Intersectoral responses to nutritional needs among people living with HIV in Kasipul, Kenya

Raising voices in health

A Participatory Reflection and Action (PRA) Project Report

Rachuonyo Health Equity (RHE), Kasipul Division Home Based Care Stakeholders Group (KDHSG)
With the Regional Network for equity in health in East and Southern Africa (EQUINET)

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Through institutions in the region, EQUINET has been involved since 2000 in a range of capacity building activities, from formal modular training in Masters courses, specific skills courses, student grants and mentoring. This report has been produced within the capacity building programme on participatory research and action (PRA) for people centred health systems following training by TARSC and IHI in EQUINET. It is part of a growing mentored network of institutions, including community based organisations, PRA work and experience in east and southern Africa, aimed at strengthening people centred health systems and people's empowerment in health.

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Executive summary

More than 220 000 people in Kenya are estimated to be in need of ART, and while ART roll out has commenced, treatment delivery and access in Kenya is complicated by famine and drought in many regions, raising demands for concurrent nutrition support, even while nutritional support provided remains minimal. Poor food security and malnutrition hastens progression to HIV related illnesses and undermines adherence and response to antiretroviral therapy. People ill with HIV-related illnesses are reported to be less able to work, to earn income or to produce food, which can lead to nutritional deficits both for themselves and for their dependants.

This work was implemented in Kasipul Division, Rachuonyo District, Kenya, where high poverty levels lead to food insecurity exacerbated by rising food prices, by the consequences of two devastating tropical storms and soaring transportation costs. Few PLWHIV own farms, or produce a marketable surplus, and illness and malnutrition interact in a vicious cycle. KDHSG and RHE implemented a participatory action research programme, within a regional programme of the Regional network for Equity in Health in East and Southern Africa (EQUINET) to explore dimensions of (and impediments to delivery of) Primary Health Care responses to HIV and AIDS. The programme was co-ordinated by Training and Research Support Centre (TARSC) in co-operation with Ifakara Health Institute Tanzania, REACH Trust Malawi and the Global Network of People Living with HIV and AIDS (GNPP+). In Kenya it used a mix of PRA and quantitative approaches to;

- Identify the nutritional needs, issues and responses for PLWHIV on treatment
- Increase voice and participation of PLWHIV and communication with health workers on their nutritional needs in relation to treatment and on responses to these needs in the clinics and community
- Increase the capacity of health workers and community to identify specific areas for engagement of partners outside the health sector on intersectoral responses to support nutritional inputs for PLWHIV on treatment.

Between June 2008 and January 2009, a pre and post intervention quantitiative survey was implemented with 80 respondents from representatives of PLWHIV, professional Health workers, and local organizations; together with exit interviews of those on treatment. This was followed by a PRA process that explored nutrition issues for PLWHIV, an action plan monitored using progress markers of what the community groups felt they (i) must and (ii) would like to achieve and a follow up survey and evaluation meeting on the outcomes.

The baseline survey indicated that treatment services are generally perceived as moderately easy to access, but that perceptions of food adequacy varied widely across groups, with food access rated very low by PLWHIV. The view of whether people on treatment default was not uniform, with PLWHIV having a more favorable view than health workers and community members, but all being somewhat ambivalent. Food was felt by many to be a factor in default. There was strong agreement that not having enough food leads people on treatment to fall ill; and while health workers generally saw that there were adequate mechanisms and communication across groups for dealing with these issues, communities had a less positive rating of this and PLWHIV the least positive rating. Exit interviews at

clinics indicated that not having enough food was a common reason for people stopping ART treatment. Food security has declined in the whole community, as food harvests have fallen in the area, but only people with low body mass index (BMI) are issued with food supplements in the local HIV clinics. PLWHIV feel compelled to share their food with family, while weakening extended family structures have limited food support from families to ill people.

A PRA process involving representatives of PLWHIV, health workers, CBOs, FBOs and NGOs, the Provincial Administration, the Kenya police, Ministry of Livestock and Agriculture, and the District Development Office pointed to a general situation of food insecurity, with PLWHIV particularly affected in terms of going without food and skipping treatment and drugs. While communities have in the past provided support to vulnerable groups, community level approaches were reported to have weakened and people to have become more dependent on individual resources, which were more limited. PLWHIV did not get adequate information on locally available health diets, had a false perception of what diets were needed when on treatment, and saw themselves as disabled dependents of support from elsewhere to obtain this. Health workers were providing information, but in a way that led people to misconstrue the information, particularly in terms of appreciating the value of locally available foods. Cultural factors such as widow inheritance were perceived to be linked to risk of both HIV infection and food insecurity.

While food supplements were seen to be a short term intervention, a fragmentation of initiatives in the area and focus on emergency responses was found to weaken the establishment of longer term approaches, leaving PLWHIV on treatment vulnerable to long term food insecurity. The groups involved identified actions currently underway to strengthen access to food by PLWHIV and communities and the local organizations providing this support. Building on this and addressing identified shortfalls, an action plan was developed and implemented over 4 months by health services, community based organizations and communities that sought to address the key features of longer term responses to nutritional needs identified, ie

1. *Awareness and information*: through training and sensitization, feedback on nutritional needs of PLWHIV
2. *Collective networking* particularly through support groups and extending their role to nutrition support to remove isolation and related difficulties
3. *Psychosocial support: .*by including nutrition counseling into Community Health worker programmes *to help patients make informed choices on available local food, their processing and meal preparation*
4. *Support for production;* through self help groups mobilizing resources for nutrition for establishing kitchen garden, poultry keeping and market gardening

In the follow up review of the actions participants noted a shift towards more locally generated, longer term strategies for nutrition support. Generally health workers view of the situation had changed significantly, with ratings closer to that of community members and PLWHIV. The PLWHIV still generally rated the situation worse than community members and health workers on a number of parameters, but far less so than in the baseline. Of importance, there was a high level of similarity across all groups in the rating of access to food and on adherence behaviours of PLWHIV. A continued perception of default due to food reflects the longer term, and deeper action needed to make real sustained improvements in access to food for people on ART treatment against the background of wider drivers of food insecurity. There was improvement across all groups in the perceived availability of mechanisms and presence of communication across groups for dealing with

these issues, and PLWHIV ratings showed the most significant change towards perceptions of improvements.

This work indicates that expanding access to treatment services needs to be embedded within a wider framework of wider health support, including the intersectoral action to address food needs, if availability is to translate into effective coverage. Nutrition support is a vital element of the chronic care and health management strategies needed for PHC responses to AIDS. This includes shifting perception of PLWHIV from that of disabled dependents of emergency support to people able to know and address their nutritional needs through local food resources. For health services this implies

- Recognising the central role that nutrition plays in ART programmes and integrating nutrition monitoring, counselling and support into all treatment programmes and community level outreach;
- Integrating into nutritional education and counseling specific information to encourage production and consumption of nutritious local foods, avoiding generalizations like “good quality diets” that may mislead;
- Encouraging community organizations to co-ordinate and shift from short term vertical responses to food needs to support for longer term strategies that enhance food security;
- Integrating nutrition and food access into support group activities to stimulate and negotiate for collective actions to support vulnerable groups and recovery;
- Stimulating exchange programmes around nutrition needs to reduce stigma and promote good practice driven from community level, with support from services and local organisations.

PRA processes were seen to be useful for building such approaches as they encourage communication and responses across agencies, and create more empowering relations between the community, health workers and other service providers.

The process challenges us to think beyond the box and to see such health initiatives as having much wider production and market impact. For example one practice referred to was a co-operation between an international and local institutions for local production of yoghurt of nutritional benefit both to PLWHIV and malnourished children, with wider income generating benefit to the community. This links the nutritional dimension of Primary Health Care responses to AIDS with approaches that strengthen local control of food production and marketing, an important wider determinant of health.

1. Introduction

The provision of treatment and care for HIV and AIDS is expanding globally, and free Ante-retroviral therapy (ART) is now provided through public sector services in many countries, with a number offering ART free at point of care ,(WHO 2007) . The number of people living with HIV (PLWHIV) benefiting from ART has expanded and a 6-fold increase in financing for HIV activities in low- and middle-income countries has been accompanied by a decline in the annual number of AIDS deaths from 2.2 million in 2005 to 2.0 million in 2007, in part as a result of the substantial increase in access to HIV treatment in recent years (UNAIDS 2008). In a number of heavily affected countries—including Kenya —the number of new HIV infections have fallen (UNAIDS 2008). Kenya's HIV prevalence rate was estimated in 2005 to be just below that of the overall rate for sub-Saharan Africa (6.7% compared to 7.5%), and to have declined (Kaiser Foundation 2006). Nevertheless the country is cited in the same source to have over a million people living with HIV and AIDS, giving an indication of the size of the demand for treatment.

