Strengthening communication between people living with HIV and clinic health workers in Kaisipul Division, Kenya
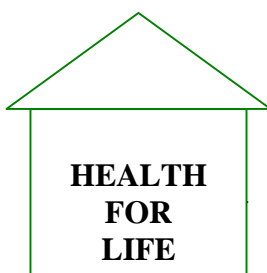

**A Participatory Reflection and Action Project
REPORT**

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Executive Summary

Kasipul Division, found in Rachuonyo District, Western Kenya has made many gains in the fight against HIV. Poor communication between HIV positive clients and clinic workers is threatening those gains, however. Despite progress in management of AIDS, there has been a rise in people defaulting on testing and treatment, and efforts to address this have not been successful.

We implemented the work reported here as part of a multicountry programme exploring different dimensions of participatory approaches to people centred health systems in east and southern Africa, through Training and Research Support Centre (TARSC) and Ifakara Tanzania in the Regional network for equity in health in east and southern Africa (EQUINET). We used participatory approaches to facilitate a programme of work aimed at
- Improving communication and understanding between HIV positive clients and the HIV clinic personnel in HIV clinics
- Raising HIV positive clients' voices and participation in improving the HIV clinic services in the division
- Promoting networking to overcome isolation, increasing exchange and co-operation through conducting joint meetings between HIV positive clients and the HIV clinic personnel

Prior to the intervention we implemented a wheel chart to draw information on what participants in the community and the HIV clinic personnel thought about the communication situation at the HIV clinics and we collected similar information after the process to review and reflect on the perceived change over the period. We used PRA tools and processes to share experience of PLHIV, explore current issues in communication between PLWHIV and clinic workers, to explore ways of improving communication and practice communication skills. We used this information to facilitate development of an action plan by communities and health workers to address communication problems identified. This plan was implemented with support from KDHSG for four months and finally reviewed through discussion and of progress markers and reflection on the final wheel chart.

The initial wheel chart showed a communication and perception gap between health workers and community members on their understanding, their communication and a low rating of the extent to which health workers and communities meet and plan responses to AIDS.

The PRA meetings identified shared concerns on the weaknesses in the communication between health workers and clients, observing that the environment of the HIV clinics discourage uptake and use of services, and undermine openness between clients and clinic workers and effectiveness of treatment.

Participants agreed to implement actions to make changes at the health services (install a suggestion box; open a room for taking vital signs before clients proceed to consultation room; involve clients interpreters, improve drug supply, and enlarge the clinic) as well as interventions to sensitise and motivate community members to use services and provide more community support to PLHIV. Participants developed an action plan to implement these changes, with progress markers that they wanted to achieve, and a goal of reducing defaulter rates by at least 30% by end of 2007.

In the period, the following areas of progress on action were reported:
- Installation of suggestion box
- Opening of a room for taking vital signs before clients proceed to consultation room
- Strict following of queues on the basis of first come first served
- Allowing clients to involve interpreters of own choice to overcome language barrier,

- Steady supply of drugs
- Selected clients were serving as health educators along side clinic workers.

The MOH has decentralized HIV care to a health center (Ober health centre). This has decongested the crowded clinic and brought services near to clients. Service uptake has improved, although it was not possible to measure the change in default rates due to data gaps. It was agreed to improve monitoring of this at clinic level.

Immediately after the initial three day workshop clients held their own meeting to strengthen their voices and participation in the health issues. They formed a new network called Kasipul Division HIV Clients against Defaulter rates (KADHICNADER) and registered it as a community based organisation (CBO) with Government. The client's network offers a peer support system and a means of dialogue with the health services that has been positively received in the community and health services, although it is new and still faces challenges in overcoming people's reluctance to discuss sexuality and health, and the fear of community stigma. Sensitisation meetings used PRA approaches to dialogue with community members, drawing out reasons for people not using services, reporting on efforts made in the health services to deal with these barriers and increasing people's confidence in using services.

In a follow up review meeting it was observed that communication goals were perceived as easier to achieve, including giving feedback and practising effective communication. Concrete tasks such as the network and progress meetings, setting up the suggestion box, setting up the customer care desk, holding joint meetings with health workers and obtaining community suggestions were largely seen to have been achieved. Less successful were the community mobilisation and sensitisation exercise and the involvement of clients as health educators. In future sensitisation meetings more facilitators needed to be oriented to spread and manage the process, facilitators needed to give equal chances to both sexes to speak, and to give more time for the exercise.

The repeat of the elements on the wheel chart showed that health workers perceptions changed little in the intervention, while those of community members showed some considerable changes. It appears that community members were more critical of the extent of current communication, perhaps realising the possibilities for improvements, but that they also felt that the effectiveness of care and extent of joint planning had improved considerably. The continuing gap between health worker and community views suggests that there are still gaps in perception and communication between these groups that need to be further addressed. New activities were suggested to build communications skills for both clients and clinic workers, to increase community awareness and to encourage clients to join the newly formed HIV positive clients' network.

Participatory approaches, while challenging and time intensive, were perceived by health workers, clients and the facilitators to be a powerful means to enhancing communication, overcoming power imbalances that are barriers to good health or effective use of services and to encouraging the sustainable, "bottom up" community involvement on health visioned in Kenya health policy documents. Real changes were made to make the services more client-friendly, including installed suggestion box, re-streamlined queuing and filling system, taking of vital signs, interpreter involvement, and ordering of bulk drug supply, while clients formed a network that would sustain the communication and reduce social isolation of PLWHIV.

While participatory processes hold promise in addressing these issues, as facilitators, we need to more deeply know and understand the barriers and distortions to these processes, such as the dominance of male over female voice in joint forums, so that their benefit and the empowerment they yield is accessed by those with greatest health and social need.

1 Introduction

AIDS has taken a huge toll of human life. Some 38 million people are living with HIV, over 24 million dwell in Sub Saharan Africa and East and Southern Africa provides home to over 17 million (EQUINET steering committee, 2007). Although the HIV epidemic has been called a 'terrible reality', good communication between HIV positive clients and clinic workers will assist us to manage it.

Kenya is one of the Eastern and Southern African countries that declared the disease a national disaster. The country, with a population of over 30 million, has registered some 1.2milion people living with HIV (PLWHIV). National Aids/STI Control Programme (2005) says, "Early in the epidemic in Kenya political commitment was limited. However, increased public political commitment was evidenced in 1999 when President Moi declared AIDS a National Disaster". In 2005, the Ministry of Health opened its doors to give HIV care services to PLWHIV free of charge. This has led to an increased number of people coming to use the free services. According to the Daily Nation (2007), Mwaniki says the scaling up of treatment with Antiretroviral (ARVs) has enhanced the quality of life of those infected with the virus.

Kasipul Division with a population of 129 854, is one of the Kenyan communities that has shown similar commitment to scaling up treatment with ARVs. The Division is one of the four divisions of Rachuonyo District, Western Kenya. According to National Coordinating Agency for Population and Development (2005), the average distance to the hospital in the area is 5 km, only 60% of households have access to the health facilities. It gives the most prevalent diseases in the area as malaria and pneumonia and life expectancy of 47 years with an infant mortality rate of 87 deaths per 1000 live births and a child mortality rate of 102 per 1000. In addition, Rachuonyo District Hospital Health Information System (2007) estimates the nurse patient ratio 1:1000, making it difficult for most people to access quality referral. Above all, the area has a high rate of absolute poverty of 77%, making the community ill prepared for the vulnerability and costs that HIV related illness and mortality could lead to.

