

Nutrition policy paper #20



Report of the 28th Session Symposium held 3-4 April 2001, Nairobi, Kenya

Nutrition and HIV/AIDS



United Nations Administrative Committee on Coordination
Sub-Committee on Nutrition

United Nations Administrative Committee on Coordination Sub-Committee on Nutrition

ACC/SCN

The UN System's Forum for Nutrition

The Administrative Committee on Coordination (ACC), which is comprised of the heads of the UN Agencies, recommended the establishment of the Sub-Committee on Nutrition (SCN) in 1976, following the World Food Conference (with particular reference to Resolution V on food and nutrition). This was approved by the Economic and Social Council of the UN (ECOSOC) by resolution in July 1977. The UN members of the SCN are ECA, FAO, IAEA, IFAD, ILO, UN, UNAIDS, UNDP, UNEP, UNESCO, UNFPA, UNHCHR, UNHCR, UNICEF, UNRISD, UNU, WFP, WHO and the World Bank. IFPRI and the ADB are also members. From the outset, representatives of bilateral donor agencies have participated actively in SCN activities as do nongovernmental organizations. The Secretariat is hosted by WHO in Geneva.

The **mandate of the ACC/SCN** is to serve as the UN focal point for promoting harmonized nutrition policies and strategies throughout the UN system, and to strengthen collaboration with other partners for accelerated and more effective action against malnutrition. The **aim of the SCN** is to raise awareness of and concern for nutrition problems at global, regional and national levels; to refine the direction, increase the scale and strengthen the coherence and impact of actions against malnutrition worldwide; and to promote cooperation among UN agencies and partner organizations. The SCN's annual meetings have representation from UN Agencies, donor agencies and NGOs; these meetings begin with symposia on subjects of current importance for policy. The SCN brings such matters to the attention of the ACC and convenes working groups on specialized areas of nutrition. Initiatives are taken to promote coordinated activities—interagency programmes, meetings, publications—aimed at reducing malnutrition, reflecting the shared views of the agencies concerned. Regular reports on the world nutrition situation are issued. *Nutrition Policy Papers* are produced to summarize current knowledge on selected topics. *SCN News* is published twice a year, and the *RNIS* is published quarterly.



Joint United Nations Programme on HIV/AIDS

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The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together eight UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its eight cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners—governmental and NGO, business, scientific and lay—to share knowledge, skills and best practice across boundaries.

**The ACC/SCN Secretariat wishes to thank and most gratefully acknowledges
funding assistance from:**

**World Food Programme
Office of AIDS Research; National Institutes of Health
USAID and the ILSI Research Foundation
The Government of the Netherlands
for the preparation and production of this Nutrition Policy Paper**

Suggested citation for this Nutrition Policy Paper:

ACC/SCN (2001) *Nutrition and HIV/AIDS*. Nutrition Policy Paper No. 20. ACC/SCN: Geneva

UNAIDS/01.78E (English original, October 2001)
ISBN 92-9173-136-6

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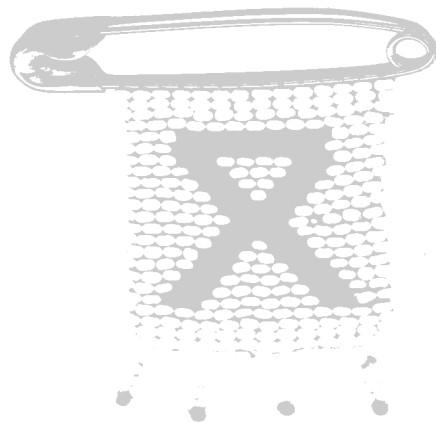
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iThemba Lethu

The watermark appearing next to chapter headings is bead work provided by iThemba Lethu, a voluntary association in South Africa.

iThemba Lethu was constituted by a group of people with a concern for the future of young people and children threatened by HIV/AIDS, especially in the Durban area.

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Foreword and Acknowledgements

This Nutrition Policy Paper is based on the ACC/SCN Symposium on Nutrition and HIV/AIDS held in Nairobi in April 2001. The objective of the symposium was, firstly, to stimulate collaboration between the nutrition and HIV/AIDS communities. The second objective was to examine a broad range of nutrition issues that have a direct bearing on policies and programmes aimed at stemming the spread of HIV and mitigating the worst effects of AIDS. This report provides technical information, policy guidance and informal reflections. It also contains the ACC/SCN statement arising from the symposium, and in Annex 1, a fact sheet on the interactions between nutrition and HIV/AIDS. I am most pleased that this report is co-published with UNAIDS, thus helping to ensure the widest possible dissemination to professionals working in both nutrition and HIV/AIDS.

The Symposium was opened by the Minister for Public Health for Kenya, Dr. Sam Ongeri, who described some of the challenges that public health officials in Kenya are facing because of the HIV/AIDS burden. The list of challenges is daunting, however, there is much that could be done in the nutrition area to bring improved quality of life for those living with HIV/AIDS, Dr. Ongeri concluded. Dr. Peter Piot, in his keynote address, noted that while he had worked in the HIV/AIDS field for some 20 years, this was the first time he had spoken to a nutrition audience. His message was clear: the voice of nutrition needs to be heard loudly and clearly in the HIV/AIDS community, where innovative partnerships can serve to move the agenda forward.

Invited papers touched upon development impacts at both micro and macro levels, principles of food security and nutrition programming and grassroots community-driven efforts to provide care services. A special presentation by Minister of Health and Social Welfare from Swaziland, Dr. Phetsile Dlamini, offered personal insights into the role that nutrition can play as a central ingredient in the care package. The panel in the afternoon and the audience discussion following it, highlighted a number of important points concerning gaps and opportunities in the delivery of nutrition programmes. Finally, Lucy Thairu's *Dr. Abraham Horwitz Memorial Lecture* described field research on mother's infant feeding choices and implications for policy makers.

The symposium drew a large audience from eastern and southern Africa, hence discussion throughout the day tended to focus on issues of relevance to this region. However, I trust this Nutrition Policy Paper will be useful as well to the ACC/SCN's wide readership of nutrition professionals in all regions, by introducing important new perspectives on effective community-based responses.

This report was edited by Sonya Rabeneck. Sincere thanks are extended to Josef Decosas, Ted Greiner, Richard Jolly, Ellen Piwoz and Marti van Liere for extensive critical comment on the draft report. Contributions from Elizabeth Johnston, Hooman Peimani and Lindsay Barrett-Gillespie towards the technical content, copy editing and artwork are gratefully acknowledged. We are most grateful to the World Food Programme; the Office of AIDS Research, National Institutes of Health; USAID and the ILSI Research Foundation; and the Government of the Netherlands for providing funding support.

Namanga Ngongi
Chair, ACC/SCN

Statement by the ACC/SCN at its 28th Session

6 April 2001, Nairobi, Kenya

Nutrition and HIV/AIDS

We, the ACC/SCN, recognize the devastating impact the HIV/AIDS epidemic is having on development, particularly in Africa. We further recognize that the epidemic is increasingly driven by factors that also create malnutrition—in particular, poverty, conflict and inequality.

HIV/AIDS and malnutrition often operate in tandem. Poor nutrition increases the risk and progression of disease. In turn, disease exacerbates malnutrition.

HIV/AIDS can be both a cause and a consequence of food insecurity. HIV/AIDS leads to reduced agricultural production, reduced income, increased medical expenses, thus causing reduced capacity to respond to the crisis. Food insecurity may lead to increased high-risk behaviors, for example, labour migration or engaging in transactional sex that increases the likelihood of infection.

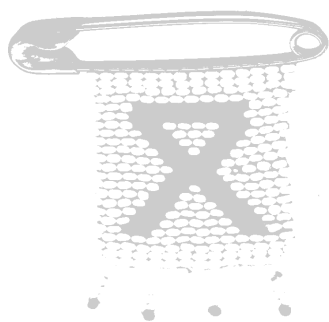
Food and nutrition play an important role in prevention, care and mitigation activities in HIV/AIDS-impacted communities.

We, the ACC/SCN, recognize that:

- 1) the HIV/AIDS epidemic is not just a health issue but is reversing hard won development gains
- 2) a community-driven multi sectoral approach must be supported to address food and nutritional needs of all vulnerable populations
- 3) access to food is one of the main problems of HIV-impacted communities
- 4) nutrition and food security is a logical entry point for assisting affected communities
- 5) over time AIDS prolongs and deepens poverty, strips all assets and depletes human and social capital
- 6) HIV/AIDS attacks the most productive segments of the population, leaving behind children and the elderly
- 7) stigma undermines social capital and limits health-seeking behavior, including prevention of mother-to-child-transmission
- 8) women who are key actors in household food security and caregiving are particularly vulnerable to the effects of disease and its impacts
- 9) HIV/AIDS impacts agriculture through labor shortage, knowledge loss and a loss of formal and informal institutional support and capacity
- 10) breastfeeding remains of fundamental importance to child survival and development, whilst there is evidence of limited transmission of HIV through breastfeeding
- 11) nutrition is a core component of the essential HIV/AIDS care package promoted by UNAIDS

We, the ACC/SCN, commit ourselves to collaborate with you in this effort by:

- 1) integrating food security and nutrition considerations into HIV/AIDS programming
- 2) concurrently addressing the HIV/AIDS crisis in our food and nutrition work, using existing nutrition networks and programmes
- 3) identifying and implementing optimal approaches to food-assisted activities as part of larger care and mitigation programs, as well as food production and processing activities
- 4) taking steps to reduce stigma and protect human rights of people affected by HIV/AIDS, including the right to food
- 5) elaborating and fully implementing nutrition care and counseling as part of the essential HIV/AIDS care package
- 6) operationalizing pragmatically the UNAIDS/UNICEF/WHO policy statement on *HIV and Infant Feeding* while protecting, promoting and supporting optimal infant feeding for child survival among all women.



Overview of the 29th Session Symposium —Nutrition and HIV/AIDS

The Minister for Public Health, the **Honorable Professor Sam K. Onger** welcomed participants to the Symposium, outlined the history of the development of HIV/AIDS in Kenya, provided a picture of the current situation and enunciated Kenya's pragmatic policy to concentrate efforts on HIV prevention. In 1990 the prevalence of HIV in Kenya was 3.9%; in 1998/99 it was 14% nationally, while several age groups have much higher rates. Amongst teenagers, 24% are HIV-positive in the year after first sexual contact; this increases to 46-50% five years after first sexual contact. In total, about 2.1 million Kenyans are infected with HIV and this number is increasing daily. About one million children are orphaned in Kenya because of HIV/AIDS. Interventions have focused on prevention through behavioural change; without these programmes in place Kenya may have seen a national rate of close to 30% by now.

One area of serious concern for the health sector is bed occupancy in hospitals. AIDS patients occupy 50% of beds in some district and provincial hospitals in Kenya. This has enormous implications for staffing and the quality of care. Minister Onger explained that if all AIDS patients were to receive appropriate treatment, the cost would amount to close to KShs 12 billion per year; whereas the budget of the Ministry of Health for all preventive and curative services is about KSh 9 billion. HIV/AIDS in Kenya, as elsewhere in Sub-Saharan Africa, co-exists with malaria, tuberculosis and other infectious diseases.

Kenya has adopted a strategic plan to combat the spread of HIV infection and to give priority to a comprehensive care services package for

those with AIDS. Nutritional care is very much part of this strategic approach. Minister Onger argued that large-scale campaigns to promote healthy behaviours and good nutrition can be effective in poor populations. However, these efforts need to be flexible, adapted to the real needs of the people, and coupled with poverty reduction strategies. In Kenya, the role of the family and the community is emphasized in programme design and implementation. Minister Onger also stressed that breastfeeding promotion, support and protection takes on a new significance and importance in the face of the HIV/AIDS epidemic. Existing programmes need strengthening, as stigma and misinformation erode past gains.

In his keynote address **Dr. Peter Piot, Executive Director of UNAIDS**, stressed that HIV/AIDS is most often one additional burden on top of many others. In Sub-Saharan Africa in particular, AIDS emerged against a backdrop of poverty, conflict and inadequate infrastructure. By eroding social capital, its effect has been to make those problems and their consequences far worse. HIV/AIDS has decimated the very generation of young adults poised to take Africa's future into their own hands. There are over 25 million people living with HIV in Sub-Saharan Africa; in some countries over one in three adults is living with HIV/AIDS. AIDS is not a disease of poverty, and often those first affected by the epidemic are the better educated and more mobile sections of a population. However, over time AIDS and poverty cement their relationship.

Dr. Piot went on to discuss the relationship between nutrition and HIV. Like poverty and HIV, nutrition and HIV operate in tandem, both

at the level of the individual and the society. For individuals, nutrition deficits make people with HIV more susceptible to disease and infection. Indeed, malnutrition is one of the major clinical manifestations resulting from HIV infection both in children and in adults. At the social level, food insecurity is a major cause of vulnerability to HIV. The impact of HIV is felt in reduced agricultural production as well as in increased fragility of affected households. However, Dr. Piot emphasized, we are not powerless in the face of AIDS. We know what works to turn the epidemic back. Effective responses to the HIV epidemic come from unified national planning, access to essential prevention and care commodities, and a public environment where people with HIV and those most at risk are not excluded, but considered part of the community and part of the solution.

Dr. Piot said that the nutrition voice needs to be heard louder and stronger in the HIV field. He called upon the nutrition community to assist with applying proven strategies on a scale commensurate with the epidemic. The time for pilot projects is over. Mainstreaming and decentralizing our work are all important. Success comes from long-term sustained commitment. Moving to specific challenges, these areas were identified as needing intensive work.

Emergencies, including food emergencies, need to be the focus for interventions to reduce HIV risk. When populations are on the move, basic security is threatened and HIV risk rises.

We must pay attention to sustainability and overcoming long-term vulnerability, while dealing with the immediate impacts of AIDS. Two examples are cultivating less labour intensive crops which may not be good food sources and keeping children in school while adults are ill and dying.

There is a need to assess the impact of rural development on the spread of HIV. Will agricultural development plans add to HIV risk? Will new transport routes increase the spread of HIV? These questions, and others, need to be built into the World Bank's poverty reduction strategies.

Nutrition must be brought into the essential care package. "Care" has somehow been narrowed to the cost of anti-retrovirals and this is counter productive.

Women need to be supported in their infant feeding choices, and this should be coupled with

...the nutrition voice needs to be heard louder and stronger in the HIV field..."care" has somehow been narrowed to the cost of anti-retrovirals and this is counter productive

confidential testing and counselling. Testing is all too rare amongst poor African women. Unless women know their sero-status they are unable to determine their risks.

Leadership, commitment and compassion are needed to attack stigma and discrimination, two of the

major barriers to effective responses to the epidemic.

HIV poses gender challenges, and these need to be faced. Addressing relationships between men and women is at the core of successful behavioural change to prevent the spread of HIV.

Mrs. Sophia Mukasa Monico, Director of The AIDS Support Organization (TASO),

picked up on many of these issues in her presentation of the work of TASO, a grassroots organization in Uganda. AIDS was first recognized as a new disease in Uganda in 1982. In 1986 a national AIDS control programme was established and the government called for collective action. By 1990, an estimated 1.5 million adults and children were infected with HIV, and, by 1992, 16% of military recruits were sero-positive. However, by June 1995, the incidence of HIV in Uganda was already falling, and the prevalence started to fall by 1997. HIV infection rates are declining in antenatal clinics in Uganda; for the country as a whole, the infection rate has declined from an estimated 24% in 1992 to 8.3% by the end of 2000. This decline has been especially evident in youth between 15 and 25 years.

TASO has played a key role in the fight against the spread of HIV/AIDS, starting in 1986 as a group of 16 family members of people living with HIV/AIDS. At this time in Uganda, hospitals were not receptive to HIV/AIDS patients, and one of the main actions of the group was to sensitize hospital staff. TASO was legally incorporated in November 1987, to provide care and support for persons with HIV/AIDS and their families at Mulago Hospital, the biggest referral hospital in Kampala. TASO was thus founded to contribute to the process of restoring hope and improving the quality of life of persons and communities infected and affected by HIV/AIDS.

TASO offers support at the individual, family, community and national and international levels. One-to-one counselling which empowers people living with HIV and AIDS to make informed decisions that improve the quality of life and facilitate a balance between rights and re-

sponsibilities, is a key area for TASO. At the personal level, TASO also provides compassionate care, early diagnosis and treatment of opportunistic infections to encourage positive living and dying with dignity. At the family level, TASO counsels family members to dispel fears of contracting HIV through casual contact. TASO also facilitates community-planned responses, community evaluation of the responses and mobilization of community resources.

Mrs. Monico discussed the role of food assistance as an incentive for clients to seek services. In TASO's experience, distributing food attracts people living with HIV/AIDS to access services. Nutrition counselling and education are important components in the TASO package of care services and help clients to use locally-available food resources wisely. The nutrition education component also aims to encourage clients to try new foods. Nutrition counselling helps clients understand that living with HIV/AIDS means living with higher protein and energy needs.

TASO shares the national outlook of the "good enough care" strategy for people living with HIV/AIDS that Uganda has adopted. This strategy includes management of opportunistic infections using readily available and affordable diagnostic and treatment strategies. Good enough care encompasses promotion and practice of positive living including good nutritional habits. TASO's view is that people have more control over their diets than nearly any other factor affecting their health.

In his presentation on HIV/AIDS and development, **Professor Oliver Saasa**, said that national HIV prevalence in Zambia is about 20%, considerably higher than in Uganda. Sentinel site surveys carried out amongst women attending clinics in major urban centers show that 27% of antenatal women are sero-positive. Similar survey findings from rural areas indicate a rate of around 14%. The epidemic is imposing an unsustainable and mounting burden on households, firms and the public sector. Long periods of illness of skilled personnel in employment result in considerable loss to employers. The AIDS epidemic needs to be viewed, Professor Saasa said, as an immense challenge to capacity building and development. Impacts at the macro-level include increased costs of production, as the quantity and quality of the labour force diminish. Impacts on industry due to working hours lost poses a serious threat to sustainable productivity. One study of

impacts on the petroleum industry in Zambia showed that the economic impact of the pandemic, the cost of medical care, salary compensation for the families of deceased employees and funeral grants more than doubled in a two-year period in the early 90s. In the education sector, deaths among school teachers will exceed total output from all primary teacher-training colleges in the country. The HIV/AIDS fight must be placed at the center of each African country's capacity-building agenda, he concluded.

In a review of generic principles for maximizing the contributions of food and nutrition programming to mitigate the impacts of HIV/AIDS, **Dr. Stuart Gillespie** developed the notion of the "HIV lens". This means taking a hard look that the role that existing interventions and policies play, or could play, in HIV/AIDS mitigation before completely new capacity-straining interventions are developed. These questions need to be asked: when do governments, NGOs, communities and development agencies need to a) improve

Programmes to address women's nutrition...need much greater support all around

the performance of existing efforts, b) view HIV-prevention and mitigation interventions through a poverty lens and modify appropriately, or c) design completely new interven-

tions to address HIV/AIDS? Dr Gillespie noted that food security programming *per se* is very weak in many countries. This is coupled with the fact that many countries do not include extensive food security policies and programmes in their overall poverty reduction strategy, which marginalizes the issue further.

Options for action were then presented at three levels: nutrition policies and programmes, programming food aid, and agricultural policies and programmes. For people living with HIV/AIDS, nutritional care and support is critically important in preventing nutritional depletion. The specific objectives might include improving the quantity and quality of the diet, to build or replenish body stores of micronutrients, to prevent or stabilize weight loss, to preserve muscle mass, to prevent diarrhoea, to speed recuperation from HIV-related infections, and to prepare for and manage AIDS-related symptoms that affect food consumption and dietary intake. Nutritional support has the potential to prolong life, an impact which will be greatest if interventions take place early in the course of the disease. Unfortunately, relatively few people know they are infected at this time.

In applying the "HIV lens" it becomes clear that breastfeeding promotion and comple-

mentary feeding programmes will need to further emphasize the dissemination of clear information to policy makers, health providers and communities about mother-to-child transmission facts. This includes risks and benefits of breastfeeding. Programmes will need to anticipate that households affected by HIV/AIDS will have even greater time and economic constraints to the provision, preparation and feeding of appropriate complementary foods. Programmes to address women's nutrition may not require substantial content changes, but need much greater support all around, especially for breastfeeding women. All nutrition programming should be community driven, not just community based.

Dr. Gillespie noted that the role of food aid in HIV/AIDS mitigation and care has just begun to be explored by field-based organizations. The biggest challenge for food-assisted interventions is to provide food to meet needs but also to programme interventions so that family members and communities are left with a means to improve their food and nutrition security after the food assistance stops. There is a role for food aid in both care and mitigation packages, however, good programming principles need to be followed. Dr. Gillespie suggested four principles: a) there needs to be a clear need for food, b) food should be provided as part of a larger package of assistance, c) food can be combined with training or income generating activities to improve food access and to increase self-sufficiency, and, finally d) close consultation with affected communities on how to target and deliver food assistance needs to be an integral part of the programme.

In her presentation on nutrition and the care package, **Dr. Phetsile Dlamini, Minister for Health and Social Welfare of Swaziland** said that in the wave of excitement about anti-retrovirals some of the practical and affordable solutions, including good nutrition, have been forgotten. Also, policies and programmes offering improved care for people living with HIV/AIDS have neglected issues of nutrition. Liking good nutrition to the strong foundation and walls of a house, Dr. Dlamini called attention to the need for programmes to promote indigenous foods, some of which are rich in micronutrients, especially anti-oxidant nutrients. The focus of nutrition work should be on sustainable community solutions such as small gardens near the home and advice on what foods to grow. Dr. Dlamini cautioned that although anti-retrovirals need to be

...policies and programmes offering improved care for people living with HIV/AIDS have neglected issues of nutrition

made affordable and available, these treatment regimes may not work optimally in a vacuum. On the role of nutrient supplementation, Dr. Dlamini suggested that making supplements available to all may

help to de-stigmatize HIV disease. Finally, there is a need for nutrition counselling to be practical, feasible, and for materials to be published in the local language.

Dr. Dlamini then joined a distinguished panel to discuss the implications of HIV/AIDS for nutrition programmes in the region. She was accompanied by Dr. Elizabeth Marum of the Center for Disease Control and Prevention, Nairobi, Dr. Ruth Nduati of the University of Nairobi, and Dr. Phillip Mwalari of Kenya's National AIDS Control Council. **Dr. Elizabeth Marum** opened the discussion by presenting the findings of an assessment of home-based care programmes in Malawi. The findings relate to the issue of hunger among people living with HIV/AIDS, and the problem of home-based care programmes, in general, which are often not well designed. Fifty patients or their caregivers were interviewed. The needs and requests articulated by the interviewees were very simple: food, pain-killing medications, soap, bed clothes and help with household tasks. Sadly, these basic needs were not being met by the home-based care programmes. While 86% of the patients reported needing food, only one patient was receiving food on a regular basis. The home-based care programmes, some of which were well funded by external donors, did not provide any food supplements. Volunteer caregivers were providing food from their own homes. Here, and elsewhere, in the region Dr. Marum said that she had observed an excessive dependence upon volunteers in care programmes. She suggested that food aid could be used to compensate the volunteers for their time.

Dr. Ruth Nduati discussed HIV and nutrition of women, and explained why energy requirements are elevated during HIV disease. She went on to pose a series of questions about the impact of increased nutritional demands of pregnancy and lactation on HIV disease progression in mothers. The co-existence of lactation and HIV is a very significant metabolic challenge. The requirements of increased resting energy expenditure, plus energy needed to support exclusive breastfeeding, are equivalent to one whole extra meal per day, providing at least 750 kcals. Dr. Nduati drew attention to the special needs of

HIV-infected women who have experienced child death. These women tend to have shorter birth intervals because they try to replace the child who has died. The role of micronutrient supplementation was touched upon: one study carried out in Tanzania amongst HIV-positive, pregnant women showed that use of vitamins reduced low birthweight by 44%.

Dr. Phillip Mwalari presented some of the approaches of the National AIDS Control Council in Kenya. The Council has set up a network that takes messages to the grassroots level. At the provincial level the Provincial HIV/AIDS Coordinating Committee has HIV/AIDS coordinating units in the public and private sectors. With this approach the Council hopes to transfer as much as 60% of the available resources to the community. Dr. Mwalari emphasized that a strong multi-sectoral approach is needed in both nutrition and HIV/AIDS work.

In introducing the ACC/SCN Dr. Abraham Horwitz Memorial Lecturer, the chair noted that **Ms. Lucy Thairu** was selected from amongst eight finalists in an essay competition administered annually by the ACC/SCN Secretariat. Ms. Thairu, a graduate student at Cornell University, based her paper on field work carried out in Kiambu district, Kenya, on infant feeding options for mothers with HIV/AIDS. In introducing her research Ms. Thairu stressed the importance of dialogue with mothers and using women's insights to guide policies. Although breastfeeding accounts for only part of mother-to-child transmission of HIV, in countries where both fertility and rates of HIV infection among pregnant women are high, the issue of HIV transmission through breastfeeding is of public health importance. For poor women living in developing countries the choice not to breastfeed is, obviously, much more problematic than for affluent women in northern countries.

Ms. Thairu first reviewed the literature on informed choice. By far the majority of pregnant women in Sub-Saharan Africa are not tested for HIV, so their status is unknown both to themselves and the health worker. Even where women get tested, some studies show that health care providers do not have accurate information to share with HIV-positive mothers, and may convey a lesser risk for formula feeding than for breastfeeding. Also, the widespread belief that all babies of HIV-positive mothers will be born infected needs to be countered with accurate information on the rate of mother-to-child transmis-

sion and current understanding of the risk of transmission through various routes. Regarding how infant feeding choices are made, in some communities a woman's authority to make infant feeding decisions may receive scant respect. Early detection of HIV will enable mothers to recognize their role in infant feeding decision-making. Ms. Thairu argued that women should receive this information as early as possible, either prior to pregnancy or during antenatal care, allowing time for reflection.

There are relatively few reports, and even fewer published studies, on women's views of infant feeding options, including exclusive breastfeeding, animal milks, wet nursing, heat treating expressed breastmilk and others. There is a paucity of data on the perceptions of mothers as decision-makers in guiding policies and counsellors' advice. Knowledge about women's ideas, opinions, feelings and experiences suggests specific ways in which health care providers can facilitate informed decision-making. Providing information

By far the majority of pregnant women in Sub-Saharan Africa are not tested for HIV

about infant feeding options needs to be individualized, and must be unbiased and accurate to help women make a decision that is in keeping with personal values and beliefs.

In Ms. Thairu's field study, women were asked what alternative they would choose if they hypothetically tested positive for HIV. A set of infant feeding options was presented to them. These included: expressed and heat-treated breast milk, milk banks, goat's milk, wet nursing, infant formula and cow's milk. Women were requested to give their opinion on all of the options presented.

Only 34% of the women stated that they were willing to breastfeed exclusively for three months if they tested positive for HIV. Only nine percent would choose to heat-treat expressed breast milk. About one quarter of women said they did not believe that heat treatment could inactivate the virus. Only 12% of women would consider banked milk. More than one half (56%) said they would consider infant formula, and some women perceived its composition as being close to that of breastmilk. A large majority of women (86%) said they would use cow's milk because it is widely available and believed to be fresh, compared with infant formula.

In conclusion, Ms. Thairu discussed her findings in the context of informed decision-making. In the case of a mother who opts to use cow's milk in early infancy, according to the purely informed decision-making model, if she is

accurately informed, she should not be persuaded to change her mind. However, she should be taught how to modify cow's milk to make it nutritionally adequate and safe. According to the shared informed decision-making model, such a mother could be educated on how to modify cow's milk and supplement it with micronutrients.

In summing up the main themes emerging from the papers and the discussion that followed, **Dr. Badara Samb of UNAIDS** identified priority areas for action for the ACC/SCN Working Group on Nutrition and HIV/AIDS. These are:

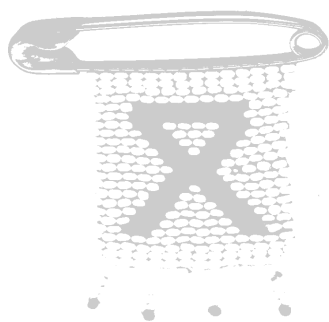
developing, testing and disseminating guidelines for incorporating nutrition into essential care packages for people living with HIV/AIDS

strengthening the promotion, protection and support of exclusive breastfeeding, especially in countries with high HIV prevalence rates

updating tables of food composition for micronutrient-rich African indigenous foods, especially those that are not labour intensive and can be grown near the home throughout the year

monitoring the food and nutrient composition of commercially-marketed food supplements aimed at adults living with HIV/AIDS

at the strategic and policy level, incorporating nutrition and HIV/AIDS programming into poverty reduction strategies.