More than 220 000 people in Kenya are estimated to be in need of ART. By the end of December 2005, approximately 39 000 people—30% of the 130 000 patients receiving AIDS care—had begun ART. In March 2006, data from the country's 218 ART sites indicated that a total of 73 528 patients had at one point started on ART, and that 69,384 were currently receiving it (ITPC 2006). A review of treatment access in Kenya specifically notes that famine and drought in many regions of Kenya have complicated treatment delivery and that in facilities providing HIV/AIDS comprehensive care, "nutritional support is still minimal except for nutritional education" (ITPC2006).

The Kenya Ministry of Health has developed an implementation framework on Home and Community - Based Care to widen access to HIV care services to the country's estimated 1.4 million PLWHIV in 2008 (NASCOP 2008). The framework seeks to facilitate recovery and mobility of PLWHIV to enable them to become active members of their community on life long anti retroviral treatment. However, as in many resource limited settings, the growing food crisis in Kenya is said to be posing a challenge to this, especially for the large number of PLWHIV in rural areas (WHO 2006).

In these settings, poor food security and malnutrition is hastening progression to HIV related illnesses and undermining adherence and response to antiretroviral therapy (UNAIDS 2004). People ill with HIV-related illnesses are reported to be less able to work, to earn income or to produce food, which can lead to nutritional deficits both for themselves and for their dependants (WHO 2005). As Randa Saadeh, World Health Organization (WHO), commented "If we don't include nutrition to our responses, we will be missing something in our care." (quoted in Markar 2008 p1).

We implemented this work in Kasipul Division, Rachuonyo District, Kenya. The area has a population of 129 854. It has poverty levels of 77% (Ministry of Planning and National Development 2002), with peasant farmers and small-scale business persons on low incomes. Malaria and pneumonia are common diseases in the area and the life expectancy ranks forty-first in Kenya (Kenya Human Resource 2008). These socio-economic conditions lead to food insecurity exacerbated by rising food prices (locally

and in the international trend market), by the consequences of two devastating tropical storms and soaring transportation costs. While this crisis has reached all levels of society, the poorest are paying the highest price (Fieser 2007). In this context those with HIV are at greater risk of poor nutrition. Few PLWHIV own farms, or produce a marketable surplus, and illness and malnutrition interact in a vicious cycle.

AIDS treatment started in the Rachuonyo District Hospital based HIV clinic in 2004 and care services have rapidly expanded to new facilities in the division; namely Ober Health Center and Matata Hospital. The move has seen many people coming forward for treatment of the disease. Yet, people in the area also tend to delay seeking medical care until their health conditions reach crisis levels, citing problems of distance to health facilities.

According to the National Coordinating Agency for Population and Development (2005) the average distance for households to travel to the hospital in the area is 5 km, with only 60% of household having access to the health facilities. However distance is not the only factor affecting uptake, and 5km can be a significant distance to cross on foot and when hungry or ill.

"It is hard to walk long distance on foot to access medication in the local clinic, particularly on empty stomach".

Community member, PLWHIV

At the clinics people face congestion and long queues and clinic personnel say they often they receive clients that complain of having not eaten for days. Understaffing in the health workforce in the area further worsens the situation. According to Rachuonyo District Hospital routine data in 2007 the area had only three nutritionists and a nurse patient ratio of 1: 1000 (Ongala 2008). Further, stigma associated with AIDS and poor attitudes from health workers complicates the management of the problem:

"Up to recently, I suffered a very bad STI but could not share my situation with health workers because I feared they would quarrel with me".

PLWHIV in Rachuonyo District

With these geographical and socio-economic barriers there is report of patients skipping or abandoning treatment programmes. Rachuonyo Health Equity (RHE) and Kasipul Division Home Based Stakeholders Group (KDHSG), two non-profit making institutions working with the community in the area, have found in previous work a number of barriers to accessing comprehensive primary health care to HIV and AIDS prevention and treatment in the area (Ongala 2008) KDHSG is a forum of care providers that meet monthly to share experiences and learning in Home Based Care (HBC). The forum begun in 2005 under the auspices of the Ministry of Health (MOH) as response to the rapid spread of HIV, increased suffering and mortality of people with AIDS. It has since pooled together over 20 local organizations and has established a multisectoral strategy for comprehensive community care systems that supports PLWHIV holistically.
In 2007, Participatory Reflection and Action (PRA) approaches were used to empower the community to demand and increase uptake of health services and to strengthen communication between PLWHIV and clinic health workers providing HIV treatment and care services, as part of a growing mentored network of PRA work and experience in

East and Southern Africa (Ongala 2008). As a consequence, the relationship between health workers and communities has improved.

Despite the achievement, nutritional challenges are threatening the gains made. While health workers emphasize to PLWHIV to 'eat well or take good food' before taking drugs, their clients perceive this to mean 'eat bulky and expensive meals'. The clients try to achieve a diet that they think achieves this, that is also costly and drains their already limited income and health. Some exchange sex for food as a survival strategy, increasing their risk of HIV. Where they cannot manage their food needs they may default on treatment. The clients that KDHSG and RHE find to be most affected by this include poverty stricken women, young men, and 'joter'; a cultural phrase for men known to inherit widows.

In their March 2008, stakeholders' monthly meeting, the organisations reviewed this problem. PLWHIV in the meeting said they were experiencing problems of taking ARVs on empty stomach because they are struggling in vain to obtain bulky, costly food. Health workers too recorded their difficulties:
"The truth is that, as health workers, we do not provide clients with food so we advise them to look for it elsewhere. Instead, we emphasize to clients the need to optimize nutrition, keep strict drug adherence and to practice safer sex but to our surprise they still skip drugs and catch terrible genital diseases. We do not know what to do".

Nevertheless, both health workers and PLWHIV felt they could work together with others in the community to address these nutritional needs and challenges among PLWHIV in the area. The situation calls for an intersectoral response to nutritional needs and issues among the social group in the area. As a result KDHSG and RHE implemented a participatory action research programme, within a regional programme of the Regional network for Equity in Health in East and Southern Africa (EQUINET) that aimed to build capacities in participatory action research to explore dimensions of (and impediments to delivery of) Primary Health Care responses to HIV and AIDS. The programme was co-ordinated by Training and Research Support Centre (TARSC) in co-operation with Ifakara Health Institute Tanzania, REACH Trust Malawi and the Global Network of People Living with HIV and AIDS (GNPP+). In Kenya it built on the 2008 work, to;

- Identify the nutritional needs and issues for PLWHIV on treatment and how these are being responded to
- Increase voice and participation of PLWHIV on their nutritional needs in relation to treatment and their involvement in decisions on responses to these needs in the clinics and community
- Enhancing communicate between PLWHIV on treatment and clinic workers on nutritional aspects of treatment, towards promoting improved nutrition support to treatment
- Increase the capacity of health workers and community to identify specific areas for engagement of partners outside the health sector on intersectoral responses to support nutritional inputs for PLWHIV on treatment.

Through this we hoped to:

- Reduce default on treatment due to nutrition
- Reduce report of nutrition as a problem in taking treatment
- Increase report of dialogue on nutrition between health workers and patients in AIDS clinics
- Build a shared perception of nutrition needs, and measures to support ARV treatment between health workers and PLWHIV on treatment

- Increase inclusion of nutrition issues raised by PLWHIV in treatment plans and programmes in clinics in Kasipul Division.
- Agree on measures and plan by health workers and community to engage partners outside the health sector for intersectoral responses to support nutritional inputs for PLWHIV on treatment.

2. Methods

Following EQUINET/TARSC/ Ifakara regional training, a participatory reflection and action programme was developed and implemented between June 2008 and January 2009. We obtained informed consent from the District Medical Officer of Health and consent form all those interviewed.

A baseline survey was implemented to assess nutritional needs and the level of identified outcome parameters, using an interviewer administered questionnaire with 50 community members and 50 PLWHIV sampled from the District Home based Care inventory. The sample was purposively selected to include those who were able and available to participate in the participatory process. While purposive sampling may introduce some bias and limit wider generalisation, we compare the baseline against a follow up assessment for the same group to assess change with the same people.

