

Strengthening Community Health Systems for HIV Treatment, Support and Care A Case study for Nkhata-bay district - Malawi



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1. Executive Summary

AIDS remains the leading cause of death globally and the primary cause of death in Africa¹. Epidemics in this region are highly diverse and especially severe in Southern and Eastern Africa where some outbreaks (i.e. cholera) are still expanding². Poverty and limited health services in rural Africa present barriers to adherence to antiretroviral therapy that necessitate innovative options other than facility-based methods for delivery of this therapy.³

In Malawi the greatest challenge is a human resource crisis, which has generally created a lack of capacity to deliver health services, especially in rural areas where primary health care is severely compromised. Malawi is a small landlocked country with a population of about 14 million people. Malawi is one of the countries which has been hardest hit by the HIV pandemic with a generalized epidemic and a prevalence rate of 12% among the productive age group 15-49. There is a higher rate of HIV prevalence amongst women than amongst men: around 60% of adults living with HIV in Malawi are female.⁴ Prevalence is highest among women (13 percent) and men (10 percent) (MDHS 2004). HIV prevalence among women is higher than that for men until age group 30-34 and 35-39.(ibid) The majority of HIV infections occur amongst young people, particularly those between the ages of 13 and 24⁵. In 2009 an estimated 120,000 children in Malawi were living with HIV, and more than half a million children had been orphaned by AIDS.⁶ HIV prevalence is around 17 percent in urban areas, compared to almost 11 percent in rural areas.⁷ However, studies suggest that prevalence is declining in many urban areas and rising in many rural ones.⁸

The Malawi National HIV policy which was formulated in 2003 among other things advocates to ensure effective participation of all sectors of society, in particular of PLWHIV, women, and vulnerable groups, in the design, implementation, monitoring and evaluation of the national response to HIV/AIDS. The HIV response is also by the National HIV/AIDS Action Framework (NAF) 2005-2009. The overall goal of National HIV/AIDS Action Framework (NAAF) is to prevent the spread of HIV infection, to provide access to treatment for people living with HIV, and to mitigate the health, socio-economic and psycho-social impact of HIV and AIDS on individuals, families, communities and the nation at large. There are a number of policies and legislative frameworks that have been developed to protect vulnerable groups in Malawi. These include the National Policy on Orphans and other Vulnerable Children (2003),

However, the country has non-discrimination laws or regulations which specify protections for certain groups of people identified as being especially vulnerable to HIV and AIDS discrimination” (NCPI-B-I-2). This PRA workshop was conducted in Nkhata-bay district in the northern region of Malawi. While the northern region in general has low HIV prevalence, prevalence in Nkhata-Bay is 9.6%⁹. Overall HIV prevalence in Malawi has stabilized at around 12.0% for the past 9 years. However, there is a decline in urban areas although prevalence is still higher than national average. Although HIV prevalence rates in rural areas are lower than in urban, the majority of the population are in the rural areas. Consequently, greater numbers of people infected by HIV in the country are in the rural areas. Hence, there is urgent need to scale up and intensify HIV prevention activities that target rural communities¹⁰.

The findings suggest that Nkhata bay district is dependent on fish, however, since fish trading is seasonal, the prices of fish fluctuate, which has an impact on how female fish traders run their business. When catches are high, enough fish is caught to be traded, but when catches are low (during the cold season), fish is more scarce, prices increase and hence the traders particularly women need to adapt their strategies to obtain enough fish to make a living. In such situations

transactional sex often occurs, when female fish traders engage in sexual relationships with fisher men in order to secure their catch, the so-called “fish for sex” deals¹¹.

As fisher men and fish traders are highly mobile as they move between fishing areas and markets, they spend weeks away from home, increasing the incidence of temporary, extra-marital sexual relationships. This increases the risk of infection for both male fisher folk and Female fish traders. The lack of accommodation in the fishing camps and at the markets further increases these risks¹².

In Malawi, fishermen have been identified as the sixth high risk group, with an HIV prevalence of 16.6%⁷. Studies by FAO (2003; 2007)¹³ show that while the fisheries sector contributes significantly to livelihoods of the poor, it has become evident that fishing in many lower income countries suffer from high prevalence rates of HIV, often five to ten times as high as those in the general population. The Malawi demographic health survey (MDHS 2004) indicates relatively high prevalence in the fishing districts¹⁴.

The study found that there was poor network among health 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 referring patients to the health center, however, transportation of patients to the health facility was a challenge.

However, with the availability of home based volunteers and health surveillance assistants (HSAs) at the local level of health care provision, there is considerable scope of achievements to substantially raise the effectiveness of HIV treatment, care and support initiatives in the district of Nkhata-bay. As observed by the research, there is need for the health system and government policies to be effective and efficient at all times in order for the HCWs and the HIV programmes being implemented to shoulder the numerous challenges they face. These measures should include; training and recruitment of more HCWs, regular reviewing of remuneration packages of health care workers by among other things intensifying provision of good housing, and energy i.e. electricity, safe water to the rural centres with the aim of ensuring that more health workers are deployed there. Government must also implement the recommendation of construction of health facility at the radius of 5km across the districts. This will curb the issue of scarcity of health facilities as well as travelling of long distances by patients.

Lack of monitoring and/or continued mentorship by HCWs to HBC volunteers is one aspect that also affects quality of service delivery amongst the many factors that were elicited during the study. However, attention to quality is essential to the success of primary health care programs, a fact that health managers with restricted budgets cannot afford to ignore¹⁵. Discussions revealed that stakeholders in the district had developed attitudes that underpin their intentions to change behaviour¹⁶ and indeed expressed their motivations to move from identification and prioritization to addressing problems being faced in the communities. To improve preventive and care-seeking behaviours, an increase in knowledge and change in attitudes is necessary¹⁷.

Communities in Nkhata-bay have an understanding of their health risks and problems. The participants to this meeting made careful judgments about health and in particular HIV and AIDS priorities on the basis of both prevalence and severity of the epidemic. Their voices need to be heeded by decision makers. Communities’ own perceptions of their problems could form a vital resource for communities and policymakers whether or not such information indicates epidemiological prevalence.

2. Background

Community Based systems in HIV Treatment

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, and 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 through:

1. Empowering local communities in their fight against HIV and AIDS through participatory research and action programmes (PRA) within the identified areas;
2. Generating evidence from target areas with high rates of HIV infection supporting learning on community based and patient-centered approaches to HIV treatment from target areas with endemic HIV infection;
3. Promoting local stakeholders advocacy towards national health policies concerning HIV and AIDS treatment set up a stable regional network for regional engagement;

Within the overall framework of the research programme, this paper presents the findings of the PRA research in Nkhata bay district. The aim of the PRA research was to:

- 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.
- 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.
- Map the resources, institutions and actors available at community and primary care level to respond to the epidemic.
- 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).
- 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)
- 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.

HIV in Malawi

Malawi is a small landlocked country with a population of about 14 million people. Malawi is one of the countries which has been hardest hit by the HIV pandemic with a generalized epidemic and a prevalence rate of 12% among the productive age group 15-49. There is a higher rate of HIV prevalence amongst women than amongst men: around 60% of adults living with HIV in Malawi are female.¹⁸ Prevalence is highest among women (20 percent) and men (18 percent) age 30-34 (MDHS 2004). The majority of HIV infections occur amongst young people, particularly those between the ages of 13 and 24¹⁹. In 2009 an estimated 120,000 children in

Malawi were living with HIV, and more than half a million children had been orphaned by AIDS.²⁰ HIV prevalence is around 17 percent in urban areas, compared to almost 11 percent in rural areas.²¹ However, studies suggest that prevalence is declining in many urban areas and rising in many rural ones.²² There is a high HIV prevalence amongst certain labour groups in Malawi. It is estimated that 70.7 percent of sex workers, 32.1 percent female police officers and 24.2 percent of male primary school teachers are living with HIV²³.

HIV policy on community based HIV treatment.