Communities in Kasipul have the advantage of having Rachuonyo District referral hospital situated in their midst, but have only one health centre and eight dispensaries. In the last 3 years, HIV related services have expanded dramatically. The level of awareness of HIV has increased, as has access to treatment with ARVs.

Our institution, Kasipul Division Home Based Care Stakeholders Group (KDHSG), is one of the local non-profit making organizations that have conducted HIV awareness in the area, working closely with HIV positive clients, HIV clinic personnel and other stakeholders in the community. Our work began in 2005 under the auspices of the Ministry of Health (MOH) as a response to the rapid spread of HIV, increased suffering and mortality of people with AIDS. We have since pooled together over 20 local organizations and have established a multisectoral strategy for a comprehensive community care system that supports PLWHIV holistically. Our focus is on advocating for and strengthening Home based care (HBC) activities.

Despite the ever-challenging socio-economic conditions in the community, we have made significant steps in supporting some 1000 PLWHIV and their families, with support from the Mildmay International and MOH. We have facilitated the training of twenty health personnel and ninety community health workers (CHWs) on HBC, distributed over 100 HBC kits and over 20 bicycles to CHWs to support their work in improving the lives of PLHIV.

Despite this progress, we have noted that although several PLWHIV have stepped forward for testing and treatment with ARVs, there has been a rise in people defaulting on testing and treatment. Exploring this in May 2005, we held a divisional HBC meeting, where participants

reported that poor communication between clients and clinic workers was threatening their relationship, compromising health among clients and leading dissatisfied clients to opt for services outside the district or stay at home. Those staying at home increased their risk of illness and death.

Several factors affecting adherence have been raised, including increased pill burden (WHO 1998). Ongala (2006) notes the risk of drug resistance from non adherence, so that ensuring adherence is a significant public issue. Identifying the local causes of non adherence is thus important in the response to HIV.

A clients' representative in the meeting to review this issue said, "*Often we do not understand or find acceptable explanations or instruction given to us by clinic workers. In fact, some of their advice does not address our real situation. The trouble is that they do not listen to us*". In contrast, health workers see it differently, as reported by one health worker in the district at this community meeting, *"I think the problem here is that of attitude. It seems most clients come expecting us to give them ART services in a particular way, yet we do not know why they are less open to us"*. HIV positive clients were thus losing confidence in the ART services, while personnel working at the HIV clinic were getting increasingly discouraged. In the meeting, participants observed that poor communication at the HIV clinic was contributing to the rise in defaulter rates, with negative consequences for health in the community. Our efforts to improve communication at the local HIV clinics had produced limited results.

We implemented the work reported here as part of a multicountry programme exploring different dimensions of participatory approaches to people centred health systems in east and southern Africa, through Training and Research Support Centre (TARSC) and Ifakara Tanzania in the Regional network for equity in health in east and southern Africa (EQUINET). The author attended a regional training workshop and implemented this work between April and November 2007.

We used participatory approaches to facilitate a programme of work aimed at
 ♦ improving communication and understanding between HIV positive clients and the HIV clinic personnel in HIV clinics;
 ♦ raising HIV positive clients' voices and participation in improving the HIV clinic services in the division; and
 ♦ promoting networking to overcome isolation, increasing exchange and co-operation between HIV positive clients and the HIV clinic personnel.

The outcomes we hoped to achieve through this included
 ♦ improved communication and mutual understanding between HIV positive clients and the HIV clinic personnel on issues of ART services in HIV clinics in the division;
 ♦ increased voice and participation of HIV clients' through organized joint meetings between them and the HIV clinic personnel to discuss measures needed to enhance ART services performance in the HIV clinics in the division;
 ♦ greater accountability and involvement of the local community in decision making process as well as in monitoring and evaluation; and
 ♦ joint action for advocating for change in the HIV clinic.

We chose to use participatory approaches to achieve these outcomes and improve communication between HIV positive clients and HIV Clinic personnel in Kasipul Division Rachuonyo District of Western Kenya as they provided a bottom up, community-based approach that would strengthen people centred health systems in line with current Kenyan Ministry of Health policy. We saw the benefit in prior work in the EQUINET/ TARSC/ Ifakara supported network of institutions implementing participatory approaches, where communities could obtain clear gains in primary health care uptake while increasing their knowledge and use of health systems.

2 Methods

The team implementing the work included Pamela Awino, Leonard Odongo, Debora Lang'o Jacob Ongala. After the EQUINET/ TARSC/ Ifakara Regional PRA Training Workshop in February 2007, Jacob Ongala, the Chairperson, KDHSG and lead researcher, trained seventeen other members of our institution on PRA methods and worked with them to facilitate the study process. The training aimed at strengthening community voice in planning and implementing primary health care and health service at primary care level. We received mentorship from Dr. Rene Loewenson, TARSC, in the research, and peer review input from colleagues in the PRA network. Our methods and approaches focused on empowering PLWHIV taking control of their health, and thus building collective forms of community analysis and organization. We obtained informed consent from Dr Jeremiah Okatch, the District Medical Officer of Health, who sent representation at the opening and personally attended the closing stages of the process.

PRA Research committee members after networking and progress meeting
Source: Ongala 2007

Prior to the intervention we implemented a wheel chart to draw information on what participants in the community and the HIV clinic personnel thought about the communication situation at the HIV clinics and we collected similar information after the process to review and reflect on the perceived change over the period.

Our design was based on the spiral model, drawing own experience from participants, reflecting on patterns, adding new information and theory, identifying strategies and plans for action. We continually referred to the spiral to focus learning. We used this process to share experience of PLHIV, explore current issues in communication between PLWHIV and clinic workers, to explore ways of improving communication and practice communication skills. This information was used to facilitate development of an action plan by communities and health workers to address communication problems identified. The plan was implemented with support from KDHSG for four months and reviewed through discussion of progress markers.

THE SPIRAL MODEL

4. Practice
skills, strategy
and plan of action

5. Apply in action

1. Start with the
experience of participants

2. Look for patterns

3. Add new information
and theory

Source: Arnold et al. ,1991 in Loewenson et al., 2006

We used the spiral model to promote dialogue among participants, asking participants to reflect on emerging issues to draw lessons from their experiences and translating them into proposed action plans to improve communication situation at the HIV clinic. We conducted the process using English, Kiswahili and Dholuo languages interchangeably, and recorded the activities on camera and video.

We implemented the baseline assessment with representatives of key stakeholders in the community. The KDHSG mandated the team of four people who coordinated the project implementation to identify six member organizations to prepare study groups in their sites. The study groups constituted HIV positive clients and HIV clinic workers who related to the nominated organisations. We implemented the covered baseline study in six different study sites using wheel chart in May 2007. The wheel chart was divided into six segments each assigned to an aspect of communications and participants in the community and HIV clinic workers separately filled in the chart , with levels reflecting their perception of that aspect of communication between the community and the clinic.

Using PRA tools in the first meeting
Source: Ongala 2007

In June 2007, we held a three day joint Client- Clinic workers workshop, involving community based organisations, KDHSG member organisations, community members and health workers and the District Medical officer. PRA tools were used to elicit input on current experiences and to propose areas for and actions towards improved communication. They included local case studies, picture codes, role-plays and "Joharis window", a method that identifies the extent of and barriers to communication between clients and clinic workers. The clients invited clinic –in-charge nurses, who discussed issues raised, responded to questions and gave information on clinic operations. Participants proposed small manageable actions, called 'stepping-stones'. They wrote the actions on cards of different colours, which they laid

across an imaginary river, with one bank labelled bad communication and the other good communication. We used this tool to propose action that participants jointly implemented to improve communication situation at the clinic.

