



Integrating Nutrition Security with Treatment of People Living with HIV: Lessons being Learned in Kenya

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Abstract

The broad objective of this study is to highlight key constraints, opportunities and challenges relating to interventions aimed at strengthening the nutrition security of people living with HIV who are on antiretroviral (ARV) treatment. The research took place under the auspices of the Academic Model for Prevention and Treatment of HIV/AIDS (AMPATH). AMPATH cares for over 27,000 people living with HIV and AIDS (PLWHA) in western Kenya, of which just over fifty percent are on ARV treatment. A short-term nutrition intervention linked to the provision of free ARV treatment was initiated in 2002. Viewing this intervention from a broader perspective of nutrition security, the paper identifies programmatic lessons and challenges to linking nutritional and other comprehensive support services with ARV treatment in a resource poor setting. Qualitative research was conducted between December 2005 and early 2006. Twenty key informant interviews, 9 focus group discussions, and 79 in-depth interviews were undertaken with a sample of patients who have either participated or not participated in the food program.

Lessons learned include the following: The intervention provides an important source of food support to the most vulnerable patients on treatment and their households, contributes to greater dietary diversity, and plays an important role in the emotional well-being of clients by lowering stress caused by insufficient access to food. Many patients in the supplementation program also self-report recovery of physical strength that allowed them to return to productive life and greater adherence to treatment. Observable improvements in patients' nutritional and health status acted as a catalyst for increased support from family and community. The main opportunity costs of participation in the program are transport and stigma associated with collection of food supplements. The implementation of enrollment criteria has posed many challenges to program staff, particularly in determining eligibility of cases that fall near enrollment guideline cut-offs.

Several programmatic challenges and recommendations emerge from this study. Weaning or transitioning clients off food supplementation is the biggest programmatic challenge facing this and similar nutrition interventions; yet it is one of the most important program components if short-term nutritional, health, and productivity gains are to be sustained. Criteria to determine a patient's ability to transition off food support need to be better clarified among both program staff and patients. Greater attention should be placed on i) seasonal changes in both the need for support and the ability of existing informal networks to adequately respond, ii) stigma which, though declining, remains an obstacle to many HIV positive individuals accessing support, and iii) assuring the link between short-term nutritional support and longer-term household nutrition security. Post-intervention monitoring systems should be put into place. This research further demonstrates the need to promote linkages with local, national, and international partners. Finally, an economic evaluation of the cost-effectiveness of the intervention should be undertaken to allow for future planning.

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The research took place under the auspices of the Academic Model for Prevention and Treatment of HIV/AIDS (AMPATH). This study was developed and supported by RENEWAL – the Regional Network on HIV/AIDS, Rural Livelihoods and Food Security -- coordinated by the International Food Policy Research Institute (IFPRI). We gratefully acknowledge core support provided to RENEWAL by USAID, the Rockefeller Foundation, the Swedish International Development Cooperation Agency (SIDA) and the International Development Research Centre (IDRC). We would also like to thank USAID Food for Peace for additional funds to support this study.

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Integrating Nutrition Security with Treatment of People Living with HIV: Lessons being Learned in Kenya

Introduction

The objective of this study is to examine the ability of a nutritional intervention to improve both the nutritional status of patients on antiretroviral (ARV) treatment and their household resilience to the shock of a chronically ill adult member. We consider the intervention within the broader perspective of nutrition security in the context of HIV and AIDS. The research took place under the auspices of the Academic Model for Prevention and Treatment of HIV/AIDS (AMPATH). This study was developed and supported by RENEWAL¹ – the Regional Network on HIV/AIDS, Rural Livelihoods and Food Security, coordinated by the International Food Policy Research Institute (IFPRI). AMPATH cares for over 27,000 people living with HIV (PLHIV) in western Kenya, of which just over 50 percent are on ARV treatment. A nutrition intervention linked to the provision of free ARV treatment was initiated in 2002. The current intervention is designed to bolster nutrition security of the most vulnerable patients on ARV treatment over a short period of time. Using AMPATH's nutrition intervention as a case study, this paper identifies programmatic lessons and challenges to linking nutritional and other comprehensive support services with ARV treatment in a resource poor setting.

Nutrition security is achieved for a household when secure access to food is coupled with a sanitary environment, adequate health services, and adequate care to ensure a healthy life for all household members. While interventions that link nutritional support to AIDS treatment are relatively new, donors, program implementers, and clinical care providers are increasingly recognizing the critical importance of integrated programming that provides services beyond clinical care for HIV-positive individuals.² The multiple impacts of HIV and AIDS on individuals and households continue to challenge development policy and programming. Here we assess the interaction of a formal nutrition intervention with individual, household, and community responses to the needs of patients on ARV treatment -- to better understand how such a formal intervention fits into the web of available informal support.³ As with other forms of food aid, issues of enrollment criteria, targeting efficiency, and transitioning off support pose challenges to program design and implementation. Using data collected by qualitative research methods, we analyze observations and perspectives from patients and other key stakeholders on the impact of the program, identify constraints facing program implementers and beneficiaries, and highlight

¹ We gratefully acknowledge core support provided to RENEWAL by USAID, the Rockefeller Foundation, the Swedish International Development Cooperation Agency (SIDA) and the International Development Research Centre (IDRC). Additional funds for this study were provided by USAID Food For Peace.

² Three recent examples: i) World Health Assembly resolution WHA57.14 passed in 2005 "*urged Member States, as a matter of priority, to pursue policies and practices that promote, inter alia, the integration of nutrition into a comprehensive response to HIV/AIDS*"; ii) the Africa Forum 2006 *Declaration on the Dual Epidemics of HIV and AIDS and Food Security* calls for the scaling up of effective integrated programming to improve food and nutrition security for those affected by HIV and AIDS, and iii) the June 2006 UN General Assembly Political Declaration on HIV/AIDS where UN member states "*resolve to integrate food and nutritional support, with the goal that all people at all times will have access to sufficient, safe and nutritious food to meet their dietary needs and food preferences, for an active and healthy life, as part of a comprehensive response to HIV/AIDS*" (UNGASS 2006).

³ Informal support is broadly defined here as support originating from social networks and traditional safety nets. Existing social support networks can be thought of as informal in that they are activated when needed, often involve informal transfers between households and individuals, and may be subject to seasonal stresses. Formal support refers to more structured and often externally originating sources of assistance.

some of the future challenges to an integrated approach to meeting the needs of PLHIV. This study contributes empirical data to the growing evidence base on the interactions between nutrition and ARV treatment – evidence that is essential for moving forward with the provision of comprehensive treatments, linked as appropriate to targeted nutrition interventions, and underpinned by enabling policy.

Background

Nutrition and immunity in HIV-positive individuals can interact in two ways. First, HIV-induced immune impairment and heightened subsequent risk of opportunistic infection can worsen nutritional status. HIV infection often leads to nutritional deficiencies through decreased food intake, malabsorption and increased utilization and excretion of nutrients, which in turn can hasten death (Semba and Tang 1999). Second, nutritional status modulates the immunological response to HIV infection, affecting the overall clinical outcome. Immune suppression caused by malnutrition is similar in many ways to the effects of HIV infection (Beisel 1996). Thirty-eight years ago, research started to shed light on this “malnutrition-infection complex” with the term “NAIDS” (Nutritionally Acquired Immune Deficiency Syndrome) being coined (Scrimshaw, Taylor, and Gordon 1968).

While these interactions are underway within the bodies of individuals infected with the virus, households with a chronically ill adult member face progressive threats to their livelihoods (Donovan et al. 2003; Yamano and Jayne 2004; Shah et al. 2001; Barnett et al. 1995). Subsequent deterioration in household food security can in turn jeopardize not only the nutritional status of the ill member but also the nutritional security of others in the household. Reduced income, increased expenditures (on health care and transport etc), loss of labor productivity, and more time being reallocated away from production to caring for sick members, can all cumulatively precipitate and exacerbate household food insecurity. Such interactions are now well documented (see Gillespie and Kadiyala 2005 for a review, and Gillespie 2006).

Returning to the individual level, according to WHO, asymptomatic PLHIV are recommended to increase energy intake by 10 percent while symptomatic individuals should increase their intake by 20-30 percent (WHO 2003). People on ARV treatment in resource poor settings may lack access to sufficient quantity and quality of food to complement their treatment, offset side effects, and encourage adherence. Castleman, Seumo-Fosso, and Cogill (2004) highlight the importance of all PLHIV maintaining adequate food consumption and nutrition intake levels regardless of whether they are taking ARV treatment. Research has shown that independent of ARV treatment, weight loss remains a predictor of mortality in HIV-infected individuals (Tang et al. 2002; Mangili et al. 2006). There is now clear evidence that malnourished individuals starting ARV therapy are far more likely to die in a given period than well-nourished individuals (Paton et al 2006). Research is also underway to investigate whether nutritional support of asymptomatic HIV-positive individuals may delay the need for ARVs.

