

## Report and policy brief from the 4th Africa Conference on Social Aspects of HIV/AIDS Research: Innovations in access to prevention, treatment and care in HIV/AIDS, Kisumu, Kenya, 29 April-3 May 2007



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### ABSTRACT

About 520 delegates from all over Africa and 21 countries attended the conference. This report and policy brief summarises the key findings and suggested policy options that emerged from rapporteur reports of conference proceedings including the following themes: (1) Orphans and vulnerable children, (2) Treatment, (3) Prevention, (4) Gender and male involvement, (5) Male circumcision, (6) People living with HIV/AIDS, (7) Food and nutrition, (8) Socioeconomics, and (9) Politics/policy. Two (11.8%) of the 17 OVC projects from the three countries were classified as best practice interventions. Of the 83 abstracts that were accepted at the conference, only 7 (8.4%) were dealing with antiretroviral therapy (ART). There has been tremendous effort by various organisations to provide information about prevention of HIV/AIDS. Information received by adolescents has been effective in increasing their knowledge, but without positive sexual behaviour change. The conference noted the contribution of gender discrimination and violence to the HIV epidemic and the different risks that men and women face in relation to the epidemic. Social scientists need to study the deep cultural meanings attached to male circumcision among different ethnic groups to be able to guide the debate on the latest biomedical findings on the protective effect of circumcision against HIV. Palliative care and support is crucial for coping among people living with HIV/AIDS (PLWHA) in order to deal with medical and psychological issues. Results from several countries have helped researchers to explore alternative ways of examining poverty in the context of HIV and AIDS. Policy frameworks which are likely to succeed in combating HIV/AIDS need to be updated to cover issues of access, testing, disclosure and stigma. In general, the conference was successful in identifying innovations in access to prevention, treatment and care in HIV/AIDS.

*Keywords: Summary, policy, social aspects of HIV/AIDS, Kisumu conference, 2007*

### RÉSUMÉ

Environ 520 délégués du continent africain et 21 pays ont assisté à cette conférence. Ce rapport et dossier politique présente le compte-rendu des résultats clés et des options de la politique suggérées qui ont émergées des bilans de débats de la conférence. Entre autres les thèmes suivants ont été abordés : (1) les Orphelins et les Enfants Vulnérables (OEV), (2) le traitement, (3) la prévention, (4) le sexe et la participation des hommes, (5) la circoncision des hommes, (6) les personnes vivant avec le VIH/SIDA, (7) les aliments et la nutrition, (8) les socio-économies et (9) la politique. Deux (11,8%) de 17 projets d'OEV entrepris dans trois pays ont été classifiés comme les meilleures interventions. Parmi les 83 résumés acceptés pour cette conférence, seulement 7 (8,4%) portaient sur la thérapie antirétrovirale (TAV). Pas mal d'organisations ont fait des efforts énormes afin de mettre à disposition des renseignements sur la prévention du VIH/SIDA. Les renseignements reçus par des adolescents se sont avérés efficaces à augmenter leur savoir sans pour autant changer leur comportement sexuel. Les débats ont fait constat du rôle de la discrimination de sexes et celui de la violence sur l'épidémie du VIH et les risques auxquels les hommes et les femmes font face vis-à-vis l'épidémie. Les sociologues doivent étudier le sens culturel associé à la circoncision des hommes parmi des différents groupes ethniques afin de diriger des débats sur les résultats biomédicaux plus récents liés à l'effet protecteur de la circoncision contre le VIH. Les soins et le soutien palliatifs sont primordiaux aux personnes vivant avec le VIH/SIDA pour pouvoir faire face à leur condition et pour qu'elles puissent faire face aux aspects médicaux et psychologiques. Les résultats de plusieurs pays ont aidé les chercheurs à découvrir d'autres voies d'étudier la pauvreté dans le contexte du VIH et du SIDA. Les cadres politiques qui ont une chance de réussite dans le combat contre le VIH/SIDA doivent être mise à jour afin d'aborder les questions d'accès, du dépistage, de révéler son statut et de la stigmatisation. En général, la conférence a réussi à identifier les innovations d'accès à la prévention, au traitement et aux soins du VIH/SIDA.

*Mots clés: Résumé, politique, aspects sociaux du VIH/SIDA, conférence de Kisumu.*

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### 1. Orphans and vulnerable children (OVC)

Professor Leickness Simbayi presented an overview of the development, implementation and progress as well as lessons from a 5-year programme whose objective was to develop best practice OVC interventions in Botswana, South Africa and Zimbabwe. The initiative brought together six organisations in the three countries - one national implementation grant maker to coordinate the delivery of OVC interventions, and one research organisation in each country - under the auspices of the Social Aspects of HIV/AIDS Research Alliance (SAHARA) network. The project was implemented at 17 sites in the three countries - as depicted in Table 1 below.

*Lessons learnt and policy implications:* The use of implementation research networks such as SAHARA to conduct multi-country and multi-site research projects is useful for providing scientific evidence for use in both OVC policy and programme development, both on an individual national basis and regionally.

