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Publisher/Éditeur:

SAMA Health and Medical Publishing Group (HMPG)

Tel: +27(0)21-530-6520

Fax: +27(0)21-531-4126

E-mail: publishing@samedical.org

Published quarterly (hard copy and online)
Publication trimestrielle (sur papier ou Internet)

Funded by the Department For International Development (DFID) (UK)
Sponsorisé par le Department for International Development (DFID) (UK)

SAHARA J is listed on www.ajol.co.za and www.sabinet.co.za
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SAHARA Journal Mission Statement

The journal publishes contributions in English and French from all fields of social aspects of HIV/AIDS (care, support, behaviour change, behavioural surveillance, counselling, impact, mitigation, stigma, discrimination, prevention, treatment, adherence, culture, faith-based approaches, evidence-based intervention, health communication, structural and environmental intervention, financing, policy, media, etc).

Déclaration de la mission du journal SAHARA

Le journal publie des communications en Anglais et en Français de tous les domaines des aspects sociaux du VIH/SIDA (le soin, le soutien, le changement du comportement, la surveillance comportementale, la consultation, l'impact, la réduction, le stigmatisation, la discrimination, la prévention, le traitement, l'adhésion, la culture, les approches basées sur la foi, l'intervention évidence-basée, la communication sur la santé, l'intervention structurale et de l'environnement, le financement, la politique, le média, etc).

Report and policy brief: 2nd Annual Conference on Social Aspects of HIV/AIDS Research, Cape Town, 9 - 12 May 2004



S Kleintjes, K Peltzer, O Shisana, C Niang, J Seager, L Simbayi, D Kaseje (Human Sciences Research Council and Social Aspects of HIV/AIDS Research Alliance — SAHARA)

This report and policy brief summarises the overarching principles, key findings and suggested policy options that emerged from rapporteur reports of conference proceedings. Detailed presentations may be viewed at www.sahara.org.za.

A total of 25 million of the 38 million people infected with HIV globally at the end of 2003 were Africans. There appears to be a stabilisation in HIV prevalence, but this is mainly due to a rise in AIDS deaths and a continued increase in new infections. Prevalence is still rising in some countries such as Madagascar and Swaziland, and is declining nationwide in Uganda. Sub-Saharan Africa is home to just over 10% of the world's population, and almost two-thirds of all people living with HIV. In 2003, an estimated 3 million people in the region became newly infected and 2.2 million died (75% of the 3 million AIDS deaths globally that year). AIDS has killed one or both parents of an estimated 12 million children in sub-Saharan Africa and far too many of these orphans are not properly cared for (UNAIDS, 2004).

At the present time, Africa appears to be moving toward substantially reduced life expectancy (from 65 - 70 years in some countries to a low of 40 - 45 years), sharp rises in mortality for adults, doubled child mortality rates since the mid-1980s, and the expected substantial reduction in active labour forces. In short, AIDS appears to be in the process of reversing many of the developmental gains made in the African continent after independence from colonialism.

SAHARA (Social Aspects of HIV/AIDS Research Alliance) is a critical response to this epidemic in sub-Saharan Africa, a vehicle for facilitating the sharing of HIV/AIDS-related research expertise and knowledge, conducting multi-site and multi-country exploratory, cross-sectional, comparative or intervention-based research projects, within an African context. The Alliance aims to generate new social science evidence for prevention, care and mitigation of the impact of the HIV/AIDS epidemic on individuals, families and communities. It aims to inform tailoring of policies, programmes and interventions to the social, developmental, cultural and economic contexts within which modern-day Africans live.

In the current context, the objective of an African Research Agenda has to be the effective prevention, care and treatment of the disease. The SAHARA initiative aims to harness available research energies to inform legislative change, policy directives and government and civil/community action toward the realisation of this objective.

As part of its concerted action, an annual conference is convened to foster the effective integration of the activities of the Alliance research partners and of other organisations and individuals active in HIV and AIDS control within the African continent and abroad, and to overcome barriers to the necessary research-policy-practice interface between researchers and decision-makers in government ministries.

Objectives of 2nd conference of the Alliance were to:

- brief researchers, policy- and decision-makers, donors and other interested stakeholders about the work of the Alliance
- strengthen links, promote collaboration and co-ordination of SAHARA, to make it an effective broad-based research network of partners committed to conducting or supporting quality research for policy, planning and implementation
- share emerging results from research sites in Africa on the social aspects of HIV/AIDS
- issue policy briefs on thematic tracts to policy makers, government representatives and inter-governmental bodies.

Dossier de rapport et de politique: 2^e Conférence Annuelle de Recherche sur les Aspects Sociaux du VIH/SIDA, le Cap, 9 - 12 mai 2004

S Kleintjes, K Peltzer, O Shisana, C Niang, J Seager, L Simbayi, D Kaseje (Le Conseil de Recherches en Sciences Humaines et l'Alliance de Recherches des Aspects Sociaux du VIH/SIDA — SAHARA)

Ce dossier de rapport et de politique présente un compte-rendu des principes dominants, des conclusions principales et des options d'une politique proposée qui font partie des communications présentées. Les communications détaillées peuvent être consultées au site www.sahara.org.za.

Autant que 25 millions sur 38 millions de personnes déjà contaminées par le VIH dans le monde entier à la fin de 2003 furent des Africains. Il semble qu'il y a une stabilisation de la prévalence du VIH, toutefois, ceci est dû à l'augmentation des morts du SIDA ainsi que l'augmentation des nouvelles contaminations. La prévalence continue à s'accroître dans certains pays comme le Madagascar et le Swaziland alors qu'elle diminue en Ouganda. L'Afrique subsaharienne compte un peu plus de 10% de la population mondiale — et à peu près deux tiers des personnes souffrant de VIH. En 2003, dans cette région, environ 3 millions contaminations ont été déclarées et 2.2 millions de personnes sont mortes (soit 75% de 3 millions morts de SIDA sur le plein mondial de la même année). Le SIDA est responsable de la mort d'un ou deux parents d'environ 12 million enfants dans l'Afrique subsaharienne. La majorité de ces enfants ne sont pas très bien soignés (UNAIDS, 2004).

A présent, l'Afrique semble se diriger vers une espérance de vie très réduite (soit de 65 à 70 ans dans certains pays à 40 à 45 ans dans autres), une augmentation très aiguë de la mortalité des adultes, un double taux de mortalité des enfants depuis le milieu des années 1980 ainsi qu'une réduction considérable du main-d'œuvre actif. En bref, le SIDA semble être dans un processus d'inverser beaucoup de bénéfices du développement du continent Africain après l'indépendance coloniale.

Le SAHARA (Alliance de Recherche sur les Aspects Sociaux du VIH/SIDA) est une réponse essentielle à cette épidémie dans l'Afrique subsaharienne, un moyen de faciliter le partage de savoir et des connaissances relatifs à la recherche sur le VIH/SIDA. Le Sahara dirige des projets de recherche exploratoires multi-sites et multi-pays, transversales, comparatives ou basées sur une intervention dans un contexte Africain. L'Alliance a pour but de générer une nouvelle science sociale de prévention, de soin et de réduction de l'impact de l'épidémie du VIH/SIDA sur les individus, les familles et les communautés. L'Alliance vise à guider la conception des politiques, des programmes et des interventions dans des contextes sociaux, culturels et économiques et le développement, dans lesquels les Africains de nos jours vivent.

Dans le contexte actuel, l'objectif d'un Programme de Recherche Africain doit être la prévention efficace, le soin et le traitement de la maladie.

L'initiative du Sahara vise à mettre en semble toutes les énergies de recherches disponibles afin d'influencer le changement des lois, des directives politiques et l'action gouvernementale et civile/communautaire vers la prise de conscience de cet objectif. Faisant partie d'une action concertée, une conférence annuelle a lieu afin de consolider l'intégration des activités de chercheurs de l'Alliance et d'autres associations et individus qui jouent un rôle actif dans le contrôle du VIH/SIDA à l'intérieure du continent Africain et en outre-mer.

En outre, afin de surmonter les obstacles qui se trouvent à l'encontre de l'interface recherche-politique-pratique entre les chercheurs et les ministères du gouvernement.

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The conference also provided an opportunity to launch the inaugural issue of the *Journal of Social Aspects of HIV/AIDS*, published by the South African Medical Association (SAMA).

The scientific programme offered 23 keynote addresses, 33 oral symposia at which 151 oral presentations were delivered, 175 individual posters, as well as round-table discussions, satellite meetings and workshops. A total of 350 delegates from 33 countries across Africa and around the world attended and contributed to deliberations, which spanned 12 key themes:

- Policies of access to care
- Human rights: legal and customary law issues on care
- Gender and HIV
- Orphans and vulnerable children
- Treatment and care
- Prevention strategies
- Nutrition and food security
- Drug- and trade-related issues
- Stigma in relation to care
- Cultural and communal mobilisation
- Financing of AIDS
- Epidemiology and HIV/AIDS surveillance.

CORE PRINCIPLES

An African approach to the effective prevention and management of the disease is essential, and would need to be premised on a belief that the reversal of the adverse impact of HIV/AIDS on the growth and development of Africa should primarily be sourced from African innovation. Ownership of solutions should come from a critical re-conceptualisation of our thinking and attitudes vis-à-vis our tendency to adopt 'top down' approaches, rather to focus on negotiation of research (and policy outcomes) with households and communities experiencing the epidemic.

A major challenge AIDS presents to the engagement of communities is the hopelessness and despair that it has evoked in Africa, as it emptied villages of its families, providers and social networks. Communities — and the social energies therein — are both the location of the impact of HIV/AIDS and the source and driver of solutions toward reducing and preventing the effects of the epidemic. African

solutions to the AIDS epidemic therefore cannot emphasise a primarily medical approach, but rather a social approach to prevention, care and treatment. People (communities and researchers) needed to be 'energised by a fighting spirit' and to take on a 'critical thinking' process. To this end, the community — and households therein — should be the units within which people are engaged to determine how to regain and maintain their health and livelihood.

Community leaders must be central to a partnership process that 'nourishes community empowerment'. Empowering people in communities will need to include the identification of indicators of movement from hopelessness to hope, and from hope to energised engagement with solutions which evidence a 'goodness-of-fit' with local cultural and social practices. Further, energised engagement should proceed to evidenced-based planning, implementation and review.

Provision of support and care for persons living with HIV and AIDS (PLWHAs) in Africa should flow from a perspective which relates to that person within the context of family and community, not exclusively on an individual level. Affected family members often suffer along with the infected person, regarding social stigma and isolation, impact on psychological well-being, and resource constraints or loss of income. This approach sees the PLWHA as the symptomatic member of an ill family or household. It proposes that where preventive and treatment strategies, approaches to clinical care, and material and other aid are provided to affected communities and the HIV-positive member of families within that community, this care and aid needs to be sufficient to enable consideration of the whole family as the unit of intervention, or as potentially in need of care or aid.

KEY FINDINGS AND POLICY OPTIONS

Human rights, legal and customary law issues on care

A study of six southern African countries found that on average, less than US\$1 per capita per year is spent on HIV/AIDS in these countries. All had signed or ratified key international human rights conventions, but most had fallen behind in implementation. In many African countries, legislative practices and frameworks are not effective in protecting the human rights of PLWHAs and those affected by PLWHAs,

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Les objectifs de la deuxième conférence de l'Alliance furent les suivants:

- donner de l'information aux chercheurs, aux concepteurs des politiques gouvernementales, aux donateurs et à tous ceux qui s'intéressent au travail de l'Alliance
- renforcer les liens, promouvoir une collaboration et une coordination du SAHARA avec le but d'en faire un réseau de recherche très à vaste portée, comptant des participants qui se sont engagés à diriger ou à soutenir une recherche de bonne qualité pour la politique, la planification et la mise en œuvre
- partager les résultats qui ressortent de sites de recherche sur les aspects sociaux du VIH/SIDA
- fournir des dossiers de la conception d'une politique sur des pistes thématiques aux concepteurs de lois, aux représentants gouvernementaux et aux organismes inter-gouvernementaux.

La conférence a également donné occasion au lancement de la première publication du *Journal des Aspects Sociaux du VIH/SIDA*, publiée par l'Association Médicale de l'Afrique du Sud (SAMA).

Le programme scientifique de la conférence a présenté 23 discours d'ouverture, 33 colloques au cours desquels 151 communications étaient présentés. Il y avait 175 poster affichés, des débats à table-ronde et des ateliers. Trois cent cinquante représentants provenant de 33 pays Africains et d'outre-mer ont assisté et participé aux discussions basées sur 12 thèmes principaux:

- Les politiques d'accès au soin
- Les droits de l'homme: les questions sur la loi et la loi coutumier sur le soin
- Le genre et le VIH
- Les orphelins et des enfants vulnérables
- Le traitement et le soin
- Les stratégies de prévention
- La nutrition et la sûreté alimentaire
- Les drogues et les issues commerciaux
- La stigmatisation vis-à-vis le soin
- Le déplacement culturel et communautaire
- Le financement du SIDA
- L'épidémiologie et le contrôle du VIH/SIDA.

PRINCIPES CENTRAUX

Une approche Africaine est essentielle à la prévention et la gestion effectives de la maladie. Cette approche doit être axée sur une croyance que l'inversement de l'impact néfaste du VIH/SIDA sur l'accroissement et le

développement de l'Afrique doit être tiré de l'innovation africaine. Les solutions qui pourraient être proposées doivent découler d'une remise en cause de notre façon de penser et de notre comportement face à notre tendance à adopter une approche dans laquelle les autorités imposent des idées à leurs subordonnés. Il faudrait plutôt focaliser notre attention sur la négociation des données des recherches (et des résultats) avec les foyers et les communautés affectés par l'épidémie.

Un défi important que le SIDA présente à la participation de communautés est du désespoir que l'épidémie a évoqué en Afrique après avoir vidé les villages de ses habitants, des pourvoyeurs et des réseaux sociaux. Les communautés et les énergies sociales qui s'y trouvent sont à la fois l'emplacement de l'impact du VIH/SIDA et l'origine des solutions vers la réduction et la prévention des effets de l'épidémie. De ce fait, les solutions africaines pour l'épidémie du SIDA ne pourraient insister sur une approche médicale, mais plutôt sur une approche sociale de prévention, de soin et de traitement. Les gens (communautés et chercheurs) avaient besoin d'être 'animés d'un esprit de combat' et d'adopter un processus 'd'une réflexion critique'. Pour cette raison, la communauté et les foyers qui s'y trouvent doivent devenir des unités dans lesquelles les gens sont préoccupés de leur santé et leur bien être.

Les autorités communautaires doivent jouer un rôle important dans le processus du partenariat qui 'nourrit le développement d'une communauté'. Pour aider les communautés à se développer, il va falloir souligner les indicateurs du déplacement partant du désespoir vers l'espoir, de l'espoir vers une participation active ayant des solutions qui s'accordent aux coutumes culturelles et sociales. De plus, cette participation doit se diriger vers une planification basée sur des preuves, la mise en œuvre et le contrôle.

Les services de soutien et de soin aux personnes vivant avec le VIH/SIDA (PVVS) en Afrique doivent découler d'une perspective qui a un rapport avec la personne qui se trouve dans d'une famille et une communauté et non pas d'une perspective qui vise un individu. Les membres de famille à l'intérieure de laquelle il y a une personne infectée, souffrent des problèmes de la stigmatisation sociale et l'exclusion, de l'impact sur leur bien-être psychologique, le manque de ressources et la perte d'emploi. Cette approche considère le PVVS comme un membre symptomatique de la famille ou d'un foyer malade. L'approche propose que là où les

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contributing toward the marginalisation of some groups of people.

Customary law operates in parallel with common law, and does not reflect the agreements and protocols to which African countries may be signatories, resulting in the continued marginalisation and suffering of women, gay people, prisoners and sex workers, among others affected by HIV. Legal review tends to concentrate on punishing wilful infection, when the reality is that consensual sexual relations within marriages are a large source of infection in Africa. Most citizens also do not know what legal aid is available, where or at what cost.

In an African context, individual rights and community rights should be addressed simultaneously. New debate and new information is urgently required to inform the directions African nations take, but this is hampered by the secrecy with which HIV-related information is managed. Confidentiality does not imply secrecy: information gathering systems should support confidentiality for people using services while allowing for the use of data for monitoring, evaluation and further planning.

Policies of access to care

There is a need to monitor the human rights implications of HIV/AIDS for the continent's people. Currently African civil society is not sufficiently engaged with monitoring and holding government accountable on human right issues, nor those related to HIV/AIDS. Civil society needs to engage more with government for accountability on human rights issues.

Locally funded support of research should be encouraged to promote commitment to sound policy and programme development. Research should become a locally driven 'navigating tool for the vehicle of health policy on the road ahead for Africa'.

Financing AIDS

Global financing of HIV in Africa, the hardest hit and among the poorest of the world's continents, is central to reversing the current trend of decimation of the African people. Financing initiatives should reflect African trends in the impact of HIV/AIDS, in particular its impact on women, children, and poor communities. Funding strategies should be cognisant of the call for the design of financing initiatives to be

enabling of the provision of care within a context of family and community settings, rather than only on an individual level.

Outside of a clear policy framework and monitored programme implementation, more money does not necessarily result in better returns in health. Where money is available, it is critical to devise and implement mechanisms to ensure that money is going to those who need it most, as reflected in policies, and determined by evidenced-based practice. Finance ministries have a crucial role in devising finance policies and informing service-related policies, which will enable the sustainability of these initiatives. Funding opportunities should as a matter of course fund capacity development for local community organisations to draw up proposals and strengthen networking, to access funding and collaborate on projects focussed on community and home-based care and support.

Drug- and trade-related issues

Widespread, free access to drugs (ARVs) appears key to the slowing of premature mortality, but uptake is currently much lower than required. Access to affordable drugs is not a patent issue in Africa, as many essential drugs are not patented in most of Africa, but only in those countries with a sizeable (elite) market, e.g. South Africa.

African governments are a potentially powerful lobby to drive down prices through bulk procurements, in order to improve free access to drugs (ARVs) as part of the comprehensive strategy to reverse the impact of the epidemic. The impact of programmes to introduce ARVs must be properly evaluated from the onset.

Nutrition and food security

Households may sell everything, including land and cattle, to pay for treatment and care of people living with HIV/AIDS. Productivity has declined radically and the poor are getting poorer, with women (and their dependents) by far the most seriously disadvantaged people in Africa. Nutritional counselling is barely offered in the cities and food-growing programmes are not standard training in schools and other community structures. AIDS and chronic malnutrition are viciously inter-related, as the infected need more food if they are not to weaken and experience rapid infections. ARV treatment also relies on good nutrition. Access to medical care and

stratégies de prévention et de traitement, les approches cliniques de soin et d'autres matériaux d'aide sont mis à la disposition des communautés affectées et aux membres de familles infectés se trouvant à l'intérieure de cette communauté, ils doivent être fournis suffisamment avec le but de voir toute la famille comme une unité d'intervention ou bien une unité qui pourrait éventuellement avoir besoin de soin ou d'aide.

