

# Antiretroviral Therapy (ART) rationing and access mechanisms and their impact on youth ART utilization in Malawi

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## Abstract

The World Health Organization (WHO) staging is a commonly used rationing mechanism for highly active antiretroviral therapy (HAART) among various HIV infected populations including youths in most developing countries. Rationing is defined as any policy or practice that restricts consumption of or access to certain goods due to its limited supply. However, as HIV prevalence is rapidly increasing among youth, understanding the capacity of the staging approach to achieve HAART uptake in youth is of considerable importance.

## Aim

This study aimed to explore how HAART rationing and access mechanisms impact on youth's utilization of HAART in Malawi

## Methods

The study used mixed methods with quantitative analysis of existing Ministry of Health Clinical HIV Unit data used to determine existing levels of youth HAART use. Qualitative methods employed in-depth interviews that interviewed nine ART providers, nine HIV positive youth on HAART and nine HIV positive youth not on HAART; and field observations to nine ART clinics were used to understand HAART rationing and access mechanisms and how such mechanisms impact youth uptake of HAART.

## Results

The findings revealed that ART providers use both explicit rationing mechanisms like WHO clinical staging and implicit rationing mechanisms like use of waiting lists, queues and referral in ART provision. However, the WHO staging approach had some challenges in its implementation. It was also observed that factors like non-comprehensive approach to HAART provision, costs incurred to access HAART, negative beliefs and misconceptions about HAART and HIV were among the key factors that limit youth access to HAART.

## Conclusion

The study recommends that while WHO staging is successful as a rationing mechanism in Malawi, measures should be put in place to improve access to CD4 assessment for clients who may need it. ART providers also need to be made aware of the implicit rationing mechanisms that may affect HAART access. There is also need to improve monitoring of those HIV positive youth not on HAART in order for the system to be able to commence them on treatment on time. Additionally, ART programmes need to address individual, programme and structural/social factors that may affect youth's access to HAART.

## Introduction

HIV prevalence in youth is increasing at alarming rates. Globally, it is estimated that 50% of all new infections worldwide are between the ages of 15 and 24 and that 30% of all people living with HIV fall within this age group. In Malawi, 18.4% of the population is aged 15-24 and HIV prevalence among this population is 6 percent<sup>1</sup>. Although the prevalence rate is lower than the national prevalence rate, significant numbers of people in the age group 15-24 are infected with HIV considering the large proportion this age group constitutes in the national population<sup>2,3</sup>. Worse

still, the rate of transmission is increasing within this age group<sup>2,3</sup>. It is, therefore, evident that young people are an important target population with respect to addressing the HIV pandemic. Youth are of particular interest as this group is a key population in terms of the future of the epidemic and, due to Malawian conservative attitudes to adolescent sexuality, may experience greater barriers to accessing HAART services.

Given the magnitude of the Malawian HIV/AIDS pandemic and the impetus to prevent further spread of the epidemic as well as reducing the effects of HIV on those infected, Malawi initiated a national highly active antiretroviral therapy (HAART) programme in 2004 with apparent success as most HIV positive people who were eligible for HAART received it<sup>4,8</sup> and has attracted global attention as a model of good practice in HAART scale-up. However, due to limited resources and in line with approaches adopted globally and in other African countries<sup>9,10</sup> the need to ration HAART in Malawi was evident as more HIV infected people demanded HAART while the availability of ARV drugs were not adequate to meet the demand<sup>8</sup>.