Over four months, June to September 2007, we implemented the joint work plan. We involved all participants in the implementation exercise.

In the review meeting we used PRA tools to share feedback on progress in implementing action, with methods such as the "but why" method to probe the causes of continuing communication problems and discuss how to address them.

In October 2007, we called a second meeting with the same group to review the implementation of the workplan. Participants discussed their markers of progress and what issues still needed to be addressed. They also collectively completed and discussed the wheelchart using the same segments as at the inception of the work in July.

The project gave us an exciting opportunity to learn lessons about communication between HIV positive clients and clinic workers in a participatory environment and to build our own skills in PRA methods. It enabled us to integrate knowledge that we had accumulated from previous learning experiences with those from the EQUINET / TARSC/ Ifakara workshop, which we applied in this study. We not only found the experience to be challenging and demanding, but also enriching and rewarding, as we discuss later in this report.

3 Implementation and findings

3.1 The baseline assessment

Participants had reported prior to the study that poor communication between HIV positive clients and clinic workers contributed to weak adherence to the ART programme among clients in the local HIV clinic. To provide a formal baseline assessment for the work, facilitators implemented the wheelchart in six different study sites in Kasipul Division. In each site, community and health worker participants rated communication situation at the HIV clinic. The study sites included O.I.P, UCCIP, Raapad, St. Francis Lombeni, Ober health centre and Rachuonyo district hospital HIV clinic.

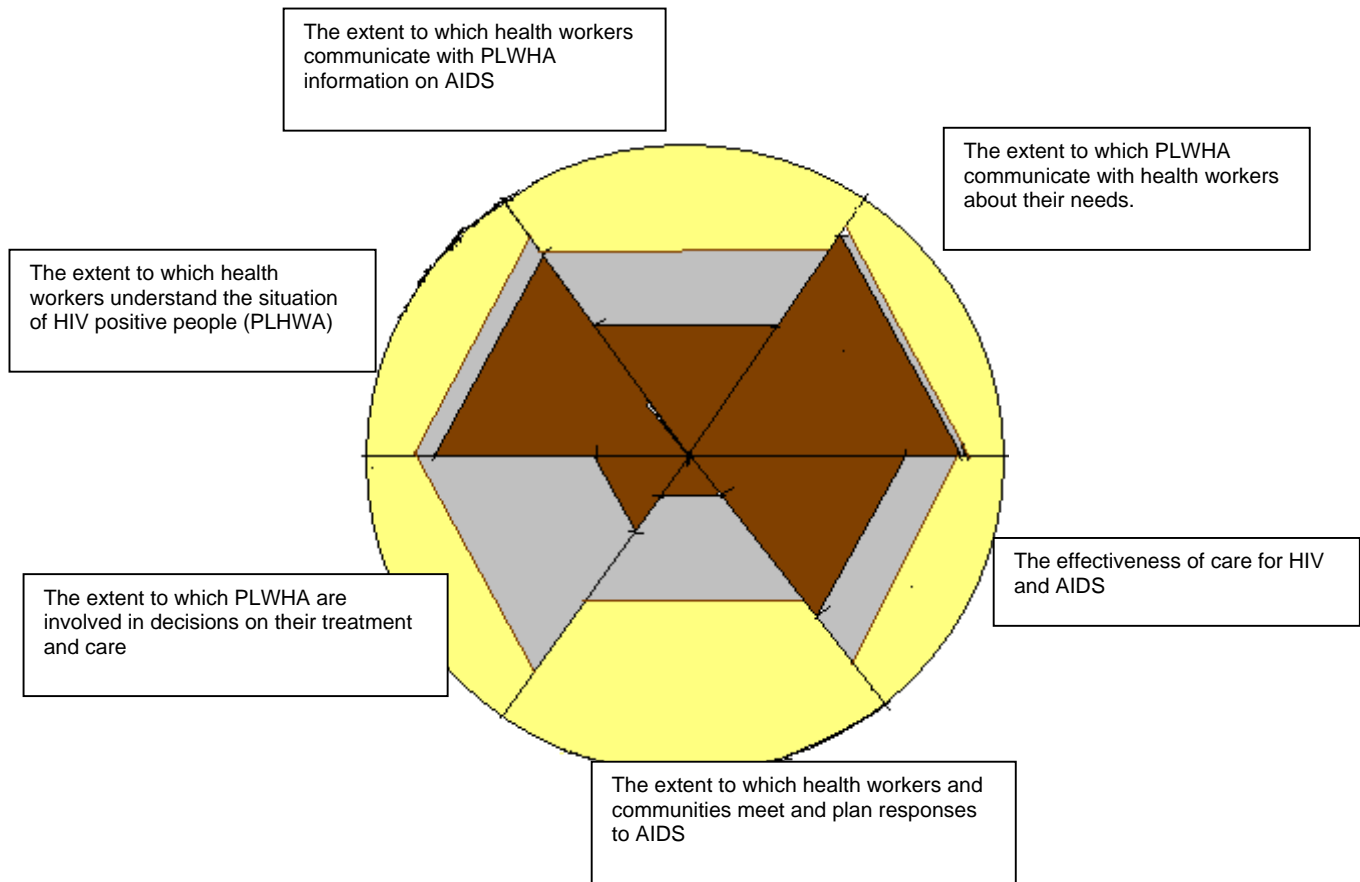The wheel segments reflected six dimensions of communication, ie

i.   The extent to which health workers understand the situation of HIV positive people (PLHWA)

ii.   The extent to which PLWHA communicate with health workers about their needs.

iii.   the extent to which health workers communicate with PLWHA information on AIDS

iv.   The effectiveness of care for HIV and AIDS

v.   The extent to which health workers and communities meet and plan responses to AIDS

vi.   The extent to which PLWHA are involved in decisions on their treatment and care

Discussing the wheel chart   Source: Ongala 2007

The baseline wheel-chart filled by the health workers is shown as an example in Figure 1 below. The height of the grey and brown coloured segments in the wheel reflects the view of each group of health workers on the issue in the segment, from low to high.

Figure 1: Wheel-chart on health workers perception of the communication about HIV

The extent to which health workers communicate with PLWHA information on AIDS

The extent to which PLWHA communicate with health workers about their needs.

The extent to which health workers understand the situation of HIV positive people (PLHWA)

The effectiveness of care for HIV and AIDS

The extent to which PLWHA are involved in decisions on their treatment and care

The extent to which health workers and communities meet and plan responses to AIDS

We summarise in Table 1 below the combined average results of the six health workers and the community members for the 6 sites, giving the levels provided on the wheelcharts a score as follows:

- 1 = very low   2 = low
- 3 = on the middle line   4 = above middle line
- 5 = high   6 = at the top

Table 1: Average rating of different elements on wheel charts in the 6 sites

Indicator	Average rating community members	Average rating Health workers	Average rating combined
The extent to which health workers understand the situation of HIV positive people (PLHWA)	2	5	3.5
The extent to which PLWHA communicate with health workers about their needs.	6	3	4.5
The extent to which health workers communicate with PLWHA information on AIDS	3	6	4.5
The effectiveness of care for HIV and AIDS	4	4	4
The extent to which health workers and communities meet and plan responses to AIDS	1	1	1
The extent to which PLWHA are involved in decisions on their treatment and care	5	2	3.5

Note PLWHA was used in this chart and the term later revised to PLWHIV

The wheel chart showed that
- Health workers have a higher rating of their understanding of the situation of PLWHIV than community members have of their understanding;
- Community members perceive that PLWHIV communicate with health workers about their needs to a greater extent than health workers think;
- In direct contrast, health workers have a much higher perception of their communication to PLWHIV information on AIDS than community members;
- Both groups have the same relatively high perception of the effectiveness of care for HIV and AIDS and relatively low perception of the extent to which health workers and communities meet and plan responses to AIDS;
- Community members have a much higher perception of the extent to which PLWHIV are involved in decisions on their treatment and care than health workers.