RÉSULTATS PRINCIPAUX ET LES OPTIONS DE POLITIQUES

Les droits de l'homme, la loi dans le sens général et la loi coutumier portant sur le soin

Une étude sur six pays de l'Afrique australe a démontré que sur la moyenne, ces pays dépensent moins de US\$1 par personne pour le VIH/SIDA. Tous ces pays ont signé et approuvé les conventions internationales de droits de l'homme, mais la plupart d'entre eux sont encore loin de la mise en œuvre. Dans beaucoup de pays Africains, les lois et les cadres législatifs ne sont pas efficaces dans la protection des droits de l'homme des PVVS et de ceux qui sont affectés par les PVVS. Cette situation contribue à la marginalisation de certains groupes de gens. La loi coutumier fonctionne en parallèle à la loi civile et ceci ne reflète pas les accords et les protocoles auxquels des pays Africains sont signataires, ce qui donne lieu à une marginalisation et une souffrance continues des femmes, des homosexuels, et du personnel de sexe, parmi ceux qui sont affectés par le VIH. Le contrôle légal a tendance à se concentrer à la punition de contamination voulue, alors que la vérité est que des relations sexuelles convenues dans des mariages sont à l'origine de la majorité de contaminations en Afrique. La plupart de citoyens ne savent pas qu'il y a une aide à leur disposition, ni où le trouver ou combien cela coûte.

Dans un contexte Africain, les droits de l'individu et de la communauté doivent être abordés en même temps. Un nouveau débat et une nouvelle information sont requis d'urgence afin de déterminer les directions que les nations Africaines doivent prendre. Cependant, ce processus est entravé par la discrétion dont on gère l'information liée au VIH. La confidentialité ne doit pas forcément être confondue avec la discrétion: les systèmes de recueillir les données sont sensés respecter la confidentialité de gens qui bénéficient des services et en même temps permettre l'utilisation de ces données pour le contrôle, l'évaluation et la planification éventuels.

Les politiques d'accès aux soins

Il faudra contrôler ce que signifient les droits de l'homme vis-à-vis le VIH/SIDA pour les Africains. Actuellement, la société civile de l'Afrique n'engage pas suffisamment de débats avec le gouvernement sur les droits de l'homme et le VIH/SIDA. La société civile doit de plus en plus rappeler le gouvernement de sa responsabilité de faire respecter les droits de l'homme.

Il faut encourager le financement local de recherche afin de faciliter le développement d'une politique saine et des programmes nécessaires. La recherche locale doit devenir 'un utile de naviguer le véhicule des politiques de santé destinées à l'Afrique'.

Financer le SIDA

Le financement du SIDA en Afrique, un des continents pauvres du monde et le plus frappé, serait décisif au changement des tendances actuelles de l'extermination des peuples Africains. Les initiatives financières doivent refléter les tendances africaines dans l'impact du VIH/SIDA, en particulier l'impact du VIH/SIDA sur des femmes, des enfants et des communautés pauvres. Les stratégies de financement doivent encourager la mise en place des initiatives financières qui vont promouvoir le soin dans un contexte familiale et communautaire, plutôt que de viser l'individu.

En dehors du cadre d'une politique claire et la mise en œuvre des programmes de contrôle, davantage d'argent n'entraîne pas nécessairement des meilleurs résultats de santé. Dans des cas où l'argent est disponible, il est important de mettre en place et d'utiliser des mécanismes qui vont assurer que cet argent aide ceux qui en ont le plus besoin comme il est défini par la politique et la mise en évidence de l'usage basé sur des preuves. Les ministères de finances ont un rôle important dans la conception des politiques financières et de la mise en place des politiques liées aux services, qui donneront une existence bien soutenue à ces initiatives.

Les occasions de financement doivent dépenser l'argent dans le développement de main-d'œuvre afin que les associations de communautés locales puissent formuler des propositions et consolider les contacts, avoir accès au financement et collaborer dans des projets de soin et de soutien basés au foyer et sur la communauté.

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psychosocial support needs to be coupled more integrally to nutrition and food security in poverty-stricken Africa.

Food aid needs to be family-based, as there is widespread loss of productive adults leading to a loss of agricultural labour and lower food production, increasing food insecurity, malnutrition, and vulnerability to infection in a terrible cycle. Attention is needed to address the fact that women and children, often the hardest hit, are often last in food allocation.

Gender and HIV

Women form 70% of the world's poor, they are largely economically dependent on men and have substantially reduced life choices. Women are more susceptible to infection than men, yet within families, men's illnesses are often regarded as more important because of the threat of loss of male wage earners, with little focus on the impact of the extensive loss of the contribution of women's labour to family and community well-being. In Africa, agricultural labour is predominantly provided by women, and with women at great risk, the continent faces a further threat to food security via loss of women's productivity in feeding.

Caregiving is traditionally done by women, with women then also bearing a greater burden of caring for the sick in the family and community. Yet, because women have the lowest incomes, their own access to care (and those who depend on them for care) is constrained by care options which are costly, highly technical and not readily accessible from the living environments of women and their families.

The continuous nature of household work, limitations on the scope of and bases from which women may acceptably conduct their activities, cultural norms which discourage females from discussing sexuality or sexual health or from attending and participating in mixed-gender initiatives, all severely limit women's participation in (health) education, planning and practice, which then affects their roles as primary caregivers. Fear of violence or abandonment may further impede women's disclosure of (and help-seeking for) their positive status.

Programmes need to address the power imbalances which permeate individual, interpersonal, and community-level gender relations. The mobilisation

and empowerment of the women of Africa is central to HIV/AIDS-related strategies. Programmes should also be aware of cultural practices which separate male and female domains of interaction, and ensure women's participation by locating activity within those settings and constraints, rather than targeting only those settings where men are more likely to participate. Women's organisations must be empowered as vehicles to drive such initiatives. Simultaneously, attention must be given to promoting prosocial — and addressing socially alienating — male socialisation constructs and practices which impact on the health, well-being and mutual support of women, children and men, both in communities at large and in regard to their impact on HIV/AIDS-related strategies. Programmes also need to engage men to promote models of masculinity which support men's involvement in prevention, care and treatment of HIV.

Orphans and vulnerable children

Poverty, inadequate nutrition, lack of access to or cessation of schooling, premature entry to the (unskilled) labour market, childhood marriage, sexual exploitation, uncertain or inadequate shelter and lack of access to health services are only a few of the more obvious hardships faced by orphans and vulnerable children.

When parents die, children seek help from the extended family. This family might be absent or find it difficult to meet the material and emotional needs of the orphaned children. Poor women and elderly relatives may inherit several dependents. Children, themselves lacking knowledge, skills or means, also find themselves having to care for other, equally needy children. These vulnerable caretakers may be forced to let child dependants leave school to work and/or marry to secure more child labour to generate income needed to support the household. Some of these children, when their families and communities are unable or unwilling to support them, may leave their homes in the hope of securing a livelihood in the informal sector on the streets, for themselves and perhaps also for their households. These young people are at risk of becoming infected with HIV, due to their exposure to exploitation, abuse and survival sex with adults and other street children, in exchange for food, shelter or protection. The extent of trauma from being orphaned 'many times' and dealing with stigma directed at these children and their families was also stressed in many presentations.

La drogue et le commerce

L'accès libre et étendu aux drogues (ARVs) semble important au ralentissement de morts précoces mais la compréhension de ce phénomène est actuellement très basse que nécessaire. L'accès aux drogues qui coûtent un prix assez abordable n'a rien avoir avec la question de fabrication en Afrique, étant donné que la plupart de drogues indispensables ne sont pas fabriquées dans beaucoup de pays Africains mais uniquement dans des pays qui ont un marché assez grand comme l'Afrique du Sud.

Les gouvernements Africains sont une éventuelle force militante pour la réduction des prix lors qu'ils achètent des grandes quantités avec le but d'améliorer l'accès aux drogues (ARVs) comme faisant partie d'une stratégie compréhensive qui vise à inverser l'impact de l'épidémie. L'impact de programmes de présentation de ARVs doit être examiné de le début.

La nutrition et la sûreté alimentaire

Pour payer le traitement et le soin des malades de VIH/SIDA, les familles sont poussés à vendre leurs possessions, la terre et les bestiaux. La productivité baisse de manière radicale. Cela veut dire que les pauvres deviennent plus pauvres. Les femmes et leurs dépendants sont les plus touchés et désavantagés des peuples Africains. Il n'existe guerre de consultations nutritionnelles dans des villes et les programmes de cultiver des aliments ne font pas partie de la formation scolaire, ni de structures communautaires. Le SIDA et la malnutrition chronique sont très étroitement liés, étant donné que les personnes infectées ont davantage besoin de manger pour éviter qu'ils soient faibles et vulnérables à la re-contamination. Le traitement ARV dépend d'une bonne nutrition. L'accès au soin médical et au soutien psychosocial doit être lié à la nutrition et la sûreté alimentaire dans l'Afrique frappée de pauvreté.

L'aide alimentaire doit être basée sur la famille, étant donné qu'il y a une perte d'adultes productifs très élaborée qui entraîne la perte de main-d'œuvre agricole et une baisse de la production alimentaire, l'accroissement non-hygiénique des aliments, la malnutrition et la vulnérabilité à la contamination en cercle vicieux. On doit prêter attention au fait que les femmes et les enfants, souvent les plus frappés, sont très souvent les derniers à recevoir les allocations alimentaires.

Le genre et le VIH

Les femmes constituent 70% de pauvres sur le plein mondial. Elles sont financièrement dépendantes aux hommes et elles ont des choix considérablement restreints. Les femmes sont plus vulnérables à la contamination par rapport aux hommes. Toutefois, dans les familles, lors qu'un homme tombe malade, sa souffrance est considérée plus sérieuse que celle de la femme car cela pose une menace de perdre le soutien de la famille. Entre-temps, moins d'attention est prêtée à l'impact de la perte de la femme qui travaille dur pour le bien-être de sa famille et sa communauté. En Afrique, la main-d'œuvre agricole est principalement assurée par des femmes. Ayant des femmes en situation de grand risque, le continent va faire face à une menace éventuelle de la sûreté alimentaire entraînée par la perte de productivité de femmes. Ceci suggère que les femmes portent un fardeau supplémentaire de soigner les malades dans la famille et la communauté. Cependant, vu que les femmes touchent des salaires minables, leur accès au soin et de ceux qui dépendent de leur soin est restreint car le soin est coûteux, très technique et difficilement accessible à partir de communes dans lesquelles ces femmes habitent avec leurs familles.

Le rôle de femmes de donner le soin est restreint par les réalités suivantes: les tâches ménagères, la liberté limitée de faire ce qu'elles aimeraient faire, il est culturellement inacceptable que les femmes discutent sur le sujet de sexualité et le sexe, les conditions culturelles qui empêchent les femmes à participer aux débats sur la sexualité et la santé en présence des hommes. Les femmes ont une difficulté de dévoiler leur état sérologique de peur de violence et d'abandon.

Afin de résoudre le problème de l'inégalité de pouvoir entre les hommes et les femmes qui nuit aux relations individuelles et communautaires, il faut mettre des programmes en place. Le déplacement et le développement de femmes africaines sont importants aux stratégies liées au VIH/SIDA. Vu que dans la culture africaine il n'y a pas d'interactions entre des hommes et des femmes lors de discussions et des débats portant sur certains sujets, les programmes doivent viser des moments d'interactions entre les deux sexes afin d'inclure les femmes. Les associations féminines sont idéales pour la gestion de ces initiatives. En même temps, il est nécessaire de favoriser une interaction sociale entre hommes et femmes. Ceci sera possible

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Some findings indicated that children not only evidence a wide range of psychological trauma related to their serial losses and lack of support, but also show remarkable resilience in devising ways to survive their difficult circumstances. The latter should also be a focus of research to broaden our knowledge and practice base on assisting children to cope. A thread woven through several presentations on orphans and vulnerable children was the need to adopt a broader concept of 'social orphans' which includes all children whose parents are unable to provide for them, rather than focussing exclusively on children orphaned by AIDS.

Currently, numerous policies and programmes are being implemented that strengthen the capacity of communities to provide assistance to children affected by HIV/AIDS. To co-ordinate initiatives there is a need for:

- clearer definitions of the scope, range and key synergies of this burgeoning area of enquiry, practice and intervention, to guide further action
- baseline data to inform efficacious policy and programme development
- development of interventions that acknowledge the call from communities to provide programmes which promote children staying at home, or within their communities, rather than in institutions
- acknowledgement in programme development that inexperienced, very young and old caregivers are supporting large numbers of children, and in turn need support for meeting their economic, social and emotional needs and their child-rearing responsibilities
- the need for the provision in statutory and customary law for the protection of widows' and orphans' rights to retain assets and access to other basic community resources.

The latter should include legal and funded programmatic initiatives to support orphans and vulnerable children and their caregivers to:

- access funds, materials, livestock, income-generating programmes and capacity building for nutritional and other support needs
- obtain free access to ARVs and other basic medical services for themselves and the children
- retain children in school for free
- access programmes for the critical area of continuing education and capacity building within families, including lifeskill training to avoid emotional and physical abuse.

The fact that children (and therefore, their caregivers) require a wide range of integrated social supports to promote a life-enhancing developmental trajectory must be built into strategies to manage orphans and vulnerable children. Strategies should cover key settings (e.g. home, community school), needs (e.g. nutrition, health care, welfare, psychosocial support, safety), and life stages (infants and young children, youth and young adults). Clear objectives for funding and programme development should be set within each of the key clusters.

The integrated network of support required to meet the basic needs of children and youth must be reflected in the development of basic packages of care and support to children affected/infected by HIV/AIDS. These packages should be integrated across departments, with clear roles and responsibilities for each tier of government, including, in clear terms, the responsibilities of national, provincial, local governments and the non-governmental (NGO) sector.

Attention is especially needed to strengthening initiatives at the interface of local government and non-profit organisations (NPO) interface for funding of services, to improve children's access to services for basic needs at local and district level. The establishment of locally implementable systems which have the capacity to fast-track access to emergency care, shelter and support for newly vulnerable children and those already on the street, is needed.

In support of the above, the development and evaluation of guidelines and policies for joint funding and monitoring of integrated initiatives requires attention. In order to provide services that achieve the best overall result for children within a limited resource environment, funders, planners and managers need data to systematically compare and evaluate existing programme approaches, in order to inform decisions on which kinds of activities to expand and support.

Prevention

Information-based programmes are insufficient to bring about lasting change in sexual behaviour. Effective programmes must be embedded in, and produce supportive change in the social units which give meaning and direction to human life to enable children, adolescents and adults to consistently choose to engage in safe sexual practices. Consistent, stable, positive social relationships, within which young

quand il y aura changement dans la socialisation des hommes qui actuellement nuit à la santé, au bien-être et au soutien mutuel des femmes, des hommes et des enfants dans la communauté et vis-à-vis les stratégies liées au VIH/SIDA. De plus, ces programmes doivent encourager les hommes à devenir des modèles de la masculinité qui participe à la prévention, au soin et au traitement du VIH.

Des orphelins et des enfants vulnérables

Entre autres, les orphelins et les enfants vulnérables font face aux difficultés suivantes: la pauvreté, la nutrition insuffisante, le manque d'accès et l'arrêt de la scolarisation, le travail forcé, le mariage des enfants, l'exploitation sexuelle, le manque d'abri et inexistence de services de santé.

A la mort de parents, les enfants se tournent vers d'autres membres de la grande famille pour l'aide. Cette famille pourrait être inexistante ou bien incapable de pourvoir aux besoins matériels et émotionnels de ces enfants. Des femmes pauvres et des personnes âgées parentés à ces orphelins peuvent adopter un certain nombre de dépendants. Parfois, les enfants n'ayant pas d'expérience eux-mêmes, ni le savoir-faire nécessaire, se trouvent dans des situations où ils doivent s'occuper d'autres enfants qui sont dans la même situation de besoin. Souvent, ces enfants sont amenés à quitter l'école soit pour se marier ou bien pour travailler afin d'augmenter de quoi vivre. Certains d'entre eux quittent leurs foyers d'accueil qui sont parfois en difficulté de les nourrir et les soutenir. Faute de quoi, ils vont dans la rue pour gagner leur vie. Les enfants de la rue sont à risque de contamination du VIH car ils sont sexuellement exploités par des adultes ou leurs camarades en échange de nourriture, d'abri et de protection. Dans plusieurs communications, on insiste sur l'importance du trauma vécu par ces enfants à force d'être orphelins à plusieurs reprises et de vivre avec la stigmatisation.

D'autres résultats ont montré que ces enfants ne souffrent pas seulement du trauma psychologique mais aussi qu'ils sont très déterminés à trouver des moyens de survivre leur situation. Cette constatation doit faire sujet de recherche afin d'obtenir davantage de connaissances nécessaires pour venir en aide à ces enfants. Beaucoup de communications traitant le sujet des orphelins et des enfants vulnérables ont indiqué qu'il faut adopter un concept plus large 'des orphelins sociaux' qui inclue tous les enfants qui manquent de soutien et de soin

plutôt que de viser exclusivement les orphelins du SIDA.

A présent, il y a de nombreuses politiques et des programmes mise en œuvre afin de renforcer la capacité des communautés à aider les enfants touchés par le VIH/SIDA. Pour coordonner les initiatives il faut:

- bien définir le champs, l'étendu et les points importants de ce domaine de recherche, de pratique et d'intervention afin de préparer l'étape suivante
- des données de base pour influencer des politiques efficaces et des projets de développement
- le développement des interventions qui reconnaissent la demande des communautés de fournir des projets qui mettra les enfant dans des familles ou des communautés plutôt que de les mettre dans des établissements
- une reconnaissance des projets de développement que les enfants et les personnes âgées s'occupent d'un grand nombre d'enfants et qu'en revanche, ils ont besoin du soutien financier, social et émotionnel pour parvenir aux besoins des enfants
- des lois qui protègent les droits des veuves et des orphelins à retenir leur héritage et d'avoir accès aux ressources fondamentales de la communauté.

Ce dernier doit incorporer des initiatives des programmes de lois et de financement qui vont soutenir les orphelins et les enfants vulnérables et ceux qui s'en occupent à:

- avoir accès aux finances, aux matériaux, aux bestiaux, aux programmes qui produisent l'argent et au développement du personnel pour des besoins alimentaires et autres
- avoir libre accès aux ARVs et à d'autres services médicaux fondamentaux pour eux-mêmes et pour leurs enfants
- garder les enfants à l'école sans payer les frais
- avoir accès aux programmes de l'éducation continue et du développement de l'habileté avec le but d'éviter les abus émotionnels et physiques.

Le fait que les enfants (et ceux qui s'en occupent) demandent un éventail des soutiens sociaux intégrés afin de faciliter une trajectoire du développement qui améliore la qualité de vie doit faire partie des stratégies de gestion des orphelins et des enfants vulnérables. Les stratégies doivent couvrir les lieux principaux (par exemple le foyer, l'école de la communauté), les besoins (par exemple la nutrition, la santé, la sécurité sociale, le soutien psychosocial, la sécurité), et les étapes de

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people have developed positive emotional connections to parents, family members, peers and teachers, have been found to exert positive influences on behaviour, including the sexual behaviour of adolescents. Children, in particular primary school children prior to sexual debut, are an important target group for prevention. Schools offer a primary target site for HIV prevention education, given that a large proportion of children and youth can be reached through schools over an extended period of time.