Malawi adapted World Health Organization (WHO) clinical guidelines for HAART to guide its rationing approach<sup>11</sup>. WHO staging system for HIV infection is a classification of the stages of HIV infection development based on clinical manifestations<sup>12</sup>. WHO staging system classifies HIV infection development into four stages: Clinical stage I, II, III and IV, and each of these stages has its own distinct manifestations<sup>12</sup>. This approach is commonly used in resource-limited settings where resources for laboratory staging of HIV infection development are scarce including Malawi<sup>12</sup>. Rationing is defined as the controlled provision of health services to clients based on criteria that qualify one to be eligible for the service or not<sup>13</sup>. The WHO clinical staging is used as a means for rationing HAART in resource poor settings<sup>14</sup>. The WHO clinical staging system for HIV/AIDS emphasizes the use of clinical parameters to guide clinical decision-making for the prioritization and management of those with HIV<sup>14</sup>. According to the WHO staging, ART is rationed based on the clinical staging an individual is classified into. Those who are in stages I and II are not eligible for ART except if their CD4 count is at 250/mm<sup>3</sup> or below. On the other hand, clients who are classified in stages III or IV are eligible to receive ART<sup>12</sup>. In practice, however, rationing can be explicit, such as policies and programmes that target specific populations, or implicit through use of other informal mechanisms such that the pattern of supply favours certain individuals' or groups' ability to access services<sup>15</sup>.

The WHO clinical staging system which has been widely used in resource-limited countries, particularly in the African Region has proved pragmatic and useful in facilities at the first level and the referral level<sup>16,17</sup>. While WHO clinical staging has been successful in HAART rationing targeting the general population<sup>16,17</sup>, its impact on HAART use by youths in Malawi is not yet documented.

## Objectives

The main aim of the study was to explore rationing and access mechanisms and how they operate in the provision of

HAART among the youth in Malawi. Specific objectives of the study were:

- To assess the proportion of youth accessing HAART in the context of clinical staging in Malawi
- To identify explicit and implicit HAART rationing mechanisms operating at community level in Malawi;
- To identify what access mechanisms are operated by youth in Malawi in attempting to use HAART;
- To identify challenges associated with the current rationing and access mechanisms in youth's pursuit of increased HAART use in Malawi.

## Methods

Quantitative and qualitative methods were used. The quantitative analysis of existing data from 2004 to 2008, collected by the Clinical HIV Unit of the Ministry of Health in Malawi were used to determine existing levels of youth HAART use and survival patterns.

The respondents in the in-depth interviews were drawn from the sampled health facilities providing HAART. Three health facilities were selected from each region using a simple random sampling using computer generated random numbers. The respondents were however selected using purposive sampling techniques in order to obtain the desired participant profiles, as follows: nine HAART providers (3 drawn from all HAART providers in two sampled sites in the Southern, Central, and Northern regions respectively); nine youth HAART recipients (3 aged 15-24 years drawn from sampled sites in the Southern, Central, and Northern regions respectively); and nine youth PLWHA (3 aged 15-24 years drawn from PLWHA organisations in the Southern, Central, and Northern regions respectively) giving a total of 27 key respondents. In the youth respondents, there were equal numbers of males and males to ensure representativeness of the youths' views on ART rationing and access.

Quantitative and qualitative data were analyzed using SPSS version 6.0 and content analysis respectively. The major themes in the content analysis were ART access mechanisms, ART rationing mechanisms and limitations of the rationing mechanisms. To ensure validity, two people transcribed the qualitative data while reliability by having two people who independently analysed the qualitative data. Besides, the two qualitative data analysts discussed the results ensuring a consensus on issues which they differed in the analysis. Ethical approval was obtained from Malawi National Health Science Research Committee and informed consent was gained from all research participants prior to the interviews.

## Results

### HIV Prevalence and HAART Access by Age and Sex

HIV prevalence is considerably high in young people. According to the 2004 Malawi Demographic and Health Survey, 11.6% of young people aged 15-24 years had HIV. These data are the best estimates available but suffer from non-response bias in that about one third of those sampled refused to be tested for HIV.

It was however observed that while 3.92% of the population who are HIV positive are those aged 15-19 years, only 1.47% of the people with HIV using HAART are from the ages ranging from 15-19 years. Similarly, while 19.42% of the people with HIV are those aged 20-24 years old, only 6.55% of the people living with HIV on HAART are from the age bracket of 20-24 years.