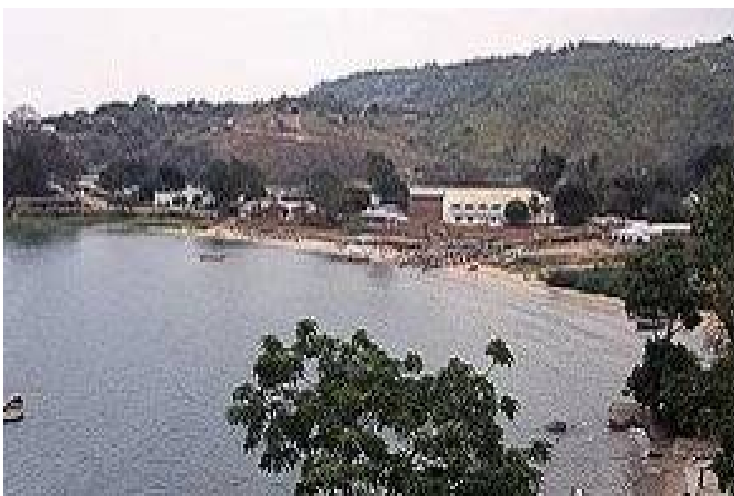
The Malawi National HIV policy which was formulated in 2003 among other things advocates to ensure effective participation of all sectors of society, in particular of PLWHIV, women, and vulnerable groups, in the design, implementation, monitoring and evaluation of the national response to HIV/AIDS. The HIV response is also by the National HIV/AIDS Action Framework (NAF) 2005-2009. The overall goal of National HIV/AIDS Action Framework (NAAF) is to prevent the spread of HIV infection, to provide access to treatment for people living with HIV, and to mitigate the health, socio-economic and psycho-social impact of HIV and AIDS on individuals, families, communities and the nation at large. There are a number of policies and legislative frameworks that have been developed to protect vulnerable groups in Malawi. These include the National Policy on Orphans and other Vulnerable Children (2003),

However, the country has non-discrimination laws or regulations which specify protections for certain groups of people identified as being especially vulnerable to HIV and AIDS discrimination” (NCPI-B-I-2).

HIV and the HIV response in Nkhata bay

Nkhata Bay is a rural district located in the northern region of Malawi. It is along the Lake shore of Lake Malawi, east of Mzuzu city, and is one of the main ports on Lake Malawi²⁴. The town sits on the flat between hills and Lake Malawi. The population of Nkhata Bay is estimated to be 213,779 as of 2008²⁵. Nkhata Bay is 413 kilometres (257 mi) from Lilongwe, Malawi's capital city. Nkhata Bay is the second "busiest resort" on Lake Malawi²⁶. Tonga is the main language spoken in Nkhata Bay and is used approximately 92% of the time²⁷, however Chichewa is the preferred language in hospitals and churches, in Nkhata Bay.

The people of Nkhata Bay are mainly dependent on fish²⁸. Farming, especially cassava, is common²⁹. The district has Rubber plantations³⁰ and tourism provides a major source of income.



Source: <http://en.wikipedia.org/wiki/>

Why Nkhata bay district?

Nkhata–Bay was chosen for a number of factors: Research shows that fishing communities are vulnerable to HIV infection fueled by *transactional sex* “fish for sex” or *cultural beliefs that involve sex for a good catch*³¹.

Fisher men and fish traders are highly mobile spending many weeks away from home and therefore increasing risk of HIV infection³². While the northern region in general has low HIV prevalence, prevalence in Nkhata-Bay is 9.6%³³. Overall HIV prevalence in Malawi has

stabilized at around 12.0% for the past 9 years. However, there is a decline in urban areas although prevalence is still higher than national average. Although HIV prevalence rates in rural areas are lower than in urban, the majority of the population are in the rural areas. Consequently, greater numbers of people infected by HIV in the country are in the rural areas. Hence, there is urgent need to scale up and intensify HIV prevention activities that target rural communities³⁴.

3. Methods

Research design

The study used mainly qualitative Participatory Reflection and Action (PRA) approaches. PRA research provides a powerful means of improving and enhancing practice by involving community dialogue in designing, planning and implementation of programmes. Thus, it builds a basis for negotiation and partnership between researchers, resource holders and beneficiaries. A PRA study protocol used in the research was developed; peer reviewed and pretested prior to Implementation (Machingura F et al 2010)³⁵. For an in-depth analysis of PRA as a research method, its strengths and weaknesses has been discussed in Machingura et al., 2010; Loewenson R et al 2006³⁶; Loewenson R et al 2007³⁷; Loewenson et al 2008³⁸; and Loewenson et al 2009³⁹. The following table shows how the methodology was staged in the protocol for each objective of the research:

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
Using this, 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

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 (Lead Researcher), Macdonald Kufankomwe, and Ireen Namakhoma. All the discussions were recorded and notes were taken.

Community mobilization and planning meeting

Local organization of the meeting was coordinated with a partner organization, Mutisunge CBO based in Nkhata bay district. The CBO members were briefed of the project, and they mobilized and arranged logistics for the participants to the PRA meeting. The PRA meeting was attended by health workers from the District Health Office (DHO), traditional leaders, District Assembly officials, and PLWHIV, support group members. The Village and Group village headmen and community representatives were invited based on geographical location of participants. This criterion was chosen with the aim of ensuring to getting representation of the different areas. A total of 30 participants attended the meeting.

Introduction to the PRA research meeting

The research team welcomed the delegates and participants introduced themselves. Programme coordinator from partner organization opened the meeting, introduced Researchers, Traditional authorities, and then group introductions followed. REACH Trust formally introduced CoBaSys in the district. The Traditional Authority for the area in Nkhata-Bay gave welcome remarks and expressed how he felt the meeting could contribute towards development in his area.

4. Findings

4.1. Mapping social and economic differentials within the districts

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.

Participants were divided into 3 social groups namely: Traditional leaders and health workers, women (who were all PLWHIV and HBC volunteers), and men in Chapumbwa, Nkhata-bay. All the groups drew their social maps which were individually presented and discussed. In plenary, the participants identified the common and different features on the maps, a final map was drawn which included all the missing features from the different groups. Notable similarities on the maps were features; a forest, New Hospital site, Research station, Market, Play Ground, Borehole, shops, the rice Scheme station, a dancing site for Malipenga⁴⁰, Kachasu (a local beer) Brewery site, Maize mill, Video show centers, Health center, Cassava fields, the Chief House, Primary school, Teachers houses. Features that made a difference among the maps included; Bars, Uchi (honey) cultivation house, graveyards, khola (kraal) of cattle, Kachasu brewery centres, river, banana fields, cassava fields, fish ponds schemes, MASAF road, Kalwe bridge, and CBOs or HBCs.

Each group then put their map on the wall where all participants went around from map to map and discussed the features on each map, members from the group answered questions and added features if needed. At the end in plenary one map was chosen and new features were added.



Social map being drawn by participants: source REACH Trust

The differences on features appearing on the maps from the different groups came about due to a number of factors. For instance, during plenary, it was learnt that men did not include a play ground on their map because they lacked the appreciation of the needs of children as compared to women. One female participant said;

“Often times men do not show interest in partnering with women when it comes to issues of raising children that is why they could not include a play ground on their map.”

echoed;

“To us men that was an obvious feature because we knew that where there is a school, there is also a play ground.” Male participant - GVH,

Another male participant

There was also a discussion on why women put a khola (kraal) on their map while men and chiefs did not include it. The following were the reasons given for the difference:

“Livestock rearing is not a main activity in this area as compared to other districts...” Male participant

“Still more, we have some farmers who rear cattle here...after all for people living with HIV and AIDS we need to observe good diets and meat and milk are some of the best foods we need that is why we remembered to include a khola on our map.” Female Participant

Participants brainstormed on the implications of such views towards what different social groups value. During the discussions others felt that the men’s attitude could affect the health of children if physical exercise was not recognized as important . One participant wondered:

“ If parents especially men do not encourage their children to do sports then the children will be denied their mental and physical fitness which would help them fight against diseases and ...contribute positively to the development of the community.”