School-based teacher and peer interventions which build on existing educational infrastructure to provide in-service training for teachers and peer supporters to deliver HIV education and support in primary schools can be effective models of programme delivery for school children. These programmes are found to be particularly effective if embedded in community structures, where training is provided for community members as part of the programme, to optimise acceptance and support within the child's entire living environment. Innovative clinic-based behavioural change interventions among people infected by STDs are yielding some exciting results. There is a need to extend such research in other clinical as well as community settings.

For lasting impact on sexual behaviour, programmes need to target the home, the school and playground, and community institutions such as cultural, religious and education structures, as social sites which can be enabled to provide socially and emotionally supportive environments conducive to sustained behavioural change in young people.

Children and youth falling outside of this potential safety net of supports, such as adolescents without caretakers or relatives, and those who are out of school, are at particular risk regarding the reduced opportunities to develop the kind of health-promoting social and emotional supports conducive to sustained behavioural change. Stakeholders involved in HIV/AIDS control activities should therefore also attend to adapting programmes for use in sites where these adolescents are most likely to congregate.

Treatment and care

Community-based interventions

Priority areas for attention in providing assistance include spiritual support (via acceptance by the

community and destigmatisation), psychosocial support, free access to medication for opportunistic infections, free or subsidised access to nutrition, with the supply of medication coupled to nutrition. Given the high levels of poverty, employment and assistance with income generation projects, as well as material support for dependents, are key supports to PLWHAs. These projects should be based on an 'affected-individual within family ownership' model of benefit from income generation project resources, rather than on communal sharing with other PLWHAs. Family participation in income generation initiatives, even if donor-funded, should be the norm. The unit of the family should not be replaced by a donor/service provider creation of an artificial family of PLWHAs, distancing the PLWHA from their identified or family-based support system.

Models of care and assistance should include PLWHAs, their dependents and caregivers in a comprehensive 'family-unit approach', rather than a 'target patient' approach. Families within communities should be acknowledged and engaged in interventions, with attention to household level communal sharing of allocated resources, including food and medication, rather than a general community sharing of resources. Funds allocated to organisations should be linked to community initiatives and communities should be involved in the utilisation of funds.

Facility-based service provision

The number of patients requiring care is steadily increasing, with the majority seeking care in the public health sector for HIV/AIDS-related illness. Non-AIDS patients and AIDS patients alike are offered sub-optimal care due to insufficient resources in public health care facilities.

Given the enormous need for care, urgent attention should be given to the training and utilisation of midlevel and community-based workers to support home- and community-based care of those affected and infected by HIV/AIDS and other patients who could benefit from home-based care, to free up the limited available facility-based care for those most in need of direct attention from health care workers. Attention should also be given to the support and care of affected and infected health care providers and home-based carers.

développement d'un individu (les bébés et les petits enfants, les jeunes et les jeunes adultes). Dans chacun des groupes, il faut des objectifs nets de financement et de programmes de développement.

Le réseau intégré de soutien nécessaire à répondre aux besoins fondamentaux des enfants et des jeunes doit être reflété dans le développement des combinaisons de soin et de soutien fondamentaux des enfants atteints de VIH/SIDA. Ces combinaisons doivent être intégrés dans tous les départements, avec des rôles et des responsabilités claires de chaque niveau gouvernemental, ainsi que des termes claires, des responsabilités nationales, provinciales et communautaires du gouvernement et du secteur non-gouvernemental.

Il faut renforcer les initiatives de l'interface du gouvernement local et les organisations à but non lucratif pour le financement des services, afin d'améliorer l'accès des enfants aux services qui répondent aux besoins fondamentaux au niveau local et zonal. On a besoin de mettre en place des systèmes qui peuvent être exécutés sur place, qui, par la suite, auraient la capacité d'accélérer l'accès au soin d'urgence, à l'abri et au soutien des enfants nouvellement vulnérables et ceux qui sont déjà à la rue. Pour corroborer ce dernier, il faut prêter attention au développement et à l'évaluation de directives et de politiques du financement et du contrôle commun des initiatives intégrées. Pour assurer des services rentables aux enfants qui ont des ressources limitées, les financiers, les raboteurs et les gérants ont besoins des données pour comparer et évaluer systématiquement les approches existantes avec le but de prendre des décisions sages à savoir quels types d'activités à étendre et à soutenir.

La prévention

Les programmes basées sur l'information sont insuffisants pour amener des changements durables sur le comportement sexuel. Les programmes efficaces doivent produire un changement qui soutien des unités sociales qui donnent sens et direction à la vie humaine avec le but de permettre les enfants, les adolescents et les adultes de choisir d'avoir des rapports sexuels protégés. On a découvert que l'influence positive sur le comportement général et sexuel des adolescents découle des relations sociales, consistantes, stables et positives dans lesquelles les jeunes ont des rapports émotionnels positifs avec leurs parents, les autres membres de la famille, leurs camarades et leurs

professeurs. Les enfants de l'école primaire (qui n'ont jamais eu des rapports sexuels) font partie d'un groupe cible de prévention. Les écoles offrent un site cible d'éducation sur la prévention du VIH, vu qu'une grande partie des enfants et des jeunes pourrait être atteint à travers les écoles durant des longues périodes de temps.

Les interventions scolaires dans lesquelles le professeur et les camarades participent, s'appuient sur l'infrastructure existante de l'éducation qui assure la formation continue de professeurs et le soutien de camarades à donner une éducation et un soutien de VIH dans les écoles primaires. Ces interventions pourraient devenir des modèles efficaces d'assurer des programmes pour les écoliers. Ces programmes deviennent efficaces lorsqu'ils font partie des structures communautaires où la formation de membres de la communauté est incorporée dans les programmes pour favoriser l'acceptation et le soutien dans la vie de l'enfant. Les nouvelles interventions du changement de comportement ayant lieu dans des cliniques parmi les gens infectés par les MSTs ont produit des résultats intéressants. Il va falloir étendre cette recherche à d'autres cliniques et d'autres communautés.

Pour avoir un impact plus permanent sur le comportement sexuel, il faut des programmes qui s'adressent au foyer, à l'école et la récréation et aux institutions communautaires comme des structures culturelles, religieuses et éducatives. Ces derniers peuvent être utilisés comme des lieux sociaux qui favorisent un milieu socialement et émotionnellement accueillant afin de maintenir le changement de comportement chez les jeunes.

Les enfants et les jeunes ne faisant pas partie de ce soutien, comme des adolescents qui vivent seuls et ceux qui ont quitté l'école, sont au risque en ce qui concerne les occasions réduites de développer une santé qui favorise le soutien social et émotionnel nécessaire au changement de comportement. Tous ceux qui prennent part dans les activités de contrôle du VIH/SIDA doivent adapter les programmes et les amener vers les adolescents.

Le traitement et le soin

Les interventions communauté-basées

Les domaines prioritaires d'aide incluent le soutien spirituel (acceptation et destigmatisation), le soutien psychosocial, l'accès libre aux médicaments des

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Traditional healing

Traditional healers are easily able to relate within the cultural and language framework of clients, and practise within a holistic, Afro-centered approach, which incorporates ancestral beliefs, rituals and traditions as part of their treatment plans. It is therefore not surprising that many PLWHAs use complementary or traditional medicines. As traditional healers are often the practitioners of choice for many patients, they are able to exercise power and authority to influence the behaviour of large numbers of people.

Traditional healers have a crucial role to play in building health systems in Africa and strengthening and supporting national responses to HIV/AIDS. It is imperative that attention be given to the development and monitoring of standards of care within the field of traditional medicine, as well as to the interface and integration of traditional medicine and the biomedical health care system. Research into the safety and efficacy of traditional medicines, promoting adherence to drug regimens, monitoring side-effects, sharing their expertise in patient communications with biomedical practitioners, as well as the development of a national database on pharmacovigilance, including the interactions between ARVs and traditional medicines, are needed.

HIV testing

Generally, research findings were supportive of public health legislation that ensures a gold standard of voluntary HIV testing with the specific informed consent of the individual concerned, the maintenance of confidentiality, pre- and post counselling, voluntary partner notification, and a specific legal framework to guide action with regard to exceptions to this standard, including provisions for surveillance and unlinked testing for epidemiological purposes. Some researchers, however, suggested that while voluntary measures are preferable, since discrimination remains prevalent, routine HIV testing offered as part of the usual package of health care, with patients having an option to decline this, might be more successful in preventing large-scale HIV transmission and providing earlier treatment to greater numbers of people. It was noted that illness in an African setting is traditionally regarded as a family affair. Thus attention should also be given to developing and evaluating strategies to assist the infected person to disclose within a family context, to promote family care and support and

planning for the future impact of the loss of resources which the individual's illness may bring. However ongoing stigma and the need to protect the human rights of infected and affected persons require careful consideration of the impact of the indiscriminate application of this approach at this time.

More work is needed to achieve the 'right mix' of focus on individual, family and community factors to optimally benefit both the affected person and the family and community units to which they are inextricably bound. Counselling, testing, disclosure and further support in a family and community-centered African setting require the development of strategies which are sensitive to this orientation, respecting the needs, human rights and interests of both infected and affected persons involved in the care matrix.

Stigma in relation to care

People living with HIV still live with the fearful prospect of possible emotional and social ostracisation or physical expulsion from family and other familiar forms of support should they disclose their status. Fear may result in denial of status to the point of continuing risky sexual and other practices for fear of alerting a partner or family members to their condition. Infected persons may believe that they are 'protecting' family members from the trauma of being faced with the possibility that they too may be HIV-positive, and subject to social ostracisation along with other infected family members. Denial and avoidance of disclosure can reduce access to care, support and treatment for the infected person, as well as for those caring for them, as families 'hide' their afflicted family members or delay accepting treatment which would identify their condition.

The PLWHA and family members are denied the opportunity to prepare emotionally and practically, and to accept the benefits of professional or community support around the impending death of the family member, as would be the case with a non-HIV-related family bereavement. Several studies reported that education and awareness proved extremely effective in promoting disclosure, reducing HIV-related stigma and enhancing family support to patients. Furthermore, disclosure in an informed environment was found to enhance the quality of home-based/palliative care. It is difficult to eliminate stigma altogether, therefore anti-stigma issues must be integrated into a wide range of interventions, targeting

infections opportunistes, l'accès libre à la nutrition gratuite ou subventionnées, avec l'approvisionnement des médicaments couplés à la nutrition. Vu les niveaux élevés de pauvreté, l'emploi et l'aide des projets qui assurent du travail ainsi que le soutien matériel pour les dépendants, sont primordiaux aux PVVS. Ces projets doivent être basés sur un modèle qui donne avantage de ressources à l'individu affecté plutôt que sur le partage commun avec d'autres PVVS. La participation de la famille dans les initiatives de générer l'argent, même si cela est financé par des donateurs, est très importante. La famille du PVVS ne doit pas être remplacée d'une famille artificielle créée par le donateur ou l'assureur de service qui va isoler le PVVS du système de soutien de la famille.

Les modèles de soutien et d'aide doivent incorporer les PVVS, les dépendants et le personnel de soin d'une approche compréhensive de l'unité familiale, plutôt que l'approche visant le patient. Il est nécessaire de reconnaître et de faire participer les familles dans les interventions de la communauté en assurant que la distribution des ressources à partager prend en considération le niveau économique et social du foyer au lieu de faire une distribution générale. Ceci est vrai pour la nourriture et des médicaments. Les fonds alloués aux organisations doivent être liés aux initiatives communautaires et les communautés doivent prendre part dans l'utilisation de ces fonds.

Assurer le service selon l'infrastructure disponible

Le nombre de patients qui demandent des soins augmente petit-à-petit avec la majorité de patients qui se rendent vers le secteur public pour le soin de VIH/SIDA et des maladies liées au VIH/SIDA. Les patients infectés par le SIDA et ceux qui ne les sont pas reçoivent des soins sous-optimaux faute de l'insuffisance de ressources dans le secteur public.

Vu le besoin énorme de soins, il s'avère nécessaire de former et d'utiliser le personnel de soins basés dans la communauté afin d'aider les patients du VIH et leurs familles et d'autres patients qui peuvent en bénéficier. Ce dernier pourrait soulager les cliniques et les hôpitaux publics pour que les ressources limitées peuvent profiter des patients qui ont besoin de l'attention directe du personnel de santé. On doit prêter attention au soutien et au soin du personnel de soins qui sont affectés ou infectés.

La guérison traditionnelle

Les guérisseurs traditionnels s'adaptent facilement dans le cadre culturel et linguistique des patients et ils travaillent manière complète, d'une approche principalement africaine qui incorpore les foies ancestrales, les rites et les coutumes dans le traitement. Il n'est donc pas étonnant que beaucoup de PVVS utilisent des médicaments complémentaires ou traditionnels. Puisque les guérisseurs traditionnels sont choisis par des patients eux-mêmes, ils ont le pouvoir et l'autorité d'influencer le comportement de beaucoup de gens.

Les guérisseurs traditionnels ont un rôle important à jouer dans la mise en place des systèmes de santé en Afrique ainsi que dans le renforcement et le soutien des réponses nationales au VIH/SIDA. Il est nécessaire de se concentrer au développement et au contrôle de niveaux de soins dans le domaine de la médecine traditionnelle. Il faut aussi faire une interface et une intégration des médicaments traditionnels avec le système bio-médical de soins. Il y a une nécessité de faire des recherches des aspects suivants: la prudence et l'efficacité des médicaments traditionnels, encourager l'adhérence aux régimes de drogues, contrôler les effets secondaires, partager l'habileté de communiquer avec les patients avec les professionnels bio-médicaux, et le développement d'une base des données nationale sur la pharmacovigilance ainsi que les interactions entre les ARVs et les médicaments traditionnels.

Le dépistage du VIH

Dans l'ensemble, les résultats de recherches ont prêté leur appui aux lois de la santé publique qui assurent les suivants: un niveau très élevé du dépistage volontaire où l'individu donne son accord après avoir bien compris la raison et les conséquences du dépistage, la confidentialité de résultats, la consultation psychologique avant et après le dépistage, informer son partenaire volontairement, un cadre particulier selon les lois qui régissent ce qu'il faut faire avec les exceptions du niveau prescrit et la surveillance et le dépistage non-lié pour des raisons épidémiologiques. Cependant, certains chercheurs suggèrent que même si le dépistage volontaire est préférable, étant donné qu'il existe de la discrimination, il vaut mieux faire un dépistage de routine faisant partie des soins que les patients peuvent refuser. Cette approche aura un succès de réduire la contamination et du traitement d'un grand nombre de gens. On a constaté que dans le milieu africain, être

Report and policy brief: 2nd Annual Conference on Social Aspects of HIV/AIDS Research, Cape Town, 9 - 12 May 2004

and empowering whole communities and PLWHAs and their caregivers in particular, by improving access to care, housing, employment and government benefits. From a long-term perspective, the fight against stigma is part of a social and political process aimed at transforming African societies by changing relationships and status that discriminate and exclude stigmatised groups such as commercial sex workers, men having sex with men, and children considered to be 'abnormal'.

Political leadership is critically needed to mobilise community awareness of stigmatisation, and to increase awareness that the real fight against AIDS is social and not purely medical. There is great need to train caregivers in non-stigmatising attitudes and care in both health care and household settings. In calling

on communities to accept and support PLWHAs, caregivers should be supported to retain their dignity and well-being via capacity development, material and psychosocial support, as they share the burden of care with understaffed public health facilities.

Epidemiology and HIV/AIDS

Surveillance is essential to track the variety of factors needed to inform and evaluate the impact of policies and interventions. Behavioural surveys are also useful in the current context, as they provide the benefit of informing appropriate programme designs for prevention, care and treatment — a key concern in developing best practices in the African context. They are growing in popularity as they complement antenatal surveys and are useful for benchmarking purposes.

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malade est une affaire de toute la famille. De ce fait, on doit développer et évaluer des stratégies qui aideront la personne infectée à révéler son état positif à la famille afin d'assurer un soutien familial et de se préparer à l'éventuelle perte des ressources que le patient contribue dans la famille. Cependant, le stigmate et la nécessité de protéger les droits de l'homme des personnes infectées ou affectées exigent une prise de conscience de l'impact de la réalisation aveugle de cette approche, en ce moment.

Il reste encore beaucoup de choses à faire avant d'arriver à réaliser la bonne formule qui adresse l'individu, la famille et les facteurs communautaires. Ceci pour rendre profit à la personne infectée, la famille et les unités communautaires auxquelles la personne est liée. La consultation, le dépistage, la révélation et le soutien dans un milieu familial et communautaire africain exigent un développement de stratégies sensibles à cette démarche en respectant les besoins, les droits de l'homme et les intérêts des personnes infectées ou affectées qui sont impliquées dans les soins.

La stigmatisation par rapport au soin

Les infectés de VIH vivent dans la peur d'être émotionnellement et socialement marginaliser ou bien d'être expulsés de la famille si jamais ils révèlent être séropositifs. La peur peut amener la personne au refus de son état jusqu'au point d'avoir des rapports sexuels risqués. Les personnes infectées sont amenées à croire qu'elles protègent leurs familles du trauma de faire face à la possibilité d'être séropositifs eux-mêmes et d'être marginalisés de la même façon que la personne infectée. Le refus et l'action d'éviter la révélation de la séropositivité réduisent l'accès au soin, au soutien et au traitement de la personne infectée ainsi que de ceux qui s'en occupent. La famille a tendance à cacher la séropositivité de la personne ou bien ils retardent l'accès au traitement de peur que leur situation sera dévoilée.

Les PVVS et les membres de la famille sont privés d'une occasion de se préparer émotionnellement et de manière pratique et d'accepter les avantages du soutien professionnel ou communautaire vis-à-vis la mort éventuelle du membre de la famille, comme serait le cas de deuil de la famille qui n'est pas lié au VIH. Beaucoup d'études ont montré que l'éducation et la prise de conscience sont extrêmement efficaces pour

encourager la révélation, pour réduire la stigmatisation liée au VIH et pour favoriser le soutien de la famille aux patients. De plus, on a découvert que révéler son état dans un atmosphère où les gens sont éduqués sur le VIH encourage de soins familiaux de bonne qualité. Il est pratiquement impossible de complètement éliminer la stigmatisation. Pour cette raison, il faut intégrer l'anti-stigmatisation dans la série des interventions qui visent et développent les communautés entières et les PVVS aussi bien que ceux qui les soignent. On peut arriver à cela en améliorant l'accès au soin, à l'abri, à l'emploi et aux indemnités gouvernementales. A partir d'une perspective à long terme, la lutte contre la stigmatisation fait partie d'un processus politico-social qui a pour objectif de transformer les sociétés africaines en changeant les relations et l'état de discrimination et d'exclusion des groupes stigmatisés comme le personnel de sexe, les homosexuels et les enfants dites 'anormaux'.