Moira Ngaru described care and support for OVC in farming communities through the Farm Orphan Support Trust (FOST) in Zimbabwe. The vision of the project is to get “all orphans’ rights realised” by proactively increasing the capacity of communities to

respond to the orphan crisis and ensuring that systems are in place to protect and care for OVC in farming communities. FOST has developed a holistic intervention that builds the capacity of the community to respond in sustainable ways, by developing support networks in communities, access to education, home-based care (HBC), development of “Kids Clubs”, alternative livelihood skills, and supporting child-headed households.

*Lesson learnt:* The most effective and sustainable way to protect and support OVC on farms is building community capacity, developing meaningful livelihoods, keeping parents alive and healthy, enhancing psychosocial support systems, and building the resilience of children themselves, rather than pure material support.

Ella Mohamadi described important aspects of Bana ba Keletso (BBK) Child care project in Molepolole, Botswana. As a response to the increasing numbers of OVC, the community of Molepolole started a joint intervention to provide care and support to OVC through a comprehensive approach of establishing a counselling centre and a child care programme to reduce the psychosocial effects of orphanhood.

**TABLE 1. OVERVIEW OF OVC INTERVENTIONS BY COUNTRY AND GRANT MAKER, PROJECTS AND SITES WITH A BRIEF DESCRIPTION**

Country and grant maker	Projects and sites	Brief description
Botswana, Masiela Trust Fund	Bana ba Keletso Motse wa Tsholofelo Mother's Union Centre Little Friends Centre Kgodisong Centre	Community child support Child care for OVC Preschool orphan care support Early childhood education for OVC Day care centre
South Africa, Nelson Mandela Children's Fund	Matjhabeng OVC JV Tapologo OVC project Child Welfare NW Diketso Eseng Dipuo	Comprehensive OVC support Household support for OVC Community child welfare Community empowerment project
Zimbabwe, Family AIDS Caring Trust	Midlands Aids Service Org Farm Orphan Support Trust Dev Aid People-People Ndzeve Centre Tyinyunyi Babili Trust FACT Nyanga Practical Action Batsirai Group	Community OVC support PSS support for farm orphans Preschool and youth-friendly corner Education/support - deaf children Community orphan support Education and PSS for orphans Community-child support Integrating microfinance in OVC

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*Lessons learnt:* BBK is an integrated community based programme, with interventions that focus on educational support for pre- school children and out of school youth, psychosocial support through counselling, camps, kids clubs, home visits, skills building and play, community educational outreach, provision of material support, and training of caregivers and volunteers on child care. Of the 6 310 orphans registered with the Department of Social Services, 520 of them are from BBK. The project is sustainable because of the high level of community involvement. There is networking and collaboration with other stakeholders to reduce unforeseen duplications of programmes and to expedite resource mobilisation.

Hilda de Bees described interventions for OVC at Tapologo HIV/AIDS project in Rustenburg, North West province. The community based care model uses four leading principles: community ownership, children's rights, child protection and child participation. The programme recruited 20 Community Care Workers (CCW) and two Community Care Coordinators (CCC) at two sites.

*Lessons learnt:* CCW identified 200 households with about 377 OVC, where they provide psychosocial counselling, management of grants, identification and dealing with violence against children, and sexual abuse. They also provide food parcels, when available, and support income generating activities at the local community centre such as knitting, sewing, gardening, fence-making, etc.

*Policy implications:* Introduce and educate tribal authorities and other community structures on OVC models to reinforce the capacitation and institutional strengthening of the community to care for their own children. It is also important to foster a sense of ownership of the programme by the broader community. It is important to provide training on care for carers and to support counselling from the social worker, debriefing and individual emotional counselling.

Geoffrey Setswe, presented a study on elements of good practice OVC interventions in 17 projects in three southern African countries. This study evaluated 17 OVC interventions in Botswana, South Africa and Zimbabwe, to determine if they were "best", "good" or "promising" OVC practices, using a combination of

reading, observing, talking and review. Researchers visited each of the OVC projects and observed how the projects were implemented, took field notes and reviewed same. They also read and reviewed annual progress reports which were submitted by project managers over the five year period. A documentary review was also done on a presentation and/or poster using ten-point criteria.

*Evidence generated:* Two of the 17 projects were classified as best practice, four were good practice and 11 were classified as promising practice OVC interventions. None of the projects were classified as poor practice OVC interventions. Deciding what is "best" is not easy. Best practices can vary over time, as new evidence and new possibilities emerge, and from place to place, depending on available resources and infrastructure. What is "best" also depends on what people want.

### 2. Treatment

Of the 83 abstracts that were accepted at the 4th SAHARA conference as papers and posters, only seven (8.4%) dealt with antiretroviral therapy (ART), five of which were papers and two were posters. This was disappointing considering the amounts of money allocated for ART.