Hence while both groups have a similar perceptions of the effectiveness of care and the low level of joint planning between health workers and PLWHIV, their perceptions of each others roles and the communication are very different, confirming the serious communication gap in the area between PLWHIV and health workers.

In the discussion of the wheel chart, the clients felt clinic workers did not bother to find out what their concern and problems were. Rather they quickly prescribed and issued drugs. As one client said,
"Clinic workers were not keen on our ideas or suggestions, instead they listened little from us then gave us drug prescription and told us what to do. Yet some of the instructions do not directly meet our needs".

The clinic workers, in contrast, felt clients were not open to receive instructions that they gave them. They said some skipped care programme, which was worrying them. A clinic worker said,
"Clients are becoming increasingly difficult to handle. Often clients come to us with fixed opinion. They expect us to handle them in a certain way but they do not say".
Another clinic worker reported being confused by the clients actions,
"We really do a lot for the clients yet they have low commitment to ART adherence. We do not know why".
The clients however had explanations for their actions:
"Whenever I walk to the clinic I expect good listening from the clinic workers but this I do not find. I have never known why they do not give us listening".

The discussion pointed to a problem of communication at the clinic that revolved around listening. Both clients and clinic workers demanded listening, but neither appeared to be able to listen to the other.

3.2 The first participatory meeting

The three day session involving PLHIV and clinic workers explored these issues further. From a discussion stimulated by case studies, clients, clinic workers and civil society organisation (CSO) representatives shared views that
- clients resort to silence because clinic workers often blame them over issues before giving them a chance to give their story;
- clients confidentiality is compromised when clinic workers discuss their health status loudly;
- clients had weak health and risked developing resistance to medicine due to unstable supply of drugs at the clinic ;
- clients were inadequately reached with care services when these operated in isolation, with low exchange and cooperation between clinic workers and their colleagues;
- clients often received low individual attention due understaffing at the clinic;

- clients that have progressed to full-blown AIDS obtained unequal distribution of care services due to stigma and discrimination, compared to care when conditions are at initial stages; and
- clients' that are unable to speak in languages other than their mother tongue are excluded from services provided by clinic workers that do not understand the languages they use.

The three groups also had different views about the current situation.
- The clients felt that they are often over medicated with drugs, are frustrated when clinic workers do not listen to them and threatened when clinic workers quarrel with them for whatever reasons. They feel they undergo frequent bouts of illnesses due to improper diagnosis because clinic workers fail to take vital signs. They are strained by the long distances they cover on foot to come to clinic and experience congested related problems at the clinic because the clinic doors are opened late and closed early.
- The clinic workers felt that clients suffer from inferiority, which limits their communication, have a nagging attitude that discourages clinic workers from communicating with them on AIDS and often press for care that is not relevant to their needs.
- The CSO representatives note that clients may be seen as forgetful or hostile due to their HIV related brain impairments. They noted that clients are strained by long queues in corridors due limited space at the clinic, respond negatively to inadequate, judgemental care from clinic workers and experience problems in care with lack of proper referrals and follow ups.

Participants felt that understaffing at the clinic largely contributed to poor communication issues at the HIV clinic. For instance, clients' representatives said,

"Many clients were undergoing life threatening situations and experiences that often overwhelmed them because the few staffs could not listen to them enough. So some of those overwhelmed either skip taking drugs or fail to honour clinic appointments; a thing that angered clinic workers".

However, a clinic worker interjected saying,
"We are often not in picture about clients' situations and experiences since they do not feel free to share them. Also we are too few to adequately listen to every client in details".

While some felt that clinic staffs were too preoccupied with clearing long queues, the clinic staff noted that they still needed to ensure quality of care. The tension between keeping people waiting and spending time

Discussing communications issues
Source: Ongala 2007

listening was discussed and participants agreed that listening to clients is important, so that the staffing situation needed to be addressed at the HIV clinic to support effective care.

Specific issues were discussed. For example, the failure of health workers to listen was reported to have led to a person over-medicating when she added a new prescription to her old medication. On the other hand, clients were also noted to take too much medicine after defaulting on treatment to compensate for the days skipped. Other barriers were raised. Clients noted that lack of food caused them to skip drugs, and the practice of only giving food to clients whose body weight had gone below internationally recognised limits meant that some who were unable to secure adequate food fell outside this strict category and faced problems with their medication. They too needed support for coping mechanisms.

Participants explored their understanding of communication, defining communication as.
- a way of passing information from one person to another (Clients), and

- Conveying information from sender to receiver and obtain feedback from receiver to the sender (clinic workers).

Participants noted the differences in their definitions. In first definition, an individual talks to others without expecting feedback from them where as in second definition the individual expects feedback from others. Simnet (1995) observed that community and professional concepts of health differ and that these differences in approach can affect how they work together.

Discussing communications issues
Source: Ongala 2007

Yet, the two definitions both paint a picture of communication as mechanical process. When we probed further, participants said communication is also about sharing views or exchanging ideas, bringing life to the individuals involved. Ministry of Health Kenya (2005) reports note that, "*Communication facilitates the transfer of knowledge and skills on health matters between individuals and families to make informed choices and decision for behaviour change*". It argues that communication creates demand for better health services and builds mutual understanding and trust among key sectors within the community.

Although participants held different views about communication, clients and clinic workers agreed that signs of good communication include.
- use of language understood by all;
- expression of empathy;
- assertive, audible, and firm in speech;
- use of kind words and friendly manner; and
- active listening and timely feedback.

Participants observed that communication needed to be strengthened to open avenue for better health services. In contrast, signs of bad communication were observed to be;
- use of harsh language, argumentative, blaming or accusing and putting people in the defensive;
- lack of flexibility, impatient, imposing of ideas, interrupting speakers;
- monologue as opposed to dialogue;
- passive, withdrawn listeners, not paying attention, with information passed mechanically; and
- shifting the focus from issues to personality and deviating from subject of discussion.

Participants agreed that both clients and clinic workers should strengthen good over bad forms of communication as a strategy for improving health care in the community.

Using Johari's window, responses indicated that there was big gap between the current type of communication and the desired type of communication. The current type of communication has strained the relationship of the two sides. Using Johari's window, participants filled the four windows as shown in Figure 2.

The current type of communication taking place at the HIV clinic was that found in window two and three and the desired type of communications was that of window four. Participants felt the gap would narrow if both clients and clinic workers learn how to share freely each other's situation and experience. Both clients and clinic workers agreed they would need to build an environment to support healthy communication. This included taking a calm approach, asking for review of hot issues, acknowledge speakers concerns, taking responsibility for what you are feeling and sharing and not interrupting the speaker.

