Exploring the challenges of HIV/AIDS

SEMINAR PROCEEDINGS

From the SAHARA sessions at the
International Aids Conference, Toronto, 2006

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Atlantic Centre of Excellence for Women's Health
Canadian International Development Agency
DALHOUSIE UNIVERSITY Inspiring Minds
DFID
HSRC
Onderwikkelings samewerking
OSISA
SAHARA

Published by HSRC Press
Private Bag X9182, Cape Town, 8000, South Africa
www.hsrcpress.ac.za

First published 2007

ISBN 978-0-7969-2194-9

Copyedited by Lisa Compton
Typeset by Simon van Gend
Cover design by Jenny Young
Print management by comPress

Distributed in Africa by Blue Weaver
Tel: +27 (0) 21 701 4477; Fax: +27 (0) 21 701 7302
www.oneworldbooks.com

Distributed in Europe and the United Kingdom by Eurospan Distribution Services (EDS)
Tel: +44 (0) 20 7240 0856; Fax: +44 (0) 20 7379 0609
www.eurospangroup.com/bookstore

Distributed in North America by Independent Publishers Group (IPG)
Call toll-free: (800) 888 4741; Fax: +1 (312) 337 5985
www.ipgbook.com

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Preface

In August 2006, representatives from around the world met together in Toronto, Canada, for the XVI International AIDS Conference to exchange ideas, knowledge and research on the urgency of advancing HIV prevention, care, treatment and advocacy on a global scale. This was the largest meeting of its kind, with more than 25 000 participants and some 12 000 abstracts submitted. Participants encountered the three major themes – that of science, research and community – in a variety of settings, from highly scientific plenary sessions to interactive community dialogues in the global village. The presence of the Human Sciences Research Council (HSRC) and its Social Aspects of HIV/AIDS Research Alliance (SAHARA) was evident during this conference through their display of materials at the booth, session hosting and participation, and presentation of papers.

Background

HIV/AIDS is an epidemic fuelled by social, cultural, behavioural and economic factors, yet up to 2001 there was a dearth of studies examining social aspects of this disease. Instead, research focused largely on medical aspects, mainly because prevention strategies were more developed than social approaches. The scientific community has since realised that the social aspects of HIV/AIDS research are key to improving our understanding of prevention, treatment, care and impact mitigation. Realising the gap, the HSRC established SAHARA, a network comprising three regions in Africa that is specifically aimed at addressing the complexities surrounding the epidemic.

As a vehicle for facilitating the sharing of research expertise and knowledge, SAHARA conducts multi-site, multi-country research projects that are exploratory, cross-sectional, comparative or intervention-based. This is done with the explicit aim of generating new social science evidence on individuals, families and communities. The research addresses the socio-economic, political and cultural environment in which human and social behaviour occurs.

The network brings together key partners in the sub-Saharan Africa region from all sectors of society, including policy-makers, programme planners,

practitioners, researchers and communities. They participate in a flexible alliance around social aspects of HIV/AIDS research, each contributing on the basis of comparative advantage. SAHARA works closely with the African Union's New Partnership for Africa's Development (NEPAD) to ensure that continental approaches or strategies to address the challenges posed by the HIV/AIDS epidemic are informed by evidence-based research. Other key multilateral partners are UNAIDS and the Commonwealth Secretariat.

Purpose

The satellite meetings aimed to reflect critically on the complexity of the HIV/AIDS epidemic in sub-Saharan Africa, and on the challenges key role-players face as they respond to it. The organisers hoped to share with participants the work done by SAHARA, particularly the progress and achievements as well as the challenges and lessons learnt from experiences of conducting multi-country intervention research on complex issues such as stigma and HIV risk-behaviour reduction strategies. The sessions provided a forum for participants to share their perceptions of key challenges that remain in reducing new HIV infections and mitigating the impact, as well as an opportunity to review and reflect on resource mobilisation, networking and cooperation vital for halting further negative impact of the epidemic.

Objectives

There were four specific objectives of the satellite meetings:

- To communicate the progress of the multi-country HIV prevention research.
- To share information on the unfolding continental developments in the fight against HIV/AIDS.
- To affirm the role of international agencies in addressing HIV/AIDS-related challenges in sub-Saharan Africa.
- To explore the gender dimensions and implications of the disease.

Acknowledgements

The HSRC and SAHARA would like to take this opportunity to thank all their partners and presenters who participated in these very successful sessions at the 2006 International Aids Conference in Toronto. We would like to acknowledge the participation and contribution made by Kristin Roe, the CIDA-funded intern who was based in Cape Town at the time. The financial contribution of the Atlantic Centre of Excellence for Women's Health, the Canadian International Development Agency (CIDA), the Commonwealth Secretariat, Dalhousie University, the UK Department for International Development (DFID), the Directorate-General for International Cooperation (DGIS) of the Dutch Ministry of Foreign Affairs and the Open Society Initiative for Southern Africa (OSISA) is very much appreciated.

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At the time of writing, Rehaaz Adams was a research intern with SAHARA. He was based at the HSRC offices in Cape Town.

Abbreviations and acronyms

AIDS	acquired immune deficiency syndrome
ART	antiretroviral therapy
AU	African Union
CDC	Centers for Disease Control and Prevention (USA)
CIDA	Canadian International Development Agency
DFID	Department for International Development, UK
DGIS	Directorate-General for International Cooperation of the Dutch Ministry of Foreign Affairs
HIV	human immunodeficiency virus
HSRC	Human Sciences Research Council
IDU	injection drug user
MSM	men who have sex with men
NEPAD	New Partnership for Africa's Development
NGO	non-governmental organisation
OSISA	Open Society Initiative for Southern Africa
PLWHA	people living with HIV/AIDS
PMTCT	prevention of mother-to-child transmission (of HIV)
SADC	Southern African Development Community
SAHARA	Social Aspects of HIV/AIDS Research Alliance
STI	sexually transmitted infection
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	voluntary counselling and testing
WSW	women who have sex with women

Overview

Dr Olive Shisana

SAHARA, in line with its mission, brought together at the 2006 Toronto International AIDS Conference policy-makers, donors, researchers and non-governmental organisations to discuss the complexity of managing the HIV/AIDS epidemic in sub-Saharan Africa and globally. The words of the South African Minister of Social Development, Dr Zola Skweyiya, continue to ring in our ears well after the conference has ended. He said: 'We require tailor-made solutions that should be directed by Africans themselves, and supported by all our partners including international organisations such as the United Nations.'

These words reinforce the reasons for the formation of SAHARA. Through conferences, Africans are able to share their knowledge, advocacy strategies and practices aimed at containing the spread of HIV/AIDS. Previously they came together in Pretoria (2002), Cape Town (2004) and Dakar (2005), and they will be assembling again in Kisumu (2007) under the banner of SAHARA to suggest research-based African solutions to the African HIV/AIDS epidemic. The financial support for these initiatives comes from DFID, CIDA, the Kellogg Family Foundation, UNAIDS, the Commonwealth Secretariat and many more partners. The outputs of the most recent conferences are summarised in two publications.[1, 2]

SAHARA usually convenes satellite meetings at global AIDS conferences. This was done in Barcelona and Bangkok and again in Toronto. At the Toronto conference, African researchers working in sub-Saharan Africa met in a satellite session to share their experiences of adapting innovative interventions shown to work elsewhere to the African context, in an effort to reduce HIV infections. The adapted interventions target people who are already HIV-positive, whether they be men who have sex with men (MSM), or the heterosexual population; the common approach is to try to reduce transmission of HIV from them to HIV-negative sexual partners. What has become very clear from the preliminary studies in southern Africa is that internal stigma continues to help fuel the HIV epidemic.

The studies show that, because of internal stigma, a significant proportion of HIV-positive people continue to have unprotected sex without disclosing their sero-status, often with multiple partners, some of whom are HIV-negative. This is clearly a significant factor in the explosive HIV/AIDS epidemic that has been tormenting sub-Saharan Africa for more than two decades. While this is so, African strategic plans do not routinely include positive prevention as an approach to curbing new infections. Instead they rely solely on those strategies (important as they are) that aim to prevent the uninfected from contracting HIV, without working with those who are HIV-positive to change their sexual practices. Such an intervention, if done in a sensitive and caring manner, can help not only prevent infections in HIV-negative people, but also prevent those who are HIV-positive from acquiring sexually transmitted infections (STIs).

The final results of these studies will form the basis for developing prevention interventions that will be implemented and scaled up in sub-Saharan Africa. Governments, donors, researchers and multilateral agencies will be included as partners in supporting the implementation of these evidence-based interventions, once they are shown to be effective in reducing new HIV infections.

A critical aspect of HIV prevention is ensuring that African women are not excluded or overlooked by prevention and treatment programmes. The second satellite session focused on identifying groups of women who are deliberately excluded or inadvertently missed by those designing prevention and treatment programmes. Together with its partners at the Commonwealth Secretariat, the Atlantic Centre of Excellence for Women's Health at Dalhousie University and the HSRC, SAHARA presented a comprehensive paper which identified the following groups of women as missing from programmes: pregnant women, non-pregnant women, women who have sex with women (WSW; these include those women who do not consider themselves to be lesbian or bisexual), non-injection-drug-user HIV-positive women in some high-income countries, non-sex workers, sexual violence survivors, domestic workers and disabled women. The paper concludes by recommending that women be given access to reproductive health services, and that societies end harmful traditional practices, address causes of women's infidelity, implement gender-based budgeting, transform the nature of relationships between men and women to ensure they are empowering, end the HIV/AIDS stigma, make

available female-controlled technologies and introduce legislation to protect high-risk groups.

The presentation was followed by a meaningful discussion that included information on the human-rights framework and how that can be used to protect women. There were also discussions on challenges HIV-positive women experience, as well as those experienced by women involved in sex work. The discussion further illustrated the complexity of managing HIV/AIDS in a gender-sensitive context.

SAHARA's work has begun to reconceptualise the prevention approaches to HIV infection. An effort is currently under way among various partners of SAHARA to inform our understanding of socio-cultural practices that promote or inhibit the spread of HIV/AIDS in Africa. Much remains to be done in our societies to tackle the traditional practices that contribute toward Africa having a serious epidemic compared to other regions. Much of the work that has been done has simply used the approaches developed in industrialised countries, without considering the socio-cultural context within which behaviour change is expected to take place. Moreover, many of the HIV-prevention interventions implemented have not taken into account the diversity of the societies and consequent responses. It is timely and highly appropriate that Minister Skweyiya's presentation reminds us of the complexity of Africa.

The multi-country research presented by SAHARA researchers takes into account the observation that the magnitude, distribution and determinants of HIV/AIDS vary by region, country and locality within countries. This is further reason for adapting interventions to local conditions, while sharing experiences at a continental level.

Upon completion of the eight-country intervention studies on positive prevention, there will be a need to cost them for implementation as part of routine service delivery.

The effort to reduce new HIV infections and spread by 2015, the Millennium Development Goal, cannot be attained without using existing knowledge and generating new scientific evidence, as well as implementing effective monitoring and evaluation programmes. This is clearly recognised by policy-makers, as suggested by Minister Skweyiya, who argued that there is a need

to integrate HIV/AIDS planning and research into all development plans and programmes, including economic policies and programmes.

For such an approach to succeed, Professor Eric Buch, representing NEPAD, articulated the need to collate research findings, particularly those from multi-country research, and ensure they are made available to policy-makers on the African continent. NEPAD has also played a role in ensuring that SAHARA provides strategic input into continental plans developed for the African Union (AU), which serves the heads of state of all member nations. Other vehicles used to disseminate information include policy briefs, fact sheets and journal articles, as well as conferences and media releases. It will surely take multiple media channels to get the message to policy-makers, programme planners, advocates and the media to ensure that there is uptake of research. But more important will be the skills of researchers in packaging the information in a digestible manner for key stakeholders. This is a goal that SAHARA is working towards.

To halt the spread of HIV/AIDS, Africa will have to work in a coordinated manner. The continental development efforts that Professor Buch outlined at the satellite meeting must be translated into action by countries at the local level. The summits, declarations and strategic plans need to be backed by financial, human and physical infrastructure for implementation on the ground. The efforts of governments, non-governmental organisations, the donor community and multilateral funding agencies, as well as private funding agencies, are to be welcomed. What Africa needs to do is build its own capacity to manage these resources to the benefit of its populations.