Table 2 below shows innovations in HIV/AIDS treatment, which included a description of gender distribution of patients on ART, clinical outcomes of patients on ART, adherence to ART, innovations in ART treatment, access to socio-economic support, factors that influence access and utilization, and an approach to delivery of ART services. Innovative methods were used to study access and treatment with ARVs. The three case studies on access to ART are valuable in studying new interventions such as the introduction of ARVs; two cross-sectional surveys on adherence to ART will help new programmes to understand factors that influence PLWHA to adhere to treatment; and a systematic review on gender distribution and clinical outcomes of patients on ART gives a broader picture of who is on treatment and whether it is effective or not. Three of the studies were from researchers in West Africa and two each from researchers in southern and east Africa. Five of the studies were targeting PLWHA on treatment, one study targeted the general community using a nongovernmental ART service, while another focused on increasing access to children receiving ART.

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**TABLE 2. CHARACTERISTICS OF STUDIES ON ART AT SAHARA CONFERENCE**

Author(s)	Innovations	Target group	Method	Country
Muula <i>et al.</i> ,	Gender distribution and clinical outcomes of patients on HAART.	PLWHA on ART	Systematic review	Southern Africa
Sow <i>et al.</i> ,	Adherence to ART and prevention in hospital and community sites	Men and women receiving ART	Cross-sectional survey	Dakar, Senegal
Mendez	Innovations in treatment and access to socio-economic support	Men and women receiving ART	Case study	Guinea-Bissau
Obinge <i>et al.</i> ,	Increasing access to HIV care and treatment	Children on ART	Case study	Siaya and Kisumu, Kenya
Malangu	Adherence to ART	PLWHA on ART	Cross-sectional survey	Pretoria, South Africa
Nduta <i>et al.</i> ,	Factors that influence access and utilisation of ARVs	PLWHA	Descriptive study	Eldoret, Kenya
Mwenda	A comprehensive approach to ART delivery at CHAK	General community	Case study	Kenya

A systematic review of gender distribution and clinical outcomes of patients on ART in southern Africa found that the median age of patients in the studies ranged from 33 to 39 years, with females exceeding 60% of patients on ART in most of the study locations. The latter finding was not surprising, but researchers believe there is need to identify factors facilitating accessibility to treatment by women (Muula *et al.*).

A cross-sectional survey among 98 men and 109 women receiving ART to determine adherence to ART in Dakar, Senegal found that 58% of them were adherent, but there were differences in the levels of adherence according to variables and treatment protocol. Social characteristics such as having children, or being a housewife and not planning to have a child in the next year, were associated with adherence (Sow *et al.*).

A case study of innovations in the treatment and access of socio-economic support in Guinea-Bissau found that the distribution of condoms was on-going and increasing, and most of those infected were still waiting for treatment. The key challenges in providing HIV/AIDS treatment services were limited resources, lack of capacity for implementation of the national strategy, and lack of necessary equipment (Mendez).

Obinge and colleagues described access to HIV care and treatment through partnership using a children's club approach, to meet the needs of children and to

help them cope with their situation. Feedback received from the children after every meeting made it possible to adjust the programme to address the needs of the children, and many beneficiaries reported positive therapeutic outcomes.

In a cross-sectional survey of patients who started ART between 2004 and 2005, to document factors associated with adherence to ART in Pretoria, the 180 patients who consented to be interviewed had a mean age of 36.7 years, 68.8% were female, 86.7% were unemployed, 73.9% had high school education and 77.8% were single (Malangu).

Nduta and colleagues found a significant relationship between age, marital status, ethnicity, religion, main occupations and current engagement of PLWHA, in accessing and utilising ARV drugs.

An integrated approach to ART delivery at the Christian Health Association of Kenya runs ART programmes at 255 sites, 25 hospitals and health centres. It includes training in ART, onsite mentoring, and training of community health workers to support home based care programmes. Community outreach for ART increased access and adherence to ARV treatment.

*Conclusion:* The 4th SAHARA conference was a missed opportunity for programmes to share research and progress on implementing ART programmes. It

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was disappointing that less than 10% of all abstracts accepted at the conference focused on ART. However, these few presentations and posters were helpful in sharing innovations in HIV/AIDS treatment. Programme implementers should be trained and supported to share research and progress on implementing ART programmes at conferences.

### 3. Prevention

There has been tremendous effort by various organisations to provide information about prevention of HIV/AIDS. However, despite these efforts, a large segment of the population is still being excluded from accessing information on the basis of their disability. The use of mass communication to provide information about HIV/AIDS has serious implications for prevention, since it does not consider the needs and limitations imposed on individuals due to disabilities. Persons with disabilities do not have correct and adequate information about prevention, treatment and care of HIV/AIDS, due to the methods used in mass communication by service providers. It was reported that experts estimate that persons with disability are about five to ten years behind the general population in knowledge and awareness about HIV/AIDS. The low knowledge of facts about HIV/AIDS among persons with disabilities is as a result of conventional methods of using print and electric media for mass communication which are not accessible to persons with disabilities. These conventional methods do not take into account that persons with disability require the use of other media such as sign language, symbols and Braille.