Figure 2: Feedback on the Johari's window tool by health workers and community members

1. **Unknown to both**	2. **Blind:** What clinic workers know
	- Rigid to western medicine knowledge - Dominate over clients - Make decisions for clients - Ignore client's suggestions - View clients as unreasonable - Discouraged by clients attitude - Do not effectively communicate AIDS information
3. **Hidden:** What clients know - Rigid to traditional medicine knowledge - They regard clinic workers as imposers - They demand special attention from clinic workers - They do not appreciate care services - They lost trust with clinic workers - They default from care services	4. **Open:** What everybody knows - Self motivated communicator - Flexible and open to new ideas - Allow interactive dialogue, active listening - Accept suggestions, appreciate each other's views - Shared understanding and decisions - Avoid biased positions and labelling of others knowledge (e.g. as Western or traditional)

A client said, "*We feel hurt, frustrated and become angry when clinic workers do not listen to us or when they make decisions on our behalf without getting our side of the story*". Similarly, MOH (2005) raised concern that some providers do not know what their clients understand, undermining care.

While clinic workers felt that clients were hiding useful health information from them, clients blamed this on lack of confidentiality. Although the law allows clinic workers to consult over clients' illnesses, it does not allow them to rake this to the public. Participants agreed that clients are entitled to privacy and confidentiality of personal information.

Through role play, participants explored how to improve communication, with debate on the options.
- Participants agreed that clinic workers and clients needed to build rapport. In the role play a participant noted: "*I think for the first time I went through what client goes through. First, the 'clinician' never called me by my name. He did not care whether I was single, married, or widowed. There was no rapport. The situation was hectic and I did not like it*". While some felt that clients and clinic workers should take the time to build rapport, others felt it would take too much time and could only work with a better clinic worker-client ratio. As a compromise people felt that individuals at the clinic need not be prisoners of time. Both clinic workers and clients should interact at personal level and issues such as calling clients by name are important, and should not be counted as time wasting, as it is therapeutic. Davis (1990) confirms this perception of more effective communication resulting from health workers appreciating the experience of clients by putting themselves in the clients place.

- Participants felt that the style of communication was important- keeping eye-to-eye contact; avoiding arguing, when upset stopping and cooling down, letting others express themselves without interrupting and paying attention, .even if they do not agree with speaker. While some felt that people should empathize, guide, direct and influence others and help them to make sensible decisions and judgment, others felt that if clinic workers over empathized, it can lead to carelessness and failure to take responsibility for their behaviour in clients. Raley (2004) defined empathy as the act of communicating to fellow human beings that we understand how they are feeling and what make them feel that way. *"I felt relieved when I saw the clinic worker understood my situation"* was a view expressed in the role play. At the same time, clients feel ignorant of the clinic workers goals. "*Though I visit the clinic I do not know what the clinic workers planned to achieve neither do I know whether they are making progress in their plans if they have any*". This has led to several problems. For instance, clients do not know how far they can go with inquiring for help from the clinic staff. Participants felt that clinic workers should share with clients their mission and goals.

Using the "horses mouth" approach, on the third day of the PRA workshop clients invited the 'clinic –in-charges' to the meeting to discuss issues they raised. The Nutrition Officer in charge of the HIV clinic accompanied by a Nursing Officer discussed issues and responded to questions raised by participants. These were wide ranging and included
- How to strengthen adherence counselling
- Issues relating to drugs and medication, including the unstable supply and shortages and the problem of taking drugs on empty stomach
- Issues relating to organisation of the clinic, including attending to clients from 8.00 am to 4.30 pm to reduce congestion, ensuring clients do not jump the queue, expanding the clinic block to ease congestion and computerizing the filling system to speed up delivery of care services
- Issues relating to health worker practices, including keeping to professional ethics to reduce stigma, desisting from harassing and using harsh language that is creating fear, improving confidentiality and using language clients can understand and allowing clients to involve interpreters of own choice to overcome language barriers where need be.
- Installing a suggestion box to channel issues and complaints to the health personnel

After the 'in charges' addressed these issues raised by participants, they kept the door open for dialogue, saying their aim was to make the clinic user friendly. Clients said that for the first time clinic in charges recognised their voices. One said, "*The meeting with you is a good gesture. It shows that you finally recognized our voices and participation*". Another one said, "*We felt humbled when you accepted the invitation we extended to you, we now feel free to work with you because we know you have us at heart*".

An issue that needed further discussion was that of stigma as it undermined communication, and reflected false understanding of HIV. A client said, "*Clinic workers avoided giving me close attention. Instead she blamed me for contracting the disease and said her reason for keeping safe distance was to avoid catching it*". Health workers recognised their own fear of infection, reporting problems of non-sterilized equipments and poor infection control technique, when invasive procedures are used where there may be direct contact with client body fluids (ICN 2000). The discussion on this revealed that this risk is low if health workers adhere to basic principles of universal precautions and that health worker prejudice would not only lead to stigma but undermine quality of care (ICN 2000).

As a result of the discussions in the PRA meeting and this dialogue participants agreed to implement some actions:-
- Install a suggestion box
- Open a room for taking vital signs before clients proceed to consultation room.
- Avoid jumping queues
- Clients to involve interpreters of own choice to overcome language barrier,

- MOH to make bulk orders of drugs
- Selected clients serve as health educators along side clinic workers.
- Decentralize HIV care to other health facilities to decongest the crowded clinic and bring the services near to clients
- Solicit funds for constructing a large HIV clinic block to further decongest clinic and give comprehension services under one roof.

After discussions using the stepping stones method, community members and health workers identified the things they wanted to achieve to improve the current situation as follows;

Participants proposing joint actions using stepping stones   Source Ongala 2007

Five things participants felt they would like to achieve

- Practicing effective communication
- Establish suggestion box
- Put up customer care desk on good communication
- Involve clients as health Educators
- Encourage and use clients' suggestions to improve clinic services.

Five things participants felt they must achieve.

- Feed back to member organizations
- Network and progress meetings
- Community mobilization and sensitization
- Joint planning meeting between health workers and clients on the proposed measures
- Programme Evaluation

Participants felt they could work together with greater involvement of the community and with minimal outside help: *"I believe we can proceed to finish this important task through joint ventures since the resources we require to use are locally available".* The workshop agreed on a joint action plan for implementation (see Table 2) and selected a committee to coordinate the implementation process.

As one outcome measure participants aimed to reduce defaulter rates by 30% by end of 2007.

Table 2: Summary of the Joint Action Plan Drawn by Participants

Date	Activity	Objective
June 2007	Feedback	To update members of participating organizations
	Networking and Progress meeting	To share Knowledge experiences, challenges and lessons learnt
July 2007	One day PRA Orientation Workshop	To prepare participants for community mobilization activities
	HIV Positive Clients' Meeting	To explore possibilities of initiating and establishing Clients' network
	Networking and Progress meeting	To share Knowledge experiences, challenges and lessons learnt
	Joint Planning meeting on ART services	To discuss ways of enhancing ART service performances in the HIV clinics in the division
August 2007	Mobilization and sensitization	To improve communication and understanding between HIV Positive clients and Health workers
	Joint Planning meetings on ART services	To discuss ways of enhancing ART service performances in the HIV clinics in the division
	Networking and Progress meeting	To share Knowledge experiences, challenges and lessons learnt
	Evaluation exercise	To review the workplan
Sept 2007	Mobilization and sensitization	Communication and understanding between HIV positive Clients and the Health workers
	Joint Planning meeting on ART services	To discuss ways of enhancing ART service performances in the HIV clinics in the division
	Networking and Progress meeting	To share Knowledge experiences, challenges and lessons learnt
October 2007	Evaluation exercise	To review the workplan

4 Follow up Actions

At the end of the three-day event participants moved back to their respective organizations. They updated their organization staff/members on communications issues raised and reflected on their analysis of the problems and the joint actions proposed. While some reported that their staff/members were happy with the progress made, others challenged the practicality of the process. They wondered whether clients and clinical workers would remain focused in pursuing the agenda outlined in the document as per the joint workshop given the short duration given to follow up actions. The implementing team nevertheless persisted with the activities as planned. One participant said she has been looking forward to take up a challenge of this kind for long. "*I am happy be a part of this change process and I have hope it will bring new life".*

Between June and October 2007, the nominated committee coordinated the exercise to translate the joint action plan into practice. Monthly networking and progress meetings were used to review progress and discuss matters arising from the reports.