The satellite sessions were well attended, and the discussions enriching. The presentations were informative, and hopefully they have contributed to a better understanding of the need to introduce new prevention approaches, to ensure that gaps in our programmes are identified and addressed, and to encourage all the partners in Africa to work together to make the difference Africa wants to see.

Postscript: It is reassuring that the South African National AIDS Strategic Plan, launched on World AIDS Day 2006, includes positive prevention as a strategy to prevent new infections. SAHARA and HSRC scientists have supported the development of these interventions and have provided technical support to help establish clear objectives and strategies for implementing them.

Dr Olive Shisana is the Chairperson of SAHARA.

Notes

1. Kleintjes, S., Peltzer, K.R., Shisana, O., Niang, C.I., Seager, J.R., Simbayi, L.C., & Kaseje, D.C. (2004). Report and policy brief: 2nd Annual Conference on Social Aspects of HIV/AIDS Research, Cape Town, 9–12 May 2004. *Journal of Social Aspects of HIV/AIDS* 1(2): 62–77.
2. Niang, C.I., Shisana, O., Andrews, G., Kaseje, D., Simbayi, L., Peltzer, K., & Toefy, Y. (2006). New approaches, new activities and new outcomes in international conferences on HIV/AIDS in Africa – Report of the 3rd African Conference on Social Aspects of HIV/AIDS, Dakar, 10–14 October 2005. *Journal of Social Aspects of HIV/AIDS* 3(2): 424–435.

SECTION A

CHAPTER 1

Putting research into policy and practice through partnership building, networking and information dissemination: The role of the SAHARA network

Dr Gail Andrews

Dr Gail Andrews discussed the importance of the SAHARA network in the context of putting research into policy and practice, especially in sub-Saharan Africa. She explored the theoretical principles that govern such a flexible yet complex network and examined the SAHARA network's vision and mission against this background. She identified the objectives of the network, highlighted its main achievements for the past year and looked at the challenges it faces in the immediate future.

She introduced the SAHARA network, elaborated on its theoretical framework and explained how it envisages operating within the African environment. In outlining SAHARA's vision and mission she mentioned the following key objectives:

- To facilitate an effective and dynamic network among researchers.
- To maintain an accessible website and a detailed and continuously updated database.
- To generate scientific material on the social aspects of HIV/AIDS and identify field-tested and documented 'best practices' for replication in the region.
- To produce a journal on the social aspects of HIV/AIDS.
- To host an annual conference on social aspects of HIV/AIDS research for the sub-Saharan region.
- To promote gender equality.

Key achievements over the last year in various areas are summarised below.

Capacity building

The research conducted by SAHARA draws on existing capacity within countries, usually located within academic institutions and implementation networks. Although the explicit aim of SAHARA research is to expand scientific knowledge, it also enhances the capacity of partners and organisations through their participation in the research process. This participation increases the group's ability to develop and conduct research, and to train individual staff members in areas of interview techniques, data entry, analysis and report writing. Students are also mentored.

Information system

SAHARA's information system continues to grow, and the capacity of the subregions has been enhanced. During this period, the SAHARA website was independently rated among the top 30 sites within South Africa. It provides multimedia platforms for effective information exchange and sharing. Information-networking agreements have been ongoing; these include the Integrated Regional Information Networks (IRIN), the Medical Research Council's SHARED-4-Africa Initiative, the SADC HIV and AIDS database and online portal project (SAHART) and DFID's AIDS portal project.

Journal of the Social Aspects of HIV/AIDS (SAHARA J)

SAHARA J is now abstracted in Sociological Abstracts, Social Science Abstracts and Worldwide Political Science Abstracts, and is indexed in IBSS. The journal's niche is currently being revised and a more policy-orientated publication in a magazine format is envisaged to attract advertising that would ultimately make the journal sustainable. *SAHARA J* prints 2 000 hard copies, distributed to the three SAHARA regions and to international libraries all over the world. *SAHARA J* distinguishes itself by being the only journal focusing on social aspects of HIV/AIDS, particularly in Africa. The journal has a mentoring programme for promoting young African researchers through African and regional writing workshops. All articles are accessible and available online in full text for free.

Annual conference

The Third Annual Conference on Social Aspects of HIV/AIDS was held in Dakar in October 2005, with more than 600 delegates attending on a daily basis. The next conference is scheduled for April 2007 and will be held in Kisumu, Kenya.

Strategic partnerships

The following strategic partnerships have been formed, each with a particular focus:

- Commonwealth: barriers to scaling up antiretroviral therapy (ART).
- Atlantic Centre of Excellence for Women's Health (ACEWH), Commonwealth Secretariat (COMSEC), Open Society Initiative for Southern Africa (OSISA) and UNAIDS: gender-based analysis and skills building.
- NEPAD: mainstreaming HIV/AIDS efforts into all sectors, strengthening national AIDS councils, and advocacy and lobbying for increased HIV/AIDS funding for Africa.
- Council for the Development of Social Science Research in Africa (CODESRIA): the HSRC and CODESRIA have signed a memorandum of understanding to collaborate on joint research projects and capacity-building initiatives. SAHARA will play a key role in the collaboration on HIV in the region.
- UNAIDS: monitoring and evaluation.
- Southern African Development Community (SADC): technical support for monitoring and evaluation.

Challenges

Dr Andrews concluded her presentation by pointing out the challenges that face the SAHARA network against a background of cultural differences and the need to forge good relationships among partners. Limited resources were cited as a key challenge, given the need for the investment of increased time and funding for development, planning and implementation.

Dr Gail Andrews is past Director of SAHARA and is now Chief Research Specialist in the Social Aspects of HIV/AIDS and Health Research Programme at the HSRC. She is based in Pretoria, South Africa, and can be contacted at gandrews@hsrc.ac.za.

CHAPTER 2

Overview and regional progress of current SAHARA projects in sub-Saharan Africa

Professor Leickness C. Simbayi, Professor Dan Kaseje and
Professor Cheikh I. Niang

Summary

To date, behavioural HIV risk-reduction interventions among people living with HIV/AIDS (PLWHA) who are aware of their HIV-positive status have not been extensively studied in sub-Saharan African populations. In most African countries, a substantial (but unknown) number of stable sexual relationships are thought to be between HIV-discordant partners. PLWHA are still highly stigmatised in many sectors of African society, making many people reluctant to be tested for HIV. Moreover, this stigma makes the disclosure of one's HIV-positive status difficult and potentially risky. Many PLWHA who are aware of their HIV status continue to hide it and engage in unsafe sexual practices. There is thus an urgent need to implement effective interventions among PLWHA for the purposes of secondary prevention in infected individuals and to prevent transmission of HIV from HIV-infected people to their uninfected sexual partners. Effective behavioural interventions targeting infected persons could reduce the spread of HIV and would complement behavioural interventions among uninfected people. Interventions for HIV-positive people would also assist in managing the adverse effects of stigmatisation associated with HIV seropositivity and AIDS, including hazards associated with disclosure of one's HIV-positive status.

This presentation provided an overview and brief report by the three regional SAHARA coordinators and principal investigators on the project currently being conducted in eight sub-Saharan African countries as an example of a multi-country and multi-site project and of how SAHARA functions. The main aim of the project is to develop or adapt interventions to reduce stigma and to prevent and control the spread of HIV infections among PLWHA who know their HIV-positive status.

Background

Although the project started in 2004 in four SADC countries (Botswana, Lesotho, South Africa and Swaziland), the four countries which were added to the project in 2005 (Kenya and Rwanda in East and Central Africa and Burkina Faso and Senegal in West Africa) have nearly caught up by building on experiences in the SADC region. In each country, formative or elicitation research has been undertaken, including some qualitative research and questionnaire-based surveys, and data analysis and report writing have commenced. The four southern African countries have gone one step further, in that they have culturally adapted the original support-group-based 'Healthy Relationships' intervention that promotes disclosure of HIV status and behavioural risk-reduction strategies among PLWHA. They have also undertaken train-the-trainer workshops in preparation for implementing pilot studies to test the efficacy of this intervention in their respective countries. In addition, they are scheduled to adapt a second intervention, which is clinician-based and known as 'Options for Health', by the end of the year.

The two interventions that were chosen as possible candidates for adaptation are the Healthy Relationships programme, based on social support groups and developed by Kalichman and his associates, and the clinically based Options for Health programme developed by Fisher and his associates. Both research teams are currently based at the University of Connecticut in the USA. These interventions are theoretically based, rigorously evaluated interventions that were developed and tested in the USA. The Healthy Relationships intervention, developed for use among HIV-positive men and women, is a multi-session, small-group, skills-building programme for men and women living with HIV/AIDS. The programme is designed to reduce participants' stress related to safer sexual behaviours and disclosure of their sero-status to family, friends and sexual partners. The programme is based on the social-cognitive theory of learning, which states that persons learn by observing other people successfully practise a new behaviour. This intervention has been found to be effective, and has been packaged and disseminated for community use as part of the Diffusion of Effective Behavioural Interventions (DEBI) initiative by the USA's Centers for Disease Control and Prevention (CDC). The Healthy Relationships intervention is now part of the CDC's Replication Project (REP) that is packaging and disseminating the intervention for community

use. It is now being implemented in several states throughout the USA and within state-wide demonstration projects for the new CDC initiative for HIV prevention.

The Options for Health intervention is aimed at assisting PLWHA to practise safer behaviours so they do not transmit HIV and other STIs to others or reinfect themselves with other, more virulent HIV strains. Options has been successfully implemented in the USA in an inner-city HIV clinical care setting by healthcare providers and is currently being tested in Durban, South Africa, using voluntary counselling and testing (VCT) counsellors. It involves a brief patient-centred protocol administered on an ongoing basis over the course of routine care, with the goal of decreasing HIV transmission risk behaviours among HIV-positive patients. The intervention is based on the information-motivation-behavioural (IMB) skills theoretical framework and employs motivational interviewing (MI) techniques as an intervention delivery system to convey critical HIV risk-reduction information, motivation and behavioural skills content. The original developers of the programme are also planning to undertake a large-scale randomised intervention trial in KwaZulu-Natal in South Africa during the next five years.

The four SADC countries are meant to test both types of interventions, while the other four countries will test the Healthy Relationships intervention only.

Aims and objectives of the overall project

The first aim is to adapt or develop and test the effectiveness of one or two types of behavioural risk-reduction intervention programmes for PLWHA who are aware of their status in eight sub-Saharan African countries. The second aim, which has been combined with the first one, is to examine HIV/AIDS-related stigma among PLWHA who are aware of their status and also adapt or develop and test the effectiveness of intervention programmes in promoting behavioural risk reduction.

Hypotheses

Overall, the following two hypotheses are being tested:

- The Healthy Relationships intervention will help reduce internalised stigma among PLWHA who are aware of their HIV-positive status, as well as promote disclosure of their sero-status to family, friends and sexual partners.
- Both the Healthy Relationships and the Options for Health interventions will reduce risky behaviour among PLWHA who are aware of their HIV-positive status.

Assumptions

Three main assumptions are made:

- There are moderately high levels of both internalised stigma and poor disclosure of sero-status to family, friends and sexual partners among PLWHA who are aware of their HIV-positive status.
- There is a high level of risky behaviour among PLWHA who are aware of their HIV-positive status, which puts both them and their sexual partners at risk of HIV superinfection and new infection respectively.
- PLWHA will be willing to participate in the behavioural intervention surveys.

Overall structure of the study

The overall project management team comprises an extensive inter-regional group that spans sub-Saharan Africa. In each country, the country principal investigators (PIs) or project directors (PDs) work together with a small group of researchers and support staff to implement the project. The intervention trial phase will involve recruitment and training of facilitators or counsellors who will implement the interventions in various settings on the ground.