This paper discusses the implication and the use of mass communication in promoting the participation of persons with disabilities in HIV/AIDS prevention, treatment and care. The use of mass communication by various stake holders to disseminate information about HIV/AIDS through print, electric and verbal media requires proper functioning of auditory, visual and cognitive processes. These processes are usually impaired in persons with disabilities and therefore, they are marginalised socially and isolated from the general society. As a result of this marginalisation, information and education on HIV/AIDS largely bypasses the members of the disability community. Although studies have shown that information is one of the strongest tools for fighting HIV/AIDS, persons with

disabilities continue to be limited in accessing information due to media used in mass communication.

National and institutional policies on HIV/AIDS should recognise the needs of persons with disabilities, and provide information through accessible disability-friendly communication channels, such as talking computers, to allow them to participate in activities leading to the prevention and care of HIV/AIDS. Various stake holders providing information about HIV/AIDS should adapt communication tools that would enable persons with disabilities to make use of the silent television set, invisible radio, indecipherable newspaper, and the unconfident parent and siblings (Edward Kochung).

*Evidence generated:* Information plays a key role in influencing adolescent sexual behavior. Studies undertaken indicate that information received by adolescents has been effective in increasing their knowledge, but without positive sexual behavior formation and change. The aim of the study was to determine the characteristics of information sources that influence adolescent sexual behavior. The study revealed that peer and media were the main sources of sexuality information, compared to FBO and parents. Peers followed by media had most of the desired characteristics such as listening, availability and openness, whereas parents were said to be knowledgeable as compared to other sources. The study showed that parents (46%) were the most preferred source, yet they had fewest of the preferred characteristics. Parents were considered to be judgmental and lacked privacy, and therefore rated among the least used source. The source of information and sexuality practice were found to be related, as those who sought their sexuality information from peers were more likely to have engaged in sex, while those who received their information from parents were less likely to have engaged in sex. The researcher concluded that each source has a unique characteristic that affects the behavior of adolescents, and that there is a need to look at opportunities for parents to gain the knowledge and skills they need to enhance the desired characteristics to effectively communicate with their adolescents about sexuality for a positive health outcome among adolescents. The research also recommended the need to enhance peer

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and media as most used sources, to make them effective in sexuality information provision (Olayo & Kaseje).

The dilemma of married couples in disclosing HIV/AIDS status was also reported at the conference. A study conducted on the experiences of VCT funded by USAID, reported that men and women who came for the testing did not come together as couples but alone. After testing they found it difficult to share their results with their spouses for fear of being blamed for having several sexual partners (Nsabagasani & Yoder).

A study was conducted to evaluate the effectiveness of abstinence and faithfulness among youth (ABY) interventions in five African countries. The abstinence programmes encourage unmarried individuals to abstain from sexual activity and only protect themselves from exposure to HIV and other sexually transmitted infections; while “be faithful” programmes encourage individuals to practise fidelity in marriage and other sexual relationships, as a critical way to reduce risk of exposure to HIV. It was found that to obtain the best evidence of effectiveness of the ABC intervention, it is essential to involve the evaluation team in the design of the plan, and to train them on the methods of the evaluation (Setswe).

*Policy implications:* Many people are not familiar with the scientific terminology, technical details and other information about HIV/AIDS. Moreover, there is a need for visual communication so that it can be more effective, understandable and interesting. Scientoons, a new class of science cartoons, which combine scientific information with humour, provide a very effective and powerful tool to tackle this communication challenge. Scientoons with their unique communication power are used worldwide. Scientoons have been very successfully used for creating awareness about HIV/AIDS in India and abroad (Kumar). Moreover, counselling should include discussion of sexual relationships, so that the risks of HIV transmission may be reduced. VCT clients need to be followed up to help them negotiate sharing sero-status with spouses.

#### 4. Gender and male involvement

The contribution of gender discrimination and violence to the HIV epidemic, and the different risks that men and women face in relation to the epidemic, was reported at the conference. These require some

consideration in the development of intervention strategies. However the papers presented made it clear that both men and women need to be informed of the interventions directed at each other, to be able to support their partners.

One of the key sessions at the conference dealt with sexual and partner violence. A sample of women attending a primary health care clinic in Limpopo province South Africa reported emotional abuse in 22% of cases, physical intimidation in 20% of cases, and physical abuse in 17% of cases. Of importance 50% implied that it was difficult to initiate talking about this, and wanted health care professionals to ask about it or investigate it further. Given that there were many more participants requesting this action from health professionals than reporting abuse, it is likely that the 17% is a considerable undercount and that there is a need to feel safe in reporting forms of abuse (Papa Gallo Sow).

Another survey in South Africa also reported levels of partner violence at 21%, with 17% of women raped. Violence was reported as coming predominantly from partners, family members, and friends. Jealousy was seen as the major reason for violence from partners. Men also reported experiences of violence from older men and women, and also on occasion from their peers (Pengpid & Peltzer).