Keynote Address

Peter Piot

Executive Director, UNAIDS

Some weeks ago I was in Malawi and met with a group of women living with HIV. As I always do when I meet with people living with AIDS and other community groups, I asked them what is their highest priority. Their answer was clear and unanimous: food. Not care, not drugs for treatment, not relief from stigma, but food.

It is easy to forget in the complicated world of global AIDS politics, that for many people around the world, AIDS is one additional burden on top of many others. AIDS does not occur in a vacuum. The basic concerns remain as they have always been: a secure, decent livelihood for themselves and their families. In Africa in particular, AIDS emerged against a backdrop of many other problems—poverty, conflict and inadequate infrastructure. By eating away social capital, its effect has been to make those problems and their consequences far worse. It has decimated the very generation of young adults poised to take Africa's future into their own hands.

Not only in Africa, but around the world, the HIV epidemic continues to grow. There were 5.3 million new cases of HIV infection worldwide during the year 2000, and three million people died as a result of AIDS—more annual deaths than ever before. Sub-Saharan Africa has been the worst-affected region, accounting for three-quarters of all the deaths caused by AIDS since the beginning of the epidemic. Today, there are over 25 million people living with HIV in this region; in some countries over one in three adults is

living with HIV/AIDS. Together with armed conflict it is the number one problem of development and survival.

As well, we need to look at the Caribbean and Central America where a number of countries are over the 2% prevalence level and should be ringing alarm bells. The same applies to some states of India, but low prevalence in other states means that national consciousness of the problem still has some way to go, despite the recent efforts of the Indian prime minister and president.

China is only at the early stages of an epidemic, but there are warning signs: escalating sexually transmitted disease (STD) rates and growing HIV prevalence in injecting drug users—reaching as high as 82% in one city.

In south-east Asia, the major epidemics in Cambodia and Myanmar continue to grow. In Eastern Europe, the epidemic has been explosive, mainly fuelled by injecting drug use. The Russian Federation had more new HIV infections in the year 2000 than all previous years combined.

This list of the most affected countries must have a depressing familiarity to those of you who have worked on food security and nutrition over many years. Of course, it is no coincidence that the maps of HIV prevalence and of undernutrition should overlap. The HIV epidemic is increasingly driven by many of those factors that also drive undernutrition—in particular poverty, conflict and inequality.

**At the social level,
food insecurity is a major
cause of vulnerability
to HIV**

AIDS is not a disease of poverty, and it is often the case that those first affected by this epidemic are the better educated and more mobile sections of a population. However, over time AIDS and poverty cement their relationship—AIDS prolongs and deepens poverty and makes it harder to escape from.

Nutrition and HIV also operate in tandem, both at the level of the individual and the society. For individuals, nutrition deficits probably make people with HIV more susceptible to disease and infections of all sorts. Malnutrition is one of the major clinical manifestations resulting from HIV infection both in children and in adults. At the social level, food insecurity is a major cause of vulnerability to HIV. The impact of HIV is felt in reduced agricultural production as well as in increased fragility of affected households.

The effect of AIDS on food production is both immediate and long-term and increasingly well documented. A study from Zimbabwe modelled the household impact of an adult death on the output of different foods, estimating reductions of 61% for maize, 49% for vegetables and 37% for groundnuts. Yet AIDS also hits long term agricultural capacity. Livestock is often sold to pay funeral expenses, and orphaned children often lack the skills to farm or look after livestock in their care.

Over the past few years, there has been a major revolution in the world's thinking about HIV. The epidemic has been understood not just as a health issue which will always remain, but as a major threat to development and to human security. However, we are not powerless in the face of AIDS. We know what works in turning the epidemic back. This is our most important lesson and conviction: otherwise there is no way we can make a difference. There is a small—but growing—number of societies in different parts of the world that have achieved sustained success against the epidemic. To the familiar examples of Uganda, Senegal and Thailand we can now add parts of Zambia and Mbeya in Tanzania. In Brazil there has been national success in curbing the epidemic.

Effective responses to the HIV epidemic come from:

- unified national planning;
- access to essential prevention and care commodities; and
- a public environment where people with HIV and those most at risk are not excluded, but considered part of the community and part of the solution.

Most importantly, we need to apply proven strategies on a scale commensurate with the epidemic. The time for pilot or demonstration projects is over. Now is the time to mainstream every aspect of our work and to decentralise. Success comes from long-term sustained commitment. Piecemeal approaches don't work. They are close to doing nothing, a waste of money.

This is a message that I know you are familiar with, because it is fundamental to nutrition practice. Let me quote from a report on HIV and nutrition by Florence Egal and Arine Valstar from the Food and Agriculture Organization:

Since nutrition requires an integrated approach to household food security, health and care, it forms a logical entry point for assisting affected communities in coping with the epidemic.

The nutrition community knows the global and the local are connected, that individual care comprises many inter-related elements, and that health always goes beyond the individual to involve the household and community. These lessons all need reinforcement within the HIV world. Therefore let me declare here that the nutrition voice needs to be heard louder and stronger in the HIV field. Let me also call on all of you to be allies in taking this message forward.

Despite what we know about how to turn back the epidemic, we are still a long way from achieving success. Let me discuss seven key challenges ahead.

First, emergencies, including food emergencies, are a major point of vulnerability to HIV. When populations are on the move and the basic security of life is threatened, HIV risks rise. Women, in particular, may often find themselves in circumstances where they are subject to sexual violence, or forced to trade sex for food. Therefore the challenge is to make sure that emergencies are the focus for interventions to reduce HIV risks. This is not easy.

We need to find innovative ways to make this happen. I am delighted, for example, that the World Food Programme is looking to use their network and logistics capacity in responding to AIDS. They will help community groups and others expert in HIV interventions to have a presence in emergency situations. They are also dealing with another very specific HIV risk that comes along with emergencies by making sure that their contract truck drivers receive intensive HIV preventive education and condom supplies. Good practice begins at home.

The second related challenge is how to break the vicious cycle between food insecurity and HIV vulnerability. As well as dealing with the

immediate impacts of AIDS, we must continue to pay attention to sustainability and overcoming long term vulnerability. Are less labour intensive crops available that are still good food sources? How do we keep children at school against the pressure for them to replace the labour of sick or dying parents? Here, we can bring together a number of initiatives that focus on schools. For example, one of the UNAIDS cosponsors, UNICEF, is working on extending the role of schools as community resource centres. This is an initiative which complements the World Food Programme's proposal that school feeding programmes should include 'take-home rations' so that whole households will have an incentive to keep children in school.

Third, we need to assess the impact of rural development on the spread of HIV. Just as environmental impact assessment has become an integral part of development programs and major projects, HIV impact assessments should also become the norm. It is disturbing to see that major investments are being planned as though HIV was occurring on another planet. Some early drafts of World Bank's Poverty Reduction Strategy Papers (the PRSPs) did not even mention HIV/AIDS. Fortunately this is changing. Will agricultural development plans break up family structures and add to HIV risk? What plans are there for addressing HIV risk if new transport routes are created? What is the HIV-related impact of cash cropping versus food security? These are important questions to be addressed during the PRSP process.

Fourth, we still have a challenge to deliver essential HIV care, and *nutrition is a core part of any essential care package*. Any discussion of the very complex issue of care and treatment of people with HIV/AIDS has been narrowed to the price of anti-retrovirals. This is a shame, it is also counterproductive. Of course, UNAIDS working with our co-sponsors has been very active in ensuring that there is progress in this area. Nevertheless I am still waiting for the day when the New York Times chooses to write a thundering editorial on the moral unacceptability of the fact that most people with HIV in Africa fail to get adequate nutrition.

Of course, we can be clever in the ways we use progress in anti-retroviral affordability. Instead of saying:

it is no use making anti-retrovirals affordable because most people don't have the clean water to take them, or they can't take the drugs on a

full stomach because their stomachs are never full

the demand should be:

now we must implement anti-retroviral access, therefore the drugs must be provided with water supplies and with food.

We are not dealing with step-by-step solutions, but solutions where we need to advance on multiple fronts simultaneously.

The fifth challenge is to turn rhetoric into reality on breastfeeding. We know breastfeeding by HIV-infected mothers carries a significant risk of HIV transmission - up to 20% in the absence of drug therapy. We also know that, HIV-transmission aside, breastfeeding is tremendously beneficial. It is one of the cheapest and most cost-effective interventions in public health and in social development. Our advice is avoidance of all breastfeeding by HIV-infected mothers when replacement feeding is acceptable, feasible, affordable, sustainable and safe.

There is a policy statement on this.

There has been so much agony over the risks and benefits of this recommendation that, perhaps, we

have lost sight of where our energies should be going. The recommendation is frankly irrelevant to most HIV infected women, because we are a long way from providing universal access to safe replacement feeding. We are a long way from exclusive breastfeeding, and even further away from providing voluntary and confidential HIV counselling and testing in the context of ante-natal care. Fewer than one per cent of women in ante-natal care in urban areas in Sub-Saharan Africa have access to HIV testing, and in rural areas their numbers are even smaller. Unless they know their status, women are unable to determine their risks. My message is that we have got to work very hard towards making progress on the ground.

The sixth challenge is to attack stigma. One reason AIDS is different from any other disease is the unprecedented stigma associated with it. It is transmitted by sex and illicit drug use. Stigma and discrimination against people living with HIV, or those thought to be most at risk, constitute two of the major barriers to effective responses to the epidemic. Unlike many of the other barriers, the costs of attacking stigma are not monetary. They take the form of leadership, commitment and compassion. Stigma is also a nutrition issue. We know of instances where, because of HIV, someone is thrown out of their

home or their village and left hungry. We also know that a woman may breastfeed in public to avoid stigma, but use formula in private to avoid transmission, unwittingly exposing her infant to the worst combination of feeding strategies.

Finally, we must face the gender challenges of AIDS. We know that women are the caregivers for the children who have lost their parents. Women do more than half the food gathering and production work. They also do more than half the care for those sick with AIDS. Now, they make up more than half of those living with HIV in Africa. Addressing relationships between men and women is at the core of successful behavioural change to prevent the spread of HIV. So, too, is addressing those gender inequalities that make the impact of HIV fall harder on women - such as, inheritance laws preventing women from holding land or livestock upon the death of their husbands.

AIDS is complex, but I don't need to tell you that. You are already accustomed to dealing with the complexities of nutrition and you know that 'magic bullets' in health are mainly an illusion and are also dangerous. They detract us and cre-

ate an appearance of safety, but we must not let the complexity of AIDS defeat us.

The solutions lie in adhering to the facts in our response, and in building new partnerships, better co-ordination, and sustainable change. Many years ago (in 1985) in Kenya, there was a silent epidemic. The research community at the time was trying to document the spread of HIV without thinking about the ultimate societal implications. What will HIV mean for the country and who should be involved in programmes to prevent transmission? There has since been a sea change, in terms of partnerships and action against AIDS. This will pay off. With a cadre of community actors Kenya will have fewer infections. One partnership that is still in its very early stages, here and elsewhere in the region, is the partnership between those whose primary concern is nutrition and those focused on HIV. We can be confident that the partnership will grow, based on the knowledge that food and nutrition policy is integral to success against AIDS.

I am sure that I can count on you to be part of that partnership.

Discussion



Comment from the audience We are off to a very good start by putting this whole aspect of HIV/AIDS and nutrition in perspective. Dr Piot, you said that the time for pilot projects was probably over. I agree with you largely, but there are pilot projects going on now in which alternative methods of feeding are being tried. This is a first, I think, for poor people in Africa to be in pilot projects where large numbers of poor women are being shown and helped to formula feed their babies. I really don't think anybody knows what the outcome of these will be, whether in fact more harm will be done than good. You explained what needed to be in place for safe alternative feeding. For most families, because poverty is so rife in Africa still, it is not feasible to do this. I really would like to hear you state whether you think countries should move beyond these pilot projects without a very careful evaluation of the risks, and it is not just the risk of diarrhoea. It is all the other infections - pneumo-

nia rates might be six times as high. If the formula is not given free there is a huge economic burden on the families. If it is given free, what happens after six months when breastmilk would still provide 80% of the nutrients and the mothers now have no breastmilk? What does it do to birth spacing if the mothers can become pregnant again in the first three months if she does not have access to family planning? I am concerned that these pilot projects are not going to be adequately evaluated so that we will not know the harm that might be done. We need to evaluate the risks before countries move to much larger implementation of those projects.

Comment from the audience There have been several references to breastfeeding but Dr. Piot you did not preface this with what seems to be emerging as the key component, *exclusive* breastfeeding. Although for years we have extolled the virtues of exclusive breastfeeding, we have not

been quite sure if it is possible. We now know that if health workers have the confidence and can transmit this to mothers, then exclusive breastfeeding is indeed possible on a population level.

Comment from the audience My first comment is a note of caution and it is something we found in our research programmes on women and AIDS and stigma and discrimination. Women face particular problems relative to the epidemic. First, sentinel sites for HIV testing tend to be in maternal child health (MCH) clinics or hospitals. That means that women are the ones who are tested in large part because men do not come to maternal child health clinics. Women are then blamed for bringing the epidemic into the household. Second, women are also viewed as vehicles for HIV transmission because of breastfeeding. Third, when supplements are given out, at MCH or other clinics, women are hesitant to take them home because this is an overt statement that they are HIV positive. These are the realities for women living with AIDS. We really need to focus on how women can protect themselves, not focus just on what happens once they become HIV positive. My second comment is that we have an opportunity now to promote the adoption of technologies that have not been given a high status, such as particular food crops and food processing technologies that will make households less vulnerable to, or will mitigate the impact of, the epidemic on women. “Women’s crops” such as roots and tubers are low status crops and post harvest food processing technologies do not traditionally generate large amounts of revenue. Little investment has been made in their development and dissemination. Yet, because women control the use and outputs related to these technologies, these are the very technologies that will help women-headed households, and others with labour constraints, maintain some level of productivity and food security in the long term.

Question from the audience Dr. Piot said that people living with HIV/AIDS in Malawi felt that access to food was their biggest problem. There is a project in Malawi, the Integrated Technology Information Education and Communication project, that focuses on community development and

uses a triple entry point in the community: food security, HIV/AIDS and population. Are there any initiatives being developed by UNAIDS in the direction of a community-based approach to HIV/AIDS?

Peter Piot First, about pilots—there are a number of things that we know about and where one should not waste time with pilots, for example, in working with young people on sex education and condom promotion in schools. There is no need for pilots in this area, although there is still a need for good evaluations. The main challenge is “going to scale” and this is not just multiplying a small project by some factor X. It is as much an art as a science. On the other hand, we have a number of things where we still have to learn what is best. We shouldn’t wait until everybody has clean water, access to aspirins, and a job, before we start talking about anti-retrovirals. There are instances where it is possible to use them now. The same thing is true when we are looking at anti-retrovirals for prevention of mother-to-child transmission. We cannot wait until the whole society is perfect. We have to wade in, and not wait for pilots, at least in the academic sense where the pilot is the final stage of the research. We need to have the courage to adapt our approach even in the middle of the project if the evidence indicates: (a) it is damaging, or (b) it is better. The key is careful evaluation and monitoring.

In terms of breastfeeding there is still a long way to go. The evidence, as I understand it from studies in Durban, is that the worst possible combination is mixed feeding, that is breast plus artificial feeding. One has to see in each environment what is attainable. We need recommendations that are practical and operational. This is an area where additional research is most needed.

In terms of initiatives for a comprehensive approach, several UN agencies are working with the government in Mozambique and using micro-credit programmes with women as the major vehicle for HIV prevention. They focus on young people, on the needs of women, including nutritional needs and integrate both the prevention and the care components. There are many more programmes happening, and even more in the pipeline.



Achievements of The AIDS Support Organization (TASO) in Uganda

Sophia Mukasa Monico
Director, TASO

AIDS or *slim disease* was first recognized as a possible new disease in Rakai district in Uganda in 1982. In 1986 a national AIDS control programme was established and the government called for collective action against the epidemic. By 1990, an estimated 1.5 million adults and children were infected with HIV; 16% of military recruits were sero-positive by 1992. However, by June 1995, the incidence of HIV in Uganda was already falling, and the prevalence started to fall by 1997. By July 2000, out of a total population of about 23 million, an estimated 820,000 people were living with HIV/AIDS. Half a million people have died from AIDS related illnesses. About

1.7 million children under the age of 14 have lost their mother or both parents to HIV/AIDS.

The good news is that HIV/AIDS infection rates are declining in antenatal clinics in Uganda. In 1992 the infection rate was around 30% in Nsambya, Rubaga and Mbarara (see Table 1), which are the major hospitals in Uganda. By 1998 the rates for antenatal attendees had dropped by one half. The median for women attending antenatal care clinics in major urban areas was 13.8%, while it was 7.7% outside the major urban areas. For the country as a whole, the infection rate has declined from an estimated 24% in 1992 to 8.3% by the end of 2000. The decrease

Table 1—HIV infection rates (%) in selected antenatal clinics in Uganda

<i>Site</i>	<i>1992</i>	<i>1993</i>	<i>1994</i>	<i>1995</i>	<i>1996</i>	<i>1997</i>	<i>1998</i>
Nsambya	29.5	26.6	21.8	16.8	15.4	14.6	13.4
Rubaga	29.4	24.4	16.5	20.2	15.1	14.8	14.2
Mbarara	30.2	18.1	17.3	16.6	15.0	15.0	10.9
Jinja	19.8	16.7	16.3	13.2	14.8	11.0	10.5
Tororo	13.2	11.3	10.2	12.5	8.2	9.5	10.5
Mbale	14.8	8.7	0.2	7.8	8.4	6.9	6.3
Kilembe	—	7.0	6.7	11.1	10.4	8.5	—
Pallisa	7.6	5.0	1.2	—	—	3.2	2.6
Soroti	—	9.1	—	8.7	7.7	5.3	7.7
Matany	—	2.8	7.6	—	2.0	1.6	1.3
Hoima	—	—	—	—	12.7	9.0	5.4
Kagadi	—	—	—	—	—	10.3	11.5
Mutolere	—	4.2	—	3.6	2.6	—	2.5
Moyo	—	—	—	—	—	—	3.2

was particularly evident in youth between the ages of 15 and 25 years. The decline in infection rates in this age group is due mainly to abstinence and staying with one partner, although condom use also played a part.

Despite the successes, the number of new infections is still high and those living with AIDS is still increasing. The demand on health care services remains very high. Caring for people who are *infected* and *affected* by HIV is an indispensable part of the response to the HIV/AIDS epidemic and that is where our organization, The AIDS Support Organization (TASO), plays a role.

The history of TASO

In 1986, a group of 16 individuals and family members affected by HIV/AIDS began meeting together in each other's homes to offer mutual support and fellowship. In the same year, this group, made up mainly of medical personnel, began sensitizing hospital staff about the needs of persons with HIV/AIDS. This was at the height of ignorance about HIV infection and hospitals were not very receptive to HIV/AIDS patients.

In early 1987, the group formed the organization TASO, and ActionAid, a non-governmental organization doing development work, provided initial funding and on-going support to this new organization. In November 1987, TASO was legally incorporated as an NGO to provide care and support for persons with HIV/AIDS and their families at Mulago Hospital, the biggest referral hospital in the capital city of Kampala. TASO was therefore founded to contribute to the process of restoring hope and improving the quality of life of persons and communities *infected* and *affected* by HIV/AIDS.

Assistance offered

TASO offers support at the personal, family, community, national and international levels, as follows:

At the personal level

One-to-one counselling which empowers people living with HIV and AIDS to make informed decisions that improve the quality of life and facilitate the balance between rights and responsibilities;

Sensitive and compassionate care which provides early diagnosis and treatment of opportunistic infections and enhances living positively and dying with dignity.

At the family level

Counselling for family members which dispels their fears of contracting HIV through casual contact;

Facilitating care of the infected and affected persons, preparing the family for and supporting them during bereavement and afterwards;

Facilitating provision of home nursing care and nutritional materials and education.

At the community level

Community counselling to empower the community to organize an appropriate response to the problems generated by the HIV/AIDS epidemic;

Facilitating community-planned responses, community evaluation of the responses and mobilization of community resources.

At national and international levels

Advocacy for better access to treatments and vaccine development;

Training appropriate personnel for service delivery;

Mobilizing resources to achieve the set organizational and national goals;

Joining of international efforts for the total defeat of HIV infection and disease.

Those who come to TASO are encouraged to live positively with HIV/AIDS. In practical terms, clients are encouraged to:

Accept their diagnosis

Promptly seek medical care

Practice safer sex

Continue to earn an income

Plan for their families and dependants

Seek counselling

Maintain a balanced diet

Have adequate sleep and exercise

Continue with normal social activities

Avoid harmful habits such as drinking alcohol and smoking

Since 1987, TASO has provided counselling, medical care and social support services to over 63,000 HIV- infected people in Uganda. Today TASO operates seven counselling centers along the East African highway, the first area that was badly hit by HIV/AIDS and one that still has

the highest infection rates. The services are also available in a hospital-based AIDS project in Arua.

The majority (68%) of TASO clients are women. In 1997, there was a decline in the registration, however, in 1998 and 1999 there was a slight increase compared to previous years. In 2000, again there was a drop in client registration which could be attributed to other organizations coming in to share the responsibility, more provision of services by government hospitals and, we hope, a decline in HIV transmission rates in Uganda.

Community involvement

By 1990, TASO realized that clinic-based services were inadequate to meet clients' needs for care and communities' needs for education on prevention and stigma reduction. Previously, TASO had delivered all of the services at the clinics, but this was becoming impossible because of the ever growing number of clients coming for services, especially medical care and food assistance. In 1991, TASO Community Initiatives began which involved working with selected sites within 35 km of the TASO centers. The TASO client became the entry point to the community.

In order to get communities involved, TASO had to find innovative methods to stimulate and captivate the communities' interest. It is not an easy task to stimulate interest in the care and support of people infected and affected by HIV, and in the prevention of further spread of HIV in the community. These methods have included equipping community volunteers with basic counselling and nursing skills, AIDS education, and using food to give a tangible value to the services that are offered. In 1991 TASO received an award from NORAD through their award programme "It Works".

In 1996, TASO started building the capacity of districts where AIDS services were either limited or non-existent. By the end of 2000, there were 22 districts which did not have TASO centers but could still deliver TASO-like services satisfactorily. TASO has trained over 120 counsellors for countries in Sub-Saharan Africa, 450 counsellors in Uganda and 150 for its own programme. By the end of 2000, TASO had worked in 94 communities and trained over 3800 community volunteers.

The volunteer counsellors are community-based people who might not have even high school education but who are committed people. They raise awareness in their communities of

HIV/AIDS, sexually transmitted diseases (STDs) and family planning. They managed to reach 86,150 people in 1999 and nearly 140,350 people in 2000. These are large numbers of clients for volunteers who are not receiving a salary but who are doing a job in their communities affected by HIV/AIDS.

Social supports and concerns

Stigma

Where stigma levels are low or non-existent the TASO centers have shown that "it works". Communities can really do a good job and clients can get services from their communities. Where stigma levels are higher and there is no well-established support, denial levels are a problem. New clients are not willing to share their positive sero-status with the community. Because some clients desperately need food, they often trade places and receive food assistance from communities other than their own. Stigma can easily lead to discrimination and might lead to violence. There was a case in South Africa where a South African woman started talking about her positive sero-status in her community and, as a result, she was beaten to death.

Food

Food assistance has attracted people living with HIV/AIDS to access services. TASO has found that in areas where food is distributed, numbers of clients will increase significantly, and management and distribution of food assistance becomes a problem. Food is a great incentive when providing care services. In Uganda, when you visit a sick person you do not visit empty-handed. If you take something you are adding value to what you are doing, especially when you are offering counselling.

TASO has relied on food donations from well-wishers. Most of our traditional donors, as well as TASO itself, feared the magnitude and implications of tackling the social needs of people living with HIV/AIDS. Food was provided sporadically by International Care and Relief and InterAid. This was at most twice a year and rations were provided only for clients. As a result of TASO's lobbying, USAID have agreed, starting later this year, to provide substantial food supplements of corn soy blend and cooking oil for five years for clients and their families.

However, in dealing with HIV/AIDS, a lot more is needed than just mere provision of food. As TASO has observed right from the beginning, most clients present with severe problems of mal-

nutrition on their first visits. Even in the absence of opportunistic infections, HIV/AIDS is very much a disease of the gut. Malabsorption is one of the frequent earliest clinical signs. This may worsen during the course of the disease aggravating complications caused by inadequate intake of nutrients as a result of anorexia, nausea, vomiting and fever. The high metabolic rate during fever contributes to the malnutrition and increases the need for energy and protein.

Therefore, for TASO clients, nutrition becomes an issue of cardinal importance in achieving the core objective of living positively and improving quality of life. Food and feeding take on new connotations. One no longer eats for the sake of reducing hunger; one eats to fight the disease and to marshal energy to maximize the effects of medication. Hence nutrition counselling and education are very important components in the TASO package of care services.

Education

TASO offers education to the care providers (mostly women) and the clients themselves. They include the mothers, sisters, daughters and spouses. In most cases, spouses are also mothers or grandmothers or aunts. Thus, our biggest target group for education is the women, even though most of these women do not earn a living and they have a very low education level.

Education entails changing adults' paradigms in the way they eat, which is not an easy thing to do. This entails teaching clients to use the foods that are available locally, and to use them in a balanced way. TASO also encourages clients to eat new foods or even foods they have never heard of. So TASO tries various ways to help clients increase their food intake so that they meet their protein and energy needs.

Approximately 75% of TASO clients have primary education or less. For them, getting a job, especially a well-paid job, is very rare. About 85% of clients who are employed earn less than US\$ 50 per month and 60% of these earnings are spent on caring for people living with HIV/AIDS in the home.

Most male clients (65%) are in a marital union compared to only 34% of the women. Most clients do not bring their partners for TASO services. The high proportion of female clients not in a marital union suggests that these clients have greater needs for social support. They do not have jobs and they are the care providers in their families. They also have their own small children to take care of. Almost all of them have children below 15 years of age.

When we talk about poverty, when we talk about all the social issues, we begin to discuss issues that are bigger than TASO's mandate and pocket. TASO's ability to manage this social component, which includes school education support and food distribution, depends on luck because TASO has never actively looked for funds to finance it. Since 1991, education support was funded by individuals, e.g. a former British High Commissioner's wife and her friend, Lady Sally March. They still fund secondary school education for 15 children at any one time. The Catholic Association for Overseas Development (CAFOD) also provided funding for primary schooling for 369 children.

In 1999, members of the US Congress contributed one million dollars to TASO for the child support initiative. The money is used on top of educational assistance to support children from the time they learn that their parents are seropositive, through child counselling and assisting parents to record their family histories and wishes for their children. This is done by writing a "memory book" for the children. Starting this year USAID is giving TASO more funds to scale up this activity. So far, only the US government has funded this activity, as a government.

Until 1999, TASO had not planned comprehensively and proactively to address issues like poverty, food security, the looming tragedy of destitute children affected by HIV/AIDS, and the provision of drugs for clients, especially expensive drugs for treatment of complicated opportunistic infections or anti-retrovirals. However, TASO "builds the ship while sailing". We are now involved on a small scale in the social concerns of people living with HIV/AIDS at the local, national and international levels.

TASO shares the national outlook of the "good enough care" strategy for people living with HIV/AIDS that Uganda has adopted. This strategy includes management of opportunistic infections using readily available and affordable diagnostic and treatment strategies. The care guidelines set out in Uganda's strategy are based on the premise that "good enough care" can be achieved with

- minimal diagnostic tests
- limited therapeutic modalities, and
- promotion and practice of positive living including good nutritional habits.

TASO's view is that people have more control over their diets than nearly any other factor affecting their health. However the reality in Uganda, especially among the majority of people

living with HIV/AIDS, is that this control is ruled by cash at hand. Consequently most clients have little choice over what they eat.

Challenges of TASO

One of the biggest challenges for TASO is maintaining community commitment and momentum for local response. The large number of AIDS volunteers we have trained work because of their personal commitment and receive no remuneration. It is a very big challenge to keep these volunteers interested and motivated. Many of them are sero-positive themselves. Another challenge is the upward trend in the percentage of TASO clients who are female. This impacts on types of services offered by TASO. Concerning the locus of TASO's work, most TASO centers are in the urban areas, where the problem has been greatest. TASO will need to expand into the rural areas in future. Clients are concerned about breastfeeding and mother-to-child transmission, also about access to anti-retroviral drugs. It is a challenge for TASO to keep abreast of policy developments in these areas and to continue to enhance and maintain quality counselling services. Finally, sustainability is a challenge. Right now TASO is funded by the government of Uganda, USAID, DANIDA, Sida and the European Union.