The maps were then interviewed and analyzed to identify the different social groups in the community how they may be at risk from HIV and AIDS. CBOs, teachers, researchers, businessmen, contractors, health workers, prostitutes, youth, fishermen, and farmers were some of the notable social groups that were linked to the features on the maps in Chapumbwa. On the other hand, it was identified that people with disabilities, the elderly, traditional healers, and tailors were some of the social groups that were not being depicted on the maps. The roles and implications of the institutions depicted on the maps showed how they affect HIV in the community.

Kachasu Brewery Centers: These were said to be promoting prostitution among young girls and increased risk of HIV in the area as most of the owners of the Brewery centers used young girls to attract men to drink beer in these centers. As a result the girls tend to be involved in sexual activities with the Men in exchange for money. It was also felt that prostitution had increased in the area because more girls had taken it as a source of their income.

Video show centers: Video shows were mentioned to be promoting and encouraging promiscuity among the youth and families because of pornographic films that were shown at night. Exposure to these films was causing the youth to have unprotected sex with an aim of experiencing sexual satisfaction as seen from the movies. Consequently, the participants concluded that this had brought about increased rates of rape and defilement cases and low condom use among the young people.

Dressing styles: Many women in this community were also said to be dressing in styles and fashions that were provocative and sexually harassing to men. For example; one male participant said;

“...they normally wear miniskirts, 'see-through clothes' that show off their bodies to attract men to have sex with them.”

Churches: Some church activities were said to be increasing the spread of HIV and AIDS. For example participants indicated that churches were conducting overnight prayers which provided a room for the church members to have sexual affairs among themselves. Some churches were also denying their members to use condoms or other protective measures, other churches discouraged uptake of ARVs while others encouraged polygamy which enhances promiscuity and unfaithfulness to one partner. Participants also mentioned that there were other church leaders who have multiple sex partners (womanize) with women within the church.

However, on the other hand, participants recognized that some churches were actually playing a greater role in combating the HIV pandemic through provision of HIV and AIDS prevention, treatment and care services. For example; some churches were cited to be running hospitals, ART Clinics and HTC centers and orphanages in which people living with HIV and AIDS access their medical care needs.

It was mentioned that churches contributed a lot in reducing the spread of HIV through Health talks and sensitization campaigns they normally conduct in coordination with the community in fighting against HIV and AIDS. The churches were even conducting prayers for people living with HIV and AIDS. Preachers in churches were also teaching against activities like; polygamy, and infidelity amongst married couples in an effort to curb the spread of HIV in the community.

The discussions revealed that there were growing concerns in the district on polygamy. Participants kept mentioning it and linking it to multiple concurrent relationships that farmers and fishermen were having by virtue of their access to high cash income on a regular basis. True to these concerns; *polygamy features highly as cultural practice that facilitates the spread of the epidemic*⁴¹. Although not very often verified empirically, the association between polygamy and HIV is evident. Polygamous marriages involve multiple partners, each of whom might introduce HIV into the household. *In concurrent relationships, the protective effect of sequence is lost*⁴². *The institution of polygamy presumably endorses the belief that men require more than one woman for sexual satisfaction*⁴³. *Polygamous societies are often also characterized by high rates of marital dissolutions and the easy re-marriage of widows and divorcees*⁴⁴. This may lead to an increase in the total number of sexual partners over a man's or woman's lifetime.

Malipenga Dance: This is a dance that involves Men, Women, Boys and Girls. This dance normally takes place during the Night. While the Dance is in progress men are at liberty to leave their wives drinking with other men while they also go and drink with other women and have sex with them. Similarly the woman also indulges in sexual intercourse with the men she hangs out with.

Hospital Development site: Government is constructing a new hospital in Nkhata Bay district which has attracted builders and contractors to come into the area.

"The hospital development site that we have in this community is acting as an interaction point for contractors and local people, this has increased prostitution because women and girls are having sex with contractors for cash hence HIV spread is higher."

These were the words of one group village headman who was at pains explaining how good and important development in the area was. Unfortunately, he also noted it came with such disadvantages.

Fishing communities: Fishermen were reported to be taking advantage of their trade and access to money to negatively impact on HIV prevention, treatment care and support. For instance one lady said:

"These people make a lot of money and as such even when they are on ART they still are promiscuous and drunkards because they know no woman would deny their proposal...in the process they disturb their uptake of ARVs and probably that of their counterparts which could result in drug resistance amongst people on treatment in this district."

Farming: In a similar manner like fishermen, farmers especially rice farmers were also perceived to be at high risk of HIV infection. One HCW narrated:

"farmers especially rice farmers take advantage of poverty in this area by over charging their commodities. What they do is that when a woman can't afford their price, they entice the woman to sleep with her in exchange for free rice."

Social Group influence in health and health systems

The participants also looked at how Social groups influence health and health systems within the community. Social groups have an influence on health and health systems in a number of ways; Social groups are either infected and/or affected with different diseases which render them eligible to seeking health care. It is therefore the obligation of health systems to respond to the call of providing health care services to diverse social groups in a community for their good health.

Similarly; social groups play a role in delivery and access to health care services in the community. For instance, participants cited the roles HBC volunteers played in bringing home based care and support towards their fellow PLWHIV. They are involved in the referral network of patients and they act as the first point of contact besides Health surveillance assistants (HSAs) where people first seek aid and/or opinions on their illnesses.

Through community participation in development, people influence health systems responses to the health needs of the community, for instance by complimenting community efforts with provision of funds and other expertise for the completion of health projects. Men, women and youths are involved in construction of health facilities as well as houses for health workers in their community (through molding of bricks, supplying sand, carpenters, builders etc). This mostly is easily achieved because the people themselves take a leading role in ensuring that health care services are available in their communities.

Youth clubs, CBOs and PLWHIV groups were also said to be involved in the provision of HIV prevention services e.g. conducting sensitization campaigns within the community about HIV prevention, HIV Testing and Counseling, and condom use. Condom distribution activities and cultivation of herbal gardens were also common especially among those people living with HIV. PLWHIV are also exposed to positive living therapies and participants reported that support groups and HBCs were encouraging PLWHIV to be strong and courageous by coming out in the open to disclose their status. One female participant said:

“...once people disclose their status, community view such people as role models. The more PLWHIV adopted the practice the more stigma would be successfully eradicated.”

CBOs were also involved in providing support and care services where people are encouraged not to stigmatize their relations when they get infected with HIV rather, they must take good care of them by supporting them in all their needs.

4.2. Priority socio-economic determinants in health service coverage

The objective of prioritizing health needs was to identify specific and collective priority health needs of vulnerable social groups i.e. shared by the different stakeholders as a whole. The common health needs in the study area, priority health needs for vulnerable social groups and their causes were identified using ranking and scoring.

During this exercise; group discussions and brainstorming were also conducted. The participants were again split into three groups of men, women, and traditional leaders and health workers, and they were asked to identify and list the main health problems. Then each participant was given an equal number of counters (stones) which they were asked to use in distributing them across the listed problems according to the individual's priority. The more the stones on a problem, the higher was the ranking. Participants were then asked to prioritize the three major problems they felt needed urgent attention in their area.

Table 2. Three Priority Health needs of the three Discussion Groups

Group 1: Chiefs and health workers	Group 2: Men	Group 3: Women
1. Lack of Health Facilities and adequate health services	1. Long distances to the health facilities – especially for people on ART	1. Shortage of health workers
2. Few initiatives to create awareness and knowledge of HIV and AIDs	2. Lack of disclosure among PLWHIV - those who do not disclose continue to engage in unprotected sexual activities	2. HCW not in their rooms to attend to patients in the ART clinics
3. Few people know their HIV status and they go about spreading or not protecting	3. Uhule (prostitution) – fish ponds, for women exchanging sex for rice or other commodities.	3. Lack of CD4 count machine in the district



Men ranking and scoring their health needs: source REACH Trust

In plenary the facilitators led the discussions on the differences and similarities among the groups and reasons for their findings were also explored. The Health priorities which were common across all groups were; shortage of health workers and long distances to the health facilities. There were disagreements between men and women as to whether stigma was on the rise or not. Women indicated that they felt that stigma was on the decrease as more women than men were coming out in the open about their status. Therefore there was no feeling of stigma amongst women as was the case with men.