Table 1: HIV Prevalence by age and sex

Age group	Women	Men	TOTAL
15-19	3.7	0.4	2.1
20-24	13.2	3.9	9.5
25-29	15.5	9.8	12.6
30-34	18.1	20.4	19.2
35-39	17.0	18.4	17.7
40-44	17.9	16.5	17.2
45-49	13.3	9.5	11.6
Total age 15-24	9.1	2.1	6.0
Total age 15-49	13.3	10.2	11.8

Source: HIV Unit Clinical Data 2004-2008

At face value, youth appear under-represented among those taking up HAART, with the exception of 15-19 year old men. Unlike youth in the youth categories' likelihood to be on HAART when HIV positive, individuals in the non-youth category are about one third as likely to be on HAART as they are to be HIV positive. Table 2 compares these estimates to the proportions of individuals accessing HAART in the Clinical HIV Unit's dataset.

Table 2: Proportion (%) of Individual Accessing HAART in Malawi

Age group	Women		Men	
	Share of HIV prevalence* (%)	Share of HAART users^ (%)	Share of HIV prevalence* (%)	Share of HAART users^ (%)
15-19	3.49	1.00	0.43	0.47
20-24	14.79	5.53	3.63	1.02
25+	39.95	54.46	37.70	37.53
TOTAL	58.23	60.99	41.77	39.01

The table shows that the population for both male and female youth currently accessing HAART is generally lower compared with other age groups. However, drawing inferences from this comparison is difficult. First, as noted above, prevalence estimates could be biased as there may be systematic bias of refusal to test across age groups, although this might be expected to be proportionate rather than disproportionate to treatment uptake which also requires the prior administration of a test. Second, the category 'suitable for HAART' corresponds to a sub-set of HIV positive individuals from the HIV positive population whose immunity has started to diminish. The proportion falling in this sub-set is likely to differ across sex and age group. The proportions of youth accessing HAART may be influenced by rationing mechanisms currently used in the provision of HAART.

### Rationing Mechanisms of HAART

Malawian healthcare providers understood rationing of HAART as the controlled distribution of a scarce resource and operationalised through both explicit and implicit rationing mechanisms in the course of their work.

#### Explicit Mechanisms

The use of explicit rationing mechanisms occurs when defined and widely understood criteria are used to determine access to HAART. This study found that commonly used explicit methods included, the development and application of clinical guidelines, specifically the WHO staging approach

which was found to be universally applied in Malawi and preference given to specific population groups. For example, HAART is preferentially available to HIV-positive mothers to reduce vertical transmission and decrease ever-increasing burden of orphan support. However, it was noted that no policy or programme existed to preferentially target youth. Ability and willingness to adhere to HAART for life and the requirement to attend a pre-treatment counselling session were also used as explicit rationing tools.

While the above rationing mechanisms were applied without stated concerns by service providers, another commonly found explicit mechanism that caused more concern among service providers, with service providers questioning the wisdom of the approach, was the fact that each clinic is given a quota allocation of the number of clients to be commenced on HAART.

*'We are given the number of clients which our facility is to commence on HAART monthly or quarterly' (ART provider, SR)*

### **Implicit Mechanisms**

Where explicit mechanisms were well defined and widely understood by healthcare providers, implicit rationing methods were found to rely on subtle decisions made by individual healthcare providers<sup>18, 19</sup> or those associated with other aspects of service delivery that lead to HAART, e.g. HTC service providers. This study found that the healthcare providers in many facilities were applying implicit mechanisms albeit with a lack of awareness.

Access to HIV testing: Some groups are targeted for HIV education and HTC services or promotion campaigns.

*'All pregnant women are taught on the importance of HIV testing and HAART. They are all encouraged to go for testing and we teach them daily about these issues when they come to the clinic. [...] We don't do that with other clients including the youth (ART provider, SR).*

Such groups had an implicit advantage over others in treatment seeking as they had improved knowledge regarding treatment and its benefits and because HIV testing is a pre-requisite to accessing ART services.