Highly Active Antiretroviral Therapy (HAART) improves nutritional status, though some side effects such as nausea, vomiting and dizziness – which are often worse for malnourished individuals – may affect adherence in the early months of treatment (Chen et al. 2003). Compromised adherence may in turn lead to the development of widespread drug resistance and the need for a whole new regimen of second line drugs that are significantly less accessible and affordable than first line regimens.

In sum, increased caloric requirements for HIV-positive individuals, undesirable side effects of treatment that may be worsened by malnutrition (but alleviated by nutritional support), and the consequent threats of declines in adherence and increased drug resistance, are all justifications for developing more and better interventions to strengthen nutrition security of individuals on ARV treatment. Such urgency applies to any context where malnutrition and high or rising HIV prevalence coexist.

While more operations research is clearly needed to understand how such interventions are working and how to improve them, there is now growing interest⁴ in linking nutritional support to AIDS treatment programs.

AMPATH's Nutrition Intervention

AMPATH's nutrition intervention is one of a limited number of innovative programs aiming to provide comprehensive treatment and care services to HIV-positive people in East Africa.

AMPATH began providing HIV preventative and treatment services in 2001.⁵ The program was established as a partnership between Moi Teaching and Referral Hospital, Moi University Faculty of Health Sciences, and Indiana University School of Medicine. There are currently 14 treatment and care centers in the western part of Kenya (North Rift Valley, Western, and North Nyanza Provinces) where patients receive treatment and care at Ministry of Health facilities. AMPATH's approach to care for PLHIV is multidisciplinary involving teams of physicians, clinical officers, nurses, nutritionists, pharmacists, social workers and outreach workers.

In the early stages of AMPATH's treatment program, it became apparent that the majority of HIV-positive patients were malnourished. Several reasons were cited: most importantly a lack of access to food, poor appetite and poor preparation of food (Siika et al. 2005). In 2002, a project to provide supplementary food to AMPATH patients was initiated through the HAART and Harvest Initiative (HHI) in response to poor nutritional status and access to food among many of the initial AMPATH patients placed on ARVs. The program established production farms in close proximity to four of AMPATH's treatment sites (one urban and three rural sites) enabling the provision of locally acceptable, nutritionist-prescribed food for any registered AMPATH patient found to be malnourished and food insecure. It was determined from the inception that food rations would be based on household size rather than just the individual patient. HHI farm production includes eggs, milk, fresh fruits and vegetables,⁶ as well as local and exotic herbs (Siika et al. 2005). The farm also purchases food from local markets and patients who are not on food supplementation to augment its supply for distribution to program clients.

In June 2005, AMPATH's food supplementation program expanded when the World Food Program (WFP) began donating enough food to meet 50 percent of the daily caloric requirement

⁴ In addition to the three policy declarations listed earlier, both the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria (GFATM) and the US President's Emergency Plan for AIDS Relief (PEPFAR) have recently developed nutrition guidelines or strategies (see OGAC 2006). The role of nutrition in treatment had an unprecedented role in research, policy, and program discussions at the XVI International AIDS Conference held in August 2006 in Toronto, and was singled out as one of the main challenges for the future in the Closing Address by the UN Special Envoy on AIDS in Africa, Stephen Lewis.

⁵ For additional information on AMPATH see <http://medicine.iupui.edu/kenya/ampath.html>

⁶ Vegetables include kales, cabbage, spinach, pumpkin, cucumber, onions, garlic, ginger, capsicum, beetroot, carrots, French beans, coriander and other local vegetables. Fruits include lemons, oranges, mangoes, bananas, pineapples, guavas, loquats, custard apples, passion fruit and tree tomatoes.

for 450 patients and their families at the four treatment sites. Between June and December 2005, WFP surpassed its goals and distributed food to 656 patients with an estimated total number of beneficiaries of over 2,200, reaching more than 60 percent of AMPATH patients living in absolute poverty (WFP 2006).⁷ The WFP rations consist of maize, beans, corn-soybean blended flour (CSB), and vegetable oil. Patients receiving the WFP ration also receive HHI fresh farm foods. Similar to HHI, the WFP ration is considered supplementary and assumes the household has other sources of food.

With the entrance of WFP, eligibility criteria for enrollment in the food program were set to target new patients beginning ARV treatment and meeting cut-offs for nutritional status and food insecurity. The following criteria were developed for the nutritionists to use when determining whether a patient should be enrolled in the food program.

- a) Insufficient access to food to support patient recovery;
- b) Body Mass Index (BMI) below 19;
- c) Household income less than 3,000 Ksh.⁸ per month, and
- d) CD4 count less than 200.

Meeting at least one of the guidelines would typically qualify a patient for enrollment, though AMPATH nutritionists often in fact made decisions on a case-by-case basis. During the field research we learned that insufficient access to food was often given the heaviest weight in the decision making process and that this determination was rather subjective. Furthermore, at the onset of WFP food supplementation, there were not enough new ARV patients meeting the criteria to allocate all the WFP rations. Therefore, some current ARV clients already receiving HHI food support were enrolled by nutritionists to additionally receive WFP rations until enough new patients were available to fill the WFP slots. Over the course of the pilot program newly enrolling ARV patients found to be food insecure replaced these current ARV clients in the WFP food program.

AMPATH staff conduct nutrition assessments during a patient's monthly clinical appointment. Weight is monitored, food prescriptions are renewed, and nutritional counseling is provided. Patients enrolled in either WFP or HHI then take their food prescriptions to the nearest distribution site to collect foodstuffs twice weekly or once a month, depending on the distance from their residence. The WFP program intends to support clients with free food for up to six months at which time they are to be "weaned off" food support. The period of six months was chosen following observations that the majority of patients gain enough strength by then to engage in normal activities of daily living (Siika et al. 2005). However, because some patients need longer, there is some flexibility in extending the food support beyond the initial six months.

AMPATH also operates a program to assist clients with income generation or food production post-intervention. The purpose of the Family Preservation Initiative (FPI) is to assist, restore and improve income status of PLHIV as part of the comprehensive recovery strategy to stabilize livelihoods. Core activities include agricultural microfinancing, business training and technical support for poultry and horticulture among others. An additional service available to all registered AMPATH patients, regardless of whether they are on treatment or enrolled in the food program, is the weekly patient-led support group meetings. Patients have the opportunity to join different groups based on gender and marital status. Support group members encourage one another, learn

⁷ WFP defines absolute poverty as households that are unable to meet their basic food and non-food needs.

⁸ At the time of the research US\$1 was equal to approximately 73 Kenyan shillings; monthly household income guideline for enrollment was less than US\$41/month.

to live positively, reinforce adherence to treatment and the need for a balanced diet, and help to deal with stigma-related stress.

In early 2006, WFP increased support to 15,000 rations with the goal of serving roughly 3,000 AMPATH patients and their dependents. As of February 2006, AMPATH was caring for over 20,000 PLHIV, of which more than 9,700 were on ARV treatment. The WFP expansion targets approximately 30 percent of the patients on ARV treatment. The current expansion phase of AMPATH's food supplementation program has required extensive coordination of food provision, new infrastructure, the establishment of additional food distribution sites and training of new distribution staff. Concurrently, the HHI program is scaling up farm production with the addition of new production farms in AMPATH's catchment area. One treatment site has also been identified for the distribution of Instamix⁹ flour donated by USAID.

Currently, it is estimated that 20-50 percent of all patients attending AMPATH clinics are food insecure. These estimates are based on monthly reporting by each clinic in the network using the aforementioned enrollment criteria. The rapidly growing enrollment of patients in AMPATH's treatment and care program and the considerable level of food insecurity (varying by clinic location) suggest that there will be increasing demand for food supplementation services.¹⁰ There are important programmatic implications for the food supplementation program as AMPATH scales up ARV treatment. When this study began there had been no formal evaluation of the food supplementation program. In December 2005, WFP administered an evaluation activity to monitor and evaluate targeting efficiency and distribution performance of WFP food support in four pilot distribution centers; findings are discussed later.

Research Objective and Design

The broad objective of this study is to analyze various programmatic issues to strengthening nutrition security of patients on ARV treatment. The paper begins with a brief description of the research design and methods. A discussion of programmatic experiences and issues of delivering nutritional support with ARV treatment follows, drawing from in-depth patient and program staff interviews. For comparison, data from interviews with patients who were not enrolled in the supplementation program are weaved into the discussion. We compare the role of informal and formal support in the overall strategy for food and nutrition security. We address programmatic issues including eligibility criteria for enrollment in the supplementation program, use of food supplements, opportunity costs of program participation including stigma and transport costs, issues of seasonality and access to a balanced diet, individual and household impacts of participation in the program and the transitioning off free food supplementation toward increased self-reliance in meeting long-term nutritional needs. We conclude by summarizing programmatic lessons and challenges, providing recommendations for the improved implementation of the nutrition intervention, and for the types of policy change that may be required to enable this.