"Women are not being stigmatized as men are insinuating. The fact of the matter is that men are still talking about stigma because they are the major perpetrators of stigma themselves, and stereotypes women and fellow men living with HIV" - Male participant

"Women care for the sick and therefore they hold a different view to stigmatize others, men do not bother about playing such roles in life therefore they are more likely to stigmatize" – Female participant

"I think we seem to differ may be because women are talking from the point of their experiences at the ART clinics, while men are considering the general picture since the advent of HIV and AIDS...but honestly the advent of HIV was characterized with high rates of stigma and discrimination, and today this is still prevalent" – Male Participant

At the end of the discussion participants agreed that stigma was indeed on the decrease but lack of disclosure was still a challenge among PLWHIV. Therefore lack of disclosure was taken to be among the major three priority health needs.

Identifying Three Major health priorities by the whole group

From the overall nine (9) health needs identified from the different groups, participants came up with collective three major health problems. Before coming into agreement with a suggested health priority, participants brainstormed and discussed why a problem should be ranked as a major priority. Finally, there was consensus on the following major three health priorities:

- Lack of disclosure over HIV status.
- Lack of health facilities and inadequate service provision
- Lack of knowledge of HIV status

Participants agreed the above three health needs because they thought that despite the fact that they were directly linked to the problem of shortage of health workers and health facilities, they could be dealt with singlehandedly and improve the provision of health care services in the midterm while awaiting the long term solutions by government.

Below are some of the quotes that supported the selection of the priority areas:

"Lack of disclosure should be first because most people do not disclose their status... most people go for HTC and ART in Mzuzu so that their colleagues here should not know about their status" - Male participant

"CD4 depends on the problem and because the results are coming from Mzuzu therefore it delays initiation of ARVs." – Female participant.

"CD4 is not a major problem for Chapumbwa only because CD 4 count examination is also not available at the district hospital due to malfunctioning of the machine. However DHO has now put a mechanism where all people requiring CD4 count are giving specimens that are taken to Mzuzu referral hospital. Depending on the willingness of the patient to wait for results, results are known same day. However, people are advised to come back on the next ART clinic day when they find their results ready." – Health worker

“We have few health facilities and inadequate services being provided, for example a dispensary at Chapumbwa means it only deals with minor health problems and people are either forced to travel straight to the district hospital or by means of referral – male participant

“The health facilities are not providing sufficient services, ARVs are not available and people from the area have to go to the main hospital. We are told that new hospital will be built in future but then what happens in the meantime” – Village head man.

“HIV is still spreading because some people do not know their status despite they have received the appropriate messages about HIV and AIDS so that they can take part on HIV prevention – Traditional Authority

At the close of the session, participants stood up to echo their sentiments on how they felt about the process of ranking and scoring. One GVH said;

“If it were not for financial constraints, we know you could go far with your efforts of transforming communities...because what we have learnt today is extraordinary. We did not know how to identify let alone prioritize our health needs and indeed our developmental needs in this area. Today each one of us appreciates that together with our colleagues from the district and our TA we have learnt these skills and came up with these priorities. We thank you”

One female participant who was an HBC volunteer also said;

“What is interesting is that together as different players have been able to agree that these are our priority health needs. It really shows that if we can embrace this approach to tackling our problems across all sectors of our society we will get transformed indeed. These skills mean a lot to us and we are thankful you considered us in your project...”

4.3. 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, they were taken through the three steps of identification of the immediate, intermediate, and underlying (root) causes. They were also asked to suggest what could be done to address the causes. The participants were divided into three groups. Each group chose one problem and then looked at the causes of the causes of the problem. In this exercise, the men’s group looked at why people do not disclose their HIV status; the women’s group discussed why people do not want to know their HIV status; while the group of health workers and traditional leaders took the problem of lack of health facilities and failure by communities to access adequate services.

Table 3. Lack of disclosure (Men’s group)

<p>Immediate causes:</p> <ul style="list-style-type: none"> - Fear of being mocked, and/or laughed at - fear of divorce - Fear of not finding a partner for marriage or chibwenzi (lover) - Fear of being labeled as a sinner – particularly at church
<p>Intermediate causes: Those with HIV are regarded as not strong – ‘okutha mphamvu’ and may not be given coupons (for the farm input subsidy programme), stigma, loss of job if known to be</p>

living with HIV, being given names, Nkhawa (anxiety)
Root causes: Lack of strong laws by government protecting one when PLWHIV's rights are violated –perpetrators are not faced with charges or imprisonment under the law – because the laws are not there then PLWHIV are stigmatized and abused anyhow.

Table 4. Few/lack of health facilities and failing to access adequate services (Traditional leaders and health workers)

<p>Immediate Causes:</p> <ul style="list-style-type: none"> - Shortage of health workers, - lack of equipment and drugs, - Poor attitude of health workers, - religious beliefs e.g. Jehovah's witnesses and this causes challenges to HCWs because these people ignore any medication, - Cultural beliefs - Lack of health facilities and adequate services enhanced people's cultural and traditional beliefs as people were seeking care from TBAs, or traditional healers, - limited knowledge on why it is important to seek health care from recognized health care institutions like hospital or health centre.
<p>Intermediate Causes:</p> <ul style="list-style-type: none"> - Staff migrating outside the country, and to NGOs, therefore few remaining in public health facilities - Few training institutions – very few of those graduating end up in the public sector. - Drug shortages due to drug pilferage, and drugs being sold in the public places - Some health facilities are unattractive to HCWs because of lack of electricity; safe water, and very far and difficult to reach places such that HCWs refuse to go and work there. - HCWs have poor attitudes because of stress due to high workload, difficult patients, other patients do not know how to communicate their problems to health workers resulting in HCWS just prescribing drugs without understanding the problem in order to attend to other waiting patients. However other HCWs have natural temperament. - Religious Beliefs – e.g. the seventh day Adventist church followers do not eat some types of fish while this is the main food available in Nkhata bay - .
<p>Root causes:</p> <ul style="list-style-type: none"> - HCW looking for greener pastures as Government is not showing great interest to motivate HCWs with good perks and conditions of service. - Government Procurement policies cause shortages of drugs and supplies. All public facilities can only buy drugs from the Central Medical Stores (CMS) and when CMS has no supply of important drugs like Cotrimoxazole, and then the facility has to get special clearance from the Ministry to purchase from other suppliers. - Poor road networks for some areas - Government policies not suitable for this age and season – for example, some of the policies are unrealistic and not being implemented, for example, the 5km radius distance for health facilities is not followed and people continue to walk very long distances to access health care. - People do not realize the importance for coming to the hospital

Table 5. Why people do not want to know their HIV status (Women's group)

<p>Immediate Causes:</p> <ul style="list-style-type: none"> - People fear that once they know their status and reveal it to relatives; the relatives are the ones that disclose their status to the public, - Fear of death - Fear of stigma
<p>Intermediate Causes:</p> <ul style="list-style-type: none"> - Lack of love by relatives, Nkhanza (Harshness by relatives), kudzikonda (selfishness by relatives)
<p>Root Causes: Perceptions or Myths e.g. HIV status is viewed as a punishment or that one with HIV is a sinner</p>

Actions being taken or that need to be taken on the identified causes

The following discussion focused to identify which causes were being acted upon already, by who, and how, what resources existed in the area, who do communities need to influence to make these actions happen, which ones need governments or other national institutions action;

The following issues emerged from the participants:

Stigma and disclosure were being acted upon by CSOs, NGOs, FBOs, and government departments. Different initiatives were being implemented in the area to tackle these issues. Government departments like Ministry of Gender, Department of Nutrition and HIV/AIDS, Ministry of Health, Ministry for People with Disability and the Elderly, Ministry of Information and Civic Education were highlighted to mainly using media i.e. radio programmes like; drama, talk shows, TV, and print media in tackling stigma and discrimination. Civil society organizations with funding from National AIDS Commission (NAC) and international donors also conduct advocacy and awareness campaigns to curb stigma and promote disclosure of people's HIV status.

