

Strengthening Community Health Systems for HIV Treatment, Support and Care Chiwamba Area - Lilongwe Malawi

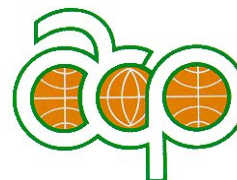
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(TARSC) in the

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For further information on the PRA programme in CoBaSys (www.cobasys.eu) please contact : Training and Research Support Centre (TARSC): Website: www.tarsc.org. For the Malawi PRA contact REACH trust

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1.0. Executive Summary

In Malawi the greatest health challenge is a human resource crisis, which has generally created a lack of capacity to deliver health services particularly HIV AIDS services in rural areas where primary health care is severely compromised. The levels of HIV infection in the adult population of Malawi have remained constant for the last seven years at 12%-17%. The level of HIV infection among adults in urban areas is over 20%. HIV prevalence is about twice as high in the south as in the north and central regions. However, the stable prevalence at 12%-17% does not mean that the HIV/AIDS problem has been solved. Every year as many as 80 000 people die from AIDS and more than 80 000 new infections occur, at least half among young people aged 15-24ⁱ.

Antiretroviral therapy services need to be rapidly decentralized beyond the district and primary hospital level to include initiation of treatment at the clinic level in order to ensure further scale up towards achieving universal access to services. The scale up of HIV and AIDS care and treatment services has been constrained by insufficient access to entry points (including services for voluntary counseling and testing, preventing mother-to-child transmission, tuberculosis and sexually transmitted infections) due to the high cost of servicesⁱⁱ.

This project is aimed at empowering community to support antiretroviral delivery programmes for patients with HIV infection in Southern and Eastern African Countries and Europe namely: Malawi, Zimbabwe, Mozambique, Namibia, Botswana, Tanzania, Italy, United Kingdom, Finland and Belgium : it is targeting at coming up with a regional network for policy advocacy targeting vulnerable groups.

The study used mainly qualitative Participatory Reflection and Action (PRA) approaches. PRA is often associated with weaknesses of time-consumption and should also not be used to provide detailed information about problems without a follow-up commitment to take action on the problems identified.

PRA research provides an intensive yet very analytical methodological rigor and technical validity. These characteristics define the primary significance of any academic or similar research. PRA research provides a powerful means of improving and enhancing practice by involving community dialogue at the very early stages of programme planning. Thus, it builds a basis for negotiation and partnership between researchers, resource holders and beneficiaries.

Local organization of the meeting in the district begun with contacts with partner organization, local CBO called Centre for youth development and social empowerment (CYDSE). The CBO briefed the community of the project, and mobilized and arranged logistics for the participants to the PRA meeting. The planning meeting was attended mainly by the District Health Officer (DHO) for Lilongwe, Traditional Authorities (TAs), MP, Health facility in-charge and CBO programme coordinators. The planning meeting introduced the programme to key stakeholders and the district authorities.

The research has shown that through use of PRA tools, communities are able to reflect and act upon issues that are of great concern to their lives as well as the general development of the area. Therefore in this regard, it can only be hoped that the spirit that was shown by participants during the discussions, would not die a natural death upon them returning back home. Rather, it would go a long way in helping them facilitate the implementation of the tasks that participants agreed to take upon themselves while awaiting government and other development partners to come by.

The FGDs also revealed that even though HIV and AIDS has become the leading infectious cause of deaths in the world, little effort has been deployed to introduce antiretroviral therapy where it is needed most. There is high rate of stigma and discrimination towards people living with HIV and AIDS across all the three districts. PLWHIV complained and reported the upsurge of cases of stigma and discrimination towards them by the community. It was mentioned that people from across all sectors stigmatized PLWHIV.

The research has also revealed that there are no good relationships amongst health stakeholders in the area. This was observed to be as a result of lack of understanding of the roles of each stakeholder in ensuring that provision and access of health services is equitable, accessible, affordable and acceptable. Each partner believes is 'superior' to the other and that those regarded to be inferior 'must' never act on any health issue without the approval of the 'superior'.

Since the effective therapy for HIV and AIDS was introduced, treatment and prevention of HIV were presented as discrete and dichotomous interventions. The argument of limited resources has been used to support a prevention-only approach even in the face of the destabilization of families, communities and economies as the death toll from HIV and AIDS risesⁱⁱⁱ.

Thus, treatment of HIV positive persons living in poor settings has been, until recently, limited to those who could pay for the therapy themselves (ibid). The unavailability of health facilities close to the people especially in resource – poor countries like Malawi in general, and in resource poor settings like Lilongwe in particular only results in deepening the inequality in access to HIV and AIDS care

HIV and AIDS prevention, treatment and care should be linked to poverty alleviation issues. The PRA meeting revealed that there is plenty of scope that communities can pursue community priorities within the broad framework of national priorities. As such, by regarding HIV and AIDS as a poverty issue or linking it to poverty alleviation programmes will help policy makers appreciate the priorities set by communities. Such an approach will also inform policy makers in identifying and accepting the fact that adapting to community-based approaches as the FGDs have demonstrated will have great impact on the lives of people especially the poor and illiterate at community level.

2.0. Background

The community based system for HIV treatment (CoBaSys) is a multi-country project being implemented in six countries across Africa including Malawi, Zimbabwe, Mozambique, Namibia, Botswana, Tanzania in collaboration with northern partners with support from the European Union, ACP Science and Technology Programme. The project has a Consortium of diverse partners from across the regions. The project overall aim is to develop a network which will promote a quality health care system in HIV treatment using a participatory approach. Specifically the project aims to empower local communities in their fight against HIV/AIDS through participatory research and action (PRA) approaches to promote a patient and community centred approach to HIV treatment.

AIDS remains among the leading causes of death globally with sub Saharan Africa being the hardest hit. The African states involved in the project currently record the highest HIV/AIDS prevalence and incidence rates in the world. While HIV treatment programmes have substantially increased, all African countries involved in the CoBaSys project face the following

challenges; sustainability of HIV programmes which are hugely reliant on donors, inequitable and limited health services provision particularly amongst the poor and in rural communities and high shortages of trained health workers (Machingura 2010; EQUINET 2007)^{iv, v}.

Malawi is one of the countries facing a severe HIV epidemic. The HIV prevalence rate is at 12% among the 15-49 age group with an estimated population of about one million people living with HIV and AIDS (MoH, 2008). Variations in HIV prevalence exist among different population groups with high rates in the urban than rural areas, and HIV infection among adults in urban areas being over 20%. HIV prevalence is about twice as high in the southern region of the country as in the northern and central regions. Every year as many as 80 000 people die from AIDS and more than 80 000 new infections occur, at least half among young people aged 15-24.^{vi} Over 800 000 children under the age of 18 are orphans. The death rate for adults aged 15-49 has tripled since 1990. The number of tuberculosis cases is three times higher than it would be without AIDS. There are huge unmet needs for orphan care, and antiretroviral drug therapy access to voluntary testing and counseling and antenatal care including prevention of mother-to-child transmission (ibid).

Malawi following the 3 by 5 initiative embarked on an ambitious plan to rapidly expand treatment with support from the Global Fund against Tuberculosis, HIV/AIDS and Malaria (MoH 2004). From 2004, HIV treatment programmes have rapidly expanded with currently over 250, 000 patients ever started on Antiretroviral therapy.