The overall project management team is as follows:

1 Project sponsor: Dr Olive Shisana, Chairperson of SAHARA
2 Overall project PI: Dr Gail Andrews, former Director of SAHARA
3 Overall project scientific director: Dr Leickness Simbayi

4 SAHARA regional PIs:
   - Professor Leickness Simbayi, Coordinator of the SAHARA SADC subregion
   - Professor Dan Kaseje, Coordinator of SAHARA East and Central African subregion
   - Professor Cheikh Niang, Coordinator of SAHARA West African subregion
5 SADC country PIs or PDs:
   - Botswana: Dr Dolly Ntseane (University of Botswana)
   - Lesotho: Ms Mapokane Kosene (University of Lesotho)
   - South Africa: Professor Leickness Simbayi and Dr Anna Strebel (HSRC)
   - Swaziland: Ms Phumelele Mthembu (University of Swaziland)
6 East and Central Africa country PIs or PDs:
   - Kenya: Professor Dan Kaseje and Ms Masheti Wangoyi (Great Lakes University/Tropical Institute of Community Health and Development)
   - Rwanda: Dr Agnes Binagwaho and Dr Immaculee Mukatete (National AIDS Control Commission [CNLS])
7 West Africa country PIs or PDs:
   - Burkina Faso: Colonel Joseph Tiendrebeogo (CNLS)
   - Senegal: Professor Cheikh Niang (Université Cheikh Anta Diop)

Phases of the project

The project is organised in the following phases:

- Pre-phase 1 Project initialisation
- Phase 1A Formative (elicitation) research
- Phase 1B Baseline surveys
- Phase 2 Adaptation of interventions
- Phase 3 Implementation of interventions
- Phase 4 Formative (process) and summative (outcomes or impact) evaluation
- Phase 5 Integrated project final report

Progress in Central and East African countries

The stigma component

Analysis of the data from the formative phase of the Healthy Relationships study has been completed for Kisumu in Kenya. Currently, one of the Kenyan research team members is working with the team in Kigali, Rwanda, to analyse their data that will then be compiled with the Kenyan report.

A design of the complex decision-making model has been adapted from the Healthy Relationships tool based on the findings of the formative research phase.

A team of researchers met in December 2005 and developed an activity plan for the study on stigma, risk-behaviour reduction, and poverty. Currently the research activities of the subregion are on track and progressing well.

The Healthy Relationships intervention component

This has been adapted by researchers in this region, and was presented for critique and methodological rigour at a seminar in February 2006 attended by former SAHARA Director Dr Gail Andrews, Professor Seth Kalichman, Professor Leickness Simbayi and Professor John Seager. There was agreement among all researchers present that the East and Central African team has succeeded in developing an excellent adaptation of the Healthy Relationships model, which includes setting up of support groups firstly among women participating in the prevention of mother-to-child transmission (PMTCT) programme. This is believed to be a more appropriate model for the East and Central African context given the paucity of support groups. Furthermore, the sensitivity associated with the introduction of condom use into long-term relationships between heterosexual couples is a major challenge that will be faced during the implementation phase of the project.

Progress in SADC countries

The Healthy Relationships intervention component

Over the past two years each of the four SADC countries has completed formative (elicitation) research involving the use of key informant interviews, focus groups and questionnaire-based surveys on various issues affecting PLWHA such as health status, stigma and discrimination experiences, social support and risky behaviours.

By the time of this conference, South Africa had completed writing up two reports, one qualitative and the other quantitative, which are summarised later. Some of the research findings from South Africa have been submitted for publication in peer-reviewed journals, and have also been presented at the 2006 International AIDS Conference in Toronto in one poster discussion and four other poster exhibitions as summarised briefly below.

The adaptation of the original Healthy Relationships intervention had also already taken place in a joint workshop attended by Professor Kalichman, who developed the original version of the intervention. The SADC countries have also conducted a joint train-the-trainer workshop on the adapted Healthy Relationships intervention; the workshop was attended by two researchers and two facilitators from all four participating countries.

The Options for Health intervention component

Because of problems experienced with getting assistance from Professor Fisher's team (which developed the Options intervention) at the time, it had been decided instead to adapt Healthy Relationships into a one-on-one counselling intervention with the assistance of Professor Kalichman and his US-based team, based on their own work on antiretroviral treatment adherence among PLWHA in Atlanta, USA. Work on this was in progress and the new version of the intervention was expected to be available for piloting by the end of the year. (Soon after the Toronto meeting, and in part due to discussions held there immediately after the satellite meeting with Professor Fisher and his associate Dr Deborah Cornman, it was decided to resort back to testing Options in SADC as the second PLWHA behavioural risk-reduction intervention as it had been tested previously both in the USA and in South

Africa. The adaptation was done during a workshop held in December 2006.)

Progress in West African countries

The stigma component

A literature review was undertaken to understand what had been done for Senegal, Burkina Faso and West Africa in general.

Workshops have been organised with partners (PLWHA, civil society, private sector, international organisations, UN agencies, CNLS, government, researchers and the SAHARA Network for West Africa) to give feedback and to elicit inputs into the research process.

Site visits and identification of the study populations have been completed. The study population includes individuals from PLWHA, affected families and children, AIDS NGOs, community leaders and decision-makers, and marginalised groups (commercial sex workers and MSM). In all the study sites, unstructured interviews have been completed with key informants from the study populations. Data-collection instruments (interview guides for individual and focus groups) have been designed and pre-tested, and investigators in Senegal have been recruited and trained. Fieldwork for data collection has been started and preliminary analysis of results has commenced. The progress with research in this subregion has been slower than in the other subregions because of the huge effort that was required by network members and staff to ensure the successful coordination of the second SAHARA AIDS conference, which was held in 2005.

The Healthy Relationships intervention component

The literature review for this study has been completed and workshops have been organised with partners (PLWHA, civil society, private sector, international organisations, UN agencies, CNLS, government, researchers and the SAHARA Network for West Africa). Site visits and identification of the study populations have been completed, as have unstructured interviews with informants from the study populations. Data elicited through the use of

interview guides was collected and analysed and the results were shared with partners. The adapted intervention is about to be implemented, after which the preliminary analysis of the data will be done.

Findings to date: South Africa

This section provides a sample of some key findings taken from the formative research that was undertaken in South Africa in order to illustrate some of the contextual issues that have informed the research process that has been followed by South Africa and other SADC countries.

Qualitative research

Description of participants: Eight PLWHA focus-group discussions were held with a total of 83 participants, as well as 14 key informant interviews with various stakeholders, including managers and representatives of AIDS NGOs.

Experiences of AIDS-related stigma, disclosure and other daily life stressors of people who are aware that they are living with HIV/AIDS

Main findings: AIDS-related stigma is still pervasive in many communities, and for PLWHA it is closely linked to the difficulty of or the resistance to disclosure of their status for fear of being rejected by family members, friends or partners. Another major finding is that many PLWHA consider their HIV status as secondary to their daily life stressors such as poverty, unemployment and gender-based violence.

Disclosure and access to social capital among PLWHA

Main findings: While stigma and gender inequalities remain problematic in communities, increased levels of disclosure by PLWHA brought wider access to bridging and bonding capital such as antiretroviral treatment, emotional and peer support from a support group, and financial support (disability grant) or nutritional support (food parcels) from government. In addition, those disclosing their status in public settings sometimes received monetary

reward, and joining networks/associations of PLWHA had further social capital benefits.

Quantitative research

Overall sample size and gender breakdown: The study was conducted among 1 054 PLWHA: 413 men and 641 women.

HIV-status disclosure to sex partners and sexual risk behaviours among HIV-positive men and women in Cape Town, South Africa

Main findings: HIV-related stigma and discrimination were found to be associated with not disclosing HIV status to sex partners, and nondisclosure was closely associated with HIV transmission risk behaviours.

Internalised AIDS stigma, AIDS discrimination and depression among men and women living with HIV/AIDS, Cape Town, South Africa

Main findings: It was found that a large minority of PLWHA had experienced discrimination resulting from having HIV infection, and one in five had lost a place to stay or a job because of their HIV status. The majority of the PLWHA also reported high levels of internalised stigma and this was closely associated with signs of depression, accounting for a unique and significant proportion of the variance in depression scores.

Stigma and discrimination experiences of HIV-positive MSM and heterosexual men

Main findings: In general, internalised stigma was high among all male PLWHA in the study (92 HIV-positive MSM and 330 HIV-positive men who did not report sexual experiences with men and hence are referred to as non-MSM), and there were no differences between MSM and non-MSM for feelings of internalised stigma. In contrast, HIV-positive MSM did report experiencing significantly greater social isolation and discrimination resulting from being HIV-positive, including loss of housing or employment. MSM were also found to be more depressed than their non-MSM counterparts.

Findings to date: West Africa

Qualitative research

Vulnerability: Social risk versus medical risk

Main findings: Condom use was found to be very low in the population groups of MSM, pregnant women and heterosexual men. Commercial sex workers reported low condom use specifically with their regular partners. Women reported difficulty in negotiating condom use because they were financially dependent on their partners, or they risked losing their partner to other women if they insisted on using a condom.

Fear of disclosure

Main findings: Respondents often missed their appointments to collect their medicine at the clinic due to the fear of disclosing their status. At the clinic they would hide their pills and prescriptions and refuse food supplements, as this was an indication of being HIV-positive.

Vulnerability and social construction of pregnancy, delivery and breastfeeding

Main findings: Access to PMTCT was challenging because just announcing being pregnant, especially before five months, was seen as being very irresponsible. Pregnancy is generally managed beyond the privacy of the individual or the couple, so that the broader family and community are also involved. Women experienced the delivery process as a personal challenge and clinics were reported to be hostile, with no respect for the patient's privacy.

Environmental/structural factors

Main findings: Women reported that they experienced having to wait long hours at the health facilities and at times they were not being attended to. They also had to wait for their partner to provide them with the necessary finances before they could go for their antenatal visits. In addition, they were dependent on the availability of one of their family members to accompany them to the clinic.

Stigma, rejection and vulnerability

Main findings: Stigma was still rife, leading HIV-positive people to a path of self-destruction with thoughts of rather being dead than alive. PLWHA reported that people in the community did not want to socialise with them or be seen with them. Even staff at the health facilities stigmatised them through their body language.

Social support status

Main findings: Respondents indicated that there were specific people in their life that they were able to trust and felt safe disclosing their status to, such as their mother or a very close friend.

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CHAPTER 3

Unfolding continental developments in the fight against HIV/AIDS in Africa

Professor Eric Buch

Professor Eric Buch discussed the unfolding continental developments in the fight against HIV and AIDS, and the importance of tackling the disease from a continental and macro perspective. During his presentation he explored questions around the niche of the continental initiative, who the players are, what has been done in the past and what the common continental themes are. He looked at ways to improve the effectiveness and impact of macro initiatives, such as harmonising African efforts at a country and regional level, building collaboration between the main stakeholders and developing clearer monitoring mechanisms, including those for civil society. He also questioned whether stakeholders are leveraging opportunities and encouraging research to support the continental role.

He pointed out that the niche of the continental level was to harmonise all elements of the fight against HIV/AIDS, achieve economies of scale, build collaboration and share learning across the continent. He also highlighted the importance of peer accountability and of ensuring that through this harmonisation the continent develops a strong voice that will speak for Africa. Operating at a continental level requires joint efforts from the following key stakeholders: heads of state, the African Union Commission, NEPAD, UN agencies, civil society, the private sector and donors through to regional economic communities, which will provide a synergistic effect in the fight against HIV/AIDS. This collaboration will harmonise all elements and provide a strong continental voice that will facilitate and mobilise efforts on a much larger scale than ever before.

Continental developments over the last five years include:

- Abuja Declaration 2001 and plan of action;
- Maputo Decision 2005;
- Gabarone Declaration 2005;

- AU Summit 2005;
- Brazzaville Commitment 2006;
- Abuja Special Summit 2006 (2010);
- Africa common position (2008 review);
- AU Commission Strategic Plan; and
- Conference of Health Ministers (Maputo 2006).

As part of continental efforts, AIDS Watch Africa was launched in 2001 by eight heads of state to ensure advocacy and monitoring and the development of a strategic plan. The AU and NEPAD developed a joint health strategy. The NEPAD Secretariat initiated a mainstreaming effort to tackle HIV/AIDS within all sectors, and several African partnership forums were held.