In the period, the following areas of progress on action were reported:
- Installation of suggestion box
- Opening of a room for taking vital signs before clients proceed to consultation room
- Strict following of queues on the basis of first come first served
- Allowing clients to involve interpreters of own choice to overcome language barrier,

- Steady supply of drugs
- Selected clients were serving as health educators along side clinic workers.
- The MOH has decentralized HIV care to Ober health center. This has decongested the crowded clinic and brought services near to clients

However, participants were disturbed that the MOH team had not constructed a larger HIV clinic block to decongest clinic and give comprehensive services under one roof as promised. Although MOH team gave hopes that they would build a larger clinic block, they were not able to develop the project within the short period given the enormous amount of funds needed. The MOH team said for sometime their budget line has not been able to support such a big project. MOH (2005) confirms that the cost of health services has escalated beyond the financing capacity of the Ministry of health. Obtaining funds for such improvements were thus reported to take time, an issue the participants appreciated.

Participants felt that the joint client – clinical worker planning meetings improved understanding between them and strengthened their relationship. The meetings gave them a chance to dialogue with one another thus removing communication barriers between them. A client said, "*I now know where to go to when ever I have information to share with fellow clients. In fact, we have flowing dialogue around key issues that threatened the gains we had made in improving our health*".

Immediately after the initial three day workshop clients held their own meeting to strengthen their voices and participation in the health issues. During the meeting, they formed a new network called Kasipul Division HIV Clients against Defaulter rates (KADHICNADER) and registered it as a community based organisation (CBO) with the Ministry of Gender Sports and Cultural Services. The network has opened an account with a local bank to manage monthly member contributions.

Although the network started with few members, it succeeded in reducing isolation and enhancing exchange and cooperation of clients, as they come for scheduled meetings every month. Clients said stigma was a major reason why some stayed in isolation. For example one said, "*I stayed in isolation for so long because I was being blamed for killing my husband with AIDS and was rejected by in-laws other family members*". Another said, "*When my husband turned HIV positive and died of AIDS people accused me for killing him with the disease. Nobody stood with me. For months, I felt lonely and spent time crying. I wanted to leave home. I even preferred death rather than have meaningless life. But the thought of my children kept me home till now*". When we probed, clients shared stories on how people with HIV led desperate living condition in villages across the community.

Clients felt that increased exchange of information in the network was good for them. A client said. "*I am now able to manage a lot on my own due to lessons I gather from the network*". Another said, "*Before joining the Network I feared to share my status however as I listened to others speak freely in the network, I discovered I was not alone so I opened up even on biting issues. I have since come along way with valuable solutions*". Another said, "*Initially I experienced coming into network as a threatening situation however I found it was a safe place for all people to be heard.*"

It takes time to overcome this fear, but those who have joined the network have done a lot to strengthen its operations. They kept passers by from interrupting meeting to ensure confidentiality.

The members organised their meetings to guide the discussion, to respect one another's opinion and refrain from use of negative, judgmental language and promoted encouragement. The network welcomed guests to come in and share topics, including but not limited to medical information, treatment options, common experiences or physical, emotional or spiritual support. Meetings started and closed with prayers.

During the network meetings, members opened up on issues, and issues hurting them, to reduce fear, secrecy and denial. ICN (2003) suggest that fears associated with HIV can be directly addressed through education and strong networking with all HIV/AIDS stakeholders, and that those who have less fear live longer and healthier lives. By sharing experiences, challenges and lessons learnt clients were increasingly accepting their status and work towards positive living. Their own words report this experience:

- *"The network has helped me to gain skills to avoid getting further HIV infection with other strains. I am also more able to protect my current and future partners"*
- *"When we meet, we engage in open forums that have positively impacted on our lives. I can now share my situation and experiences freely"*
- *"People gave me less than 1 year to live. I felt devastated and had no one to turn to until I joined the clients' network whose members have supported me. This has drastically reduced stress from my life. Today I am working to normalize my positive status"*

The client's network offers a peer support system. Concerned colleagues were willing to share their situations and experiences in a participatory environment. This gave them opportunity to deal with one another's vulnerability, fears and prejudices. However, issues of sex education were reported to remain a difficult issue to discuss. While some noted the positive impact of such education on their behaviour and decisions, increasing their control over these issues, others were uncomfortable with having this topic and for how it would be perceived in the wider community. On balance the network felt that well planned education on sexuality would be helpful to members, and would save people from documented risks of re-infection and spread of sexually transmitted infections (Obbo 2006).

Since the clients network representatives began holding monthly joint meetings with clinic workers, the two have established stronger co-operation between them. Participants said the monthly joint meetings had been useful forums for bring them together; for sharing experiences, for disseminating results, for mutual accountability and for sustaining change momentum. A clinic worker said, "*There is value in holding regular joint meetings. Through the meetings we have generated new ideas that we have successfully incorporated in our care system and shared with our development partners for wider consumption*". The clinic coordinator also valued these meetings: "*At the clinic, we see the joint planning meetings as useful because they act as feedback on how clients feel about the quality of care services that we give them. Through the meetings we learn what works well, what does not work well and what we need to do differently. We have developed strategic actions and made for improvement on care delivery at the facility*". Such joint monitoring and evaluation meetings have been documented elsewhere to provide support to continuing care (Kinghorn and Gamlin 2001)

Although still in its early stages, the clients' network has attracted support from the local ministry of health team, who have developed close working relations with them. They have sent students from Kenya Medical Training College on clinical placement to the group to learn about HBC activities from its members. Through these programmes, medical students from Kisumu, Kakamega and Thika have visited and gained valuable lessons from the network.

While there had been HIV awareness activities in the community, the fact that people had withdrawn from seeking

A member of PLHIV client's network discussing with health personnel
Source: Ongala 2007

services at the local HIV clinic made mobilisation and sensitisation a challenging exercise. In addition, many people were beginning to deal with the disease at a personal level.

A one day PRA orientation meeting was held by the programme leader to equip eleven participants with skills for community mobilization and sensitization. A workplan for community sensitisation was incorporated into the overall joint work plan and the trained participants worked closely with the other participants in the programme. The sensitisation meetings used PRA approaches to dialogue with community members, drawing out reasons for people stopping using services, such as the concerns about communication and quality of care raised in the PRA workshops reported earlier.
"I do not know why they quarrel with people, we do not know what they actually want to achieve in our community" said a community member.

However, the study team noted that when they discussed the issues the villagers raised, things calmed down, generating an atmosphere of understanding. Another member of the study team reported that acknowledging their concern and responding to their questions led villagers to listen to information on new developments regarding communication issues and progress made at the health facility. This influenced the villagers to change their attitude towards the clinic workers. Some villagers promised to visit the clinic for HIV testing and treatment, although some raised the continuing barrier of long distances that needed to be covered on foot. Other cost barriers in the context of high poverty levels included costs of laboratory investigations, food and other care related commodities.