⁹ A fortified, precooked, blended flour product produced by Insta Products, Ltd. a Kenyan food processing company.

¹⁰ This derives from the number of people who actually come to the clinic to test and seek treatment services, not the national or regional HIV prevalence rates. As people become more aware of the program and stigma declines, AMPATH is seeing more people utilizing their services and is therefore geographically expanding their coverage area to meet the demand. Additionally, AMPATH is expanding into more remote areas where in some cases patients have no cultivable land, no income, and no property (personal communication AMPATH Nutrition Services).

This study is part of a larger interdisciplinary research design incorporating clinical, longitudinal survey, and in-depth research methods. Approval of the qualitative research design was granted by Moi University – Moi Teaching and Referral Hospital Institutional Research and Ethics Committee as an amendment to the already approved protocol on “Economic Impacts of Disease and Treatment on Household Welfare in North Rift Region, Kenya.” Here we present the results from qualitative research conducted between December 2005 and February 2006 on the Mosoriot Rural Health Center-AMPATH Clinic patient population. Results from the analysis of clinical indicators measured pre- and post-intervention are forthcoming and will be discussed elsewhere.

Research site

Mosoriot Rural Health Center is located approximately 25 kilometers south of Eldoret town and is the main health care facility in Kosirai Division in the Nandi North District of Rift Valley Province. Kosirai Division has an area of 195 square kilometers and a population of 35,383 individuals and 6,643 households (Central Bureau of Statistics, 1999). Kosirai Division is predominantly inhabited by the Nandi ethnic group. The health center mainly provides outpatient care and has a limited inpatient capacity. Mosoriot was the first rural site in the AMPATH treatment network and the first of four pilot sites for the food supplementation program.

Methods and Sample

Qualitative data were collected from 18 interviews with key informants, 9 focus group discussions, and 79 in-depth patient interviews. Key informants from the food supplementation program, AMPATH clinical staff, and village leaders were identified and invited for individual interviews during December 2005. The interviews followed a semi-structured guide on issues related to individual and household vulnerability to food insecurity, nutritional needs of people living with HIV, the role of informal social support networks, and observations on the nutrition intervention. Next, focus groups were organized, stratifying by gender, marital status, and participation in the supplementation program and other AMPATH services. AMPATH program staff assisted the research team in inviting 8-12 individuals to attend a two to three hour meeting. Nine discussions were conducted in January 2006. Group composition for the discussions is shown below in Table 1.

Table 1. Sample Characteristics of Focus Group Discussions

No.	Focus Group Composition	Participant s	Percent of participants who are women	Mean age in years
1	Current HHI/WFP food clients	10	80%	39
2	Weaned HHI/WFP food clients	7	86%	35
3	Caregivers of patients in food program	9	22%	41
4	Female ARV patients not in food program	6	100%	33
5	Male ARV patients not in food program	6	--	39
6	Single Patient Support Group members	12	92%	36
7	Male Patient Support Group members	11	--	39
8	Widowed Patient Support Group members	11	91%	44
9	Family Preservation Initiative participants	13	62%	36

The in-depth sample was designed to capture patients with experience in the food supplementation program as well as others who initiated ARV treatment at a similar time but were not eligible for food supplementation. Four groupings were constructed to include patients more recently initiating ARV treatment and receiving both WFP and HHI food support as well as

patients with a longer history of ARV treatment but only receiving HHI food support. The sample groups containing approximately 20 patients in each are described below:

1. Newly¹¹ enrolled ARV patients meeting the criteria for WFP and HHI and receiving food supplements from both sources.
2. Newly enrolled ARV patients not meeting the criteria for WFP or HHI supplementation.
3. Currently¹² enrolled ARV patients meeting criteria for HHI supplementation before WFP program was initiated and possibly still on HHI food support.
4. Currently enrolled ARV patients who were never in any of the food programs.

The sample of non-food clients (Groups 2 and 4) is intended to serve as a comparison group, albeit an imperfect one, for the examination of nutrition security among patients on ARV treatment. The construction of a pure control group is impossible because patients that qualify for food supplementation cannot ethically be denied the free food support. The authors acknowledge an inherent sample bias of patients enrolled in the food program in that they are more likely to be more food insecure and malnourished than non-food clients. Challenges to accurately implementing the enrollment criteria may have further affected these groupings.

Patients were recruited for in-depth interviews at clinic visits during three weeks of February 2006. A random start date was selected and the research team solicited interviews on site at the clinic until they filled quotas of 20 patients per sample group.¹³ All interviews were conducted in private at the Mosoriot Rural Health Center in Kiswahili, Kinandi or English according to informant's preference. Using the preliminary findings from the key informant interviews and focus group discussions, in-depth interview guides had been developed for these individual patient interviews. The main topics covered included patient experiences with the food supplementation program, use of food collected from the program, impact of the food, transition off food support, meeting nutritional needs while on ARVs, ARV adherence, economic activities of the household, and social support networks. Individual informed consent was solicited and collected before beginning each interview and patient names were not recorded at anytime. Only one individual refused to be interviewed. Patients were reimbursed a flat rate for transport.

Table 2 presents the characteristics of the in-depth sample. Approximately 60 percent of AMPATH patients are women, reflecting the combined outcomes of women being more likely to be infected, to know their HIV status, and to seek treatment in Kenya (Central Bureau of Statistics 2004). Our sample captured a somewhat higher proportion of women (77 percent) than is representative of the patient population. Respondents ranged in age from 20 to 63 years with a higher median age among men (48) than women (33). The majority of women in the sample were either single or widowed while marital status among men was highly skewed towards married men. A slightly higher proportion of men (39 percent) had post primary schooling compared to women (36 percent). The data illustrate how more women regularly attend AMPATH sponsored support groups compared to men.

Data Analysis

Interview transcripts were translated into English and entered electronically. Analysis of in-depth data was conducted using QRS N6 qualitative data analysis software. The authors coded

¹¹ AMPATH patient enrollment date after June 30, 2005.

¹² AMPATH patient enrollment date before June 2005.

¹³ Originally, patients were to be randomly selected from the monthly appointment list, but later it became apparent that this was not feasible as patients may not report on designated days and it would extend the time necessary to complete 80 interviews beyond a month.

interview transcripts for themes and patterns relevant to answering the research objectives. Summary findings from the qualitative data are discussed in the following sections of the paper.

Table 2. Characteristics of In-depth Patient Sample

Variable	Women	Men	Total
<i>Total Sample Size</i>	77%	23%	79
Group 1	89%	11%	18
Group 2	71%	29%	21
Group 3	62%	38%	21
Group 4	89%	11%	19
<i>Age in years</i>			
Average	35	48	37
Median	33	48	36
<i>Marital status</i>			
Single	43%	6%	34%
Married	15%	78%	29%
Widowed	26%	11%	23%
Separated	16%	5.5%	14%
<i>Household size</i>			
Average	5.8	4.2	5.4
Median	5	4	5
Range	1-18	1-12	1-18
Average no. children <18 years living in household	2.8	1.6	2.5
<i>Highest level of education completed</i>			
None	8%	5%	8%
Incomplete primary	25%	17%	23%
Primary completed	31%	39%	33%
Incomplete secondary	16%	17%	16%
Secondary completed	15%	11%	14%
Post secondary schooling	5%	11%	6%
<i>Support Group Membership</i>			
Regularly attends a support group	46%	28%	42%

Programmatic Issues in Delivering Nutritional Support with ARV Treatment

In this section we address programmatic issues in delivering nutritional support to patients on ARV treatment based on the qualitative data. We discuss nutrition security pre-intervention, patient and programmer experiences with enrollment, use and types of food supplements, seasonal food security, and opportunity costs of program participation.