Alternative protection technologies that are under the control of women were raised as important. Attitudes towards the diaphragm were investigated among female sex workers. The researchers found high levels of acceptability from the women and their male clients, who were often not even aware of the use of the diaphragm. However partners were concerned that they were excluded from decisions making. Of importance is to establish what protection diaphragms offer in relation to STDs (Okal *et al.*)

PMTCT constitutes an important intervention to protect children from infection and is primarily directed at women. Research found that awareness and informed knowledge regarding the programme was low amongst men, and requires further input from health workers towards men. Women attending the programme also need to be skilled to educate men (Onyango *et al.*)

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VCT is a potentially powerful prevention tool, but it requires either that partners test together or that they are prepared to disclose to each other, especially in the context of marriage. A study found that men and women tend to test separately and that those who do test positive find it difficult to disclose this to their partner, with only about half of the sample being prepared to reveal their results to their partner. Efforts need to be introduced to facilitate partners being able to attend VCT together and to be able to talk to each other about positive results (Nsabagasani & Yoder). A similar ignorance of information was shown in relation to nosocomial infection in the DRC, thus requiring additional input (Bukondo & Disashi).

### 5. Male circumcision

Social scientists need to study the deep cultural meanings attached to male circumcision among different ethnic groups, to be able to guide the debate on the latest biomedical findings on the protective effect of circumcision against HIV. According to Professor Cheikh Niang of the Institute of Science and Environment, Cheikh Anta Diop University, Senegal, African social scientists should look beyond the evidence of trials conducted in Kenya, Uganda and South Africa on the protective effect of male circumcision, and 'reconceptualise' the findings to fit into African cultural perspectives. Niang was contributing to a roundtable discussion on the preventative impact of male circumcision on HIV at the conference. He argued that to promote male circumcision as a Western-type biomedical hospital procedure would not be widely accepted and supported. All African ethnic groups have deep cultural and spiritual meanings attached to circumcision, and these should be uncovered and reintegrated into African sexual life, in order to get wide acceptance of circumcision as a protective measure against HIV and AIDS.

Prof Agot Kawango from the Department of Microbiology and the project coordinator of the Kenyan study on the protective impact of male circumcision on HIV released in February 2007, kicked off the discussion, emphasising the importance of the social acceptance of male circumcision, especially in areas where circumcision is not a cultural practice. Three studies have now shown remarkably consistent findings on the protective effect of male

circumcision against HIV/AIDS: the Orange Farm randomised trial conducted in South Africa (60% protective effect), the Kisumu study (59% protective effect) in Kenya, and the Rakai study in Uganda (51% protective effect). None of the studies showed that circumcision was harmful. He said for circumcision to be accepted as a means of protection, there were key social aspects that need to be resolved, including:

- How to communicate the benefits, while also explaining that circumcision is not 100% effective.
- The cost aspect: the willingness to pay in communities where circumcision is not a cultural or religious obligation.
- Access: what level of health facility and cadres of personnel should do circumcisions?
- Can traditional circumcisers be trained to provide safe circumcision?
- How to encourage young men to go to health facilities.
- How to identify qualified circumcisers, and educate parents and sons on how to find or identify them.
- Wound care and after-care.

Adera Osawa, the deputy secretary general of the Luo Elders – a community that do not practice circumcision – said there were strong cultural emotions against circumcision, and some 'very derogatory words' were used for someone who is circumcised. But because AIDS is 'a very dreaded disease that scares us all', he said the Luo community did not challenge the scientific findings. 'We as the Luo Council cannot force people to accept it [circumcision], as a policy. We don't reject people who do it, but accommodate them.'

In one of the sessions, Professor Leickness Simbayi, a research director at the Human Sciences Research Council, suggested before governments consider male circumcision as a potential public health policy and HIV prevention strategy, it would be prudent to wait for the results of long-term follow-up studies of the Kenya and Uganda studies, due in 2009. He said the long-term 60% protection offered by circumcision should first be established before this could be made public policy. He presented a South African study that was based on a further analysis of data obtained from the first national population-based survey of HIV/AIDS conducted in South Africa in 2002, consisting of a sub-sample of 3025 men over 15 years

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of age and older. It found that just over a third (1067 or 35.3%) were circumcised. Most white, coloured and Indian men in the sample were circumcised in hospitals during childhood, whereas most African men in the sample were circumcised outside a hospital during adolescence. Of these, 432 (40.5%) circumcisions took place after the men's sexual debut. Simbayi *et al.*, found no significant differences in HIV prevalence between all the circumcised men and uncircumcised men in the sample (11.1% vs 11.0%), even when the comparison was restricted only to those who were sexually active (12.3% vs. 12.0%). The results remained consistent, even when the researchers compared the age at which the circumcisions were done, namely before the age of 12 and after the age of 12; and when only those who were sexually active were considered.

### 6. People Living with HIV/AIDS (PLWHA)

Care and support is crucial for coping among PLWHA and OVC, in order to deal with medical and psychological issues at home, and in schools and communities. In most countries palliative care services are available for PLWHA and cancer patients. Palliative care is based on the principles of holistic care, with the main focus on enhancing quality of life for the terminally ill, by providing love and support, and controlling the suffering of patients and their families. The WHO definition of palliative care includes early identification, assessment and treatment of pain and other social aspects. Thus, the continuum for palliative care involves: Diagnosis – Therapies to modify disease – Control suffering – Life closure – Death – Bereavement.