**First Come, First Served:** Although the 'first come, first served' principle was adopted as an explicit rationing mechanism to prevent queue jumping, an implicit rationing mechanism, the principle itself was seen to also act implicitly to ration HAART access. It was found that all facilities treated everyone who was medically eligible until the supply of drugs and/or diagnostics (CD4 count results) ran out, the exception being pregnant women who, as discussed previously, are afforded priority treatment. Therefore, eligible clients who arrived after supplies had run out may be put on the waiting list to receive drugs, sent to another facility or simply sent away.

**Use of WHO Staging for ART Enrolment:** The study found that on a number of occasions patients who were staged I or II, according to WHO staging criteria, who had the opportunity to have their CD4 count assessed were found to have CD4 counts below 200/mm<sup>3</sup> and therefore were eligible for enrolment based on CD4 levels. An ART provider summed this up, as follows

*'It happens that sometimes a client is grouped into stage 1 and after CD4 count you notice that the client's CD4 count is far below the cut-off point, say about 120/mm<sup>3</sup> of*

*blood- meaning that s/he needs to receive HAART. [...] If client is assisted at health facility without CD4 count machine, s/he will be delayed to start HAART until s/he goes to a facility with CD4 count machine (ART provider, CR)*

**Favouring the Elite:** One of the questions in the interview guide probed healthcare providers regarding prioritizing who should receive HAART first. Answers to this question, perhaps unsurprisingly given the universal reference to following the explicit guidelines, consistently indicated that there was no stated preference given to any population group, with the previously noted exception of pregnant woman. However, field observations at ART clinics showed that preferential access to HAART was given to those with social, economic and political influence. Such people were involved in a high degree of queue jumping, which was tolerated by healthcare providers. Given that the 'first come, first served' principle is clearly stated and well understood within the Malawian HAART programme, it is not surprising that healthcare workers were unwilling to prioritize groups for access to HAART within the interview. However, given Malawian society that can be characterized by patron/client-type relationships, it is equally not surprising that those with power used it to gain access to HAART.

*'Some elite can just come and jump other clients on the queue; enter the consultation room and they get assisted without questions from providers' (Youth on HAART, NR).*

### **ART Access Mechanisms**

The study found some enabling and inhibiting factors that affected access mechanisms in achieving HAART uptake by youth. These factors were seen to work at individual, programmatic, social and structural levels.

#### **Individual Level Factors**

At the individual level, personal motivation and individual self-efficacy were found to be important in accessing HAART. Motivation was defined as a personal willingness to access HAART

*'I thought the only way to improve my health is to come and start HAART, otherwise ..... (Youth on HAART, CR).*

Self-efficacy was defined as their belief that they could access HAART;

*'I thought so because I knew that I had HIV so such treatment could help to improve my body immunity' (Youth on HAART, SR)*

Another important factor at the individual level was the individual's perception of disease severity with youth more willing to access HAART services when their condition was deteriorating.

*'When I saw that I have been having frequent illnesses, I just made up my mind to come and start taking HAART' (Youth on HAART, SR)*

Increasing perceived benefits of treatment led to greater access. The study found that some youth chose to access HAART services when they saw that their friends were improving when on HAART.

*'I started taking HAART because my friends who were on HAART had fewer illnesses as compared to me' (Youth on HAART, CR)*

#### **Programme Level Factors**

There was a host of factors that supported or inhibited youth's access to HAART at the programme level. Factors such as provision of free HAART at government health facilities increased youth's self-efficacy that they could access HAART. Similarly, pre-HAART counselling, which is conducted as part HAART of ART enrolment, encouraged youth to access HAART



*The pre-HAART counseling sessions helped me to understand the importance of HAART and improved my confidence that I can take the treatment without any problem' (Youth on HAART, SR)*

Availability of appropriately trained human resources also supported youth's access initiatives.