People that were living with HIV who had disclosed their HIV status were taken as role models and were being involved in HIV sensitization campaigns. They speak to the public through media and open day activities about the importance of disclosing one's status.

Participants mentioned traditional chiefs and the health committees could play a major role in curbing issues of stigma. The chiefs and the committees could provide counseling services to the households or individuals concerned with stigma and discrimination. Chiefs could also impose fines on perpetrators of stigma in the community upon failure to comply with advice or counselling given by the chiefs. In this way, participants felt stigma could be reduced.

It was felt that the unavailability of ARVs, the establishments of additional ART sites, lack of CD 4 count machine at the district hospital could be acted upon by other players and not the community. Participants suggested that the District Health Office, NGOs and the donor community were better placed in tackling this cause. For instance; participants cited the construction of a new hospital in the area as an avenue where these stakeholders could start reaching out to donors for possible funding of such needs with the aim that by the time the hospital project finishes, people will be assured of the availability of all of these services at the facility.

Government and other human rights bodies should liaise with churches that are dehumanizing people living with HIV under the pretext that HIV is a punishment to sinners to stop the malpractice and urge them to support PLWHIV by supplying them with spiritual and material support.

4.4. 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.

For FGDs the Tanahashi steps (model) were also used to stimulate the discussions on levels of barriers affecting community - health systems interactions. In plenary; the priority problems identified above in section 4.2.for each social group were revisited. Participants were divided

into three groups and 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 given a flipchart with a staircase on showing the levels of; resource or service Availability, accessibility, acceptability, and contact coverage.

During this exercise, participants referred back to the social maps that they drew at the beginning of the session. Participants were asked to refer to the map in order to identify and understand the resources that were available in the area, brainstorm on whether the resources were available, accessible, acceptable, usable and if they were effective to the people.

Men's group chose orphans as a social group they could reflect on, women chose PLWHIV while the group of health workers and traditional leaders chose the youth.



Stepwise diagram as drawn by participants:
Source: Reach Trust 2010

Availability Coverage

On availability coverage Services and resources available for AIDS for the selected social groups included; Health Center, drugs, Community Based Organizations (CBOs), Play Grounds, Health Surveillance Assistants, schools, research station, clinic, guardians, food, shelter, forest, teachers, Church Aid, CBCCs for orphans; Clinic, HBC Volunteers, Drugs, food, Shelter, Schools for PLWHIV; and Video Show Centers, Play Ground, Schools, Dispensary, Food for the youth.

Participants noted that the following services and resources were not available in their area in as far as the selected social groups were concerned: Vocational Center; ARVs, Counselors, CD4 Count Machine, Farm inputs, HBC kits; HTC, Youth Clubs, Resource Centers, ART Services, and

Reproductive Health Services.

Only actions to be conducted by the community and actions in the interface between communities and health system were identified:

Recommendations and actions to address flaws in availability Coverage	
Actions in the community	<ul style="list-style-type: none"> • Community should go to social welfare and mention that they want to be taught skills in home based care • Community volunteers should be committed to show that they want to work • Communities should show love and unity in working with volunteers and HCWs, other stakeholders delivering HIV and AIDS services in the village • Communities should not sell all their farm produce • Churches should increase their role of supporting those with HIV • Community should strive to strengthen cultivation of herbal gardens and diversified crops for food sufficiency and good nutrition to

	<p>compliment food intake when ill or living with HIV</p> <ul style="list-style-type: none"> • Churches should increase their role of supporting those with HIV • committees and traditional leaders must ensure that boreholes that are not working need to be maintained • Community should strive to strengthen cultivation of herbal gardens and diversified crops for food sufficiency and good nutrition to compliment food intake when ill or living with HIV • People in the area should burn bricks; collect sand and quarry stones, contribute funds as well as provide land for development purposes.
Actions in the interface between the community and health system	<ul style="list-style-type: none"> • Community leaders should encourage or pressurize management in the health system to participate fully in development in the area. • Health system should enlighten the community about the dangers of not having enough equipments at the health center • Both HCWs and communities should act as police or informants of those engaged in theft and selling of drugs • Both HCWs and communities should ensure that everyone in the community should have an access to Safe water. HCWs must enhance on their sensitization campaigns on hygiene and sanitation, while communities through

Accessibility Coverage

We learnt of several factors that influenced service accessibility among the social groups. For instance; Good Road network in the area was said to have eased the accessibility of health services across social groups; Good rapport that exists between the church and communities had also enabled PLWHIV to access HIV and AIDS services as provided by the church. Provision of Health services by the church had increased access to health care services in the community.

Availability of HSAs in the community had also helped people to accessing health services e.g. safe water and hygiene and sanitation awareness provided by HSAs; Availability of HBCCs also created a good environment for the orphans in accessing health care services through guardians who take care of them through provision of their basic needs.

Provision and availability of free Health services, Public transport, HBC services, food, shelter and drugs also facilitated good accessibility to HIV and AIDS in the communities. Actually, according to the youth, it was learnt that almost all the resources mentioned in the availability coverage were accessible.

However, despite making such bold declarations, participants still presented other factors that facilitated the impediments to accessibility of health care services in the study location. For example, we found out that: Lack of financial support in most of the community Based Care Centers (CBCCs) in the community affected the provision of health services to the Orphans in the area particularly those on ART; Inability of CBOs to cover the whole area under study also contributed to inaccessibility to the services by populations from some parts of the area.

Long distance to the Clinic, Unfriendly health workers, higher transport costs, higher costs of Farm inputs, Lack of other services like ART Services, Lack of CD4 Count machine, Lack of well qualified and trained Health workers and Health surveillance Assistants (HSAs) posed as barriers to service accessibility. Few HBC volunteers trained and lack of funding to train more

HBC volunteers. Transport problem to reach health facility, and limited resources for referring patients to the health facilities.

“We fail to access health services because of few health facilities with ARV drugs and distance between where we are living and where the health centers area.”

Recommendations and actions to address flaws in accessibility coverage	
Actions in the community	<ul style="list-style-type: none"> • Parents to take part in educating the youth about HIV/AIDS
Actions in the interface between the community and 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)
Actions in the health system	<ul style="list-style-type: none"> • Deploy more health service providers

Acceptability Coverage

In a similar pattern, we also learnt that some of the services being provided were either acceptable or not by the communities. The following emerged as some of the factors that participants reported to influence the acceptability of health services across social groups: Friendly services at the Clinic and Health Centers make people to accept the services that are provided by these institutions; Community involvement in Health initiatives made people accept and own the institutions and services provided; existence and location of the Clinics, Health Centers, Churches, and CBOs run by local people made communities accept services run by the institutions. Here is what one participant said:

“As a community we accept and own what we have in this community. So having what we have mentioned here we are happy with them and we appreciate”.

On the other hand; Lack of nutritious foods due to higher interest on Commercial Farming; and unfriendliness of health workers contributed to unacceptability of services. Participants narrated scenarios like; the tendency where people sell all their food produce and staying without food and their preference to traditional healers as products of the above factors. Lack of HBC kits, lack of coordination between local leaders, the volunteers, health workers and other stakeholders to discuss the needs of the community; Cultural and church beliefs;

“Some churches refuse its members not to access, accept and utilize health services”.

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. fisi and denial of medical care) • 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.
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.

Contact coverage.

Resources and services that were being used by communities included; Church, HSAs, Clinics, Maize mill, Schools, HBC Volunteers, Drugs, Food, shelter, and HBCCs. Different social groups felt several factors influenced why and how some of the services and resources were not being utilized. For instance participants outlined such issues as; lack of Sporting or recreational centres and materials impeded the youth from utilizing the play ground they have in the community; Inadequate or shortage of teachers affected delivery and access to education by the youth; Lack of parental guidance and care induced many orphaned and vulnerable children to engage in prostitution or commercial sex work to earn a living.