Lessons learned

Caring for people living with AIDS helps to prevent the transmission of HIV. The two go hand in hand.

A comprehensive program including counselling, medical care and social assistance is needed.

Integrated services for AIDS care, family planning and sexually transmitted diseases are feasible, beneficial and necessary.

Data-based decision making is the most effective way to make decisions.

Communities can be mobilized to share the responsibility for AIDS care and HIV prevention at the local level. In TASO, people living with HIV/AIDS are not just service recipients. They are also partners in community work. They use their skills through music, dance and drama. They go into communities to raise awareness about HIV and prevention and care for people living with HIV/AIDS.

Collaboration is critical among all stakeholders.

Personal commitment to a positive response to the epidemic is essential among TASO staff, clients, volunteers, donors and governments.

Sustainability of services or interventions is higher in communities where it is deeply integrated into the existing community infrastructure.

By taking services to the community, we have managed to demystify HIV and AIDS. This helps to reduce stigma in the community and facilitate access to services.

Community care and home based care reduce costs like food, transport and bedding.

The dignity of people living with HIV/AIDS is preserved, upheld and promoted in the communities where TASO services exist.

Discussion



Chair What TASO has done illustrates grass-roots reality. TASO brings hope and gives people confidence to come forward and get counselling even if there are no physical assets for them in care packages. TASO also helps to educate and mobilize communities. TASO encourages testing and sharing experiences in communities. Finally, TASO disseminates knowledge so that people can do better with the resources they have.

Question from the audience We have a lot to learn from TASO. You talked about nutrition counselling and challenges for the future, one of which is clients' concerns about breastfeeding. What is TASO doing now as far as counselling on breastfeeding and infant feeding is concerned?

Question from the audience One major challenge in this region is maintaining momentum in a mobilized community when community health workers are working for free, without any token of appreciation. What is TASO doing to maintain momentum?

Question from the audience Please comment on the disparity between the percentage of men and women who avail themselves of TASO services. Sixty-eight percent of TASO clients are women. This is a large proportion. And why do men not bring their partners?

Sophia Monico TASO is not involved with counselling on breastfeeding apart from giving information to clients. We refer most of our clients to antenatal clinics, which are doing a good deal as far as infant feeding is concerned. The message given by antenatal clinics is: breastfeeding, but no breastfeeding if you can get alternative feeding. There is a lot of stigma associated with formula and other alternative feedings. At TASO, we are not really doing a lot apart from giving information through counselling.

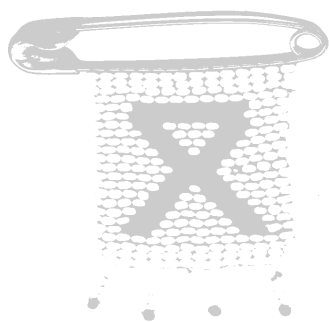
Concerning motivating field workers, we recognize in Uganda, in TASO especially, that a community worker does not look for the same remuneration as an employee. If you are given counselling skills and the community recognizes you as a community counsellor, then it is very difficult to refuse to counsel your neighbour. The people who come to you for counselling are actually your own community members and you give

counsel without realizing it. You might be given a hen or some bananas. The first remuneration is given by the community members themselves through social recognition. This motivates some community members to become community health workers. They use it to climb socially into the political arenas in their communities as well.

Another motivation is education. The certificate that TASO offers is a selling feature. Refresher courses are also offered. We also give incentives like bicycles to facilitate travel of community workers. However, at the end of the day, the volunteers often come back and ask if TASO can give them some money, which unfortunately, we cannot. We have integrated the costs of these kinds of incentives into the district HIV/AIDS budget. The district then gives incentives to their district members.

About the disparities between men and women, one big factor might be that men can afford to go elsewhere for services. TASO services are practically free. When you come to TASO, you are ready to tell the whole world "I am living with HIV". Not everybody would like to disclose their sero-status, especially men. Women are often poor and need free services. For those men who *do* seek TASO services, why do they not bring their women? Maybe they are not prepared to disclose their sero-status within their own families.

Editor's Note: Further discussion of Sophia Monico's presentation can be found on page 28, at the end of the discussion of Oliver Saasa's presentation.



HIV/AIDS and Development—Unsolved Challenges For Africa

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The Poverty Challenge

Poverty in eastern and southern Africa touches about 150 million people or about half of the population of the region. The portion of the population living below the national poverty line ranges from 11% and 25% in Mauritius and Zimbabwe respectively, to 70% in Madagascar and 86% in Zambia. A review of dollar poverty data shows that the portion living on less than one dollar per day ranges from 11% in South Africa to 64% in Zambia, while 87% in Zambia and 89% in Madagascar live on less than two dollars per day.

Most poverty in Sub-Saharan Africa is found in the rural areas. Rates of poverty in the rural areas are very high (around 90%) in some countries, namely Malawi, Rwanda and Zambia. The principal economic activity for the rural poor will continue to be agriculture. If an agricultural/rural development effort can bring the countries with the lowest per capita income up to the level of the top low-income performer, this would imply significant strides in improving living standards. Poverty prevalence by county is shown in Table 2.

There are only two countries in the region (Burundi and Uganda) where the percentage of the population below the poverty line in urban areas exceeds that of rural areas. This may be because of migration to urban areas as a result of the war. In general, the rate of poverty is highest among small farmers, herders and fishermen. Smallholder agriculture is by far the main source of income and livelihood of the poor. Poverty in rural Africa, broadly speaking, is associated with lack of ownership or control over assets such as

land, water, livestock and capital, insufficient access to a nutritionally adequate food basket, vulnerability (physical, economic and social), low and insecure income, weak social support networks and loss of dignity.

Within the agricultural sector, subsistence farmers are poorer than cash crop farmers while households with regular off-farm employment are better off than both. In Zambia, 89% of the poor work either in semi-subsistence agriculture or engage in casual farm labour in exchange for food. In Namibia, 75% of the poor live in rural areas and depend on subsistence agriculture, cash transfers and wage employment on commercial farms. In Zimbabwe, 89% of subsistence farmers in communal areas are poor compared to the national average of 6%. In Malawi, own-farm production is the main source of livelihood of the poor and accounts for 65% of smallholder income.

Poverty tends to be concentrated in households with farm sizes under one hectare and especially among those with less than one half hectare. However, across Sub-Saharan Africa there is wide variation in land productivity by agro-ecological zone. For example, in dryer areas smallholder farms are slightly larger on average sometimes reaching five to eight hectares. However, low land productivity in conditions of limited rainfall means that these farms may not even cover household subsistence needs. In most countries, poverty increases with decreasing land per capita.

Table 2—Poverty rates by country, %

Country	Population living on < USD1/day	Population living on < USD2/day	Survey year	Population below the National Poverty Line			
				Total	Urban	Rural	Year
Burundi	58	—	90	60	66	58	97
Ethiopia	31	76	95	34	32	34	97
Kenya	27	62	94	42	29	46	92
Lesotho	43	66	93	49	28	54	93
Madagascar	63	89	97	70	47	77	93
Malawi	42	—	94	54	—	90	91
Mauritius	—	—	—	11	—	12	92
Mozambique	38	78	96	71	62	69	97
Namibia	35	56	93	67	67	70	91
Rwanda	36	85	85	51	—	93	93
South Africa	11	36	93	—	—	—	—
Tanzania	20	60	93	51	20	50	91
Uganda	69	92	90	35	39	10	00
Zambia	64	87	98	86	46	88	93
Zimbabwe	36	64	91	25	10	31	91

Source: World Bank (1998) *World Development Indicators*. World Bank: Washington DC.
 UNICEF (1999) *State of the World's Children 2000*. UNICEF: New York.
 UNDP (1998 and 2000) *Human Development Report*. Oxford University Press: New York.

The human development approach gives more direct attention to people and the improvements of their lives as the central concern of development strategy and analysis. In place of GNP, the human development approach focuses on human development *achievement*, and the Human Development Index or HDI has been developed to measure this. This human development dimension is expressed, for the purposes of measurement, by a number of variables, namely, life expectancy at birth, the educational index measured by a combination of adult literacy and the rate of attendance in primary, secondary and higher education taken together; and standard of life, as measured by real per capita GDP (converted to dollars using purchasing power parities). In short, the HDI is a composite of three basic components of human development: longevity (measured by life expectancy), knowledge (measured by a combination of adult literacy and mean years of schooling), and standard of living (measured by purchasing power based on real gross domestic product per capita adjusted for the local cost of living). The HDI for a country shows the distance that it has to travel to reach the maximum possible value of 1.0, or its short fall. HDI values also allow comparisons across regions. HDI values for eastern and southern Africa (Table 3) are generally below 0.5, and several countries (Botswana, Burundi, Kenya, Zambia and Zimbabwe) have seen a reversal in

progress made in previous decades in building human capability. The reversal is largely due to a drop in life expectancy due to HIV/AIDS.

Since the concept of human development is much broader than what the HDI shows, the UNDP Human Development Reports have, over the years, constructed more specific and disaggregated indices. Among these is the Gender-related Development Index (GDI), which uses the same variables as the HDI. However, GDI adjusts the average achievement of each country in terms of life expectancy, educational level and income, in accordance with the disparity in the achievements of women and men. The greater the disparity in basic human development, the lower will be the GDI of a country, compared to its HDI.

Per capita income can be a misleading indicator of poverty. While countries with a low per capita income tend to have a high portion of the population living under the poverty line, there are exceptions. Only ten percent of the rural population in Uganda lives below the poverty line, while the national GNP per capita in 1998 for that country was \$330. Namibia and Botswana with relatively high per capita incomes, \$2210 and \$3310 respectively, still have a large share of the rural population living below the poverty line (70% and 55% respectively). These contrasts are set out in Table 4, which also shows comparative rankings of rural poverty rates and GNP per capita.

Table 3—Human development indicators by country

Country	Life expectancy at birth, years		Infant mortality per 1000 live	Adult illiteracy %		Access to Safe Water %	Human Development Index,	GNP per capita (1997) US\$
Angola	45	48	170	44	71	31	0.405	260
Botswana	45	47	38	27	22	90	0.593	3 310
Burundi	41	44	106	45	64	52	0.321	140
Comoros	58	61	67	34	48	53	0.510	400
Eritrea	50	53	70	34	62	22	0.408	230
Ethiopia	42	44	110	58	70	25	0.309	110
Kenya	51	52	75	12	26	42	0.508	340
Lesotho	54	56	94	29	7	62	0.569	680
Madagascar	56	59	95	28	42	40	0.483	250
Malawi	39	40	134	27	56	47	0.385	210
Mauritius	68	75	19	13	20	98	0.761	3 870
Mozambique	43	45	129	42	73	46	0.341	140
Namibia	50	51	57	18	20	83	0.632	2 110
Rwanda	40	42	105	28	43	79	0.382	210
Seychelles	68	75	14	17	14	—	0.786	6 910
South Africa	50	56	60	15	16	87	0.697	3 210
Swaziland	58	63	64	20	22	50	0.655	1 520
Tanzania	47	49	91	17	36	66	0.415	210
Uganda	40	42	84	24	46	46	0.409	330
Zambia	40	41	112	16	31	38	0.420	370
Zimbabwe	43	44	59	8	17	79	0.555	720

Source: World Bank (1998) *World Development Indicators*. World Bank: Washington DC.
 UNICEF (1999) *State of the World's Children 2000*. UNICEF: New York.
 UNDP (1998 and 2000) *Human Development Report*. Oxford University Press: New York.

The Human Poverty Index (HPI) has also been introduced to include, in a composite measure, several characteristics of deprivation in order to reach an overall judgement about the extent of poverty. It concentrates on deprivation in three essential areas of human life, already reflected in the HDI, namely, longevity (or vulnerability to death at a relatively early age), knowledge (exclusion from the world of reading and communication) and decent living standard (in terms of overall economic provisioning). Deprivation of the provisions required for a decent standard of living is measured by a combination of lack of access to clean water, and to health services and by the proportion of underfives who are severely and moderately underweight. The UNDP Human Development Report (2001) provides HPI estimates for 85 countries. The HPI exceeds 50% in Ethiopia and Mozambique; while for Malawi, Zambia and Uganda human poverty is around 40%.

These various measures are useful. However, caution needs to be exercised in quantifying poverty. Poverty is deeply human. Numbers cannot capture the whole story. This does not mean that economic growth indicators are unim-

portant. Economic growth *can be* a powerful means to eradicate poverty. Growth can raise the productivity and incomes of poor people, expanding opportunities and choices in a variety of ways. Sustained national GDP growth, combined with rising wages and productivity, was an important part of the historic ascent from poverty in the industrial countries. But these successes contrast with present realities in many developing countries of Sub-Saharan Africa. In too many countries, growth has failed to reduce poverty, either because growth has been too slow or stagnant or because its *quality* and *structure* have been insufficiently pro-poor.

Poverty in Sub-Saharan Africa is prevalent and continues to threaten the quality of life of the majority of people in this region. Poverty poses a serious challenge to the development of the continent and one of its outcomes, increased malnutrition, has complicated the current social welfare improvement efforts of many governments. The entry of HIV/AIDS has brought a new dimension to the continent's developmental challenge in a number of ways. The remaining part of this paper attempts to draw linkages between HIV/AIDS and development in Africa.

Table 4—Countries ranked by rural poverty rates and GNP per capita

<i>Population living below the poverty line, in the rural areas, %</i>	<i>Country</i>	<i>Rank by rural poverty rate</i>	<i>Rank by GNP per capita</i>
93	Rwanda	1	5
90	Malawi	2	4
88	Zambia	3	12
83	Eritrea	4	7
77	Madagascar	5	8
70	Namibia	6	16
69	Mozambique	7	3
65	Angola	8	9
58	Burundi	9	2
55	Botswana	10	17
54	Lesotho	11	13
50	Swaziland	12	15
50	Tanzania	13	6
46	Kenya	14	11
34	Ethiopia	15	1
31	Zimbabwe	16	14
19	Seychelles	17	19
12	Mauritius	18	18
10	Uganda	19	10

Source: IFAD (2000) *Report of IFAD's Workshop on Rural Poverty*. IFAD:Rome.

UNICEF (1999) *State of the World's Children 2000*. UNICEF:New York.

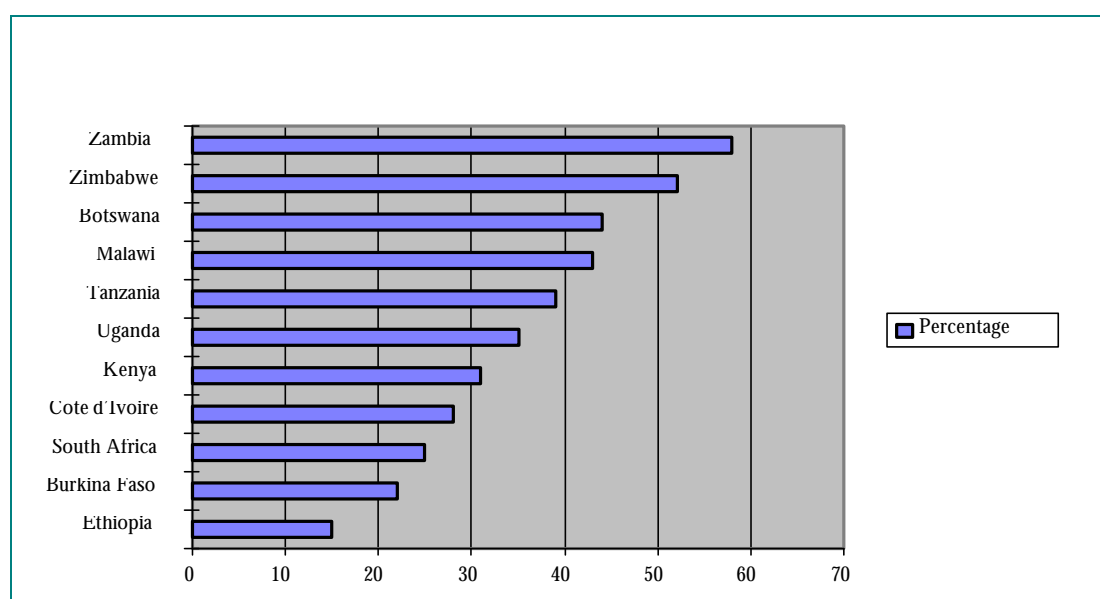
World Bank (2001) *World Development Indicators*. World Bank: Washington DC

The HIV/AIDS Challenge

Sub-Saharan Africa accounts for more than 70% of all HIV/AIDS cases globally. It is the only region where women living with HIV/AIDS outnumber men. Nearly 25 million Africans are living with HIV/AIDS, the vast majority of them adults in the prime of their working and parenting lives. Some 15 million people in Africa have already died of AIDS, with devastating social and economic impact. In the 30 Sub-Saharan African countries with the highest HIV/AIDS prevalence levels, the average life expectancy has already started to decline, standing at about 47 years, roughly seven years lower than what would have been the case in the absence of the pandemic. The lifetime risk of dying from AIDS has been rising in most African countries, standing at over 60% in Zambia, Zimbabwe, Botswana and Malawi (Figure 1).

The epidemic is costing the region close to one percent of economic growth each year, while imposing an unsustainable and mounting burden on households, firms and the public sector. While deteriorating health indicators and high levels of poverty are likely to make control of the

epidemic more difficult, they too are in part the result of the epidemic. If new resources are not found, the decline in available public resources for HIV/AIDS prevention in Africa may severely undermine national capacities to mount timely and effective responses. Whereas people from all population groups may be exposed to HIV infection, some groups are more vulnerable to the infection than other groups. These include certain occupational groups accustomed to leaving their homes and families for extended periods of time, as well as sex workers. Street children and adolescents are also vulnerable. With limited alternative sources of income available, many girls enter into sexual relationships in exchange for money. The vulnerability of youth to HIV infection is also related to unclear perceptions about what constitutes risky behaviour, insufficient knowledge and incorrect information about sex, sexuality and sexual health. Traditionally, parents, guardians and teachers in Africa are uncomfortable discussing issues of sexuality with their children, a phenomenon that further complicates the intervention efforts. A summary of the facts about the spread of HIV in Africa is presented in Box 1.

Figure 1—Lifetime risk of dying of AIDS in selected African countries

Source: UNAIDS (1999) Presentation at the 11th International Conference on AIDS and STDs in Africa. Lusaka, Zambia.

Impacts at the macro-level

The challenges of HIV/AIDS on the public and private sectors of Africa are obvious. AIDS threatens Africa's capacity building effort.

Unlike most other communicable diseases, AIDS strikes the educated and skilled as well as the uneducated. Consequently, it reverses and impedes the continent's capacity by shortening human productivity and life expectancy. The long periods of illness of skilled personnel in employ-

ment result in considerable loss to the employer. The AIDS epidemic must be viewed as an immense challenge to capacity building and development. The social and economic devastation caused by HIV/AIDS in the last decade is greater than the combined destruction of the continent's wars.

The complex relationship between economic growth and HIV/AIDS is increasingly being recognised: the epidemic affects economic

Box 1—AIDS in Sub-Saharan Africa

- ❑ With only 10% of the world's population, Africa has 70% of global HIV/AIDS cases. Today there are some 24.5 million Africans living with HIV/AIDS, 23.4 adults and about one million children up to age of 14 years. Women living with HIV/AIDS outnumber men; on average, more than 3,800 adults are infected with the virus every day in Africa.
- ❑ Adult prevalence rates vary widely from country to country from 1-2% in Benin, Gambia, Guinea and Niger, to around 25% in Zimbabwe and 35% in Botswana. Several countries have over one million adults and children living with HIV/AIDS: DR Congo, Ethiopia, Kenya, Mozambique, Nigeria, South Africa, Tanzania and Zimbabwe.
- ❑ Some 12.1 million children have been orphaned in Africa because of HIV/AIDS. These children have lost either their mother or both mother and father.
- ❑ AIDS deaths have contributed to falling life expectancy in several countries. For example, Zimbabwe has seen life expectancy drop to 44 in 1998, compared to 50 in 1970. In Zambia and Uganda, life expectancy has gone from 46 to 40 during the same time period. There are 1.3 to 2.2 million deaths from AIDS in Sub-Saharan Africa each year.
- ❑ AIDS has overtaken malaria and other diseases as the leading cause of death for adults between the ages of 15 and 49 years in Botswana, Burundi, Malawi, Rwanda, Tanzania, Uganda, Zambia, Zimbabwe, and in capital cities such as Abidjan, Addis Ababa, Nairobi and Ougadougou.
- ❑ Up to 50% of hospital beds are occupied by AIDS patients in many parts of Sub-Saharan Africa.
- ❑ HIV infection rate has stabilized at a relatively low level in Senegal and the very high rate in Uganda has been reduced. However, in most Sub-Saharan countries adults and children are acquiring HIV at a higher rate than ever before.

Source: United Nations (1998) Department of Public Information. *Africa Recovery. Volume 2.* United Nations: New York.
UNAIDS (2000) <http://www.unaids.org/>

growth and economic growth impacts on the epidemic. In most African countries, the economic shock of AIDS on the labour market has translated into severe loss in economic productivity. Given that AIDS disproportionately affects the working-age population, the epidemic affects both the quantity and quality of the labour force. The cost of overall production is likely to increase. An indirect effect on all sectors is the drop in consumer spending as the economic effects of AIDS spread throughout society. Correspondingly, a reduced access to income leads to adverse welfare impact on the household as resources for food and other basic necessities dwindle.

Families can exhaust their entire savings long before their infected members die, a phenomenon that has a serious adverse effect on the nutritional welfare of households

Impacts on families

While economists have placed considerable attention on the impact of HIV/AIDS at the macro level, the epidemic is taking a heavy toll at the household level, especially under ill-conceived home-based care programmes that do not take into full account the cultural, social and economic considerations that may compromise the health and safety of the caregivers. This is particularly so in countries where most people are poor and are ill equipped to shoulder the added expenses of caring for the sick.

At the household or family level, the impact of HIV/AIDS varies by geographic areas (rural/urban), by socio-economic status and size of the family and by the number and ages of independent children. The majority of those who die of AIDS are in their most productive years and often the sole breadwinners in the household or cluster of families. Impacts are felt through the loss of income, changes in the pattern of household expenditure, high expenditures on drugs (when there is access to drugs) and medical services, and dissolution of normal social relationships within the family. Families can exhaust their entire savings long before their infected members die, a phenomenon that has a serious adverse effect on the nutritional welfare of households. The illness and death of economically active adults result not only in higher medical expenses and lower incomes for family members, but it also creates hardships for survivors, especially women and children, having to lose access to land, housing, livestock and other assets. In some countries in Sub-Saharan Africa, women have no protected rights to inherit property from

their husbands or fathers. Neither children nor women have any legal recourse to recovering their husbands' or fathers' property removed from them.

The HIV/AIDS epidemic has also compelled many households and extended families to absorb orphaned children and to care for the chronically ill patients. In 1996, a UNICEF-supported survey^{1,2} of 1,000 households in Zambia found that 72% of households care for at least one orphan, up from 37% reported by a similar survey in 1993. In Zambia, there are some 650,000 children up to the age of 14 years who are orphaned because of AIDS.

Impact on industries

Businesses in those African countries where AIDS prevalence rates are high suffer from increases in mortality and morbidity among their workforce due to the pandemic. This has affected productivity and recruitment, while resulting in the loss of trained personnel in particular. The number of hours lost to illness and funerals continue to increase. This poses a serious threat to sustainable productivity. A study carried out at the Indeni Petroleum Company in Zambia³ showed that the economic impact of the pandemic, the cost of medical care, salary compensation for the families of deceased employees and funeral grants more than doubled between 1991 and 1993, and had exceeded profits by 1996. Medical expenses and training costs increased while person-hours were reduced.

As the epidemic persists, the private sector will be adversely affected in a number of ways. The workforce will change in structure by becoming younger, inexperienced and less well trained. A disproportionately high number of skilled personnel will be lost, contributing to reduced productivity. Stigmatisation and discrimination in the workplace targeted at people who are HIV-positive have evidently continued to compromise morale and performance⁴.

Impacts on agriculture

Agriculture, too, is adversely affected by HIV/AIDS and related illnesses as agriculture-based communities are depleted of able-bodied workers. Of particular concern is that the agriculture sector employs a large percentage of the labour force

and accounts for a major portion of the gross domestic product and export earnings in many African countries. The effects of HIV/AIDS on this sector are, therefore, likely to reverberate throughout the national economies. The influences of the drought from 1990 to 1999 and severe flooding in recent years, particularly in southern Africa, have complicated an analysis of the impact of HIV/AIDS on the agricultural sector in the southern part of the African continent. Nevertheless, the loss of a productive labour force will have one or more of the following consequences:

- ❑ Reduction of land use under cultivation, as people are physically unable to work in the field;
- ❑ Reduction in crop yields, due to delays in carrying out certain agricultural interventions such as changes in cropping pattern;
- ❑ Changes in cropping patterns as some families have been known to switch to less labour-intensive crops;
- ❑ Decline in the range of crops per household as AIDS-affected families reduce the number of crops under cultivation to one staple crop;
- ❑ Reduction in the ability to control pests such as through weeding and other inter-cultivation measures due to shortage of labour;
- ❑ Loss of agricultural knowledge and farm management skills, due to the loss of one or both parents to AIDS, and
- ❑ Decline in livestock production as the urgent need for cash may force some families to sell their animals.

Impacts on education

High rates of mortality and morbidity aggravate existing human resource constraints. In addition to dwindling financial resources, human resources have been lost at an alarming rate - partly in response to relatively unattractive terms and conditions of service, but also by illness and death. In Zambia, for example, the Ministry of Education reported in 1998 that 1,331 teachers died as a result of AIDS⁵. A recent study noted that any capacity building within the Ministry of Education "must take into account the likelihood that some 20% of Ministry of Education personnel are HIV-positive, that the death rate will rise from 2.2-2.5% in 2000 to 4.2% in 2005, and that hours lost to sickness and funeral attendance will increase dramatically"⁶. The same report estimates that by 2005 deaths among teachers will amount to between 1,850 and 2,200 per year; that is, five

or six teachers will die each day. This loss is larger than the current total output from all primary teacher-training colleges. The impact on education is not confined to the cadre of teachers, but also affects ministry staff and partner institutions, including the private sector.

Impacts on the health sector

There is an increased need for financial resources to handle escalating demand for hospitalisation. Bed occupancy in hospitals is now severely constrained in Sub-Saharan African countries. This means that treatment of opportunistic infections, especially those requiring admission, continues to place an unprecedented burden on the delivery of health services in these countries. There is an increased need for human resources to handle respond to the demand for care, while AIDS-related mortality among hospital personnel undermines the quality of service delivery. A study on mortality rates among nurses in two rural districts in Zambia (Monte and Choma districts in the Southern Province) were estimated for three time periods, 1980-85, 1986-88 and 1989-91. The mortality rate in the second period showed a fourfold increase compared with the first period and, by the third period, the increase was thirteenfold (26.7 per 1,000 population). Information available from death certificates suggested that AIDS was the cause of the rise in mortality^{7,8}. The situation in Zambia, one of the hardest hit African countries, is summarized in Box 2.

The Way Forward: the need for crosscutting interventions

Firstly, at the broad crosscutting level, the first step should be the identification of the real constraints to economic and social progress which currently seem to explain, to a large extent, the adversity experienced in Africa today. They include the prolonged economic decline and successive droughts resulting in food insecurity in many communities, the costs and implications of debt and debt servicing, the very real limitations imposed by a limited and over-stretched government capacity, and the difficulties of introducing institutional reform. Programmes should address not only the immediate needs of the poor that are made worse by poverty, malnutrition and the HIV/AIDS epidemic. They should also address the underlying causes of these problems through effective broad-based strategies.

Secondly, the HIV/AIDS fight must be placed at the center of each African country's ca-

Box 2—HIV/AIDS in Zambia

- ❑ The national HIV prevalence rate in Zambia is 20%. This translates into 870,000 adults and children living with HIV/AIDS, of whom 450,000 are women between the age of 15 and 59 years, and 40,000 children from birth to 14 years.
- ❑ Sentinel site surveys carried out amongst women attending antenatal care clinics in major urban centers show that 27% of these women are sero-positive. Similar survey findings from rural areas indicate a rate of around 14%.
- ❑ There are 650,000 orphans in Zambia due to HIV/AIDS. One projection estimates that by 2014 there will be one million children who have lost either their mother or both parents to AIDS.
- ❑ Infant and under-five mortality rates in Zambia continue to fall, however, the rate of progress has slowed. Under-fives mortality was reduced from 213 to 202 over nearly 40 years (1968 to 1998), while infant mortality now stands at 112 per 1000 live births, down from 126 in 1960.
- ❑ Tuberculosis cases have increased five-fold since the beginning of the epidemic, with more than 40,000 cases occurring in 1996. By the year 2014 the number of new cases each year attributable to HIV infection alone will exceed 41,500.
- ❑ The Government in Zambia is trying to engage all sectors in HIV prevention, from education to health and agriculture to industry.