*'Staff at the clinic is friendly and very welcoming. No youth has ever complained about breach of confidentiality at the clinic' (Youth on HAART, NR)*

Well trained staff was also associated with provision of quality care that could enable youth to access HAART

*It happens that some youths who come for HAART are not given sometimes due to failure of the provider to correctly classify them in the right stage. [...] Instead of classifying them into stage 3, they may be classified as stage 1 or 2 (ART clinician, CR).*

While a number of factors were found to support youth access mechanisms at the programmatic level, a wide range of issues was identified as inhibiting factors to youth's HAART access. Some of the barriers included non-comprehensive approach to HAART provision and youths' misperception of the advice not to take the drugs on an empty stomach. As inadequate food supply is a reality of many Malawians lives, this advice could discourage some youths from taking their treatment and result in poor HAART adherence.

*'I only take my ARV drugs when I have eaten something. [...] The doctor advised me to take after food.....' (Youth on HAART, CR).*

Another barrier is that while ART drugs are provided free at CHAM facilities, associated services (consultations, CD4 count) required to access HAART attract a fee at CHAM clinics are another barrier. This is so despite the existence of service level agreement (SLA) which allow maternal and child health (MCH) clients to access all MCH free at all CHAM facilities. These costs of the associated services could ration out youth who cannot afford them.

*'The problem here at facility X is that pregnant women who come for HAART are asked to pay K100 for consultation or K500 if they want CD4 count before they are given HAART. If they don't have the money, women return home without collecting ARV drugs' (ART provider, CR).*

Distance to an HAART clinic was identified as a common barrier to youth accessing HAART. This was related to inconvenience of travelling to the clinic, in terms of monetary and non-monetary costs, and the travel and inconvenience of journeying to a referral hospital for additional services, such as CD4 count. As such, youth who were further from clinics or referral hospitals or could not afford the time to make the journey or the cost associated with the journey failed to access ART services.

*'Most clients who come for staging and have been grouped in stage 1 or 2 are advised to visit XX hospital for CD4 count because we don't have that machine at our facility. Most people however do not go the district hospital because of the distance and hence high cost for transportation. [...] We hear that most of these people die in the communities before they access ARV drugs' (ART Provider, NR).*

Lastly, it was noted that existence of mandatory guardian presence in the process of youth accessing HAART in some facilities could also reduce youth access to HAART.

*When I came to start HAART, I was advised to go back and come with my guardian for my pre-ART counseling; but I didn't want my guardians to know that I visited the clinic (Youth not on HAART, SR).*

### **Social and Structural Level Factors**

At the social and structural levels, a number of factors relat-

ing to an individual's social network were found to positively impact on a youth's ability to access HAART. For example, some youth's decision-making regarding accessing HAART was positively shaped by the opinions of others, be their family members, friends, partners or influential community members.

Another positive influence stemming from the youth's social network was found to be that if people within their network or those already on HAART had a positive perception of HAART, this positively influenced the youth's behaviour regarding accessing HAART themselves.

As observed at the individual level, youth's experience of directly observing improved health among other HAART clients within their social network also positively influenced youth's attitudes towards seeking treatment.

Level and source of interpersonal support also emerged as a significant catalyst for self-efficacy and sustained motivation. Family members were often reported as important sources of hope and courage that could help youths to seek HAART and integrate therapy into daily life by providing practical support, encouraging them to go for HAART, reminding them of appointments, or to take their drugs.

Although a number of social and structural factors were found to facilitate youth access to HAART, a number of other factors that operate at the social and structural level acted to inhibit youth access. Beliefs around the causes of AIDS could reduce motivation to access HAART.

*AIDS is not a condition caused by a virus ... is result of sin against God; hence doesn't require medical treatment (Youth not on HAART, NR)*

Related to this, beliefs that AIDS is caused by witchcraft and can be cured through spiritual healing or traditional medicine, whilst not as widely held these days, were still found to limit some youth's ability to access HAART.

*'You can also see that when you ask them about their illnesses they think they are caused by witchcraft. Even with HIV/AIDS, they think it is caused by witchcraft especially if they had quarrels with their relatives' (ART Provider, CR)*

Misconceptions and rumours related to HAART that generate mistrust was another set of barriers to youth access to HAART.