Les dirigeants politiques doivent sensibiliser les communautés au problème de stigmatisation et au fait que la lutte contre le SIDA est un exercice social et non pas purement médical. Nous devons former le personnel de soin à donner des soins et à éviter les attitudes de stigmatisation dans les foyers et les établissements de santé. Dans l'effort de faire appel aux communautés d'accepter et de soutenir les PVVS, il faut en même temps soutenir et aider le personnel de soin à garder leur dignité et leur bien être par le biais du développement personnel, le soutien matériel et psychosocial vu qu'ils partagent le fardeau de soin avec les établissements de santé qui manquent d'effectifs.

L'épidémiologie et le VIH/SIDA

Un système de contrôle est nécessaire afin de tracer des facteurs qui déterminent et évaluent l'impact des politiques et des interventions. La recherche sur le comportement est utile dans un contexte africain vu qu'elle fournit des avantages dans la formulation de programmes appropriés à la prévention, le soin et le traitement. Ce dernier est nécessaire dans le développement des meilleurs usages dans le contexte africain. Les recherches sur le comportement deviennent de plus en plus populaires vu qu'elles complètent bien les recherches prénatales et elles sont utiles pour faire des points de référence.

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ABSTRACT

The Microbicide Division of the Department of Medical Microbiology at MEDUNSA, South Africa, recently completed a phase II expanded safety trial of the candidate microbicide Carraguard. A microbicide is a vaginal product that women might use, if proven safe and effective, to protect themselves from HIV and possibly other sexually transmitted infections (STIs). The study participants were from Ga-Rankuwa and its neighbouring areas, an historically disadvantaged residential township near Pretoria. We conducted six focus group discussions with phase II trial participants to evaluate their experiences with trial participation and their psychological needs. Participants spontaneously talked about their experiences with the study gel and speculum examinations. They felt that they had received high quality medical care. They indicated that their personal hygiene and knowledge of the female reproductive system, HIV and other STIs had improved, which helped their families and empowered them as women. Participants valued being able to discuss their anxiety about HIV/AIDS with study staff. They felt that the study provided them with a supportive environment in which their personal problems (not necessarily restricted to HIV/AIDS) could be addressed. Some recommended that the study staff improve their professionalism and punctuality. They suggested the formation of participant support groups, and expressed a preference to remain involved in the trial. Some participants appeared to have become dependent on services provided during the trial. We have taken the results of these focus group discussions into account during planning for a phase III efficacy trial of Carraguard to be conducted in the same and other similar communities.

Keywords: HIV prevention, South Africa, microbicide, ethical challenges in microbicide trials.

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RÉSUMÉ

La Division de Microbicide du Département de Microbiologie Médicale de l'Université Médicale d'Afrique Australe, MEDUNSA, Afrique du Sud, a récemment accompli la phase II de l'épreuve de sûreté renforcée du candidat microbicide Carraguard. Un microbicide est un produit vaginal que les femmes pourraient employer, s'il est prouvé sûr et efficace, pour se protéger elles-mêmes contre le VIH et probablement d'autres infections sexuellement transmises (STIs). Les participantes à l'étude étaient de Ga-Rankuwa et de ses environs, une banlieue noire résidentielle historiquement désavantagée près de Pretoria. Nous avons conduit des discussions en six groupes d'étude avec les participants à la phase II de l'épreuve pour évaluer leurs expériences concernant la participation à l'épreuve et leurs besoins psychologiques. Les participantes ont spontanément parlé de leurs expériences relatives aux études du gel et aux examens du speculum. Elles ont estimé qu'elles avaient reçu le soin médical de haute qualité. Elles ont indiqué que leur hygiène et connaissance personnelles du système reproducteur femelle, de VIH et de tout autre STIs s'étaient améliorées, qui ont aidé leurs familles et les ont émancipées comme femmes. Les participantes ont estimé qu'elles étaient en mesure de discuter leur inquiétude au sujet de VIH/SIDA avec le personnel de l'étude. Ils ont estimé que l'étude leur a fourni un environnement de soutien dans lequel leurs problèmes personnels (pas nécessairement limités au VIH/SIDA) pourraient être adressés. Certaines ont recommandé que le personnel d'étude améliore son professionnalisme et ponctualité. Elles ont suggéré la formation des groupes de soutien de participantes, et ont exprimé leur préférence de rester impliquées dans l'épreuve. Quelques participantes ont semblé être devenues dépendantes des services fournis pendant l'épreuve. Nous avons tenu compte des résultats de ces discussions de groupe d'étude pour la planification de la phase III de l'épreuve d'efficacité du Carraguard qui devra être conduite dans la même communauté et d'autres communautés semblables.

Mots clés: prévention de VIH, Afrique du Sud, microbicide, défis éthiques dans des épreuves de microbicide.

Background

The Microbicide Division of the Department of Medical Microbiology, MEDUNSA, South Africa, recently completed a phase II expanded safety trial of the candidate microbicide Carraguard gel (Population Council, New York, USA). Carraguard is a carrageenan-based gel made from a seaweed extract. It is inserted into the vagina using a disposable, plastic applicator. If proven safe and effective, it is hoped that women can use it to protect themselves from HIV and possibly other sexually transmitted infections (STIs). This would be a significant breakthrough in HIV prevention, because many women find it difficult to negotiate condom use with their partners (van de Wijgert & Coggins, 2002).

The study participants were from Ga-Rankuwa and its neighbouring areas, a historically disadvantaged residential township next to MEDUNSA, approximately 45 km northwest of the city of Pretoria. The trial was conducted in the Ga-Rankuwa community because of its high HIV prevalence rate — 19% of women screened for the phase II trial tested HIV

positive (Coetzee, Hoosen, Blanchard, de Kock, Sebola, Friedland *et al.*, 2002). This community is therefore in need of novel HIV prevention strategies such as microbicides and HIV vaccines.

Implementing microbicide trials is challenging from both a methodological and ethical point of view (Mauck, Rosenberg, Van Damme & The International Working Group on Microbicides, 2001; Kilmarx & Paxton, 2003). For example, in addition to the microbicide being studied, researchers are ethically obliged to provide all study participants with interventions that are known to reduce HIV risk, such as condom promotion, voluntary HIV counselling and testing, safer sex counselling, and treatment of curable STIs and vaginal infections (De Zoysa, Elias & Bentley, 1998; Potts, 2000; De Zoysa, Elias & Bentley, 2000; van de Wijgert, Elias, Ellertson, McGrory, Blanchard, Friedland *et al.*, 2000; Pollack, Pine & Beattie, 2000; Lurie & Wolfe, 2000; Stein, Meyer & Susser, 2003; Padian, 2003; Jones, van de Wijgert & Kelvin, 2003). In the phase II trial, we provided all of these services to the participants free of charge. However, the study counsellors noticed early in the

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trial that many study participants were in need of more extensive psychological support, often not directly related to trial participation or HIV/AIDS. The study counsellors addressed these needs as best they could by providing support themselves or through referrals. However, while many consider providing participants with medical and psychosocial services essential, providing extensive services that are otherwise not available in the trial community may also be construed as undue inducement (CIOMS, 1993; World Medical Association, 2000; Pollack *et al.*, 2000).

Several studies have shown that ensuring truly informed consent is challenging, particularly when working with vulnerable populations (Friedland, McGrory, Marumo, Sebola, Magwaza & de Kock, 2002; Qwana, Morar, Mantell & Ramjee, 2002; Coletti, Heagerty, Sheon, Gross, Koblin, Metzger *et al.*, 2003). Participants often have difficulty understanding complex research concepts (such as randomisation and placebo), and 'wishful thinking' is common. For example in microbicide trials, participants often believe that they are receiving an active microbicide, even though the efficacy of the microbicide under study is not known, and they could have been randomised to the placebo group. Furthermore, it is not yet clear how best to involve male partners in microbicide trials without compromising the autonomy of the female participants (van de Wijgert, Khumalo-Sakutukwa, Coggins, Dube, Mwale & Padian, 1999; Coggins, Blanchard & Friedland, 2002).

To prepare for future microbicide trials in the same and similar communities close to MEDUNSA, we conducted focus group discussions with experienced phase II trial participants to further investigate these topics. This paper presents the focus group findings.

Method and process

Phase II expanded safety trial of Carraguard

We conducted a phase II, triple-blind, randomised, placebo-controlled, expanded safety trial of the candidate microbicide Carraguard at two sites in South Africa: Ga-Rankuwa near Pretoria and Gugulethu, Cape Town. Women were eligible for trial participation if they were 18 years or older, not pregnant, HIV-negative, STI-free (women had to be treated before being enrolled in the trial), planning on living in the study area for at least 1 year, not participating in any other clinical trial, and if they had

had no genital tract abnormality or surgery in the previous 6 weeks. They were also required to understand and agree to undergo the study procedures, including regular HIV testing and being informed of the test results, and regular gynaecological examinations. Written informed consent was obtained from all women who were eligible and agreed to participate.

In Ga-Rankuwa, a total of 200 women were recruited. Half of the women were randomised to Carraguard gel and the other half to a matching placebo, methyl cellulose gel. Women were asked to insert one applicator of study gel three times a week (with or without sex), and to use study gel with condoms every time they had sex. They were asked to visit the study clinic monthly for a minimum of 6 and a maximum of 12 months. At each study visit, they underwent HIV and safer sex counselling, a blood draw for HIV testing (quarterly), a speculum exam including sampling for a variety of reproductive tract infections, a face-to-face structured interview regarding their sexual behaviour and use of study gel and condoms, and they were given new supplies of study products. Participants regularly interacted with the following members of the phase II study staff: a receptionist, administrative staff, study coordinator, research nurses, interviewer/counsellors, and a community liaison officer. Study staff communicated with participants in the local language (Setswana) and/or English. Most of the participants could read and write.

Focus group discussions

We planned to conduct eight focus group discussions with randomly selected phase II participants, but we reached information saturation by the sixth group. The six groups varied in size from nine to 12 participants, and included a total of 64 of the 200 phase II trial participants. Written informed consent for the focus group discussions was obtained from each volunteer and verbally confirmed at the beginning of each discussion.

The discussions were conducted in local Setswana. Two facilitators led the discussions and two assistants audio-recorded them and took notes. The facilitators and assistants were female, local Setswana speakers, and independent from the phase II trial staff. To minimise courtesy and other biases, they had had no prior contact with the study participants or study staff. The

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facilitators were senior MSc Clinical Psychology students at MEDUNSA who had experience with facilitating group discussions. The tape-recorded discussions were transcribed verbatim and translated into English.

The facilitators first explained the main objectives of the discussion to the group and then gave each participant a chance to give feedback about her trial experiences. These spontaneously mentioned experiences were recorded on a flipchart and discussed in the group. Thereafter, the facilitators continued the discussion using a semi-structured moderator's guide, including the following main focus areas:

- In what way did you, your partner, and your relationship benefit from the study?
- What did you and your partner like and dislike about the study?
- How did you relate to study staff and what they did?
- How did you relate to study concepts, study procedures, and the study gel?
- What improvements or changes could be made?
- What did the study not cater for that you would like to be included in future studies?

We conducted a qualitative, thematic analysis of the transcripts and flipcharts.

Results

Spontaneously raised topics

Participants in one group spontaneously gave feedback about their experiences with the monthly gynaecological examinations. Their opinions about the speculum examinations varied. Some women reported experiencing discomfort when certain nurses inserted the speculum; others thought that the discomfort could be related to the participant herself being tense and anxious during the examination. Yet other women thought that the discomfort could have been the result of the wrong size speculum being used; others were not aware that the speculum came in different sizes. A few women claimed that they were never questioned about their gynaecological history during the clinical examination whereas others said that they were. This gave rise to a heated debate in the group.

In three groups, the participants spontaneously talked — with enthusiasm — about their experiences using study gel. (Note: at the time of these discussions, the

women did not yet know which study gel they had used). In one of these groups, some participants felt that the gel enhanced sexual pleasure by acting as a lubricant and by facilitating contraction of vaginal muscles. Others thought that the gel tended to be messy, dripping out after insertion, making them feel wet and uncomfortable. It is not clear from the data which of these opinions about the gel predominated. Some male partners had complained about the wetness, thereby causing concern among the women that gel use might, in some cases, have a negative effect on sexual relationships. In a second group, participants said that they sometimes even stopped using study gel after their partners complained. A few women from a third group reported having had difficulty squeezing all the gel out of the applicator. They recommended that the applicator opening be widened. One woman from one of the groups thought that the gel has cleansing properties; another reported a marked reduction in menstrual pain when using study gel. The majority of women in a fourth group suggested that if the research were to be successful, they should be able to purchase the microbicide at a reduced price, because they took a risk by participating in the study.

Most participants in two of the groups spontaneously mentioned the high-quality medical care they received during the study. They thought that the care they received was much better than the care they would normally receive at local community clinics. When asked how the medical care could be further improved, some women expressed a wish for contraception to be provided at the study clinic; they indicated that they did not like going to local community clinics because they often felt judged by the clinic staff and were not given a choice of contraceptive methods. They also felt that the nature of microbicide trials called for free provision of contraception as a benefit of trial participation. Others suggested the addition of blood pressure and diabetes screening to the services provided at the study clinic, as well as a thorough clinical examination after completing study participation.

All participants spontaneously expressed appreciation about the generally positive interactions with study staff. Some participants in two of the groups thought that when presenting with a problem it would have been better if they could have consulted the same study nurse and counsellor until the problem had been

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resolved. In addition, they felt that they should have been allowed to choose a counsellor without fear of offending other study staff.

Results from the guided discussions

Perceived study benefits for self and partner

During the semi-structured part of the group discussions, using the focus group guide, most participants in all groups confirmed that they felt that they had received high-quality treatment for STIs and a few other illnesses during the study. This is evident from the following quotes:

- 'I received good medical examinations at no expense.'
- 'I gained knowledge of my health status.'
- 'The study provided me and my partner with effective treatment for sexually transmitted diseases.'

Most participants also indicated that their personal hygiene, awareness of femininity, and knowledge of the female reproductive system, HIV and other STIs had improved. This often resulted in improved self-esteem and self-confidence:

- 'Using the gel and discussing female sexuality with the study clinicians and counsellors have helped me improve my personal hygiene and this has improved my self-confidence.'

Almost all of the participants in all groups thought that their sexual relationships improved during the study. They cited an increased sexual drive, easier penetration when having sex, better communication with their partners, and feeling emotionally closer to them. Several women in one group said that they experienced a sense of loss when they reached the end of the study; they felt that their partners became more distant when the study gel was no longer being used.

Most participants in all of the groups thought that their partners benefited from the study in other ways as well: they gained knowledge about condom use, learned to communicate more freely about sex, were indirectly screened for STIs, and received treatment, or referral for treatment, for STIs when necessary. Some participants felt that the study staff should provide STI treatment to all male partners at the study clinic, instead of referring some of them to local community clinics, to ensure high-quality treatment. Some participants also felt that their partners should be invited for HIV testing at the study clinic.

Most women said that their partners were supportive of them throughout the study; they would, for example, often remind them to insert study gel. However, a few participants reported problems with their partners because they experienced the study gel as messy. A few women in one group indicated that their partners would sometimes refuse to use a condom during sex because they preferred to use the study gel alone, even after they had explained the risks involved. Several women indicated that the study booklet and pamphlet helped to explain those risks to their partners. They felt that even though their partners were invited to come to the study clinic for information, better efforts should be made in the future to give male partners an opportunity to ask study staff questions.

Participant relationships with study staff

Most participants in all groups reported that the study increased their knowledge about sexual transmission, prevention, and treatment of HIV and other STIs. They stated that their anxiety and fears of HIV/AIDS were addressed, and that myths and misconceptions were clarified.

- 'The knowledge that I gained from the study staff made me change my lifestyle — I can say no to unsafe sex.'
- 'The study staff gave me the confidence to convince my partner to use a condom and show him its correct use.'

Many women said that they were able to pass this knowledge on to their families, friends and community members at social clubs or at church during group discussions on women's issues, which empowered them as women. They reported improved communication about sexuality with their spouses and children. They also reported that the study provided them with a supportive environment in which their personal problems (not necessarily only related to HIV/AIDS) could be addressed.

Most participants in all of the groups said that their relationships with study staff were generally satisfactory. They experienced the study staff as supportive and even helpful with problems that were not directly related to the study. However, a few complaints surfaced as well. In four of the groups, participants indicated that some study staff sometimes appeared impatient, moody, or judgmental, and some were perceived as providing preferential treatment to certain participants. Several participants in three of the

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groups were annoyed with long waiting times and delays at the study clinic. They suspected that too many appointments were scheduled, which not only caused long waiting times at the clinic, but also exhaustion of study staff.

Participant experiences with study concepts and procedures

The focus group results indicate that most participants had a good basic understanding of the requirements of the study, including the purpose of the informed consent process and the need to use condoms during sex. For the most part participants said they appreciated receiving repeated explanations of study concepts by study staff during study follow-up; they thought that this improved their understanding of study concepts. Generally participants in all groups understood that they were at risk for contracting HIV or other STIs when not using a condom during sex. One woman, however, admitted that she had lied about condom use during the study interviews with counsellors. She was worried at the time that she would lose study benefits if the study staff found out that she had not used condoms. A few participants in three groups had difficulty understanding the purpose and need for randomisation. Many women in one group indicated that they would like to know now that the study has been completed which study gel they had used.

Participant recommendations for future studies

As noted above, participants recommended the addition of a few services offered at the study clinic, including STI treatment of male partners (in the phase II trial mostly done by referral), provision of contraception, and screening for high blood pressure and diabetes. A few women indicated that they would like to choose their own counsellor and have access to this same counsellor throughout the study. However, most participants did not have a problem with interacting with different study staff members. When asked how best to address participants' psychosocial support needs, many women from five of the groups suggested the addition of a psychologist or social worker to the study team and the formation of support groups for participants during (and even after) the study. This would enable them to share information, solve problems related to study participation, and support each other. The participants thought that these support groups should be coordinated by study staff, preferably a psychologist or social worker.

Several participants in two of the groups expressed discontent with the meal coupons that they received in order to get a free meal at MEDUNSA hospital while attending the study clinic. (Participants were given meal coupons in lieu of refreshments.) They felt stigmatised by the remarks made by cafeteria staff referring to them as 'the coupon people'. Some participants suggested that participants be given money or grocery coupons instead of meal tickets, which they could then use to buy food for their children.

Many participants in two of the groups wished for continued involvement in the study and recommended post-study follow-up visits, such as quarterly visits to check their health. Several women felt abandoned after completing the study, particularly because they no longer received the various benefits. Some women suggested that participants who completed the study be given the opportunity to assist with recruitment for the next study; they thought that this would create jobs for the many unemployed women. They also suggested that experienced phase II participants be given the opportunity to serve in the community advisory groups (CAGs) for the upcoming phase III effectiveness trial.