Nutrition Security Pre-intervention and the Role of Informal Support

Prior to enrolling in the food supplementation program, patients (Groups 1 and 3) met their food needs through a combination of strategies that included farming, livestock rearing, purchase, transfers from relatives, casual jobs paid in food or cash, trading businesses, begging or borrowing from others, and even passively waiting for well-wishers to visit with food donations. According to the qualitative data, the family and extended network of relatives plays the biggest role in informal support. The main forms of support include in-kind and cash transfers to meet food needs, financial assistance with transport, medical expenses and school fees, accommodation, care giving and emotional support and encouragement. Support from friends

and neighbors appears to be less formal and less consistent before the shock of falling ill or learning one's HIV status. Reciprocal loaning and sharing of food and labor resources were common types of support. Some patients reported an absence of support after falling ill or learning their HIV status which they attributed to the inability of family members – who themselves are overburdened – to lend financial support, or to HIV-related stigma. Several patients who required additional support claimed their families did not invest in supporting them because they thought she/he was going to die soon. Other patients in our sample were able to meet their own needs and did not require support from their social network even after learning their status. Data from the first round of the socioeconomic survey conducted in the Mosoriot catchment area in 2004 showed that individuals in households with an HIV-positive individual were more likely to receive cash and in-kind transfers than individuals in the random sample of households (Goldstein et al. 2005). It was further concluded that households with an HIV-positive individual were less able to provide support to others within their social network.

Support from religious institutions is typically conditioned on membership and activated in times of need. Respondents gave few examples of any regular support from church members prior to knowing their HIV status or experiencing a period of health decline. They explained how some churches overtly condemn people with HIV as sexually immoral. As a result, many patients are reluctant to disclose their status within their church and prefer to seek support from family and neighbors, thus limiting their disclosure.

Within Kenya, communities have a traditional fundraising system – *Harambee* – which acts as a safety net for mobilizing support to orphans and other vulnerable children. A *Harambee* is typically organized to mobilize resources for educational expenses, medical debts, farming or housing for needy community members. The local administration of chiefs and village elders identify households in need, verify the circumstances, and invite community members to contribute financial resources. Once collected, the funds are managed by a committee to ensure they are applied to the intended expenditure. Another example of community-based sources of support included merry-go-round savings and loan groups. There were no examples of organizations specifically providing services to people living with HIV and only a handful of psychosocial support groups not affiliated with AMPATH.

Patient perceptions on why some people are supported, and others are not, provide insight into existing barriers and how unmet needs may be addressed by formal interventions. Three main reasons cited for providing support were: a) a recognition that the sick person cannot meet her or his own needs; b) sympathy toward the person in need; and c) family obligation. The main reasons given by our respondents for the lack of support when they were sick included the following: a) stigma associated with HIV and fear of contracting the virus; b) the attitude that the sick individual is going to die anyway, making support futile; c) poor interpersonal relations with family and in-laws; d) competing needs and inability of others in the social network to assist; and e) not having disclosed one's HIV status or not outwardly appearing to be in need of support.

Eligibility for Enrollment

Patients with experience in the food program recounted that, prior to enrolling, the majority had ceased practicing their former income generating or domestic activities for extended periods of time as a result of poor health and weakened physical ability. When asked why they started collecting food from the supplementation program, the most frequent reason reported (64 percent) was the inability to meet their nutritional needs because they lacked a source of food at home or could not produce food or work to earn an income. One patient in the food program explained,

I didn't have any source of food. Whenever we borrowed from neighbors, we would be chased 'hatutaki watu wa ukimwi' (we don't want people with AIDS).

(Married female age 32 with two household members under age 18, current WFP client)

Poor clinical health status including low CD4 count, malnourishment, and weak physical condition was the next most frequent (26 percent) reason for starting food supplementation. Two patients reported lacking access to the types of foods recommended for a balanced diet and one individual did not know the reason for enrolling in the program but just accepted food that was being given out during nutrition classes.

Patients that have never been enrolled in the supplementation program, (Groups 2 and 4 of sample), meet their nutritional needs through a combination of farming, livestock rearing, purchasing what they do not produce, and transfers from relatives. Those without access to farmland or livestock rely entirely on purchasing food. Most of the non-food patients interviewed in our study did not experience difficulty in accessing food, suggesting that the program is not mistakenly excluding households with major food access problems. However, it may be the cases that fall near the cut-off for enrollment that present the greatest challenge in targeting.

Program nutritionists use an initial encounter form to collect clinical, nutritional, and socioeconomic data on each patient to determine their eligibility for enrollment in the food program. The implementation of this procedure is more complex in practice than in design. One challenge facing nutritionists at each site is how to classify patients who are of borderline eligibility for food supplementation. During the course of the field research we discovered some issues that brought into question the systematic application of these criteria. Efforts are underway to standardize decisions about such cases; currently they are marked for follow-up with a home visit by an AMPATH social worker in order to verify enrollment criteria. At the time of the study, there was only one full-time social worker at Mosoriot's AMPATH Clinic and it reportedly could take up to three months for her to get out to a patient's house to verify the criteria. There is clearly a shortage of labor allocated to verification of eligibility. However, the multiple responsibilities shouldered by the social worker at each clinic precludes wider home visitation. Additional staffing constraints will be addressed in the section on the post-intervention program services to assist patients in the transition off food support.

The post-distribution evaluation conducted by WFP in December 2005 calculated overall targeting efficiency at Mosoriot to be 64 percent, with 17 percent incorrect exclusion and 19 percent incorrect inclusion in the program (WFP 2006). Errors in exclusion measure the degree to which deserving patients have been erroneously left out of the supplementation program. This further highlights the need for better targeting and follow-up of eligibility criteria, as corroborated in the qualitative research.

Unlike programs that use proxy indicators of chronic illness, AMPATH is directing food support to households with a known HIV-positive individual. Distributing food through a clinic population will inevitably overlook individuals that are not under treatment or do not yet know their status – but it does guarantee that all beneficiaries are HIV-affected households. Still, challenges to accurate targeting remain and require greater attention during the current expansion phase.

Use of Food

With any targeted food aid program, there is concern about whether the rations are reaching the intended beneficiaries or whether households dilute rations through unfair distribution or even non-consumption. There are no regular home visits by program staff to assess how patients and

their households use the food collected from the program. This study relied on patient recall about how they used the food they last collected from the program.

The most common (46 percent) pattern of food allocation was sharing program food among household members with some preference for allocating particular foods to the patient. Foods often used only by the patient or young children included eggs, milk, and corn-soybean blended porridge flour (CSB). Of these foods, only the CSB is specifically distributed in a ration intended for patients, pregnant women, and children under five, whereas all the other foods are distributed based on household size. Another 38 percent report sharing the food equally among household members without any gender or age discrimination in allocation. Patients who live by themselves consume the food alone. These data suggest that intra-household food allocation is on par with program objectives. Only three patients report using all the food entirely for themselves while living in a household with other members. This occurred under the special circumstances where the patient's food support was extended with a monthly ration of porridge flour intended only for the patient. The qualitative data do not suggest any difference in allocation pattern with regard to gender of the food client. The WFP evaluation of all four pilot sites, concluded that 97 percent of households in their sample¹⁴ consume the WFP dry rations equally among members (WFP 2006).

As part of the services provided at the health clinic, nutritionists counsel patients and their dependents not to sell or give the food to other households but to use it for themselves as part of their treatment and household food security. No one in our sample admitted to having sold any of the food they last collected. The WFP evaluation found only one case of selling food rations among a sample of 82 households in the pilot food program's four sites (WFP 2006).

Appropriateness of Food Supplements

To assess appropriateness and acceptability of foods distributed through the supplementation program we asked food clients and program staff about each of the foods distributed. Among food clients and their households, the importance of each food item collected depended largely on what food resources are available at home, whether or not they farm and own livestock, and sources of income. Patients ranked foods that they perceive as giving them strength and having the most obvious impact on improving their physical health status as most important, such as milk and eggs. They also listed foods associated with health benefits such as protein for strength, vitamins to resist skin problems, and foods that induce weight gain. Almost a quarter of the respondents considered all the foods important because they claim they were the only food available to their household at the time.

Feedback provided by food program staff indicates that the HHI farm-grown foods are readily accepted because they consist of local foods found in the regional diet. The maize and beans provided in the WFP rations are widely accepted, as they are also local staples. Some of the foods unfamiliar to the region provided through WFP, such as split peas, have required the nutritionists to first teach patients and caregivers how to prepare the item using demonstration classes. One distribution worker recounted how clients initially disliked the CSB flour until they learned how to prepare it. After the initial demonstration, program staff report general adoption of the new foods. Program staff emphasize to the patients that these foods are a form of medication and will help them become healthier.

¹⁴ WFP sampled 82 households enrolled in food program in the four pilot sites. They did not specifically evaluate use of HHI farm foods.