This baseline information was complemented by exit interviews conducted among 30 patients in three local HIV clinics in the area over five days. These were selected randomly and patients interviewed after seeing health workers and before they left the facility. Key informant interviews were used to collect information from health workers, clan elders, chiefs, and school heads about the nutritional needs of PLWHIV with regard to their treatment. We also collected relevant information on the total number of patients referred to the local HIV clinic, organizations responding to HIV prevention and treatment programs and patients response on supplementary food uptake and staffing from the health information system from the three local HIV clinics.

The interviews were all conducted in English and local languages interchangeably. Some loss of meaning could have arisen in translations. We involved interpreters and explained the terms and phrases used. We probed further where participant responses were unclear or uncertain. A majority of study participants were cooperative, but there were expectations from respondents that could not be met, including for financial payments for interviews. This led to two people not taking the exercise. Sampling was continued until target numbers were reached to deal with this. Unpredictable rains dispersed participants causing delay during the survey. The experience provided learning on the need for thorough processes of preparation before moving to the field.

The purposive sample of participants selected was included in the PRA process to capture a spectrum of inputs from community and other stakeholders. A total of 38 participants were involved, including representatives of PLWHIV, professional Health workers, Community Based Organisation (CBOs), Faith Based Organizations (FBOs) and Non Governmental Organizations (NGOs), the Provincial Administration, the Kenya police, Ministry of Livestock and Agriculture, and the District Development Office. The processes were facilitated by a team from RHE (Jacob Ongala, Janet Otieno, Mary Awino, George Wambwaya, Beldine Adhiambo); and from Ministry of Health, Rachuonyo District (Judith Rajwayi , Elizabeth Ongala) with support from TARSC (R Loewenson) and Ifakara (S Mbuyita) for design and peer review of tools and findings and TARSC (R Loewenson) for the technical and copy edit of the report.

The PRA meetings used the range of tools shown to:

- Identify nutritional needs and issues for PLWHIV on treatment using picture codes;
- Discuss how these are being responded to by patients, families, communities, health services and other sectors through focus group discussion;
- Identify the treatment programmes at the clinics and where this enables or disables nutrition support during treatment using human sculpture;
- Discuss the communication between PLWHIV on treatment and clinic workers on nutritional aspects of treatment stimulated by role plays;
- Identify the priority areas for action and actions towards promoting improved nutrition support to treatment in patients, families, communities, health services, other sectors using the stepping stones method
- Set up a joint action plan and co-ordinating mechanism
- Set up progress markers as things people MUST see and would LIKE to see by the end of 5 months

Between August and December 2008 the participants implemented the follow up actions developed in the PRA workshop. The Divisional Task Team (DTTPA) led the implementation of the plan. A final joint PRA workshop was held to review and assess programme achievements using the progress markers and PRA tools and, as noted above, the baseline assessment survey was repeated in the same sample.

3. Findings

3.1 The baseline assessment

The baseline assessment asked questions to assess perceptions amongst community members, health workers and PLWHIV. The questions related to perceptions of

- Access and adherence to treatment and care services
- Access to food and association with adherence to ART
- Mechanisms for dialogue across communities and health workers on treatment and nutrition issues

The results of the baseline are shown in Table 1.

Generally health workers had a far more favorable view of the situation than community members and PLWHIV on ALL indicators. PLWHIV rated the situation worse (by more than a small margin) than community members and health workers on a number of parameters, particularly on food adequacy. Further health workers and community members had a poorer view of the adherence behaviour of PLWHIV on treatment than they did themselves.

The results of the baseline indicated that

- Treatment services are generally perceived as moderately easy to access and knowledge of ART and adherence to ART to be moderate;
- Perceptions of food adequacy vary widely across groups, and food access is rated very low by PLWHIV;
- The view of whether people on treatment default was not uniform, with PLWHIV having a more favorable view than health workers and community members, but

all being somewhat ambivalent. Equally food was felt by many to be a factor in this;

- There was strong agreement that not having enough food leads people on treatment to fall ill;
- While health workers generally saw that there were adequate mechanisms and communication across groups for dealing with these issues, communities had a less positive rating of this and PLWHIV the least positive rating.

Table 1: Baseline Survey results: average ratings on the likert scale
(using a likert scale with 1= strongly agree to 5= strongly disagree)

Research Questions	**Results at Baseline survey**		
	Comm. members N=50	**Health workers N=30**	**PLWHIV N=50**
1. People in our community find treatment services for HIV and AIDS easy to access	1.9	1.2	2.2
2. People in our community generally have adequate food	3.7	2.1	4.1
3. People in our community who do not have adequate food get supplements from the clinics	3.1	2.0	3.9
4. People in our community who do not have adequate food are looked after by relatives or community members	3.0	1.8	3.7
5. People living with HIV (PLWHIV) in our community generally have adequate food	3.0	2.2	3.9
6. People living with HIV (PLWHIV) in our community understand how to take Antiretroviral therapy (ART) treatment for it	2.4	1.1	1.9
7. PLWHIV on treatment do not miss their appointments for ART treatment	2.5	1.8	2.0
8. PLWHIV on treatment often skip taking their pills for ART treatment	2.4	1.3	2.9
9. PLWHIV on ART treatment do not default on taking their treatment	2.7	1.9	2.4
10. Health workers in our community communicate well with people on ART treatment	2.5	1.0	2.0
11. Health workers in our community always advise people on ART treatment on what foods to eat	2.2	0.9	1.8
12. People on ART treatment generally have adequate food	3.2	2.2	4.1
13. Not eating enough food can cause people to feel ill when they take treatment for HIV	2.1	1.1	2.0
14.Not having enough food is a common reason for people stopping ART treatment	2.3	1.4	3.0
15. The barriers stopping PLWHIV from getting adequate food during ART treatment are being dealt with by health workers	3.1	1.9	3.7
16. communities and health services are working with other sectors and services to make food more available to PLWHIV	3.0	1.5	3.6
17. We have committees or mechanisms where communities and health workers discuss nutrition and ART treatment issues	2.7	1.3	3.3
18. Our community is taking action to improve access to food for people on ART treatment issues	3.0	1.7	3.3
19. Our health workers are taking action to improve access to food for people on ART treatment issues	3.3	1.5	3.4

20. Community members, especially women and health workers meet regularly to discuss ART treatment and nutrition	2.4	1.7	3.5

In the exit interviews and key informant interviews a number of issues were raised that help to further understand these findings:

PLWHIV generally understood their treatment programmes and nineteen of the thirty interviewed on exit interviews felt that since the prior PRA intervention (Ongala 2008) communication with health workers at the HIV clinic had greatly improved.

"It is now easier for me to explain myself and get medical care unlike before", said a participant. She added that, "The health workers even keep reminding us on what food to eat".

The greater difficulty PLWHIV have with accessing treatment services appears to be less related to geographical barriers than to their physical abilities, as many are weak. Getting to and from the clinics on empty stomach can cause PLWHIV to skip treatment appointment dates. For clients from remote Kokwanyo location, distance is a problem, with public transport only available on a Tuesday and Friday, being market days. This causes some patients from this area to miss clinic appointments, leading to poor treatment adherence amongst them. Those staying near and far from hospital facilities said that they were struggling to raise meals and saw gathering the necessary foods for a balanced diet as an expensive exercise. They were also not sure how to correctly compose a well balanced diet from locally available foods.

"Balance diet is something I take once in while because eating different types of foods is an affair I cannot afford."

PLWHIV Rachuonyo Distirct

In twenty six of the 30 exit interviews people felt that not having enough food is a common reason for people stopping ART treatment, citing problems in raising food for their families on daily basis. Food security has declined as food harvests have fallen in the area. Only people with low body mass index (BMI) are issued with food supplements in the local HIV clinics. Those that do obtain food supplements at the local HIV clinics said the amount issued is inadequate to cater for their needs, perhaps seeing it more as a full ration than a supplement. While some PLWHIV who have disclosed their status are benefiting from nutritional assistance given through support groups, others don't access this support due to non disclosure and stigma. Community members said that though HIV is less stigmatized in the health services, stigma is still high in the community and homes. Nearly all patients in the exist interviews said they feared sharing their HIV status with relatives, even when those relative have the potential to assist them, because most relatives in the area tend to abandon patients on realizing they are HIV positive. Relatives were also reported to be less likely to provide food support to ill people because extended family structures have greatly weakened.

"My own relatives are tired with me and none in the neighborhood is ready to give me food yet the food in the HIV clinic is issued only to thin people".