In relation to improving effectiveness and impact, Professor Buch asserted that it is important to collate the common themes existing in Africa, harmonise the African effort and build collaboration throughout the continent. There should be better follow-through and communication, and there is a need to develop clearer monitoring mechanisms, including that for civil society. Institutions like the Regional Economic Community (REC), AU and NEPAD should also assist in providing capacity support where it is required, and the role of the Bureau of Health Ministers needs to be grown to ensure this.

He pointed out that the common continental themes in the fight against HIV/AIDS revolve around access to prevention and antiretroviral treatment, which highlights the need for the availability of affordable medicines, effective health systems and adequate human resources. This would require a gender and human rights framework, political leadership with local and foreign resource mobilisation, and strong monitoring and evaluation efforts.

In considering whether various stakeholders are leveraging opportunities, he pointed out the need to look at how committed countries are to continental frames and how well coordinated they are. He then posed the following questions: Are we sufficiently utilising our positions in a global context? Does civil society know the opportunities open to it and is it utilising them? Do we link advocacy and monitoring to these opportunities, and how well are we monitoring them?

Professor Buch looked at whether research adequately supports the role of the continent in its effort to deal with HIV/AIDS in Africa. He raised the question of whether evidence from research undertaken is translated into advocacy and

policy decisions. Research needs to be collated and made accessible, especially multi-country research that can be utilised by the continent. There is a need to develop continent-wide responses to national AIDS councils, funding (in particular the Global Fund for HIV/AIDS, TB and Malaria), human resources, leadership, mainstreaming and adherence to antiretroviral treatment.

He mentioned that the NEPAD health strategy has advocated from its inception for the use of antiretrovirals, as this is a critical component to offset the huge impact the disease is having on families, communities, societies and economies. Recent developments have made a wider use of antiretrovirals more feasible. However, there is still a gap between the emerging policy shift towards such provision and the effective operationalisation of this decision. Although there are many impediments to effective expansion in Africa that need to be addressed, the continent cannot develop if more than two million people a year continue to die of AIDS, and there is also a very human imperative to care – all of which points to the importance of greater harmonisation of efforts in Africa.

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CHAPTER 4

Keynote address: The complexity of the HIV/AIDS epidemic in Africa and the need for creative responses

Dr Zola Skweyiya

We recognise the global significance of the HIV and AIDS epidemic.[1] We cannot but recall and salute the contributions of all the heroes and heroines in our midst and millions across the world who continue to be in the forefront of this war against HIV and AIDS. In recognising these efforts, I am reminded of the timely words of President Thabo Mbeki and Prime Minister Blair, who in 2001, in a joint communiqué titled 'Dare to hope for Africa's children', wrote: 'Never in history have Africans faced a more critical choice. Never in the history of a continent has the world been more challenged to take a stand.'

Indeed, humanity cannot continue to be indifferent to the fact that the impact of HIV and AIDS has been felt by more than 15 million children globally. I must also hasten to note that of those children over 12 million reside in the sub-Saharan region. It is also significant to note that even though sub-Saharan Africa constitutes slightly more than 10 per cent of the world's population, it is home to more than 67 per cent of people living with HIV and AIDS globally. Despite these shocking statistics, we in Africa remain optimistic and are determined to ensure that we extricate Africa from this malice ourselves. We therefore see this XVI International AIDS Conference as yet another opportunity to assess global progress, identify future challenges and work out collective mechanisms to bring to a halt the devastating impact of HIV and AIDS.

In assessing global progress and Africa's progress in particular, it is important to note that the epidemic is not spreading at the same rate in all African countries. It is more prevalent in southern Africa, decreasing in East Africa and remaining stable in West Africa. But even this categorisation is too simplistic. A closer examination of the situation in southern Africa reveals that Angola continues to have very low HIV and AIDS prevalence, and yet its neighbour

Botswana has the highest rates. Similarly, Zimbabwe is experiencing a decline in HIV prevalence, while South Africa is starting to experience stabilisations in the rates of infection. In East Africa, Kenya continues to show declines in HIV prevalence, while Uganda has remained stable and Ethiopia shows signs of levelling off. West Africa is also not homogenous, decreasing in Burkina Faso but increasing in Ghana.

This clearly shows regional disparity in the magnitude of the epidemic, and probably reflects the requirement for different responses to the epidemic, thus giving evidence to the complexity of the epidemic. These complexities include the disproportionately higher infection rates in urban and informal settlements, which have been fuelled by poverty and migration. No doubt the latter is occasioned by the continuous and vicious cycle of no work opportunities and limited choices in rural Africa, which ultimately leads to large-scale poverty and social exclusion.

Thus in assessing this progress we must ask the hard questions related to the integration of HIV and AIDS planning and research in all our development plans and programmes, including our economic policies and programmes.

We must also recognise that in the African context, the face of HIV and AIDS as well as poverty is that of a woman carrying a child on her back. Therefore, any meaningful attempt to address this epidemic in our region must address issues related to patriarchy. This can be achieved through, among others things, gender-sensitive approaches which must ultimately change power dynamics and structural arrangements between males and females. We need to ensure that we root out all elements in our cultures which make women subservient to men. We must also interrogate the patriarchal nature of our societies, and promote true equality between men and women. This will ensure that women and men discuss sexuality and HIV prevention without fear of violence and discrimination. The starting point of such an exercise is to raise boys who respect the rights of girls. Consequently we must do all that is possible to ensure that both boy and girl children enjoy equal access to quality education and other basic human rights.

In an attempt to assess our own national progress, we recently hosted a conference on orphans and other children made vulnerable by HIV and AIDS and other social ills, during which time we brought together policy-makers, politicians, donor organisations, development agencies, civil society

organisations and some members from SADC. We deliberated and agreed on possible ways of improving the socio-economic conditions of orphans and other children made vulnerable by HIV and AIDS. During the conference it became abundantly clear that

- psychosocial support for affected individuals and households is paramount to all our solutions;
- effective partnerships among stakeholders is a prerequisite for any successful strategy;
- socio-economic needs ought to be addressed as an intricate part of our solutions; and
- we must develop responsive policies and programmes that address immediate needs of affected and vulnerable individuals and families.

We therefore see our participation in this conference as an opportunity to put some of the issues that I have just alluded to at the forefront of the global agenda. The struggle against the HIV and AIDS pandemic can only be successfully won through solidarity and joint action. In this context we must therefore build durable partnerships between governments, communities, development agencies, civil society organisations and the business sector.

Unfortunately, the sad reality is that HIV and AIDS continue to cause untold miseries to the very institution that we all value – the family. The family is the basic and most critical unit of society, as it is the foundation upon which communities and nations are built. We therefore need to do all we can as governments and other stakeholders to provide support to families, especially in the light of the challenges we face. The social impact of the HIV and AIDS epidemic results in family, community and social disintegration. This is evidenced by the increase in the number of orphans, child-headed households and vulnerable children affected by HIV and AIDS. This negative impact is further complicated by the inability of the extended family system to provide such children with basic requirements such as shelter, food, medical care, education, love and support. In strengthening the family we must also ensure that we deepen all our awareness campaigns and accelerate implementation of our ABC messaging which must be complemented by prevention, treatment, care and support programmes.

Our initial aim must be to maintain those who are HIV-negative to remain negative and to care for those who are affected and infected in a compassionate manner. Our ultimate aim should be to rid society of this

pandemic; therefore, the attention we pay to young people will be critical in defining all our approaches. We have noted and remain determined to address the alarming trend that in our country shows that women tend to be infected early in their youth, with infection rates peaking around the ages of 25 to 29 years. We have also noted the linkages between the likelihood of increased vulnerability to the virus and the utilisation of mind-altering substances such as alcohol and drugs.

In noting these and other trends, our message is clear: Away with one-size-fits-all solutions. We require tailor-made solutions that should be directed by Africans themselves, and supported by all our partners including international organisations such as the United Nations.

The outcomes of this international conference are critical for millions of our people and we therefore approach this conference with conviction, determination and hope. We hope that the deliberations and outcomes will enrich the individual and collective efforts of our respective countries and governments and further the achievement of the social development agenda. We also hope to build partnerships that will enable us to respond effectively to people and communities affected by HIV and AIDS.

I wish once again to applaud the organisers of this satellite session and each and every one of you who joined in this global coordinated effort to fight the HIV and AIDS epidemic. The outcomes of this session will hopefully equip us with the knowledge and expertise to reverse and turn the tide against HIV and AIDS in our subregion and region.

It was Kofi Annan who, on the occasion of the Special UN General Assembly on HIV and AIDS, reminded us that 'in the war against HIV and AIDS there is no us and them . . . only a common enemy that knows no frontiers and threatens all peoples'. Indeed, at the height of the struggle against apartheid, we were also confronted by a common enemy and we dared to hope that South Africa could achieve liberation. Having achieved that objective, we must again dare to hope that Africa can seize the opportunity to build a new future of prosperity and renewal. And so we dare to hope for Africa's children, and pledge our unwavering support to turn these hopes into reality, through the adoption and implementation of measurable, pragmatic and timely interventions.

Dr Zola Skweyiya is the Minister of Social Development in South Africa.

Note

1. Dr Skweyiya's speech is reproduced verbatim.

CHAPTER 5

Summary

This session provided SAHARA with the opportunity of reporting on the research it is currently undertaking in Africa. The presentations clearly highlighted the need for an African network like SAHARA to generate scientific evidence and ensure its dissemination. It confirmed the need for all stakeholders in Africa to collaborate, work jointly and harmonise efforts to ensure that the continent deals adequately with managing the complexities of HIV/AIDS. It is evident that Africa needs to speak with one voice, and that there is a need for evidence-based research that can inform decisions and policies. Africans need to share their experiences and expertise collaboratively across Africa, so that they can tackle jointly the challenges of the HIV/AIDS epidemic.

SECTION B

Preamble: 'Missing the women'

Experiences in HIV/AIDS research, programming and policy indicate that globally women are often overlooked or excluded. At the same time, there is recognition that increasingly HIV/AIDS has a woman's face. Women and girls are disproportionately affected by HIV/AIDS for a variety of reasons:

- Physiological differences;
- Lower socio-economic status;
- Systemic gender discrimination;
- Cultural taboos;
- Ethnic, racial and familial discrimination; and
- Lack of political will and government action to address gender-based discrimination.

It is therefore imperative that we explore why we continue to 'miss the women' in research, policy and programmes, and seek ways to ensure that women's voices do not go unheard.

For this reason the HSRC and SAHARA, together with its partners the Atlantic Centre of Excellence for Women's Health, the Commonwealth Secretariat, Dalhousie University and OSISA, arranged a satellite session with a main presentation and four discussants to elaborate on the main threads highlighted in the presentations at the XVI International AIDS Conference.

The main presentation was given by Dr Olive Shisana, who spoke about the reasons for 'missing the women' in the HIV/AIDS pandemic. The four discussants were:

- Sisonke Msimang, who discussed reasons why policy does not reflect the evidence regarding women and HIV/AIDS.
- Joanne Csete, who focused on the erosion of women's rights in recent years and on the need to work within a rights-based framework to create gender-sensitive policy.
- Meena Seshu, who presented the needs and experiences of marginalised women and the challenges they face with regard to research and policy responses.
- Jennifer Gatsi Mallet, who spoke about the issues facing HIV-positive women and girls who live with the daily realities of stigma, discrimination and a lack of enabling policies.

CHAPTER 1

'Missing the women': Exploring key challenges in policy responses to HIV/AIDS

Dr Olive Shisana and Julia Louw

Introduction

Experiences in HIV/AIDS research, programming and policy indicate that globally we are 'missing the women'. At the 2002 International AIDS Conference in Barcelona, a mere 9.6 per cent of research presentations focused on women or the gender dimensions of the pandemic. In 2004, no substantial improvement was noted at the World AIDS Conference in Bangkok, with only 8.3 per cent of total presentations addressing gender issues despite the increased awareness of the growing impact of HIV/AIDS on women and girls. The HSRC and SAHARA, together with its partners the Atlantic Centre of Excellence for Women's Health, the Commonwealth Secretariat and OSISA, realised it was imperative to explore further why women are consistently 'missing' in HIV/AIDS research, policy and programmes, and to seek ways to ensure that women's voices do not go unheard but are included to inform the way ahead in the fight against HIV/AIDS. The paper begins by stating that women are still not the major subject of international AIDS conferences, despite their being the most affected by HIV/AIDS. The paper provides insight into the magnitude and impact of HIV/AIDS on women, specifically noting that the disease is growing faster among women than among men.