Seasonal Changes in Demand for Food Assistance

From a treatment and nutrition standpoint it is important to identify periods of greater food vulnerability among the patient population. Both patients enrolled in the food supplementation program and non-enrolled patients face seasonal changes in their ability to meet their food needs and access a balanced diet. Annual cycles of dry and wet seasons dictate food availability in the region. The dry season can extend from January through May making vegetables and milk scarce while driving prices upward. The onset of the dry season corresponds with the start of the school year and demand for educational expenses and agricultural inputs. Before the rains arrive, the vegetable shortages and price increases limit patients' access to the variety of foods recommended by AMPATH nutritionists. At the same time, casual jobs become less available and food assistance from one's social network wanes as food stores decline throughout the region. Patients report seasonal periods of greater vulnerability when existing informal social networks experience increased demands for cash and other resources, rendering them less able to respond to any additional needs. The qualitative data illustrate that from April onward many households are vulnerable to food insecurity and may require short-term food supplementation despite adequate access to food during the harvest and immediate post-harvest season.

With the arrival of the rains, usually around April or May, vegetables start to become available again. By August, the bean crop is ready for harvest and in October the maize harvest commences. At this point in the year, food security is generally better for most households. Patients identified September through November as the period when food assistance is least required because most households have maize, prices are lower, and they can more easily access assistance from relatives and friends if necessary. However, our informants were careful to note that seasonality applies more to households that practice farming; for non-farming households food assistance may be necessary year round if a breadwinner is ill.

In order to compare patients in households with relatively better food security and socioeconomic status, we asked non-food program patients which foods in the recommended diet are most difficult to access. Milk was the most difficult to access when households do not have a cow or when milk production declines during the dry season. Beans, vegetables, and eggs were also mentioned as difficult foods to acquire in the dry season. Access to fruits depends on cash to purchase because most households do not grow them on their farms. Meats, especially liver and beef were also considered difficult to access because of their price. The more food secure households represented in Groups 2 and 4 of the sample also experience seasonal shifts in food availability, but to a lesser degree.

Opportunity Costs of Food Collection

Food supplementation is provided free of charge to eligible patients and their households. The patient or a designated caregiver is required to collect the food from local distribution sites. We identified the main opportunity costs of patient participation in the food supplementation program as transport and stigma.

Transport costs

The biggest challenge patients face in collecting food is meeting the cost of transport. Just over half of the current or past food clients in our sample mentioned transport as their biggest obstacle. On average, the food clients spend 157 Ksh. (~US \$2.15) on round trip transport each time they collect food. Frequency of food collection depends on the ability of the patient or her/his caregiver to get to the distribution sites. Patients who live close to the farm or distribution sites collect food as frequently as twice per week, thus regularly accessing fresh produce. Arrangements are made for patients who reside far from the sites to collect their food in bulk

once or twice a month combining food collection with their monthly clinic appointment to save on transport costs. However, food clients that collect less frequently miss out on regular collection of the fresh farm foods. We were told that some patients might fail to collect food because of the long distance to the distribution sites. After considering the transport costs, some opt to buy the recommended foods on their own. A third of the food clients interviewed report no challenge to food collection.

Stigma and food collection

Food assistance targeting HIV-affected individuals and households can carry the added stigma of poverty and disease. AMPATH staff and patients were candid in their discussions about stigma and the food supplementation program. The two main issues involve collection and packaging of the food.

Both program staff and patients agree that stigma was initially associated with food collection. Patients and caregivers feel they are easily identified by the green food bags handed out at the distribution sites. They report cases of gossip and negative attention when collecting, leading many to conceal their packages in other bags or luggage. Many food clients keep their collection secret from family and friends due to fear of discrimination, especially when they have not widely disclosed their HIV status. Some prefer to collect food from the main HHI farm rather than the distribution site closest to their home, or resort to collecting the food very early in the morning to avoid being seen by neighbors and friends. Others, we were told, do not collect because of stigma and miss out on the free supplementation. It is not possible from our data to assess how many eligible patients forego collection because of stigma, but there is speculation that it is a problem. Focus group discussions suggest that men are affected most by such stigma and as a result try to quickly collect their food and hide their parcels as they depart the distribution sites. In one group discussion, participants suggested that food distribution sites be open in the evenings to encourage more men to collect food.

With time and familiarity with AMPATH's services, the gossip seems to die down as one patient stated, "*waliongea mpaka wamechoka*" – they talked until they got tired. Some patients even report that community members have begun to appreciate the program upon seeing the health of a previously ill neighbor improve after collecting food for some time. They see it as a form of assistance to the needy in their community.

We also learned that specific food items produce discriminatory reactions by family and friends. Among the foods distributed to patients enrolled in the supplementation program, the buttermilk or *maziwa la la* was repeatedly singled out as attracting the most stigma because of its packaging. The milk packets have labels with messages about AIDS and ARV treatment. Many patients expressed their reservations about drinking the milk in front of others and instead consume it before leaving the farm. Other patients explain how they transfer the milk into their own container to disguise its origins. Patients argue that the milk packaging does not respect confidentiality by revealing their HIV status when many have not yet disclosed to family and friends. After a lengthy discussion about the milk, participants in one focus group requested that AMPATH "*let food be food*" and remove the stigmatizing labels. These patients argue that they receive education and messages about nutrition and ARV adherence at the clinic; and there is therefore no need for such information on the food packets.

Stigma attached to HIV programs and services is well documented. A recent RENEWAL study in South Africa (Norman, Chopra, and Kadiyala 2005) focuses on the pivotal issue of disclosure of HIV status, providing examples where disclosure can lead to improved and more varied options for support. The social environment to a large extent determines whether disclosure is a gateway

to “positive living” or alternately, to stigma and discrimination. In this region in Kenya, the climate appears more conducive to stigma. But, as Bond (2005) states in her analysis from Zambia, stigma is fuelled by poverty too – and can be an economically fuelled response of poor communities who simply do not have the means to support affected individuals or households.

Benefits of the Nutrition Intervention: Individual and Household-Level

Nutrition interventions linked to treatment are relatively new and there has been little evaluation to assess impacts. A food supplementation program of this type has the potential to impact patients and their households in different ways including improved access to food, ARV adherence, nutritional status, use of financial resources, household labor supply, and other sources of support. The qualitative component of this study provides preliminary evidence of individual and household level benefits, based on patient and programmer observations. Analysis of clinical indicators is forthcoming and will triangulate with perceptions from patients and program staff.

Access to Food

Food clients report increased dietary diversity and diet quantity as one of the most important benefits of the program. For many past and current food clients, the food supplementation program provided access to different types of food previously unavailable in the homestead. For example, households without access to livestock were able to access eggs and milk. Food clients further acknowledge that without access to the free supplementary foods, the cost of some of the recommended foods would be too high, resulting in a less varied diet.

Upon initiation of ARV treatment, many patients experienced an increase in appetite. The supplementation program helped clients meet their nutritional needs and satisfy their appetites by providing a secure source of food in the short-term. Caregivers reported no longer needing to constantly ask neighbors and friends for assistance because the patient they cared for could access their own food through the program. Patients further claim they no longer have to go begging for one to two days worth of food. Data from focus group discussions also suggest that the food program plays an important role in the emotional well-being or mental health of patients. Eighty-two percent of food clients in our sample indicated that the food program reduced their stress and worries about where and how they would access food for themselves and their households. One patient described the effect of collecting food.

I am no longer worried about what my children and myself will eat. I am never worried about lack of food. (Widowed female age 32 with 2 household members under age 18, WFP client enrolled January 2006).

Nutrition Education

Application of the nutrition education provided by AMPATH extends beyond food clients to all patients on ARV treatment. Both food clients and non-food clients in the in-depth sample widely acknowledge the benefit of the nutrition education they received. Patients report increased knowledge about the types of foods and frequency of meals that best complement their drug regimen. Across the sample, patients compared their maize based diet prior to receiving nutrition education and discussed how they currently incorporate more vegetables and fruits into their diets. Non-food clients also mentioned the importance of trying to balance their diet to improve their health status. The cooking demonstrations carried out by the nutritionists and food distribution workers have been useful to teach preparations of different types of recommended foods and introduce unfamiliar program foods to the local diet.

Treatment Adherence

AMPATH outreach staff report that the nutrition education and food supplementation program have facilitated ARV adherence because patients are taught that ARV treatment requires a balanced diet. Among food clients in the sample, 58 percent perceive that access to food from the program has made their adherence to their treatment regimen easier because the food they collected lessened unfavorable side effects of ARVs including increased appetite, dizziness, and vomiting. Many patients reported the food helping to offset the strength of the ARV drugs experienced when taken without adequate food or a balanced diet.

[Food program] ...assisted because I could take ARVs easily as now the side effects were lessened. Before, the drugs used to really affect me.

(Single female age 20 with 2 household members under age 18, weaned off WFP program)

Eleven percent of food clients reported no change in their ability to adhere to treatment. Among the 40 non-food clients in our sample, 78 percent self-report perfect adherence to their ARV treatment. The main causes cited by patients reporting some adherence problems in the past (23 percent) are lack of money to pay transport to collect their refills or stress at home.