Discussion

The focus group discussions showed that most participants generally felt that they had benefited from their participation in the Carraguard phase II trial. They talked spontaneously about their experiences with the study gel and speculum examinations, and the high-quality services they received at the study clinic. They indicated that their personal hygiene and knowledge of the female reproductive system, HIV and other STIs had improved and that this had helped their families and empowered them as women. Participants valued the opportunity to discuss their anxiety about HIV/AIDS with study staff. They felt that the study provided them with a supportive environment in which their personal problems (not necessarily restricted to HIV/AIDS only) could be addressed. However, the participants also expressed some criticism and made recommendations for improvements in future trials. These will be discussed in more detail below.

Participant opinions about the monthly speculum examinations varied and their memories about the procedure were inconsistent. The phase II trial data

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clearly show, for example, that women were questioned about their gynaecological history at every study visit, and yet, some participants claimed that this was not the case. Furthermore, a quantitative survey with 100 experienced phase II trial participants at the MEDUNSA site showed that when asked how often they would ideally want to have a speculum examination the majority preferred monthly examinations over bimonthly, quarterly, or biannual examinations (van de Wijgert, Jones, Pistorius, de Kock, Sebola, Friedland *et al.*, 2002). We therefore hypothesise that the speculum examination is often not very well liked, but at the same time considered an essential part of high-quality medical care.

The participants stressed the importance of study staff members' professionalism and punctuality. Unfortunately, while microbicide trial staff are almost always trained in counselling, interviewing, and relevant medical procedures, they are often not trained in client management using a client-centred approach, clinic management, time management and/or stress management. Such training could greatly improve study staff ability to manage clients effectively. Furthermore, future clinic schedules should allow for unscheduled study visits, meetings, and trainings, and back-up study staff should be available to replace absent team members when necessary.

Although most participants seemed to have a basic understanding of the study concepts and procedures, not everyone seemed to understand the need for randomisation. Furthermore, it is not clear from our data whether we were able to adequately address the wishful thinking effect. For example, some women seemed to attribute their study gel experiences to Carraguard, even though they did not know at the time of the discussion whether they had used Carraguard or placebo gel. Other studies confirm that many clinical trial participants struggle to understand the concept of a randomised, placebo-controlled clinical trial (Featherstone & Donovan, 2002; Qwana *et al.*, 2002, Coletti *et al.*, 2003) and that wishful thinking is common in microbicide trials (Qwana *et al.*, 2002). This may result in a false sense of protection from HIV and increased risk-taking (Foss, Vinckerman, Heise & Watts, 2003). We tried to address these problems in subsequent trials by evaluating, improving, and expanding the informed consent and participant education process (Friedland *et al.*, 2002). Among other things, we adapted the phase II study

booklet and added a video to the participant educational materials (Friedland, Marumo, de Kock, Skoler, Ngcozela, Monedi *et al.*, 2004) for the phase III efficacy trial of Carraguard. Additional research is needed to determine how best to minimise the wishful thinking effect and improve understanding of difficult clinical trial concepts. It may also help to better educate and inform the general public about microbicides and clinical trials.

Several participants indicated that they felt abandoned at the end of the study. They were not happy about not having access to high-quality services at the study clinic. They requested post-study support groups, continued access to medical and psychosocial services, and (paid) involvement in future trials (e.g. helping with recruitment or taking part in CAGs). The fact that most study participants were poor raises ethical questions about participants becoming dependent on study services. While everyone agrees that it is important to provide good services at study clinics, it is important to strike a balance between providing good services and encouraging study participants not to become dependent on the study clinic. This may be achieved in several ways.

Firstly, it is important to ensure that participant expectations are realistic from the outset; they should be aware that a (temporary) study clinic cannot replace community services provided by clinics and other service organisations in the long run. Even if trials are conducted at existing clinics, there has to be a limit to the services provided within the context of the trial.

Secondly, research teams could help build and strengthen services in the community, and refer participants to these community services as opposed to providing all services at a study clinic. The extent to which this is possible will depend on what services are already available in the community, the willingness and availability of local governments, service providers, and community-based organisations to cooperate with the research team, and the availability of funds (e.g. funds for strengthening services in the community could be included in trial budgets). However, too many unrealistic demands on research teams could overwhelm them, and slow down the product development process.

Thirdly, the input of the community itself is crucial.

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Hence during 2002 we started discussions with the community in Ga-Rankuwa, Soshanguve and nearby communities by conducting a community stakeholder analysis and subsequently establishing CAGs. This process was started long before the phase III was to begin, in order to develop CAGs to be involved in the phase III trial plans.

CAGs have been established successfully, and have proven to be useful in several other microbicide trial communities (Kilmarx, Ramjee, Kitayaporn, & Kunasol, 2001; Limpakarnjanarat, Manopaiboon, Tharawan, Kilmarx, Korattana, Elias *et al.*, 2000).

Finally, the establishment of participant support groups, as was suggested by the participants themselves, may also facilitate self-reliance. While study team members could help establish these groups, the groups should be encouraged to function autonomously as quickly as possible to maximise self-reliance and sustainability.

The women talked with enthusiasm about the study gels, but had mixed feelings about some aspects of the gels, particularly their lubricating properties. Quantitative acceptability data from the phase II trial show that the gels were found to be acceptable overall (Blanchard, Coetzee, Hoosen, Friedland, Sebola, de Kock *et al.*, 2002). However, different women have different sexual needs and preferences, and this was evident in the group discussions. Several participants believed that they should have access to Carraguard at a reduced price because they participated in the study. Whether and how microbicide trial participants will benefit from the development of a safe and effective microbicide is a topic of intense debate among advocates, product developers, researchers, financial sponsors, and policymakers. However, research teams should make sure that their participants understand that it will still take many years before such a safe and effective microbicide is on the market (if ever). Furthermore, participants should understand that these complex, macro-level decisions involve many key players in different countries, and that it will not be clear for a long time which benefits — if any — specific trial communities might get.

In preparing for the large-scale phase III efficacy trial of Carraguard, the study team considered the recommendations made by the study participants. We decided to provide contraception at the study clinics.

We made an effort to involve male partners by including men in the CAGs, inviting men to attend community workshops on microbicides, and organising educational workshops for male partners of trial participants. However, the study team decided that it was not logistically feasible to allow each participant to see the same study nurse and counsellor throughout the study. Furthermore, results from a quantitative survey of phase II trial participants showed that the majority of them had no problem having to interact with multiple study staff (van de Wijgert *et al.*, 2002). To avoid future complaints about preferential treatment, the study team drafted a policy on how to handle such requests consistently.

In conclusion, the focus group discussions provided useful feedback to the study team and helped to prepare for an upcoming phase III efficacy trial of Carraguard in this community as well as other communities in South Africa.

Acknowledgements

The authors thank the phase II study participants (particularly those who participated in the focus group discussions), the phase II study team at MEDUNSA, and members of the phase II team at the Population Council (Charlotte Ellertson, Kelly Blanchard, Gugu Ndlovu, Heidi Jones and Elizabeth McGrory) and the University of Cape Town (Nicol Coetzee and Alana de Kock). We are grateful to the late Nsoake Ntseane for coordinating voluntary participation and written consent of the focus group participants. This publication was made possible through support provided by the Office of Population and Reproductive Health, Bureau for Global Health, US Agency for International Development, under the terms of Award No. HRN-A-00-99-00010. The opinions expressed herein are those of the author(s) and do not necessarily reflect the views of the US Agency for International Development.

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Gender and HIV/AIDS impact mitigation in sub-Saharan Africa — recognising the constraints

J Seeley, R Grellier, T Barnett

ABSTRACT

In discussions of gender and HIV/AIDS, attention has focused on prevention. This is a vital area. However, we argue that there is also a need to focus more attention on the resulting impact of the epidemic, because inequalities that promote the spread of infection are also hampering containment and impact mitigation. We propose a framework highlighting the gendered constraints exacerbated by the epidemic. These constraints are reviewed under the following headings: *Gender-specific constraints*: stemming from the specific nature of gender relations themselves, such as the availability of labour in agriculture, business and for household tasks, as well as access to services and markets, and the incidence of gendered violence. *Gender-intensified disadvantages*: stemming from the uneven and often inequitable distribution of resources between men and women, including cultural/religious conventions, and the social rules and norms that regulate property rights, inheritance practices and resource endowments. *Gender-imposed constraints*: resulting from biases and partialities of those individuals who have the authority and power to allocate resources. These include provision of credit, information, agricultural extension and health care. The differential involvement of men and women in development programmes affects access to resources, as does political participation, including involvement in the formulation of policies aimed at poverty reduction. These constraints take us beyond gender relations and sexual behaviour. But women's lives will not change in the short term. The challenges they face in mitigating the impact of HIV/AIDS will not be addressed by focusing only on their specific vulnerability to HIV/AIDS infection. Unequal gender relations and the nature of 'development' need to be changed too.

Keywords: gender, HIV/AIDS, impact mitigation, sub-Saharan Africa.

RÉSUMÉ

Pendant les discussions de sexes et du VIH/SIDA, la prévention fut le centre d'intérêt. Ce dernier est un domaine primordial. Cependant, nous débattons qu'il est aussi nécessaire de se focaliser sur l'impact de l'épidémie car les inégalités qui favorisent la dissémination de l'infection ont tendance à entraver l'enraiment de l'épidémie et l'atténuation de l'impact. Nous proposons un cadre qui met en relief les contraintes de sexes aggravées par l'épidémie. Ces contraintes sont re-examinées sous les titres suivants: *Des contraintes particulières aux genres*: découlant de la nature particulière des relations de genres, comme la disponibilité du travail en agriculture, dans les affaires et à domicile ainsi que l'accès aux services et aux marchés et la fréquence de la violence de sexes. *Les inconvénients intensifiés par le genre*: découlant de la distribution irrégulière et souvent inéquitable des ressources entre les hommes et les femmes. Ceci inclue des conventions culturelles/religieuses

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ainsi que les règlements sociaux et des normes qui réglementent les droits aux propriétés, les pratiques de l'héritage et les dotations de ressources. *Les contraintes imposées par le genre*: résultant des préjugés et des partialités de ceux qui ont le droit et le pouvoir d'assigner les ressources. Ceci inclue l'approvisionnement du crédit, l'information, l'extension dans l'agriculture et les soins sanitaires. L'écart de participation des hommes et des femmes dans le développement des programmes a une incidence à l'accès aux ressources, comme c'est le cas dans la participation politique ainsi que la participation dans la mise en place d'une politique visant la réduction de la pauvreté. Ces contraintes nous amènent au delà des relations de genres et le comportement sexuel. Cependant, la vie des femmes ne changera pas du jour au lendemain. Les défis auxquels elles font face en atténuant l'effet du VIH/SIDA ne seront pas prise en charge uniquement en se focalisant sur leurs vulnérabilité particulière vis-à-vis l'infection par le VIH/SIDA. Les relations inégales de genre et la nature du développement doivent être changés également.

Mots clés : le genre, le VIH/SIDA, atténuer l'impact, le Sous-Sahara.

Introduction

'All too often, HIV prevention is failing women and girls' said Peter Piot, Director of UNAIDS, at the launch of the Global Coalition on Women and AIDS, in London on 2 February 2004. But it is not only prevention which is failing women; access to treatment and initiatives to mitigate the impact of the epidemic are also failing because the HIV/AIDS epidemic is fuelled by existing inequalities. This inequality is not just between women and men. There are also inequalities of wealth, ethnicity, caste, age and geographical location. How can governments hope to reach their populations with antiretroviral therapy when the roads are poor and the public health system is overstretched, poorly resourced and understaffed? Add to this the reality of corruption which means that resources may not go where they are supposed to, and it is apparent that even if all governments have access to 'adequate' supplies of antiretroviral therapy tomorrow, that alone cannot mitigate the impact of HIV/AIDS.

There is a need to highlight the importance of taking gender inequality seriously at all levels and addressing the resulting inequities. This is an important part of mitigating the HIV/AIDS epidemic. There is a link between unequal gender relations highlighted in the literature on sexual behaviour and HIV/AIDS, and the conduct of women and men's livelihoods.

In 2003 we reviewed the vast amount of literature generated on 'gender and development', and more specifically in recent years on 'women or gender and HIV/AIDS' (Seeley, Sutherland, Dey & Grellier, 2003). We then carried out a rapid survey of on-going initiatives to mitigate the impact of the HIV/AIDS

epidemic in four countries in Africa: Uganda, Tanzania, Malawi and Zambia. These countries were chosen on the basis of known high impact levels of HIV/AIDS and accessibility. Ten days were spent in each country, visiting a total of 34 organisations involved in reducing the impact of HIV/AIDS on rural livelihoods, to gain an overview from people working in these organisations about the work they are doing (Seeley *et al.*, 2003, pp. 41-86¹).

From discussions with people working with these issues in Africa and South Asia it is apparent that 'gender' analysis and subsequent interventions have changed little over the years. Discussion of women's lack of access to information, skills, assets, credit, technology and health care continues. But these constraints remain the most critical facing women in many countries, particularly in the face of the HIV/AIDS epidemic.

We describe below a range of gendered constraints influencing mitigation of the impact of the epidemic and provide an overview of the areas where gender inequalities need to be challenged.

Framework for the analysis of gender constraints in rural livelihoods as they impact on HIV/AIDS mitigation

HIV/AIDS exacerbates the constraints that men and women face in making a living in rural communities.² Kabeer and Tran Thi Van Anh (2002) have developed a typology for assessing the nature of gendered constraints, which is useful for identifying areas that might be amenable to policy intervention:

- *Gender-specific constraints* stemming from the specific nature of gender relations themselves

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- *Gender-intensified disadvantages* stemming from the uneven and often inequitable distribution of resources between men and women, as well as boys and girls
- *Gender-imposed constraints* resulting from the biases and partialities of those individuals who have the authority and power to allocate resources.

Gender-specific constraints

Labour

Loss of labour is often highlighted as one of the main economic impacts of HIV/AIDS (for example Barnett & Blaikie, 1992; FAO 2002; Gillespie, 2001; Lisk 2002). In Kenya, FAO (2002, p.2) reports that ‘the latest figures from the Ministry of Agriculture and Rural Development predict that if present trends continue the total number of lost workdays in the agricultural sector due to HIV/AIDS will reach 329 000 person years in 2020’. A recent study by Fox, Rosen and McCleod (2004) details the costs of these losses in the commercial sector in Kenya. Labour is not only lost from agriculture and business, it is also lost because of care or shifting time and energy to other tasks (like child care) because of the loss of the person who performed such reproductive roles.

Barnett and Blaikie (1992) were among the first to focus attention on the vulnerability of farming systems to labour loss. At the household level the labour input of somebody with HIV/AIDS disease gradually diminishes as s/he succumbs to sickness, and the labour of other household and extended family members is diverted to care for the person who is sick. The death of a productive member of the household constitutes permanent loss of one source of labour. Harvey (2003, p.14) summarises the findings of four studies on the impact of AIDS on agricultural production and household labour (Table I.)

Whitehead and Kabeer (2001) have argued in relation to sub-Saharan Africa that women’s access to labour and/or to the capital to mobilise labour is often more central to well-being than access to land. Gender roles, which define the allocation of productive and reproductive roles in the household, contribute to this shortage of labour.

But when considering the impact of HIV/AIDS on labour, it is important not to focus exclusively on so-called productive roles. When people are sick or die the socially reproductive as well as productive labour has to be done by someone else. This socially reproductive labour is the foundation and precursor to economic production. Without social reproduction — or people, positions and beliefs — economic production is not possible. In the (considerable) literature on ‘AIDS orphans’ the role of grandmothers (and sometimes grandfathers) as carers who take on the reproductive role for their lost children, particularly daughters and daughters-in-law, has been highlighted (Appleton, 2000; Hunter, 2000; Smith, 2002; USAID/UNICEF/UNAIDS, 2002). Child or adolescent managed households are also described in this literature (Daniel, 2003).

The HIV/AIDS epidemic has meant that labour constraints have certainly increased. But issues around access to and control of labour for certain people and types of household predate HIV/AIDS. Indeed, access to labour, particularly women’s labour and how it is used as a ‘bargaining tool’, is a key illustration in Kandiyoti’s explanation of the patriarchal bargain. She describes how women may observe a rigid adherence to gender norms and the sexual division of labour in return for security and protection: ‘protection in exchange for submissiveness and propriety’ (Kandiyoti, 1988, p. 283).

TABLE I. THE IMPACT OF HIV/AIDS ON AGRICULTURAL PRODUCTION AND HOUSEHOLD LABOUR

Study	Impact on agricultural production and household labour
Yamano et al., 2002 Kenya	Death of a household head decreased net output by 68% and a spouse’s death reduced total net output by 46%
Kwaramba, 1997 Zimbabwe	A study of the smallholder sector which found reductions in production in households with an AIDS death ranging from 61% for maize to 29% for cattle
Shah et al., 2002 Malawi	Decreased agricultural productivity was experienced by 72% of households affected by chronic sickness
Tibajjuka, 1997 Tanzania	When a household contained an AIDS patient, 29% of household labour was spent on AIDS-related matters including care of the patient and funeral duties

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Mobility

The influence of gender roles and relations on mobility is most apparent in societies where women observe some form of culturally prescribed seclusion. But even where women do not observe 'purdah', the division of productive and reproductive roles between women and men (as neatly illustrated in Moser's [1993] 'Triple Role'), will influence the ease with which either women or men can move into the other's sphere of work and responsibility. Although women's mobility is often curtailed by childcare responsibilities they may also have to cope with an unfamiliar 'public' sphere of government officials and private enterprise, while for men it may mean interacting in a more private sphere of child care. Of course, it is impossible to generalise. There are regional cultural differences, for example in many parts of Africa market women operate very successfully in the public sphere. But gendered roles often prescribe where you can go and what you can do and cultural stereotypes may stigmatise the independent movement of women, with restrictions on the movement of women at night or in unfamiliar areas often being reinforced by the fear or threat of violence. Not only may movement be prescribed but also the means of movement. Thus in south-west Uganda women affected by HIV and AIDS were discouraged from riding bicycles. This had serious implications for widows wishing to take over their deceased husbands' petty trade.³

Mobility constraints aggravate gender inequalities in access to medical treatments and health services, which limit women's access to HIV/AIDS treatment, care and support (including antiretroviral therapy) (Gilks *et al.*, 1998; Koestle, 2002). Access to agricultural extension services, the judiciary and financial services may also be affected. Such access may be restricted by distance of travel but it is also influenced by gender-imposed constraints, such as norms over who is perceived to be the correct person in a household to access such services. This particularly affects young or widowed women.

Greater mobility may not, of course, always be perceived as such an advantage. It was clear from interviews in Uganda, Tanzania, Malawi and Zambia (Seeley *et al.*, 2003) that, as a result of the impact of HIV/AIDS, women's mobility is no longer largely confined to key life stages — a known feature of many societies. A new and significant implication is

that women's levels of mobility are occurring at different ages largely as a result of their lack of secure access to resources, education and employment opportunities.