Despite this achievement, several challenges impede expansion of the HIV treatment, amongst them shortages of trained health workers, limited infrastructure for immunological and virological patient monitoring^{vii, viii}. The health worker shortages in health is the greatest challenge which has generally created a lack of capacity to deliver health services, especially in rural areas where primary health care is severely compromised. While most of the people living with HIV reside in rural areas, a third of those infected live in urban areas and two-thirds in rural areas, antiretroviral therapy expansion has been concentrated in urbanized areas. Evidence has shown that stigma, high transport and opportunity costs present major barriers to people living with HIV (PLHIV) to access and adhere to treatment^{ix, x}.

Antiretroviral therapy services need to be rapidly decentralized beyond the district hospital level to primary health centre level which has potential of reaching the poor and rural populations. However at the moment this is hampered by the lack of qualified personnel at this service level. Experiences drawn from the East and Southern Africa have shown that for HIV treatment programmes to be equitable and reach those in need, they need to have the following features:

- Free services at point of delivery
- Provision of community outreach
- Intra- sectoral links to support with nutrition, transport inputs etc
- Comprehensive and integrated prevention, treatment and care services which are close to the community
- Social and community action to demand service outreach, participate in decisions on new developments and facilitate uptake and effective use of services (EQUINET 2007:86)^{xi}

Taking into account all the problems experienced by HIV treatment programmes, it is clear that the capacity of the communities need to be strengthened and the role of the communities should be enhanced so that the voice and local available resources of the communities are taken on board in decision and policy making by policy makers.

It is in this context that the CoBaSys project aims to *identify and generate evidence on* current experiences, perceptions, determinants of community based and patient centred treatment for HIV and AIDS. This study therefore presents the findings of identifying and reviewing practices, experiences and perceptions of community members from Chiwamba area in Lilongwe district on community based HIV treatment systems.

Within the overall framework of the research programme, **the Chiwamba PRA research aimed to:**

1. Map the socio economic differentials within the communities that affect the risk and vulnerability to HIV and AIDS, and that may have an impact on uptake of available services for prevention, treatment and care of AIDS.
2. Identify the nature of the epidemic in the community in terms of risk groups and environments, the public health stage and burdens of the epidemic and discuss the nature of the responses in needed for key social groups.
3. Map the resources, institutions and actors available at community and primary care level to respond to the epidemic.
4. Identify for key social groups the priority social and economic determinants at individual household, community and system level that facilitate and block availability, access, acceptability, uptake, quality of care in and adherence to the resources above the prevention, treatment and care for HIV and AIDS (Including community knowledge on social rights).
5. Review the evidence to assess the opportunities and mechanisms to enhance facilitators and overcome priority blocks to availability, access, acceptability, uptake, quality of care in and adherence to services: (e.g. opinion leaders and HCWs attitudes and practice, communication processes and skills, mechanisms for social dialogue and communication; resource transfers, services organizations and so on).

Description of the study area

Lilongwe rural has a population of 1,228, 146 people^{xii}. Among the productive age groups (15-49) in Lilongwe, HIV prevalence has declined from 26% in 1998 to 17%^{xiii}. There has also been a reduction in HIV infection levels among young women (15-24 years) attending antenatal clinics in Lilongwe from about 26% in 1996 to 16% in 2004. Chiwamba in Traditional Authority is located in Lilongwe rural but is close to Lilongwe city which has a high HIV infection. Chiwamba area also has a relatively high population with limited ART centres.

3.0. Methods

The study used mainly qualitative Participatory Reflection and Action (PRA) approaches. The study used the PRA protocol developed peer reviewed and pretested prior to implementation^{xiv} and peer reviewed by PRA experts, University of Manchester, University of Eduardo Mondlane, University of Namibia, University of Botswana, University of Modena, University of Helsinki, REACH trust Malawi and by the University of Zimbabwe.

Table 1 presents the areas that were explored under the objectives of the study during the PRA implementation and the tools that were used at each stage. The following publications Loewenson R et al 2006^{xv}, 2007^{xvi}, 2008^{xvii}, and 2009^{xviii} and Machingura F et al 2010^{xix} provides more information on the methods and tools used).

Table 1: Staging of Methodology and how each of the aims was addressed

Objective	Method
Map the social economic differentials within the communities that affect risk and vulnerability to HIV and AIDS, and that may have an impact on uptake of available services for prevention, treatment and care of AIDS	<ul style="list-style-type: none"> • Social mapping, • Map interview • Discussion
Identify the nature of the epidemic in the community in terms of risk groups and environments, the public health stage and burdens of the epidemic and discuss the nature of the responses needed for key social groups.	<ul style="list-style-type: none"> • Stepwise diagram and Focus Group Discussion (use FGD guide)
Map the resources, institutions and actors available at community and primary care level to respond to the epidemic.	<ul style="list-style-type: none"> • Stakeholder analysis • Plenary roundtable (community roundtable)
Review the evidence to assess the opportunities and mechanisms to enhance facilitators and overcome priority blocks to access	<ul style="list-style-type: none"> • Leaping blocks • Market place • Discussion
Identify strategies for strengthening these opportunities and mechanisms as recommended by communities, health authorities, opinion leaders and key stakeholders, the actions that can be taken in the medium and long term for these strategies and the progress markers for these actions	<ul style="list-style-type: none"> • Margolis wheel • Spider web • Group discussions • Market place
Identify for key social groups the priority social and economic determinants at individual household, community and system level that facilitate and block availability, access, acceptability, uptake, quality of care in and adherence to the resources for prevention, treatment and care for HIV and AIDs (including community knowledge on social rights)	<ul style="list-style-type: none"> • Ranking and scoring • Problem tree • Discussion

Description of the study area

Lilongwe rural has a population of 1,228, 146 people^{xx}. Among the productive age groups (15-49) in Lilongwe, HIV prevalence has declined from 26% in 1998 to 17%^{xxi}. There has also been a reduction in HIV infection levels among young women (15-24 years) attending antenatal clinics in Lilongwe from about 26% in 1996 to 16% in 2004. Chiwamba in Traditional Authority is located in Lilongwe rural but is close to Lilongwe city which has a high HIV infection. Chiwamba area also has a relatively high population with limited ART centres.

3.1. Study Participants

A total of 30 participants across Chiwamba area participated in the research. The participants included health workers (Health Centre in-charge, nurses and clinicians providing HIV services) home based care providers and (HBC), people living with HIV/AIDS (PLHIV), representatives of Youth groups, Community Based Organizations, and support groups, local traditional leaders,, religious group representatives, and general community members. Selection of the study participants which was decided upon in consultation with the community representatives was

done based on geographical location of participants and their roles in the community. This criterion was chosen with the aim of ensuring to getting a representation of the different players across the area.

3.2. Study Team

The research team comprised of 3 people who had had experience in PRA and had been trained on the PRA protocol prior to implementation. These Included (Kingsley Chikaphupha, Macdonald Kufankomwe, and Love Masanjala).