Overview of the paper

Using the literature published in health, medicine and the social sciences as well as global information published by UNAIDS, the paper identifies specific groups of women who are frequently missed in prevention, treatment and care activities, as well as in research. While women overall have been the focus of prevention, treatment and care, specific groups of women have been excluded and hence marginalised. These are pregnant women in low- and middle-

income countries, non-pregnant women living in some countries where the dominant mode of HIV transmission is not heterosexual, HIV-positive WSW (including those who do not identify themselves as lesbian or bisexual), non-injection-drug-user HIV-positive women in some high-income countries, non-sex workers, sexual violence survivors, domestic workers and disabled women. The paper identifies critical evidenced-based interventions aiming to control the epidemic, and explores how this evidence has been applied at country level. A conceptual framework guiding the understanding of the relationship between gender and HIV/AIDS is presented. Sufficient evidence exists on how to prevent HIV infection and treat those living with the disease, but too few women are accessing the services. Recommendations are made on how best to develop policies and programmes that meet the needs of women.

Objectives

The five main objectives were as follows:

- To consider what evidence has been produced that addresses women and girls in the HIV/AIDS pandemic, and which women's voices are privileged in this evidence.
- To explore what has been done with available evidence on women, gender and HIV/AIDS, and which research questions and research participants have been ignored or overlooked.
- To understand the micro and macro dynamics that prevent researchers, programmers and policy-makers from paying attention to the voices of diverse groups of women and girls.
- To examine the barriers to translating evidence about the realities of women's lives and experiences into effective and appropriate policies and programmes.
- To develop recommendations about how best to undertake policy and programme development and implementation to meet the needs of women and girls infected and affected by HIV/AIDS.

Impact of HIV/AIDS on women

When the epidemic began, it had the face of men, mainly gay men. Concerned about the lack of prevention efforts, white gay men in San Francisco and New York City as early as 1982 mounted programmes designed to increase awareness of AIDS and to provide basic information about the disease and risk-reduction strategies (CDC 2006a). They later advocated for development of treatment options and, when these became available, they became beneficiaries of new ART drugs even before they were widely available. It is no surprise that male-to-male sexual transmission in the USA constituted 40.1 per cent of all AIDS cases between 2001 and 2004, down from 51.1 per cent between 1981 and 1995 (CDC 2006b). Men empowered with resources and knowledge managed to advocate for action to contain the spread of HIV and to fast-track the development of drugs to treat AIDS. The story of powerless women is different.

The epidemic is spreading at a faster rate among women than among men. Globally by 2005, 50.8 per cent or 17.3 million of 34 million adults living with HIV/AIDS were women. This is up from 43.0 per cent in 1998. In sub-Saharan Africa, where the majority of adults living with HIV/AIDS are found, 61.1 per cent of them are women, with female youth overall having a prevalence of two to six times that of male youth. The impact of AIDS on women has already changed life-expectancy patterns in some countries, such as Kenya, Malawi, Zambia and Zimbabwe, where the life expectancy of women is now below that of men (UN Population Division 2006).

The epidemic affects women not only in terms of morbidity and mortality, but also with respect to fertility. Women who are HIV-positive have reduced fertility rates, a reduction of between 25 and 40 per cent (UNAIDS 2006). Women living with HIV/AIDS are often subjected to stigma and are made to feel ashamed of being infected; consequently they feel personally responsible for their HIV status, even in cases where they were infected by the only man with whom they had sex.

Impact on minority populations

Minority women populations in high-income countries have growing HIV/AIDS epidemics. For example, non-Hispanic blacks and Hispanics in the USA, and indigenous populations in Canada, are experiencing increased AIDS prevalence, despite the availability of effective prevention techniques and treatment regimens. Non-Hispanic blacks and Hispanics now account for 51 per cent and 20 per cent respectively of all AIDS cases in the USA (CDC 2006b). In Canada aboriginal women are over-represented in HIV/AIDS statistics (cited in Commonwealth Secretariat 2002).

Common to these minority populations is a high prevalence of poverty, racism and sexism, and a lack of power to advocate for policies that would benefit them. All these factors create fertile ground for the development of social problems such as risky sexual behaviour, alcohol abuse, substance abuse and violence against women.

Impact of HIV/AIDS on sex workers

UNAIDS estimates that there are tens of millions of sex workers and hundreds of millions of clients. The majority of sex workers are young and female, and clients are mostly male. The prevalence of HIV among sex workers has been found to be as high as 73 per cent in Ethiopia, 50 per cent in Ghana, and 68 per cent in Zambia (UNAIDS 2006). Women sex workers are marginalised by political, legal and social exclusion, which leads to problems in reaching them through programmes aimed at changing sexual and other behaviours (Cohen 2000). There is a dominant moral disdain that leads to criminalisation of activities related to women's role in prostitution (Davidson 1998). Consequently, these women are less likely than men to seek help and protection from the law, thus becoming vulnerable to rape and other risky sexual behaviour that is forced on them by their clients.

Sex workers are arrested for soliciting and must constantly be on guard against police arrest, especially if they are street prostitutes (Commonwealth Secretariat 2002). An association of sex workers in Brazil, NEP, reported that HIV/AIDS was not always high on its list of priorities; the group focused instead on persecution by the police (Hinchberger 2005). Further, the illicit

status of sex work stigmatises and penalises, thus leaving control of sex work in the hands of criminals (Cusick 2005). In a study conducted in Zambia, sex workers were vilified and labelled as the 'suppliers of AIDS' (Bond et al. 2002), which leads to ostracism.

HIV/AIDS among drug users

Women drug users are exposed to three major risks: use of unsterile needles; unprotected sex; and the use of mind-altering substances, which affect decision-making and increase sexual risk-taking. To support their drug use, women may exchange sex for drugs. In Vancouver, Canada, Spittal et al. (2002) found the incidence of HIV to be 40 per cent higher for female than male injection drug users (IDUs). The differences were attributable to unequal power relations, with women reported to have had more non-consensual sex compared to their male counterparts. Research in China shows that women who use drugs tend to have more sexual partners and also engage in more sexual acts compared to women who do not use drugs (Logan & Leukefeld 2000).

Leggett (2001) found that client volumes of sex workers were tied to drug use. He found that 43 per cent of sex workers who had more than 20 clients a week had a drug habit, as opposed to 16 per cent who had less than 10 clients per week. Interestingly, he found an inverse relationship between drug use and HIV among sex workers, a result confounded by race. White sex workers were less likely to be HIV-positive despite the observation that they had more sex clients and used drugs for longer periods. In contrast, black sex workers who had fewer clients and seldom used drugs had a higher HIV prevalence. This is an interesting finding that needs to be researched further; it may suggest that white prostitutes are more likely than black prostitutes to practise safe sex in this high-risk occupation.

From the information presented it is obvious that women are more affected by the epidemic than their male counterparts. The impact is large whether they are part of the majority population in low- and middle-income countries or part of the minority population in high-income countries. They become infected when having sex with their partners, some with their clients, and still others through a combination of sex work and drug use.

Gender and HIV/AIDS conceptual framework

There are conceptual models such as masculinity (Gilmore 1990) and script theories (Simon & Gagnon 1984) that are used to understand the relationship between HIV/AIDS and gender. Gupta's theory (2000) is selected for use here because it helps planners to go beyond the analysis of the relationship between gender and HIV/AIDS and frame the development of gender-sensitive interventions and policies in prevention, treatment and care.

Gupta's seminal paper on gender, sexuality and HIV/AIDS (2000) provides a framework for developing interventions that effectively address the gender and HIV/AIDS intersection. Gupta argues that gender-neutral approaches, while they do no harm, are less effective because they do not address the gender-specific needs of individuals. It appears that although there is a dearth of empirical studies comparing the efficacy of gender-neutral versus gender-sensitive interventions in HIV prevention (Exner et al. 2003), preference is generally for gender-sensitive approaches, which meet the needs of both men and women. Female-controlled barrier methods such as microbicide gels and female condoms are good examples of gender-sensitive approaches. However, these technologically-based interventions are still either in the development stage (microbicide) or are unaffordable (female condoms). Some of these interventions can do more harm than good, as with Nonoxynol-9 (WHO 2006) and more recently cellulose sulfate, which inadvertently led women to acquire HIV infections when they were supposed to prevent them. Behavioural intervention using a gender-sensitive approach, such as that conducted by Kelley et al. (1994), demonstrated that an intervention that gave women sexual negotiation skills, allowing them to discuss concerns about HIV, resist sexual coercion and manage behaviours that make women vulnerable to engaging in unsafe sex, was more effective than a health-education intervention focusing on nutrition.

Gupta's model also contains approaches that aim to transform the nature of sexual relationships between men and women. These approaches target men, with a view to helping them change their behaviour towards women and encouraging them to develop relationships that promote respect and equality (Gupta 2000). Since the latter half of the 1990s, there have been new randomised controlled trials assessing the efficacy of gender-sensitive interventions using transformative approaches. An example is an intervention

which went beyond the male condom and gave women skills to refuse or not engage in unsafe sex, to have non-penetrative sex and to seek mutual HIV testing (Ehrhardt et al. 2002).

Gupta's last gender-sensitive approach is that of empowerment of women. This approach focuses on increasing access to information, skills, services and technology, and also on decision-making. One example, reported by Gordon et al. (2005), is a randomised controlled trial conducted among African-American women living with HIV who participated in an intervention called Women Involved in Life-long Learning from Other Women (WILLOW), based on a social-cognitive theory of gender and power. Specifically, the intervention focused on 'gender pride, maintaining current and developing new social network members, HIV transmission risk knowledge, communication and condom use skills, and the benefits of having supportive social network members, including sexual partners' (Gordon et al. 2005: 11). The comparison group consisted of a group of women receiving an HIV treatment adherence and nutrition intervention. The study found that over a year, women who were in the WILLOW intervention had a lower incidence of bacterial infections and had modified behaviour.

Although there are many other theories not discussed here, Gupta's model helps in understanding how relationships between men and women put women at risk for HIV and how this understanding can be used to develop gender-sensitive interventions. In the next section, we examine whether opportunities have been lost to include women in research or service delivery.

Missing the women

Despite the evidence showing that women constitute the majority of people living with HIV/AIDS, they are in general often missed in research, prevention and treatment programmes; however, there are specific groups that are more affected than others. These are pregnant women, non-pregnant women living in some countries where the dominant mode of HIV transmission is not heterosexual, HIV-positive WSW (including those who do not identify themselves as lesbian or bisexual), non-IDU HIV-positive women in some high-income countries, non-sex workers, sexual violence survivors and domestic workers. Evidence exists to suggest that these women have been

either deliberately or inadvertently excluded from research, prevention or treatment actions.

Heterosexual women living in countries where the dominant mode of transmission is not heterosexual

In the USA, for many years those who classified AIDS cases inadvertently increased the focus on some groups to the exclusion of others. Pregnant women who could transmit HIV vertically and drug users were at the top of the list, while heterosexual women were always at the bottom of the list. This led to an underestimation of the HIV epidemic in the heterosexual population. Gollub argues that the 'lack of immediate sustained attention to heterosexual transmission in the USA's early epidemic's years had a dire consequence for women' (1999: 1479). It was no surprise that the incidence of AIDS among women in the USA increased by 1 per cent and AIDS mortality declined by 12 per cent at the time when AIDS morbidity among men decreased by 8 per cent and AIDS mortality by 26 per cent (Gollub 1999). These figures suggest that fewer women than men had access to prevention, treatment and care services.

Until 1993, women who lived with HIV/AIDS were excluded from official CDC statistics in the USA, mainly because they presented with invasive cervical cancer and recurrent vaginal yeast infection. It was only after activists put pressure on the CDC, and with the availability of data, that the CDC decided to host a consultation meeting, which led to an expansion of the definition of AIDS-defining diseases. Suddenly more women were counted as having HIV/AIDS. The consequence of their exclusion meant that there was a delay in women being diagnosed and treated (Exner et al. 2003).