Violence

Domestic violence is often the product of strained gender relations. As such it is a part of the gender-specific constraints experienced by women and also, not infrequently, by men — particularly if one considers 'violence' in the broadest sense including, for example, verbal abuse. Such violence includes any act of force or coercion that gravely jeopardises a person's life, body, psychological integrity or freedom. But as Heise (1993) observes, gender violence against women often occurs in the service of perpetuating male power and control. Gender violence may include rape, battery, homicide, incest, psychological abuse, forced prostitution, trafficking in women, and sexual harassment (Gordon & Crehan, 1998; Heise, 1993).

Koenig *et al.* (2003) have recently reported that in Uganda about one in three women living in rural Rakai district experienced verbal or physical threats from their partners, and 50% of them received injuries. This finding is significant. It is based on a sample of 5 109 women and 3 881 men. Female to male violence did occur, but was less common.

On the basis of the research reported here, we underline the strength of links between domestic violence and the consumption of alcohol, as well as a partner's perceived risk of HIV infection.

Where violence is mentioned, it is usually in the context of the spread of the epidemic.⁴ However, we should not lose sight of the fact that the consequences of the HIV/AIDS epidemic, which require mitigation, are themselves causal factors for further transmission (Zierler, 1997). A Human Rights Watch report (2002) on HIV transmission to girls in Zambia notes that because of poverty, girls, particularly orphans, often take up domestic service where they are vulnerable to sexual abuse. Interviews in Tanzania and local press reports (Seeley *et al.*, 2003) indicate that young orphaned boys migrating to urban and peri-urban areas are also increasingly vulnerable to sexual abuse through child prostitution.

Hence the circle is closed between efforts to mitigate the poverty that results from the loss of the child's

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family and their own later infection. Desperation, which comes from poverty and the need to survive in the wake of the loss of family members, may also lead women and girls into exploitative, although non-sexual, relationships: long working hours, poor conditions and low wages about which they are in no position to complain.

The Human Rights Watch report cited above describes a breakdown in social values that has contributed to a rise in sexual violence and coercion because of the strains of the economic situation and the loss of social safety nets for children. This has been reported in great detail in relation to HIV/AIDS in Tanzania by Philip Setel (1999). Purna Sen (1998) in research on domestic violence in Calcutta describes interventions to stop domestic violence. She found that there were three important contributors to the resolution of physical and sexual abuse in intimate relationships. The first is networks: contacts with family, neighbours, with women's organisations and with legal advice centres. The second, women's education beyond primary level, was very strongly associated with cessation of violence. The third is employment, which allowed women to 'set up independent lives' away from a violent partner.

HIV/AIDS erodes social safety nets that are important not only for the care of the sick and orphans but offer support and protection in addition. HIV/AIDS also disturbs the education of children who may have to help in fields, the home or earn a living rather than attend school (Bennell 2003; Mutangadura, Mukurazita & Jackson, 1999).

Gender relations, men and masculinities

Discussion on men and masculinities in the literature on HIV/AIDS tends to focus on sexual relations between women and men, and women's 'lack of power to determine where, when and whether sex takes place' (Mane & Aggleton, 2001, p. 26). The linkage between gender-based violence and HIV/AIDS has turned attention to how perceptions of 'what it is to be a man' in many cultures might be reconsidered so that to be 'masculine' may not just mean 'macho', powerful and strong. The idea of being strong, a true figure-head or patriarch, is linked to other facets of masculinity such as the value put upon being the sole 'bread winner' upon whom the family depends (Connell, 1995).

But concern about transforming concepts of masculinity is not only about addressing gender-based violence, just as gender relations are not only about sex. Recent growth of research about and discussion of 'masculinities' has evolved from recognition that to address inequalities in gender development one must not just address one gender, women; one also needs to look at men in development — and involve them.

While there is a serious and frightening reality behind the stereotypes of what male behaviour is, too often these stereotypes become the only way in which all men are characterised. What needs to be questioned is how representative these images are, which men are they representative of and why, and which men do they misrepresent and why? Do these negative stereotypes breed negative behaviour? For example, during discussions in Uganda we learned that according to the past experience of the AIDS/HIV Integrated Model District Programme (AIM), the tendency for gender to be translated into 'women only' projects (understandably) created resentment among men. This resentment may have taken on various negative forms — drinking, domestic violence, preventing women from accessing household income — serving only to reinforce both the negative behaviour and negative views of 'what men are like'. This concern finds substance in the work of Silberschmidt (2001) who observed a growing disempowerment of men hidden behind the stereotypes in East Africa: 'With sexual identity being a major element in men's social identity, sexual exploits by disempowered — not to say emasculated — men in Kisii and Dar-es-Salaam seem to be a key element in terms of male identification and central to men's self-esteem, social value and masculinity. With men's control over women being an important social index for their masculine reputation many seem to have "chosen the lifestyle" [...] of (aggressive) sexual behaviour with multiple partners' (2001, pp. 667–8).

Chant (2000) highlights some arguments for male inclusion in 'gender and development' which are relevant to the argument that men should be included in discussions of 'gender and HIV/AIDS' not only as sexual partners of vulnerable women, but also as partners in the making and sustaining of livelihoods. Chant says that changing global structures of production and reproduction have weakened 'traditional icons' associated with male dominance, such as the roles of breadwinner and head of family.

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She highlights the fact that in a number of countries boys have falling rates of educational attainment (falling behind girls in many subjects, even science where they had been traditionally stronger). Whether it is positive or negative, what is happening to men and boys affects women and girls too. She argues that '[W]omen rarely operate as autonomous individuals in their communities and daily lives so programmes which take into account, and incorporate male members of their households and neighbourhoods may well make interventions more relevant and workable' (Chant, 2000, p. 12).

Gender-intensified disadvantages

Land

The gender-based constraints for women in accessing and controlling land and property have been extensively discussed. Whitehead and Tsikata (2003) provide an authoritative overview of these debates for sub-Saharan Africa, but interestingly do not mention the impact of HIV/AIDS. They set their review against the backdrop of 'local populations all over Africa [are] being affected by pressure on land resources' (2002, p. 2). Studies which are specifically on HIV/AIDS and land tenure or use (Drimie, 2002; Mbaya, 2002; Rehmtulla, 1999; Rugalema, Weigang & Mbwika, 1999) focus on the scarcity of labour to work the land and sales/leasing of land to cope with the impact of HIV/AIDS, although an impressive study from Kenya (Aliber *et al.*, 2003) takes into account the impact of land scarcity on inheritance in the areas studied. The question of women's inheritance of land is often raised in both the general literature on land rights and the emerging work on land and HIV/AIDS, because the control over land can strengthen an individual's fallback position, not only through direct access to the resource but also by converting the land to other forms of capital (Agarwal, 1997).

What complicates the discussion on gender and land is the diversity of ownership and inheritance patterns. In many African countries a dual legal system consisting of Western-based statutory law and customary law exists with overlapping and sometimes conflicting jurisdictions. Customary tenure usually allows people to transact in land and supports a range of 'derived and secondary rights, within the household but also across wider communities' (Quan, 2002, p. 10). In

many communities in East and Southern Africa, for example, where customary systems are patrilineal and patriarchal, a household's access to land is frequently dependent on the presence of an able-bodied male adult. So, in cases where the household headship passes from a male to a female, because of the death of the male, the ability of that household to access and retain the land cannot be guaranteed. Mbaya (2002) reports that among women living in the matrilineal belt of Malawi, Zambia and Tanzania, where customary user-rights are held by and through women, a woman's tenure is at the discretion of her maternal uncle. 'Of particular significance to women in this situation is the fact that the apparent primary rights to land that she enjoys neither translate into the power to control the use of the land nor its products' (Mbaya, 2002, p. 8).⁵ This uncertainty of tenure and use has prompted many calls for land reform, arguing that women's rights require strengthening under both customary and statutory systems of tenure. The Presidential Commission in Malawi has noted public preference for a rule that would permit direct inheritance to all categories of property by surviving spouses and children in both matrilineal and patrilineal systems (Mbaya, 2002, p. 7).

Concerns over land and property grabbing from widows and orphans is widely referred to in the general literature on the impact of HIV/AIDS: 'Where property grabbing is rife, the poverty of the surviving remnants of households is deepened making recovery all the more difficult' (Baylies, 2002, p. 619). The few studies that specifically discuss the impact of HIV/AIDS on land tenure present a mixed picture of 'land grabbing', largely because of the complexity in land tenure practices noted above. Rehmtulla (1999, p. 3) observes that 'the status of widows in Tanzanian society is very low [...] incidences of relatives of husbands grabbing property that widows have accumulated have been witnessed'. In Kenya, Aliber *et al.* (2003, p. xiv) comment that: '[W]hile the tenure and security of widows and orphans is the most visibly affected by HIV/AIDS, different types of widows have different degrees and types of vulnerabilities and other sub-groups also have distinct experiences that must not be ignored, for example separated and divorced women, especially those with children and young men from land poor households whose prospects of acquiring sufficient land to support their own families are poor.'

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Interviews in Uganda, Tanzania, Malawi and Zambia revealed a mixed picture on the importance of 'land grabbing'. Some, like members of the organisation 'Women for Change' in Zambia, told us that land grabbing from women is on the increase because of HIV/AIDS, while Oxfam Zambia said that land is not an issue because it is plentiful in rural areas and women can appeal to statutory law.⁶ We interviewed NGOs in Malawi and Uganda who are helping women legally retain ownership of assets, including land, but their services are limited and not accessible to women living in rural areas.

Given variations in tenure systems and the availability of land it is hardly surprising that such a mixed picture emerges. Who says what about the land situation will also depend on who they are and how they may or may not be disadvantaged by the existing system. It is also important to remember that for landless households in many parts of the world the opportunity to inherit land is a distant dream and not something necessarily conceivable in women's own assessment of their rights and entitlements (Grace, 2002). Land may provide an important part of that security but other rights are also important. A secure place to live with the family and a livelihood with which to support them are important for mitigating the impact of HIV/AIDS.

A review of the legal framework on land tenure underlines the gendered disadvantage of women and, as emphasised in the work of Whitehead and Tsikata (2003) and Walker (2002), policy and legislative change is required. Ensuring that women (and men) and children are aware of their existing rights to land and property, particularly where customary and statutory practice conflict and where the legal framework is modified, is a difficult but vital task.

Financial assets/property

Illness and death from HIV/AIDS invariably cause depletion in household resources. In the study by Steinberg *et al.* (2002) of 771 AIDS households in South Africa, two-thirds of the households reported a fall in household income as a result of having to cope with HIV/AIDS. Similar results have been found in other studies (Desmond, Karen & Gow, 1999; Seeley, 1993; UNAIDS, 2000). Assets, when people have them, are sold or pawned to cover a shortfall in income. This quite obviously leaves less money for investment in education and capital accumulation, let

alone to use for health care and day to day consumption, to mitigate the impact of the epidemic. In her study of rural livelihoods in three villages in Uganda, Dolan (2002) notes that capital constraints contribute to gender differences in the capacity of male and female headed household to invest time and resources in 'non-farm' income generation. Female heads, specifically, expressed a desire to cultivate new crop varieties. However, the majority lacked resources to purchase inputs (seeds, fertilisers, pesticides) and/or hire the labour to assist them (Dolan, 2002). Decreased income, increased costs, and the ability of the household to survive as a viable unit have been linked to a number of different household characteristics. A study in Cote d'Ivoire (Bechu, 1998) found that the fall in expenditure on basic needs was greater if the infected adult was female.

Lacking the cash to hire labour for agricultural production compounds the labour shortages noted above. Baylies (2002, p. 622) comments 'when asked about relatives helping out [with agricultural production] when HIV/AIDS afflicts a household, another laughed with derision, asking "who is going to help you in Zambia if you have no money?"' Lack of financial capital and saleable assets is a major part of poverty, often compounded by a lack of social support, skills and education. The relationship between poverty, gender and HIV/AIDS is broader than financial poverty, and draws together the different levels of 'gendered constraint', so we return to this below.

Gender-imposed constraints

In this section we look briefly at constraints imposed because of the power of those who have the authority to allocate resources.

Access to credit and enterprise development support

Gender-based institutional barriers that exclude women from formal credit have been widely documented (for example, Buvinic, Sebstad & Zeidenstein, 1979; and FAO, 1984). Gender imbalances are perpetuated by various social norms and practices, sustained by male control of property and, in most places, patrilineal inheritance, which deprive women of collateral. An IFAD study (2000) on women's access to formal financial services in Ghana found that poor farmers have difficulty accessing formal credit services because of the costs of the trip to the bank — both in terms of time and

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money. Securing a loan may take many trips. Women are further multiply disadvantaged because: they have to find someone to take care of children and household chores while they travel to the bank; while at the bank they find male staff intimidating (90% of staff are men); their lack of control of assets limits their eligibility for a loan; low literacy skills make it difficult for many women to cope with the paper work; and 'Since the banks' ability to lend has been constrained by inflation-induced de-capitalisation, often there are insufficient funds available to finance loan requests. In such cases, it is the women who receive lowest priority.' (www.ifad.org/gender/learning/sector/finance/42.htm; p. 2) In a review paper on 'gender biases in finance', van Staveren (2001, p. 10) adds that 'financial markets tend to ignore the role of women in the supply and demand of finance, and government financial policies often suffer from inherent gender biases'. Lack of access to cash, savings facilities and loans undermine female (and household) economic security and enterprise.

Even small-scale financial services can help to counter vulnerability to seasonal, domestic and other crises and women's lack of access to resources and socio-economic opportunities generally. Many credit schemes have been designed and implemented to facilitate access to financial resources for the rural poor, particularly women. Indeed, women's 'savings and credit' groups are the cornerstone of many Women in Development focused projects. One of the strategic objectives in the Beijing Platform of Action is to provide women with access to savings mechanisms and institutions and to credit. Achievements of these credit programmes have been limited because lack of working capital remains a major constraint for the poor. HIV/AIDS makes the situation considerably worse.

A number of initiatives to provide micro-finance to AIDS-affected communities have emerged in recent years in Africa and elsewhere. While welcoming these initiatives, experience to date of the ability of such approaches to consistently reach the poorest women (which means not only enabling them to join groups but ensuring that they can sustain membership), should make us cautious about viewing micro-credit as a panacea for HIV/AIDS mitigation for poor women and men.

Access to health care and treatment

Health and fitness are important assets for everyone. Days lost to sickness can undermine the livelihoods of both women and men. Access to health care can be strongly gender-differentiated because of mobility, as noted above. But there are also differences in the type of health service accessed. Cornwall (1999) reports evidence suggesting that men have better access to curative care, while women are more likely to benefit from preventive care during their reproductive years. Older women's health needs are often neglected — of some additional significance when charged with the care of orphans. But gender issues arise not only in respect of access, or the mix of services available, they are also directly related to the consequences of gender inequality. Men may play a determining role in decisions over when and where to seek curative care in several cultural contexts (Koblinsky, Timyan & Gay, 1993) particularly when cost is involved. Health services in many places continue to be dominated by men in senior positions (doctors/consultants) with women as nurses and the ones caring for the sick at home. 'Women form a high proportion of informal and community-based health providers [...] as well as lower-level professional or ancillary staff in formal health services' (Oxaal & Cook, 1998, p.16)

Differential access to health care has an impact on the care of people with HIV/AIDS-related infections. It also has an impact on access to antiretroviral therapies. Supplies of and access to antiretroviral therapy are hotly debated subjects at the moment internationally and nationally, a debate which is beyond the remit of this paper. However, the fact that access to treatment is already influenced by gender, socio-economic status and geographical location is playing a part in access to antiretroviral therapy. Morales, Pedraza and Souteyrand (2003, p. 454) observe that 'success of scaling up access to antiretroviral therapy will depend not only on financial issues but also on issues regarding the organisation of the health system itself, especially the drug distribution process'. Barnett and Grellier (2003, p. 84) comment that the 'logistic and cost challenges of any strategy that includes ARVs [antiretroviral therapy] are considerable', and those challenges are made considerably worse by existing inequalities. The gender-imposed constraints, which exist in many health services, can be expected to compound the problems of access.

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Development projects and women and men

Over the last few decades, the gender-imposed constraints of development have become more apparent as gender issues have gained increased prominence in development debates. Development specialists have found a voice to insist that women should be integrated into the development process, which has resulted in an increasingly high profile for women's issues and gender issues within development policies, programmes and projects. Meanwhile, women from southern countries are increasingly involved in pushing the gender agenda in government departments, NGOs and in donor organisations working in their countries.

These issues have been highlighted at the International Women's Conferences, most recently in Beijing, and through UN conventions such as the 'Convention on the Elimination of All Forms of Discrimination against Women' adopted by the UN General Assembly in 1979, which came into force as a treaty on 3 December 1981, 30 days after the 20th member nation ratified it.

Because of the inherent inequalities that persist in society, gender bias continues in many development initiatives, particularly where control of resources determines who participates in particular development activities. But this bias does cut both ways. A focus on women's programmes, because they are seen as more efficient savers and investors than men, runs the risk of alienating men and over-burdening women (Cornwall, 2002, p. 226).

Ann Whitehead (1999) has been among the more vocal critics of the 'lazy man in Africa' approach of some gender and development commentators. In a discussion of the literature of gender spending patterns in the household in Africa, Whitehead and Kabeer (2001, pp. 19-20) observe: 'It is the case that men's income generation either through agriculture or off-farm far exceeds that of women's. While these incomes are not pooled, neither are they spent entirely selfishly. Empirical evidence from various studies suggests that they may be spent on investment [...] and also on basic needs for household and family members, including food [...]. It is also worth noting that while the 'booze-and-fags' effect may partly reflect more individualised spending patterns by men, it may also signify the use of alcohol and tobacco as a

form of investment in social networks and a medium of exchange in mobilising work parties.'

Ensuring that men are not left out of 'gender mainstreaming in HIV/AIDS' is not only important to address transmission of infection but also to ensure that men and boys are supported and engaged in the mitigation of the impact of the epidemic. People who are left out of development initiatives can become resentful opponents and, if they are in positions of authority, it can make matters worse for groups receiving support. Stories abound of women being left worse off after a short- or medium-term initiative that men perceived to have disturbed cultural or family norms. Working with both men and women also has the benefit of relieving women's burden.

Political participation

The Beijing Platform of Action and the Millennium Development Goals call for greater political participation of women in politics. Women continue to be in the minority in national parliaments, with an average of 13% worldwide in 1999, despite the fact that women comprise the majority of the electorate in almost all countries. A number of international instruments have affirmed the principle of equal participation of women and men in power and decision-making, including the Charter of the United Nations, the Universal Declaration of Human Rights and the UN Convention on the Elimination of All Forms of Discrimination against Women.