Source: UNAIDS (2001) <http://www.unaids.org/>
UNICEF (1999) *State of the World's Children 2000*. UNICEF: New York.

capacity building agenda. To the extent that AIDS depletes human capacity in many African countries, the epidemic must be confronted head-on. Specifically, capacity building in the health sector service delivery system is an imperative. There is need for health sector restructuring programmes to be responsive to the HIV/AIDS challenge. This calls for modes of health services delivery through, inter alia, strengthened capacity for hospital-based care for patients with HIV/AIDS. Similarly, there is an urgent need for capacity strengthening at the level of implementation through the development of integrated reproductive health frameworks that take into consideration a sufficient supply of drugs targetting the control and treatment of sexually transmitted diseases, the harmonisation of HIV/AIDS interventions by various sectors and training of both public and private sector health and allied workers. Both prevention and mitigation strategies can be found in several sectors beyond the health sector. Ministries of education, defence, information, youth, and women's affairs, must harmonize their interventions through defined frameworks of co-operation and coordination. More importantly, the planning process that takes into account all these considerations should be decentralised and involve policy makers and decision-makers at the provincial/regional and district levels in a manner that is participatory and inclusive.

Thirdly, there is need to develop robust, timely, and dependable monitoring and evaluation capacity as it relates to the HIV/AIDS epidemic. Unless countries have reliable data on HIV/AIDS prevalence and geographical patterns as well as information on those affected by the spread of

epidemic (orphans in particular), it will be difficult to establish priority targets. In this regard, national sentinel surveillance data should be developed and monitoring and evaluation frameworks should be de-centralised to provincial and district levels. Lastly, innovation in home-based care systems is needed, and the support that they need made available. The aim should be to ensure better quality home-based care at the household and community levels.

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Discussion

Chair The poverty and economic aspects of nutrition and HIV/AIDS are important. Poverty, particularly in this part of Sub-Saharan Africa is really a rural phenomenon. As Mrs. Monico pointed out, we have difficulty providing services to people in rural areas. In Africa, 83% of poverty is in the rural areas.

Question from the audience Why do we still see in many countries in this region poverty reduction strategies that do not address nutrition? Nutrition colleagues in these countries are struggling to be heard. Where is the accountability?

Comment from the audience The focus on poverty and malnutrition is well placed and very important. However, sexual practices are also an important factor in HIV/AIDS. Perhaps the hardest part of the epidemic to discuss is the power imbalance between men and women. This makes it very hard for women to protect themselves against HIV/AIDS.

Question from the audience It is disturbing to hear that in Zambia there is the practice of sending widows and orphans away from their father's

or breadwinner's property. This also happens in Kenya along the Lake region. How can this be redressed?

Comment from the audience What Professor Saasa said is completely correct, but when we talk about Africa we need to bring up a couple more things to make the picture complete. This region is characterized by emergencies and armed conflict in more than half of the countries. This affects civilians more than soldiers. It is a private war. Private economic interest is the reason we have wars in so many countries. We need to understand this privatization of war. The situation is actually becoming worse. We also need to understand why the donors have left Africa and why they are not prepared to provide any significant support unless they control governments. More decisions are taken about matters of importance to Africa in the capitals of Europe and in Washington than by African governments themselves, and we need to understand this. Finally, when it comes to governance we are seeing an increase in corruption, not a decrease. We see the poor get poorer and the rich get richer. Just because we have so-called "multi-party elections" we don't

necessarily have democracy. These things need to be brought into the picture to understand why the HIV/AIDS catastrophe is very serious for the survival of this part of the world.

Question from the audience An emphasis on the health, nutrition, survival and productivity of those who remain behind when this terrible disease is dealt with is well placed. However, your interpretation of what is being done about breastfeeding is worrying. Exclusive breastfeeding, not mixed feeding, is the best method of infant feeding. Replacement feeding with formula should only be done if it is feasible, safe and there is adequate health care. Is it likely that all these things would be available? We cannot forget that 80% or more of the children who are breastfed are not going to get HIV from breastfeeding.

Oliver Saasa Nutrition strategies are not really factored in when developing poverty reduction strategy papers, currently, in countries in this region. We need to put this challenge to governments. We economists voice our concerns, but it really is a government issue. To what extent are governments prepared to listen and come on board? Nutrition and malnutrition are important areas and they ought to be addressed in poverty reduction strategies.

Sexual practices and imbalances between men and women are definitely areas of concern. The difficulty is what approach to take in programmes. One has to be very careful in designing interventions. Regarding "property grabbing", in Zambia, we have legislation that stops people from coming in and grabbing property of the deceased away from the surviving spouse and children. The biggest problem is implementation. We have failed to use our legal system to bring the perpetrators to justice for several reasons. These reasons involve government and corruption. People have been released for crimes that should not have been forgiven. No government can be excused for allowing someone, such as an uncle, to grab everything and leave the children to die from poverty. The children are unable to obtain an education, unable to find adequate food. This is happening under our noses and under the governments' noses and not much is being done about it.

Question from the audience Mrs. Monico, you talked about preparing counsellors for working with those infected with HIV/AIDS. Is this similar to peer counselling? Does TASO train those who are infected with HIV to counsel others who are infected?

Sophia Monico Yes, we do and we actually train even the caregivers to counsel themselves. We call it the "careful carers programme". We also carry out peer education within companies where employees can go to fellow employees without coming to TASO.

Question from the audience A previous discussant was absolutely right to identify some of the underlying economic and political factors which make it so difficult to address this problem of HIV. Professor Saasa focused on the effects of HIV on peoples' economic well being, on human resource capacity, on employment, and on agricultural productivity. Little was said about the reverse, apart from a brief reference by Dr. Piot. How is the current global macroeconomic situation impacting on the epidemic? How much is the rapidly accelerating inequity between and within nations driving this epidemic? How much is the increased poverty in rural and urban areas of Africa driving the epidemic by forcing women into sex for cash? It has been well documented that macro-economic deterioration is undermining basic health services so that effective and early treatment of sexually transmitted diseases becomes increasingly difficult in many countries. Even in South Africa, probably the richest country in Africa, we are finding that supplies of essential drugs to primary care centres are erratic. Why has so little been done to assess how economic policies are actually fuelling this epidemic? And why are the nutrition community and some of the UN agencies silent about these kinds of economic policies? These economic policies and institutions, particularly the World Trade Organization, are impacting on peoples' ability to access cheap pharmaceuticals to treat HIV-related problems. They also affect trade relations among countries where poor countries are becoming increasingly dependent and increasingly bereft of the meagre economic resources which they have.

Oliver Saasa These economies exist within the global environment and therefore what happens at the global level in terms of resource transfers, commitment and actual direct transfer is pertinent. The policies that the multilaterals promote to encourage poverty reduction do have far-reaching implications. Take, for example, structural adjustment programmes. The idea was to reduce poverty but the instruments used were not sufficient to address poverty. Balancing the budget, lowering interest rates, expanding international trade are all good things in terms of net economic growth. However, they are not a remedy to poverty reduction. They are very impor-

tant interventions. The World Bank and the IMF emphasized these aspects but they are not sufficient and, increasingly, we realize this. In fact, in the past two years the World Bank and the IMF have come out with more participatory approaches to poverty reduction. I do not know the situation in Kenya but, for me, the poverty reduction strategy papers that had been developed across Sub-Saharan Africa are apologies. The Bank and the IMF failed to come out and explain their transgressions. They then u-turned and said they have seen budgets being balanced and GDP growing, while poverty worsens. The sorts of policies that were encouraged from outside have not factored in the peculiarities of these countries, which to a large degree, do explain the extent of poverty. Poverty in Africa is not an isolated phenomenon which can only be explained by the problems of Africa and by Africans. We need to see whether the multilaterals are actually doing enough in terms of policy prescriptions and net transfers. The debt burden has to be addressed and UNICEF is at the forefront raising awareness of the consequences of debt. Debt severely constrains a country's ability to tackle the HIV/AIDS epidemic. Therefore, it is important that Africa be understood and African initiatives be viewed in the context of the global situation.

Comment from the audience There is a loss of traditional livelihoods and there are no replacements in sight. The loss of livelihoods is having an effect on family integrity and cohesion which feeds into a whole series of problems in the region, including conflict. In other words, a loss of authority structures within households and within lineages coupled with poverty and disease, are feeding these problems.

Question from the audience How will TASO use food aid? How will TASO rationalize its use? Will food be tailored in terms of the nutritional needs of the AIDS client or as an income transfer for the household? A related concern is the lack of testing for HIV. Another speaker said that only one percent of mothers in antenatal settings know whether they are HIV positive or not. Why are the testing levels so low? Not only is testing important for food therapy and breastfeeding, it is also important in terms of human rights and the mobilization of people in terms of their own interests.

Sophia Monico Concerning food, USAID will advise TASO on the best uses of food aid. Although there is a transfer element, we are not considering income transfer. If TASO distributes corn soy blend (CSB) and cooking oil, this will

generate savings from household budgets and clients can buy something else with the savings. Yet CSB is a supplement because it is a porridge and no one can live on porridge alone. Other foods are needed to complement the food supplies that TASO gets from USAID. CSB is very nutritious, so the food component of TASO's work will add significantly to the nutritional value of clients' diets.

About testing levels, one thing we have to realize (and this is why I say Uganda is fortunate) is that people only test when they see an advantage in testing. Why test at all? If there is a support system then I might test. If there is stigma and discrimination why should I test? Most people don't test because of the environment in which they live. We have shown that wherever we have a TASO centre, we must also have a testing facility. All clients at TASO have been tested. Where we don't have a centre, the testing facility does not work very well because there is no support system.

Chair In my travels over the last few weeks, I asked people involved in raising awareness of HIV/AIDS if they themselves had been tested. The answer was usually no. Somehow we have to get those who are involved in community mobilization to stand up and say "I have been tested".

Question from the audience Please comment, Professor Saasa, on the correlation between malnutrition and expenditure budgets for military hardware, especially in the sub-Saharan Africa. In very poor countries, a big component of public resources is spent on the military.

Oliver Saasa The point is valid regarding how to apportion a small cake in the face of competing demands. Wars in Africa are a source of concern. Wars deplete limited human resources. Sometimes countries go to war for reasons of maintaining political stability which is required for economic development. This is made worse when external players come in and fuel the problem. The concern about military spending is also valid. Neighbouring countries do team up to solve a civil wars, using military tanks from another country; this is difficult to understand.

Question from the audience Why is it that the educated and skilled people in Africa are dying from AIDS? We have linked HIV/AIDS and poverty and we are talking about the rural poor. Yet, it is ministers, permanent secretaries and directors who are dying of AIDS. How many of us would not spend the whole night fighting with

our spouses if we found condoms in their pockets? How many of us distribute the resources of Information-Education-Communications programmes to communities, yet we do not take these resources home to our spouses?

My second question is on the linkages between nutrition and HIV/AIDS and development. The linkages are obvious. Nutrition was seen as a sectoral issue: health. HIV/AIDS was seen as a sectoral issue: health. Now both are seen as development issues. Malnutrition leads to death, though not as loudly as AIDS. We have been talking about incorporating nutrition into development programmes and we can incorporate nutrition into HIV programmes, however, how can we incorporate the prevention of HIV transmission into nutrition programmes? This goes beyond breastfeeding and mother-to-child transmission. It concerns incorporating the prevention of HIV/AIDS into all aspects of nutrition. Can the international organizations guide us at the national level?

Chair From the international organizations' point of view, first, we must realize that the problem of HIV/AIDS is multisectoral. We have to work together. The first defence is awareness. If people are aware we can begin to take action. Second, in many places even if testing is promoted, there is no testing equipment. Thus, national governments and international assistance both need to prioritize testing. If people are not tested it is difficult to know what kinds of packages to make available in communities. Nutrition programmes, indeed development activities in general, cannot and should not be done in isolation. No nutrition programme just comes to a community and says: this is what you are going to eat. It is important to work through community institutions. Nutrition education programmes can incorporate health messages. Schools can be used as centres for community mobilization. There are many activities at schools which could be built around messages for HIV/AIDS, such as messages about condoms. There is great resistance in some communities to even pronouncing the word condom.

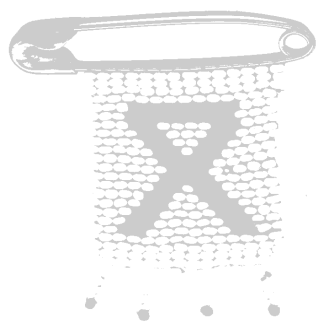
There are many communities with activities on prevention or care, but the word condom is taboo.

Oliver Sassa Concerning the question why is it that the educated directors and ministers are the ones that are dying -- actually, this is not the case. Their deaths hit the media, while the deaths of 200 people in a remote Kenyan village do not. The poor are hit severely, but the rich are not spared. The rich can afford to buy treatment for AIDS, they can afford to pay for services. However, death is not confined to the educated. Another aspect is that when an educated person dies, not only does the death capture the media, there is a ripple effect across society. Similarly, if the breadwinner dies an entire family of five or six or more members, is affected.

Sophia Monico The poor die less quickly in Uganda because they are more likely to seek services. In some circumstances they are more likely to get quality services. They can learn to cope with the disease burden. TASO has used food assistance to attract people to come for services. Most people who are very poor cannot afford food. Therefore food is an incentive for people to come for services.

Question from the audience Mrs. Monico, TASO is heavily reliant on food aid. Food aid is never sustainable. Is TASO looking at more sustainable means, or approaches that use locally-produced food?

Sophia Monico We do rely on food aid, but we are starting a programme with assistance from the World Food Programme called Food for Training. TASO will offer training to family members to use the little plots around their houses to plant food. This can complement what they buy in the markets. TASO may not be able to train clients because, in most cases, they are ill and weak. Nevertheless, we can train family members, even young children.



HIV/AIDS, Food and Nutrition Security: Impacts and Actions*

Stuart Gillespie, Lawrence Haddad, IFPRI
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The magnitude and depth of HIV/AIDS impacts in Sub-Saharan Africa are staggering. Livelihoods are being devastated and the food and nutrition security of millions of households seriously undermined. This paper is an attempt to shed light on the various impacts and pathways through which HIV/AIDS affects food and nutrition security, the types of responses made by households and communities in trying to reduce these effects, and their policy and programme implications, including any lessons from recent attempts at direct impact mitigation. The specific role of food aid is examined since inadequate access to food is one of the first signs of distress in an HIV/AIDS-impacted household.

Over 36 million individuals are currently living with HIV/AIDS, 95% of whom are from developing countries. More than 150 million people are affected by the disease, if we assume that each HIV/AIDS case directly influences the lives of four other individuals¹. Sub-Saharan Africa is the region most affected, where HIV/AIDS is now the leading cause of adult morbidity and mortality. Most, if not all, of the 25 million people in Sub-Saharan Africa who are living with

HIV/AIDS will have died by the year 2020, in addition to the 13.7 million Africans already claimed by the epidemic.

HIV/AIDS also is spreading dramatically in Asia. India is estimated to have three to five million HIV infections and, though national data are not reliable, some Chinese specialists estimate up to 10 million HIV infections in China. Asia will overtake Sub-Saharan Africa in absolute numbers before 2010 and by 2020 Asia will be the HIV/AIDS epicentre¹.

Is HIV/AIDS a unique shock ^{a?}

The HIV/AIDS pandemic is transforming the landscape upon which development must take place in much of the developing world, but it is different from other diseases or shocks for the following reasons:

It is incurable and fatal. It kills the most productive members of society. Thus, it increases household dependency ratios, reduces household productivity and caring capacity, and impairs the inter-generational transfer of local knowledge and skills. The effect on the household may be permanent;

This bleak prognosis makes intervention efforts (prevention or mitigation) difficult. Most development interventions can offer some hope of some improvement in human welfare. Effective HIV prevention can only offer an absence of

* This paper represents a collaboration between a research organization and an operational agency, both concerned with issues of food and nutrition security, and both concerned with how best to respond to the raging HIV/AIDS crisis in Sub-Saharan Africa. It builds on and complements previous work done by Haddad and Gillespie, which in turn benefited from a consultation on HIV/AIDS and rural livelihoods, held at IFPRI in January 2001, and supported by DFID. It also encompasses the main findings of five country studies of heavily impacted countries undertaken by WFP, aimed at improving understanding of the appropriate uses of food aid in prevention, care and mitigation.

a. A "shock" is here defined as an unanticipated event that has a significant (usually negative) impact on a large number of people's ability to fulfill their capabilities.

decline. Effective HIV mitigation can only offer a temporary improvement in human welfare from an already HIV/AIDS-lowered level;

Life-prolonging treatment is too expensive for most HIV-infected people, although there is significant scope for major cuts in the prices of drugs;

It is socially invisible. The private nature and divergent cultural attitudes towards sex lead to silence, denial, stigma, and discrimination at many levels. This makes effective prevention and mitigation difficult to implement;

HIV has a very long incubation period between infection and full-blown symptoms during which individuals are infective. In the absence of routine HIV testing, infected individuals have less of an incentive to alter risky behaviour and a long period over which to undertake those activities. Both invisibility and long duration increase chances of HIV transmission. Individuals who are unaware of their HIV status and their families cannot begin to alter livelihood strategies in response to the coming shock;

It has both rural and urban dimensions. As with poverty, the death of one or more income-earners in rural households often forces survivors to migrate to seek work in cities. A death of an urban worker may force survivors to send children back to rural extended families to be cared for;

It affects both the rich and the poor, though it is the poor who are most severely exposed and most severely impacted;

It affects both sexes but is not gender-neutral. To the extent that women are marginalized and powerless, they are more at risk of being exposed to HIV. Women are also more likely to succumb rapidly to HIV/AIDS, as they are more biologically vulnerable;

Finally, one of the most disturbing aspects of the pandemic is the fact that, as it intensifies with a parallel need for action, the actual *capacity to act* is decreasing. Organizations that are located in areas that are experiencing a high HIV/AIDS prevalence, are characterized by high absenteeism, high turnover, a loss of institutional memory, and reduced innovation. As individuals in government and nongovernmental organizations continue to die, the capacity gap—between what is needed and what can be delivered—is becoming an abyss.

The poverty dimension

HIV/AIDS and poverty (a large part of which relates to food insecurity) interact in a vicious cycle. Poverty increases the exposure to, as well as the impact of, HIV. It diminishes the perceived value of avoiding HIV ("we will die soon anyway"). It increases the relative costs of both avoiding and treating the illness, and it exacerbates the impact of weakened immunological integrity as a result of a more hostile bacterial and viral environment. Poverty also increases the radius of impact of HIV on family and friends. For the poor, informal coping mechanisms are more dependent on family and friends and less so on insurance companies and the state.

In the reverse direction, HIV/AIDS also impoverishes. It increases poverty in the short to medium run by stripping assets of many kinds—human, social, financial, physical, natural, informational and political. Asset rundown

leaves individuals, families and communities more exposed to future shocks—children are pulled out of school to help with labour needs and young women may be forced to become commercial sex workers.

Nevertheless, as compared to other aggregate shocks, the nonpoor are thought less able to avoid HIV infection and its impacts. While this might generate wider political support to confront AIDS, it undermines the ability of middle income-staffed governments, private sector firms and other formal organizations to mobilize human resources to combat it. There is also a danger that public sector health budgets will become more skewed towards the wealthier and more vocal urban HIV/AIDS population to the detriment of the rural poor in general. Primary health care clinics may become increasingly poorly equipped. Waiting and travel times for the poor might also increase as a consequence, further stretching the demands on the remaining able-bodied labour.

The gender dimension

Women are biologically, socio-economically and socio-culturally more at risk of HIV infection than men^{2,3}. Biologically, the risk of becoming infected with HIV during unprotected vaginal intercourse is between two and four times higher for women than for men⁴. Women are also more susceptible to other sexually transmitted diseases (STDs) and less likely to seek treatment. If untreated, STDs may multiply the risk of HIV trans-

**Women are biologically,
socio-economically and
socio-culturally more at risk of
HIV infection than men**

mission by 300-400%. This biological susceptibility further threatens reproductive health status. Pregnancy and child bearing now involve considerably greater risks not only for women but also for their future offspring, while STDs can be potentially life threatening.

HIV/AIDS also exacerbates social, economic, and cultural inequalities that define women's status in society. Women are often more susceptible to HIV infection and more vulnerable to AIDS impacts than men for the following reasons. The predominant culture of silence and passivity regarding sex stigmatizes women who try to access STD treatment services. The norm of virginity restricts adolescent girls' access to information about sex and increases risk of sexual coercion. Economic vulnerability increases the chance of exchange of sex for food and money. Male power is often manifested in sexual violence. Susceptibility to HIV infection is increased through sexual practices, including genital cutting, dry sex and ritual cleansing. Finally, women are discriminated against with regard to inheritance rights.

Other important changes in gender asymmetries relate to less personal but nonetheless crucial assets. Premature adult male death may deprive the female of the necessary time to build up a set of extra-family levers (such as access to community land, to community groups, and to micro-finance groups) that can be used to exert power within the family. If property and user rights for a whole range of assets are not clearly and equitably defined or are not enforced, women are likely to become less able to shape their own destiny. This lessening of women's relative power will tend to be reinforced via the subsequent diminished ability to control decisions relating to their own needs and those of their children in terms of health care, food intake and work time^b.

Impacts of HIV/AIDS on nutrition, food security and livelihoods

In this section, we examine the type of impacts that HIV/AIDS may have on households and

communities with regard to their food and nutrition security, in the context of their livelihoods, particularly with regard to rural populations dependent on agriculture.

There are three points to be made at the outset. First, impacts are often revealed through the responses, or "coping strategies"^c, made by households and communities. In this paper we prefer to use the term responses rather than coping. Second, it is important to differentiate susceptibility to HIV infection (the likelihood of becoming infected with the virus) from vulnerability to the different types of impacts, once infection has taken place. Third, it is important to recognize that different stages of the HIV/AIDS epidemic will have different

indicators, different impacts and different responses. There are also differences between countries or sub-national regions with regard to the gradient and the peak

prevalence of the HIV/AIDS epidemic relating in part to the velocity of transmission, which itself is related to behaviors and the pathogenicity of the particular HIV strain. An illustrative scenario of the dynamics of the impact and response of HIV/AIDS in an agriculture-based household is provided in Box 3.

Impacts on Nutrition

HIV/AIDS has significant impacts on nutrition at the level of the individual, household and community. Malnutrition in turn increases both the susceptibility to HIV infection and the vulnerability to its various post-infection impacts.

At an individual level, HIV infection accelerates the vicious cycle of inadequate dietary intake and disease that leads to malnutrition (Figure 2) while malnutrition increases the risk of HIV transmission from mothers to babies and the progression of HIV infection⁶. HIV infected individuals have higher nutritional requirements than uninfected individuals, particularly with regard to protein and energy. They are also more likely to suffer a loss of appetite, even anorexia, thus re-

c. The term "coping" may not always be accurate simply because many responses are those of distressed households which are not coping. Coping implies a reversible management strategy. It also somehow suggests that the adoption of such strategies is not too costly. The reality is that many households are forced to make distress sales or change livelihood strategies in ways that are irreversible. The price of such short term "coping" may be long-term deprivation or even destitution.

b. However, the greater economic independence of women under conditions of weak control of choice over sexual partners may actually place women at a greater risk of HIV infection if such independence is associated with greater livelihood mobility.

Box 3—Dynamics of HIV/AIDS impacts and household responses in an agriculture-based livelihood

The following is an illustration of possible impacts and responses of an agriculture-dependent household containing an adult who contracts HIV. Many of these impacts have been shown in studies; some are speculative albeit plausible. Context is obviously crucial with regard to type and sequencing of impacts and responses at different stages of the epidemic.

Adult becomes sick
 S/he reduces work
 Replacement labour is "imported", perhaps from relatives
 Adults work longer hours on farm
 Health care expenses rise (e.g., drugs, transport)
 Household food consumption is reduced
 Households switch to labour-extensive crops and farming systems and small livestock
 Nutritional status deteriorates
 Adult stops work
 Increased care for the sick adult, less time for child care
 Divisible assets are disposed (e.g., livestock)
 Debts increase
 Children drop out of school to help with household labour
 Adult dies
 Funeral expenses arise
 Household may fragment as other adults migrate for work
 Reduced cultivation of land, more left fallow
 Inappropriate natural resource management may lead to increased spread of pests and disease
 Effects of knowledge loss intensify
 Increased mining of common property resources
 Access to household land and property may be affected (regarding rights of surviving widow)
 Solidarity networks strained, possibly to point of exclusion
 Partner becomes sick
 Downward spiral accelerates....

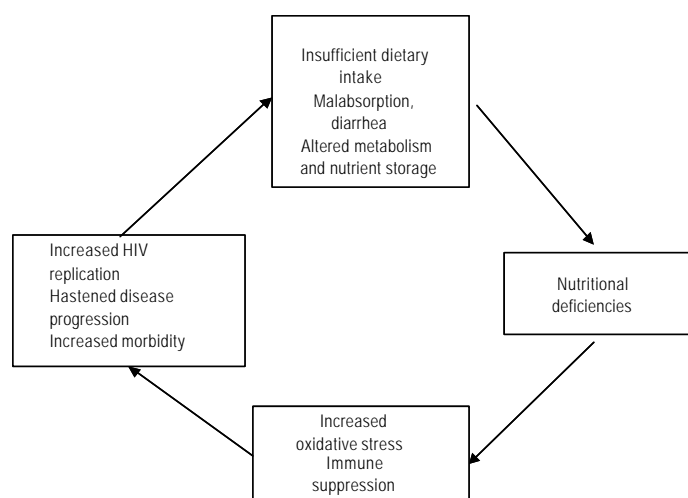
ducing dietary intake at the very time when requirements are higher. Moreover, such interactions are thrown into starker contrast for the poor who are more likely to be malnourished prior to becoming infected.

Research shows that the onset of the disease and even death might be delayed in well-nourished HIV-positive individuals, and diets rich in protein, energy and micronutrients help to develop resistance to opportunistic infections in AIDS patients ⁷.

Mother-to-child transmission (MTCT, or vertical transmission) of HIV, which may occur during pregnancy, at birth or via breastfeeding, is a major nutritional issue. Recent studies conducted in South Africa ^{8,9,10} confirm that there was no significant difference in HIV transmission between babies who were exclusively breastfed for the first three months of life and babies who were never breastfed. However, babies who received both breastmilk and formula were at significantly increased risk of transmission. By 15 months, exclusive breastfeeders had the lowest transmis-

sion of all three groups. Exclusive breastfeeding facilitates enterocyte junction closure of the intestinal mucosal barrier decreasing exposure to dietary antigens and environmental pathogens, which occur with the premature introduction of other foods and liquids (and formula). This causes intestinal irritation and inflammation to allow direct contact of the virus with the infant's blood-stream¹¹.

These are the predominant direct impacts on infected individuals. There are other important *indirect* impacts at the household and community levels. These may be brought about by, for example, a diminished capacity of caregivers to care for themselves, for their young children, or for AIDS-infected household members. In many poor households, even those unaffected by the pandemic, child care may be compromised in the short term to ensure food security in the long term. Any adverse impact on the quality or quantity of child care of such decisions are likely to be exacerbated by shocks such as HIV/AIDS that may drastically reduce household caring capacity.

Figure 2—The vicious cycle of malnutrition and HIV

Source: Semba RD and Tang AM (1999) Micronutrients and the pathogenesis of human immunodeficiency virus infection. *British Journal of Nutrition* 81: 181-89.

Impacts on agriculture and other livelihoods

A livelihood represents the interaction between assets and transforming processes and structures that generate a means of living, all conditioned by the context that individuals find themselves in¹². Agriculture is the main livelihood of most rural populations in Sub-Saharan Africa. Regarding assets, HIV/AIDS strips individuals, households, networks, and communities of different forms of capital (human, financial, social, physical and natural) as described here.

Human capital

Most obviously, HIV/AIDS attacks human capital. Infected individuals die prematurely, prior to which their productivity will have already declined following the onset of AIDS-related opportunistic infections such as tuberculosis. However, the full impact of HIV/AIDS on labour is greater than this, as the labour of healthy individuals is diverted into other crucial activities such as caring for those infected and attending the funerals of those who have died.