Shortage of Health workers; unfriendly health workers; shortage of drugs; theft (Health workers are stealing drugs and plumpy nuts in the health centers); habit of selling maize and other food stuff led to food insufficiency in many families (Focus on commercial farming); ignorance is also another big problem in this community which made many people not to seek medical care and practice poor treatment adherence; unavailability of drugs at the health centers. lack and/or shortage of qualified Health workers in facilities; lack of needed Health services in the area. All these were said to be inhibiting utilization of services in the area.

Recommendations and actions to address flaws in contact coverage	
Actions in the community	<ul style="list-style-type: none">• Community should go to social welfare that they want to be taught these skills in home based care• Community volunteers should be committed to show that they want to work• There should be unity between volunteers and people in the community.

Effective Coverage

Following thorough discussions and analysis of different levels of health care coverage, we were also able to identify what services were being effective and which ones were not. Reasons for effectiveness and non-effectiveness of coverage of services were also explored. In the same line, Schools; Guardians; Churches; were said to be effective.

It was also reported that Health status of people in this area had improved due to the utilization of health services and other resources that were being provided in the area. HBC Volunteers were cited to have helped in disseminating health messages which contributed to changed Health seeking behavior pattern of people to the better in the area.

Depending on the level of utilization of the resources that we have, many of the youth have seen the effectiveness of utilizing them. For example Schools that we have, have helped the youth to acquire knowledge of HIV and AIDS on how they can contract the disease, prevent and spread and where they can get its medication. While Playing grounds have enabled the youth to be free from the disease through being busy playing at these grounds instead of being busy doing sexual intercourse.

Persistent prescription and/or provision of painkillers as compared to real drugs reduced effectiveness of drugs that people access at the clinics. For instance, one participant said;

"the problem is that each time you go there the drugs that are available are painkillers...they say we have found you with malaria but we have no anti-malarials so here is panado...how can one recover from malaria when all he is taking is panado?"

Recommendations and actions to address flaws in effective coverage	
Actions in the community	<ul style="list-style-type: none"> • To ensure that everyone in the community should have an access to Safe water boreholes that are not working need to be maintained. • Communities should not sell all their farm produce and opt for only commercial farming • Churches should increase their role of supporting those with HIV • Parents to be educated on the goodness of guiding their young people on life styles •
Actions in the interface between the community and health system	<ul style="list-style-type: none"> • There is need to combat pilferage of essential drugs in health facilities • Introduce tough laws to combat maternal and neonatal mortality e.g. on maternity: no pregnant women shall deliver their babies at a traditional birth attendant (TBA), whoever is found must be fined.
Actions in the health system	<ul style="list-style-type: none"> • HBC volunteers need to be strengthened with adequate training.

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

The systems and mechanisms of referral care 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. Emphasis was on documentation and communication systems.

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. Group discussions and market place also helped in understanding the mechanisms on referral systems, the patient flow mechanisms and clinical mentoring in target areas.

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, one: (Health workers and opinion leaders), two (community members); Group one discussed clinical mentoring and patient flows at the first and second level of health facilities; Group two discussed the referral network and patient flow at the first and second level of health facilities; Focus group discussions 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 is networked including communication from the primary care workers like HBC givers, and village health workers and the clinical mentoring that compliments the referral network. What mentoring they received and how adequate it was? Participants discussed the patient flow at the clinic and the immediate referral point.

There was poor network among health 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 referring patients to the health center, However, transportation of patients to the health facility was a challenge. Here is what one participant said on this issue:

“Referral network in this community is very poor; it takes many hours or even a day for the critical patient to be referred to central hospital for proper medical care and treatment this is due to lack of transport more especially a hospital ambulance and Mobile community ambulance that can be transporting patients from their Homes to the Health Center”.

The participants also said when referred to the health facility, they stayed or waited for a long time before they were attended to. 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.

According to the existing institutions in health in the area of Chapumbwa, it was learnt that people report different illnesses to HSAs, or HBC volunteers and these people refer patients to the dispensary where if the illness is not critical they are assisted right away. However, if the illness is beyond the capacity of the dispensary, patients are referred to the district hospital. Through this process, depending on the type of illness, people are also advised to undergo HIV testing and counseling. Similarly, HBC volunteers indicated that if people in the area identified chronic patients that were avoiding seeking health care in the area, people reported such cases to the HBC volunteers. Such patients were firstly being counseled on one or two visits by HBC volunteers, depending on the cooperation and willingness of the patient to be counseled and helped. Later, they referred such patients to the mobile HTC clinics in the area, where if tested HIV positive; they would be taken through the process of HIV and AIDS treatment and care where patients are either initiated on ART or Cotrimoxazole.

For cases at the District hospital requiring further care, they are referred to Mzuzu central hospital.

However, in the community of Chapumbwa, access to HIV and AIDS services was said to be difficult due to a number of gaps that participants identified. Distance between where people live and where the health centers are was long. This led to increased deaths when people were going to access medical care particularly if they are in critical condition. Late health service delivery; unfriendliness of health workers; Lack of first aid Drugs; health workers attitudes towards clients; lack of adequate ambulances and communication mechanisms; lack of good road network; no clear referral forms; delay in referring patients to the hospital were also some notable factors that affected referral network in the area. For instance, one participant mentioned that:

“Many patients are dying because of delays to be referred to the hospital. There is poor or ineffective referring system.” Female participant

“But the challenge is also topography because most of the times people in a lot of areas here have to use boats to the health facility, ambulances are only in a few health centres...secondly, there is also a challenge of communication, people have to use their personal mobile phones to call the ambulance because health workers always say they don't

have airtime...and yet network accessibility is so erratic, you have to search for it all over. All this causes unnecessary delays..." male participant

"Because of long distances expectant women deliver on the way and when they get to the hospital with the baby it is such a very pathetic situation 'timaona misozi" (women burst into tears). Sometimes these HCWs need to understand things because the way they act is as if they do not know that sometimes labour might start early for example at 6 months and yet when this happens they shout at the patients." Female Participant

Similarly, ideally, the community perspectives were that HIV and AIDS services meant availability of ART. Participants reported that though ART was available from the district hospital, they still did not have good access to HIV services. Due to the long distance they were travelling to the district hospital, their adherence to ART was affected. Health care costs were massively high leading to unwillingness or inability by clients to access health care in spite of the fact that health care provision was free of charge in public health facilities. They asked for the construction of health facility that would be providing ART close to their community.

The challenges associated with the patient flow system from the community perspective included shortage of health workers; disorderly queues amongst clients when fighting for entry into the consultation room; late opening of health facility; poor history taking by health workers of patients; long waiting time; patients' failure to express their illness; Stigma and discrimination; All appeared to influence patient flow at the health facility.

The assessment of patient flow that reduced efficient outcomes or that affected the effectiveness of the service from the health worker and health system point of view. 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, misbehavior by patients (where by many 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 illness were reported to be affecting effectiveness of the service. The following are some of the quotes presenting what participants said:

"The patient flow at this hospital is high up to the extent that some people they even go back to their homes without receiving treatment. District Assembly official

"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

These factors implied that people had poor access to the HIV and AIDS treatment and care services. Lack of continued clinical mentoring to HBCs meant that the many HBCs volunteers assisting people in the area were unable to handle patients professionally. Participants feared that in absence of clinical mentoring patients might have been exposed to improper drug prescriptions in cases where these volunteers gave first aid treatment to their clients. Therefore the major gaps identified 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 among referral networks.

Recommendations for referral network

Using the market place, participants were asked to critically look at the gaps in the referral network and clinical mentoring, the challenges in the patient flow system and identify could be done to address these gaps and strengthen these processes?

The participants suggested several action points that they thought were needed in order to address the gaps identified. The recommendations were targeted at different players; the health care workers, community and the policy makers.