Patient, Exit interview

Community members and PLWHIV felt not enough was being done to address these nutritional issues, and some health worker key informants also recognized the challenges this posed to adherence:

"Many clients are coming to terms with positive living and are working hard to keep on drugs. Even bedridden clients are being assisted to take drugs by community health workers. However, we see a number of PLWHIVs hit by low food problem skipping drugs"

Health worker at Rachuonyo District Hospital HIV Clinic

Other health workers felt differently. They said that the community had adequate food, including clients and that clients with greater nutritional needs were being given food supplements at local HIV clinics, while others are being provided for by relatives or by community support groups. Some institutions, like the Adventist Development Relief Agency (ADRA), were reported to be working with the community to provide lunch programmes in local schools.

Yet community members raised the deteriorating food production generally in the area: Deteriorating soil fertility, increased cost of farm inputs and unreliable erratic rains were seen to have reduced harvests and low incomes to have limited choices on what foods to eat.

The baseline survey and interviews indicated that community members, local institutions, health workers and PLWHIV needed to identify how to effectively address such nutritional challenges in the division. While they are not seen to impact on the aggregate statistics of treatment programmes, they do affect access and adherence for some PLWHIV, and this appears to be greatest for those with least resources.

3.2 The PRA meeting

A four day meeting was held using PRA approaches to explore the nutritional needs and issues in the community relating to AIDS. As noted in the methods section, the participants included representatives of PLWHIV, health workers, CBOs, FBOs and NGOs, the Provincial Administration, the Kenya police, Ministry of Livestock and Agriculture, and the District Development Office.

On the first day we shared the situation and experiences of PLWHIV in relation to their treatment and food situation in Kasipul division. We used picture codes, case studies, brain storming and group discussions to capture participants' views regarding patients' situation in the division. The discussions pointed to a general situation of food insecurity, with PLWHIV particularly affected in terms of going without food and skipping treatment and drugs. PLWHIV are told to follow good diets with their treatment, but when they demand certain foods from relatives, the cost of these were reported to lead families and caregivers to neglect or abandon them, saying the patients are a liability.

The PRA session reinforced earlier information that PLWHIV when ill find searching for food and accessing treatment difficult due to weakness. It raised as a new issue the self perception of some clients with HIV as disabled, limiting their perception of their own role in raising food or income for themselves. Others lacked specific knowledge on what available foods make up a "balanced diet". The experience and perceptions raised in the

PRA session indicated a common misconception that expensive food is needed to gain good health, leading people to skip drugs when they do not obtain such foods.

A probe into historical patterns through focus group discussion explored how the community cared for ill people to learn from past experiences. Participants observed that ill people in the past belonged to the community, and were cared for through extended family structures, using locally available resources and indigenous medicine knowledge. There was thus greater emphasis on locally controlled community approaches. This was contrasted with the current situation, where individualism prevails and the paradigm has shifted to one of reliance on imported resources.

It emerged that a number of problems were affecting the situation

- Community level approaches had weakened and people were more dependent on individual resources, which were more limited;
- PLWHIV did not get adequate information on locally available health diets, had a false perception of what was needed for this when on treatment, and saw themselves as disabled dependents of support from elsewhere to obtain this.
- Health workers were providing information, but in a way that led people to misconstrue the information.

Health workers felt they were asking PLWHIV to eat "*a balanced diet made from locally available foods* " , and noted the fact that while some people were not eating, others were eating unhealthy foods thinking they were "dying soon".

One of the PLWHIV said, *"Something should be done to remove ambiguity that rises from phrases used during HIV clinic health talks. Or more and more PLWHIV are going to get confused as many are poor and are frustrated because they are not finding it easy to access ordinary foods let alone obtaining 'bulk and expensive ones; this is close to impossible'.*

Although Kasipul community has agriculturally productive land, participants pointed to the combination of farms lying fallow, poverty, inadequate cash for farm inputs and illness undermining labour as factors in poor food security for PLWHIV.

"I have eight people looking to me for food and up-keep yet I can not effectively feed myself let alone them. And lately, HIV infection has progressed to AIDs in my health making me too weak to work. As well I do not have income to hire labour to work on my farms."

PLWHIV Rachuonyo Distirct

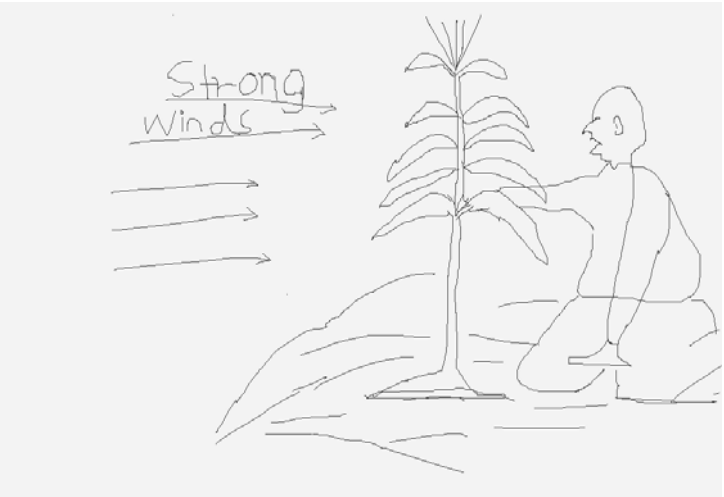
These economic factors are added to by social factors. The Kasipul community has strong cultural norms and women whose husbands die must go through widow inheritance rites before they are allowed to possess ancestral land or to cultivate them. Widows that resist this are denied access to family properties including land. For this reason, some widows move with their families from their marital homes to stay in the local market centers, where they engaging in sex for food and income as a survival strategy. The community's insistence on widow inheritance is a cultural driver that is linked to risk of both HIV infection and food insecurity.

Health workers noted that the food supplements cannot compensate the wider food shortages that exist due to these more structural determinants. The heavy reliance of PLWHIV who face food insecurity on local institutions providing nutritional support for food handouts and other livelihood support to survive was further discussed. In the wake of high poverty levels in the community, many patients share the food supplements they get with family members.

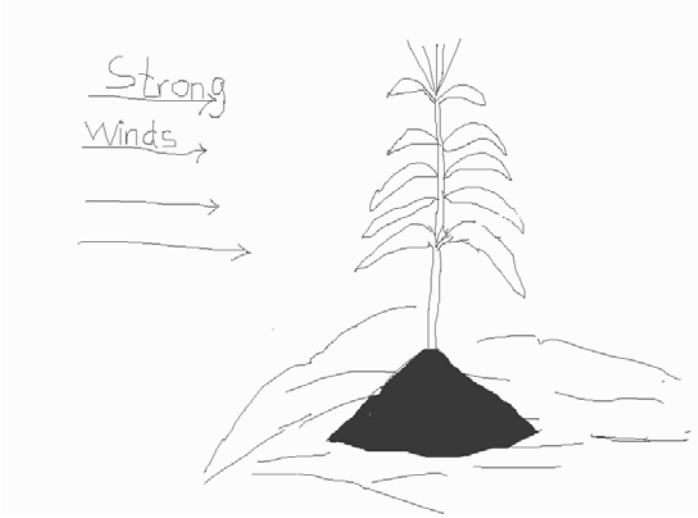
We used picture code shown in Figure 1 below to explore the nature of the approaches to the problem.

The discussion on the picture codes (not labeled when provided) raised a range of experience: For instance, for over three years one local non profit institution noted that it has been short listing households that are infected or affected by HIV and AIDS in the community and providing them with maize, beans, cooking oil and children's school uniforms yearly. Another initiative has been preparing meals twice a week for PLWHIV coming for group meetings. Participants felt that this has led to a small number of people being supported, heavily dependent on these inputs and thus vulnerable when they are withdrawn.

Figure 1: Picture codes on types of responses to food security challenges



A. Support based programmes
Source: Ongala, 2008



B. Empowerment based programmes
Source: Ongala 2008

"When I look around I see support programmes in our community serving only a limited number of people at a time and in short periods. I see most of them dying immediately the individuals or institutions that start them withdraw. Eventually their beneficiaries are left crying and sinking back to same past problems if not getting worse. This is unlike empowerment programmes that can benefit many at a time and can carry on with multiplication effect even after those that initiate them exit."