With regard to agriculture, obviously farming systems that are less dependent on labour will be better able to respond to these losses. Studies have investigated the characteristics associated with vulnerability and resilience of farming systems in the face of loss of labour^{13,14,d}. Other impacts on land and land use include the cultivation of crops that are less labour intensive, but less nu-

tritious (e.g. some tubers) and the fallowing of land.

The impacts of HIV/AIDS on the commercial agricultural sector are less well understood^{15,16}. If the commercial sector is dependent on migrant labour it is susceptible to HIV/AIDS, especially if the labourer is resident without his or her family. Social networks will also tend to be weaker for labourers in the commercial sector. However, the commercial sector can be a force for good in the sense that it can provide information and training for prevention. It might provide opportunities for AIDS orphans to learn some essential agricultural skills.

However, human capital is about much more than manual labour. It is also about knowledge. The severe illness and death of adults in their prime by HIV/AIDS abbreviates the ability of individuals to transfer knowledge both within their generation and from their generation to the next. Both verbal and role model mechanisms are interrupted by HIV/AIDS. New generations are less able to draw on the body of knowledge that dies along with their parents. They are deprived of "learning by doing" under the guidance of someone more experienced.

d. At the semi-subsistence level, the impacts on farming practices have been summarized in a number of reviews^{3,14,16,17,18}.

The ability to acquire and use information is also impaired by HIV/AIDS as younger generations are pulled out of school to bolster the family's ability to provide care to the ill and to maintain its current livelihood or to develop new ones. This is an example of an ultimately destructive "coping strategy." Tomorrow's livelihoods are sacrificed to hang on to today's.

Financial capital

Financial capital is damaged by HIV/AIDS in a number of ways. Because drug, burial and related transport expenses become major items in budgets, families need to find ways to maintain current consumption levels. In terms of financial capital services (credit, savings and insurance) poor families have to sell stores of value (e.g., jewelry and livestock) and assets (e.g., equipment or tools); borrow funds in a sustainable manner or, most unlikely, secure access to some kind of insurance, health, or otherwise.

The poor invariably are reliant on informal credit at high interest rates or on group-based microfinance services, both of which are vulnerable to aggregate shocks. Even when the epidemic is in its early stages, the affected family is less able to avoid default and hence is less attractive to group-based liability schemes. Despite these limitations, private credit has been described as the key distress response to adult death from HIV/AIDS—at least in the well-studied area of Kagera in Tanzania¹⁹. No doubt the ability of microfinance institutions to respond to the changing needs of their clients will be crucial to HIV/AIDS mitigation efforts.

Social capital

Social capital (or the strength of associational life, trust, and norms of reciprocity) may be undermined by HIV in several ways. First, social reproduction in terms of the role-modeling of norms of trust and good citizenship is impaired. Future generations not only do not witness farming practices, they do not experience the informal exchanges of knowledge, tools and animal draught labour that are often embodied in such livelihood activities. Second, the incentives for coordinated group action may be diminished due to the heavy discounting of the future benefits of such action. This has a particularly negative consequence for natural resource management practices that are dependent on collective action such as integrated pest management, social forestry and watershed development²⁰. Third, the formal institutions, which also contribute to social capital formation such as church groups, sports clubs, and professional associations, are likely to be weakened as

members die. Fourth, social networks tend to be spatially concentrated. The networks, which are more heterogeneous, should have a greater carrying capacity. However, those members who are highly mobile or live in urban areas will make a network more susceptible to HIV/AIDS. Fifth, social capital may be weakened through an increased exclusiveness of network membership. The stigma attached to HIV/AIDS is not conducive to the establishment of crosscutting ties involving the different strands of social capital²¹. HIV/AIDS might lead to the generation of a type of social capital formation, which is exclusive.

Physical and natural capital

The basic infrastructure and productive equipment, which are relied upon for the pursuit of livelihoods, also comes under threat due to HIV/AIDS. The possible sale of productive equipment or mortgaging of land in response to large health and funeral expenses has been noted, as well as the possible neglect of health infrastructure for the poor. As time becomes an ever-scarcer commodity in HIV/AIDS areas, access to water and energy sources must be improved. This is particularly important given the fact that these activities are socially determined to be the responsibility of women who most often care for their family members, irrespective of their HIV/AIDS status. HIV/AIDS might undermine the ability of communities and user groups to pool risk and act collectively to manage sustainably common property including rangeland, cropland and river basins.

Clear and equitable delineation of property and land rights become more important as individuals leave their dwellings to search for alternative livelihoods or to help out friends and families outside of their community. If dwelling or land rights are linked to physical presence, property rights might be impaired, especially when widows and orphans are the primary claimants.

Policy and programming principles

This section provides a list of key generic principles for maximizing the contribution of food and nutrition programming to mitigate the impact of HIV/AIDS. These principles have been derived from a review of the existing literature and from the main findings of a series of case studies carried out by the World Food Programme.

Do no harm

Any public sector attempts to respond to HIV/AIDS in terms of mitigation must "first, do no

harm." A number of private sector responses has deliberately reduced the abilities of households with infected members to mitigate the effects of HIV/AIDS. Examples from South Africa include the capping of medical benefits for HIV-infected employees, reductions in funeral leave, and reductions in company contributions to funeral expenses¹⁶. More difficult to detect, but perhaps less difficult to amend, are the interventions or policies that inadvertently increase the risk of HIV infection, e.g., actions that reinforce gender imbalances in power or those that displace individuals without adequate HIV monitoring and prevention efforts³.

Mainstream HIV/AIDS

The painfully slow recognition of HIV/AIDS as a major global developmental crisis, not just an isolated health problem, has finally dawned. Yet, strategies where they exist, tend not to go beyond prevention and remain in the domain of the health sector. Very little is happening in mitigation and very little in reviewing food and nutrition security policies and programmes through an HIV lens. Many government/public servants who work in agriculture or rural development do not understand the link between HIV and food security. Programming is *ad hoc*.

Effective advocacy is vital to mainstreaming

HIV/AIDS. Advocacy strategies, which consider the role of values, attitudes, and interests as well as information *per se* need to be developed. These strategies should be undertaken by skilled policy entrepreneurs, ideally backed up by nationally prominent individuals, need to be developed.

Ensure strategic balance

Conventionally, a distinction is made between prevention aimed at reducing HIV infection through behavioural change, and mitigation aimed at reducing the severity of HIV/AIDS impacts on households, communities and other institutions. Care interventions focus on those who are HIV positive, though they may also benefit other family members.

The focus on programming for HIV/AIDS has been largely on prevention, care secondary and mitigation relatively neglected until recently. This needs to change. It is increasingly obvious that not only are all these strategies vital in the long run, they should be integrated as far as possible. Interventions need to be designed and assessed not only in terms of their ability to mitigate the current impacts of HIV/AIDS, but also

in terms of their ability to reduce susceptibility to future infection and vulnerability to various types of impact.

Use an "HIV lens"

A hard look should be taken at the role that existing interventions and policies play, or could play, in HIV/AIDS mitigation before completely new and capacity-straining interventions are developed. What is the extent of HIV/AIDS-specificity required for an intervention to be effective in lessening the impacts of HIV/AIDS? Specifically, when do governments, NGOs, communities, and development agencies need to: i) improve the performance of existing efforts, ii) view HIV-prevention and mitigation interventions through a poverty lens and modify appropriately, iii) view agriculture, anti-poverty, and nutrition interventions through an HIV lens and modify appropriately, or iv) design completely new interventions to address HIV/AIDS?^e Development practitioners should not be blind to the threat of HIV/AIDS, but neither should they be blinded by it.

Food security programming *per se* is very weak in many countries. Programming for food and nutrition security rather than just agricultural production is difficult due to the multi-sectoral nature of the issues. Linking it with HIV/AIDS complicates the matter even more. This is coupled with the fact that many countries do not include extensive food security policies and programmes in their overall poverty reduction strategy, which marginalizes the issue further.

Context

Context in general, and the context of poverty in particular, is not taken into account in programming sufficiently. For those who are poor, HIV/AIDS is just one more event or shock, which affects their ability to get ahead and improve their lives. Programming for mitigation needs to look very closely at the other constraints, which impact food security for HIV/AIDS affected households. It is often these other constraints which affect the success of the intervention and determine how HIV/AIDS impacts different households and different members of the household. Because of the complexity of these interactions, it can be difficult to identify activities which are sus-

e. The "lens" essentially refers to an approach to viewing potential solutions to a problem (e.g. poverty) that derives from evolving knowledge of the important linkages with another problem (e.g. HIV/AIDS).

tainable, to address food and nutrition insecurity and to contribute to the prevention of HIV infection.

Targeting

There is a need to recognize the different stages of the disease in different parts of a country. In some areas, the biggest issue is prevention. In others, where there has already been a clear impact on households' ability to ensure their food security, mitigation becomes increasingly important. Different interventions will also be required for different groups. The impact of HIV/AIDS on food security of a pastoralist group is likely to be different from that on an agriculturalist community. Particularly susceptible and vulnerable are communities affected by complex emergencies, which are usually epicentres for the transmission of the disease.

There is no need to identify HIV-infected individuals or households even if it is feasible. To avoid the stigma attached to HIV, community-based targeting is usually the most appropriate option. If the programme is designed to identify the poorest for safety-net schemes or food aid development projects, for example, using known community structures appears to be the best way to target. Programmes targeting very poor food insecure households which have been impacted by factors other than HIV should not be considered an inclusion error.

Scale

Most HIV/AIDS programmes are very small scale in nature. They have been referred to as "expensive boutiques" available only to a small percentage of the affected population²². For example, in Kagera, Tanzania, a highly studied region, only two of five districts are covered by HIV/AIDS preventive services to which a mere five percent of the population have access. Multisectoral top-down coordination of integrated rural development programmes failed in the 1970s and 1980s²³, mistakes which should not be repeated. Nonetheless there remains a need for some top-down support of bottom up processes in the areas of setting of policies and programme parameters, cofinancing programmes, facilitation and training, monitoring and evaluation²². The challenge is to find ways of scaling up locally relevant, community-driven approaches.

Scale relates also to sustainability. As the use of an "HIV lens" in policy and programming becomes progressively systematized, sustainability is likely to increase. It is also important to re-emphasize that the short- and long-term nature

both of impacts and of mitigation responses need to be thought through clearly.

Partners and collaboration

Effective interventions are rooted in a community response and depend heavily on the participation of local health authorities, community representatives and people living with HIV/AIDS. The greater involvement of people living with HIV/AIDS in all aspects of related programming can be a powerful and influential factor in effective prevention, mitigation and care interventions. Many of the best organizations to partner with are community-based. However, these groups tend not to be national in scope and can be difficult to locate. They are often unable to scale up interventions.

It is also important also to look outside the usual nutrition and food security networks in order to identify partners working on HIV/AIDS with whom mutually beneficial partnerships may be forged. Many of the organizations aiding and supporting people living with HIV/AIDS and their families have religious affiliations. Food security programmes need to maximize the inputs of such organizations while recognizing the possible remaining constraints and gaps that remain. For example, in many areas, religious groups are active in home-based care, but they do not promote the use of condoms for HIV prevention. In these situations, other partners will need to be drawn in. As HIV/AIDS partner organizations may be very small with limited capacity, capacity development will be an essential element of support.

Monitoring

It is difficult for policies and programmes to respond to HIV/AIDS if the epidemic cannot be monitored effectively. A monitoring system that is relatively simple, but able to track the changing HIV/AIDS situation and its impacts on food and nutrition security, with the required accuracy and reliability to guide timely ameliorative action remains elusive. This is likely to be due both to a weak demand for such information and a weak ability to supply it. How to generate such a demand is a difficult question to answer. The stigma, denial and silence attached to HIV/AIDS makes the task more difficult than, for example, developing early-warning drought indicators. Moreover, the capacity to generate such information is undermined by HIV/AIDS.

A number of generic indicators have been suggested in the literature. Examples are suggested from the types of household and commu-

nity impacts and responses mentioned in the previous section. Data from health centres on STDs, TB, and adolescent pregnancies are all relevant if they can be accessed. Again, it is not necessary to re-invent food and nutrition security indicators, but to apply the HIV lens to existing ones. A balance has to be found between indicators that can be compared across communities and administrative units, and a community-driven process that can generate more context-specific indicators. Community knowledge will be invaluable not only in identifying indicators, but in clarifying their use and delineating what is feasible in terms of who will collect relevant data.

Programming in emergencies

Programming in emergencies should focus on controlling HIV/AIDS in the affected population and prevent further spread of the disease. This can be done through the provision of free condoms, provision of information, prevention of HIV transmission through blood transfusions and adherence to universal precautions for all health staff. Efforts should also be made to protect women from gender-based violence. In addition, the UN uniformed services are at high risk of both transmitting and contracting the disease and represent a good target group for education and prevention.

Options for Action

In this section we review some of the *specific* options for action to mitigate HIV/AIDS impacts on food and nutrition security, starting with nutrition-relevant policy and programming^f before considering the role of food aid and finally the options for mitigation via the agriculture sector. It is important to keep in mind the generic principles described above when considering such options.

Nutrition policies and programmes

There are several different approaches to designing and implementing appropriate nutrition-relevant actions aimed at preventing and/or mitigating HIV/AIDS impacts. A first distinction needs to be made with regard to the objective. For people living with HIV/AIDS, nutritional care and support is critically important in prevent-

ing or forestalling nutritional depletion. Relevant specific objectives might include to improve quantity and quality of the diet, to build or replenish body stores of micronutrients, to prevent or stabilize weight loss, to preserve (and gain) muscle mass, to prevent diarrhoea and other digestive discomforts associated with fat malabsorption, to speed recuperation from HIV-related infections, and to prepare for and manage AIDS-related symptoms that affect food consumption and dietary intake.

Nutritional support has the potential of significantly prolonging the life of individuals for their own benefit and those who are dependent on them for care, e.g., young children²⁴. Such interventions are likely to have the greatest overall impact early in the course of disease by prolonging the period of relative health with asymptomatic infection⁶. Unfortunately, relatively few people know they are infected at this time. Nutrition interventions may also be targeted to *communities* with the objective of preventing and/or mitigating impacts through reducing the interactions of HIV/AIDS with malnutrition, either upstream or downstream of HIV infection.

Any nutrition intervention should take into account the three main preconditions of good nutrition, i.e., food security, health and environment services, and care. For people living with HIV/AIDS this means that appropriate treatment of opportunistic infections, stress management, physical exercise, and emotional, psychological, and spiritual counseling and support are all relevant²⁵, along with conventional approaches such as home-delivered, ready-to-eat foods for home-bound AIDS patients who are unable to prepare their own meals.

Beyond a clinical setting, there is a major issue as to how to do this in a way that does not stigmatise the beneficiary. As mentioned, targeting to affected communities (not households) using whatever proxy indicators are relevant is likely to be most appropriate. A second-stage targeting might be employed with regard to stages in the life cycle that are particularly susceptible and vulnerable (e.g. adolescent girls, pregnant women, and young children).

Looking through the HIV lens, breastfeeding promotion and complementary feeding programmes will need to further emphasize the dissemination of clear information to policy makers, health providers, and communities about mother-to-child transmission facts, including risks and benefits of breastfeeding (Box 4). They will also need to anticipate that households affected by HIV/AIDS will have even greater time and economic constraints to the provision, preparation,

f. In the section on nutrition policies and programming it is understood that much of the discussion applies to nutrition and care programmes which use food aid.

Box 4—How does mother-to-child-transmission change policy?

The finding that HIV is transmitted through breastmilk has complicated infant feeding recommendations²⁶. Recognizing breastfeeding as a significant and preventable mode of HIV transmission, the Joint United Nations Programme on HIV/AIDS (UNAIDS), WHO, and UNICEF issued new guidelines on HIV and infant feeding²⁷. These guidelines call for urgent action to educate, counsel, and support HIV-positive women in making decisions about how to feed their infants safely.

Evidence of the protective effect of exclusive breastfeeding^{8,10} only emerged after these guidelines were published. Further confirmation of this finding and the benefits of "safer" breastfeeding practices, on the risk of mother-to-child transmission of HIV is a necessary first step in the development of a policy recommendation that would permit infants to benefit from the myriad benefits of exclusive breastfeeding while avoiding the risk of HIV transmission through partial breastfeeding. Much of the debate and controversy in this area has revealed a limited understanding of the multiple extra benefits of exclusive breastfeeding and the serious trade-offs and dangers of moving away from such a policy recommendation.

Yet despite these findings slowly gaining acceptance, there remains a strong resistance on the grounds that exclusive breastfeeding is both rare²⁸ and difficult to promote. Much remains to be done. Breastfeeding promotional efforts need to be rapidly improved, including expanding the Baby Friendly Hospital Initiative (BFHI) to rural hospitals, and strengthening its links with communities (the 10th step in the Innocenti Declaration). As well, advocacy is needed for the breastfeeding rights of working women using, for example, the new ILO Maternity Protection Convention 183 and Recommendation 19 which advocates longer paid maternity leaves and other needed workplace support.

and feeding of appropriate complementary foods. Programmes to address women's nutrition may not require substantial content changes, but need much greater support all around, especially for breastfeeding women. Again, these challenges will be further accentuated by the progressive weakening of health care and other delivery systems.

Affected communities may be targeted for the following types of interventions: nutrition counseling in health facilities, community settings or at home to change dietary habits, to increase consumption of key foods and nutrients or to manage anorexia and other conditions that affect eating patterns; water, hygiene, and food safety interventions to prevent diarrhea; and supplementary food baskets for home preparation.

As with all nutrition programming, it is important that it is not just community based, but community driven. Process is thus a major consideration. At the community level the key is to create space and develop capacity for an iterative process of assessment, analysis and action.

It is also important to build partnerships and foster convergence of relevant programmes. As a multi-faceted subject requiring action from several sectors, nutrition is, and has always been, vulnerable to bureaucratic inertia derived from compartmentalized organizational structures that offer few incentives for integration or convergence. Magic bullets have generally been the preferred way to go, as reflected in the prominence attached to vitamin A capsule distribution and salt

iodization during the 90s. There is nothing intrinsically wrong with magic bullets unless they end up crowding out other important and necessary longer-term holistic approaches to nutrition. This has certainly happened, as borne out by the relative stagnation of child anthropometric outcomes when compared to micronutrient indicators²⁹. While micronutrient supplementation (particularly vitamin A) will have a role in nutritional support to AIDS affected communities, this mistake should not be repeated in the case of HIV/AIDS communities, not least given the significantly raised energy and protein requirements of people living with HIV/AIDS that cannot be met by pills.

Programming food aid

The role of food aid in HIV/AIDS mitigation and care has just begun to be explored by field-based organisations. The biggest challenge for food assisted interventions is to provide food to meet needs but also to programme interventions so that family members and communities are left with a means to improve their food and nutrition security after the food assistance stops. Issues of sustainability are difficult and yet need to be fully resolved.

Recent work has shown that there is a role for food aid in both care and mitigation packages^{30,31}. However, certain programming principles should be followed.

If HIV/AIDS impacted families and com-

munities are to be targeted for food assisted interventions, there must be a clear need for food among the recipients. Tested and reliable methods for determining the relative level of a household's food and nutrition security exist and are used in most targeted food aid interventions;

Food should only be provided as part of a larger "package" of assistance which will depend on country and community specific conditions, but would include, as far as possible, information, education and awareness (i.e. prevention) components;

Combining food with either relevant training or income generating activities (e.g. micro-credit) appears to be a way to both assist households in dealing with reduced access to food and to build self-sufficiency in affected households;

Close consultation with affected communities on how to target and deliver food assistance needs to be an integral part of the project. Appropriateness includes not only issues of taste and nutrition but also preparation, including cooking. For example, decreased family labour can have an impact on the supply of household energy, such as firewood. Communities often have their own means of identifying the poorest households and selecting those who need food. In order to avoid stigma, households which are poor and food insecure but which have not been visibly impacted by HIV/AIDS should still be included in the beneficiary group, if selected by the community.

Food assisted projects present certain challenges. For many reasons they can be more complicated for implementing organisations than other types of development projects. Most of the community-based HIV/AIDS organisations, which would assist in the implementation of food aid projects, are very small and operate on minimal funds. They frequently lack the expertise and full capacity to undertake expanded activities and lack experience in transporting, storing, handling and distributing food. Organisations dealing in food assisted projects need to recognise this capacity gap and plan for capacity building and training in these areas. Furthermore, many of these organisations have never used food in their programming. Education concerning the role food should play in either a care or mitigation intervention is essential.

Where to concentrate HIV/AIDS food assisted programmes and projects may present a challenge. Food aid is generally targeted to the geographic areas of a country that are the most food insecure, and then within those areas to those communities/families which cannot meet their food needs. In many countries these are not

the areas that have the highest prevalence of HIV/AIDS³². Food insecure areas are often more remote, have low production potential and weak market structures. Areas with high infection rates are often located in or around urban or semi-urban areas, or areas where markets and transportation networks function relatively well and where commercial activities, including agricultural trade takes place. Towns near or on trucking routes, and zones with active commercial markets often have high prevalence rates.

In order to target food aid effectively in areas which are considered food secure, food assisted interventions need to be able to locate and identify those families and communities which have been impacted by AIDS and are having difficulty meeting household food needs. Local institutions, NGOs, or community-based organisations working with HIV/AIDS affected populations will be key.

Furthermore, food assisted programmes dealing with HIV/AIDS need to broaden their reach in terms of prevention activities. Many organisations that deal with food aid also transport it within countries, either through their own trucks or through contracting local transportation companies. Because long-haul drivers are known vectors for the spread of HIV, it is important to include this group in education and awareness campaigns and training, including condom distribution.

Several options for programming food aid are listed in Box 5. By slightly changing existing food aid projects, the specific needs of food insecure HIV/AIDS impacted families can be taken into account. For example, school feeding in particular has potential as a means to encourage school attendance of orphans and to prevent school drop-out. By providing take home rations for families fostering orphans as part of a regular school feeding programme, families are encouraged to continue caring for children whose parents have died and orphans are encouraged to attend school.

Although food can and should be distributed to and through institutions, caution must be exercised to avoid undermining household and community care strategies. For example, by supporting orphanages with food and other inputs, communities might be encouraged to send orphans there rather than finding foster families where children can stay in a family environment.

Agricultural policies and programmes

The options for policy and programme response in agriculture can be grouped around the main clusters of impacts: labour losses, knowledge

Box 5—Examples of prevention, mitigation and care-related intervention options that use food aid

Prevention

Using food distribution sites to enable partners to raise awareness on HIV and AIDS, provide prevention information and promote and distribute condoms

Making certain that long-haul truck drivers are provided with risk reduction and prevention information and an ample supply of condoms

Training of community health workers in methods of optimal breastfeeding practices

Training of youth peer educators to provide information on STD and HIV/AIDS risk reduction and prevention as well as voluntary testing and counselling

Mitigation

Food for vocational training for street children and orphans

School feeding with special take home rations for families caring for orphans

Food for training programmes which promote income-generating activities (mushroom growing, tie-dyeing, etc.) and are linked to small scale credit facilities for women and older orphans

Food for training and food-for-work to support farmers through animal traction schemes and the provision of seeds and agricultural tools

Food for work to support increased agricultural production through home gardening to improve diet diversification and increase intake of micronutrients

Food for work and food for training to support the introduction of small scale, low labour livestock activities to (a) increase the intake of high energy, high protein food and (b) provide capital/savings that will increase over time

Care

Providing food for women living with HIV/AIDS and their children in order to prolong the life of the mother while ensuring the nutrition of her children

Supporting the training of HIV/AIDS home-based care workers in nutrition counselling to emphasize optimal nutrition and advise on optimal foods for their patients

Providing nutritional support to tuberculosis patients to protect their food security and as an incentive to complete their full treatment protocol (TB is one of the most common opportunistic infections found in people living with HIV/AIDS)

Source: World Food Programme (WFP) (2001c) Food Security, Food Aid and HIV/AIDS: Project Ideas to Address the HIV/AIDS Crisis. WFP: Rome.

losses, and weaknesses in institutions. These tend to be most noticeable beyond the initial phases of the epidemic. All are compounded in a downward spiral whenever asset depletion is a short-term response.

Discussion of HIV/AIDS issues can, and should as far as possible, be included in agricultural services provision. Examples include Integrated Pest Management (IPM) programmes in Southern Africa that have incorporated information on HIV prevention, care and mitigation into IPM training. Also, in Southeast Asia, farmer field schools and IPM student field schools have addressed HIV prevention issues¹⁶. There may be a benefit to targeting scarce extension resources to higher risk groups such as seasonal agriculture workers, estate workers, and fishermen.

Research on national agricultural systems should be encouraged into the substitutability of labour and capital in local farming systems in anticipation of severe labour shortages.

But perhaps the most profound challenge to the agriculture sector in countries threatened by HIV/AIDS is the need to develop agricultural and natural resource management systems that are more labour-extensive and use less purchased inputs but support sustainable livelihoods. In the absence of new technology and techniques, farmers are switching to feasible low input, low output farming that is preferable to infeasible labour-intensive, higher input farming³⁴. Yet, in so doing, they run the risk of adopting an ultimately destructive "coping strategy." If the loss in agricultural productivity from pre-epidemic levels is

sufficiently large, farm and nonfarm incomes will slowly cycle downwards.

The move to low input low output farming buys some time but is unlikely to be a sustainable solution. The challenge for the agricultural community and specifically for the agricultural research community is to develop farming practices that adapt to the reality of HIV/AIDS affected environments and yet maintain productivity levels. For this to happen, surviving farmers should be ever more closely involved in planning and implementation of supporting research³⁵. One simple example of a technological adaptation to an HIV/AIDS environment is the development of lighter ploughs for use by women and youth¹⁶.

Proposed methods for combating information and knowledge losses include farmer field schools where experienced farmers share their knowledge with less experienced farmers (youth and widows). For example an initiative in Zimbabwe involves participatory training for AIDS widows in the production of cotton, a crop normally grown by men¹⁶. Extension services, themselves severely depleted by the epidemic, must focus more on youth to "fill the void." Information losses are also crucial in terms of the role traders play in bridging the gap between farm and market. Recent research has emphasized the important role played by trader-farmer networks of information and social relations that embody reciprocity based on trust³⁶. This is one of the forms of social capital that HIV/AIDS is thought to undermine. Mobile traders are likely to be relatively susceptible to HIV/AIDS and given the already thin nature of agricultural markets in many parts of Sub-Saharan Africa the consequences are likely to be serious. Efforts to support these networks need to be developed.

Agriculture does not take place in a vacuum. Successful efforts to strengthen the institutions that support farming in the face of the HIV/AIDS onslaught are difficult to find. An important first step is to improve the access to HIV prevention information and technology for members of that institution. Second, it is necessary to clarify the ability of the institution to strengthen itself. We do not know enough about which types of capacity constraints are most binding and which have been most damaged by HIV/AIDS. This is another important step to take before increasing resources for staff development and recruitment.

Recent experiences from some of the most badly affected countries have demonstrated the ability of an important rural institution, micro-finance, to innovate and develop products that better meet the needs of the emerging clientele,

especially as in Uganda where national leadership has openly confronted HIV/AIDS³⁷. The roles of micro-finance institutions and the NGO community that helps animate them will be crucial in the prevention and mitigation of HIV/AIDS in the new HIV/AIDS battlegrounds of South and Southeast Asia, where so much micro-finance innovation has taken place in general. If such types of innovation are to occur at the intersection between community and institutions that are accountable to them, donors will need to be more creative in the programming of resources.

Research

The research base upon which HIV/AIDS impacts are assessed and upon which interventions for mitigation are evaluated is very narrow. A small number of good studies do exist in refereed journals, and more exist in the unpublished literature. Yet, given the scale of the problem, the research base is remarkably small.

There is no consensus as to whether information gaps are more constraining than funding gaps, but clearly better analysis and information can lead to a better use of existing resources and provide a firmer basis for arguing for more. There is a sense that many experiences in mitigation in the food, agriculture and nutrition field are not getting out to as wide an audience as they need to. Innovative practitioners have little incentive to document their experiences given the complex environment within which they work and in any case, the demand for such information may be muted due to the silence surrounding HIV/AIDS. Mechanisms for information sharing, for giving those at the front line a "voice," have to be found.

Second, tools for the assessment of capacity need to be developed and employed. Capacity as a constraint to effective interventions is often overlooked with disastrous consequences, and the fact that HIV/AIDS directly undermines this capacity makes it even more important to assess what remains. The evaluation of HIV/AIDS mitigation through food, agriculture, and nutrition interventions is an area in which immediate work must begin. The work must be action oriented for advocacy and ethical reasons but it must conform to high scientific standards—a difficult but not impossible challenge as action research outside of HIV/AIDS and indeed HIV/AIDS prevention work has shown.

g. For a detailed description of the type of information gaps concerning appropriate mitigation responses to HIV/AIDS impacts, the reader is referred to a recent paper by Haddad and Gillespie³⁸.