Clients said the common understanding in the community was that sexual issues are matters pertaining to the private domain, which is why individuals do not really feel secure or comfortable to share them publicly. This made communication about sex related issues difficult, and led to gaps between what is said in public and what is done in private. In situations where people cannot openly discuss HIV and human sexuality, discussing sexual issues become embarrassing and uncomfortable and people may ignore it, as has been found elsewhere (ICN 2005). The client forums for education of sexuality were set up in the community to educate people on the benefits of dialogue around sexual issues.

Despite these difficulties, hearing about the ongoing improvements in communication at the HIV clinic generated new interest among clients. One villager said, "*If the clinic workers are listening more to us then I have reasons to continue pursuing care services at the HIV clinic despite difficulties*". At the same time clinic workers reported during the intervention a small rise in the number of clients visiting the HIV clinic between June and September 2007.

Figure 2: Number of HIV positive clients attending the HIV clinic 2007
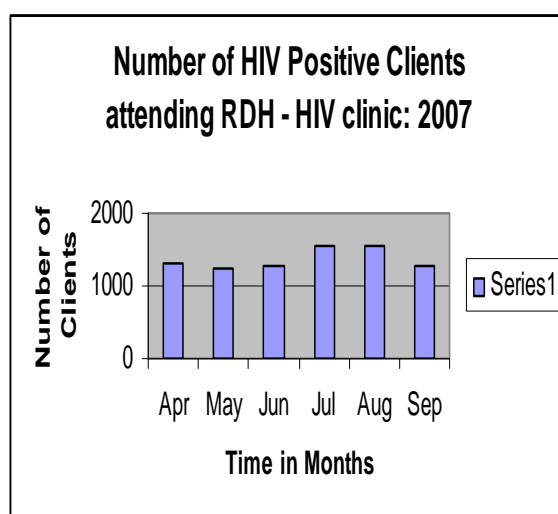
Source: Rachuonyo District Hospital Health Information System (2007)

Health workers reported a drop in defaulters as observed from number of clients returning to treatment but during the period under review, but the lack of data recorded on made it hard to measure this important outcome. Many clients had been transferred to Ober Health center where data was equally lacking. Participants recognised this challenge and agreed that the HIV clinic in charge collect this information in future.

5 Review and reflection on the intervention

In a review meeting in October 2007, 36 participants from the health workers and community that were involved in the initial exercise gathered to evaluate the exercise. Tables 3a and 3b show the numbers who perceived that they had achieved these goals.

Table 3a: Participant assessment of achievement of goals set as things that MUST be achieved N=36

5 things participants agreed they MUST achieve	No (%) of participants think things were achieved		No (%) of participants think things were not achieved	
Feedback	34	94%	2	6%
Network and progress meetings	32	89%	4	11%
Joint planning meeting on ART services	29	81%	7	19%
Community mobilisation and sensitisation	27	75%	9	25%

Table 3a: Participant assessment of achievement of things that they would LIKE to have achieved N=36

5 things participants agreed they would LIKE to achieve	No (%) of participants think things were achieved		No (%) of participants think things were not achieved	
Practice effective communication	34	94%	2	6%
Establish suggestion box	32	88%	4	11%
Put up customer care desk	29	81%	7	19%
Involve clients as health educators	27	75%	9	25%
Encourage and using clients suggestions to improve clinic services	30	83%	6	17%

Communication goals were felt to be easier to achieve, including giving feedback and practising effective communication. Early feedback from the meeting made report back easier, as did the initial motivation of the organisations involved. Concrete tasks such as the network and progress meetings, setting up the suggestion box, setting up the customer care desk, holding joint meetings with health workers and obtaining community suggestions were largely seen to have been achieved. Less successful were the community mobilisation and sensitisation exercise and the involvement of clients as health educators. A participant said, "*Villagers turned out in unexpected large numbers that we found hard to control*". This made it difficult to give everyone time to air their views, especially women and this needed to be dealt with in future work.

In future sensitisation meetings more facilitators needed to be oriented to spread and manage the process, facilitators needed to give equal chances to both sexes to speak, and to give more time for the exercise. The participants planned to revisit villages that were most affected and spread to new villages.

We used same Wheel chart used in the baseline and the same indicators to assess change. This encouraged a lot of debate before joint agreement on the new levels for each segment. We summarise in Table 4 below the results of the health workers and the community

members for the baseline (shown earlier in Table 1) and for the post intervention assessment, giving the levels provided on the wheelcharts a score as follows:

1 = very low
2 = low
3 = on the middle line
4 = above middle line
5 = high
6= at the top

Table 4: Rating of different elements on wheel chart

	RATING					
	Community members		Health workers		Combined	
Indicator	Before	After	Before	After	Before	After
The extent to which PLWHA communicate with health workers about their needs.	6	2	3	3	4.5	2.5
The extent to which health workers communicate with PLWHA information on AIDS	3	3	6	6	4.5	4.5
The effectiveness of care for HIV and AIDS	4	5	4	4	4	4.5
The extent to which health workers and communities meet and plan responses to AIDS	1	4	1	1	1	2.5
The extent to which PLWHA are involved in decisions on their treatment and care	5	6	2	2	3.5	4

The repeat of the elements on the wheel chart showed that
 ◆ Community members perceptions of the extent of communication by PLWHIV with health workers about their needs had fallen, while that of health workers had not changed.
 ◆ Health workers continued to have a much higher perception of their communication to PLWHIV information on AIDS than community members, and neither group changed their perceptions on this;
 ◆ Both groups have the same relatively high perception of the effectiveness of care for HIV and AIDS, with some improvement perceived by community members;
 ◆ Health workers continued to have a relatively low perception of the extent to which health workers and communities meet and plan responses to AIDS, but community members perception was of a considerable improvement in this;
 ◆ Community members continued to have a much higher perception of the extent to which PLWHIV are involved in decisions on their treatment and care than health workers, this further increased, while that of health workers remained the same.

It appears that health workers perceptions changed little in the intervention, while those of community members showed some considerable changes. It appears that community members were more critical of the extent of current communication, perhaps realising the possibilities for improvements, but that they also felt that the effectiveness of care and extent of joint planning had improved considerably. The continuing gap between health worker and community views suggests that there are still gaps in perception and communication between these groups that need to be further addressed.

Participants discussing the intervention
Source Ongala 2007

As a result of this discussion the team felt that they needed to continue working on efforts to improve health workers ability to communicate with clients' information on AIDS, and to improve clients ability to communicate with health workers about their needs. They also needed to strengthen joint health workers and clients planning meetings and improve health workers understanding on the situation and experience of HIV positive clients.

New activities were also suggested: Holding training of trainers workshop on effective communication in HIV clinic; for both clients and clinic workers, developing a manual for training of trainers workshop on effective communication in HIV clinic both clients and clinic workers and conducting community awareness and encouraging clients to join the newly formed HIV positive clients' network. It was also suggested that joint clients and clinic workers dialogue days be held to share issues raised by clients and answer the questions as well as updating them on clinic operations.

As next steps, participants proposed to

- Share the findings of this work with the community and continue collecting information on what they currently think about communication situation at the HIV clinic;
- bridge communication gaps and initiate dialogue on key health issues in ways that encourage community to have their voices heard and are action oriented;
- promote networking to overcome isolation in ways that increase exchange of information among key actors in the health system at community level;
- advocate for greater accountability and involvement of the local community in decision making process on health issues; and
- Keep reviewing actions through monitoring and evaluation.