3.3. Community mobilization and planning meeting

Mobilization of the study participants was carried out in conjunction with a local organization in Chiwamba area, Centre for Youth Development and Social Empowerment (CYDSE). A planning meeting was held prior to the PRA meeting where REACH Trust and CYDSE briefed the community key stakeholders of the project. The planning meeting was attended mainly by a representative from the District Health Office (DHO) for Lilongwe, Traditional Authorities (TAs), Member of Parliament for the area, Health facility in-charge of Chiwamba Health Centre and CBO coordinators.

3.4. Introduction to the PRA research meeting

There were a total of 30 delegates for the PRA meeting. The CYDSE Programme Coordinator opened the meeting, introduced the researchers and the Traditional leaders and opened the meeting. All the participants introduced themselves. REACH Trust then briefed the participants about the CoBaSyS project in the district. Then Traditional Authority of the Chiwamba area made his welcome remarks and expressed about the importance in the meeting.

During the workshop, note taking was done using flip charts and filling a record book. At the end of each day's activities, researchers gathered information from the flip charts which was also fed into the recording book.

4.0. Findings of the PRA research

4.1. Mapping social and economic differentials within the area

The exercise was aimed to map the social economic differences within the communities that affect risk and vulnerability to HIV/AIDS and that may have an impact on uptake of available services for prevention, treatment and care of AIDS.

herbs). Such initiatives were being encouraged in the area to help people living with HIV get medication on some of the opportunistic infections that affect them. CBCCs, on the other hand were said to be catering for orphans who were mentioned to be increasing in the area as well. This exercise showed that gender and age played a role in determining the features that were to be included to them according to what each different group perceived as important or not.

At the end of the exercise in plenary one map was chosen and new features were added based on the discussions and the features presented on the all the maps.

Interviewing the Map

The services, features and conditions in the area that affect health and the common health needs and conditions in HIV were also looked into. This was conducted in order to understand the community environment and to reflect on its implications on community based HIV treatment.

The Maps drawn by the participants showed that the area had features that provided both formal and informal health care services. The common feature that appeared in all the maps in relation to the different social groups' needs was a health centre. Participants indicated that as a rural community; a health centre was the best place where they could access different health services including for HIV and AIDS. However, people complained that there were several factors that were impeding their access to Health care services. It was alleged that these factors had contributed to rise in deaths of people living with HIV and AIDS in the area. Below are issues that emerged during the exercise:

- Lack of an ART Clinic at the health center within Chiwamba area which meant people had to travel to access ART services from facilities within Lilongwe city.
“there is no ART Clinic at this Health Center, this has made us not to access the ARVs right here in Chiwamba instead we travel to area 25 Health center or Kamuzu Central Hospital in town which is about 35 kilometers away from here and as such our adherence to ART is being compromised”
- Higher travel costs as both facilities where ART was accessed were not within walking distance.
“Many people are dying with HIV and some people are developing a problem of Drug resistance to ARVs because they are unable to access the ARV drugs easily. Transportation costs from here to the Central Hospital, or Area 25 Health Center and other centres where the ARVs are provided are very high”.
- Lack of Public transport.
“We are failing to access Health Services because of lack of public transport as most people live far away from this Health Center (Chiwamba Health Centre) and we walk a long distance to get health services here, therefore we tend to stop accessing the HIV health services because of distance as we cannot manage to walk a long distance while we are sick”.
- Shortage of staff and poor attitudes of health staff:
Although these are theoretically different issues, participants argued that in the context of Chiwamba area, shortage of staff and poor attitudes of health workers, meant the same thing because of their interrelation. Since there were few health workers at the health facility, Health workers were usually overburdened and overworked which resulted with them being unfriendly to clients.

One participant said;

“We hardly go the health centre nowadays because we fear we will be exposing ourselves to heavy torture...we are harshly treated by these health workers when we get there”.

- Shortage and lack of drugs; This challenge was realized by the health workers themselves and one had the following to say on the issue:
“many times this health center experiences shortage of Drugs which has made people to lose trust in the services which we provide as many of patients go back home without receiving treatment”.

Participants also perceived that there were a lot of people that were living with HIV in the area who had not yet started ART. Participants mentioned that among the reasons that contributed to this situation included:

1. Their nearest health centre (Chiwamba) did not offer ART services.
2. People were unable to travel long distances to the city to access ART.
3. initiatives run by CBOs e.g. support groups which act as fora for PLWHIV in order to support one other are failing to provide adequate support. For instance, the food stuffs and other necessities run out more often hence people dropped out of the groups.

Poverty and underdevelopment also contributed to people’s failure to access health services in general and HIV and AIDS services in particular. Lack of public transport for people to travel to and from the health centre let alone for general movement of people in the area people that could not afford to own an ox-cart or bicycle to simply sit idle in homes when they could have sought medical attention.

While bicycles and ox-carts were available for hire, they tend to be more expensive than public transport or matola as such poor not afford to hire the services resulting In poor accessibility of health services amongst the majority of the population of Chiwamba. In view of this, participants suggested that more health centers were needed in areas like; Mbununu, Mwazeze and Sajiwa to shorten the distance people have to walk to access the health services.

Participants also felt an upgrading of the Chiwamba HC into a rural hospital could enhance an efficient health system particularly if this was complimented with the construction of new health centres.

4.2. Priority socio-economic determinants that facilitate and block health service coverage.

The objective of prioritizing health needs was to identify specific and collective priority health needs of vulnerable social groups and their causes using ranking and scoring method. During this exercise; group discussions and brainstorming were conducted. This ensured that the discussions that followed should be based on the participants own perceptions of priority health conditions and needs. For this exercise, the participants were again divided into three different groups – men, women and youth. Each group came up with a list of their perceived health needs/problems and from this list each group was asked to prioritize three major needs/problems.

Women ranking and scoring their health needs: source REACH Trust 2010



4.2.1. Priority health needs by different groups

After ranking and scoring the men's group three major health needs were:

- 1) Lack of an ARV clinic at Chiwamba HC
- 2) Inadequate health care providers (health workers)
- 3) Long distance to the hospital resulting in transport problems.

The women's group health needs priorities included:

- 1) Lack of ART Clinic and Unavailability of ARVs.
- 2) Insufficient health centers/clinics in the area
- 3) Unavailability of hospital equipments e.g. CD4 count machine, TB screening capacity.

The youth group came up with eight health needs/problems out of which their priorities were:

- 1) There was no designated places where young people can get counseling about the dangers of HIV/AIDs
- 2) No vocational training centers in the area to keep the youth busy
- 3) Unwillingness to talk and discuss about issues on HIV/AIDs (disclosure of their HIV status) among the youth

In plenary, groups came together to report back their prioritized health needs. They were asked to justify why they thought the selected health problems needed to be given most attention. The following questions were *also asked and justifications follow:*

- Which were the priorities that are common across all groups?
- Which were the priorities that are different across the groups? Why do the differences occur?

The priorities that appeared to be common across all groups were:

- *Unavailability of ARVs at the health centre*
- *Distance people have to travel to the health centre*

The priorities that occurred to be different across all groups were:

- *Vocational training centers for the youth*
- *Place where youths could get education and counseling concerning HIV/AIDs*

There was general consensus by the participants that lack of an ART centre in the area was a great contributing factor to the rising number of deaths. Participants argued their area was being deprived of accessing quality HIV and AIDS services as Chiwamba area was large and most residents had to travel long distance for the services.