The HCWs' recommendations to government were that; government must construct rural hospitals/health centres and ensure that it recruits more health workers; It must facilitate in civic educating both the communities and health workers on the need for them to foster harmony on issues of development; Community recommendations were: government must provide bicycle or motorbike ambulances to rural areas for smooth delivery and access to health care services; District commissioners and assemblies need to provide strict monitoring mechanisms on how CBOs operate;

4.6. Community Systems and Mechanisms for Clinical Mentoring in HIV treatment

On Clinical Mentoring – participants were encouraged to look at the following: Whether they received any mentoring or whether they mentored anyone on HIV clinical procedures. If yes, participants were asked to write down the number of site visits over a specified period of time for each mentor; number of mentor hours per month per facility; monitoring the knowledge and skills of mentees across a period of time; mentee feedback after each mentor visit; review of mentors' and mentees' logbooks; and periodical mentors' review meetings: a forum for exchange of experiences among mentors. If not, participants were asked to mention if at all they would want to be mentored? They were also asked to explain why?

Each group was also asked to discuss each point in the first level of the health system that each patient goes through and sketch their understanding of their own patient flow and discuss implications on the overall HIV treatment process; Market Place:

In Chapumbwa, Clinical mentoring for HIV and AIDS was taking place; Participants described that health workers were being trained by the Ministry of Health (MoH) on ART and general HIV and AIDS management. These then oriented home based care volunteers who were expected to orient guardians as well. However, there was no or little mentoring for home based care volunteers and guardians. The participants also mentioned that there was no continued cycle of mentorship in terms of mentors visiting mentees and providing refresher trainings to those already mentored.

Participants suggested that this problem could be addressed by ensuring that health workers conducted intensive follow up or monitoring visits to their mentees in order to make sure that what they are taught is implemented. The follow up visits would also provide moral support and increased morale as volunteers would regard themselves as important players in the provision of HIV and AIDS services in their community. One participant reported;

" they just orient us and off they go. This leaves us wondering if at all they really want this to bear fruit or not...if they were paying us such visits it would invigorate us to working hard and i don't think we could be talking of such a gap here. Even the issue you have asked

of mentoring they could be the ones encouraging us to teach others as well, but they don't say anything.'

It was learned that apart from MoH, CSOs and FBOs like; Lutheran church and World Vision International (WVI) were also offering mentorship to health workers so they could in return mentor local HBC volunteers. The District Social Welfare office also trains HBC providers. At the Health facility there was an HBC coordinator and all people trained at the end of the month were expected to submit monthly reports of their activities. The District Health Office (DHO) supplies the HBCs with HBC kits and then wait for HBC activity reports. Because of lack of mentorship and supervision some of the HBCs were not submitting activity reports and DHO concluded that those HBCs were ineffective which at times might not be the case.

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

This aimed at linking actions to different providers at community level and identified community perceptions on who should provide what services. Actions (from previous sessions) were mapped with service providers on HIV treatment, support and care, how these address priorities and causes, who is covered by these actions and what gaps exist. We mapped institutions, actors and resources available at the community and primary care level to respond to the epidemic. These institutions and actors were: NGOs like Lutheran church, and World Vision International (WVI), the district hospital, health centres, dispensary, District assembly, Illovo sugar company, MoH, CBOs, FBOs, HBCs, traditional leaders, and traditional healers.

The institutions provided services including; running private ART clinic in the case of Illovo company, training for health care workers as well as funding for health related activities in the area, and championing community advocacy and referral for early health seeking behaviours amongst communities with much emphasis on HIV testing and counseling.

There were institutions identified that provide services that contributed to HIV treatment systems in the district. These institutions were mapped by communities using the stakeholder analysis tool. The tool mapped the actors and identified their actions. However, the stakeholder analysis highlighted that the actors providing services were not covering all social groups and were not providing the resources and services to optimum levels.

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



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

This activity was done through a community roundtable discussion in direct reference to previous discussions on: priority health needs identified, referral networking, stakeholder analysis and stepwise diagram on effective coverage. A variety of issues and relevant stakeholders were looked at and discussed during these discussions. A summary of what participants felt were urgent issues and actions was reached and presented below:

Health workers must ensure that HBC volunteers are offered adequate training and mentorship should be strengthened.

Communities must establish a local initiative of making small financial contributions out of which the funds would be used to repair all non functioning boreholes in their areas thereby ensuring access to safe water. The **Police** must work hand in hand with communities to combat drug pilferage at the district hospital and ensure that all perpetrators are punished.

HBCs/health workers/Ministry of Agriculture (MoA) must provide civic education to all PLWHIV and communities not to sell all their farm produce because the tendency had brought unnecessary lack of food to people simply because they opted to have money other than save their harvests. Inadequate food in households with PLWHIV causes non adherence to treatment as patients claim they cannot take drugs on an empty stomach. **FBOs/churches** should increase their role of supporting those people living with HIV in the district.

The discussions also recognized that efforts to curb stigma and discrimination had yielded positive results though they were still some people who were still perpetrating stigma. Participants agreed that embarking on intensified civic education on the need for people to disclose their status would be the right channel to root out stigma and discrimination. On this point, participants suggested that it was the responsibility of all stakeholders to see to it that once tested people must be open and not live in denial rather they should declare their status so that they can live positively.

4.9. Determinants of HIV treatment systems at primary care level

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

The activity highlighted that stakeholders present in the district had little coordination. For unknown reasons to the participants, it was learnt that there was no common approach to issues by civil society organizations and government in the district. For instance, participants mentioned that it was not clear what role the research station that was mainly engaged in agricultural research was when in their area there was lack of food at the time of the research.

Stepping stones also revealed that cultural Beliefs and religious beliefs posed as challenges to equitable delivery and access to health care services in the district. For example; Jehovah's witnesses faithfuls were not forthcoming to undergo HIV testing as their religion prohibits any act of blood tests. Another notable experience was highlighted by the HCWs who bemoaned the tendency that majority people preferred to seek care from the traditional healers as compared to modern health care facilities.

Communities on the other hand reported that for instance in the maternity ward, there were some midwives that were so cruel, who either left women giving birth all alone or they would help them very harshly;

“There are some pieces of matabwa (wood) which they use to hit women so that they can give birth early”. Female Participant

As a result of this it was learnt that a lot of women preferred going to the Traditional Birth Attendants (TBAs) other than seeking maternal care at the facilities.

Another factor blocking access to health care was largely the reliance on getting assistance from the HSAs and/or the village clinics that are close to the people. However, participants reported that most villages did not have HSAs. This meant that people had to travel directly to the distant health facilities and participants mentioned that due to lack of funds they found that most of the times they were unable to travel to the health centres.

“ most of times people have to travel directly to the health facilities and transport is the major challenge to accessing health services”. Male participant

Overall, the exercise also learnt that there was little knowledge amongst communities in the district as regards the importance of seeking health care as early as possible. Participants indicated that this negatively affected health seeking behaviours as well as access to the available HIV and AIDS services.

4.10. Strengthening communication opportunities for health workers and communities

Margolis Wheel and spider web - These tools were used to assess communication between patients and health providers in order to suggest social dialogue systems that support HIV treatment. It was reported that there was bad relationship between these health workers and patients. There was finger pointing where patients blamed the HCWs and HCWs blamed patients for the bad relationship between them.

The most recurring issues contributing to poor communication between health workers and patients during the discussions were: attitudes and/or harsh treatment by health workers towards patients; people’s behaviour of reporting late for medical care i.e. either during the night or staying long taking traditional concoctions and only report to the facility in bad shape. The latter forced health care workers to refuse attending to critical patients and in the process quarrels were the order of the day between health workers and patients or guardians. Delays in transporting referred patients were also another major issue that caused commotion at the health facilities, hence poor relationship between health workers and communities.

