledged that they had never used these therapeutic means. Some related studies pointed that religious beliefs negatively influenced adherence [20, 21], it was found in this study regarding the management of the disease (AIDS) through prayers or in churches that, all respondents unanimously acknowledged never to have used this therapeutic means. The finding of this study also revealed that adolescents dread the future because it is uncertain. Adolescents' parents and guardians gave us the opportunity to realize that people living with HIV are often left out during recruitment and from some competitive entrance examinations into training schools. This situation could contribute to the deterioration of their living conditions. Many examples were given to pinpoint highly professional training schools such as Inter-Arms Military School (EMIA) and the National School of Administration and Magistracy (ENAM)... They pointed out the fact that they should *"Establish a quota of people living with HIV for competitive entrance examinations into training schools and recruitments"*. The recommendation could encourage adolescents to continue with their studies and training they could follow career paths. This finding is supported by two studies which found that factors that favor medication adherence among adolescents may be subject to beliefs which could aggravate the illness and kill the desire to live and to have a future [27]. This same discriminatory and stigmatizing feeling was pointed out in another study with adolescents with HIV/AIDS and their caregivers [23]. Discrimination can lead people to isolate themselves and might become another factor hindering medication adherence. As such the lives of ALHIV should be normalized in such a way that stigma and discrimination do not compromise their quality of life and treatment adherence.

### **4.3 Health care related factors**

Health care provider characteristics can affect adolescent adherence to ART. The interviews showed that adolescents scrupulously respected appointments in some HFs but not in others. According to parents, the staff from health facilities took time to listen to adolescents and guide them through counseling. Some of the health facilities visited had developed, each at their level, strategies to help adolescents on ART to take their drugs. Some health workers indicated the issue of lack of psychosocial support, untrained staff and finance to do home visits. Also, elements were mentioned by health workers such as those that may have a negative influence on adherence in adolescents on ART like the quality of services late disclosure, lack of therapeutic education and information about HIV, non-compliance with appointments, lack of active involvement of some adolescents, poor supervision, lack of moral and social support and transition from adolescence to a poorly prepared adult life. The lack of support tools for therapeutic education for adolescents could be due to the fact that this unique target (adolescents) is not yet a priority target for the fight against HIV in Cameroon. Also, the result justifies the fact that few studies have been conducted for adolescents living with HIV in Cameroon.

### **4.4 Suggestion for optimal adherence**

For adolescents and parents/caregivers, in supporting adherence to medicine intake, it would be important to develop approaches that facilitate and help people to adequately comply with medicine intake such as text messages, calls, creation of WhatsApp groups or develop an application for recalling medicine intake time and for sharing experience and given mutual support. The use of short message service among youths has been found to improve self-reported adherence in reports on the benefits of cell phone use among adolescents and young adults [28]. Adolescents and caregivers suggested counseling with health providers for the improvement of adherence rate on ART. This result corroborates with other studies that were conducted in 2011 and 2012, which revealed that in both developed and developing countries, ART adherence may be influenced positively by the availability of counseling, enhancing adolescents psychosocial support [29, 30]. Most of the health care providers proposed that a competition be organized for this target population that will motivate them to adhere to their treatment. Thus, it can be said that those who have undetected viral loads will receive motivation to come up. Some adolescents suggested that counseling sessions should be carried out by their adolescent peers. This approach has been used among adults and pregnant women living with HIV in terms of improving adherence. It will be important to use it also among adolescents.

## **5. Conclusion**

Adherence is a major challenge among adolescents living with HIV. The findings of this study pointed to personal, social, economic, medication and health system factors as influences on adherence. Provision of several interventions of integrated adolescents centered and friendly approaches is needed to increase adherence rate in HIV programmes in Cameroon. Our findings support the development and implementation of contextualized, multilevel interventions for adolescent ART adherence. These factors should be considered when designing appropriate interventions to improve adherence to ART for this vulnerable population. In addition advocacy is urgently required for the development of motivation in the form of recruitment in some national institutions. Finally, further study is

needed to prospectively assess the impact of adolescent interventions on adherence; no adolescent living with HIV should die from AIDS in an era of accessible ART.

### **Limitations**

The study did not do the quantitative assessment. Also, the adolescents involved were not randomly chosen but prospectively selected for group participation. The study did not include information on adolescents who did not know their status. This research was conducted in French before translated in English and not ensured that the English version respected what was said in the French version.

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### **Authors' Contributions**

AK, FM and MNN: designed and implemented the study; AK and AN collected the data; AK and AN: analysed and interpreted the data; AK: initiated the manuscript; HN and AN: revised the initial version of the manuscript; All authors: revised and approved the final version of the manuscript.

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### **Conflict of Interest**

The authors have no potential conflict of interest to declare.

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