The high demand for palliative care services is due to the fact that, although there are free ARVs, there are still no solutions to medical problems such as cancer for people who need palliative care, especially those with AIDS. Moreover, palliative care services need to be strengthened, due to their cost-effectiveness for the health care system; increase in mortality rates from cancer (21,000 per annum) and AIDS (140,000 AIDS deaths annually), and inaccessibility to ARVs (only 50% of those in need of ART have access). In most African countries access to palliative care is limited to patients with conditions such as Kaposi's Sarcoma, diarrhoea, cryptococcal meningitis, chronic pain, and genital herpes.

Most of the papers demonstrated that areas covered for palliative care services include hospitals, hospices, schools, home based care, community centres, use of motorbikes to reach patients in unreachable areas, open air treatment, programmes such as road side mobile clinics, and the rural AIDS home care programme. A multi disciplinary approach is used with a good referral system established. Involvement and participation of communities in palliative care is visible in countries such as Uganda, Kenya and Canada. Palliative care is cost effective, improves quality of life and saves life.

Some problems and challenges with palliative care include:

- Generally there is still poor accessibility and utilisation of palliative care services such as home based care, due to stigma, since communities are not adequately equipped to deal with terminal illness, death and dying. Utilisation of hospice services such as home based care are not fully utilised, e.g. in South Africa due to stigma toward people using services and the community health workers. In Uganda palliative care is fully effective; nurses prescribe morphine and help in managing and helping patients.
- Palliative care is stigmatised, therefore support comes late for PLWHA, leading to high mortality rates
- There is a need to have more trained nurses and community health workers (CHW). CHW play a crucial role in linking communities and formal health care systems.
- Access to resources such as space, ART, chemotherapy, radiotherapy for palliation, staff, and pain alleviating drugs are still a problem.
- National policies on palliative care need to be developed or revised, e.g. legislation on stocking, dispensing and prescribing opioids or narcotics is still a barrier in many African countries.
- Lack of funding and resources
- No incentives, recognition and motivation for CHW

#### Way forward and policy implications

- There is a need to do more advocacy, awareness, education, policy review, research projects, needs assessment, capacity building through training, facilitation and supervision, collaborations and partnerships, strategies on scaling up palliative care services, community mobilisation, implementation

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of national strategy, stigma reduction and changing attitudes towards PLWHA.

- Palliative care should be structured according to the culture and needs of communities - this is called "culturally appropriate care".
- There is a need to develop expertise in communities, and affirm communities to care for themselves
- There is also a need to build in more psychological support in models of care

### 7. Food and nutrition

Mainstreaming HIV/AIDS in development programmes was seen to be a big concern, that came with many questions such as: is there any difference in nutritional requirements between men and women?, what is the ability of good nutrition to delay HIV progression?, without adequate nutrition is there any need for ARVs intervention?

The papers presented appear to focus on ensuring food security for all, whether HIV infected or not, because it is believed that this makes it easier for ART intervention. This includes the establishment of kitchen gardens where people will be able to grow their own crops. There were discussions on nutritionally superior indigenous vegetables, especially the bitter vegetables that are viewed as medical. Having the right information on nutritional requirements prior to the intervention can help ensure the right nutritional status. Another option that was presented at the conference was camels' milk, which is also proven to be nutritious and rich in phytochemicals. However, in food intervention, the concern primarily lies in nutrition education especially in the era of HIV/AIDS, where recommendations for nutritional requirements for those living with HIV are needed (Owino & Konyole).

Policy formulation on how to fill the gaps to encourage production of enough, nutritious foods was also presented at the conference. Giving farmers a subsidy was presented as a policy option that would increase the production of nutritious food. It starts with the provision of safe drinking water and reduces cross-contamination in cases of replacement feeding; and also focuses on fortifying food, especially if the government can subsidise and ensure proper quality control, by doing the processing centrally through

social marketing and seeking private public sector partnerships. A policy framework (government intervention) is needed to mainstream these issues by allowing small-scale agriculture in the urban centres. This was seen as practical, as compared to rural communities who do farming as a seasonal activity and prefer to do it on a large scale. A policy should also emanate to clarify the roles of nutritionists, identify the problem and then advocate for the need for such positions (Owino & Konyole).

Some services support what they think is the core service and should be de-linked from the health facilities, with nutrition integrated more into health service provision. HIV further complicates the issue of malnutrition, and people with knowledge should embark on outreach programmes to deliver the message more, and this should also include partnerships and networking. Nutrition and HIV policy formulation in Kenya has been slow; this is probably because the current parliament has few (2) nutritionists who have tried to mainstream HIV and nutrition issues into the policy. Nutrition and dietetics bill was presented to have reached second stage of debate, to address issues like supplements used without control. Regulation is needed to eliminate the inadequate supplements. The regulation of education was shown to be significant in order to help channel right information to the people. Research presented at the conference shows that adequate nutrition can help postpone the progression of HIV/AIDS and emerging issues on nutrition and HIV especially among children is necessary to avoid complications (Owino & Konyole).