The differences occurred amongst groups on the health needs because participants believed that as people of different ages they had different aspirations and needs that would best suit them. For example; One village head man said:

“Most of the times we as old people put much emphasis on the broader picture of what we need by critically analyzing the merits and demerits of the issue at hand...youths are mostly driven by peer pressure or competition with their colleagues from other locations for them to identify what they need”.

The youths cited vocational centres and education (library) and HTC centres, which were very different issues to those raised by the men and women, because young people wanted to keep themselves busy by learning skills that would help them refrain from engaging in activities that predisposes them to HIV and AIDS. They also pointed out that there were inadequate secondary schools as such most of the youth were not in school. The lack of skills building was seen to make the youth into less effective and/or passive players in development initiatives taking place in their area and nation as a whole.

4.2.2. Agreed Priority health needs by the Participants

After discussion in plenary, the groups came up with three major health needs, these were:

- they needed health centers close to where they lived
- The health centre at Chiwamba should be upgraded into a rural hospital so that the ARVs can be administered there. The upgrading will also ensure deployment of more health staff thereby changing the face of health service delivery and access in the area.
- Vocational training centre to keep the youth busy to avoid getting involved in sexual activities that might lead to their getting infected by HIV.

The issue of Chiwamba health centre not being an ART centre took centre stage as participants mentioned that it was not easy for a person who was diagnosed HIV positive to access ART. Moreover, if and when people are to be initiated on ART, they normally have to travel back to the ART facility to get the ARVs as per given date. Participants bemoaned this as tiring, costly and an unaffordable process. They suggested that if the health centre was upgraded into a rural hospital and be established as an ART site, it would serve a lot of people.

4.3. Identifying the underlying, intermediate and immediate causes of health needs

After prioritizing health problems participants were taken through a session of how they could identify the causes of the prioritized health needs. Using a picture of an ideal tree, participants were asked to determine the causes of the health problems and to make suggestions as to how the causes could be addressed;

- The immediate causes (the socioeconomic causes at individual, family and community level).

- The intermediate causes (the health systems related causes, communication, clinical mentoring, patient flow mechanisms and wider referral systems factors)
- The background causes (the wider macroeconomic, political causes)

Participants were divided into their three groups (Youth, women and men) and each group focused on one of the collective priority health problems identified from the activity in 3.2.2. The reports of each group and actions that could be taken to address the situation are detailed below.

4.3.1 Factors leading to increased HIV among the Youth

The youth group discussed about factors that lead to increased HIV risk amongst the youth and the findings are presented in Table 2 below.

Table 2: The factors that cause Youths in getting infected with HIV

Problem	Immediate causes	Intermediate causes	Background causes
Why many youths were getting infected by HIV/AIDS	Lack of proper parental care, support and guidance	Parents and youth illiteracy (many people in this area are illiterate)	Lack of counseling and guidance information centers.
	Alcohol and drug abuse amongst youths, and early engagement into sexual activities Prostitution	Early marriages Cultural beliefs Peer Pressure Unemployment	Lack of counseling and guidance information centers.
	Lack of youth involvement in development and issues concerning HIV and AIDS	Lack of youth empowerment programs Lack of condom use and HIV awareness campaigns	Lack of community support in eradicating alcohol and Drug abuse and sexual activities among the youth. Unavailability of vocational training center

During plenary discussions, it transpired that alcohol and drug abuse amongst youths, and early engagement into sexual relationships (youths being sexually active), lack of proper parental guidance, and lack of adequate vocational centres and secondary schools were major background causes to the youths' laxity and immorality. In the end girls were getting unwanted pregnancies and spread of STIs and HIV and AIDS amongst the youth was increasing in the area. Lack of proper parental guidance and poverty were also said to influence prostitution to support themselves and their families.

While some CBOs were striving to tackle some of the issues raised, it was felt that their impact was very minimal and there was need for more efforts to address these issues.

4.3.2 The causes of unavailability of ARVs

The women's discussed about the causes of limited access of ARVs in Chiwamba .

Table 3: Factors that causes limited access to ART

Problem	Immediate causes	Intermediate Causes	Background Causes
The factors causing limited access of HIV treatment in Chiwamba	Lack of access to effective opportunistic treatments	Long distance to health centers that provide HIV services	Unavailability of ARVs
	Non-disclosure of HIV positive status to the Family members	Lack of knowledge on positive living	
	Denial of being HIV positive	Stigma and discrimination	
	Late start of ARV treatment.	Higher transportation costs	Lack of ART Clinics
		Lack of Nutritive food supplements.	

During the men’s group discussions on the causes of inadequate hospitals or health centers in the area the following emerged:

- Weak political leadership – The elected members of parliament were not paying great attention to improvement of health service delivery and access of the same in the area. It was felt the members of parliament (MP) were more interested in advancing party agendas and ideologies at the expense of the rural poor.

One health worker cited an example saying;

We had an MP here who after being voted into office came and dissolved the health centre committee that was selected by all stakeholders here and imposed on us his own committee...there was chaos because as facilitators of that process we at the health centre refused to recognize that committee...we were forced to accept due to political pressure and threats as we were deemed to support his rival political party...”

- Hospital committee members are not educated on their duties on how to run the hospital. When health centre committee is elected, there is need for the health workers to train or orient the committee on its roles and duties. However, there is no formal training for the health center committee members. As such, they do not know what to do.
- Unhealthy relationship amongst political leadership and stakeholders in health sector (MP, chiefs, committee members, health workers, CBOs, and other community leaders). Men shared with the rest of the participants a factor which revealed that there was poor or no good relationship between key stakeholders i.e. MP, chiefs, health workers and other community leaders like those in CBOs.

It was mentioned that often times MP only consulted with chiefs on particular issues or sought favors from the chiefs out of fear of losing support from the chiefs so that they can maintain their parliamentary seats but tended not even consult the health workers, CBOs and community at large. Similarly, health workers do not take into account the needs of CBOs and community at large. Participants felt MPs regarded some influential health workers and CBO leaders as people wanting to overpower or disgrace them by posing to be more developmental conscious. Therefore in order for MPs to be seen that they were above everyone in terms of political power

they ended up ignoring any involvement with such stakeholders and ensuring abrupt death of different important initiatives that could benefit the communities implemented by CBOs.

The same was true between health workers and CBOs; health workers alleged that most of the times CBOs and NGOs sidelined them in planning of health projects and only invited them during launch of the projects. On the contrary, CBOs alleged that health workers had immersed themselves deeply into the politics of the community and thereby developing negative attitude to initiatives brought up by community based organizations. An example was given in order to illustrate poor coordination amongst stakeholders by one of the VGHS. He said;

“People from mbununu village had previously molded bricks, identified a cite, and contributed MK400, 000, 00 for construction of a health centre...as I speak nothing has been done at the cite because all these people seem not take interest in ensuring that such projects are realized here... timangokhalira kukokana kuno...ndalamazo zikungokhala ku banki panopo olo mutafuna titha kukupititsani mukachitire umboni (we are very good at fights here while the money is just idle in the bank. If you doubt what I am saying we can take you to the bank for verification)”.