Third, more basic research needs to be undertaken on the dynamics of shocks, including HIV/AIDS. Which communities, families and individuals are best able to minimize the damage due to HIV/AIDS and why? Pragmatism needs to prevail if the research is to have payoffs within 2-3 years, and all efforts must be made to build on earlier data collection.

Finally, the policymaking process needs to be better understood. Why does HIV/AIDS register more quickly as a threat to development in some countries but not in others? How do policy makers learn and what is the role of research, communication and advocacy?

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Discussion

Chair Clearly, there are many connections between nutrition and HIV/AIDS. Nutrition has an impact on HIV/AIDS and HIV/AIDS impacts on nutritional status. Breastfeeding is an important element in the discussion, but there are many other angles as well. The problems are so big that we need to attack them on different levels. We need to consider small-scale rural programmes as well as policy development. Research is also needed so that programmes are well designed and based on sound scientific evidence.

Question from the audience When considering how to accelerate programmes, there must be some focus on the critical points and not a long list of "priorities". Is it possible to look at the critical points first rather than a long list? What are these critical elements? Of course, we would not want to neglect other issues totally, but can we focus on a very few things first?

Question from the audience When we talk about the relationship between food security and the distribution of HIV/AIDS, there would probably be regional differences. The distribution map for HIV/AIDS and the food security map for India are totally different. Is it possible to generalize?

Comment from the audience Many in this audience recall that 20 years ago we discussed multisectoral nutrition planning. The HIV/AIDS problem has many similarities with the nutrition

planning problem. We say that HIV/AIDS is a complex problem, that it needs multisectoral action which is all about behaviour change and changes in practice. The fascinating thing is that the response so far is exactly the same response we had to nutrition 20 years ago. Countries set up big national committees, nutrition councils, regional and international planning meetings and developed a language that only the nutrition experts could understand. Can we learn from the last 20 years in nutrition and then jump ahead 20 years? We have learned that unless people and communities are incorporated into the solution nothing will happen. This is where I see the whole work with HIV/AIDS today. It should be oriented towards building capacity in the community. That is why I think the nutrition community can play an incredibly important role in saying to the HIV/AIDS people: look here my friends! We made that mistake long ago. You don't need to repeat it!

Chair Let us hope the nutrition community really will say that. From community to community, malnutrition is present but where are the actions to combat malnutrition in those same communities? Mrs. Monico described what TASO is doing in Uganda by working at the community level. The point has been made that governments should take HIV/AIDS seriously. If governments are going to take HIV/AIDS seriously they have to set up some kind of government machinery to look after HIV/AIDS. Of course, we should work at the community level, but it is not

an “either/or” situation. Maybe we should shift more emphasis towards the community level, but we must maintain a balance somehow. Nutrition cannot be tackled in a vacuum at the community level. Let’s try to encourage those who are working at the community level and others to develop national legislation. Discrimination against widows that leads to loss of land rights should be eliminated. This cannot be only a community level effort. Children who are orphaned should go to school. That cannot be only a community level effort. There are so many issues which need to be taken on board by a central administration.

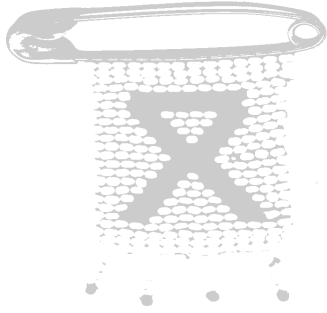
Response from the audience I agree that it is not an “either/or” situation but I am frustrated and I am in good company. You come to a village in Kenya, Tanzania or Zambia. You meet an old lady who takes care of 20-30 children. You ask her: is there anything we can do? She comes with a very modest request, perhaps a few hundred shillings. Next day, I sit in a meeting in Geneva or New York or Nairobi and listen to donors saying “we are increasing to 100 million dollars...” or “we are increasing to one billion dollars...”. I do not see anything happening at the community level from these enormous promises. Second, we have to remember *those who cope*. Even with a 25% infection rate there are 75% not infected. They have already found a solution. We can learn from them. I still remember the frustration we had in the nutrition community and I was one of the most committed nutrition planners in the early 70s. I gave up because I realized that planning has limitations and solutions are constantly being produced at the community level.

Stuart Gillespie I agree entirely. This last point helps to answer the first question with regard to what we actually do. It has to be both top down and bottom up. However, there needs to be a

significant shift in emphasis towards the community and understanding community needs, supporting as far as possible capacity building and the ability to respond and cope. There are many similarities with nutrition. Yet, we must not reinvent the wheel in terms of believing that multisectoral HIV/AIDS committees are going to be the answer.

With regards to India and the mapping of food security with HIV/AIDS, India right now is in phase one of the epidemic. I don’t know if the relationship between HIV prevalence and food insecurity would still apply in phase three. It may or may not, but certainly the situation in sub-Saharan Africa is mostly phase three and there is a significant overlap and a linkage between poverty and food insecurity and HIV/AIDS.

Comment from the audience I liked the broad coverage of this presentation and the variety of topics. However, Dr. Gillespie did not talk about safe infant feeding and maybe that was not intended. We are in danger of having a new increase in malnutrition and other micronutrient deficiencies. We don’t know what is going to happen with those mothers who are living in poor families who are persuaded to use some alternative method than breastfeeding. We need to discuss this and know more about it and the situation needs to be monitored. Increasingly one goes to countries and sees mothers being persuaded, or deciding for themselves, not to risk breastfeeding their babies. If they come from poor families, we do not know what the extent of the increased malnutrition will be. Will these children be getting more illnesses? The cost of mothers themselves getting medical care was mentioned, but infants are going to need more medical care as well. One of the nutritional implications of HIV/AIDS is going to be that if mothers who are poor choose not to breastfeed their babies and use one of the alternatives, then malnutrition will get worse.



Nutrition and the Care Package

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Swaziland is a small country with a population of about one million where children under 15 years of age represent about 45% of the population. It is a very young population with a high dependency ratio. When AIDS kills the active young adults, many children are left unsupported. There are many elderly people who are called *elderly orphans*. These are our mothers and grandmothers, who were hoping to have a better life after educating their children. They are now left behind to look after their grandchildren and great-grandchildren and they are unable to cope.

The first known case of HIV/AIDS in Swaziland was in 1986. In a survey two years later, HIV/AIDS affected three per cent of the population. For some reason we were lulled into believing that someone must have imported this problem and that it would pass. However, prevalence rates have increased progressively in antenatal women; in 1998, the rate was 31%. You can imagine what this means for the women of Africa, especially those in rural areas where hard physical work is such a burden. These women provide for their family and farm the land when the men go to seek work in the urban areas. A recent study¹¹ showed a rise to 34% of pregnant women infected. This is a devastating situation. The four most affected countries for HIV/AIDS are the countries of southern Africa. Hence, this is a real problem for the region and we need practical and affordable solutions, not fancy statements.

...It is like building a house. If you have a roof but there are no walls and no foundation, the house is not very useful. It is similar with HIV/AIDS care. We need to build that house with walls and foundation made of nutritious food

Other countries such as Senegal and Uganda have very good stories to tell, but we see teenagers dying in Swaziland. These teenagers were not infected at birth; they were infected further down the line. Life expectancy is being reduced to the late 30s and early 40s in the region. With a general population prevalence rate of 20-25%, a good section of society is not well enough to be productive and not well enough to do their daily work such as farming. Academics, skilled and semi-skilled workers are being lost. Thus, land utilization and food production will actually

go down. Malnutrition and HIV/AIDS are intertwined. Both are worsened by poverty, while both deepen existing poverty. We are losing all the health gains, economic gains and societal advancements of the previous decades in a very short space of time.

When we talk about care we need to look at what we really understand about care. Many people talk about care and instinctively they are thinking about anti-retrovirals. This is a gross mistake because we know anti-retrovirals are mainly beyond our reach. We would like them to be affordable, but in the wave of excitement about anti-retrovirals, we have forgotten some of the solutions that are affordable and available locally. Good nutrition is one of these solutions. We have seen, together with other countries, policies and plans on how we care for people affected by HIV/AIDS but there is very little coverage on issues of nutrition. It is like building a house. If you have a roof but there are no walls and no

foundation, the house is not very useful. It is similar with HIV/AIDS care. If you include drug therapy but you do not have adequate nutritious food, you will not be able to fight the infection. We need to build that house with walls and foundation made of nutritious food. In trying to fight the HIV virus we sometimes forget to use the ammunition that is available to us. We look for sky high solutions and forget the ones that are very close to us which are affordable and could impact tremendously on our societies.

In a survey² of the nutritional status of the Swazi people carried out in 1983-84, we found that 30% of our children under five years were stunted. We were hoping to have reduced that stunting to below 20% by the year 2000, but by 1995, we had only managed to reduce it to 27%. Another study² in 1997 showed that one percent of children are wasted. Wasting is a form of acute malnutrition. Furthermore, 8.2% of babies delivered in hospital were below 2.5 kg. This is a reflection of maternal malnutrition because mothers who are not well fed or have other diseases have a greater risk of delivering low birthweight babies.

A study² completed in 1993 showed that there was iodine deficiency in some regions of our country varying from six to 38%. We also found vitamin A and iron deficiencies. Some of the interventions³ focus on solving these problems, such as adding vitamin A capsules to national immunization programmes. There is legislation requiring that all salt be iodized. Also, we are negotiating with the sugar industry, one of the biggest income earners in the country, to fortify sugar with vitamin A. This experience shows that it is possible to identify nutrition problems, and have solutions ready in a short time.

Why do we believe that nutrition is the most important solution for Africa, whereas other regions have found other solutions that work for them? When HIV invades, it enters the immune cells that protect against disease. The virus goes

right into the cell, sits there comfortably and quietly for three months or even for many years and then it multiplies. As the virus multiplies, it destroys this host cell. As it destroys the cells, harmful chemicals are released, such as cytokines and free radicals, which can further damage the body. It becomes a vicious cycle as the cell environment promotes replication. This is a complex process put very simply. The critical question is "What can we influence in that cycle?"

A recent book by Piwoz and Preble⁴ summarizes the importance of nutrition in influencing this cycle. The macronutrients (carbohydrates, fats and proteins) along with vitamins and minerals are necessary for building and repairing tissues. Put simply, foods contain nutrients that can help protect the immune cells which have been invaded by HIV. HIV and its host can

live symbiotically for a very long time. This is where we, as health workers, nutritionists and politicians, may have lost sight of our purpose. All we concentrate on is the inevitability of death once a person gets the infection. There are many things that we can do in the intervening period between contracting the infection and death.

For people living with HIV/AIDS, malnutrition often first

appears as weight loss and muscle wasting. Metabolism is altered and there is increased utilization and excretion of nutrients. Deficiencies of vitamins and minerals needed by the immune system to fight infection commonly occur; these include vitamins A, C and E, as well as selenium and zinc. These different forms of undernutrition often co-exist. People with the infection more easily become debilitated which results in a loss of independence and inability to carry out daily activities. Good nutrition, especially beginning at the early stages of HIV disease, helps prevent weight loss and strengthen the immune system. Good nutrition thus plays an important role in positive living with HIV, and may help delay the progression of HIV disease. Because of the high energy demands during infection, adequate energy and protein intake and adequate anti-oxidant intake are important.

We need to be reminded of the nutrition-related activities in which we in Africa can engage. Yes, we do need the therapeutic agents. We need the anti-retrovirals to be affordable and available to everybody. However, these will not work in a vacuum. You need to be well-nourished for some

...the focus should be on sustainable community solutions such as small gardens near the home and advice on what foods to grow. We need to encourage our communities to grow indigenous foods

Box 6—Swaziland's care package summary

Broad Issues include ...

- Poverty reduction
- Economic empowerment
- Food security and agriculture
- Improved farming of relevant plants
- Food storage

Good nutrition includes, specifically, measures to ...

- Increase energy intake
- Increase protein intake
- Increase vitamin and mineral intake, especially antioxidants (vitamin A, C, E, selenium and zinc)
- Provide nutritional supplements and packages in home care
- Expand school feeding programmes
- Provide educational packages

Medications also have a role ...

- Provide vitamin and mineral supplements
- Treat opportunistic infections
- Anti-retrovirals where affordable

Counselling and Support

- Religious
- Family support
- Legal provision for orphans and families

of these medicines to work. The secret is that if you can stay well through improved nutrition for as long as possible you may actually even defer the need for anti-retrovirals. Consequently more focused attention is needed on affordable solutions. Here is a series of propositions (summarized in Box 6).

Let us look at the broad issues such as the reduction of poverty so that at least each household can have food on the table in sufficient quantities and in a balanced way so that each member of the family is able to survive. Now, how do we do that and still retain economic empowerment? It is good to have handouts and it is good to have assistance, but the focus should be on sustainable community solutions such as small gardens near the home and advice on what foods to grow. We need to encourage our communities to grow indigenous foods. To support this we need to analyse our indigenous foods for their food value so that when we advise people to grow peanuts or mug beans, we will know what the nutrient composition is. What is the best source of vitamin A? What is the richest source of ribofla-

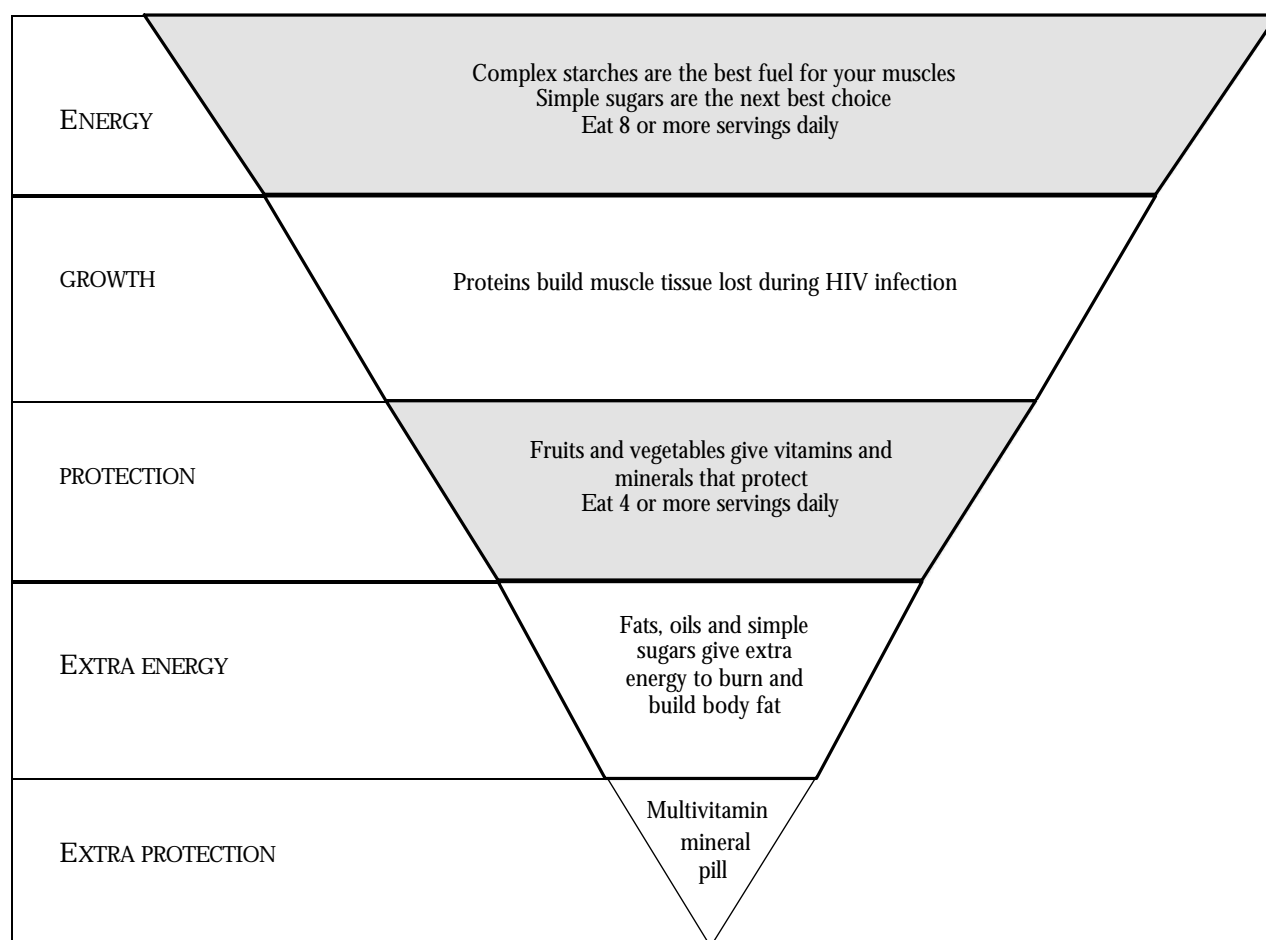
vin? Growing one's own food leads to economic empowerment; let people do as much as possible.

There is life between the time of initial infection and the development of AIDS. We should make the quality of life as good as possible and enable people living with HIV to do something for themselves because it restores their dignity. Even if people are HIV-infected they do not want to be made to feel they are already patients. They want to feel they are contributing to society. These are the problems when we talk about economic empowerment. If women cannot farm, they can still be involved in other sustainable solutions. As the Chinese say: "Teach them to fish and not provide the fish all the time".

Food security and agriculture is another important issue. Africa is besieged with fluctuations in seasons. Africa has droughts, floods, often severe winters and naturally occurring lean seasons. How can communities best breach those times of need? We have to look at how to store and process our foods during times of plenty and develop and impart these skills within the local communities so that we can really have simple

Box 7—The Right Food

A guide to daily food choices for people living with HIV



Eat a variety of food to get the nutrients your body needs

Source: Adapted from Kraak V, Hernandez Y, Kaplan C (1994) Living with HIV: A Nutrition Guide with Emphasis for People In Recovery. God's Love We Deliver: New York.

solutions to our problems. The ability to store food would bring enormous benefits to communities, especially those most severely affected by the HIV/AIDS epidemic.

The second big issue in nutrition is increased energy and protein consumption. Families need assistance in estimating their new needs, especially of the staple food. It is not useful to come to a village and say to a mother or grandmother, "You have to have 500 grams of cheese". We do not know how to make cheese and we do not know how to store it. Cheese is expensive to buy, it probably needs to be refrigerated. So the challenge is to think of local solutions and to learn more about what is available locally. Nutri-

tion supplement packages are possible and again we are excited about this. In its fight against HIV/AIDS our neighbour South Africa is producing packages of highly-fortified powder from local foods, such as sorghum. These can be taken as a drink to supplement the diet. Making supplements for everyone may help to de-stigmatize HIV disease as well as improve the nutritional status of the overall population. Having said that, special attention should be given to those who are infected. For school age children, especially orphans, we need to look at school feeding schemes as well. As part of our fight, all countries should have their nutrition brochures or flyers in local languages. They should be written simply and in-

dicating what to do for common ailments such as diarrhoea. By identifying simple solutions, and describing them in easy-to-understand language, we can make nutrition part of the solution to keeping our communities healthy for as long as possible.

Vitamin and mineral supplements can be given to the population. However, to be honest, there is a chance that we will miss many people who are sick at home. Vitamin and mineral supplements are included in Swaziland's food pyramid, so as not to forget the potential role they can play (Box 7). However, it is better to teach about what can be grown in home gardens. Treating opportunistic infections early and using anti-retrovirals where affordable are also important.

Finally, I think that emotional and counselling support goes a long way, whether it is religious or spiritual counselling, family support or providing legal advice for orphans and widows. The AIDS Support Organization in Uganda is working with memory books and living wheels. These help people cope, especially young children. In Swaziland, we have community volunteers who are trained in home care and treating ailments. If a child has diarrhoea or an injury, they will provide the care right in the community.

In conclusion, maybe this is not the time to have repeated meetings and workshops. It is time to work with communities and to work on local solutions that come from the ground up. It is also important not to leave the policy makers behind. It is important not to demonise governments with all the weaknesses they have. It has

been said that some donors have decided not to fund programmes in Africa anymore if they cannot control the recipient government. This is very alarming. We have to bring everybody on board, governments and NGOs, so that we find solutions together. The starting point should be the government's commitment of some funds to community programmes, no matter how small. We need to stimulate interest to move towards long lasting nutrition strategies that receive visible support from everyone. Of course this process has to start in our countries. Just as we need more relevant research on African indigenous foods and medicinal plants, Africa needs more home-grown initiatives to fight the HIV/AIDS epidemic. Our people are dying.

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Discussion



Question from the audience I am interested in your experience and practical views regarding refugees, especially refugees living in camps where the population is closed in and stigma from HIV/AIDS is very high. Most of the time refugees depend on food rations from the World Food Programme and have very little access to income to buy additional food. We need to be guided by practicality when incorporating nutrition in our HIV/AIDS strategy for refugee camps. It is okay to say “do no harm”, but the “how” part is very important.

Comment from the audience Dr. Dlamini's paper shows how Swaziland approaches the process of capacity building and strengthening to promote nutritional well-being of all citizens. Swaziland is one place where nutrition units or councils are surviving, unaffected by the trend in the rest of Africa where nutrition councils or units are virtually dying. In Swaziland, nutrition is seen as a most important element of health care for people living with HIV/AIDS. Swaziland has also taken very seriously the principle of avoiding harm. For example, they are proceeding very carefully in terms of advice on what the infant feeding op-

tions really are. Programmes are evidence based. The government requested a study on infant feeding so that the basis for policy can be solid; study results are being discussed at the highest level. Community-based approaches are also very important in Swaziland. Community motivators, who work as volunteers, continue to be strengthened and are involved in all public health approaches including care for HIV-positive people and for nutrition promotion.

Question from the audience The reference to traditional foods is much appreciated because this can be a sustainable intervention, affordable by the very poor who perhaps have to make a decision on whether to plant cowpeas or pumpkin on a very small piece of land. However, there is little information on the nutritional composition of these foods. Firstly, what is being done in Swaziland to disseminate existing information and to encourage further analysis of these traditional foods? Secondly, in some of our communities people are programmed to think that these foods are inferior to “exotic” foods. What interventions are there to promote these traditional foods and to raise their status?

Comment from the audience Clearly the type of community involvement in Uganda and Swaziland is very good, but it has not gone far enough yet. In the early 80s, Thailand mobilized a huge number of volunteers: one per ten households. This meant that in every community several persons were trained in health and nutrition. Initially training was in the area of nutrition and community development. The same mechanism was then used to bring all pregnant women for antenatal care. With quality services low birthweight was reduced from 18% to about 7% and pre-school underweight from 51% to about 10% within ten years with the rapid rate of reduction in the first five years. The same mechanism was then used for prevention and control of HIV/AIDS because volunteers were selected on the basis of socio-demographics. The volunteers were respected in their communities. People living with HIV/AIDS were not hesitant to seek services through the volunteers.

The first HIV case in Thailand was documented in 1984. By 1994 there were 400,000 cases and by 2000 one million cases were reported. By now the number has fallen to 800,000, in large part due to community based programmes. The whole process could be seen as “social immunization”. At the national level, Thailand accepted HIV/AIDS as a key problem.

This was debated at first because of fears that HIV/AIDS would affect the tourist trade. HIV/AIDS was also perceived as a shame. Once the problem was recognized, one key message was used in all prevention and control programmes: “Only safe sex will prevent HIV/AIDS”. Condoms were promoted widely in the country. The incidence of sexually transmitted diseases has gone down quickly with the use of condoms. People living with HIV/AIDS have been encouraged to become community workers. Schools are also involved in information dissemination, including information on community care of people living with HIV/AIDS. In Thailand, religious leaders are very important in community care. They encourage meditation, physical exercise, home gardening and community work (cleaning temples and schools). As for nutrition, community care stresses optimal use of existing resources. Fish and unpolished rice are advised as well as leafy, green and yellow vegetables, which are high in antioxidants. Treatment for symptoms is based on locally available plant products, such as cumin and aloe vera.

Question from the audience How do people translate the information they get from the counselling guidelines on good nutrition to actual practice? The treatment of opportunistic infections is considered an essential part of the care package and it has a close link to nutritional care. What is the thinking in the region in terms of accelerating access to essential drugs and some of the life-saving tools, like gloves for health workers in maternity wards? Sick pregnant women are expected to provide these as part of cost sharing. How can health sector reforms be implemented so that the essential tools for prevention of transmission of infection do not become items of cost sharing?

Minister Dlamini's response Swaziland received refugees when Mozambique went through a difficult time. We did not know how long their problems would last, so we set up camps. These were really villages big enough so that people could have a patch of garden near their houses, so they could farm. The government decided that refugees would be eligible for employment if they could find it. Many were involved in self-generating employment; some found employment in the theatre and others helped to implement the HIV/AIDS prevention and control strategies. Working together it was possible to identify a range of opportunities for employment and community work. Refugees feel caged in if they are idly receiving rations. They want to earn a living. It is up to each country to find the most relevant

way to handle the situation. Swaziland developed an HIV/AIDS prevention and control strategy for the camps. Implementation of these strategies must involve the youth leaders who, after all, are the ministers of tomorrow.

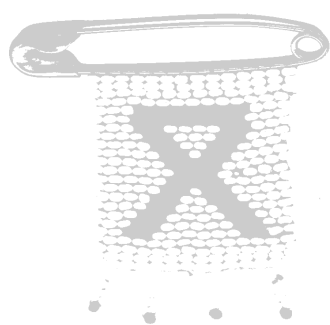
The national nutrition council in Swaziland has been strengthened. The council is shared between the Culture and Health Ministries and legislation was passed in March 2001 to expand the council and give it budgetary support. Regarding infant feeding, Swaziland has adopted an attitude of giving mothers all the information available. We owe it to women to let them know the full implications of each infant feeding method. We are sensitive to the new scientific evidence that indicates that exclusive breastfeeding for the first six months may be more protective than mixed feeding. We promote exclusive breastfeeding.

Indigenous or traditional foods have been downplayed in Africa and they need to be brought back into fashion. Here is an example. Swaziland's Queen Mother celebrated her birthday recently and she offered all the foods that I used to see my grandmother cook. Those present preferred to eat the indigenous foods, while they left the rice. "Civilization" can be regressive and the more modern African diet can contribute to chronic disease. In the past in Swaziland one would eat a good meal in the morning, work in the fields all day, then have a small evening meal of one or, at most, two foods. The more modern African diet can include a large mixture of foods. In Africa we need to work towards bringing back into fashion the traditional eating patterns and the indigenous or forgotten foods. As Minister of Swaziland, if I eat Kenyan green spinach one would think, "Our minister is poor but she is supposed to be rich." My reply would be, "Oh, *this* is fashionable." How we portray nutrition is important. We have to sell it and market it. This is what I hope will become part of the nutrition strategies. Reliable nutrient composition data on African indigenous foods is lacking; our universities should be engaged in analysis of indigenous foods rather than the imported more modern foods.

As in Thailand, one of our biggest partners is people living with HIV/AIDS themselves. The president of our AIDS Care organization in Swaziland is a young man who promotes nutrition materials that we have co-developed with the assistance of UNICEF and other collaborators. He was diagnosed sero-positive in 1993; so he is eight years post diagnosis. He is well and he has not taken any anti-retrovirals. At first people did not believe him, but now they do. He has become a living symbol. We have to involve the communities.

In Swaziland we can supply gloves in the hospitals. This is a problem in other countries where women ready to deliver must furnish all the basic needs. Governments should bring in reforms and make a commitment that there is a basic package of care. In our country, there is a clause in our legislation providing for free treatment if you are unable to pay. Many people do not know about this clause. Occasionally I remind people that it is in our legislation. We need to face the challenges together and not make cost sharing a burden, so that cost sharing becomes *poverty sharing*. Some end up with no care at all because they are cost sharing. Governments have a commitment to look after their people.

The ministers from central, southern and western Africa are meeting to determine how we can obtain drugs for opportunistic infections (such as tuberculosis and pneumonia) by purchasing these drugs at reduced prices. This means negotiating reduced prices from the pharmaceutical companies, not an easy task. Bulk ordering as communities or groups of countries may also be helpful, but we need our finance ministers to assist us with this. We also need to look at the World Trade Organisation and the TRIPPS Rules. The economists are now telling us that we can legislate access to generic drugs and obtain licenses for companies to manufacture them in the region, as long as we do it before the year 2005.