*'People say that it's better not to take ARV drugs because they shorten your life once you start taking them' (Youth not on HAART, NR).*

Furthermore, misunderstanding about the incompatibility of certain behaviours with HAART was found to negatively impact youth's ability to access HAART. For instance, perceptions given by health workers that drinking alcohol, smoking, and engaging in sex were incompatible with HAART led to decreased levels of motivation to using HAART.

*'The nurse told me that if I start HAART, I should stop taking beer, smoking and I should always use condoms during intercourse. I don't think one can just stop drinking beer and smoking abruptly' (Youth not on HAART, SR).*

Power dynamics between the genders was also found to act as a barrier to young women's efforts to access HAART.

*'When I wanted to go for VCT, my husband was against my decision. I could not go to the VCT clinic until he was convinced that VCT was necessary - having frequent illnesses' (Youth not on HAART, NR).*

Another set of inhibiting factors that operate at the structural level were identified as relating to poverty, such that they constrained the individual's ability to access HAART. For example, youth referred to inadequate nutrition levels,

directly related to poverty, as a factor leading to delayed or missed consumption of ARV drugs.

*Not many Malawians could afford a good diet because of poverty[ ...] Food is very important when taking drugs and doctors emphasize not to take HAART on an empty stomach and since getting food is difficult, it is a challenge for those on HAART (Youth on HAART, SR).*

A final set of inhibiting factors that operate at the structural level relate to the challenges faced by youth at boarding school who have difficulty gaining permission to leave school to attend HAART clinic appointments. Some youth even have problems to keep and take HAART drugs whilst in boarding schools due to fear that their friends would laugh at them if known to be keeping drugs every time or taking drugs daily.

*It's not easy to be in boarding school and taking HAART. I remember, one day one of my friend asked what type of drug I was taking daily since I came to the boarding and she was keen to know what problem I had. It was not easy to answer the question. From then on, I had to ensure that no one was seeing me when taking the drugs (Youth on HAART, CR).*

The study revealed that there are several explicit and implicit factors that may affect rationing and access mechanisms among youth who have HIV. While rationing is a factor that can affect youth access to HAART, there are some individual, programmatic and structural/social factors that could affect youth's access to HAART.

## Discussion

This study provides further evidence that Malawi's HAART programme is working in an equitable manner with respect to rationing and that the explicit rationing mechanisms, the adapted WHO guidelines, are being applied consistently by HAART service providers. However, the findings suggest the existence of several critical areas that need understanding to improve the efficiency of rationing and access mechanisms for the increased uptake of HAART by the youth.

### Staging as a Rationing Mechanism: Improving Health System Efficiency?

While staging is an easy way of rationalizing HAART, it appears to have some negative effects that could affect the performance of the health system. As noted, staging due to its lack of objectivity in its application means that inexperienced HAART providers could wrongly classify some youths into stages that could deny them of the opportunity to access HAART even if they actually qualify.

Furthermore, though there is referral system that aims to improve the efficiency of the system in the form of CD4 count in case there is mis-staging clinically, the referral system appears to have minimum effects on improving efficiency of the system due to lack of affordable means to facilitate the transportation of clients from small health facilities without CD4 count to ones with the equipment<sup>9,10</sup>. The fact that most of the health facilities are long distances from the district hospitals also negatively impact on the role of the referral system as most clients may not be able to walk to the hospitals with lack of public transport apart from money to pay for the transportation. In this case, the current rationing mechanisms are in a way making some clients not access HAART and thereby worsening their immune system as they wait for the time when resources are available to access the CD4 count.

### Explicit and Implicit Rationing Mechanisms

Staging provides a rational and objective approach to making

decisions regarding how HAART should be provided to youth clientele living with HIV. While staging is rational, there are factors that could influence HAART rationing. As noted from the findings, both explicit and implicit rationing mechanisms were found to be in operation in the health system with the later favouring the 'elite or those connected with the providers' who control HAART service provision. With lack of agreement regarding socioeconomic criteria of rationing ART in Malawi, the trend of favouring other groups in accessing HAART is likely to be part of the system.