Below are tables summarizing problems that both parties highlighted towards the other and their suggested solutions to ending the conflicts between them:

Community communication Problems	Solutions/Recommendations as suggested by Health workers
<ul style="list-style-type: none"> -Health workers delay in opening ART clinics -Late opening of health facilities -Health workers are harsh and shout at clients always -There are delays or no means of transport to refer patients to the district hospital -Health workers have no fixed or known time that they start and finish their work -There are only two days in a week when ART clinics open 	<ul style="list-style-type: none"> -Communities must learn to seek health care as early as possible instead of wasting time with painkillers or traditional medicines -Communities must learn to understand and appreciate the challenges rocking the health system and always work hand in hand with health workers to work with resources available to address health needs -Communities must realize that their rights to getting medical care go hand in hand with responsibilities to also respect and/or listen to

	what health workers say
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Health worker communication problems	Solutions/Recommendations as suggested by communities
<ul style="list-style-type: none"> -Every client wants to be the first one to be attended by HCW -Community believe they are bosses over HCWs as such disregard welfare of HCWs -Communities have very poor health care seeking patterns and always report to the health facility in critical state -Communities always wait for ambulances to pick them from home when in critical conditions instead of rushing to the facility when sick -Health system has very few and limited ambulances to ferry patients from one point to another -Communities threaten and even beat health care workers 	<ul style="list-style-type: none"> -Health workers should be conducting civic education to enlighten clients on the need to observe order when at the facility -Health workers must desist from intimidating patients and always engage them in proper dialogue and clarity of issues at the facility - Health workers must not be afraid of patients rather they should endeavour to civic educate them on issues which they don't know other than regarding them as more knowledgeable of health issues. -Health workers must desist from the habit of poor history taking and rushing into prescription of drugs without capturing correct information from the patient. -ART clinics must be open all week long i.e. five working days as opening them on designated days brings confusion and leads to missing of doses and appointments

5. Conclusions and Recommendations

The findings of the study on increased risk of HIV in fishing communities are in agreement with other studies who also reports *that fisher folks' complex combination of biological, social cultural and economic factors contributed to their susceptibility to HIV* (Kambewa et al. 2009; Gordon, 2005)⁴⁵. *Among them the demographic structure as fishermen tend to be young and with low perceptions of risk with access to high disposable cash income; High rates of mobility and migration; Poverty and gender inequality marginalize women in commercial transactions, making them more vulnerable to sexually exploitative relations; Culture of risk taking and perpetration of low social status among many fishermen; Poor health infrastructure, condom availability and access to specialized centres where voluntary counseling can be done; Generally poor health and hygiene status in fishing camps and among mobile populations.* Malipenga dances, video show centres, prostitution and drunkenness are catalysts to the HIV prevalence in the district.

In Malawi, fishermen have been identified as the sixth high risk group, with an HIV prevalence of 16.6%⁴⁶. Studies by FAO (2003; 2007)⁴⁷ show that while the fisheries sector contributes significantly to livelihoods of the poor, it has become evident that fishing in many lower income countries suffer from high prevalence rates of HIV, often five to ten times as high as those in the general population. The Malawi demographic health survey (MDHS 2004) indicates relatively high prevalence in the fishing districts.

Communities in Nkhata bay as in many other rural communities in Malawi have difficulties in accessing health care. Health facilities are miles apart. For instance, there was only one dispensary in the area of Chapumbwa (the village under study), and the second point of health

care was said to be the district hospital which was also located very far away from Chapumbwa. Inadequate health equipments and essential drugs, shortage of health workers were all mentioned to be factors depriving people in the district access to quality health care services.

The dispensary in Chapumbwa only offered limited services, HTC, antenatal, and under-five clinic services beside these services all other HIV services and critical illnesses have to be referred to the district hospital. Generally, most people did not access even these services because of the distance they had to cover to get to the district hospital in Nkhata-bay. As such the existence of CBOs and other support groups played a crucial role in supporting PLWHIV through the provision of emotional and moral support, sensitization on positive living and curbing stigma as well as nutrition interventions.

Referral of patients to the district hospital was a challenge. While overall, there is a huge problem of accessibility to health care services, due to the of topography of the area, there are also delays in the release or availability of ambulances from one point to the next referral point. In other areas of Nkhata bay, people have to use boats to transport sick people to the health facilities when referred. People have to use their own mobile phones or public pay phone centres to call for an ambulance as the dispensary sometimes does not have the means of communicating with the district hospital. Lack of monitoring and/or continued mentorship by HCWs to HBC volunteers is one aspect that also affects quality of service delivery. However, attention to quality is essential if the success of primary health care programs is to be realized, a fact that health managers with restricted budgets cannot afford to ignore⁴⁸.

There seems to be disagreement in the community as regards HIV stigma and discrimination with some members reporting high rate of stigma and discrimination towards people living with HIV and AIDS in Nkhata-Bay. PLWHIV especially women complained and reported the upsurge of cases of stigma and discrimination towards them by the men folk. Community members reported that even the church (some faiths) are in the fore front stigmatizing such people calling them outcasts from the church However, some members particularly women felt stigma was not as high and some reporting that it was decreasing and only remained high amongst the PLWHIV themselves particularly the men.

With the availability of home based volunteers and health surveillance assistants (HSAs) at the local level of health care provision, there is considerable scope of achievements to substantially raise the effectiveness of HIV treatment, care and support initiatives in the district of Nkhata-bay As observed by the research, there is need for the health system and government policies to be effective and efficient at all times in order for the HCWs and the HIV programmes being implemented to shoulder the numerous challenges they face.

These measures should include; training and recruitment of more HCWs, regular reviewing of remuneration packages of health care workers by among other things intensifying provision of good housing, and energy i.e. electricity, safe water to the rural centres with the aim of ensuring that more health workers are deployed there. Government must also implement the recommendation of construction of health facility at the radius of 5km across the districts. This will curb the issue of scarcity of health facilities as well as travelling of long distances by patients.

Communication gaps between health workers and other health care providers e.g. Central or District Hospital causes a lot of challenges to the community when it comes to the services the community needs. The provision of ARVs and ambulances at Chapumbwa would have reduced the gaps in the provision of health services.

Community mobilization strategies such as this PRA workshop in Nkhata-bay might be effective at reducing effects of HIV prevalence and even morbidity as they can draw on the collective capacity in communities to solve problems and make community voices heard by decision makers.

The study shows that through the focus group discussions; through collectively sharing experiences among the community, health workers, traditional leaders and the wider stakeholder group from the district in the delivery of health care services in the community; they could identify, recognize how important health services are and how they would want to address the flaws that exist within the framework of ensuring equitable distribution and access to health care services in their district.

Discussions revealed that stakeholders in the district had developed attitudes that underpin their intentions to change behaviour and indeed expressed their motivations to move from identification and prioritization to addressing problems being faced in the communities. To improve preventive and care-seeking behaviours, an increase in knowledge and change in attitudes is necessary⁴⁹.

The findings from this PRA meeting suggests that a great deal of capacity towards achieving that change already exists in communities; where research and/or anecdote evidence can suggest that communities do not have a comprehensive awareness of the problems that affect them^{50,51} This study suggests that this capacity can be accessed and channeled through such community meetings where stakeholders collectively discuss issues affecting them. Because of poor community involvement in decision making about health priorities, there has been low priority of health care service delivery at community level by policymakers. There is need for communities and all stakeholders to ensure that they prioritize the implementation of their locally found solutions to the challenges affecting delivery and access to health care services. Communities' own perceptions of their problems could form a vital resource for communities and policymakers alike to find lasting solutions to Community based HIV treatment and prevention.

6. List of Acronyms

ART	Antiretroviral therapy
AIDS	Acquired Immune Deficiency Syndrome
CBO	Community Based Organization
CBCC	Community Based Child Centre
CSO	Civil Society Organization
COBASYS	Community Based HIV systems in HIV Treatment
DHO	District Health Office (r)
FGD	Focus Group Discussion
FBO	Faith Based Organization
FAO	Food and Agriculture Organization
GVH	Group Village Headman
HCW	Health Care Worker
HTC	HIV Testing and Counseling
HBC	Home Based Care
HBCG	Home Based Care Giver
HIV	Human Immune Virus
HSA	Health surveillance Assistant
MDHS	Malawi Demographic and Health Survey
MASAF	Malawi Social Action Fund
MoA	Ministry of Agriculture
MoH	Ministry of Health
NGO	Non Governmental Organization
NSO	National Statistical Office
NAC	National AIDS Commission
PRA	Participatory Reflection and Action
PLWHIV	People Living with HIV
REACH	Research for Equity and Community Health
TA	Traditional Authority
TARSC	Training and Research Support Centre
TBA	Traditional Birth Attendant

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