Heterosexual women in the East are also likely to be missed. Women who are not pregnant are less likely to know their HIV status and hence are likely to delay getting treatment. In Bangkok's two largest maternity hospitals, Teerarartkul et al. (2005) found that only 13 per cent of seropositive women were diagnosed before they became pregnant. The overwhelming majority (73 per cent) were diagnosed for the first time when they were pregnant. This clearly suggests that non-pregnant women, who constitute the majority of women, are seldom tested for HIV. Since most women undergo HIV testing during pregnancy, mainly to protect their babies, they are the ones who are

likely to get access to VCT, which may lead to treatment. All other segments of the female population, including older women, are less likely to get access to these services, suggesting that they are likely to remain undiagnosed, perhaps until it is too late.

Women are often missing in research even where the opportunity to study them exists. A good example is the Therapeutics Research Education and AIDS Training in Asia (TREAT Asia) HIV Observational Database, which was set up to assess the natural history of treated and untreated patients in the Asia-Pacific region (Zhou et al. 2005). The researchers recruited nearly 1 800 patients, of whom 72 per cent were male and 78 per cent contracted HIV heterosexually. The absence of women in this sample is disturbing, especially considering that those who received ART had a 69 per cent undetected viral load in six months. Since the men acquired HIV heterosexually, the opportunity to include women existed, but was lost.

In high-income countries, heterosexual women who are not IDUs, sex workers or survivors of sexual violence are less likely to be included in the statistics (Dworkin 2005). To diagnose a case as heterosexual requires ruling out IDU. This is occurring despite the observation that heterosexual women constitute more than half of all people living with HIV/AIDS in sub-Saharan Africa (Exner et al. 2003).

Older women

Few women older than 50 years have received any attention. It took African countries to conduct population-based surveys in which high rates of HIV were observed in this population. For example, in South Africa, which has a very high prevalence of HIV and AIDS, the rate of HIV among women aged 50–54 is 7.5 per cent, and among women aged 55–59 it is 3 per cent (Shisana et al. 2005).

Grandmothers who take care of orphans and vulnerable children, in many cases using their meagre pension benefits, often do not receive state grants for the services they provide. Few low-income countries have social security systems that support these women.

Disabled women

Although researchers have studied the disabling effects of HIV/AIDS on previously healthy people, little is known about HIV/AIDS and people with disability (Groce 2003). It is commonly assumed that disabled individuals are not at risk. They are incorrectly thought to be sexually inactive, unlikely to use drugs and at less risk for violence or rape. There are significant risk factors for disabled populations around the globe. Despite the assumption that disabled people are sexually inactive, those with disability and in particular disabled women are likely to have more sexual partners than their non-disabled peers. Extreme poverty and social sanctions against marrying a disabled person mean that they are likely to become involved in a series of unstable relationships. Awareness of HIV/AIDS and knowledge of HIV prevention is low in this group and sex-education programmes are rare (Collins et al. 2001).

HIV-positive WSW

Women who have sex with women and are HIV-positive are seldom included in research and service delivery or advocacy efforts of AIDS service organisations, due to a lack of information which would need to be collected by health professionals (Arend 2003; Hughes & Evans 2003). There is a belief that such women are not at risk of contracting HIV (Fishman & Anderson 2003), yet they are exposed to multiple risks, such as drug use and sex work, and identify themselves as heterosexual or bisexual, or gay/lesbian or women who have sex with women and men (Arend 2003). They may very well engage in sex with partners whose sero-status they do not know. In high-income countries, studies have shown that a number of females who are IDUs are also WSW and they exhibit increased HIV infection and risk behaviours (Arend 2003; Young et al. 2005). According to Hughes and Evans (2003), some WSW participate in high-risk behaviours that may lead to the acquisition of HIV and hepatitis, such as injection drug use and unprotected intercourse with homosexual or bisexual men, or anal and oral–penile intercourse (cited in Dworkin 2005 and CDC 2006b). These WSW are left out of the research arena and interventions because they do not fall neatly into the defined categories used in classifying risk groups (cited in Dworkin 2005).

Domestic workers

Women migrants who work as domestic workers are also often missing in HIV prevention and treatment programmes, despite the observation that they have a very high risk of HIV. The risk is from the male partner who often has other sexual partners because of the absence of the wife from home, or from the wife because she is away from the husband for long periods. She is also at risk because of forced sex by her employer. Furthermore, she is not well informed, as recently identified in Botswana (Botswana News Agency 2006).

Women caught in armed conflict

Another group that is missed consists of women who are caught in armed conflict, causing them to flee and seek refuge in or out of their own countries. According to Holmes (2001) there is a need for protection and care of people displaced by armed conflict. Displaced women and men are often exposed to sexual assaults, and women and children make up 80 per cent of refugees. A survey among Burundian refugees identified that 26 per cent of women had experienced sexual violence since becoming a refugee (Holmes 2001), a major risk factor for HIV.

From this brief review, it is apparent that researchers, policy-makers and programme implementers are missing specific categories of women.

Evidence-based interventions designed to benefit women

Research has been conducted to generate evidence to support HIV prevention and treatment interventions targeted at women. The research covers prevention of transmission of HIV from mother to child, treatment of sexually transmitted diseases, ART, condom use among sex workers, and risk factors promoting HIV infection among women.

Pregnant women

Experimental research studies have been undertaken to identify interventions that would prevent transmission of HIV from pregnant mothers to their unborn or breastfeeding children. The studies revealed that zidovudine provided to women and children combined with breast-milk substitutes reduced the chances of children acquiring HIV. The randomised, double-blind, placebo-controlled clinical trial conducted by the Pediatric AIDS Clinical Trial Group Protocol 076 demonstrated conclusively that giving a long course of zidovudine during the ante-partum and intra-partum period reduced the risk of HIV transmission by 67.5 per cent (Connor et al. 1994). Other randomised controlled studies demonstrated conclusively that a short course of zidovudine is both effective and safe in preventing HIV transmission from mothers to children (Dabis et al. 1999; Shaffer et al. 1999).

Because of the high cost of zidovudine, a search for affordable interventions was undertaken. Studies were carried out to test nevirapine in reducing mother-to-child transmission of HIV. The landmark HIVNET 012 study showed that a single dose of nevirapine, given to the mother and child, reduced HIV transmission from mother to child (Guay et al. 1999).

Unfortunately, these studies focused on the child and ignored the mother. The single-minded focus on protecting the child gave the impression that mothers did not matter, even though ART was already being provided to women in developed countries and in the developing country private health sector.

Voices of women who asked for treatment to save their lives were not heard, until funding became available to introduce PMTCT–plus, a programme which entailed administration of prophylactic ART and breast-milk substitution to mothers and children, and ART for mothers, where indicated.

STIs and HIV infections

The evidence on the role of biological factors in HIV transmission has been studied extensively and the conclusion reached is that the biological make-up of women increases their susceptibility to HIV infection. Biological factors identified to facilitate HIV transmission in women include STIs, particularly ulcerative ones (Laga et al. 1993). There is still a lack of clarity on the

pathophysiologic mechanism by which the HIV virus infects the reproductive tract (Myer et al. 2005). However, theories based on available evidence suggest that the presence of STI increases HIV infectiousness because of increased viral load in genital secretions. STIs are also thought to increase susceptibility to HIV due to the disruption of the epithelial barrier and increased cell receptivity to HIV (*in vitro* data). Finally, genital ulcers and other non-ulcerative STIs are associated with increased shedding of HIV.

There is sufficient biological and epidemiological evidence generated from non-randomised and randomised controlled studies to conclude that HIV infections can be prevented through appropriate treatment of STIs. In Mwanzaa, Tanzania, researchers demonstrated a 38 per cent incidence of HIV reduction by treating STIs (Grosskurth et al. 1995). However the results from the randomised controlled study in Rakai, Uganda, did not show any impact of STI treatment on HIV incidence (Gray et al. 1999). Differences in the two studies might have been due to measurement errors of diagnostic and screening tests (Orroth et al. 2003).

ART

The advent of ART has contributed to reduction of morbidity and premature mortality. Murphy et al. (2001) assessed the benefits of ART with advanced AIDS using a prospective, multi-centre cohort study and showed that ART independently reduced mortality and morbidity. The assessment of the impact of ART on mortality was extended from cohort studies to vital registration data. In Brazil, Saraceni et al. (2005) assessed the profile of AIDS-related mortality in Rio de Janeiro between 1995 and 2003, the same period that ART and protease inhibitors were made available, and found a 47.5 per cent reduction in AIDS deaths. They also found an increase in the proportion of women who died of AIDS.

Sex workers

Sex workers have gained the attention of researchers. Sometimes researchers make the assumption that sex workers are responsible for transmitting HIV to men without considering the reality that without men seeking their services there would not be sex workers. Further, some sex workers may actually

be more at risk of getting or transmitting HIV from or to their intimate partners than from their paying customers. Among commercial sex workers in Glasgow, UK, 90 per cent used condoms with their clients while only 17 per cent used condoms with an intimate partner, even among frequent drug users (UNAIDS 2006). Evidence is beginning to emerge from local studies that women sex workers are not necessarily at higher risk for HIV than women in the broader community. In South Africa, Leggett (2001) found that white sex workers had a lower HIV prevalence (18 per cent) compared to black sex workers (66 per cent). Of concern is that 70 per cent of these sex workers with boyfriends reported not using condoms with them. In Umbilo in KwaZulu-Natal, South Africa, the incidence of HIV among sex workers was no different from that of the Vulindlela community sample (7.5 versus 7.2 per 100 person years; S. Abdool Karim, personal communication).

Migration

Research indicates that migrant men workers in developing countries leave their families behind when they get jobs in the mines. Mine workers often establish parallel families between urban and rural areas, thus creating opportunities for transmitting HIV between urban and rural areas (Lurie et al. 1997). It has always been assumed that the direction of HIV infection is from the migrant partner to his spouse at home; however, a cross-sectional study of migrants and non-migrant partners found that some females whose spouses were working in the urban area were HIV-positive while their male partners were not infected, meaning that women left in rural areas may sometimes be exposed to HIV from other sexual partners while their spouses are away (Lurie et al. 2003). Some women left behind by migrant men engage in transactional sex as a survival strategy (Evian 1993).

Transactional sex

Evidence exists that some women engage in sex work for economic reasons. Young women turn to sex work because they cannot find other work (Cohen 2000), or are pressured by parents either to have sex in exchange for money or sometimes to marry to bring dowry (Gregson et al. 2002). In some societies young women who are not necessarily sex workers may have two boyfriends:

an older one to provide financial security and a younger one designated as a future husband. However, because of their lack of financial independence, many of these women are not able to negotiate safe sex. Research shows that those who are financially empowered are able to negotiate safe sex. Many women who become sex workers have histories of sexual violence, rape and oppressive relationships with men (Gysels et al. 2002).

There is ample evidence to demonstrate what interventions work to prevent new infections and to treat those who have AIDS, as well as evidence on the determinants of HIV infection in women. We now look at missed opportunities for implementing the evidence generated from research.

Missed opportunities to apply the evidence

In this section we first assess the environment that influences implementation of evidence-based interventions and then we examine those missed opportunities.

Politico-socio-cultural and economic barriers to implementation of evidence-based interventions

The opportunities to implement gender-sensitive evidence-based public policies and programmes depend on the political and financial situation in each country. Some countries, including those that channel resources to multilateral organisations and to countries through bilateral support programmes, have stringent policies that tie funding to specific policies. They may require excluding organisations that provide services to sex workers, abortions and harm-reduction services from benefiting from funds allocated. Others have policies that make it difficult for countries to promote condoms, preferring to fund only programmes that promote sexual abstinence. Others prescribe the age at which children may get sexual information from schools, resulting in boys and girls reaching sexually active years with no information to protect themselves against HIV infection.

Some national policies empower or disempower women in terms of accessing employment, welfare services or property inherited from deceased husbands. Others treat women married in community of property as minors requiring

them to have the permission of their husbands to open a business. All these policies can either promote or undermine women's independence from men and hence have an indirect impact on women's health. Policies that are disempowering reduce the chances of women accessing prevention and treatment services, as Gupta's model (2000) has shown. Many middle- and low-income countries lack programmes that provide social security for women. In the absence of social grants that cushion them against poverty, or enable them to pay for childcare so they can work, some women engage in transactional sex, which increases their risk for HIV.