While lack of consensus on socioeconomic criteria of rationing ART may be a challenge in the explicit rationing mechanism, lack of skills by ART providers to appropriately and rightly stage the clients could affect the efficiency of the system. In addition, the focus on explicit rationing mechanisms in the guidelines and not on potential implicit mechanisms reduces awareness of the providers of the other factors that could bias their decisions when rationing HAART. Moreover, lack of adequate training on the use of WHO staging approach could fail other providers to correctly stage their clients, a factor that can affect one's access to HAART.

Although the explicit rationing mechanisms existed, it should be acknowledged that other implicit mechanisms, though they restricted youth access to HAART (eg HIV testing) were not directly under the control of the ART providers but rather appeared to be artefacts of the context in which this programme is run, specifically with respect to access to HIV testing and a by-product of the explicit rationing guidelines with respect to the 'first come, first served' principle<sup>4,20</sup>.

Without detracting from the achievements of the HAART programme, this study identified a number of areas that could be further improved, notably; the limitations of using staging approach to HAART enrolment and the reality of monthly quotas and how those quotas impact on the ability to access HAART of those with the greatest need.

### *The limitations of using the staging approach to HAART enrolment*

As noted, rationing based on the WHO staging criteria for HAART enrolment could deny other clients from accessing HAART due to lack of adequate skills and experiences to use the approach. It was obvious from the findings that it is possible to present for diagnosis with symptoms that are consistent with stage I and II, which would indicate that the patient is ineligible for HAART enrolment while when CD4 count is used the client may be eligible for HAART. This was argued to increase the risk of HIV/AIDS related deaths as people with significantly reduced immunity would not access HAART and hence become vulnerable to contracting other opportunistic infections. This situation could further be compounded by lack of a proper monitoring system for HIV clients who were deemed ineligible for HAART enrolment at their first presentation.

This limitation of the rationing approach could be addressed by improving access to CD4 machines so that they could be used to confirm the unsuitability for HAART enrolment<sup>9,10</sup>. Furthermore, developing a monitoring system to track HIV positive youth not enrolled on HAART at their first presentation could ensure that people are able to access HAART as their disease progresses.

### *Reality of monthly HAART quotas and their impact on HAART access for those with the greatest need*



The provision of HAART enrolment quotas to health facilities appears a logical way to ensure that rationing is conducted in a fair and transparent way across all facilities. The challenge with monthly quotas however is connected to the 'first come, first served' principle that results in a situation where a less ill people who come at the beginning of the month could be enrolled on HAART, whereas more ill people who come at the end of the month may fail to access the treatment. Overcoming this limitation is challenging as the 'first come, first served' principle is an integral part of how the Malawi HAART programme has been rolled out. It is suggested that, through consultation with stakeholders, including PLWHA, a compromise position may be identified whereby monthly quotas could be apportioned on a weekly basis and a weekly assessment made as to those in greatest need. This would not completely address the limitation but would give an opportunity for need to assess in relation to others.

### ***Addressing Determinants of Youth Access to HAART***

Rationing of HAART could not on its own improve youth's access to HAART. With respect to the determinants of youth's access to HAART, it was found that such factors operate at different levels of the ecological framework and that these factors could serve to support access to HAART or to inhibit access. As there are individual factors like personal motivation and self-efficacy; programme factors like the free-of-charge nature of HAART distribution, the mandatory pre-HAART counselling and the availability of trained health personnel; and social and structural factors like youth's social network that affect youth's ability to access HAART, it is suggested measures should be put in place to ensure that these determinants at various levels are addressed in order to have positive impact on youth's access to ART. It is striking however that the barriers to youth's achieved HAART uptake centres on factors that negatively impact youth's access initiatives rather than service providers' application of implicit rationing mechanisms, as was previously anticipated.

### ***ART Access Mechanisms***

Access mechanisms play an important role in HAART uptake by youth. However, the study suggests that youth access to HAART could depend on the way HAART provision system is strengthened. Provision of quality counseling services and health information that is not vague and ambiguous could promote youth access to HAART.