Policy intervention should be introduced to help such urban cases to enhance the capability of IGAs and allow the provision of ARVs as a package. It was noted at the presentation that linking with agricultural extension people would help the nutritionists to channel efforts towards the targeted production. Food distribution should also not only target one sector but the whole population. The changing face of HIV/AIDS and other nutritional related diseases has caused an increase in demand, because of growing recognition of the important role of nutrition. On the other hand, all farmers whether small or large scale, should have credit access, and clean and safe drinking water available. Communities should also have access to

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nutrition education. Land ownership still has loopholes and contributes to food insecurity, since there is land-grabbing and so production for the household is reduced. Policy gaps exist to control the mushrooming of dubious manufacturers, especially of products with unconfirmed nutritional benefits. Implementation of some of the policies should be followed up to ensure practicality, and adjustments made accordingly.

### 8. Socioeconomics

Professors Dan Kaseje (Kenya), Cheikh Niang (Senegal) and John Seager (South Africa) convened a symposium to present preliminary results of a SAHARA multi-country study being carried out in South Africa, Kenya and Senegal on the socio-economic impacts of HIV and AIDS. The study was funded by the governments of the Netherlands (DGIS), United Kingdom (DFID), Canada (CIDA) and the Ford Foundation. Quantitative studies were reported for Kenya and South Africa, and a qualitative exploration of the nature of poverty for Senegal. The quantitative studies utilised similar semi-structured questionnaires, which were administered to 600 households in rural Kenya and 300 households in a peri-urban area in South Africa.

The symposium began with the presentation of a *conceptual framework developed to assist in understanding the dynamic nature of the relationship between HIV infection and poverty* (Seager & Ganyaza-Twalo). The framework explored the relationships between HIV and poverty at the various stages, from initial infection, through AIDS, to death. The model identified both how poverty contributes to risk of initial infection and how negative feedback loops related to illness and death exacerbate poverty.

The next paper, *interactions between poverty and HIV/AIDS at the household level* (Seager & Ganyaza-Twalo), explored methodological challenges in identifying HIV-affected households, and categorised households using both known HIV status (volunteer PLWHA) and proxy indicators for HIV impacts, such as young adult deaths from typical opportunistic infections, and presence of orphans within the household. The study then explored the relationship between several composite indicators of socio-economic status and household HIV status in a peri-urban area of Cape Town. Significant relationships were

reported between HIV and asset depletion and hunger. Funeral costs were a substantial economic shock to households, equivalent to about one to two years income in a poor household, but were offset for the majority of households by access to insurance (formal or informal).

The Kenyan study was carried out in a rural sub-district and was presented in four components: *study background and demographic information* (Oyui et al.); *impact of HIV/AIDS on economic impacts and spending patterns* (Kaseje et al.); *impact of HIV/AIDS on food and nutrition security* (Ariga et al.); and *coping mechanisms for economic shocks* (Owii et al.). Background data included an absolute poverty rate of 65%, food poverty of 55%, and HIV prevalence of 35% (KDHS, 2003). The study identified HIV-affected households using health facility records and an informed consent procedure. Control households were selected from two immediate neighbours. Disease staging (available from clinical records) was used to provide a “quasi-longitudinal” study design, i.e. assessing impacts from early to late stage disease. Relative to control households, the index households spent a greater proportion on food and health care, and less on investments, education and house construction or repairs. Decrease in asset ownership over the past six months was related to stage of disease, with 8.8% of stage 1 households having decreased asset ownership, rising to 18.2% by stage 4 and dropping to 11.8% for households experiencing a death (stage 5). HIV-affected households planted and harvested significantly less maize than control households. The index households also kept less livestock. Both results may be indicative of the affected households avoiding labour-intensive activities and selling off livestock to meet medical and other essential expenses. Hunger was significantly more frequent in index households. In response to adult deaths, a greater proportion of HIV-affected households used social support from relatives as a coping strategy, unlike the control households who depended on the sale of assets or cereals. The analysis showed that HIV-affected households experienced more economic shocks than non-HIV-affected households, and resorted to more desperate measures in response. Strategies for sustainable mitigation of the impacts of HIV among rural households should address food availability and affordable health care.

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The final paper in the seminar was *A qualitative assessment of the impacts of HIV/AIDS on families in Senegal* (Niang). Niang argued that poverty needs to be re-conceptualised since it is understood differently in different cultures. In some languages, there is no direct translation of the word poverty, but rather an understanding of poverty as “a lack of something”. This lack may include economic capital, social capital, human capital or political capital. By way of illustration, a millionaire might be considered poor if he has no social capital or is “alone”. A lack of political capital was described as a state in which a person is described as one who “when he calls, nobody will come”. The emotional effects of illness may lead to depression, which can have direct economic impacts if the patient feels unable to work. Health seeking behaviour can be costly, especially when a PLWHA or their relatives become desperate and seek many different forms of care, including both western and traditional medicine. The death of a head of family often results in the scattering of his family members (wives and children) who go into other homes (remarriages, remarriage of widows and children). HIV/AIDS is affecting the size and the composition of families. Families with PLWHA (especially if the person is the head of this family) have relatively fewer children staying with them than families without PLWHA. Beside the fact that funerals impoverish families, they disturb children’s lives, because they are the first family members to sleep on the floor and leave their beds to visitors if they are not sent to neighbouring homes. Few people take the trouble to look after children on such occasions, and they may be overwhelmed with errands or housework, which can affect their school results. In traditionalist families, many people can share the same meals, even if they don’t live in the same compound. This is sometimes seen as a sign of wealth or social prestige. With AIDS, the number of people who eat together may decrease. The drop in the number of people who usually have meals together can be made sharper by stigmatisation, which leads to the relative isolation of families with an HIV-infected member. In conclusion, although Senegal has a low prevalence of HIV/AIDS in its general population, the socio-economic impacts of HIV/AIDS on infected and affected individual families are devastating. The ongoing research may lead to new suggestions on how to measure and how to make these impacts more visible.