The requirement that many countries produce Poverty Reduction Strategy Papers (PRSPs) has provided an additional forum for political participation by civil society. One of the most significant innovations of PRSPs is the requirement that governments draw them up with the participation of a wide range of national stakeholders, including civil society.⁷ The quality of the participation has been one of the most widely scrutinised aspects of the whole PRSP process. Ann Whitehead (2002, p. 12) observes 'Although flawed, the efforts at broader participation have had one highly significant spin off, despite being heavily criticised by civil society [...]. New spaces for influencing policy have been created'. However, in her analysis of the PRSP formulation in Tanzania, Bolivia, Malawi and Yemen, she concludes (as other authors have done, World Bank, 2002, for example) that the opportunities for participation in the process by

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‘women citizens and gender advocates’ were often quite limited. Adeyi, Hecht, Njobvu and Soucat (2001) note that HIV/AIDS is only one of many problems that countries need to address in PRSPs and inevitably the mainstreaming of HIV/AIDS in the papers has been patchy. They note that ‘[I]n order to be convincing, advocates of the use of debt relief savings for HIV/AIDS need to demonstrate that an effective national HIV/AIDS programme will contribute to the fight against poverty’ (2001, p. 11). This poses a challenge to those seeking to ensure that the gendered dimensions of the HIV/AIDS epidemic are high on the political agenda. Much depends on the support national leaders give to these issues and who is sitting in positions of influence in government, civil society and donor agencies.

More women in politics and a mobilised feminist presence in civil society is probably a good indicator of the extent to which democratic freedoms are shared in a society. But these do not translate automatically into greater well-being for women and more gender-sensitive development policies. States do not remove socially entrenched gender relations merely by including more women in government. However the presence of more women in policy-making fora is definitely a critical step in changing culture, concerns and the capacities of government.

Conclusion

Governments, donors, civil society organisations and communities themselves are well aware that today’s HIV/AIDS impact is a harbinger of what is to come in the decades ahead. But denial, particularly at national government level, remains a factor in failure to engage with this challenge. Despite their growing awareness of the long-term impacts of HIV/AIDS, donors themselves are generally funding relatively short-term interventions. The FAO’s Integrated Programme on HIV/AIDS and Food Security has been running in a research capacity since 1999, with a view to producing recommendations for the implementation of specific mitigation strategies. The implementation period for these strategies however is only 6 months. How appropriate is it to spend 6 months encouraging vulnerable households to adopt new working patterns, technologies, marketing activities etc. when support may only be available for such a short period of time? How appropriate are such short-term interventions when one of the defining characteristics of an HIV/AIDS epidemic and

its effects is its long-term nature — stretching over many decades. Most donors seem unable to assimilate this simple point into their strategic and programmatic thinking.

Perhaps the onus should be on all organisations and individuals involved in development programmes to look for ways to ensure that the impact of HIV/AIDS is incorporated into existing development initiatives, instead of creating parallel, specific HIV/AIDS programmes. Donors also have a vital role to play in supporting the sharing of information and pushing for activities that are sensitive to the impact of HIV/AIDS and multi-sectoral in their approach. This is important, because there is an implicit tension around ‘mainstreaming HIV/AIDS’ where ‘mainstreaming’ is seen as a discrete activity, which is funded through separate interventions, rather than being interpreted as ensuring ways to address the HIV/AIDS epidemic are being integrated into on-going programmes (Putzel, 2003).⁸

While gender is most certainly not a new area for intervention, and while many donors, NGOs and CBOs have some kind of gender policy, the same gender issues that existed before HIV/AIDS are still present and are being exacerbated by the epidemic.

Similarly, ‘gender’ analyses and interventions seem to have changed little over the years. The debate over women’s lack of access to information, skills, assets, credit, and technology still appears to be one of the most critical issues facing women in many countries. Equally, interventions attempting to address these issues have a familiar ring to them — micro-credit, reproductive health education and so on. It is apparent that inequality between men and women, old and young, and the inequitable distribution of resources are constraining attempts to prevent the spread of HIV/AIDS and reduce its impact.

Communities themselves are generally highly effective at ensuring their own survival, development and protection but mechanisms that were reliable in the past are now becoming severely constrained in the face of HIV/AIDS (Topouzis, 1998). In other words, the progressive degradation of capacities for social reproduction and economic production is occurring in societies where HIV/AIDS has long since become a generalised endogenous factor. Provision of anti-retroviral therapy is one emergency way of winning a

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window of opportunity for these societies to rise to the enormous challenge. But it is only a window of opportunity. Provision of antiretroviral therapy will run into the familiar problems of inequality, and gender inequality is bound to be a major factor in determining who does and does not gain access to treatment.

HIV/AIDS is a huge problem. Its gender aspects are manifold. It demands novel responses. Right now the academic community, the policy community and donor community are not thinking those novel thoughts or identifying novel responses. To do this, recognition of the long-term nature of the problem is essential. 'Gender' and 'mainstreaming' in any conventional senses will not be enough!

Acknowledgements

This paper is drawn from the findings of a project funded by the UK Department for International Development (DFID) and we are grateful for that support. The project was funded under the DFID Programme of Advisory Support Services for Rural Livelihoods. However, the views expressed are not necessarily those of DFID. We are grateful for the contributions of a large number of people who enabled us to cover a lot of ground and carry out this research in a short space of time, particularly Kirsten Sutherland who carried out the country visits with Rachel Grellier.

Footnotes

¹ The present paper is partly based on those findings.

² Recognising that for many 'rural livelihoods' are intimately linked to urban livelihood options.

³ Observation from Barnett, during field work in Rakai, 1989.

⁴ "Sexual abuse in Zambia fuels girls' AIDS epidemic" (www.afrol.com/news2003/zam003_hiv_abuse.htm) is an example of one such feature highlighting the findings from the Human Rights Watch report 'Suffering in silence: Human rights abuses and HIV transmission to girls in Zambia'.

⁵ In a matrilineal system a man's rightful heirs are his sister's children. On the death of the holder the man's children 'lose' control of the land to their cousins. Mbaya comments that the Presidential Commission in Malawi identified the rule that a man's rightful heirs are his sister's children and not his own as a major cause of conflict over property (including leases), between cousins.

⁶ The respondent went on to comment that customary law does not recognise women's right to inherit or own property so recourse to customary law would not guarantee a woman's right to land (Seeley *et al.*, 2003, p. 27).

⁷ See the World Bank website for background on PRSPs, and the PRSP source book. www.worldbank.org/poverty/strategies/sourctoc.htm

⁸ It also seems that a 'competition' for time and funds is emerging in some ministries (and perhaps also donor organisations) between HIV as a cross cutting issue and gender as a cross cutting issue. The concept that HIV/AIDS and gender issues can be complementary needs to be nurtured.

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Leon Swartz, Niel Roux

ABSTRACT

The primary goal of this study was to survey local government HIV/AIDS projects in South Africa. A total of 240 questionnaires were sent to local municipalities nationally between May and July 2002. A total of 44 municipalities returned their questionnaires, covering 53 projects. Most projects focused on prevention and awareness and the majority had awareness/prevention/information as part of their objectives as well as their activities. Home/community-based care was also prominent. It seems that in the future the focus of programme development will shift in this direction. Major constraints were a lack of funds, transport and trained personnel. Future emphasis must thus be put on these components. In addition government needs to put more resources into local government HIV/AIDS programmes since this tier will be the nodal point for national combatting of the HIV/AIDS epidemic.

Keywords: local government, HIV/AIDS, home/community-based care, Department of Social Development.

RÉSUMÉ

Le but principal de cette étude fut de sonder des projets du VIH/SIDA dans le gouvernement local en Afrique du Sud. Deux cents quarante questionnaires ont été envoyés aux municipalités locales du pays à partir du mois de mai jusqu'au mois de juillet 2002. Au total, 44 municipalités ont renvoyé leurs questionnaires. Ce derniers couvrent 53 projets. La plupart de projets se sont concentrés sur la prévention et la prise de conscience alors que la majorité de projets incluent la prise de conscience, la prévention et l'information parmi leurs objectif et leurs activités. Les soins à domicile ou dans la communauté étaient également saillants. Il semble que dans l'avenir le développement de programme se focalisera vers cette direction. Les contraintes majeures furent le manque de fonds, du transport et du personnel qualifié. De ce fait, dans l'avenir l'accent doit être mis sur ces facteurs. De plus, le gouvernement doit procurer davantage des ressources pour les programmes du VIH/SIDA au gouvernement local vu que cette étape sera le centre d'intérêt vis-à-vis le combat national contre l'épidémie du VIH/SIDA.

Mots clés: le gouvernement local, le VIH/SIDA, les soins à domicile ou dans la communauté, le Département de Développement Social.

Introduction

HIV/AIDS will affect each and every municipality in South Africa in some way or another. The disease will decrease life expectancy, increase the infant mortality rate, intensify the need for health care, fuel poverty, widen existing inequalities between rich and poor residents, increase the proportion of orphans, and alter

the existing age distribution. In sum, the disease will most likely escalate socio-economic and health needs while at the same time undermining municipalities' capacity to provide for such needs. The rates base will be severely cut down as an increasing number of poorer households struggle to pay for services. At the same time a combination of rising needs, less money

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and the loss of skilled staff will place added pressure on already stretched resources. This will further undermine the capacity of local governments to carry out their core functions of local service delivery. (Educational & Training Unit, 2001; Whiteside & Sunter, 2000; World Bank, 2003). The CDE (2003) warns that the situation will be aggravated by what they call 'unfunded mandates'. Municipalities will accordingly be expected to assume greater responsibility for a mounting range of programmes (including health, housing, water and land reform) without receiving additional resources from national or provincial government (UMP, 2001). The multi-faceted impact of HIV/AIDS leaves local governments with no other choice but to become involved.

Local governments are increasingly expected to perform a more central role in responding to the HIV/AIDS epidemic. As the level closest to communities, they are responsible for ensuring a good quality of life for citizens and for promoting sustainable social and economic development. Even though many programmes have been launched in the recent past, few projects have been successful and sustained. Not surprisingly, local governments are typically hamstrung by competing demands for human and financial resources. Although local responses to HIV/AIDS have been highlighted as an important component in the fight against the disease, little has thus far been done to understand the challenges local governments face in dealing with HIV/AIDS.

The main aim of this study was to survey the HIV/AIDS projects undertaken at local government level nationally. In particular, the study sought to assess the spatial distribution of these projects, identify opportunities for improvement of services, provide pointers for strengthening local government capacity, develop a database of local government HIV/AIDS projects, and lastly, encourage the establishment of more HIV/AIDS-related projects.

Local government policy framework in South Africa

Governance in South Africa is constituted as three distinctive yet interdependent and interrelated spheres of government on national, provincial and local level. There are presently 284 municipalities in South Africa. These newly demarcated entities amalgamated

843 racialised structures, and incorporated urban and rural areas into a single (often much larger) municipal system (Atkinson, 2003). According to Naudé (2003) this change in size (determined by the Demarcation Act of 1999) was primarily driven by economies of scale imperatives.

Municipalities are split into six category A municipalities (metropolitan councils), 231 category B municipalities (local municipal areas), and 47 category C municipalities (district councils). The latter governs a local government district. District municipalities encompass a number of local municipalities (category B), as well as district management areas (DMAs). The latter areas are mostly rural areas not directly governed by local municipalities. Metropolitan councils (category A municipalities) govern in the six metropolitan areas.

In addition to creating the aforementioned structures, local governments are obliged to fulfil a 'developmental' role (Atkinson, 2003; Naudé, 2003). This new developmental function of local government is defined in the White Paper on local government (South Africa, 1998, p15) as 'working with citizens and groups within the community to find sustainable ways to meet their social, economic and material needs and to improve the quality of their lives'. Integrated development plans (IDPs) are meant to guide municipalities in their transition towards becoming development agencies by empowering local authorities to prioritise and focus their activities and resources according to the needs of the people. Municipalities are expected to live up to the standards set by their IDP. However, in reality, many municipalities are not up to the challenge. Atkinson (2003) and Ambert (in Kelly, 2003) contend that tight deadlines (municipalities were required to hand in their IDPs by March 2002), inappropriately skilled consultants, a general lack of leadership and strategic direction, restricted involvement by national or provincial line departments, and limited public participation combined to create impractical 'wish lists' bearing little resemblance to socio-economic realities. In the process real development questions, including poverty alleviation strategies and cross-cutting issues such as support for HIV/AIDS planning and forums, were largely neglected in many IDPs.

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This disregard of HIV/AIDS came amid attempts to ensure that the impact of HIV/AIDS is considered in planning, by including a section on the disease in the guidelines for IDP development. In fact, the guidelines called for HIV/AIDS to be addressed at the analysis, strategy, project, integration and approval phases. Very few IDPs however address the disease in any depth. An evaluation of IDP training shows that HIV/AIDS was not really covered in the training of officials responsible for IDPs; that the HIV/AIDS components of IDPs are not well developed nor build on community consultation; and are often oblivious of available resources and best practices and policies (Kelly, 2003; South Africa, 2003).

Despite the clear importance of HIV/AIDS for municipalities, many are hamstrung by internal resource and capacity problems and the feeling that national and provincial governments are not doing enough to support the developmental role, that they are in fact further weakening local governments by placing additional demands on them (Atkinson, 2003). In particular, local governments are not receiving sufficient support in dealing with the epidemic (World Bank, 2003). Local authorities are still plagued by power struggles between various tiers of government and a lack of unity between national, provincial and local structures (Kelly, 2003; Medical Research Council, 2000). The result is often a duplication of services in some areas and a complete lack of services in other areas. The inertia is exacerbated by the general indifference towards mainstreaming HIV/AIDS in development initiatives (South Africa, 2003).

The framework within which all sectors should develop their HIV/AIDS responses is set out in the National HIV/AIDS and STD Strategic Plan for South Africa (2000–2005) (South Africa, 2000). The primary goals of the plan are to reduce the number of new infections and to reduce the impact of the epidemic on individuals, families and communities. Four areas are identified, namely: prevention; treatment, care and support; human and legal rights; and monitoring, research and surveillance. Although preventing new infections must remain paramount, being more cost effective than treatment (Whiteside & Sunter, 2000), the apparent lack of success of prevention thus far means that municipalities will

increasingly be called on to deal with the impact associated with the illness and death of large numbers of people. The 'new' developmental role demands that local governments provide strong leadership, establish openness, co-ordinate efforts, and create effective partnerships with stakeholders, residents and private businesses. These are precisely the elements that make local government responses advisable (Kelly, 2003). It is realised that HIV/AIDS is not merely a health problem and that a multi-sectoral approach is hence indispensable.

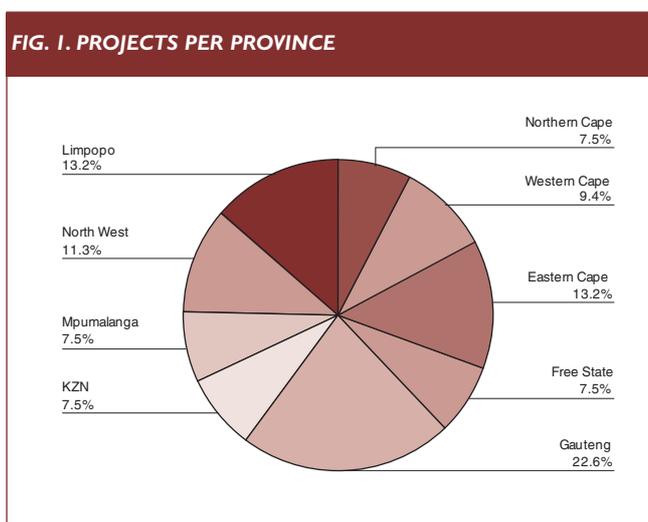
Methodology

The study is the result of efforts by the Chief Directorate: Population and Development (Department of Social Development) to survey all the HIV/AIDS projects undertaken at local government level nationally during 2002. A population universe was compiled of information retrieved from the demarcation board website (www.demarcation.gov.za). Municipal managers were noted as contact points and it was decided to direct all future correspondence to them. Initially local governments were only requested to submit copies of their HIV/AIDS business plans or programmes. Due to poor reaction and many incomplete responses, a short questionnaire was developed to elicit information. Local governments were particularly asked to confine their answers to ongoing or completed activities, not planned ones. The questionnaire asked municipalities to list the name(s) of any project(s) they might have implemented or completed, together with its main aims, objectives, activities, achievements and shortcomings or constraints. In addition, local governments were asked to indicate their main source of funding for the project, and the total budget in rands. Questionnaires were faxed or e-mailed directly to municipal managers. Due to incorrect or missing information on the universe, only 240 municipalities were contacted. Forty-four municipalities responded to the questionnaire between May and July 2002. The responses were captured using the Inmagic computer programme and analysed through SPSS between November 2002 and January 2003. Although the low coverage prevents generalisation to other municipalities, the results of the survey do provide a clear idea of the situation concerning HIV/AIDS projects at local government level during the early part of 2002.

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Results

A total of 44 local governments, running 53 projects between them, responded to the questionnaires. Although it is difficult to explain this exceedingly low response rate (less than 20%), one can speculate that it was negatively influenced by the concurrence of the survey with the frantic months before and after the IDPs were submitted. Additionally, many municipalities without any specific HIV/AIDS programmes did not return the questionnaires. It is unfortunate that existing integrated local authority responses by the local councils, in particular the metropolitan areas of eThekweni (Manning, 2003) and Johannesburg, were not reported. The distribution of projects by province is presented in Fig. 1.



The majority of projects for which responses were received were situated in Gauteng province (23%), followed by the Eastern Cape and Limpopo provinces with 13% each of the 53 projects. The provinces in which the lowest number of projects was reported were the Northern Cape, Mpumalanga, KwaZulu-Natal and the Free State. Municipalities in these provinces reported about four projects per province. Many of these programmes developed in an unsystematic fashion over time in response to particular needs. This, together with the poor participation of local governments relative to local NGOs, points to an urgent need to develop local government responses to HIV/AIDS (Kelly, 2003).

Local governments reported a wide variety of aims for the projects. This is presented in Table 1. Not

surprisingly the single largest proportion of projects (20%) listed prevention as the main aim. This was followed by awareness, and home-based and community-based care (HCBC) at 14%. Other important aims include education (12%), reducing impact (10%) and coordination and empowerment of people, both at 6%. In general it is clear that most projects are still primarily aimed at prevention rather than impact mitigation. This is difficult to understand given the severe need for care in communities.

TABLE 1. AIMS

	N	%
Awareness	7	14
Education	6	12
Prevention	10	20
Coordination	3	6
Partnership	1	2
Youth empowerment	1	2
HCBC	7	14
PWA	2	4
Access to treatment	2	4
Reduce impact	5	10
Service identification	1	2
Train prisoner counsellors	1	2
Capacitate people	3	6
Multidisciplinary care	1	2
Total	50	100

More than a quarter (28.4%) of reported local government programmes listed awareness/prevention/information as an objective. This is indicated in Table 2. This was, not surprisingly, followed by training/education and HCBC, which both stood at 13.8%. Other significant objectives were the creation of PWA (people living with AIDS) support groups, establishing

TABLE 2. OBJECTIVES

	N	%
Awareness/prevention/information	49	28.4
Training/education	24	13.8
HCBC	24	13.8
Health and social services	13	7.5
Research and statistics	4	2.4
PWA/support groups/human rights	17	9.8
Coordination & collaboration	6	3.4
Community participation	12	6.9
Youth/peer groups	9	5.2
VCT & counselling	9	5.2
Identify orphans	3	1.8
Job creation	3	1.8
Total	173	100

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human rights (6.9%), establishing health and social services (7.5%) and community participation (6.9%). To a lesser extent emphasis was put on identifying orphans and job creation, both at 1.3%.