Besides, health system strengthening that could provide support to the structural and social factors affecting access to HAART is essential. This could be in various forms including community involvement in HTC and HAART programmes, establishment of HTC and HAART support networks and improving follow-up of HIV positive youth and those on HAART.

Referrals are common in HAART provision in order to ensure appropriate rationing through access to CD4 count. However, as the referral system appears to be inefficient due to the referred clients' transport problems, reviewing how the HAART provision system operates could help to address the problem. For instance, ensuring provision of comprehensive HCT and HAART services at each health facility could help to improve access and utilization of HAART services by youth especially from rural areas.

While introduction of service level agreement (SLA) could improve access to HAART services by pregnant young women in areas where CHAM facilities exist, lack of clear guidelines on what services should be provided to the clients provided an opportunity for some providers in some CHAM facilities to implement policies that could hinder pregnant young women from accessing HAART services. In this case, reviewing the memorandum of understanding on SLA could help to improve access of pregnant youths to HAART.

Apart from the above approaches to improve youth's access initiatives to HAART, this study suggests that there are a number of areas that could be focused on. Efforts could be undertaken to highlight the importance of social support and social acceptance of youth accessing HAART and the positive personal testimony and outcomes of other youth on HAART. Such efforts would serve to support motivation and self-efficacy to access HAART, critical behavioural determinants in successfully accessing HAART.

Other barriers identified at the programmatic level, such as mandatory guardian involvement, CHAM fees, and the non-comprehensive nature of HAART provision with respect to nutritional supplements could be addressed through a review of the HAART guidelines, Service Level Agreements and HAART programme structure respectively. However, and in particular regard to the latter two barriers, it is anticipated that such programmatic changes would have considerable cost implications, which may be unrealistic given Malawi's current financial resources.

In respect to the range of beliefs that were found to have a detrimental effect on youth's access initiatives, it is acknowledged that changing beliefs is a very difficult process and it may therefore be more appropriate not to focus on changing such beliefs directly but rather to support youth access, as described above, and to allow the impact of improved access to erode negative beliefs over time.

As ART providers agency is crucial element if access to HAART by youth is to be achieved, HAART programmes need to put in place guidelines, training and supervision activities that would encourage HAART providers to be in the fore-front promoting youth access to HAART. This could be done through the provision of youth-friendly HAART services in all health facilities.

### **Conclusion**

Evidence from the study suggests that there is a considerable proportion of youth who have HIV and would require HAART. However, there are several explicit and implicit factors that may affect rationing and access mechanisms among youth who have HIV. Among others, rationing mechanisms has room for biased rationalization of HAART due to providers' non-sensitivity to existence of implicit rationing mechanisms. Also, the individual, programmatic and structural factors could also negatively impact on HAART access by youth. As such, improving the rationing approach and addressing other individual, programmatic, structural and social determinants of HAART access by youth could have great impact on youth access to the treatment.

The study recommends that while WHO staging is successful as a rationing mechanism in Malawi, measures should be put in place to improve access to CD4 assessment for clients who may need it. ART providers also need to be made aware of the implicit rationing mechanisms that may affect HAART access. This would improve efficiency and effectiveness of

the Malawi health system in managing clients with HIV. There is also need to improve monitoring of those HIV positive youth not on HAART in order for the system to be able to commence them on treatment on time. Additionally, ART programmes need to address individual, programme and structural/social factors that may affect youth's access to HAART.

As Malawi moves to implement WHO's Option B regimen, known locally as Option B+, in a phased manner which will see access to the most recently approved regimen rationed to very specific population groups (pregnant women, lactating women, TB co-infected and those on HAART with significant side effects, such as lipodystrophy) it will be critical for issues identified in this paper to be addressed. It will also be of further interest to monitor how the introduction of this more complex approach, where two first-line regimens are in operation in Malawi simultaneously, impacts service providers ability to follow explicit guidelines and to ration HAART effectively and youth, and other population groups', ability to access HAART.

Lastly, there would be a need to conduct the qualitative component of the study on a larger scale in order to have accurate understanding of the explicit and implicit rationing and access mechanisms of ART among youth in Malawi.

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