Despite the challenges, the participants said they had found the work enjoyable and rewarding, and giving a basis for sustainability. They felt that participatory approaches are valuable for promoting community based health issues, with various views put forward about its usefulness. It was noted that participatory approaches use a bottom up approach, whereas processes that are more conventional target and obtain leaders views, and that the process stimulates critical thinking and sustainable solutions as it draws from people's own experiences.
"I noticed we had similar information but with different perceptions. The PRA has helped as to share them thus gaining strength".

"At the beginning I was afraid because I fear that a joint clients - clinic workers forum could easily turn into unnecessary hot exchanges that could be futile so I asked the conveners to hold separate meetings; one clients and another for clinic workers for the sake of peace but to my surprise this has turned to be one of the best meetings I have ever had"

The joint PRA meetings were felt to be a good approach to improving communication and understanding in the community, to change negative perceptions and overcome communication barriers on both sides, ie both health workers and clients.

"Through joint sessions, I came to learn that we had for a long time perceived clients as unreasonable making it hard for us to listen to their critical views. I hope to do things differently."

"Since I found it difficult to communicate my inner feelings to the clinic staffs I just walked away in silence until this PRA project came".

The process was also useful in raising and tackling issues that were potentially a source of conflict in a positive way.
"I have resolved to give listening on how clients wish us to handle their health. We can argue our case that aim to rectify the historical injustices without upsetting the clinic staffs"

In the study team, we felt that participatory approaches are a powerful means to bringing peace and healing to communities. Its use has removed fear of risk of intimidation as it overcomes power imbalances that are barriers to good health or effective use of services. For instance, some participants feared that clinic workers could take actions against clients who register dissatisfaction about the quality of care services offered at the HIV clinic. This fear seemed to have died during the PRA process.

We perceive that PRA processes could help communities to raise and address a range of barriers to access health care services in their localities. We worked with villagers in open forums, including under trees, gave various representatives time to speak out on their different views from different perspectives and saw people speaking without fear, on issues that they had initially regarded as 'tense'. Communities can freely discuss their health needs, including deeply seated challenges, in joint forums if they believe those forums can and will effectively address those issues.

We also found that open community dialogue reduces irrational and often exaggerated fears or stigma, and health workers themselves need to use these to make their work more effective and sustain community action. According to MOH (2005), "*It is to be realized that households have the deepest interest of their own health at heart and are always trying their best even if when what they do appears unreasonable. Yet the providers do not listen enough to hear what the consumers are expressing in their own terms and context, because providers tend to be rooted from their socio-cultural contexts. This leads to loss of trust as local efforts and initiatives are ignored or displaced by temporary actions that fizzle away*".

Participatory approaches provided a unique way of bringing people with differing perceptions together. It provides them with a mutually respectful environment for sharing their differences and harmonising dialogue, opening expression of views, and bridging gaps between people with differing views. This recognition of one another's knowledge and intelligence was a foundation for people's desire and ability to work together continually for sustainable change in the community.

6 Conclusions and next steps

The findings and review reported above indicate that the intervention generated a number of valuable outcomes;

- Participants came away from the workshop more aware of the situations and experiences that HIV positive clients undergo and how these affect their ability to communicate their needs to clinic workers and their health seeking behaviour;
- The range of communication problems that pose barriers to service uptake were identified and actions implemented on some that led to perceived improvements both in health workers and community joint planning and in quality of care and some improvements in service uptake;
- Real changes were made to make the services more client-friendly, including installed suggestion box, re-streamlined queuing and filling system, taking of vital signs, interpreter involvement, and ordering of bulk drug supply, while clients formed a network that would sustain the communication and reduce social isolation of PLWHIV.
- There was wider benefit in the confidence and participation of local community members in improving their health and the willingness of health workers to listen and involve the community in improving health service use and delivery, particularly due the perceived success of the change process by both groups.
- It was felt across both groups that a more enabling environment was created for sustainable community action on health and ownership in the local health system,

drawing on expanded community roles in appraising health needs, while also understanding the work and issues facing health workers in meeting these needs.

The participants from the community and health services identified further interventions discussed earlier that strengthen the interpersonal relations and communication among clients and clinic workers, including through supporting materials and training activities. We realised that sharing information with the community on tangible changes was important to reinforce their commitment to the process. We also realise that community members need information and support on areas such as knowing the dangers of skipping clinic appointment dates or services, speaking about problems that cause them to default without fear. At the same time health workers, need further support to improve and expand HIV care services, including in the number of health workers at primary care levels of health services.

Working to reduce stigma and discrimination against clients continues to be an important component of communication interventions, including dealing with misconceptions about AIDS among clinic workers, while other aspects of responses to HIV need to be addressed in the community.

While participatory processes hold promise in addressing these issues, as facilitators, we need to more deeply know and understand the barriers and distortions to these processes, such as the dominance of male over female voice in joint forums, so that their benefit and the empowerment they yield is accessed by those with greatest health and social need.

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Acknowledgements

Equity in health implies addressing differences in health status that are unnecessary, avoidable and unfair. In southern Africa, these typically relate to disparities across racial groups, rural/urban status, socio-economic status, gender, age and geographical region. EQUINET is primarily concerned with equity motivated interventions that seek to allocate resources preferentially to those with the worst health status (vertical equity). EQUINET seeks to understand and influence the redistribution of social and economic resources for equity oriented interventions, EQUINET also seeks to understand and inform the power and ability people (and social groups) have to make choices over health inputs and their capacity to use these choices towards health.

EQUINET implements work in a number of areas identified as central to health equity in the region:
- Public health impacts of macroeconomic and trade policies
- Poverty, deprivation and health equity and household resources for health
- Health rights as a driving force for health equity
- Health financing and integration of deprivation into health resource allocation
- Public-private mix and subsidies in health systems
- Distribution and migration of health personnel
- Equity oriented health systems responses to HIV/AIDS and treatment access
- Governance and participation in health systems
- Monitoring health equity and supporting evidence led policy

EQUINET is governed by a steering committee involving institutions and individuals co-ordinating theme, country or process work in EQUINET: R Loewenson, R Pointer, TARSC, Zimbabwe; M Chopra MRC, South Africa; I Rusike, CWGH, Zimbabwe; L Gilson, Centre for Health Policy, South Africa; M Kachima, SATUCC; D McIntyre, Health Economics Unit, Cape Town, South Africa; G Mwaluko, M Masaiganah, Tanzania; M Kwataine, MHEN Malawi; M Mulumba U Makerere Uganda, S Iipinge, University of Namibia; N Mbombo UWC, South Africa; A Mabika SEATINI, Zimbabwe; I Makwiza, REACH Trust Malawi; S Mbuyita, Ifakara Tanzania

The Kasipul Division Home Based Care Stakeholders Group (KDHSG), is a non-profit making organization conducting HIV awareness in Kasipul district Kenya. We work closely with HIV positive clients, HIV clinic personnel and other stakeholders in the community. Our work began in 2005 under the auspices of the Ministry of Health (MOH) as a response to the rapid spread of HIV, increased suffering and mortality of people with AIDS. We have since pooled together over 20 local organizations and have established a multisectoral strategy for a comprehensive community care system that supports PLWHIV holistically. Our focus is on advocating for and strengthening Home based care (HBC) activities.