The above issues were therefore summarized as follows:

The immediate causes

- Weak leadership
- Uninformed community on their rights and involvement in their community

The intermediate causes

- Unhealthy relationship between political leadership and key stakeholders on development issues in the community (MP, chiefs, health workers, CBOs, NGOs and other community leaders)

The background causes

- The leadership that has no vision for the future of the area
- There is no sensitization on human (social) rights like; right to health and development where people could also be enlightened of their responsibility to participate without infringing on others' rights to the development of the area.

In view of the above power dynamics at play, men summarized that there was need for found table discussions to iron out differences amongst stakeholders for the sake of development of the area.

4.4. Defining HIV/AIDS responses for key social groups in health services coverage.

Stepwise diagram and FGDs were used to identify the services, features and conditions in all the areas that affect health and the common health needs and conditions in; identifying the nature of the epidemic in the communities in terms of risk groups and environment, the public health stage and burdens of the epidemic and discussed the nature of the responses needed for key social groups.

A group of men discussing one of the tasks given: Source: Reach Trust 2010



For FGDs the Tanahashi steps (model) were also used to stimulate the discussions on levels of barriers affecting community and the health systems interactions.

The priority needs that were identified in section 3.2.1 were revisited at this stage and participants were divided into three groups. Participants agreed on three social groups in the community for whose needs for community systems and services around AIDS are higher but effective coverage is low. Each group was asked to identify factors that affect the levels of; resource or service availability, accessibility, acceptability, and contact coverage for access to different resources or services in their communities. The process also aimed to identify what strengths existed in the communities that needed to be built on.

The process also discussed on the following:

- What did the findings mean for what needed to be done inside communities?
- What did the findings mean for what needed to be done inside the health system?
- What did it mean for what needed to be done between communities and health? System?

The men's group targeted the general community, the youth reflected about themselves (youth), and women chose to look at PLWHIV.

4.4.1. Availability Coverage

The groups identified the following services and resources to be available in the area: Health Centre, Health Workers, drugs, shops, markets, latrines, water points, CBOs, FBOs and other local NGOs, support groups, youth groups and HTC centres.

During the discussions participants identified these factors to be unavailable in their community: an ART Clinic, dental clinic, lack of antenatal clinic/PMTCT services, lack of electricity at the health center, lack of equipments such as CD4 count machine, TB screening machine and ambulance, limited vocational skills training centres, unavailability of financial lending institutions, public transportation, lack of youth friendly health services, lack of information centers (library), Lack of civic education on HIV and AIDS issues in general, and ART adherence in particular.

4.4.1.1 Recommendations to address the flaws on availability coverage

To Address Availability	
Actions in the community	<ul style="list-style-type: none"> • People in the area should burn bricks; collect sand and quarry stones, contribute funds for construction of health centres • Traditional leaders must provide land for development especially for construction of the health centres
Actions in the interface between the community and health system	<ul style="list-style-type: none"> • Community and health system should always strive to work together in order to ensure good service delivery and access. • Community and health system should learn to respect each other group's human rights as enshrined in the constitution.
Actions in the health system	<ul style="list-style-type: none"> • Health system should enlighten the community about the problems affecting delivery of health care services and not insult communities. • Government should provide adequate number of health staff at the health centre to eliminate problem of shortage of health workers. • Government should build health centers in appropriate places or sites and ensures that all health services are provided. • Encourage or pressurize management in the health system to participate fully in serving the communities for the development of the area.

4.4.2. Accessibility coverage

Services were accessible only to those who lived near the health center. People living with HIV accessed treatment for opportunistic infections only within their community and not ART.

Blockers of service accessibility included: Failure by the health centre not providing ART to those people diagnosed with HIV; very few organizations supporting PLWHIV; long distances to access ART; lack of mobile clinics; financial problems due to (high travel costs).

The youth were unable to access the services due to the following factors; Limited places for applicants to the vocational skills training centre; fear of harsh treatment by HCWs; lack of source of income; lack of parental guidance and support; Lack of transportation blocks the accessibility of health services in the area.

4.4.2.1 Recommendations and actions to address flaws in accessibility coverage

To Address Accessibility	
Actions in the community	<ul style="list-style-type: none"> • The community has to burn bricks near the areas where the clinics are needed, so that the clinics can be built where the people are. • Communities should be engaged at public works like; reconstructing road network for easy accessibility of services
Actions in the health system	<ul style="list-style-type: none"> • Health system to take a big role in educating community on how to care for the sick at a community level (HBC) • Deploy more health service providers in the area

4.4.3. Acceptability coverage

While resources can be available and accessible to the population, these services may not be Services were perceived to be acceptable by communities. The facility and services that are provided by Health Center, CYDSE and other stakeholders are accepted by the youth and the whole community. PLWHIV however tended to shun services provided by the health centre and instead accepted those provided by organizations.

Factors that blocked acceptability ranged from: Religious and Cultural beliefs (for example apostolic faith church did not allow its members to take medicine); lack of knowledge and ignorance; stigma and discrimination; harsh treatment by HCWs; ignorance and lack of knowledge on health issues; cultural beliefs especially amongst some men who believed could be cured by having sexual intercourse with a virgin, hence they completely ignore ART or default therapy intentionally.

4.4.3.1 Recommendations and actions to address flaws in acceptability coverage

Actions in the community	<ul style="list-style-type: none"> • To stop some cultural beliefs, community should be educated on the dangers of some cultural and religious beliefs (e.g. <i>fisi</i> and denial of medical care by Apostolic faith church folk) • Traditional authorities always involved and be sensitized on the importance of sending patients to the hospital rather than sending them to the traditional healers.
Actions in the interface between the community and health system	<ul style="list-style-type: none"> • Health system and communities must always collaborate in addressing the myths making rounds in the area about HIV and AIDS • Government must facilitate in civic educating both the communities and health workers on the need for them to foster harmony on issues of development
Actions in the health system	<ul style="list-style-type: none"> • Health system to educate community on how to use traditional medicine (herbs) that are authorized by the government.

4.4.4. Contact coverage

While there is utilization of services or contact with health services, only few people that live near the Health Centre and near the CBOs providing health services, utilize the resources and services particularly the PLWHIV, nevertheless utilization is low amongst the youth; Distance and poverty continued to deny majority of people the chance to utilize these services.

In addition, minimal utilization of services was mainly due to the following factors:

Shortage of staff; unfriendliness of health staff; shortage of drugs; high flow of patients;; and lack of effective communication between health service providers and the community; inadequate resources; lack of youth friendly health services e.g. privacy; and lack of mobile HTC clinics; those with financial hardships could not get to the hospital; women living with HIV were being forced to stop treatment by their spouses; and lack of knowledge on the importance of accessing health care services;

“We have less health workers at our health center” complained one health worker. “There is only one clinician, one nurse, four hospital attendants and two maternity attendants. This is another reason why the services are poor because the population this health center has to serve is about 100,000 people”.