In Zambia, a food supplementation program for patients on ARV treatment in Lusaka, based on similar WFP commodities and high energy protein supplements, was piloted as part of a comprehensive adherence support package. The study found that food assistance improved adherence by 40 percent compared to case-controls without supplementation, but that the effects were not noticeable during the first 6 months of support. CD4+ response was also significantly better at 12 months of therapy for patients in the food program. It is also important to note that 90 percent of the patients in this pilot required extension of supplementation for an additional 6 months (Megazinni et al. 2006)

Recovery of Physical Health

The qualitative data do not allow us to isolate the effect of the food supplementation from the effect of ARV treatment on physical health status because there are no matched controls in the sample, but the data suggest that some patients would not be able to meet their recommended nutritional needs without the program.¹⁵ In interpreting their health improvements, patients inevitably blend the effects of ARVs and food supplementation. Nevertheless, self-reported observations about recovery of strength, weight gain, and return to labor activities illustrate the tangible benefits patients experience from the combined effects of supplementation and treatment. All but one respondent (97 percent) claimed that the food program led to improvements in their physical health status. In a group discussion, current food clients claimed that before starting ARV treatment they were often too sick to do any work including household chores. Initiating ARV treatment led to an increase in appetite and consumption of a greater quantity and variety of foods as recommended by the clinical staff. In the discussion with weaned food clients, participants explained how prior to ARV treatment they did not eat a balanced diet and that the variety of food they collected from the farm greatly improved their health status.

The research methods used here do not allow us to separate the effects because the groups represent *a priori* selection bias toward most vulnerable nutritional status and access to food (Groups 1 and 3) and patients on treatment but not food supplementation who have better nutritional status (Groups 2 and 4). However, their subjective interpretation of what causes their improvement is useful to understand when designing programs. For example, if linking nutrition education with ARV treatment produces good dietary behaviors among non-food program clients as well, it may be a useful pathway to rehabilitation of nutritional and clinical health status.

¹⁵ Future analysis of rounds two and three of the socioeconomic survey will address this issue.

Household Nutritional Needs

Food rations are distributed on the basis of each patient's household size recognizing the importance of supporting not just the individual but also household food security. Twenty-four (62 percent) of new and current food clients in the sample report a spillover effect of improved health status of other members of their households, especially young children. Collecting food from the program enabled their households to consume a diet that was better both in quantity and quality than before.

It improved the health of the children and in fact they increased their weight too. We had a chance to have a variety of foods which were balanced and this enhanced the health of the kids. (Widowed female age 40 with 2 household members under 18 in the household. Former HHI client who chose to stop collections).

Eleven respondents (28 percent) reported no household level impact mainly because they either resided alone or the program food was used only by the patient and not shared among other household members.

The socioeconomic survey in the larger research design includes anthropometric measurement of children under five years of age. Analysis of data from the first round socioeconomic survey in this population found children in households with at least one HIV-positive patient in AMPATH's program to have significantly worse weight-for-height indices than their counterparts from a random sample (Goldstein et al. 2005). Future analysis of change in nutritional status between rounds two and three will provide an objective indicator of the impact of the food program on patient and household nutritional status.

Household Labor Supply

The majority (61 percent) of food clients reported that as a result of the food supplementation they regained enough strength to return to their household chores, farming activities, or income earning activities. The amount of labor available in their household increased as the patient recuperated. Eleven percent report having time to look for employment while enrolled in the food program. However, another 11 percent reported that they are still too weak at the time of the interview to seek any employment.

Since I started the food program, I began feeling better, had a lot of appetite and so it has given me strength and a chance to go on with my clothes and shoes business. (Single female age 35 with two children under 18 in the household, weaned off HHI and re-started short-term CSB flour).

Analysis of first and second round Mosoriot survey data found that within six months after initiation of ARV treatment, patient households demonstrate a significant increase in labor supply. Patients also showed a 20 percent increase in the likelihood of participating in the labor force (Thirumurthy, Graff Zivin, and Goldstein 2005).

Reallocation of Household Resources

Participation in the food supplementation program has enabled the majority (76 percent) of patients and their households to reallocate resources within the household while collecting food. Money previously used to buy recommended foods was allocated toward other expenses including education, basic necessities, rent, clothing, and transport. The impact on educational expenditures was of particular importance to our respondents. More than a third (38 percent) of food clients in our sample report re-directing money that would have been spent on food toward educational expenses such as school fees, uniforms and stationary supplies. At the same time 28

percent of food clients reported no observable change in their expenditures on education because the savings from food was not enough to cover educational needs; they still needed to use money to buy additional food, or their household's education expenses were particularly high. A small number of respondents (13 percent) report an indirect impact on education whereby the food collected from the program enabled their children to attend school on full stomachs and concentrate better.

Community Impacts

The current intervention focuses on how individual and household nutrition security can be strengthened in the context of HIV. Community-level linkages in addressing long-term treatment and care needs are weaker. AMPATH does however link with community-based initiatives in other program areas such as training of Traditional Birth Attendants (TBAs) and patient-to-patient outreach for support in adherence to treatment, but the food component is primarily aimed at patients and their dependents. Respondents did not provide much evidence of community level impacts of the food supplementation program – probably due to limited knowledge within their communities that they collect food from the program. Almost half of the food clients admit that only their families know they collect or previously collected food from the program.

Indirectly, patients residing in communities where there is wider awareness of AMPATH's food supplementation program report members viewing the program favorably when they observe visible improvements in the health of a sick community member. There is mixed evidence from focus group discussions suggesting a reduction in stigma arising from direct improved health status of the PLHIV and improved nutrition knowledge on balanced diets for chronically ill people through community forums. An HIV-positive individual may have received no assistance initially, but as her/his health status and physical appearance improved after initiating ARV treatment and improving their diet, some people's attitudes changed. Patients report being welcomed back into the homes of neighbors and friends despite earlier discrimination.

When implementing a formal intervention to provide food support to people living with HIV, it is important to understand the role of informal social networks in providing food and other forms of support. The potential impact of the nutrition intervention on an individual's access to informal support largely depends on the extent of pre-existing support. For some individuals in our sample the formal intervention acted as a catalyst for additional support. In other cases, AMPATH's food program substituted or temporarily alleviated the demand for assistance from their informal network. Still, some individuals in our sample never had a well-functioning support network prior to knowing their HIV status and others lost support because of stigma, poor economic circumstances, or marital dissolution. In such instances, the food program filled a void where no informal support previously existed or had been withdrawn. We found no evidence that the food program was negatively impacting informal support networks or eroding informal systems of support.

Post-Intervention: From Food Supplementation to Food Security

A major challenge facing the food program is the transition from short-term assistance to long-term options for nutrition security. The process of transitioning clients off food supplementation – or “weaning” – is complex. Widespread poverty, lack of livelihood opportunities, insufficient program resources to assist food clients in the transition off food support into productive activities, problems of dependency on free food, as well as variations in the time required for patients to recuperate sufficient health to become productive, are all important factors here. One key informant working closely with the transition process stated that,

There is a lot of anxiety among the patients about weaning; some have done nothing toward sustainable food provision during the six months. Or maybe FPI may not have worked or hasn't reached them yet. There is a gap between food aid and an alternate strategy to provision your own food.

Program Services

According to procedure, patients should receive reminders of the amount of time remaining in the program during monthly clinic appointments. At this time, nutritionists and social workers are also supposed to ask patients what steps they are taking toward meeting their future food needs post-intervention. As mentioned, AMPATH has a program, the Family Preservation Initiative (FPI), intended to assist patients with strategies to meet their longer-term nutritional needs. Patients are referred to FPI for assistance on ways of generating income or producing their own food post-intervention.

FPI's approach was initially grounded in business training and micro-finance for patients. Program managers later came to realize that many referred patients were not sufficiently entrepreneurial to benefit from micro-credit. Loans were often being used for consumption rather than productive investments, leading to the failure to meet repayment schedules. Currently, the program is tailored more to specific problems patients face and is exploring locally viable income generation options.

The agricultural extension component of FPI is based on the HHI farms and works with patients who have regained some physical strength after having been on ARV treatment and food supplementation. Based on resources available at their household, the patient can choose an activity they will be able to start after four to six months supplementation to prepare for their transition from food support. Extension officers teach simple farming techniques to patients at their homesteads. One HHI extension agent observed that a successful return to farming is easier for patients who are educated and/or better-off financially before falling sick because they can grasp the new information quicker and implement it with their resources. Farming is a critical area for promoting long-term strategies for food security, yet human resources are limited and Mosoriot had just one extension officer assigned to it at the time of this field research. The staff attention required for each case is considerable and current human resources may be insufficient to make all the necessary visits and decisions on an individual basis.