Opportunities exist to implement gender-sensitive evidence-generated policies to curb mother-to-child transmission, to provide women with ART, to provide syndromic management of STIs, to target marginalised groups at high risk such as sex workers and to target children. However, there are challenges that policy-makers need to address.

Prevention of mother-to-child transmission of HIV

Many countries are unable to implement fully the PMTCT of HIV intervention because their health systems are simply not able to cope with the demand for services. Many are inadequately funded, lack suitably trained personnel and have insufficient access to the medicines necessary to prevent HIV infection. Despite the availability of HIV/AIDS financial resources at a global and country level, they seem not to reach the very women and children who need them, as demonstrated by only 9 per cent coverage in low- and middle-income countries (UNAIDS 2006).

ART

Many countries are unable to implement ART programmes, again because of inadequate infrastructure, but also because of lack of political commitment, although this has begun to change recently, as shown by the number of countries that have initiated treatment. The failure to reach the WHO target of five million people receiving ART by 2005 is indicative partly of a lack of political commitment to prioritise those living with the disease, as well as lack of human resources, financial resources and access to medication. Recently, funds were disbursed through the Global Fund to fight AIDS, TB and Malaria,

but these were not sufficient to revive healthcare systems to enable them to cope with the number of patients seeking care.

Treatment of STIs

Although evidence exists to indicate that STIs can be managed using the syndromic approach, the attitudes of healthcare workers often serve as a barrier to patients accessing the services. For example, teenage women in Zimbabwe admit that STIs are a problem but are afraid of the rebukes they receive when they seek treatment at health clinics (Gregson et al. 2002). Lack of privacy and the stigma associated with a disease linked to sexuality also reduce the number of young people who seek available services. As observed, clinics are also perceived to lack privacy and confidentiality (Abdool Karim et al. 1992).

Stigma

Barriers to women accessing preventive services may include social factors such as stigma. HIV-positive women have been studied extensively to gain a better understanding of how stigma is associated with their sero-status, often with a view to informing policies and prevention and treatment programmes. On the basis of qualitative metasynthesis of studies on stigma in HIV-positive women, Sandelowski et al. (2004) found that women experienced and feared the negative social effects on their children, family, sexual partners and health workers. The negative effects include social rejection, discrimination and violence. Experience of stigma as well as internal self-stigmatisation was common to such an extent that it affected the women's behaviour related to disclosure or non-disclosure. HIV-positive women managed stigma through a variety of means, such as normalising of HIV infection, education, advocacy, setting up and belonging to support groups, and controlling who had information regarding their HIV status. Disclosing HIV status was a double sword: on the one hand it enabled self-healing and self-understanding to cope better with the diagnosis; on the other hand it threatened women's access to services, prevented them from having socially productive relationships and interfered with self-healing.

Social mores

Social mores also play a role in determining whether women will have access to services. For example, although evidence exists that women have higher rates of HIV infection than men, that condoms reduce the chances of contracting HIV and that VCT services provide an opportunity for men and women to know their HIV status, Kenyan women were less likely to undergo VCT services and take condoms. (Should female condoms be available, it would be interesting to see whether women would take these.) The main reason was fear of stigma, and the belief that only those who engage in risky behaviour should go for HIV testing. In other settings, condom use is associated with infidelity. Other reasons are the societal norms that dictate that men are responsible for getting condoms, and/or that married women consider themselves not to be at risk for HIV (Taegtmeyer et al. 2006). These barriers to access to vital prevention services such as VCT and condoms make it difficult to deliver services, even where such services exist in abundance (such as in Kenya). Other socially determined norms include harmful traditional and customary practices such as early marriage, wife cleansing and female genital mutilation, which make women and girls more vulnerable and put them at risk of HIV infection (Commonwealth Secretariat 2002).

Capacity to plan

Women are denied prevention and treatment services because translating existing knowledge into operational plans is a challenge, often requiring the assistance of specialist scientists. Unfortunately, too often researchers and policy-makers may not work harmoniously; hence an opportunity is lost to benefit women.

Bureaucratic obstacles

Unintended consequences of stereotyping or classification of women into groups may be responsible for women being missed in programmes. When policy-makers at global or local levels require ruling out IDU to classify a woman as having acquired HIV heterosexually, this implies that they do not expect a woman to acquire HIV heterosexually. She must somehow have engaged in a socially undesirable behaviour.

Missed opportunities to develop interventions based on evidence generated from research

In this section, an assessment is made of the opportunities seized or lost to develop HIV prevention policies, programmes or interventions based on evidence generated from research.

Treatment of STIs

A very small percentage of countries reported the proportion of males and females with STIs who were appropriately diagnosed, treated and counselled in 2005. Benin and Trinidad and Tobago were the only two countries that reported 100 per cent coverage with this service, with many others reporting rates ranging between 10 per cent (Zambia) and 92.4 per cent (Uganda), suggesting that the majority are not receiving treatment for STIs. Since STIs are often unrecognised in women, failure to diagnose them is a missed opportunity to prevent HIV infection.

ART

With the advent of ART and the global community's effort to support low- and middle-income countries to treat people living with HIV/AIDS to reduce morbidity and prolong life, according to the WHO's 3 by 5 initiative, most countries were already providing ART at the end of 2005, but not in large enough numbers. Globally, 1.3 million people with advanced HIV infection were receiving ART in 2005, and more females (3.8 per cent) than males (1.4 per cent) in 54 countries were reported to be receiving ART, missing the target by 30 per cent. Although more females than males with advanced HIV infection received ART, the coverage was too low to bring about a significant reduction in morbidity and mortality rates. Further examination between countries shows a mixed picture. There were instances where more females than males needing treatment received antiretroviral combination therapy (Cote d'Ivoire, 24.6 per cent versus 19.3 per cent; Malawi, 19.7 per cent versus 14.9 per cent; Seychelles, 87 per cent versus 78 per cent; Ukraine, 41 per cent versus 29.1 per cent; and Honduras, 53.7 versus 26.0 per cent). Only in Mali did more males (16.8 per cent) compared to females (8.1 per cent) have access

to ART. There were a few instances where access to this therapy was equal for males and females (Central African Republic, Mozambique, Fiji, Georgia).

Prevention of mother-to-child transmission of HIV

Pregnant women became the focus of HIV/AIDS research mainly because they were easy to access because they attended antenatal clinics. The women themselves did not benefit much from the research on PMTCT, as the intervention focused on children, as has been noted already in this paper. It is only recently, through strong global advocacy and the provision of resources, that pregnant women, albeit a small percentage, have begun to receive antiretroviral treatment.

Condom use among sex workers

Although sex workers have been studied extensively and interventions have been introduced, their human rights are often violated. Sex-worker advocacy groups have raised serious concerns regarding, for example, the 100 per cent condom-use policies in Asia, Latin America and Africa. Regarding what UNAIDS calls 'best practice', the advocacy groups raised concerns that the measures used to implement this policy are punitive to women. For example, some governments instruct brothels to require sex workers to refund money to clients who refuse to use condoms, as if they have the power to force men to use condoms. Sex workers are required to be identified and taken to clinics by the police for testing for STIs, often at their own cost. A compounding factor is stigma and legal status that make it difficult for sex workers to access relevant health services. Some may not seek healthcare since diagnosis of an STI may cause them to lose their licence and hence their means of support (Commonwealth Secretariat 2002). Men do not experience such harassment.

Recommendations

To ensure that specific categories of women are not missed in HIV prevention and AIDS treatment programmes, specific actions are recommended.

1 Use conventions and laws to give women their right to reproductive health services

As a first step, we need to build on agreements reached at the International Conference on Population and Development (ICPD) held in Cairo (1994) and the Fourth World Conference on Women held in Beijing (1995), which have created the framework for legislation and policies that give women the right to better reproductive health. Since 179 countries pledged to combat HIV/AIDS, improve access to sexual and reproductive health, as well as recognise associated rights, we need to encourage each one of these countries not only to domesticate these international agreements and other UN conventions aiming to promote gender equity, but also to ensure the participation in policy and programme development by those affected, implementers and enforcers. Domesticating international conventions through laws and policies should be followed by implementation of appropriate gender-sensitive training programmes for the judicial system and other service providers to ensure that their decisions are not disempowering to women.

2 End harmful traditional practices

Non-governmental and community-based organisations are encouraged to mobilise women to end harmful practices often perpetuated by women, such as female genital mutilation, and the social mores that encourage boys to develop cultural practices that put women at risk, such as machismo and treating women as inferior, as well as claiming to be knowledgeable about sexuality even when they are not. It is critical that women be mobilised to adopt practices that protect men and women against risks for HIV infection. In societies that still have certain traditional ceremonies associated with coming of age, these ceremonies should be used as vehicles to challenge gender issues as they relate to HIV/AIDS.

In addition, given that some societies condone harmful traditional practices that allow early marriages and dowry, son preference to the detriment of the girl child and violence against women, there is a need for governments to pass legislation designed to end these practices. Good examples are Bangladesh's Dowry Prohibition Act of 1980 and Child Marriage Restraint Act Amendment

Ordinance of 1984, and South Africa's Domestic Violence Act of 1998. More countries need to pass laws that prohibit and prosecute offenders.

3 Address causes of women's infidelity

Given the evidence that marital infidelity is not confined only to men, it is essential to focus on this risk. A recent study has found that in 30 to 40 per cent of sero-discordant cohabiting couples, women were infected while their male spouses were negative, even where the relationship was more than 10 years old (Walque 2006). Furthermore, women must also play a role in reducing their own risks by not engaging in multiple sexual partner relationships. This can be done through interventions that empower women to be able to protect themselves and reduce the need to transact sex for money, and by encouraging access to employment opportunities and income-generating funding and opportunities. This will lead to empowerment of women and reduce dependency.

4 Implement gender-based budgeting

To ensure effective implementation of plans, it is critical that the budget should take into account the needs of men and women, bearing in mind that some programmes are targeted at women, others at men. Partner organisations such as UNAIDS, WHO, the Global Fund to Fight AIDS, TB and Malaria, the Commonwealth Secretariat, regional structures and major private philanthropies should partner with individual countries to support them to do gender-based budgeting and finance resources for services based on this budget.

5 Involve multiple key stakeholders in developing policies

Given the complexity of using a gender analytical tool that takes into account intersectionality, race, class and socio-economic status, it is conceivable that policy-makers and programme planners would have difficulty translating theoretical concepts and evidence generated into concrete policies and programmes. Because of this, scientists are urged to participate in forums with policy-makers, programme planners and those infected and affected by

HIV/AIDS in crafting model policies and programmes for implementation. Such policies would address not only men, women and children, but also different categories of women and men. For women, they would address heterosexual women, female IDUs, pregnant women, older women, younger women, WSW, bisexual women, low-income women, ethnic minorities and women who do not know their HIV status, as well as those who are living with HIV/AIDS.

6 Transform the nature of relationships between men and women to be empowering

Combating HIV/AIDS will require a concerted effort by men to develop programmes targeting vulnerable men, just as gay men did at the beginning of the epidemic. Vulnerable men are those who believe that it is their right to have multiple sexual partners, those who force themselves on their partners as well as those who are bisexual but are unable to disclose their sexual orientation to their female partners. Researchers and policy-makers are encouraged to support these men's groups as they develop intervention plans for different groups of men. These are heterosexual men, MSM, bisexual men, IDUs, men belonging to ethnic minority populations, men in the low-income group, uncircumcised men, macho men, men who do not know their HIV status and those who are already seropositive. It is critical that the focus on women should not ignore men, because AIDS cannot be addressed if men are not part of the solution.

Resources should be made available to build women's skills in sexual negotiation, to work with women to change their sons' concept of masculinity in favour of equality, and to give young girls and boys sexuality information at early ages before they are sexually active. This approach is likely to enable behaviour change that is sustainable.

7 End HIV/AIDS stigma

Because of stigma experienced by HIV-positive women, the recommendation by Sandelowski, Lambe and Barroso (2004) to pilot-test the stigma-management programmes targeting seropositive women without them carrying the sole responsibility by including seronegative women in such

interventions is crucial, especially because the latter are also affected by stigma.