4.4.4.1 Recommendations and actions to address flaws in contact coverage

To Address Contact	
Actions in the community	<ul style="list-style-type: none"> • Parents to take part in educating and encouraging the youth about the services they can get on HIV/AIDS • Community should realize that the use of either bicycles, ox-carts to ferry patients is a positive way of ensuring contact services. • Communities must be mobilized in issues of taking part in sending patients to the hospitals so that they should fully participate in referral network
Actions in the health system	<ul style="list-style-type: none"> • Introduce an ART clinic at Chiwamba in order to make people contact such services as HTC, PMTCT and ARVs closer to them • Government must construct more health centres to ensure that health care services are contacted from within the government recommended 5km radius • Government should buy bicycle ambulances and put them in referral points to ease the transportation problem that is there

4.4.5 Effective Coverage

The effectiveness of the services was found to be largely synonyms with nearness to the health centre or to the service. For example; at a vocational skills training centre run by CYDSE, only 15 young people are able to access the services from across the area; Women mentioned that services were effective because despite lack of an ART clinic in the area, people living with HIV were still accessing treatment for other opportunistic infections.

Largely, these factors constituted blockers to effectiveness of the service delivery: Lack of equipments such as CD4 count machine, TB screening machine, and ambulance; shortage of staff; unfriendliness of health staff; shortage of drugs; community ignorance and lack of knowledge on how to utilize the services; Services not reaching out to the whole community; services not youth friendly; lack of youth involvement on health issues lack of proper nutritional supplements; financial problems affecting travel to ART clinics for refill; long distance to health centers contributed to people’s missing of doses and eventual stoppage of treatment leading to drug resistance and death; Lack of effective communication between health workers and PLWHIV on dosage uptake; religious beliefs were causing some PLWHIV to take treatment in secrecy which affects adherence to treatment; men living with HIV deny using condoms with their sexual partners.

Lack of comprehensive and integrated health services was a challenge to effective coverage as there were no antenatal and PMTCT services at the health centre. Plenary discussions further

revealed that a small room with two beds was used as a labour ward ending up with women sleeping on the floor as in the quote below:

“We need to have a maternity wing here because we normally find problems during delivery. For example when I was delivering this child I am holding in my hands, I was lying on the floor with no mattresses. I experienced huge pain because of this. Currently, this health center is using a very small waiting room as a maternity wing which has only one bed and women are suffering... no pregnant woman shall deliver at a traditional birth attendant, once your are found you have to pay a fine; but the government has not provided enough space and health workers in hospitals and health center to cater for the large number of pregnant women who flock to the hospitals and health centers”...

Youths ready for presentation after their discussion; Source: REACH Trust 2010



Few people continue with secondary education as there is only one secondary school. This is seen to contribute towards a lot of youths engaging in immoral behaviours because they seem to have nothing to do after their primary education.

4.4.5.1 Recommendations and actions to address flaws in effective coverage

To Address effectiveness	
Actions in the	<ul style="list-style-type: none"> • Parents to be educated on the goodness of guiding and providing

community	<p>counsel to their young children on life styles.</p> <ul style="list-style-type: none"> • Introduce tough laws e.g. on maternity and safe motherhood : no pregnant women shall deliver their babies at a traditional birth attendant, whoever is found must be fined heavily in order to contain maternal and child mortality
Actions in the interface between the community and health system	<ul style="list-style-type: none"> • Government, Non-governmental Organizations, Churches and traditional leaders and all stakeholders should build a strong network and Endeavour to meet regularly so that community based HIV treatment care and support interventions are a success.
Actions in the health system	<ul style="list-style-type: none"> • Health system to educate or orient health center committee on their duties and role in running the health center.

4.5. Community Systems and Mechanisms for Referral network in HIV treatment and clinical mentoring

The systems and mechanisms of referral and clinical mentoring were identified including the coordination of primary care workers (HBC givers and village health workers), with health workers at a health centre/clinic level and the district health team including services provided in the study areas.

Using Group work and Market Place the links and gaps in referral points and patient flows in relation to management, execution and co-ordination across the institutions and groups taking action were looked at; community views and perceptions on these were explored. Participants were asked what they understood by referral network in HIV treatment, patients flow and clinical mentoring (health workers in community based treatment systems); Participants were divided in two groups, group one consisted of community workers while group two had Health workers and opinion leaders., Group one discussed the referral network and patient flow at the first and second level of health facilities; During the Focus group discussions participants were asked on whether participants have had experiences with referral points. If no experiences were shared, participants were asked to discuss what is not provided and who should provide the services; Participants also discussed how the referral system is networked including communication from the primary care workers like HBC givers, and village health workers to the health centre levels; Participants discussed the patient flow at the clinic and immediate referral point;

Group two discussed clinical mentoring and patient flows at the first and second level of health facilities; Participants discussed the clinical mentoring that compliments the referral network. What mentoring they received? How adequate it was?

4.6.1 Referral Network in HIV treatment

The discussion showed that there was poor referral network among workers in community based treatment systems in general as well as in HIV treatment, care and support services. The community had very few village and home based care workers to reach all that needed help. Home based care workers were also referring patients to the health center. However, in the absence of affordable means of transportation, patient referral remained a great challenge as is expressed by one participant below:

“Referral network in this community is very poor; it takes many hours or even a day for a critically ill patient to be referred to central hospital for proper medical care and treatment this is due to lack of transport and a hospital ambulance or a

mobile community ambulance that can be transporting patients from their Homes to the Health Center”.

In addition the community said they waited for a long time before they were attended to at the health centre. Although they understood the pressure that the health workers faced due to shortage of staff, the community members were of the view that starting time for work was not being adhered to in public health facilities. Stigma and discrimination; high patient inflow; late opening of health facilities also attributed to causing problems in the referral system.

It was agreed that communication was very important in the referral system from the primary care workers like HBC givers, Village Health workers to the health facilities. Participants suggested that in order to achieve effective and efficient referral network in all referral points, primary health workers like HBC givers and village health workers must be encouraged to refer patients from their point of referral to the points of accessing treatment. As regards to identifying the points of the patient flow that inhibited utilization of services and reduced efficient outcomes or that affected the effectiveness of the service utilization. It was reported that attitudes of patients; high patient inflow; shortage of patient wards; and shortage of drugs were among the factors that inhibited utilization of services. On the other hand, Misbehaviour by patients (where patients did not follow procedures that need to be followed when receiving health services); favouritism by health workers late opening of health centers; harsh treatments from health workers; lack of other medical equipments and drugs; as well as patients' failure to explain their illness/problem were reported to be affecting effectiveness of the service. The following quotes depicts what participants said:

“The patient flow at this health centre is high up to the extent that some people they even go back to their homes without receiving treatment”. Traditional leader

“Our service delivery is compromised because of these problems...we normally experience shortages of drugs, lack of time to rest and provision of improper treatments due to tiredness.” Health worker

Another challenge identified was that it was very difficult for a patient to be referred from Chiwamba health centre to the central hospital or other facilities within the city as some health workers demanded bribes or patients are told to wait until there are several patients before an ambulance can be summoned and this means sometimes it is too late for medical attention.

“The other thing is that patients are forced to pay a certain amount of money to the Health Center Clinician in order for him to call an Ambulance from the Central Hospital to pick them”.

“When we get there with a patient they say that an ambulance cannot come all the way to pick just one patient or they say it is only critical conditions that would push them to call for an emergency ambulance...we are forced to wait until there are two or three patients in order for them to be referred to the Central Hospital.