Patient Experiences with Weaning

Former food clients discussed their experiences with the transition off food supplementation during focus groups and individual interviews. Thirty percent responded that although they struggle at times, they were generally able to meet their food needs after transitioning, while, in contrast, almost half (48 percent) claim they were unable to meet their nutritional needs or eat a balanced diet compared to the period when they collected food from the program. Many patients in the latter group are stressed about accessing food and report post-program declines in food consumption. Five of the patients interviewed have restarted food support in some capacity, one of whom describing her situation thus:

After weaning my health went down because I wasn't eating well. This led the nutritionist to re-introduce me back to the program. As my health deteriorated I could not do more work to get an income, which made me weaker because there was less to eat. This made me start collecting again. (Single female age 46 with 3 household members under age 18, reenrolled HHI client).

We triangulated such patient accounts with program staff who confirmed that patients, once weaned, might have to restart food supplementation for several reasons including the following:

problems with adherence to ARVs; they start a regime of second line drugs and need food; a change in socioeconomic status; inadequate preparation and poor timing of weaning; inability to resume productive activities despite FPI training; or a change in resource needs such as increased educational expenses which compete with resources for food.

Length of Supplementation

The original HHI food supplementation program provided food to patients for extended periods of time. However, the current WFP program aims at providing food for only six months, or 12 months in special cases. The six-month period was introduced in June 2005. In the early stages of AMPATH's ARV treatment program many patients were receiving food through HHI and thus grew accustomed to continual support. Comparing the current program to the past, one patient explained how there used to be enough food to remain in the program over long periods. As a result patients came to think food support would continue indefinitely. This may have created dependency and negatively affected patients' ability to plan for meeting their nutritional needs post-intervention.

Whether six months is sufficient time for physical recovery to levels where patients can meet their nutritional needs is unclear. This is an area that needs more research and monitoring. One key informant observed that when patients initially learn their HIV status or begin ARV treatment, many cannot think long-term and only think about their short-term food needs because of their often-poor health condition and lack of alternate food options. The following quote from a focus group participant captures a feeling widely held by many informants.

The six-month period of food collection only improves their health status but does not give them a chance to think on what to do next or what plans to cater for their weaning.

Similar programs providing supplemental food to patients on ARV treatment in Africa have used six to 12-month time intervals for supplementation (see Megazinni et al. 2006; Nabyiro 2006). In the aforementioned pilot program in Lusaka, Zambia, 90 percent of the food insecure patients required extension for an additional six months beyond the initial period of supplementation (Megazinni et al. 2006). It is not clear whether this interval is applied because of donor conditions on food supply; whether it is a meaningful benchmark to review clinical indicators; or whether it is associated with physical recovery to produce or purchase food. Programmers, clinical care providers, and researchers need to collectively determine what constitutes an appropriate duration for food supplementation to patients on ARV treatment and develop tools for individual assessment. More evidence from programs providing supplementary food to patients on ARV treatment is necessary to resolve this debate.

Patient Expectations in the Transition off Food Supplementation

Patients who currently collect food, but were scheduled to be weaned off support in the near future discussed their expectations for the transition. One striking observation from the focus groups is that some patients were surprised to learn that the food support was for a fixed period and that their eligibility to collect food would eventually end. Among patients in the in-depth sample who still collect food, 60 percent were able to state when they would be weaned off the program, while 40 percent did not know for how long they would receive food support.

Among the clients currently collecting food, 20 percent were confident that they have a plan for meeting their food needs after weaning. Another 67 percent were optimistic about having a plan, but it was usually contingent on "hoping" to access capital without having identified any secure source. We asked patients what problems, if any, they anticipated once they would be weaned off food supplementation. The main expectations involved psychosocial stress over where to get enough food to meet their nutritional needs, balancing competing food needs with other

household resource requirements, and having less food available, which they further predicted would cause a decline in their strength and health status.

Within the patient population there are also more destitute patients that cannot easily transition back to meeting their own needs because they lack land for farming and/or are not capable of productive activities. Such cases pose challenges to programs offering short-term support. These examples from patients currently enrolled in the food program draw attention to the need for much better preparation and proper strategic planning to enable successful transition off food supplementation.

One question that emerges from this research is whether or not a program aimed at short-term nutrition security for the most vulnerable patients promotes increasing self-reliance or fosters dependency on the formal program. To avoid dependency, in addition to recuperation of nutritional status and clinical indicators, patients and their households need to achieve a point where they can return to greater self-sufficiency or rely on informal networks to meet their long-term needs.

The qualitative data suggest that members of informal networks may initially support people when they are sick, but their long-term ability and willingness to support, as the needs of the individual with HIV may wax and wane over the course of the disease, is uncertain. Taking a broader perspective on nutrition security, it is critical to address who can, and will, fill this role after the short-term intervention ends. Even a comprehensive and currently well-funded program such as AMPATH cannot create and maintain a system of social protection for patients that spans the duration of their care. Demand for treatment is expected to increase as ARVs become more available, more people utilize voluntary counseling and testing services, and stigma declines.

Seasonality and Timing of Weaning

A final programmatic issue in the transition off food supplementation is timing. Seasonal food availability has implications for the timing of weaning. Not only does the patient need to have a feasible plan for meeting her/his own food needs, but also such a plan must align favorably with the agricultural calendar. Patients perceived the timing of transition off food supplementation as not always corresponding with their ability to meet their own food needs. Agricultural extension workers and patients alike commented that weaning might occur too far in advance of the planting season leaving a vulnerable gap in food needs. One patient, for example, stated:

I would not be ready by April to meet my food needs as my maize won't be ready by then. It will be difficult. The drugs will start again making me weak. I will not be able to do any work and I don't know if the same well-wishers would come to assist me. I wish they could wait [to wean her] until I harvest my maize. (Separated female age 30 with 6 household members under 18 in the household. Started WFP in January 2006 and set to wean in April 2006).

Lessons Learned

Experiences from AMPATH's nutrition intervention provide practical lessons for modifying program delivery as well as for informing the future development of similar initiatives to effectively link nutritional support to treatment and care for people living with HIV. These findings further illustrate the need for comprehensive interventions to bolster nutrition security and their concomitant challenges. The main lessons from this field research are presented below, with recommendations discussed in the following section.

- The nutrition intervention provides an important source of food support to the most vulnerable patients receiving treatment through AMPATH.
- For many of the current and past food clients, the food supplementation program enabled the patient and her/his household to access food that would not have been available otherwise, thus alleviating food insecurity to some extent.
- Because stigma associated with HIV and AIDS remains a significant barrier to accessing support from informal social networks, formal support programs such as AMPATH's nutrition intervention are necessary for many patients in the clinic population. It may be the only source of supplementary food support for some patients.
- The data suggest that the supplemental foods are reaching the intended beneficiaries. Collected foods are shared among the household members with some preferential allocation to the HIV-positive individual.
- The types of foods distributed by the program are widely accepted, especially the fresh farm foods. Some foreign foods require initial education and demonstration, but overall patients accept them because they regard the foods as part of their comprehensive treatment and balanced diet.
- The main opportunity costs of participation in the program are transport and stigma associated with food collection.
- Determining program eligibility can be difficult for cases that fall near enrollment guideline cut-offs. Limited human resources to verify the borderline candidates may impact targeting efficiency.
- Many households become seasonally vulnerable to food insecurity during the dry season and may require seasonal food supplementation despite adequate access to food during harvest and immediate pre-harvest seasons.
- The supplemental food contributes to increased dietary diversity for patients and their households enabling access to a wider range of foods that are not normally available or easily accessed.
- Similarly, the nutrition education provided to all patients on ARV treatment appears to have a positive effect on dietary diversity.
- Patients that enrolled in the supplementation program while already on ARV treatment self-report greater adherence to their medication, fewer food-related side effects, and a greater ability to satisfy increased appetites. These findings will be triangulated with forthcoming clinical data analysis.
- The food program plays an important role in the emotional well-being of patients and lowers stress caused by insufficient access to food. This indirect impact may be important to the well-being and quality of life for this chronically ill patient population and even outweigh any possible stigma attached to the food.

- The majority of current and former food clients in the study sample report health outcomes of weight gain, recovery of physical strength, and return to labor activities while enrolled in the food supplementation program and on ARV treatment.
- Not all households with an HIV-positive adult are initially food insecure. There is great variability and the in-depth sample captures some of it. Comparisons with patients who have never been on supplementation illustrate that many are able to meet their nutritional needs and follow recommendations for a balanced diet on their own. However, in cases where an HIV-positive adult household member cannot continue productive and reproductive activities the household may become temporarily food insecure. This has implications for the ability for patients to transition off food supplementation and return to productive activities. Households with low initial assets and resources may be less able to transition toward greater self-sufficiency.
- Transition from short-term food supplementation to long-term strategies for nutrition security is a complex process. Several factors affect the ability of a patient to successfully transition off food support including patterns of dependency, insufficient program resources, socioeconomic status, and individual trajectories of nutritional recovery.