Panel Discussion on the Implications of HIV/AIDS for Nutrition Programmes

Dr. Elizabeth Marum

Centre for Disease Control and Prevention, Kenya

Dr Piot talked about food and the lack of food being the number one problem mentioned by people living with HIV/AIDS in Malawi. Professor Saasa raised the issue of “ill conceived home-based care programmes”. In Malawi we did an assessment of home-based care programmes throughout the country. Our findings relate to the issue of hunger among people living with HIV/AIDS, and the problem of home-based care programmes, which are not well designed. We interviewed 50 patients or their care givers in their homes and 47 home-based care volunteers serving these patients. We also had focus group discussions. We looked at a number of issues including food and nutrition. Sixty-eight percent of the patients were women and only one in four female patients was married and living with her husband. The rest were being cared for primarily by female care givers, similar to what has been observed by TASO in Uganda. The average age of the male patients was 46; the women were considerably younger, with an average age of 32. We found that the needs and requests they had were very simple. They needed food, pain-killing medications, soap, bed clothes and help with household tasks. The sad story is that these basic needs were not provided by the

home-based care programmes. There was an acute *unmet* need for food supplementation for these patients and their children.

Eighty-six percent of the patients reported needing food but only one person was receiving food on a regular basis. It is important to note that these were not people living with AIDS who we found in the community.

Our concerns about sustainability and the complexity of the problem should not prevent us from making sure that people living with HIV/AIDS in Africa have enough to eat

These were patients who were enrolled in HIV/AIDS home-based care programmes and yet only one was receiving food on a regular basis. Another 13 received food sometimes, but not often enough. The food they were receiving unfortunately came directly from the volunteers themselves, from *their own* food supplies. The home-based care programmes, some of which were reasonably well funded by external donors,

did not supply any food supplements. We heard repeatedly from the volunteers that they could not continue doing this, that it was putting their own families under constraint. These data highlight that food supplementation for people living with HIV/AIDS is an acute problem and one which home-based care programmes do not adequately address. Colleagues in Kenya report a similar situation. In Uganda the availability of food supplementation was a motivation to be en-

rolled in home-based care. It was also motivation to get tested.

We also found that the treatment of even simple opportunistic infections was very inadequate. For example, 43% of the adult patients reported recent symptoms of oral thrush but not one was receiving correct treatment. Two of these patients had received some form of traditional treatment, and one had received pain medications. However, none had received the relatively simple and inexpensive drug which treats oral thrush. Untreated oral thrush can contribute to dehydration and malnutrition because eating becomes difficult and painful.

Another major issue is that of compensation for volunteers working in these programmes. In almost every home-based care programme and community HIV/AIDS programme that I know of, there is an excessive dependence on volunteer labour. In Malawi, Uganda and Kenya there are people who are motivated to help their communities but they have their own problems at home. To always assume that these counsellors can do this work on a volunteer basis is really not very helpful. Why don't we use food aid as a way to compensate people doing volunteer HIV/AIDS work? The model of "food for work" programmes in India and Bangladesh could be adapted to "food for HIV/AIDS work" for people in rural communities who are giving their time.

The HIV/AIDS community needs to pay more attention to nutrition issues. Many programmes do not factor in nutrition adequately. Just as there are now gender assessments, there should also be nutrition impact assessments. The

gender community have been very effective in making sure that gender issues receive attention in all kinds of development programmes, including HIV/AIDS programmes. The nutrition community needs to speak up and to engage the HIV/AIDS community, to ensure that nutrition is taken fully into account.

Another important problem is the issue of testing and the lack of voluntary counselling and testing. New technologies can help us in this regard. The latest rapid test kits are very simple; we do not need machines any more. The new test kits are also reliable and accurate. They can be done with just a finger prick. What this means is that voluntary counselling and testing can move away from labs, away from hospitals, out of health centres, to the communities. These test kits were introduced for same-hour results in Malawi. There was a four-fold increase in people coming in for voluntary counselling and testing. Early diagnosis of HIV infection means that nutritional interventions for people living with HIV/AIDS can be offered early.

The final issue I would like to discuss is sustainability. I recognize, without being an expert in this area, that there are complex relationships between food aid and food security. Giving out food to people living with HIV/AIDS may affect local food production. However, I feel very strongly that no person living with HIV/AIDS should also be living with hunger. Our concerns about sustainability and the complexity of the problem should not prevent us from making sure that people living with HIV/AIDS in Africa have enough to eat.

Dr Ruth Nduati

University of Nairobi

HIV/AIDS is expanding rapidly in Africa, and contributing to poverty, malnutrition and endemic illness. In adolescent girls HIV/AIDS and malnutrition co-exist. About two thirds of people who are infected actually get infected when they are adolescents¹. It is not unusual for a teenager to get pregnant and become HIV-infected the first time she has sex. These girls are the mothers of the undernourished underfives; some 30% of underfive children in this region are stunted. These children will grow up to be malnourished mothers who give birth to low birthweight babies,

and the cycle continues. In the Sub-Saharan region 20-30% of pregnant women are HIV-infected, and 25-35% of these will transmit the virus to their infants, either during pregnancy, at delivery or through breastfeeding. We are able to reduce mother-to-child transmission (MTCT) through the use of anti-retroviral drugs. In the developed world we talk about eradicating MTCT. In the developing world we have had some significant advances with these drugs, however, gains have been modest because the infants are still exposed to HIV when they breast feed.

In Africa, reduced transmission has not translated into improved survival of children of HIV-infected women. In addition to preventing viral transmission, much more needs to be done to improve the well-being of young infants in Africa.

I want to focus my discussion on HIV, nutrition and women. First, what effect does maternal malnutrition have on the outcome of pregnancy? Second, what is the impact of increased nutritional demands of pregnancy and lactation on disease progression in mothers and what is the impact of nutritional supplementation on infant and maternal outcomes? We know that HIV-infected individuals have increased resting energy expenditure (REE) of approximately 10% above that of non-infected persons². This is equivalent to about 150 kcals per day. If there is co-infection, such as tuberculosis or diarrhoea, there is a 34% higher resting energy expenditure compared to an uninfected individual who does not have any co-morbidity. There is also a correlation between REE and viral load; as viral load increases so does REE³.

We know that death in patients with HIV, or in other chronic wasting diseases, can be predicted by the amount of weight lost. Death usually occurs when one third of lean body mass is lost. There are several studies in the developed world, mainly in men, that have looked at weight loss in HIV infected people^{4,5}. In addition to the elevated REE, anorexia and depression reduce energy intake in HIV-infected patients while some drugs suppress appetite. The HIV-infected person has an abnormal metabolic response to her disease. Under normal circumstances if energy intake is low, REE falls to compensate for the decrease. However, with HIV infection it is not possible to reduce REE. The body conserves energy by reducing physical activity. An HIV-infected woman will reduce her physical activity by curtailing cooking, gardening and other household tasks. This will further aggravate her disease because she does not have access to the meals she would have cooked for herself and her family.

Lactation is energy demanding. Healthy women produce around 600 to 700 ml of milk in a 24-hour period. This requires about 600 kcals per day in additional food. Healthy women meet these demands by eating more, by breaking down the fat they stored during pregnancy, and possibly by reducing physical activity. Malnourished women are able to make adequate milk for their babies. However, if food intake is poor and there are no fat reserves, maternal muscle will be bro-

ken down to meet the demands of the baby. Women who are malnourished and who get enough to eat during lactation actually gain weight when they lactate. The co-existence of lactation and HIV is a very significant metabolic challenge. The requirements of increased resting energy expenditure, plus energy needed to support exclusive breastfeeding, are equivalent to one whole extra meal per day, providing at least 750 kcals. HIV-infected women who have experienced child death have special needs. These women tend to have shorter birth intervals because they try to replace the child who has died. Frequent reproductive cycles may contribute to nutritional depletion.

**Most research has focused
on infant outcomes
and not on impacts
on the mother**

I want to highlight data from recent studies that bring home this interaction of nutrition and HIV in women starting with maternal nutrition and infant outcome. Malnourished women have increased rates of premature deliveries, low birthweight and intrauterine growth retardation⁶. In 1998, a meta-analysis was carried out on

31 published cohort studies comparing HIV-infected women to uninfected women⁷. HIV-infected women had a higher risk of low birthweight (LBW), higher risk of preterm delivery, higher risk of intrauterine growth retardation, and also increased risk of perinatal mortality. In an analysis of developed versus developing countries these differences were much more marked⁷. This interaction between poor nutrition and non-fatal outcomes has been confirmed by the work of Dr Fawzi and others in Tanzania. In a randomized clinical study of micronutrients supplementation in pregnant HIV infected women, these authors showed that use of vitamins reduced preterm births by 39%, low birthweight by 44%, intrauterine growth retardation by 43% compared to women who received iron/folate and prophylaxis for malaria.⁸ These findings are exciting and have important implications for programmes.

Many studies, particularly in the developed world have looked at whether pregnancy accelerates HIV progression^{9,10}. Most have found that it does not. However, a recent meta-analysis demonstrated that there was a non-significant increase in maternal deaths among HIV-infected women and a progression of their HIV disease. Also, they were more likely to have an AIDS-defining illness¹¹. This was more prominent in women from the developing world. A community-based study in Malawi looked at maternal mortality and found that among HIV-infected women the rate was similar to uninfected women (that is during

pregnancy and the first 42 days after). However, in the first year after delivery the risk of death in HIV-infected women was tenfold more than in uninfected women¹².

Most research has focused on infant outcomes and not on impacts on the mother. In Sub-Saharan Africa, breastfeeding is the choice for many HIV-infected women. Our randomized clinical trial of breastfeeding and formula feeding among infants of HIV-infected women carried out between 1992-98 showed that the rate for breastmilk transmission was 16.2%¹³. The unique design of this study allowed us to look at the impact of lactation on maternal health. In our study, breastfeeding and formula feeding mothers were comparable both for health and social and demographic parameters. The median duration of breastfeeding was 17 months; 95% were breastfeeding at three months, 89% at six months and 80% at 12 months. The median age of introduction of complementary feeding was 3.8 months. Overall mortality among breastfeeding women was ten percent, while among formula feeders it was three percent. This was a threefold increased risk of dying among breastfeeding women. Sixty-nine percent of maternal deaths in the breastfeeding group were attributable to breastfeeding. Median weight loss in the first five to nine months was one kg, while the group using formula did not lose weight. The women in this study were all relatively malnourished; they lost

very little because they had little to lose. Normally a woman will lose about 0.6 kg or less per month in the first six months of lactation^{14, 15}. The average weight loss of the women who died in this study was at least 4.2 kg¹³. We concluded that these deaths were attributable to nutritional depletion aggravated by the metabolic demands of lactation.

We must target women to improve birth outcomes and nutritional status of children. We can improve lactation performance and improve survival of mothers so there are fewer orphans. We have to strengthen health services. This is not the time to reinvent the wheel. We need to take what we already know and apply it wisely and aggressively. We have many nutritionally valuable foods in this region that are under-exploited and need to be promoted. We should distribute iron/folate and B vitamins during pregnancy, prevent malaria through chemoprophylaxis and provide anti-helminths to reduce intestinal parasites. An unpublished study in this region found that only 30% of pregnant mothers who turn up in government health facilities actually receive anti-helminths. Many obstetricians do not know that we must give iron and folate to pregnant women because there is not enough in the diet to meet nutritional requirements.

Dr Phillip Mwalari

National AIDS Control Council, Kenya

Africa accounts for 70% of the world's HIV cases but 80% of deaths due to AIDS. This indicates that there is another factor in Africa which makes those infected not survive as long. In Kenya, before the 1999 census, the projected population was 30 million but the census showed we had 28 million. We looked at trends related to HIV/AIDS and showed that HIV/AIDS contributed to the drop to 28 million. Approximately 75% of infected people in Kenya live in the rural areas. According to the census about 80-85% of the population live in rural areas—so in fact the

...we hope to shift as much as 60% of the resources to the community

prevalence of HIV/AIDS might be getting close to what we see in the urban areas. We need to move very fast to have control programmes in the rural areas. When HIV/AIDS landed in Africa it found a very fertile environment to grow and spread – poverty, poor nutrition and an immuno-compromised population. Socio-cultural norms have enabled HIV to spread as well. Poverty and overcrowding promote opportunistic infections that accelerate death. AIDS also found poor health-seeking behaviours in the population.

In 1999, Kenya realized that the magnitude

of the problem was such that we needed to take action. Hence, HIV/AIDS was declared a national disaster and this led to the formation of the National HIV/AIDS Council. This Council has set up a network that takes the message down to the grassroots level. At the provincial level the Provincial HIV/AIDS Coordinating Committee has HIV/AIDS coordinating units in the public (e.g., ministries) and private sectors. At the community level we have Constituency HIV/AIDS Coordinating Committees to promote community mobilization. We realize that there is a lot of common ground between the spread of HIV/AIDS and malnutrition. Knowing that poor nutrition will make HIV/AIDS worse and vice

versa, there is a need for us to integrate HIV education into our programmes. Within this approach we hope to shift as much as 60% of the resources to the community, leaving 40% or less for other aspects of fighting AIDS. A strong multi-sectoral approach and an opportunity for nutrition promotion in this country involves all the ministries and takes programmes to the grassroots.

There is a need for applied research on the nutrient composition of traditional food crops as well as operations research on the best ways to promote consumption of these crops. These crops are not widely consumed anymore, although some of them are very nutritious.

Discussion



Question from the audience Preliminary data have been published recently from a study carried out in South Africa on mortality among HIV-infected mothers¹⁶. There was no difference between breastfeeding and non-breastfeeding mothers. How does this study compare with the Kenyan one?

Question from the audience Regarding the quick test for HIV in mothers and children, in Tanzania, we find that if we, as counsellors, spend a few minutes or even an hour to counsel these mothers before the quick test, it is more beneficial than simply doing the test with no counselling. The problem is how to scale up. Scaling up will require much larger counselling facilities to accommodate everyone. Every mother should be counselled on how to manage and how to care for herself. If mothers are not counselled properly and the child dies she will certainly come back pregnant the next year. This test may be very cheap, but it is not available free even in Tanzania. Only at the blood banks and in areas where projects are operational are quick tests available. Finally, we should not rush to formula feeding. In Tanzania only 30% of our people have access to clean water. Similar rates are found elsewhere in Africa. As long as we cannot improve the water supply we cannot improve hygiene.

Comment from the audience So far we have discussed only women. It is important to involve

men. Men must be more fully involved so that they can participate in the care of the mother and child.

Question from the audience Solutions to the HIV/AIDS pandemic are not just sectoral or country specific. When it comes to drugs, why do we not strategize as a continent? Is there a continental initiative at the level of the Organization of African Unity? The pharmaceutical companies are very powerful and to negotiate effectively with them one needs a collective position.

Comment from the audience This was the first panel that spoke about the mother and infant together. This issue of the mother and HIV and breastfeeding has to be looked at, as well, with *the infant* and HIV and breastfeeding. Dr. Nduati's work is important in this respect because it begins to look at the dyad. Finding "cheaper formula" is not the issue. With "cheaper formula", the birth interval will be shorter and the needs of the new baby must be met. Even if there is enough money to buy any kind of formula, the mother can be fed much cheaper than the baby. In the USA, it would cost an estimated 50 cents a day to give the mother enough extra energy for breastfeeding. It would be less in other countries. It is important to think about the mother's survival and the baby's survival together, not separately.

Question from the audience Regarding supplementation, nutrient requirements of people living

with HIV/AIDS are very high and it may be difficult to meet these requirements through food alone. There are many companies in Uganda that are marketing products they claim meet these high needs. The companies are making a lot of money from the sale of these food supplements. Should we, as nutritionists, encourage these companies? Should we encourage people living with HIV/AIDS to purchase these supplements?

Question from the audience Firstly, is the rapid test kit reliable and affordable? Is it available? Secondly, I have a comment on the use of the term “prevention of mother to child transmission”, or PMTCT. So long as we continue to use the term prevention of *mother-to-child* transmission of HIV/AIDS, we lay the entire responsibility and the blame for the transmission at the mother’s doorstep. Can we not make a recommendation to be a little more progressive in the language we use? It is not a semantic issue; it is a matter of principle. Can we not move to using prevention of *parent-to-child* transmission where the father’s role is recognized?

Question from the audience I am a community nutritionist working with people living with HIV/AIDS. I am concerned about sustainability of our nutrition efforts for children. We already have child-headed families. Firstly, how sustainable are our programmes targeting this very deprived group? Secondly, I am concerned about economic empowerment at the community level. How are we approaching economic empowerment for these communities? Are we promoting locally available resources? We hear about food supplements and medications. However, we do not hear about traditional knowledge. Some of the opportunistic infections can be treated locally at the community level. Should we not promote local solutions? In our programme, we find that UNIMIX (a porridge meant for children) is used by some mothers because they cannot take solid food.

Ruth Nduati The South African study did not find an increase in mortality, whereas the Kenyan study did. The two studies^a are different. Our study is a randomized clinical trial whereas the other is a cohort study. The duration of breastfeeding in the two studies is very different. In the South African study the medium duration of

a. Editor’s Note: on 7 June, 2001 the World Health Organization issued a statement on the effect of breastfeeding on mortality among HIV-infected women. This statement is reproduced in Annex 2.

breastfeeding was six months. In our study it was 17 months. I think our study is the first to report this and we need to replicate it. It is also the first to report increased mortality among lactating women. We need funding now for a randomized clinical trial of supplementation. We will probably try energy plus micronutrients to see whether we can mitigate the deterioration of mothers’ health during lactation.

Regarding formula, there are women who will choose to formula feed when they are HIV-infected as a way of protecting their infant, especially mothers who have lost other children to HIV infection. I believe they have a right to make that choice and we should be able to support them. The majority of mothers will breastfeed and we need to support them in their efforts to *exclusively* breastfeed. We are not doing this currently.

The question of supplements for HIV-infected women or for pregnant women is very important. Adequate energy can come from food alone, but some micronutrients, iron in particular, will be needed as a supplement. This has a beneficial impact on the infant’s iron status as well. Zinc is also a micronutrient needed, most probably, as a supplement. In general, where there is little animal protein in the diet there is a need for micronutrient supplementation. The private sector is already involved. Widespread fortification of foods that are commonly consumed by the whole population will help to improve the overall nutritional status of the population.

There is the biological definition of prevention of *mother-to-child* transmission and the social definition. When we talk of prevention of *mother-to-child* transmission in the biological sense, we are speaking specifically of the time points of pregnancy, delivery and breastfeeding when transmission takes place. Fathers are indeed significant regarding transmission in the social sense. However, for the purposes of this discussion we should adhere to science and use terminologies that will help us communicate exactly what we are talking about.

Regarding orphans and child-headed households, we have not begun to scratch the surface in terms of developing programmes that will support their needs. Programmes are needed to address their nutritional well-being, but also their social development.

Elizabeth Marum Regarding HIV testing, we should not do wholesale testing without counselling. Pre-test and post-test counselling is the essential component of voluntary counselling and

testing. A test result, in and of itself, does not help people change their behaviour. However, counsellors do sometimes discourage people from getting tested. We need to encourage an environment in which knowledge of sero-positive status is one of the first and most important steps in determining what behaviour and choice should be in decisions on pregnancy and family planning. We can take advantage of this new technology along with the counselling. There is no shortage of counsellors, in my opinion, in many countries in Africa. Hundreds of nurses in Kenya, Uganda and Malawi have been trained as counsellors. They can use the new test kits, simply and easily, to inform people who come for testing and counselling. The rapid kits are exceedingly reliable, in part because they are read on the same day, eliminating lab and recording error. Costs range from US\$1.20 to \$1.80 per test.

Phillip Mwalari On the question of sustainability of programmes, we have Constituency HIV/AIDS Control Committees at the community level. They have been in existence for awhile and have shown managerial skills and capacity. These groups will be supported so they can continue their important work. This will be more sustainable than pushing activities and interventions onto the communities without their involvement. Of course, we are also trying to mobilize local resources within the communities.

The question concerning traditional healers is relevant. We believe everybody who shows interest in HIV/AIDS control should be invited to come on board. We have created a forum for traditional healers to come forward and work towards a common goal. If we truly want a decentralized approach to HIV/AIDS we need to bring traditional healers on board. On the question of nutritional supplements promoted by the commercial sector, some of these products are good. However, prices are too high for most people. We look to the professional nutrition community to monitor the composition and overall quality of these products.

Minister Dlamini Regarding child-headed families and sustainability, when people come to assist they sometimes think we need to build orphanages or somehow bring the children to homes where they can be cared for. When a parent is lost, it is a lot for the child to deal with. However, when the child is removed from the family environment, siblings, school friends and neighbours are also lost. So in fact the orphans are traumatized by parental loss, sibling loss and loss of

friends. Some efforts to help them have actually damaged further an already extremely difficult situation. This is what we have come up with in Swaziland.

Swaziland is a small country where we have traditional chiefs. In other countries, you would call this local government. These chiefs know the families in their community. The communities, or villages, can be clustered geographically so that 10 to 15 homes form a cluster. The children in a cluster know one another. When a mother falls ill, the children can tell the neighbour within the cluster. The neighbours can assist and give support. When the mother dies, the children will not lose their home, even if the father is gone. They stay right there. We are building this into the legislation, but the state should assist these people to look after the children and keep them in school. This means, also, that our educational system should change. We were trained, by the British system, to look for jobs and to be employed. We should review our educational system and train our children to create employment and to be creative. Then, even as youth they can have little projects and earn a living and still stay in school. The children are supported by a network. This network rests on our traditional values because in the past we always supported each other.

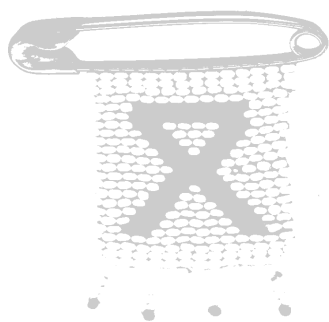
As far as sustainability, people living with HIV/AIDS want to do something. They may not be able to garden, but they can become involved locally in income-earning projects. We teach them and they teach each other. Marketing can be facilitated by government. Above all, it is crucial to sit and learn from people living with HIV/AIDS and ask them what they would like to do.

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Infant Feeding Options for Mothers with HIV —using women's insights to guide policies

Dr. Abraham Horwitz Memorial Lecture
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The objective of this paper is to discuss the difficult and controversial topic of mother-to-child transmission of HIV through breastfeeding. Based in part on a small study conducted in the Kiambu district of Kenya last year, women's ideas, opinions, feelings and preferences regarding infant feeding options for mothers with HIV are presented. The importance of dialogue with mothers in the selection of a feeding choice is discussed and specific ways in which women's views can be used to guide policies on HIV and infant feeding are suggested.

Mother-to-child transmission of HIV^a: importance of the problem

An estimated 590,000 infants acquired HIV-1 from their mothers in 1998; 90% were in Sub-Saharan Africa. About two-thirds were infected during pregnancy or at delivery and the other one-third through breastfeeding¹. Although breastfeeding accounts for only part of mother-to-child transmission of HIV, in countries where both fertility and rates of HIV infection among pregnant women are high, the issue of HIV transmission through breastfeeding is of public health importance². There is a pressing need for countries to develop sound policies on HIV and infant feeding³.

a. In this paper, Human Immunodeficiency Virus (HIV) means HIV-1. Cases of mother-to-child transmission of HIV-2 are very rare.

Infant feeding options for mothers with HIV: the dilemma

Breastfeeding significantly improves child survival by protecting against diarrhoeal diseases, pneumonia and other potentially fatal infections, while it enhances quality of life through its nutritional, psychosocial and many other benefits. As a result, not breastfeeding presents substantial disadvantages and risks to both children and mothers³. Balancing the risks of not breastfeeding, such as increased child morbidity and mortality, versus the risk of HIV transmission through breastfeeding, presents a serious dilemma particularly for mothers in poorer countries, and also for policy makers and health workers⁴.

For poor women living in developing countries the choice not to breastfeed is much more problematic than for affluent women in northern countries⁴. Poor women have inadequate access to resources, including resources necessary to obtain sufficient breast milk substitutes, as well as equipment, fuel and potable water to prepare it safely⁴. If tests were used that showed a mother had infected her infant with HIV in utero or intra partum, then the mother would be advised to breastfeed her infant.

Mothers' rights

Guidelines prepared jointly by UNAIDS and two of its co-sponsors (UNICEF and WHO) in 1998² recommend that breastfeeding should continue to be protected, promoted and supported among HIV-negative mothers and among mothers of unknown HIV status. The guidelines promote fully informed and free choice of infant feeding

methods for HIV-positive mothers. Counseling HIV-infected mothers should include the best available information on the benefits of breastfeeding, on the risk of HIV transmission through breastfeeding and on the risks and possible advantages of alternative methods of infant feeding. The consequence of these recommendations is as follows: compared to HIV-negative mothers for whom the decision to breastfeed is supported by international and national recommendations as well as long-standing cultural practices, mothers with HIV are expected to assume increasing responsibility for infant feeding decisions⁵.

Most previous discussions have focused on weighing competing risks of HIV transmission through breastfeeding against risks of increased child morbidity and mortality associated with not breastfeeding⁶. The opinions of women themselves regarding infant feeding options in the face of HIV have not been reflected in these discussions^{6,7}. As well, relatively little attention has been directed to the problem of preparing mothers to play a more active role in infant feeding decision making.

Challenges for the informed approach

By far the majority of pregnant women are not being tested for HIV, so their status is unknown both to themselves and the health worker⁸. Even where women do get tested, some studies, particularly in Sub-Saharan Africa, indicate that health care providers do not have accurate information to share with HIV-positive mothers^{6,9,10} and may convey a lesser risk for formula feeding than for breastfeeding^{6,9}. The importance of accurate information is illustrated in a study in KwaZulu Natal, South Africa¹¹. In this study, a woman was reported to have said:

I was never told anything about HIV and breastfeeding. I breastfed my baby for 11 months. If I knew anything, I would not have fed him poison, and maybe my baby would have lived a longer time....

According to the authors, because of lack of adequate information, this woman was assuming that her child was necessarily infected through breastfeeding, whereas the child could have been infected in utero or intra-partum.

Considering the complexity of information to be imparted, informed decision-making also faces educational challenges related to common misperceptions regarding HIV/AIDS and mother-to-child transmission of HIV¹². The widespread belief that all babies of HIV-positive

mothers will be born infected which is documented in various studies^{6,9,10,12,13,14} would need to be countered with accurate information on the rate of mother-to-child-transmission and current understanding of the risk of transmission through different routes.

In some communities, a woman's authority to make infant feeding decisions may receive scant respect^{6,7}. For example, in Zimbabwe, decisions about infant feeding are made by the infant's father, the woman's mother-in-law and often the woman's own mother¹⁵. In other countries, some studies suggest that many women refuse to question their health care providers about decisions, partly because they trust them since they possess requisite knowledge^{12,16} and partly because of paternalistic attitudes held by many health care providers.

Early detection of HIV is also needed to enable mothers to recognize their role in infant feeding decision-making¹⁶. Women should receive the information as early as possible, either prior to conception or during prenatal care, to allow sufficient time for reflection¹⁶. The importance of early detection in influencing infant feeding choice is evident in Cape Town⁶. Seventy-three out of 88 HIV-positive mothers interviewed were not aware of their HIV status at the time of their child's birth and only discovered it when their child, or they themselves, became ill. According to the authors, women who knew their HIV status at the time of their child's birth were more likely than others to abstain from any breastfeeding.

Since women are expected to assume responsibility for infant feeding decisions, and also to bear the consequences of whatever method they choose, they should be allowed to voice personal values and preferences related to the options, and make informed choices under conditions of uncertainty about possible outcomes¹⁷. According to Bassett, by learning from those who must make decisions and live with these hard choices, public health workers will be in a better position to offer advice⁷.

There have been relatively few reports, and even fewer published studies, on women's views of infant feeding options, including exclusive breastfeeding, animal milks, wet nursing, heat treating expressed breast milk and others. There is a paucity of data on the perceptions of mothers as decision-makers in guiding policies and counselors' advice. Little attention has been directed to the views of ordinary women in the community, the views of the decision-makers themselves.

Knowledge about women's ideas, opin-

ions, feelings and experiences suggests specific ways in which health care providers can facilitate informed decision-making¹⁸. Providing information about infant feeding options needs to be individualized. This information must be unbiased and accurate to help women make a decision that is in keeping with their personal values and beliefs¹⁸. Truly informed decision-making can only take place when the mother is given both the fullest possible information from which to draw her conclusions, and appropriate, culturally-located support for the course of action she chooses.

Mothers' views of infant feeding options in the Kiambu district of Kenya

Mothers' views on infant feeding options were investigated in one Kenyan community. Mothers were asked what alternative they would choose if they hypothetically tested positive for HIV. A set of infant feeding options was presented to them. These included: expressed and heat-treated breast milk, milk banks, goat's milk, wet nursing, infant formula and cow's milk. Women were requested to give their opinion on all of the options presented.