“I also agree with what has been said. I came at the health center with my brother who was vomiting blood. We arrived at this health center around 10pm but the health workers refused to give him treatment. We waited until morning but we were not assisted, instead we were referred to the central hospital and we had to wait for more time for the ambulance to come, but when it came it was too late, my brother died upon arrival at the hospital.”

It was suggested by the delegates that construction and establishment of many clinics, deployment of adequate health workers, timeliness in terms of opening of health facility and friendliness of health workers would improve the situation being experienced.

4.6.2 Recommendations for strengthening the Referral System

Using the market place, participants were given questions the following questions for recommendations to improve the referral system:

- What are the gaps in the referral network and clinical mentoring?
- What are the challenges in patient flow system?
- What are the implications on community based HIV treatment (clinical mentoring, patient flow and referral network?) What else can we do to address these gaps and strengthen these processes?

The responses showed that gaps in the referral network ranged from transportation of patients from one referral point to another, lack of clinical mentoring, lack of training to home based care providers, and poor communication in the referral networks. It was also reported that in relation to patient flow system; there were long waiting queues and few health workers at the health centre that sometimes caused patients to return home unattended. Often times people went home unattended because health workers either told patients that the facility had no drugs, or they liked prescribing half dosages for illnesses instead of full doses. In some rare instances some dedicated health staff sacrificed their lunch breaks in an attempt to serve more people but this led to fatigue and could not serve people well.

4.6.3 Mechanisms for Clinical Mentoring in HIV treatment

On Clinical Mentoring – participants were encouraged to look at the following: Whether Community based workers/volunteers and village health workers received any mentoring on managing on basic management of HIV conditions. It was learnt that clinical mentoring did not take place in Lilongwe although the health workers knew that they were obliged to do so, they never did it. One health worker said this:

“As health workers we know we have to conduct clinical mentoring as well as monitoring the progress amongst those we are mentoring who presumably we believe could also become mentors to others. However, this is not possible because we don’t have the time to do this”.

4.6. Mapping community resources, institutions and actors that respond to HIV AIDS

The stakeholder mapping in Chiwamba revealed that of the many organizations present in the area, the organizations that were notably implementing health related initiatives were: World vision international, Development aid from people – to – people (DAPP), NASFAM, CYDSE, Mkhupa FBO, and Chiwamba health centre, traditional healers and the church.

The services being provided included; nutrition talks, promoting adherence to ART and knowledge and skill impartation on how to grow and use herbs for PLWHIV provided by CYDSE which conducts meetings with HBCs and support groups. CYDSE also provided mobile HIV counseling and testing (HTC). Mkhupa FBO was also engaged in provision of home based care services though on a small scale. The FBO had also cultivated a demonstration field garden on

cultivation of herbs right at the health facility where they were imparting knowledge and skills to patients at the facility on how they could have a garden of their own.

It was also reported that apart from these initiatives; World Vision International (WVI) and Development AID for People to People (DAPP) were encouraging people on animal farming. The institutions distributed cattle, chickens, goats, and pigs for different projects e.g. cattle for milk production. NASFAM was engaged in distribution of farm inputs as well as drilling farmers in modern farming technologies so that people in the area were able to produce adequate agricultural produce there by becoming self sufficient in terms of food at household and community levels.

Participants' discussions revealed that some of the services offered by these organizations were specifically targeted at PLWHIV, orphaned children particularly those child/female headed households, and farmers. However, it was reported that in most cases women were the main beneficiaries of these initiatives as a lot of men were shunning such activities. When probed as to why this was the case, a representative from CYDSE mentioned that;

“men were shying away from these groups because they felt inferior to mix with women and undertaking such activities...they say that we run so many initiatives targeting women therefore we should also form their own groups...we are in the process of establishing these now. However, the way we have started it is already giving doubts if at all what men said was true”.

However, the linkage of institutions to services proved that there were no institutions that were undertaking water, and sanitation projects which were identified as the crucial for good health.

4.7. The role of stakeholders in HIV treatment prevention and care

This activity was done by means of community roundtable discussion in direct reference to previous discussions on: priority health needs identified, referral networking, stakeholder analysis and stepwise diagram on effective coverage.

It was reported during this discussion that communities needed to be passionate and show willingness to participate on issues of HIV and AIDS. Specifically, participants mentioned that communities could play a role of becoming agents of behaviour change amongst people, encouraging acceptance of one's HIV status amongst PLWHIV as well as promoting adherence to ART.

Therefore participants agreed that actions to root out stigma and discrimination so that access to HIV testing and disclosure of HIV status are encouraged , as well as actions on nutritional education using locally available resources must be prioritized by stakeholders at community level as summarized in the following quote:

“We grow a lot of ground nuts here and I think if people know that eating porridge mixed with ground nut flour in the morning or evening and vegetables mixed with the same flour during lunch or dinner is so nutritious, patients would not be crying for tea only. The problem is that persistence to the very types of food we know shuts us up and we regard such stories as lies”

Participants noted that resources and services were not equitably distributed, as such there was need for institutions to come together to agree on priority health issues and spread the resources across the entire area. This was observed from the fact that most CBOs were concentrated in the same villages while other villages had none. On this point it was pointed out that the area had a network of 22 organizations called 'Chiwamba community led care coalition' that was specifically established to tackle such issues. However, participants argued that the

network was not functional and that its formation was not based on addressing health related issues in the community but focused on wider developmental activities.

A lady participant presenting what her group discussed: Source: REACH Trust 2010



Participants therefore agreed to revive this network and assign it with the mandate to monitor the issue of allocation of health resources across the area. They suggested that if the network would be strengthened, the distribution of health resources would be equitable with a clear direction or focus that initiatives should benefit the whole community. It was agreed that such a network through representatives like the TA, GVHs, and the MP could also be used to voice out concerns on issues of health financing and also monitoring the impact and effectiveness of community based organizations in benefiting ordinary people so as to curb the concern below:.

“These CBOs think they know everything simply because they get donor funds...they don’t even do anything apart from boasting with riches when they buy cars or build houses at the expense of the poor. In fact all they know is to buy expensive cloths and move from one workshop to the other...they can’t even point at what impact they have brought with their so called projects”.

4.8. Determinants of HIV treatment systems at primary care level – Defining patient-centered health systems.

Using Leaping Blocks/stepping stones the activity explored factors that facilitate and block access, uptake and adherence to HIV treatment individually, socio-economically and structurally/systems factors.

4.9.1 Informal Health service provision

Participants during this exercise reported informal initiatives that were being implemented in the area that were targeted at providing health care services to the PLWHIV and other social groups. These included home based care (HBCs), support groups, and mobile clinics. For example, CYDSE in addition to operating mobile clinics, it was establishing support groups and HBCs. It was also conducting early child education to children aged from 5 to 15 mainly targeting orphaned children.

Participants also indicated that in some instances, especially when people were critically ill and they doubted the possibility of getting satisfactory services from the health centre, they opted to go to the traditional healers. People also favoured religious leaders for healing than going to traditional healers. For instance, it was learnt that 5 children had died during the week prior to the meeting in one of the villages due to measles because their parents had refused to take them to health centre and opted for prayers. The parents said they believed God would heal them. Apparently, with the outbreak of measles across Malawi at the time of the research, it appeared that such cases were rampant and media reports indicated that in order to avoid the deaths of many children, police had started arresting people and leaders of the congregation who were keeping children from the measles immunization and also denying them of accessing health care when sick from measles^{xxii xxiii xxiv}.