Community member, MANI Initiatives-Kamaga

The health workers commented that food supplements should be a bridge to longer term programmes that build sustainable food production. Others noted that the fragmentation of initiatives in the area also weakens longer term approaches, with institutions poorly connected and often responding to short term shocks. While valuable assistance for the immediate, the focus on financing of food relief after disasters with poor links across organizations or with wider production or household food support was observed to leave clients vulnerable to long term food insecurity.

The PRA meeting participants through discussion of the picture code characterized programmes they felt would be more supportive in the long term:

- Linking short term support to inputs to support longer term security;
- Bottom up instead of top down, owned among communities and
- With formal institutions that link and complement each others' work.

Empowering approaches were felt to start with the way PLWHIV and health workers communicate on nutritional in the treatment and care programmes. Through two role plays participants explored the issues around communication.

In brief:

In the first role play, a patient was telling a smartly dressed health worker how he had gone for days without food. The patient could not express himself well because he had uncontrolled coughing and was harassed to cut short his explanations and leave the room. The health worker seemed to fear that she would be infected through the coughs.

In the second role play a health worker listened keenly to an HIV positive patient. The health worker explored with the patient a range of options for improving their health, listening to what the client raised, and including nutritional aspects.

Participants observed that the first was not an unusual situation. Similar incidents were reported. Some participants empathized with the health workers, noting the conditions they work under. Others empathized with the patients. The second role play situation was seen to be rare in the local HIV clinics. While previous PRA work had improved communication, transfers out in the clinic health workers threatened to reverse these gains.

Participants exploring communication issues through role play
Source: Ongala J (2008), Kenya

Frequent transfers of staff were reported to undermine relationships with the community and trust with clients. For instance, the current and only Clinical Officer in Rachuonyo District based HIV clinic is the fourth staff member to serve in this capacity in the two years between 2007 and 2009, and three nurses had been replaced in the period.

"The rampant transfers of health workers lead to situations that are intimidating as the newly posted staffs are often unfamiliar with past progresses. They do not give patients ample time to share their health concerns with these health workers and so many clients leave the clinics dissatisfied and disappointed which is not good".

Community member, Umoja Christian Community Integrated Project -Sikri

Incoming health workers were seen to be unfamiliar with the reforms made in the clinics, or the patients' specific health needs and issues. The health workers also complained that they are increasingly overwhelmed with work because the local HIV clinics are congested with patients. They said the great amount of work in the clinics causes them to experience frequent burnouts that make them impatient and easily angered. The situation was seen to be responsible for the many incidences of tense communication. The lack of supportive interaction in the clinic setting was felt by participants in the discussion on the role plays to leave PLWHIV very isolated when they are also neglected by family. A community member said,
"Today many people with HIV are falling victims of fear of neglect by family members so even if they are going without food they suffer quietly. Others have food but are too weak to come out of bed yet they are without someone to prepare and serve them with meals. Eventually, they die not from the virus but from stress and hunger".

The responses to this situation were discussed through exploration of the experience triggered by discussion of a human sculpture depicting treatment programs at the clinics.
Participants raised through the discussion that:

PLWHIV team raising their views
Source: Ongala J. (2008), Kenya

- There was need for processes and mechanisms to bridge communication and build positive attitudes towards each other by health workers and PLWHIV.
- Health workers needed to be trained to build rapport with clients before providing them with care, to listen to patients. They need to explain to other patients if someone is seen ahead of turn.
- Health workers should debrief their colleagues to enable continuity and cut down on stress
- Clients should observe their clinic return dates and bring their follow up cards
- A more user friendly environment is needed at the clinics: Staffing, especially in government dispensaries, should be improved. Once clients pick their cards / numbers they should be able to wait in the sick bay and be seen in turn.
- There should be a referral system so that health workers can refer clients to other local institutions for further nutritional support.

It was felt that the clinic presents an entry point to build different practice, so that patients feel free to share their health concerns with health workers. Health workers in the meeting said plans were underway to expand the capacity of current HIV clinics and further decentralize HIV care services to other health facilities in the area. Participants felt that equal investment should be given to empowering PLWHIV towards positive living to optimize their treatment programmes.

The actions currently underway to strengthen access to food by PLWHIV and communities were identified through focus group discussion to include

- By PLWHIV, food vending, and in a more limited way, collective kitchen gardens to raise own food;
- By community members, food support interventions for sick people;
- By community based organizations and churches, food support, livelihoods training, training on income generation and referral across institutions;
- By health workers and care providers, nutrition education and counseling and food supplements to those with low body weight.

The local organizations providing this support were also identified.

Participants explored ways of strengthening the aspects of these initiatives they felt addressed longer term needs in a more empowering way. These generally related to a mix of awareness and information, collective networking such as through support groups; and psychosocial support. They also involved support for production of appropriate food crops and co-ordination across institutions working within the community. Various resource transfers were identified as important for these activities, such as inputs for kitchen gardens, or to support the activities of support groups namely, facilitating trainings, home visits, refills of Home based Care Kits (HBC), referrals and burials. It was noted that this did not need *new* organizations, but improved collaboration across existing organizations. Organizational mapping was used to explore the linkages that can be made between organizations acting on nutrition in PLWHIV on treatment.

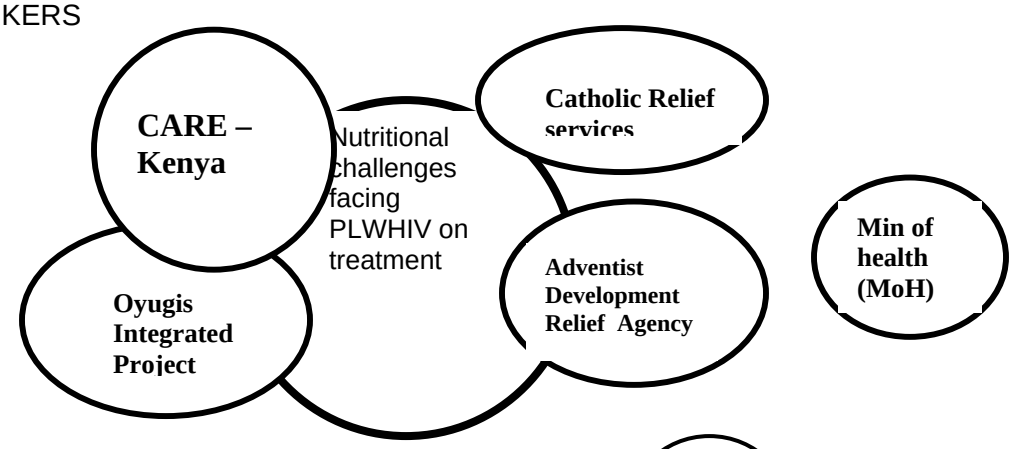
In three different groups namely health workers, PLWHIV and community people mapped the organizations, their cooperation (through overlap of circles) and their accessibility to clients (through their proximity to the central circle of PLWHIV.

Whereas the five circles were mapped around nutritional challenges facing clients in the area, overlapping circles indicate cooperation between or among the institutions handling nutritional issues. The separate circles show no linkage across roles, while circles far from the core PLWHIV circle means institutions are less accessible to clients. The maps indicate that while there are a number of institutions involved with nutritional issues for PLWHIV and in the community, they are poorly linked, lack a coordinating body, and potentially duplicate activities or leave gaps in coverage. In the community, PLWHIV heavily rely on their limited provision for nutritional support including food handouts and other livelihood support.