8 Introduce female-controlled methods

A concurrent focus on behavioural intervention and development of social contexts that enable behaviour change is key to preventing HIV/AIDS. The policies and programmes need to integrate gender-sensitive approaches as part of national prevention strategies. These would include infusion of substantial resource investment to fast-track the development of women-controlled HIV prevention technologies such as microbicides, and to make female condoms affordable and distributed in large quantities.

9 Introduce legislation to protect the human rights of specific groups

Change laws that criminalise sex work and non-disclosure of HIV-positive status (for example, California's 'wilful exposure law') to a sexual partner (Sears 2000), as well as isolation of people living with HIV/AIDS (Reidpath & Chan 2005). Such laws not only violate the human rights of those concerned, but are also a public health hazard, in that they cause men and women to 'go underground' and not access services, hence encouraging further spread of HIV. Some of the laws penalise even those who are at the receiving end and raise an unrealistic obligation to make sure the partner wears a condom (such as California's 'wilful exposure law').

10 End gender inequity

Finally, it is important to remember that because gender inequity is a key obstacle to halting the spread of HIV infection (Shisana & Davids 2004) we must all play our part to end gender inequity – starting with ourselves.

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Note

We wish to acknowledge Alison Bullen for searching the literature, and Thomas Rehle, Pelisa Dana and Nompumelelo Zungu-Dirwayi for their reviews of the paper. The services of Professor Anna Strebel and Professor Dan Ncayiyana for technical editing of this paper are greatly appreciated. The mistakes and insights in the paper remain those of the authors.

CHAPTER 2

Responses to 'Missing the women'

Issues such as stigma and discrimination, marginalised groups, violations of human rights and policy gaps as well as failures were highlighted. Dr Shisana identified areas where the absence of a gender focus renders research, policy and practice incapable of adequately meeting women's practical needs and strategic interests. A panel of four discussants responded to the paper that initiated a dialogue on this very important issue.

Why women are 'missing' in HIV/AIDS policy

Sisonke Msimang's presentation reflected on what many agreed was the underlying theme of the Toronto conference: the need for universal access to treatment for people with HIV. The question she posed was:

> If universal access is the underlying theme of this conference, how are women within this context being addressed? In the last five years we have begun to see good programmes for women, yet particular types of women are missing. They are missing because of issues related to human rights and the inability to be considered and accommodated for in mainstream policies.

She agreed that those groups of women identified in the paper as 'missing' are indeed marginalised, and reinforced the argument by asking why we keep missing these particular groups of women. She pointed out that an increased budget for a particular programme does not mean there is capacity to spend the money on the needs of women affected and infected by HIV/AIDS.

Ms Msimang argued that women's human rights were lacking in terms of universal access and that the international community needed a way of understanding why particularly the issue of marginalised women was not being addressed. In ensuring that women in southern Africa have reproductive rights, she asserted that there are some policies in place, yet they have not been translated into action. Ms Msimang expressed the solution as

follows: 'We need to examine who is sitting at the table, who is controlling the money, and what is happening with this money, to ensure that these policies are implemented. It is crucial to ensure that those holding these positions are speaking and advocating for the rights of women, especially for the rights of these women.'

In addition to policies that are in place but not adequately implemented, she noted that there are still many current laws that state that it is illegal for someone to knowingly infect a person with HIV, but such legislation fails to include and understand the needs of women at a reproductive stage. She asked: 'Does this mean that a woman with HIV cannot breastfeed her child? Does she have access to treatment that will prevent transmission to her child?' It is evident that in the development of these laws, gender inequality is entrenched.

She concluded by advocating for a framework of analysis within the context of HIV/AIDS for understanding why specific needs of marginalised women are not being reached as a necessary step in addressing these needs. When women are not included in mainstream policies, it is indeed their human rights that are violated and this needs to change.

Sisonke Msimang is the Programme Manager of OSISA. She is based in Johannesburg, South Africa, and can be contacted at sisonkem@osiafrica.org.

Human rights within the framework of global HIV/AIDS policy

The issue of human rights within the framework of global policy is one that Joanne Csete spoke to in greater detail. She mentioned that 'the nature of this discussion so far has been a reflection of the gaps that we have in programme and policy understanding of crucial next steps, because women have been missing from cutting-edge discussions on programme scale-up and policy reform'. In her address, it was clear that gender inequality surrounds HIV/AIDS and the question she posed was what our response was to that reality.

She argued that women are missing in various kinds of research and absent from organisations that fund and manage research. She further noted that in

most countries, these women do not engage with powerful policy-makers, donor structures and decision-makers.

She elaborated on Dr Shisana's discussion of women's risk of HIV transmission through injection drug use, and emphasised the need to understand why women's risk of HIV transmission through injection drug use suggests a higher risk than men's in some studies. She mentioned examples where women who have sexual partners who use drugs are more likely to use drugs themselves. She also highlighted that women often need assistance injecting, that women are physiologically more easily affected by smaller amounts of drugs than men, and that women's servile dependence on sexual and drug-using partners does not disappear just because they use drugs. It is clear that women who use drugs are at a much higher HIV risk than their male counterparts.

Her response added insight into the missing link between current policies and community organisations run by women, and the lack of rights and autonomy these organisations have. She noted: 'Women's groups in the most hostile circumstances, in the most AIDS-affected places, in the most male-dominated societies, are fighting and sometimes winning battles that are about the fundamentals of women's status and power in society.' She then asked, what will it take to improve the support of these organisations and what kind of protection do they need? It is essential to determine the ways in which policies can be applied to better support organisations that assist women.

Joanne Csete is the Executive Director of the Canadian HIV/AIDS Legal Network. She is based in Toronto, Canada, and can be contacted at jcsete@aidslaw.ca.

Challenges faced by women involved in sex work in India

Meena Seshu captivated the audience through narrative accounts of women involved in sex work. In particular, she recounted a story of sex workers in India who were given buffaloes by the government of India as part of an economic empowerment programme. The buffaloes needed to be fed and vaccinated and to be part of a breeding programme. The sex workers found that in order to comply with these requirements, they had to do more sex work to obtain the necessary resources. This illustrates that programmes for

sex workers in India do not reflect their needs, and place an additional burden on them.

This is a clear illustration of the inability to accommodate and facilitate the needs of marginalised women in society. In planning programmes, the voices of women in marginalised groups need to be heard to ensure that their choices and experiences are respected, and women's voices should inform programming designed for women. She concluded the story by stating that what sex workers really need is a programme designed to assist them in a harm-reduction approach to their work. In this case, if the government of India had listened to the sex workers, the implementation of this programme would have benefited these women.

Through this story, she provided the participants with personalised experiences of the challenges women involved in sex work in India face, and the lack of policies that adequately meet their needs. Her accounts of women who are in prostitution and sex work underscored their vulnerability and the high risk of sexual abuse. This is an area that is not often adequately researched and rarely spoken about. She stated that in general 'women in prostitution are clearly missing in every aspect of policies, programmes and research'. She pointed out that since HIV transmission is most efficient in a situation of repression and abuse, women in prostitution and those who have been trafficked are at a greater risk of contracting HIV. She argued that the HIV/AIDS epidemic has singled out people in prostitution and sex work as 'carriers and vectors of the spread of HIV'. Apart from the stigma already attached to their work, society has further marginalised them as core transmitters of HIV infection.

In addition, Ms Seshu reminded the participants in the session that we must continually ask critical questions, and listen closely to women. If, for example, women are sharing their own experiences on sex work and providing suggestions for better treatment, we must use this feedback to design better programmes. She then called for better analysis of current policies, asking, 'Are we going to ask men to change their behaviour as well?' Ms Seshu stressed that this needs to happen and that we must work together for positive change because women in India have no voice.

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Challenges faced by HIV-positive women in Namibia

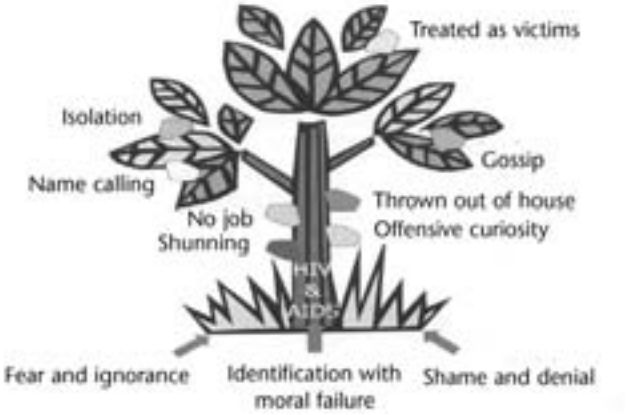
Jennifer Gatsi Mallet gave a very emotional account of the consequences for women living with HIV/AIDS in Namibia. She recounted examples of women with HIV who suffer in silence and the stigma that they face when disclosing their status. Her personal experiences of the ways in which women with HIV are being judged were insightful. She said that too often it is the woman who is 'blamed' for bringing the disease to her husband and consequently she faces danger because of her status:

> Stigma and discrimination operate as a tool of social control; it exudes and exercises power over women and girls and reinforces pre-existing prejudices. In blaming women and girls, society excuses itself from its responsibility towards women and girls. Women and girls are burdened in many societies and are seen as transmitters of STIs and other diseases, treated differently from men if they are HIV-positive, rejected by their families and are blamed for infecting and killing their husbands and children.

She quoted a Ugandan woman who said that 'stigma is like trying to catch an eel in a bucket of oil; every time you think you have got a grasp on it, it eludes you'. Daily experiences of stigmatisation are clear reminders of how crucial it is to continue to work in the field of gender and HIV/AIDS. Ms Mallet then asked: 'If domestic violence is real, especially for women with HIV, and research shows that in all southern African countries women are more affected by HIV, then why is it that most of these countries fail to include laws on domestic violence?' There is a distinct gap between HIV disclosure and violence against women.

The challenge for policy-makers and governments is to act on their commitments by ensuring the protection and empowerment of women and girls in the face of the HIV/AIDS pandemic. Without adequately addressing the phenomena of stigma and discrimination among women and girls, the failure to include women in policy decisions will continue. She used a diagram to illustrate the different levels of stigma experienced by women living with HIV/AIDS, reproduced on the next page.

Levels of stigma experienced by women living with HIV/AIDS



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CHAPTER 3

Conclusion

The paper helped fuel a very important dialogue that needs to happen on a broader scale. We agree that the pandemic is fuelled by gender inequality; now we must work harder to better understand the complexities and act on them. While the opening ceremonies of the conference declared the theme of 'Time to Deliver', it was clear from the discussion stimulated by Dr Shisana's paper that not enough is being done and that women are still largely missing from efforts in HIV prevention and treatment programmes and policies. In order to ensure that strategies geared to address women in the context of HIV/AIDS are successful, full participation of marginalised women must be ensured. Indeed, it is well beyond the time to deliver for women, as their absence in research, policy and programming efforts have had a profound impact on the failure to deliver, and this has far-reaching implications for women in halting the spread of HIV. Dr Shisana paved a clear way forward in proposing key recommendations in her paper to ensure that specific categories of women are not missed in HIV/AIDS prevention and treatment programmes. It is important to remember that gender inequity is the key obstacle to halting the spread of HIV (Shisana & Davids 2004); there is therefore a dire need for all of us to play our part to end gender inequity – starting with ourselves.

CHAPTER 4

Sources of information for 'Missing the women'

This paper is based on information gathered from the literature published in diverse data sources using a combination of the key words 'gender', 'women', 'HIV', 'AIDS', 'human immunodeficiency virus' and 'acquired immunodeficiency syndrome'. The fields searched were subject terms and abstracts covering the following databases: Aidsearch (NISC), Blackwell Synergy, Ebscohost web-Academic Search Premier, Medline, Oxford University Press, Proquest Research Library, SAEPublications, Science Direct, SpringerLink, ISI Web of Science and CSA Sociological Abstracts. Additional information was obtained from the UNAIDS tenth anniversary report on the global epidemic and from international conferences, and to a lesser extent from articles published in non-peer-reviewed journals or grey literature. Use of non-peer-reviewed publications was not as systematic as that of peer-reviewed articles. An attempt was made to review articles that would help to generate evidence of research undertaken to address the gender issue and HIV/AIDS issues, look for theoretical models frequently used to study gender and examine papers to assess whether particular women were missing or not.

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