4.9. Strengthening communication opportunities for health workers and communities

The Margolis Wheel and spider web were used to assess communication between patients and health providers in order to suggest social dialogue systems that support HIV treatment.

Amongst the problems that health workers raised were; shortage of staff, lack of equipment and shortage of drugs. Health workers also told communities that they were making their work harder as communities misunderstood human rights when they insulted health workers that they were not attending them when they knew that there were staff shortages and the available health workers were doing their best to deliver services. Health workers bemoaned the tendency of communities barging into the consultation rooms or causing mayhem at the outpatient waiting area if the health worker took time attending to patients in the consultation/treatment rooms.

Similarly, communities also mentioned that the problems they faced with health workers were that health workers were not professional in the way they handled clients. Patients expected to be addressed on any problems that hindered the effectiveness of the health workers in order for them to understand and not complain of the services. The meeting agreed that to ensure good communication between health workers and communities, the two parties needed to respect one another. If respect was embraced, it was felt health workers would always treat patients as equals and informed them of the problems that existed at the centre. This would ensure that patients would appreciate the challenges that existed. Likewise, community members would appreciate the efforts these few health workers put in providing health care services.

5.0. Discussion and Conclusion

The research has shown that through use of PRA tools, communities are able to reflect, analyze challenges and opportunities within their communities and develop actions to address issues that are of great concern to their lives and for the development of their area.

The research showed that a number of challenges exist within the community which affect a comprehensive response to HIV and AIDS prevention, treatment care and support. These included limited access to HIV treatment due lack of an ART clinic within the community, shortage of health workers and shortage of drugs for effective treatment of HIV related conditions and other health issues in general. In addition high patient inflows and inability of health workers to provide satisfactory services in the face of limited supplies caused health workers to have poor attitudes resulting in poor relationship between health workers and the community members.

Despite these challenges, there are a number of initiatives within the community by different players and stakeholders who were complimenting the health service delivery on HIV and AIDS by providing HIV testing and counseling services in the community as well as offering care and support services. Activities addressing HIV and AIDS included the provision of emotional and moral support, sensitization on positive living amongst PLWHIV and programmes to address stigma and discrimination. There were also other programmes also providing services to mitigate the impact of HIV and AIDS, for example by skills in modern farming technologies, providing farm inputs, and livestock. These had potential to improve the economic livelihoods of community members as well as improve nutrition and improve food security.

However the role of CBOs was limited due to limited capacity as such could not be involved in the provision of such services as HTC and other HIV and AIDS services across the area. As such very few CBOs had capacity to offer meaningful services. CBO activities were not able to reach all the people who needed their services in the community due to human resource and financial constraints.

The study also showed that access and adherence to antiretroviral therapy is a huge challenge as services are far away and costly to access. As such it was perceived that most people requiring the drugs might not access them.

There was also need to strengthen the referral network from the Community based providers to referral hospitals. The study showed that the referral network at community level is weak and patients referred by the community workers face multiple challenges including corrupt health workers and delays availability of emergency transport from the primary level facilities to the referral hospital. This compromised the smooth delivery and access of HIV and AIDS services in particular. In addition, there was generally lack of transportation means across the area. Poverty causing financial problems was another reason why people fail to access health care in general.

It was interesting to identify that the priorities and needs of the youth were very different from those of adults. Their emphasis on the need for vocational training centers in the area is also another developmental initiative that can improve and meet the needs of the youth. This meant that the youth would gain new skills which could sustain their livelihoods and also help to keep them from being involved in risky behavior. However it was recognized that parents and guardians needed to realize the crucial role they play in advising and shaping their children to be useful citizens and maintain cultural values. The youth need to be guided and counseled on

the dangers of indulging themselves in early sexual activities and it was believed that this could be best done by the guidance and support of the parents and guardians.

During the workshop, there seemed to understand among the participants that health service delivery is the responsibility of the health workers and the few organizations involved in HIV and AIDS service delivery. However by the end of the workshop it was observed different stakeholders understood that together they could take such a partnership approach and achieve better results by coming up with responses which are locally-driven and owned. The research had brought about the sense of promoting the values and principles of primary health care.

Lack of monitoring and/or continued mentorship of HBC volunteers by HCWs is one aspect that also affect quality of service delivery in Community based Care systems. It is important that care providers at the community level are supported with appropriate skills and resources so that they are effective. In the same way mechanisms to orient health centre committees are important so that there is clear distinction of roles, between HCWs and the committees as well as between traditional leaders and the committees.

The coming together of a team of diverse players in the PRA workshop health provided the following lessons:

1. There are diverse players within the community that are providing prevention, treatment, care and support for HIV and AIDS. However lack of coordination, resources and the magnitude of the area prevents most people from benefitting from such programmes.
2. Hence the reviving of the community based taskforce (NGO coalition network), as suggested by the participants to the workshop, will ensure that community based programmes are coordinated will serve as a link between the community members and the different stakeholders including the health facility to address the different challenges that people in Lilongwe face as regards access to HIV and AIDS programmes.

However, it is clear that to improve health services in the area responses should also address underlying issues such as poverty and infrastructure (road networks and more health centres) which may be beyond the community actions alone. This calls for increased resource allocation by both national and international (donor) sources, expanded health worker training and recruitment, and major health system reorganization that are community based and patient centred. Otherwise, the success of these community based interventions will remain fairly small. At the same time, it should be recognized that community members were willing to contribute towards such initiatives, for example through providing land, bricks and sand for construction of more health centres.

In conclusion, it is hoped that the spirit that was shown by participants during the discussions, would not die rather, there would be continued efforts to facilitate the implementation of the tasks that participants agreed to take upon themselves while awaiting government and other development partners to assist. This can only be achieved if the agreed action points are shared with the entire community so that the whole community becomes well informed, as it is when a community is well informed that it makes good decisions and choices. This is because in developing countries like Malawi, the success of lifesaving preventive, treatment and care services is dependent on the willing participation of the communities^{xxv}.

6.0. List of Acronyms

ART	Antiretroviral Therapy
AIDS	Acquired Immune deficiency Syndrome
CBCC	Community Based Child Centre
CYDSE	Centre for Youth Development and Social Empowerment
CBO	Community Based Organization
DHO	District Health Office (r)
DAPP	Development Aid from People to People
HCW	Health Care Worker
FBO	Faith Based Organization
FGD	Focus Group Discussion
HTC	HIV Testing and Counseling
HIV	Human Immunodeficiency Virus
HBC	Home based care
NGO	Non- Governmental Organization
MoH	Ministry of Health
REACH Trust	Research for Equity and Community Health Trust
TARSC	Training and Research Support Centre
WVI	World Vision International
NASFAM	National Association of Smallholder Farmers in Malawi
PRA	Participatory Reflection and action
PPP	Public-Private Partnership
PLWHIV	People Living with HIV
PMTCT	Prevention from mother to child
TA	Traditional Authority
GVH	Group Village Headman
MP	Member of Parliament
STI	Sexually Transmitted Infections

7.0. References

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