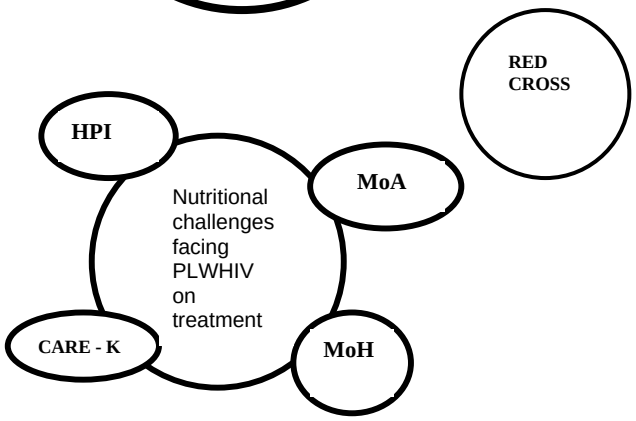
Exploring nutritional challenges around HIV and AIDs treatment
Source: Ongala J. (2008), Kenya

Figure 2: Institutional responses to nutrition in PLWHIV and their links
MoA = Min of Agriculture

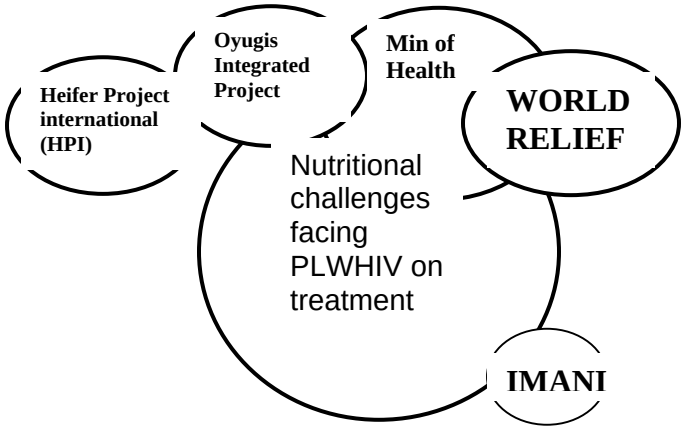
HEALTH WORKERS



PLWHIV



COMMUNITY



Hence while community access to AIDS treatment programmes and nutrition education and counseling has improved, the resources within communities is limited, weakening uptake. The poor linkages across institutions involved in nutritional issues at community level and short term strategies of these institutions, such as through food handouts, also

weakens the comprehensive PHC response. In addition to these community level constraints, PLWHIV were reported to be sharing foods provided with family members, who also face food shortages, while some live in isolation or face stigma and fear of discrimination, in part due to cultural norms, leading them to hide their HIV status to people or to local institutions that could help them overcome nutritional needs.

Reflecting on these experiences, participants resolved to implement a range of intersectoral responses to nutritional needs, including;

- Capacitating PLWHIV with nutritional knowledge and skills for longer term solutions;
- Working with community groups to mobilize resources for long term measures on nutrition;
- Encouraging organizations to widen their scope and include new activities to meet the longer term nutritional demands among food insecure PLWHIV and their families; and
- Ensuring community based programmes include greater involvement of the affected people.

3.3 The Action plan

Participants divided into three groups where they discussed the joint actions to be taken by communities and clinic workers to improve nutrition among PLWHIV on treatment. The action plan drew from the prioritized problems, ie nutritional needs of PLWHIV, and sought to address the key features of longer term responses to nutritional needs identified, ie

5. *Awareness and information*: through training and sensitization, feedback on nutritional needs of PLWHIV
6. *Collective networking* particularly through support groups and extending their role to nutrition support to remove isolation and related difficulties
7. *Psychosocial support: .*by including nutrition counseling into Community Health worker programmes *to help patients make informed choices on available local food, their processing and meal preparation*
8. *Support for production;* through self help groups mobilizing resources for nutrition for establishing kitchen garden, poultry keeping and market gardening

Participants developing joint steps to address food problems among PLWHIV in the area
Source: Ongala J. (2008)

Participants set up joint action plan as indicated in the tables below:

Table 3: Joint action plan developed in the PRA process

Date	ACTIVITY	OBJECTIVES RESPONSIBLE PERSONS
Aug to Nov. 2008	Strengthening the focus on nutritional issues in ART adherence counseling	Ministry of health; Community health workers; private clinics, peer counselors
Aug to Oct. 2008	Mobilizing and sensitizing PLWHIV to join / start new support groups to increase awareness on nutritional needs and issues for self reliance	RHE, Divisional Task Team on Plan of Action (DTTPA), Ministry of health; Community health workers; PLWHIV, Community groups
Oct 2008	Training PLWHIVs on sustainable agriculture for own consumption and commercial purposes	Divisional Task Team on Plan of Action, Ministry of agriculture; Ministry of labour
Oct 2008	Training CHWs as nutrition counselors among PLWHIV on nutrition and counseling	Divisional Task Team on Plan of Action, Ministry of health;
Aug and Sept 2008	Conducting local and international fundraising for providing for realizing the above said needs	Divisional Task Team on Plan of Action, Ministry of health; Provincial administration, District Development Office

In implementing these plans, six "progress markers" participants felt they must achieve were;

- Participants institutions having increased knowledge about nutrition needs among PLWHIV
- Adherence counseling including a focus on nutritional issues
- Increased knowledge of nutrition values among patients with HIV
- Increased number of support groups and involvement of individuals from the community
- Increased capacity for resource mobilization with a focus on nutrition to self help groups
- Increased ability to provide nutritional counseling among CHWs and caregivers

Participants also felt they would like to achieve some further progress markers, but may not expect to in the period;

- Increased coordination and reduced duplication of activities through a body set up of PLWHIV to address nutritional issues
- Improved quality of food taken by patients with correct composition of balanced diet through standardized approach in self help groups and community health worker (CHW) support;
- Increased information on HIV and AIDS to communities, with reduced fear, stigma and discrimination
- Increased disclosure of HIV status to people in local institutions to stimulate increased support for nutritional needs; and
- Increased food security among participating institutions through continuous training on small group management.

4. Implementation of the actions

A Divisional Task Team on Plan of Action (DTTPA) incorporating the suggested actions guided the implementation of the joint plan of actions in the ensuing four months.

During that period, health workers stepped up adherence counseling with a focus on nutrition to help PLWHIV address nutritional needs and issues. They provided clients with literature on optimizing nutrition and involved selected PLWHIV as peer educators to share experiences on nutritional issues and needs during clinic health talks. The problem of understaffing and limited funding at the clinic hindered the health workers from carrying out follow up among patients. Nevertheless, health workers provided community health workers with training on basic principles of nutritional counseling, including listening, empathizing, exploring options, guiding to take actions to help make informed choices to help them strengthen follow up of clients during home visits.
The teaching and counseling was changed from a 'eat good food' message to clearer shared messages advocating consumption of locally available nutritious foods such as amaranth, goat milk, guavas, pumpkin and pumpkin leaves, and eggs.

The health workers linked with United Nations Children's Fund (UNICEF) and ensured bulk food support for distribution to all local HIV clinics free of charge. Patients with low body mass weight were issued with the supplements to help increase their weight, but contrary to the previous arrangement where health workers gave food supplements based on the individual, the new portions were based on household size. DTTPA members and representatives from the wider implementing body educated households in the community on the significance of the food supplements. They encouraged them to restrict distribution of food supplements to patients to enable them grow strong and gain weight as a health requirement. Despite this increased share, in the context of extreme poverty, many clients shared the supplement with their wider extended families, limiting the amount for themselves.

The health workers linked clients to civil society organizations to establish support groups at village, location, division, district levels. Seventy two people from different local groups were trained on palliative care and nutrition with support from local services and organizations. Health workers worked with PLWHIV to constitute a special body for PLWHIV to address nutritional issues. In this group, PLWHIV registered with Kshs 50 to register the group with the government authorities and open a bank account to resource support activities. Over the period 400 patients joined support groups and 36 new groups were formed. The support groups in the period encouraged PLWHIV to share experiences and situations and engaged local organizations on their nutritional concerns. They held joint dialogue with representatives from local institutions to widen their nutrition support programmes, and held exchange programmes to encourage new practice, for clients to explore how others were addressing nutrition in more sustainable ways, such as in demonstration farms.

One PLWHIV said, *"Joining support groups gave me greater visibility besides empowerment and I think I am now ready to live more positively with HIV".*

During the intervention period, members of the Provincial Administration set up a working committee, and with support from a German NGO (Agroaction) distributed vouchers for farm inputs and poultry to over 600 households. Although the programme targeted internally displaced persons, a majority of beneficiaries were PLWHIV. The shift to distribution of farm inputs, and start up capital over food handouts to PLWHIV able to work was a longer term approach to food security. However funding limitations meant that they only reached about 27 000 people.

Community organizations also played a role. One community organization, Umoja Christian Community Integrated Project (UCCIP), trained PLWHIV affiliated to their organization to plant a range of highly nutritious vegetables and food crops for food and income. By end of implementation period, PLWHIV were beginning to harvest fresh nutritious food from these initiatives and to sell surplus in their neighborhood. Similarly another, Oyugis Integrated Project (OIP) gave PLWHIV farm inputs and not food handouts in the intervention period, particularly for those who had regained strength and were back to active life in the community. Their clients prepared crops and had harvested adequate foods and generated income to their households. Another, Imani Initiatives, started a Tomato Production Project in green houses. By end of the period under review, they had registered clients in groups of ten, asked them to choose their leaders, pay fee for water connection and started work in farms. They expected this strategy to generate income for establishing a food bank for their clients.