Site, sample selection and access to sample

Mothers of unknown HIV status attending Nazareth hospital in the Kiambu district of Kenya between June and August 2000 were invited to participate in the study. The criterion for eligibility was to have an infant less than 2 years old. A clear verbal description of the research, its aims and methods, was given to each woman in the local languages (English, Kiswahili or Kikuyu). Only those mothers who gave informed consent were interviewed. Interviews were tape-recorded and transcribed verbatim where consent was given.

Measuring instrument

Since little empirical research exists in this area, a qualitative inquiry seemed to be the most reasonable approach for answering the research question¹⁹. In the first phase of this study, in-depth interviews were carried out with the mothers. Using themes emerging from these in-depth interviews, a semi-structured questionnaire was designed in the second phase. This instrument provided a basic framework for common areas of

beliefs associated infant feeding options in the face of HIV while allowing individual respondents to explore and define particularly relevant issues²⁰. Interviews ranged from 30 minutes to one hour in length.

Data analysis

Data were first displayed in a conceptually ordered matrix in which several research questions were clustered together so that meaning could be generated more easily²¹. This matrix allowed comparison between respondents and lent itself easily to cross-case analysis.

Once the sample of texts were established, data were carefully reviewed line by line, typically within a paragraph, while looking for processes, actions, assumptions and consequences²¹. Beside the paragraph, labels were generated. These labels represented key concepts contained in the paragraph and were phrased in the person's own words, such as *the virus can't die* and *babies should only drink their own mother's milk*. Using this "grounded" approach to coding allowed the researchers to be more open-minded and more context-sensitive compared to using pre-fabricated codes²¹.

Little attention has been directed to the views of ordinary women in the community, the views of the decision-makers themselves

Findings

The data presented in this paper are drawn from 75 face-to-face interviews with mothers about infant feeding options the mothers would consider if they hypothetically tested positive for HIV. The respondents ranged in age from 15-39 years and their HIV-status was unknown to the interviewers. Where appropriate, the respondent's own words have been used to illustrate some interpretative points.

Level of education

As previously mentioned, these women had a moderate level of education. One woman never attended school, 34% of the women had some primary school education, 39% had some high school education, 23% some college education and one woman had university education. Having some college education was interpreted as having undergone some formal training after high school. For instance, tailoring and secretarial training, which typically takes less than two years to complete in Kenya, was included in this category.

To breastfeed or not to breastfeed?

In this study, women seemed undecided about whether they would breastfeed if they tested positive for HIV. Some of the women (55%) stated that they would breastfeed as usual. Among them, some 50% expressed their strong belief that, because their babies would necessarily be HIV-positive even before being tested, breastfeeding could not possibly pose a risk for infection. However, some women (45%) reported they would stop breastfeeding if they tested positive for HIV. One of the respondents said:

The viruses are not so strong in the baby's body, they will get finished with time, if I continue breastfeeding, the viruses will continue getting into the baby's body and the baby will eventually die.

Exclusive breastfeeding

Although 98% of the women in the sample breastfed^b, none of them had exclusively breastfed^c for more than a few weeks, and all infants had been fed water and cow's milk before two months of age. Only 34% of the women stated that they were willing to breastfeed exclusively for three months if they tested positive for HIV. Those who would not choose to breastfeed, gave reasons including the following:

- ❑ *Water is necessary to prevent stomach problems*
- ❑ *If I don't [give him water] he will get hard stool*
- ❑ *I must give him other things to help him grow*
- ❑ *I have to give him water to dilute the milk in his stomach and help in digestion*

Stigmatization if women do not breastfeed

One of the respondents interviewed alluded to the issue of stigmatization. She cited the example of her HIV-positive friend who was advised by doctors not to breastfeed, and who told people why she was not breastfeeding. According to the respondent, people were very understanding and did not stigmatize the HIV-positive woman. This respondent narrated:

[I know this HIV positive woman who was] advised by the doctors not to breastfeed. This woman told people why she was not breastfeeding her child. In such a case everybody... would understand. But in a case where [a mother] decides just like that not to breastfeed her child, I don't know whether one should not be taken to the police ... of course people may think that the mother is one of these arrogant mothers.

Heat treating expressed breast milk

Only 9% of the respondents would choose to heat-treat expressed breast milk. Some 23% expressed their disbelief that heat treatment could inactivate the virus. One respondent said:

Me, what I believe is that a virus is very strong, I know that they cannot even die through boiling.

Some women, (34%) thought that human milk cannot be boiled *like cow's milk* while others (43%) expressed concerns including *disgusting* and *unhygienic practice*.

Milk banks

Regarding the use of banked milk, only 12% of the women interviewed would consider this option. Reasons against milk banks included *not done in our culture* (62%), *not hygienic* (19%) and *fear of disease transmission* (14%). Regarding culture, one of the respondents noted:

Some people believe in culture, they say, oh, my kid cannot be given milk that belongs to someone else, oh, my kid when she is given such milk [she] will die.

Wet nursing

As with the above infant feeding options, women had strong views about the acceptability of wet nursing. Only 35% would have their infants wet nursed if they tested positive for HIV. Reasons against wet nursing included the belief that *babies should only drink their own mother's milk!* (51%), *fear of disease transmission* (26%) and *not done in our culture* (21%).

Infant formula

Fifty-six percent of the women would consider infant formula. Some women perceived its composition as being close to that of breast milk. Among women who would not consider this option, 65% expressed fear that this milk would have passed its expiry date in the local shops and 20% strongly believed that infant formula *contains things that are not good*. One of the respondents ex-

b. The definition of breastfeeding was open to the respondent's interpretation; thus, breastfeeding included both exclusive and mixed feeding.

c. Exclusive breastfeeding is defined as not giving any other foods or liquids to the baby except breastmilk and medication.

plained:

You know cow's milk is being milked there and then. You can see it is fresh. Tinned milk [infant formula] may have stayed in the shop for long. You can sometimes buy and when you give the baby it might not be good for her.

Goat's milk

Only 23% of the respondents would opt for goat's milk. Women were generally unfamiliar with this option. Some 42% of women said they had never heard of goats being milked. One respondent asked:

Are goats milked? Do they have milk? [laughter]

Some women (31%) were concerned about the thickness of the milk, which would cause constipation, while others (23%) thought that because *even adults don't* infants should not be fed goat's milk.

Cow's milk

Some 87% of the women stated that they would use cow's milk without being prompted. Reasons included its wide availability and the belief that it is "fresh" relative to infant formula. However, women did not seem to know how to modify cow's milk to be nutritionally adequate. Regarding dilution, 64% thought that, for cow's milk to be nutritionally adequate for any two-week old infant, the volume of milk should be more than that of water, 18% thought that water should be more than milk, and another 18% that both volumes should be equal. Regarding supplementation, only ten percent of the women would add glucose, salt or sugar to the milk; none of the women would include a micronutrient supplement.

Discussion

In this setting, the majority of women thought that cow's milk was the most acceptable alternative. In Kiambu district, cow's milk is sold in local shops and kiosks, and is relatively cheap. A price comparison showed that the cost of cow's milk is 12% that of infant formula in the local shops (\$28 versus \$232 for six months' supply for an infant).

However, according to Yeung and co-workers, the use of unmodified cow's milk for

infant feeding is not ideal and may present additional challenges, especially if it is used to replace either breast milk or formula in the first six months of life²². This is because unmodified cow's milk may lead to iron deficiency anemia²³ and, due to its high protein content relative to breast milk, cause constipation in young infants²⁴. Modifying cow's milk to make it nutritionally adequate for young infants requires dilution as well as supplementation with iron and other micronutrients².

This study indicates that women do have strongly held views and opinions about the acceptability of infant feeding options in the context of HIV infection. However, it is important to recognize that a group of mainly Kikuyu women from Nazareth hospital is probably not representative of all African, Kenyan or Kikuyu women. These women were peri-urban. They were neither affluent, nor very poor. Most of them had some schooling and they had reasonable access to health care. Such characteristics may not be present in much of Africa. Hence, the conclusions of

this research cannot be generalized to other women with different socio-economic status, access to health care and level of education may be different. The need for policies and

advice to be appropriate for cultural settings, geographic locations and levels of living cannot be overemphasized.

In addition, women in this study were asked a hypothetical question about infant feeding choices if they tested positive for HIV. One way to assess acceptability is to ask women what they think and what they would do, given a choice⁷. This hypothetical scenario is more successful at capturing negative responses. If women do not like something hypothetically, they will probably not use it in practice. However, experience suggests that the best way to assess what women will do is to offer them choices and see what they actually do. In actual decision-making, significant individuals such as husbands and mothers-in-law may influence women's infant feeding choices. The validity of answers to these hypothetical questions cannot be assumed.

Recommendations: using women's views to guide policies on HIV and infant feeding

For each mother to be able to make a truly informed choice in the face of this complex issue,

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information developed from an understanding of mothers' perspectives is needed. Developing this "grassroots" knowledge is crucial because of the dramatic shift in the locus of decision-making for infant feeding that has occurred with HIV. For HIV-negative mothers, the decision to breast-feed is supported by international and national recommendations as well as long-standing cultural practices. However, according to international guidelines, for HIV-positive mothers the decision whether or not to breast-feed is to be made by each mother. This decision should be fully informed and of free choice.

As recommendations for fully informed and free choices of infant feeding methods are made for HIV positive mothers, it is necessary to reflect on what fully informed decision-making really means. Compared to paternalistic decision-making where health care providers have the responsibility to make decisions, the medical literature indicates that there are two models for informed decision making. In the first model (shared informed decision) the health care provider helps the woman assess the impact of her choice with regards to her values and lifestyles. In this case, both the woman and the health care provider reach the decision and the option is consistent with the woman's values and preferences. In the second (purely informed decision), the health care provider also informs the mother about the options available to her. However, the mother alone is responsible for making the decision (assuming she is accurately informed), whatever choice she makes is the correct one, and she should not be persuaded to change her mind²⁵.

In the case of a mother who opts to use cow's milk in early infancy, according to the purely informed decision making model, if she is accurately informed, she should not be persuaded to change her mind. However, she should be taught how to modify cow's milk to make it nutritionally adequate and safe. According to the shared informed decision-making model, such a mother could be educated on how to modify cow's milk and supplement it with micronutrients; or she might be persuaded to choose another feeding option.

If services are to be shaped by women's views, methodologically sound ways of obtaining their views and encouraging them to come forward and present them are needed. It is not easy to get representative views, for all countries have their bias, and opinions change over time. In all cases however, providing women with accurate, high quality, up to date information is an important starting point²⁶.

Conclusions

At present, the proverbial black box exists between the policy of fully informed and free choice of infant feeding method, and women's actual infant feeding decisions. In this paper, some new approaches in facilitating fully informed and free choice of infant feeding method in the face of HIV have been suggested. As previously mentioned, many factors may influence women's infant feeding decisions, including values and preferences, significant others and the availability of resources.

This paper has discussed women's beliefs, values and feelings about different options, and how these may affect their infant feeding intentions. It is important to recognize that views may be much influenced by women's current knowledge regarding options discussed. For example, as discovered, if women do not know about goats being milked or even about milk banks, then these options will not be adequately considered. In addition, it is suggested that women may be educated to shift away from an option they chose. However, to modify women's beliefs, values or preferences, these have to be known in the first place, and this "grassroots" knowledge used to inform appropriate policies on HIV and infant feeding.

Since each mother will bear the consequences of whatever infant feeding option she chooses, it is important that information be developed from an in-depth understanding of the mother's own perspectives. The mother's values, preferences and feelings should be respected. Finally, her views, the views of the potential decision-maker herself, should be used to inform policies and programs on HIV and infant feeding.

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Acknowledgements

The author extends sincere gratitude to Cornell University professors Edward Frongillo, Jean-Pierre Habicht and Michael Latham who have been not only a source of constant intellectual stimulation in the preparation of this paper, but also a source of encouragement and support. Thanks also to Susan Njeri who helped carry out the interviews; the mothers who participated in this study; Cornell University and the First Presbyterian Church of Ithaca for a student research grant; and Dr. Olivia Yambi and Arjan De Wagt in the Nairobi office of UNICEF for technical assistance during the research project.

Discussion



Question from the audience This paper raises some controversial areas that will be discussed for the next few years. Firstly, within UNICEF, I have criticized the UNAIDS/UNICEF/WHO Guidelines because our own staff see only two options: breastfeeding and infant formula. In our pilot trials to prevent mother to child transmission, in all countries except Tanzania, UNICEF has actually convinced mothers to use infant formula. Those in the nutrition community, who really support exclusive breastfeeding, and the infant formula companies, have similar views on the range of options available to mothers: they see only two options. The infant formula companies write on the package labels “exclusive breastfeeding is best but if you can’t do that you should use formula.” Nutritionists tend also to see only exclusive breastfeeding as a choice and no other feeding method. Lucy Hair’s paper deals with all options available to mothers which opens up research and this is most welcome. Secondly, can mothers really make informed decisions? I believe that children have a right to be breastfed and mothers have an obligation to breastfeed. In addition, all the people around those mothers have an obligation to make it possible for mothers to breastfeed. If the mother does not breastfeed her baby, we should not blame the mother. We should look carefully at the environment in which she lives. How can we expect a poor mother, who lives in terrible conditions and who is HIV positive, to make informed decisions?

Lucy Thairu To discuss whether informed choice is possible or even relevant in Sub-Saharan Africa, it is important to first look at its origins. In Europe and in the United States, informed decision-making has its origins in consumer science and in product development where people are given all available information regarding different choices before they make a decision. Another origin is the feminist movement where informed decision-making counters the paternalistic model in which doctors make decisions for women. Here, the informed decision-making model empowers women to make their own decisions.

Question from the audience We, the UN agencies, have been promoting alternatives to exclusive breastfeeding and not only formula. This is part of the UNAIDS/UNICEF/WHO Guidelines. Concerning the field questionnaire, have these mothers been supported in the past in their efforts to exclusively breastfeed? There is evidence from randomized controlled trials in different settings (including poor and middle income communities in Sri Lanka, Mexico, Brazil and Bangladesh) showing that it is possible to increase the rates of exclusive breastfeeding with counselling. There is a training course on breastfeeding counselling and there is a tool on HIV and infant feeding counselling. These tools deal with informed choice.

Lucy Thairu The issue of exclusive breastfeeding is important. Some mothers in the survey felt there was a need to dilute their breast milk with water so their infants would not get constipated. They said the same thing about cow’s milk. If exclusive breastfeeding is to be promoted effectively we need to find out what mothers are thinking about exclusive breast feeding and then make policies and programmes that are coherent with their views. Women’s views on exclusive breastfeeding have been studied extensively in both Sub-Saharan Africa and Latin America. We need to put these findings to good use, and meet mothers half way.

Comment from the audience UNICEF and the infant formula companies may promote only two options, but nutritionists in countries in this region have a broader perspective. In Zimbabwe our guidelines for the prevention of HIV transmission describe all the alternatives. Sometimes we find that the international agencies do not want to listen to us.

Question from the audience What about adding micronutrients to cow’s milk? As in Kenya, mothers in Tanzania feel the need to add water to cow’s milk. Why not provide a supplement to the infant via cow’s milk?

Lucy Thairu Women in my study were unsure about how they should modify cow's milk. When I asked them what volume of water should be added to cow's milk, 64% said that water should be more than cow's milk, 18% indicated that water should be less than cow's milk, while 18% of them said half and half. None of the women said anything about addition of micronutrients but they often added sugar to the cow's milk. Therefore, if mothers with HIV choose to use cow's milk, they would need information on how to modify cow's milk to make it nutritionally adequate.

Minister Dlamini In Africa, we need more local studies like this to document nutrition-relevant behaviours so that programmes are not designed in a vacuum. Concerning informed choice and decision-making, HIV has brought many difficulties for service providers whether it is in a hospital setting or society at large. Even in the simplest society where illiteracy is prevalent, illiteracy must not be mistaken for stupidity. When people are literate or semi-literate, it makes our job much easier. We owe it to all individuals to supply them with the information they need to know so that they can decide what is best for them. I don't agree that we should use one standard in the West and another in Africa. This is immoral and unethical. The challenge for us is to communicate simply and clearly in everyday vernacular. Let us tell them what is available and let them decide.

Question from the audience In terms of how to treat mothers in their decision-making, are we promoting the idea of shared information? And does not shared information compromise and commit the service provider in that decision making process?

Lucy Thairu The data collected in this study was not on shared, informed decision-making. This study was about what women's feelings and perspectives are about different infant feeding options. More research is needed in terms of shared, informed decision-making that would investigate in particular interactions between HIV-positive women and their health care providers.

Comment from the audience In our work we found very similar results about what women would do should they find that they were HIV positive. We have followed up the women who tested HIV positive. Most often these women really don't have much choice. Even if they say they would make a particular choice (should they test positive) in the absence of providing alternatives to these women, 95% choose to breastfeed.

Comment from the audience The recent technical consultations^a set up to review issues surrounding mother to child transmission have recommended possible alternatives to breastfeeding, but workers in the field ask "Where do we start?" This field study provides findings that can influence policy because it starts with what mothers already know about and can build upon.

^a Editor's Note: These consultations include the WHO Technical Consultation on Infant and Young Child Feeding held in Geneva, March 13-17, 2000, and the WHO Technical Consultation on Mother-to-child Transmission of HIV, held in Geneva, October 11-13, 2000.

Annex 1

The facts about Nutrition and HIV/AIDS

(excerpted from Piwoz EG and Preble EA (2000) *HIV/AIDS and Nutrition: A review of the literature and recommendations for nutritional care and support in Sub-Saharan Africa*. SARA Project, Academy for Educational Development: Washington DC)

The effect of HIV/AIDS on nutrition

HIV/AIDS affects nutrition in these ways:

Reductions in food intake—Reductions in food intake may be due to painful sores in the mouth, pharynx, and/or esophagus. Fatigue, depression, changes in mental state (sometimes due to specific nutrient deficiencies), and other psychosocial factors may also play a role by affecting a person's appetite and interest in food. Economic factors affect food availability and the nutritional quality of the diet. Side effects from medications—including nausea, vomiting, metallic taste, diarrhea, abdominal cramps and anorexia—also result in lower dietary intakes.

Nutrient malabsorption—Nutrient malabsorption accompanies frequent bouts of diarrhea commonly experienced by people with HIV/AIDS. In addition, some HIV-infected people have increased intestinal permeability and other gut defects, even when asymptomatic, that contribute to nutrient malabsorption¹. It is believed that HIV infection of the intestinal cells may also cause epithelial damage and nutrient malabsorption. Malabsorption of fats and carbohydrates is common at all stages of HIV infection in adults and children. Fat malabsorption, in turn affects the absorption and utilization of fat-soluble vitamins further compromising both nutrition and immune status.

Metabolic alterations—Changes in metabolism may occur as a result of severely reduced food intake as well as from the immune system's response to HIV infection. Anorexia, fever, and the break down of muscle frequently accompany this response. When the body responds to invading pathogens, it releases pro-oxidant cytokines and other reactive oxygen species. This leads to the increased utilization of "anti-oxidant" vitamins (vitamins A, E, C and beta-carotene) as well as utilization of several minerals that form anti-oxidant enzymes (such as zinc and selenium). Oxidative stress occurs when there is an imbalance between the pro-oxidants and anti-oxidants, causing further damage to cells, proteins, and enzymes. Oxidative stress is believed to increase HIV replication and transcription, leading to higher viral loads and disease progression.

Increased energy and protein requirements—The body's cytokine-mediated reactions to infection adversely affect metabolism. The result is an increase in energy and protein requirements of people living with HIV and AIDS. This increase ranges from about 10-15% for energy requirements among asymptomatic HIV-infected persons, to up to 50% for protein requirements². This translates roughly into an additional 300 kcals and 25 g of protein per day, which could be met through snacks or an extra serving of the family meal.

In summary, the impact of HIV/AIDS on nutrition results in weight loss and the wasting that is common in people living with AIDS. During the early stages of HIV infection, weight loss is mainly associated with reduced dietary intake and secondary infections, particularly diarrhoea³. This weight loss may be addressed, and even reversed, by nutritional or dietary management. However, once the metabolic abnormalities begin to play a leading role, it becomes very difficult, perhaps impossible, to reverse the nutritional consequences of the disease.

The effect of nutritional status on HIV disease progression

Studies from both industrialized and developing countries have shown that HIV-infected individuals have decreased absorption, excessive urinary losses and low blood concentrations of vitamins A, B1, B2, B6, B12, C, E as well as folate, beta-carotene, selenium, zinc and magnesium^{4,5}. It is *not known* whether these deficiencies are independent markers of disease progression resulting from a compromised immune system, *or* whether they are causally related to HIV disease progression and mortality. This distinction is important in order to determine whether the nutritional deficiencies can be reversed, and whether nutritional therapy and management can slow or alter the course of disease. Randomized, controlled trials are required in order to assess a causal relationship between these nutritional observations and HIV outcomes. Relatively few such trials have been carried out.

The body of literature reporting on trials in Africa (mostly of vitamin A) and in industrialized countries (on vitamin B12, E, selenium and zinc) suggests that nutritional status affects HIV-related disease progression and mortality, and that improving nutrition status may improve some HIV-related outcomes. Current understanding of the potential impact of nutritional interventions is incomplete and there are issues to consider when extrapolating findings from research undertaken in North America and Europe to populations where malnutrition is widespread.

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What does this mean for programmes?

Providing early and adequate nutrition support and care may be one of the most important interventions for people with HIV, to:

- maintain and build body stores of energy, protein and anti-oxidant nutrients
- prevent diarrhea by promoting hygiene and food safety
- minimize the nutritional impact of secondary infections when they occur
- improve the quality of life and prolong independence.

In addition—the nutrition community can take these first steps to help national health officials and policy makers meet the broader challenges associated with HIV/AIDS:

Strengthen the involvement of persons living with HIV/AIDS in policy and program interventions to prevent transmission and control the epidemic.

Promote Government commitment to address food security and nutrition problems for all persons infected and affected by the epidemic.

Support and encourage community-based care.

Develop, test and disseminate practical guidelines for health workers and community volunteers on nutrition care and support for persons living with HIV. Materials developed should be culturally acceptable, and feasible. Involve people living with HIV in the development process.

Promote and mainstream voluntary counseling and testing services.

Place the commitment to fight HIV/AIDS at the center of the national capacity building agenda.

Tailor and share information that will empower and enable politicians, policy makers, program managers and service providers to mobilize partnerships for HIV/AIDS prevention and control.

Annex 2

Effect of Breastfeeding on Mortality among HIV-Infected Women

WHO Statement, 7 June 2001

A recent paper by Ruth Nduati and colleagues in *The Lancet* (26 May 2001)¹ reported a three-fold higher mortality rate in HIV-infected mothers who breastfed their infants compared with those who fed their infants with formula.

These results arose from a secondary analysis of a randomised trial of breastfeeding compared with formula feeding conducted in Nairobi, Kenya, between 1992 and 1998². The trial was designed to assess the rates of mother to child transmission of HIV according to mode of infant feeding. Eighteen of 197 women randomly allocated to breastfeed their infants died within 24 months of delivery compared with six of 200 women allocated to the formula-feeding group. The cumulative 24-month mortality rates were 11% and 4%, respectively, corresponding to a 3.2-fold higher risk of death (95% confidence interval 1.3 - 8.1). Since assessing mortality in mothers was not the primary objective of the trial, this unexpected observation must be interpreted cautiously. Preliminary results on mortality were communicated in July 2000 in Durban³.

A strength of the study was the random allocation to mode of infant feeding, and the authors correctly present their primary results according to randomised group. However there was considerable non-compliance with the allocated infant feeding group (4% of those allocated breastfeeding did not give any breast milk to their infants and 29% of those allocated formula feeding also gave breast milk). Potentially useful additional information could be obtained by considering the mortality rates according to a measure of milk production, such as the proportion of daily infant feeds given as breast milk.

The authors suggest that the high energy demands of breastfeeding in HIV-infected mothers may accelerate the progression to HIV-related death. If this is true then a higher death rate should be apparent in women who breastfed their infants exclusively compared with those who gave their infants food supplements or avoided breastfeeding altogether.

By contrast, Coutoudis and colleagues have published an analysis of morbidity and mortality in mothers enrolled in a randomised study of Vitamin A supplementation conducted in Durban, South Africa, analysed according to their chosen method of infant feeding⁴. This secondary analysis was conducted to specifically address the concerns raised by the preliminary results from Nduati and colleagues and showed that two of 410 (0.5%) women who ever breastfed their infants died compared with three of 156 (1.9%) who never breastfed. In addition there was no excess of any reported morbidity in mothers who breastfed compared with those who did not (12.7% and 14.7%, respectively). While these results are reassuring, the limitations of the analysis must be recognised—women chose whether or not to breastfeed their infants, and the numbers of women involved was small. The study had at most 50% power to exclude a 3-fold increase in mortality in mothers who breastfeed.

Neither of these studies provided detailed information on the mode, duration and quantity of breastfeeding and the associated mortality risks. In addition the two groups of women enrolled in the trials are not directly comparable. Those in Durban were in general healthier, as evidenced by a lower prevalence of anaemia and better immune status at enrolment, than the women in Nairobi. The overall mortality rate in the Durban cohort was less than 1% with an average follow-up of 10.5 months compared with overall mortality rates over 4% at 1 year and 7% at 2 years in the Nairobi cohort.

One of the two reports shows a three-fold excess risk of death within 2 years among women who breastfed compared with those who formula fed their infants, while the second suggests no additional risk. Limitations of the data suggest a cautious interpretation. Nevertheless the findings are important and additional research on this issue is urgently required. Further analysis was also called for by Newell in her commentary⁵.

The preliminary results from the new study had been communicated in July 2000 and were considered by the Technical Consultation convened by WHO in October 2000⁶. The new results do not warrant any change in current policies on breastfeeding nor on infant feeding by HIV-infected women. These are:

1. Exclusive breastfeeding should be protected, promoted and supported for 6 months⁷. This applies to women who are known not to be infected with HIV and for women whose infection status is unknown;
2. When replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-infected mothers is recommended; otherwise, exclusive breastfeeding is recommended during the first months of life^{6,7};
3. To minimize HIV transmission risk, breastfeeding should be discontinued as soon as feasible, taking into account local circumstances, the individual woman's situation and the risks of replacement feeding (including infections other than HIV and malnutrition)⁶;
4. HIV-infected women should have access to information, follow-up clinical care and support, including family planning services and nutritional support⁶.

The most recent results from the study in Nairobi emphasise the need for proper support to mothers who are infected with HIV and provide a further reason for women to know their HIV infection status. This particularly applies to preg-

nant women who should be given access to programmes to prevent mother-to-child transmission (MTCT) of HIV and also access to care and support programmes for HIV-related conditions. WHO recommends that these should include the prevention and treatment of opportunistic infections, treatment with antiretroviral drugs where possible and psychosocial and nutritional support.

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List of Abbreviations

ACC/SCN	Administrative Committee on Coordination, Sub-Committee on Nutrition (of the United Nations)
AIDS	acquired immunodeficiency syndrome
ARI	acute respiratory infection
BFHI	Baby Friendly Hospital Initiative
CCA	Common Country Assessment
CGIAR	Consultative Group on International Agricultural Research
CSB	corn soy blend
DANIDA	Danish International Development Assistance
DFID	Department for International Development (UK)
EU	European Union
FAO	Food and Agriculture Organization
GATT	General Agreement on Tariffs and Trade
GDI	gender-related development index
GDP	gross domestic product
GNP	gross national product
HDI	human development index
HIV	human immunodeficiency virus
HPI	human poverty index
IFPRI	International Food Policy Research Institute
IMF	International Monetary Fund
IMR	infant mortality rate
IU	international units
IUGR	intrauterine growth retardation
IUNS	International Union of Nutrition Scientists
kcal	kilocalorie
LBW	low birthweight
MCTC	mother-to-child transmission (of HIV)
MI	Micronutrient Initiative, Ottawa
NGO	non-governmental organization
NCDs	non-communicable diseases
OECD	Organization of Economic Cooperation and Development
ODA	overseas development assistance
PLWHA	people living with HIV/AIDS
PPP	purchasing power parity
PRSP	poverty reduction strategy paper
REE	resting energy expenditure
SASO	Swaziland AIDS Support Organization
Sida	Swedish International Development Cooperation Agency
STD	sexually transmitted diseases
TASO	The AIDS Support Organisation, Uganda
TRIPS	trade-related aspects of intellectual property rights
UNAIDS	United Nations Programme on HIV/AIDS
UNDAF	United Nations Development Assistance Framework
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNHCR	United Nations High Commission for Refugees
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
WABA	World Alliance for Breastfeeding Action
WFP	World Food Programme
WHO	World Health Organization
WTO	World Trade Organization

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