Challenges and Recommendations

Based on the programmatic lessons identified in this analysis, we discuss some of the challenges to linking nutritional support with treatment for PLHIV and suggest recommendations for modifying policies and programs.

Transition off Supplementation

Weaning or transitioning clients off food supplementation is the biggest programmatic challenge facing this and similar interventions. Yet, it is one of the most important program components if short-term improvements in clinical and nutritional outcomes are to be sustained. Qualitative evidence from this sample suggests that constraints to meeting nutritional needs persist even after a degree of physical recovery. Nutrition interventions may be short-term in delivery, but the overall objective is to foster longer-term nutrition security for PLHIV and their households. Individual and household resilience to the impacts of HIV and AIDS involves both short and long-term strategies. It is recommended that AMPATH and similar programs strengthen their investment in the process of transitioning clients off food supplementation. Similar future programs should establish strategies for transition off food from the outset of program design.

Weaning should ideally occur when secure strategies for meeting food needs are in place, either through a patient's return to productive activities or their household's generation of food and/or income. Resource constraints and increasing patient enrollment pose obstacles to such an ideal progression. The current six-month period of supplementation may be too short for many patients to recover sufficiently and make long-term plans for food security. Programmers, clinical care providers, and researchers need to collaborate in determining what constitutes an appropriate duration of food supplementation for patients on ARV treatment. These guidelines then need to be translated to donors to ensure that timelines for supplying resources for food supplementation are meaningful in the context of beneficiaries.

Criteria to determine a patient's ability to wean off food support need to be better clarified among both AMPATH program staff and patients. The stress and anxiety food clients experience about ending food supplementation should be addressed. Information about the purpose and duration of

the nutrition intervention needs to be clearly communicated to each client by program staff to avoid creating false expectations or misunderstandings about the extent of support available.

One question that emerged from this review of a short-term nutrition intervention is whether long-term strategies for meeting nutritional needs should be in place before any patients are weaned off food supplementation. The growing global interest in linking nutrition care to ARV treatment must not overlook the parallel need for long-term strategies to ensure nutrition security. Yet, as with other strategies to mitigate the impacts of HIV and AIDS on individuals and households, the epidemic is moving too fast to wait until well-functioning systems are in place. The rising enrollment in AMPATH's treatment program each month mandates continued action and provision of services while these challenges are addressed.

Post-intervention Monitoring Systems

Tools for individual assessment need to be further developed. Anthropometric and clinical indicators should be coupled with assessments of a patient's ability to meet their nutritional needs post-intervention when determining suitable time frames for ending supplementation. The need to establish appropriate exit criteria for supplementary food programs is emphasized in the Office of the US Global AIDS Coordinator's recent "Report on Food and Nutrition for People Living with HIV/AIDS" (OGAC 2006). Currently, there is no systematic analysis of data on how AMPATH patients who have transitioned off food support are meeting their nutritional needs post-intervention. There is no system in place to assess whether the intervention has achieved its goals beyond the period of food supplementation. One limitation of this study is that it did not follow up patient households to assess their food security status post-intervention. Meeting long-term objectives requires regular monitoring of patient nutritional status and their ability to meet their nutritional needs. AMPATH has the advantage of a state of the art electronic medical records system that stores regular clinical and nutritional data on all patients enrolled in the treatment and care program. Building on this existing resource, steps to monitor and evaluate post-intervention outcomes could be developed.

The real possibility of patients requiring re-introduction to food supplementation should be taken into consideration in program design. Monitoring data can also be used to detect when a patient experiences a decline in nutritional status that necessitates additional food supplementation. Beyond clinical indicators, qualitative data on why the patient's nutritional status deteriorated post-intervention would help program staff to respond to the specific vulnerabilities a patient faces after transition off food and facilitate the development of long-term strategies for nutrition security.

Program Monitoring and Evaluation

Action to treat HIV-positive individuals should not be stalled because of lack of downstream program evaluations. The evidence base of what works continues to grow, with nutrition interventions poised for systematic evaluation and documentation. In the meantime, a learn-by-doing approach has to be adopted and remain adaptable to feedback of new information. This calls for putting in place monitoring and evaluation systems and operational research designs. Formal operations research can speed up the efficiency in identifying program successes and shortfalls so as to develop strategies to modify the nutrition intervention as necessary.

Build Linkages with Partners

Through local and international partnerships, AMPATH's comprehensive model for patient care, medical education, and research has proven a success in delivering ARV treatment in resource poor settings (Wools-Kaloustian et al. 2006). Outreach and support services play an important

role in reducing stigma. Education and prevention campaigns need to partner with community-based organizations to work toward decreasing stigma. AMPATH should continue to intensify community outreach to educate and involve communities in the long-term care for people living with HIV and strive to reduce stigma that remains a barrier to mobilizing support and further remove obstacles to testing and accessing treatment.

However, one institution cannot be expected to meet all the needs of patients and their households. The food supplementation program further demonstrates the need to promote linkages and external partnerships based on comparative advantage. For example, one area where AMPATH should continue to expand its current network of partners is long-term sustainable rural livelihood strategies. The urban-based Imani Craft Workshop is one example where AMPATH has successfully partnered with international artists to create secure employment opportunities for patients. But, as the majority of AMPATH's patients depend on agriculture for their livelihoods, greater linkage with local and national institutions may be necessary to achieve its goals. Forging linkages with institutions that have a comparative advantage in developing rural income security programs is one possible step forward to address the challenge of long-term needs. AMPATH could also forge stronger linkages with the national agricultural sector on issues of food production.

Seasonal Shifts in Demand for Food Supplementation

Just as treatment should be for life, so should the application of lessons learnt about the importance of good nutrition. AMPATH's strong education component has made patients aware of their special nutritional needs and now each patient and their household faces the challenge of meeting those needs. For some, few obstacles exist to accessing the recommended balanced diet; we learned that even non-food program patients apply the new knowledge and modify their diets accordingly. However, in resource poor settings, we can expect a high proportion of PLHIV to be food insecure and to face additional obstacles to following nutritional recommendations. Within AMPATH's network of 14 treatment centers, levels of food insecurity vary anywhere from 20-50 percent. Some households may experience periodic food insecurity and require food assistance. The available number of food rations should take into account seasonal patterns in food insecurity and adjust upwards during the dry season to respond to increased needs for assistance by patients and their households.

Reducing Stigma Associated with Food Collection

Stigma associated with collecting food from program distribution sites appears to fade with time. However, in seeking to "do no harm," AMPATH's HHI program may in the future consider removing the labels on the fermented milk packets they distribute that contain HIV-related messages and graphics – especially given widespread perception by patients that they receive sufficient education and counseling at the clinic. Labeling any of the supplemental foods with AIDS-identifying messages, even when intended for educational purposes, is inappropriate in a population of patients that have not widely disclosed their HIV status to family and friends. To quote the informants, "*let food be food.*" Similar programs should incorporate initiatives to reduce stigma in program objectives.

Initiation of Supplementation

Other tough programmatic questions relevant to the international community emerge from this research. Clearly all malnourished individuals, HIV-positive or not, are in need of improved nutrition through whatever means are appropriate and feasible. We now know of the critical importance of good nutritional status at the time of initiation of ARV therapy, as mentioned earlier. For those who are living with HIV, knowing that energy requirements increase even in

asymptomatic individuals begs the question of when nutrition interventions should be initiated. It is plausible (and currently being researched) that better nutrition may prolong the asymptomatic period of relative health and delay the need to initiate antiretroviral therapy. The universal provision of nutrition education to all AMPATH patients regardless of whether they are on ARV treatment or not is one measure to address these needs. But more may be needed. This is a critical area for further research.

Economic Sustainability

Finally, an economic evaluation of the cost-effectiveness of the nutrition intervention should be undertaken to allow for future planning. Donor funding has been considerable up to this point, but longer-term financial planning for a sustainable initiative is important to ensure that these services can continue to meet demand. This may even include a comparison of the current direct distribution of supplementary foods with cash transfers, both in terms of the ability to strengthen individual and household nutrition security and costs incurred directly by the program and clients.

Programming for the treatment and care needs of people living with HIV in sub-Saharan Africa must take a comprehensive approach because of the complex and wide-reaching impact of the epidemic on individuals, households, and communities. The importance of integrating nutrition security into program objectives is increasingly being recognized. A greater commitment of resources to support such interventions will be necessary, thus requiring more evidence of the interactions between nutrition and treatment outcomes.

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