A participant from the United Christians Community Integrated Project (UCCIP) said, *"In the period under review, we combated the food crisis by giving weak PLWHIV food handouts, while involving the stronger ones in establishing and scaling up their garden work to reduce dependency problem and our efforts are bearing fruits".*

While the food supplements were expected to benefit patients and family members, during the actions new issues were raised, including by PLWHIV, about how the needs of people with other health conditions experiencing nutritional stress would be dealt with and the fairness of targeting one group. As raised by one of the PLWHIV: *"It is interesting that poverty is biting almost all of us (PLWHIV) in the area yet health workers are employing a discriminatory approach to distribution of food supplements at the clinic. For instance, they are giving only a section of us (PLWHIV) food supplements that they eat and share with their relatives. If you can reach non-patients with the supplements, why not target all patients? Are you not reading discrimination here yet everyone is pinched by food crisis?"*

5. Follow-up assessment

In November 2008 a workshop was held with the same participants as those who were involved in the first PRA workshop to evaluate the programme outcomes using discussion and progress markers.

Table 4: Participants assessment of goals set as things that "must" be achieved

Activity	Highly	Achieved	Less	Not

	Achieved		achieved	achieved
Participants institutions informed about nutrition needs among PLWHIV	X			
Increased knowledge on nutrition and local foods in PLWHIV		X		
Increase number of and involvement in support groups around nutritional issues		X		
Increased capacity for resource mobilization for nutrition in self help groups			X	
Increased ability of PLWHIV and CHWs to implement nutrition counseling	X			

The outcomes relating to feedback, mobilization, and integration of nutrition into existing activities were achieved to a greater degree than those relating to new activities related to training, resource mobilization or support groups. Yet most activities had commenced despite the short time period for the plan, and were planned to continue. Those involved had begun to see changes and themselves were changing their perceptions, giving some optimism for the activities being sustained.

A health worker said, *"Today we see great cooperation from the community and more groups are partnering with us to address community health concerns".*

The limits to achieving the plans were identified as mainly financial, administrative, and technical. Lack of resources particularly affected training activities. Not surprisingly, fewer of the things people said they would *like* to achieve were done than those "must do" activities shown earlier (see Table 5).

Table 5: Participants assessment of goals that they would "like to" achieve

Activity	Highly Achieved	Achieved	Less achieved	Not achieved
Increased coordination of activities on PLWHIV nutritional issues				X
Improve quality of food taken by patients through standardization in self help groups	X			
Increased information on HIV and AIDS, reduced fear, stigma and discrimination and increased disclosure of HIV status		X		
Increased production of foods for improved diets among PLWHIV, supported by CHWs		X		
Increased local food security backed by continuous training support				X

The organization of PLWHIV and interactions through exchange visits and follow up were easier to achieve than changes to operating procedures of groups or training, particularly as limited resources could be mobilized in the relatively short time period. Individual support groups started working closely with local and international organizations to address nutritional concerns in line with the DTTPA plan for joint approaches.

Co-operation across sectors was however strengthened in the period, with the District Development Office (DDO) liaising with the Ministry of Gender, Sports and Cultural

Services to give support supervision and encourage exchange programmes amongst local groups. The exchange programs sometimes faced a limit in the ability of PLWHIV to travel for health reasons.

While participants to the process thus saw improvements in the actions and outcomes they had set, with a shift towards more locally generated, longer term strategies for nutrition support, we also repeated the baseline survey in the same people as we did during initial survey to assess how far perceptions of nutrition outcomes for PLWHIV had shifted (See Table 6).

Generally health workers view of the situation had changed significantly, with a less favourable rating after and a rating that was closer to that of community members and PLWHIV. This was a major shift and indicated that the exercise had exposed the health workers to the realities of these other groups. This is important for bringing groups together around shared plans.

The PLWHIV still generally rated the situation worse than community members and health workers on a number of parameters, but far less so than in the baseline. Of importance, there was a high level of similarity across all groups in the rating of access to food and on adherence behaviours of PLWHIV.

The follow up survey indicated that

- Treatment services are still generally perceived as moderately easy to access and knowledge of ART and adherence to ART to be moderate without much change in this respect;
- Perceptions of food adequacy are now similar across groups, and there has been an improvement in perceived food access in the community and in clinics by PLWHIV;
- The views of whether people default from treatment were now more uniform across groups, although all groups had a less favourable view of this issue after the intervention. Food was felt to be a factor by a similar as in the baseline.
- There was improvement across all groups in the perceived availability of mechanisms and presence of communication across groups for dealing with these issues, and PLWHIV ratings showed the most significant change towards perceptions of improvements.

PLWHIV team putting their views together
Source: Ongala J. (2008)

In the discussion of the findings it was noted by the team that these efforts are still only benefiting a limited number of PLWHIV and that addressing stigma to enable disclosure and links to support groups and nutritional support needs an expanded coverage of such interventions.

Table 6: Final Survey results: average ratings on the likert scale
(using a likert scale with 1= strongly agree to 5= strongly disagree)

Research Questions	Results at Baseline survey			Results in second survey			
	Comm. Members N=50	Health workers N=30	PLWHIV N=50	Comm. Members N=50	Health workers N=30	PLWHIV N=50	
1. People in our community find treatment services for HIV and AIDS easy to access	1.9	1.2	2.2	1.5	1.2	2.7	
2. People in our community generally have adequate food	3.7	2.1	4.1	3.5	3.4	3.3	
3. People in our community who do not have adequate food get supplements from the clinics	3.1	2.0	3.9	3.1	3.0	3.1	
4. People in our community who do not have adequate food are looked after by relatives or community members	3.0	1.8	3.7	3.4	3.4	2.7	
5. People living with HIV (PLWHIV) in our community generally have adequate food	3.3	2.2	3.9	3.8	4.0	3.9	
6. People living with HIV (PLWHIV) in our community understand how to take Antiretroviral therapy (ART) treatment for it	2.4	1.1	1.9	1.7	2.0	2.6	
7. PLWHIV on treatment do not miss their appointments for ART treatment	2.2	1.8	2.0	3.1	2.8	3.0	
8. PLWHIV on treatment often skip taking their pills for ART treatment	2.4	1.3	2.9	2.7	3.0	3.1	
9. PLWHIV on ART treatment do not default on taking their treatment	2.7	1.9	2.4	2.7	4.4	3.0	
10. Health workers in our community communicate well with people on ART treatment	2.5	1.0	2	2.0	2.0	2.0	
11. Health workers in our community always advise people on ART treatment on what foods to eat	2.2	0.9	1.8	1.5	2.2	1.4	
12. People on ART treatment generally have adequate food	3.2	2.2	4.1	2.2	3.2	3.1	
13. Not eating enough food can cause people to feel ill when they take treatment for HIV	2.1	1.1	2.0	2.2	2.0	2.3	
14.Not having enough food is a common reason for people stopping ART treatment	2.3	1.4	3.0	2.4	2.0	3.0	
15. The barriers stopping PLWHIV from getting adequate food during ART treatment are being dealt with by health workers	3.1	1.9	3.7	3.1	3.4	2.9	
16. communities and health services are working with other sectors and services to make food more available to PLWHIV	3	1.5	3.6	2.1	2.4	2.1	
17. We have committees or mechanisms where communities and health workers discuss nutrition and ART treatment issues	2.7	1.3	3.3	1.8	2.6	1.9	
18. Our community is taking action to improve access to food for people on ART treatment issues	3	1.7	3.3	2.4	1.4	2.0	
19. Our health workers are taking action to improve access to food for people on ART treatment issues	3.3	1.5	3.4	2.0	3.0	1.7	
20. Community members, especially women and health workers meet regularly to discuss ART treatment and nutrition	2.4	1.7	3.7	2.1	3.4	3.4	

"*Indeed stigma is still high in the villages which worrying but as, PLWHIV that form or join support groups will soon reap dividends their testimonies will definitely motivate many PLWHIV to see need to join the existing groups to the betterment of their lives."*

Community leader, Kowidi Location

Health workers, PLWHIV saw the support groups and community health workers as key to this expansion and to addressing the information, communication and outreach needed to improve responses to nutritional needs during treatment. The perception of continued default due to food reflects the longer term, and deeper action needed to make real sustained improvements in access to food for people on ART treatment against the background of wider drivers of food insecurity. Nevertheless the shared appreciation of this issue and its integration across a spectrum of areas of intervention (counseling, support, information, production, income support) have provided a beginning to a longer term approach than what was found to be poorly understood messages and short term supplements taking place before the intervention.