The symposium offered a unique opportunity to compare results from several countries and to explore alternative ways of examining poverty in the context of HIV and AIDS. Further analysis is planned and the presenters will be seeking to publish several papers at the same time so that inter-country comparisons can be made.

### 9. Politics/policy

This section of the report is based on the presentations and discussions made by presenters who represent a mix of politicians and managers of organisations that deal with policy and other interventions on HIV/AIDS, including: The honourable Dr. Gerard Menya Simon, Ugandan MP, Christina van Furstenberg, UNESCO, The honourable Ms. Margaret Mensah-Williams, Namibian MP, The honourable Dr Bani Leon Bio Bigou, Benin MP, The honourable, Mr. Charley Mbock, Cameroon MP, and Ms. Alloys Orago, National AIDS Council, Kenya

*Perspective:* The politicians emphasised the importance of scale and consideration of global trends in the fight against HIV. Globally 42 million people are infected, and 5 million are infected every year. 30 million have died already. Of these figures sub-Saharan Africa represents the highest proportion of those infected. The sad part is that while prevalence was declining in some states, in recent years it is increasing due to lack of resources and capacity. In some countries, government communicates with researchers regularly. As a result different governments have started introducing policies and laws to address socio-economic factors related to HIV/AIDS. However, African governments still need to synchronise evidence drawn from research with legislation and policy.

*Challenges:* HIV and AIDS have negative impacts on the socio-economic conditions of most African states, which complicate struggles against inequality, poverty, unemployment and alcohol abuse. The epidemic has reduced development gains made in recent times. Most African states experience loss of skilled workforce. Women are the most affected and infected because of their vulnerability, exacerbated by socio-economic and cultural factors. Very few people take HIV tests despite governments’ free access policy to health care. There is still a lot of ignorance and lack of knowledge about government policy in most African states. As a result,

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government laws seem to address the needs of parliamentarians rather than those of communities. People are left out of the legislation process. It seems that governments do utilise communities to implement their mandate. This problem is compounded by political and religious differences. In some states leadership remains a major challenge. As result efforts to combat HIV/AIDS are disjointed and uncoordinated. The civil society is not active enough to put pressure on governments to prioritise HIV/AIDS issues. Governments do not have sufficient funds to commission research. Accountability remains a problem, because some public programmes on HIV/AIDS are abandoned because of lack of funds or funds not used for the programmes but for other things.

*Evidence generated:* It seems initially most African states were doing well in reducing HIV infections. However, this trend has not been sustained. It seems that the increase in HIV infections may be attributed to reduced funding, and lack of communication of government policies. Most governments have begun introducing progressive interventions to curb intentional infection and abuses arising from HIV/AIDS. However, the laws still need to be integrated with results from research, best practices in Africa and comparative models successful elsewhere.

*Lessons learned:* Reduction in infection rates requires urgency, sustained interventions and communication.

Parachuting programmes as once-off interventions does not help. PLWHA are vulnerable. In a social climate laced with discrimination, human rights abuses and historical problems, there is a need for more regulations to protect vulnerable groups, especially PLWHA. Government intervention is necessary to ensure that PLWHA are protected. Partnership with researchers is important in making scientific knowledge accessible to policy makers. In this way governments will draw lessons from best practices in the world, and also utilise local socio-cultural innovations to combat HIV/AIDS.

*Policy implications:* The purpose of the roundtable was to highlight major gaps in policy. Policy frameworks which are likely to succeed in combating HIV/AIDS need to be updated to cover issues of access, testing, disclosure and stigma. Generally, socio-economic environments fettered with religious and cultural beliefs need to be regulated to protect PLWHA. Religion and culture, when used unscrupulously, nurture discrimination and human rights abuses. The private sector needs to be brought on board in the fight against HIV/AIDS. They are an important role player in the economy. Without them the economies of different states may collapse.

### Reference

Conference programme and abstract book: 4th Africa Conference on Social Aspects of HIV/AIDS Research: Innovations in access to prevention, treatment and care in HIV/AIDS, Kisumu, Kenya, 29 April-3 May 2007. Kisumu: Great Lakes University (Available online at [www.sahara.org.za](http://www.sahara.org.za))

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