"We still do not benefit from food from out side because we are too weak to fight for food in the market yet current prices are too high for us. We are hoping the market supply will increase to reduce the scramble as well as lower food costs".

PLWHIV West Kamagak

Beyond this more limited intervention, support groups may thus also begin to work towards wider production goals, including as reputable suppliers to local markets and to link specific initiatives to support PLWHIV to wider initiatives that seek to develop local farm products and markets.

6. Learning on Primary health care responses to AIDS

6.1 Learning on PHC responses to AIDS

This work indicates that expanding access to treatment services needs to be embedded within a wider framework of wider health support, including the intersectoral action to address food needs, if availability is to translate into effective coverage. Not having enough food was a common reason for people stopping ART treatment, and nutrition is in any event a major factor in health and immune status. With declining food security due to environment and market factors, there is need to move beyond short term emergency responses to secure nutrition in people in lifelong ART. Nutrition support is a vital element of the chronic care and health management strategies needed for PHC responses to AIDS. This includes shifting perception of PLWHIV from that of disabled dependents of emergency support to people able to know and address their nutritional needs through local food resources.

The actions taken in this PRA process to support more locally generated, longer term strategies for nutrition support were found to support such a shift over a relatively short period, although they need to be tested over a longer term for their sustainability and longer term impact. They included

- *Awareness and information*: through training and sensitization, feedback on nutritional needs of PLWHIV
- *Collective networking* particularly through support groups and extending their role to nutrition support to remove isolation and related difficulties
- *Psychosocial support: .*by including nutrition counseling into Community Health worker programmes *to help patients make informed choices on available local food, their processing and meal preparation*
- *Support for production;* through self help groups mobilizing resources for nutrition for establishing kitchen garden, poultry keeping and market gardening

For health services this implies

- Recognising the central role that nutrition plays in ART programmes and integrating nutrition monitoring, counselling and support into all treatment programmes and community level outreach;
- Integrating into nutritional education and counseling specific information to encourage production and consumption of nutritious local foods, avoiding generalizations like "good quality diets" that may mislead;
- Encouraging community organizations to co-ordinate and shift from short term vertical responses to food needs to support for longer term strategies that enhance food security;
- Integrating nutrition and food access into support group activities to stimulate and negotiate for collective actions to support vulnerable groups and recovery;
- Stimulating exchange programmes around nutrition needs to reduce stigma and promote good practice driven from community level, with support from services and local organisations.

6.2 Learning on PRA

Participants said the PRA work opened their eyes to methods for developing sustainable community based programmes because it started and ended with the people. They indicated that they would use participatory approaches to intensify the implementation of intersectorally responses to nutritional needs among PLWHIV. Others felt that PRA approaches created more empowering relations between the community and health workers.

"We are now applying PRA approaches in all our community programme because it enhances our voices and participation right from the bottom to the top. In fact PRA is helping us to put little recourses in one end of programmes while gaining much on the other end".

A community member, East Kamagak

"PRA process has helped to remove power barriers that existed between us, health worker and other State argents. From now, I feel strong enough to use PRA approaches to empower fellow community members to demand for services from health workers and other government personnel".

PLWHIV, Kowidi

The approach is nevertheless demanding, requires quick thinking and takes time to build consensus.

6.3 Next steps

We see a need to further develop this work as part of strengthening comprehensive primary health care oriented health systems in the community.

Participants in the process themselves identified the need to continue with ;

- Continuous health education on the importance of nutrition and ART uptake.
- Encouraging PLWHIV to form or join exiting support groups.
- Networking with one another and do follow-ups
- Conducting adherence counseling with a focus on nutritional issues and
- Mobilizing resources for proposed trainings

This signals the understanding that such processes are not events but long term and consistently repeated processes if they are to achieve change.

Some of the participants from the second PRA workshop
Source: Ongala J. (2008)

They also felt there was need to initiate:

- Incorporating Ministry of Agriculture on new farming techniques including bee keeping and growing of Amaranth for food and income
- Mobilizing pregnant mothers and HIV exposed children for Voluntary counseling and testing
- Local production of foods for supplementary, including for distribution among PLWHIV
- Training of CHWs on nutrition and counseling and strengthen reporting among them

The representative from the District Development Office (DDO) said, his office looked forward to working with stakeholders to continue implementing the joint Plan of Action saying the pandemic will not stop spreading in the community until AIDS is fully uprooted. At the same time participants were challenged to think beyond the box and to see these initiatives as having much wider production and market impact. The District Nutrition Officer equally supported the ingoing work and also pointed to the potential of the foundation laid to widening the lens on it. For example he referred to a co-operation between an international and local institutions for local production of yoghurt of nutritional benefit both to PLWHIV and malnourished children, with wider income generating benefit to the community. These wider potentials resonate with the history of health support in the area through local community networks and resources raised earlier. They also link the nutritional dimension of Primary Health Care responses to AIDS with approaches that strengthen local control of food production and marketing, an important wider determinant of health.

References

1. Fieser R. (2007), Facing A Food Crisis in Haiti http://www.crs.org/haiti/food-crisis-protests/ , accessed 2nd December 2008)
2. International Treatment Preparedness Coalition (ITPC) (2006) Missing the Target, ITPC, USA accessed at http://209.85.229.132/search?q=cache:7t6bIIAFV7UJ:www.aidstreatmentaccess.org/itpcupdatefinal.pdf+kenya+AIDS+treatment+access&cd=1&hl=en&ct=clnk&gl=uk May 2009
3. Kaiser Foundation (2006) The HIV / AIDS epidemic in Kenya, Kaiser Foundation, USA at http://www.kff.org/hivaids/upload/7356.pdf accessed May 2009
9. 4. Markar M. (2008), Health-Asia: Nutrition Is Key to AIDS Treatment Say Experts http://ipsnews.net/news.asp?idnews=39646 accessed 30th March 2009Ministry of Planning and National Development (2002), 'Rachuonyo District strategic Plan 2005 – 2010 for implementation of the Nation Population Policy for sustainable Development'. Ministry of Planning and National Development, Nairobi , Kenya
10. NASCOP (2008), Home and Community Based Care for People Living with HIV/AIDs; An Implementation Framework for Home and Community Based Care in Kenya, Ministry of Health, Nairobi Kenya.
11. National Coordinating Urgency for Population and Development (2005), District Strategic Plan 2005 – 2010 for Implementation of the National Population Policy for Sustainable Development, Ministry of Planning and National Development, Nairobi Kenya
12. Ongala J (2008) Strengthening communication between people living with HIV and clinic health workers in Kasipul Division, Kenya, EQUINET PRA paper, KDHSG Kenya, EQUINET, Harare
13. Pambazuka (2008), Criminalization HIV transmission will increase women's risk to violence, Pambazuka News, http://www.pambazuka.org/en/category/hivadis/52373 accessed 2nd December 2009
14. UNAIDS (2008) 2008 Report on the global AIDS epidemic, UNAIDS Geneva accessed at http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp accessed May 2009
15. WHO (2005), AIDS treatment, nutrition and food supplements, Fact sheet, http://www.who.int/3by5/mediacentre/fsFood/en/ (Date accessed 30th March 2009)
16. WHO (2007), Significant Growth in Access to HIV Treatment in 2006.http://www.who.int/mediacentre /news/release/2007/pr16/en/index.htnl(25th May 2009)
17. WHO (2008), Globalization and health, United Nations General Assembly, unu.edu/globalization (Date accessed 30th March 2009)

Acronyms

APHIA II	- Aids Population and Health Integrated Assistance Programme II
CHW	- Community Health Workers
DTTPA	- Divisional Task Team on Plan of Action
DDO	- District Development Office
EQUINET	- Regional Network for Equity in Health in Eastern and Southern Africa
HIV	- Human - Immuno - Virus
IGAS	- Income Generating Activities
KDHSG	- Kasipul Division Home based care Stakeholder Group
MOH	- Ministry of Health
OVC	- Orphans and Vulnerable Children
OIP	- Oyugis Integrated Project
PLWHIV	- People Living With HIV
PRA	- Participatory Reflection and Action
RHE	- Rachuonyo Health Equity
TARSC	- Training and Research Support Center
UCCIP	- Umoja Christian Community Integrated Project
WHO	- World Health Organization

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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

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