Most activities in these projects were related to training/education (26%), followed by awareness and information activities (25%). HCBC (13%) and counselling (12%) also played a prominent role. Gardening and prevention of mother to child transmission (PMTCT), both at 2%, were emphasised to a lesser extent. This is indicated in Table 3.

	N	%
Awareness & information	41	24.9
Training/education	43	26.2
HCBC	22	13.4
Counselling & VCT	20	12.2
Research & statistics	6	3.7
Workplace policy	4	2.5
PWAs & support groups	4	2.5
Identify vulnerable children	4	2.5
PMTCT	3	1.8
Project planning & development	14	8.5
Gardening	3	1.8
Total	164	100

Just over a quarter (25.2%) of projects reported education and training as achievements (Table 4). This was followed by HCBC and support group activities (16%) and awareness and information (15%). Fewer achievements were recorded in the fields of openness and attitude change (9%) and programme establishment (7%).

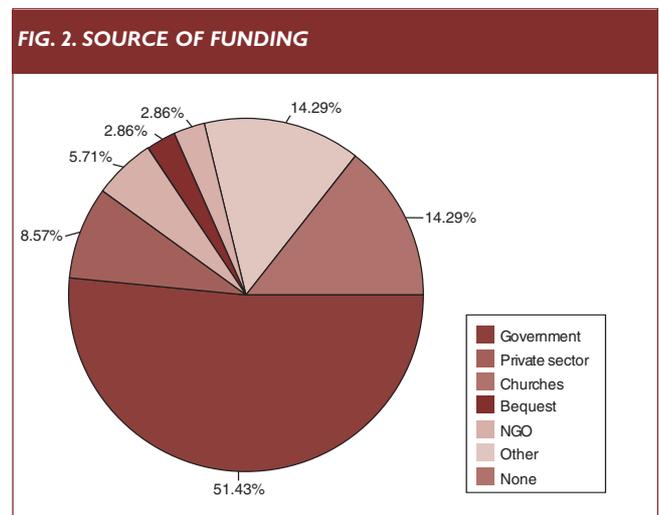
With regard to constraints, funding, not surprisingly, seemed to be the most significant constraint (37%)

	N	%
Awareness & information	13	14.9
Education & training	22	25.2
HCBC & support groups	14	16.2
Community involvement & forums	11	12.7
Networking, cooperation & partnerships	13	14.9
Openness & attitude change	8	9.2
Establishment of programmes	6	6.9
Total	87	100

(Table 5). This was followed by a lack of equipment in a distant second place at 17%. Other constraints that could be viewed as important were staff shortages (10%), a lack of trained personnel, transport problems and stigma and ignorance, all at 9%. Communication did not seem to be a major constraint for most local government programmes (2%).

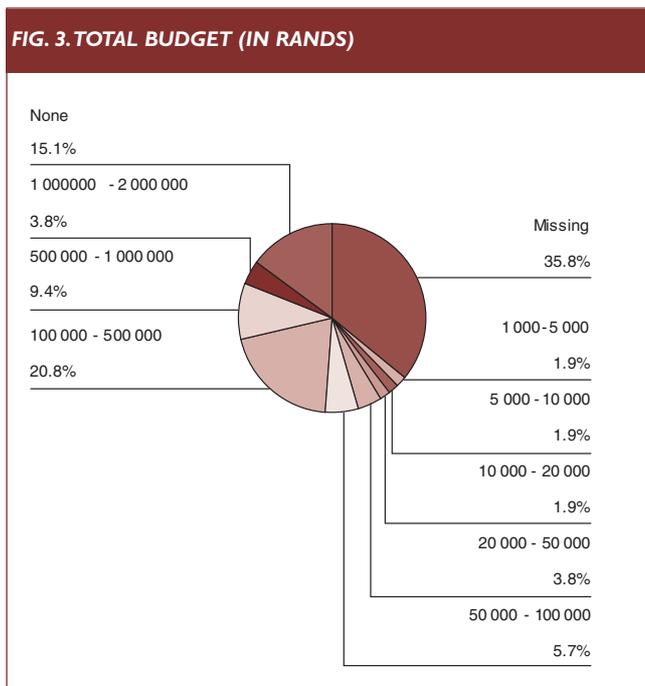
	N	%
Lack of trained personnel	9	8.7
Lack of equipment/material	17	16.5
Budget/funding	38	36.8
Staff shortage	10	9.7
Transport problems	9	8.7
Shortage of office space	5	4.8
Stigma & ignorance	9	8.7
Lack of cooperation	4	3.8
Communication problems	2	1.9
Total	103	100

Responding municipalities were also asked to list each project's main source of funding (Fig. 2). It is significant that slightly more than a half (51%) of projects were funded by the government. Funding agencies included in the 'other' category and the private sector were respectively funding 14% and 9% of reported projects. About 14% of projects contended that they received no funding at all. This is significant as it means that funding is a problem when it comes to programme implementation. Just over a third of responding local governments did not complete this particular question.



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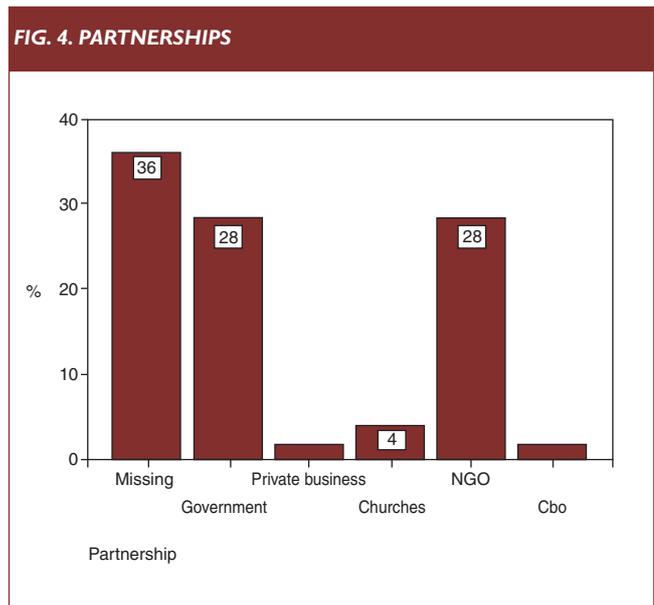
Regarding budget spending, more than a fifth (21%) of the reported local government projects fell into the R100 000 - R500 000 category, followed by nearly a tenth (9%) in the category R500 000 - R1 million (Fig. 3). Only 4% projects had a budget in the region of R1 million and above. It is again important to note that 36% of projects did not indicate any source of funding and that 15% indicated no budget at all. This again raises important questions about the lack of money for projects.



With regard to partnerships, Fig. 4 indicates that government and NGOs were the main partners in most projects, with both standing at 28%. Churches, with a total of 4%, followed this. It is important to note that 36% of projects either indicated that they had no partners or did not give any data for this category.

Discussion

Although only 44 municipalities responded, responses were received from right across South Africa. It is unfortunate that only the metropolitan areas of Tshwane and Buffalo City responded to the survey. In addition, it is disconcerting to note that a large proportion of programmes are still aimed at prevention, rather than care and support. The latter programmes will inevitably become more important as the epidemic starts to reach a peak nationally.



Although the study showed that only 24% of the reported projects were aimed at amelioration and care, this is definitely set to change as the disease reaches maturity and the need for treatment increases. In addition, government recently announced that an antiretroviral service point will be opened in every local municipality before 2008 (IRIN Plus News, 2004). While this extension of treatment is sure to be accompanied by some additional funding and capacity, it might nevertheless stretch service delivery in local authorities beyond breaking point. As it stands, inadequate primary health care facilities at the local level drive many HIV patients to tertiary health care facilities, thus overburdening the tertiary sector. Numerous studies have showed home-based care and household coping mechanisms to be a priority focus areas. These are however difficult to target and by no means a conclusive solution. Due to the legacy of apartheid, rural poverty and migrant labour, local government structures cannot rely on existing household and community networks for the care of people living with HIV/AIDS (Kelly, Parker & Gelb, 2002). To be successful, networks will have to be encouraged and fostered on a continuous basis.

As always, funding and budgeting were identified as serious constraints. Despite these complaints, under-spending at particularly the provincial level remained an 'urgent and critical' problem, scarcely 6 months before the study under consideration was completed. According to Stoppard (2001) provinces only managed to spend 36.5% of the total HIV/AIDS grants that

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were available to them in 2001. Meanwhile local government projects battled, according to the result of this study, to collect adequate funding for the programmes. This should however not come as a surprise. A World Health Organisation Report for 2000 (2 years before the study) ranked South Africa 57th when it came to the availability of funding and resources for health, but only 175th regarding the efficiency of health care delivery (Kelly, Parker & Gelb, 2002). Although the situation might have improved since 2000, the fact remains that local authorities will remain hesitant to take on functions requiring substantial funding, significant re-allocation of funds or the re-deployment of staff if severe staff and resource constraints are not addressed to start with. Municipalities cannot deal with HIV/AIDS without the cooperation and support of other government departments, religious, welfare and community organisations and volunteers. To become 'developmental', local governments are expected, amongst other things, to maximise social and economic development, integrate and coordinate development activities, empower communities, and provide leadership. In line with the principles of the IDPs, local governments should play a coordinating role in identifying and mobilising key actors in each community. Local government is by its very nature and extent of responsibilities arguably the best conduit for developing and implementing multisectoral strategies.

In particular, more should be done to involve the private sector in these projects. Only 6% of projects under study were funded by the private sector. It is crucial to emphasise the mutual advantage of joint ventures to private sector companies. There is a tendency among many companies and private business concerns to view social and economic development issues as separate, rather than inherently intertwined. Although there are encouraging signs that the private sector has developed a comprehensive understanding of the impact of HIV/AIDS on productivity, the buying power of populations and the sustainability of many industries, a recent study by the Bureau for Economic Research has shown that most businesses have hitherto failed to respond to the HIV/AIDS epidemic (*Sunday Times*, 2004). Many analysts only expect businesses to start doing so once the disease begins to impact on their bottom line. This sluggish response however is expected to change with the strengthening of state responses.

As can be expected, the study shows that government and NGOs are the most important partners in projects. A significant percentage of projects (36%) had no partners. Although this points towards some ingenuity on the side of the local governments involved, it does not really provide long-term solutions to a very serious problem. Local governments first need to rally support from a variety of sources for programmes to have any lasting developmental impact.

Conclusion and recommendations

Local governments are likely to be the focal point of the fight against the HIV/AIDS epidemic for some time to come. It is thus of paramount importance for both the government and civil society as a whole to channel resources — human as well as financial — towards the initiatives undertaken by local government.

Local municipalities appear to have definite problems incorporating HIV/AIDS programmes into their local IDPs. The whole idea of IDPs and HIV/AIDS is new to them, and there seems to be a lack of capacity with regard to this issue. The Departments of Provincial and Local Government, Health and Social Development should spend more time empowering these local municipalities regarding project development and implementation. In particular, they need to address the lack of HIV/AIDS programmes in provinces with high sero-prevalence rates, i.e. Kwazulu-Natal, Mpumalanga and the Free State.

It is no surprise that funding seems to be a major constraint for most projects. It is evident that the private sector does not play a prominent role in this regard. Mechanisms should be put in place to channel more funds from the private sector as well as international donors to local municipal projects. Municipalities should use cooperative ventures in which partners have bought into the idea of HIV/AIDS programmes as an integral part of social and eventually economic development strategies. Most of the aims, objectives and activities focus on awareness and prevention. This is to be expected and in line with current practice. However, more needs to be done to promote and strengthen HBCB and other mitigation strategies. Until the antiretroviral treatment points are located in every municipality, HBCB programmes will remain an important part of the fight

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against the epidemic. While it is too late to reverse the adverse effects of the epidemic, it is still possible to reduce its impact and duration.

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Willingness to pay for treatment with highly active antiretroviral (HAART) drugs: a rural case study in Cameroon

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ABSTRACT

This paper reports on the willingness of HIV/AIDS patients to pay for the most affordable triple therapy combination of antiretrovirals in a local setting in Cameroon. Questionnaires were used to evaluate willingness to pay, and patients who could still afford their medication 6 months after the survey were also investigated, to give an indication of actual ability to pay. In addition, oral interviews were carried out for clarification. In all, 84 patients out of a total of 186 were involved in the study. Results indicated that more men (39%) were willing to pay than women (22%), although more women (56%) were afflicted than men. Willingness to pay was directly dependent on cost with 69%, 22% and 9% of respondents indicating willingness to pay \$1, \$2 and \$3 a day respectively. After 6 months of treatment, 22% of patients were still on therapy. A majority of patients stopped taking the drugs after 6 months due to financial constraints. Apart from cost, stigma, disbelief and side-effects of medication were found to be the main factors militating against willingness to pay. Improved counselling and provision of information, reduced cost of drugs including laboratory tests, and destigmatisation programmes are recommended to improve patients' ability to pay for antiretrovirals.

Keywords: HIV/AIDS, treatment, access to antiretrovirals, drug costs, affordability.

RÉSUMÉ

Cette communication porte sur une bonne volonté des patients souffrants du VIH/SIDA à payer un prix assez abordable de la thérapie triple des anti-rétroviraux dans un milieu rural au Cameroun. Des questionnaires ont été utilisés afin d'évaluer cette bonne volonté à payer les médicaments. De plus, les patients qui avaient les moyens d'acheter leurs médicaments 6 mois après ces épreuves furent interviewés également. En plus de cela, les patients ont été interviewés avec le but d'obtenir des éclaircissements. Parmi les 186 patients, 84 participaient à l'étude. Les résultats de cette étude ont démontré que davantage d'hommes (39%) avaient la bonne volonté de payer des médicaments que des femmes (22%), tandis que les femmes sont plus souffrantes (56%) que les hommes. Cette volonté de payer était directement liée au coût des médicaments avec 69%, 22% et 9% des interviewés qui veulent bien payer une somme de \$1, \$2 et \$3 par jour respectivement. Au bout d'une période de 6 mois de traitement, 22% de patients étaient encore en thérapie. Une majorité de patients ont arrêté le traitement au bout de 6 mois faute de manque d'argent. En dehors du coût, le stigmate, l'incrédulité et les effets secondaires des médicaments étaient les facteurs principaux qui étaient contre la volonté de payer. Il est conseillé d'améliorer les services de consultation, de fournir de l'information, de réduire le coût de médicaments ainsi que les essais en laboratoire et l'élaboration des programmes de destigmatisation afin d'améliorer la capacité de patients à payer pour les anti-rétroviraux.

Mots clés: le VIH/SIDA, le traitement, l'accès aux anti-rétroviraux, le coût de médicaments, avoir des moyens d'acheter.

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Introduction

HIV/AIDS remains the most challenging health problem for policy makers in sub-Saharan Africa. With over three million deaths being recorded last year (UNAIDS, 2002) there is every reason to believe that if unabated, HIV/AIDS will be the most lethal epidemic recorded in history. However, a glimmer of hope currently exists, not only in the availability of drugs which can reduce mother-to-child transmission by at least two-thirds (Marseille, Khan, Mmiro, Gouy, Musoke, Glenn Fowler *et al.*, 1999; UNAIDS 1997), but also the fact that HIV/AIDS can be effectively treated. The United States has shown how stringent health policies can effectively reduce the HIV/AIDS death rate (Berwick, 2001; Martin, 1996). With proper care and active prevention strategies, millions of years of active life could be saved. This would not be possible without access to antiretroviral (ARV) drugs. The issue of access to drugs has recently received a great deal of international support. The recent withdrawal of the lawsuit by the Pharmaceutical Manufacturing Association against the South African government over proposals to allow importation and production of less expensive ARVs is a case in point.

Critics of the 'free drugs programmes' have pointed out that attitudes, cultural traditions and gender discrimination would still have an adverse effect on the fight against HIV/AIDS even if the drugs were free. Furthermore, infrastructure is not in place to distribute medication and manage effective treatment. Pronyk, Kim & Porter (2001) have called for activism in support of the reduction in the price of AIDS drugs to be tempered by an understanding of the complexity of the problem within countries that have few resources and many other health priorities apart from HIV. They further argue that successful international activism leading to cheaper AIDS drugs would undoubtedly increase stress on individuals working within already strained systems. However Berwick (2001) states that removing barriers of drug costs would empower policy makers with the zeal to tackle such issues, and that the high cost of ARVs is being used as an excuse for avoiding other related issues. Interestingly, an international response to the treatment of multiresistant tuberculosis that led to a dramatic decrease in the costs of antituberculosis drugs has reportedly recorded success rates of over 80% in patients in Haiti who were literally condemned to death 5 years ago (Farmer & Jy, 1998; Farmer, Leandre, Mukherjee, Claude, Nevil, Smith *et al.*,

2000). Berwick pointed out the fact that high costs meant that drugs were out of reach; thus it seemed futile for poor countries to try to build infrastructures capable of managing patients. When drugs became affordable, building a proper health care system would be a task worth tackling. However, health improvement is only one of many pressing development challenges (ranging from reducing illiteracy to providing infrastructure and expanding job opportunities) involved in raising people's living standards. As Prescott (1997) points out, analysing the financing options for ARVs leads straight into the affordability question that is of such importance in low and middle-income developing countries. Policymakers need to reject alternatives to government involvement that are not financially affordable, otherwise they will get locked into unsustainable policies that undermine the objectives of getting involved in the first place.

The Republic of Cameroon has officially reported a national HIV prevalence rate of 12% (UNAIDS, 2002). The national HIV/AIDS policy has placed great emphasis on awareness creation and prevention programmes through the National Aids Control Committee. Although widely publicised programmes on the use of nevirapine to prevent mother-to-child transmission are in place, effectiveness of these programmes is yet to be evaluated. In April 2001, the government negotiated for the provision of triple therapy for HIV/AIDS victims at a cost of \$1 per day. This implies that the government provides the drugs at this cost and the patients pay for them alongside associated costs such as those for laboratory investigations, monitoring, treatment for side-effects and opportunistic diseases. Cameroon is among the highly indebted poor countries with over 70% of the population earning less than US\$1 per day. Furthermore with a majority of the population being subsistent farmers, payment for ARVs by patients does not seem to be feasible theoretically. On the other hand per capita GDP provision of ARVs free of charge by the government is unsustainable because of non-availability of funds. Apart from the issue of the cost of drugs, the fact that over 70% of the population is in rural areas with very bad roads and rough terrain, the lack of trained personnel to manage HIV/AIDS patients, as well as the costs of laboratory/monitoring facilities all militate against a large-scale implementation of treatment programmes.

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Moreover, despite its terrible human toll, HIV/AIDS is only one of many health problems facing developing countries, including Cameroon. This means focusing on the subset of ARV alternatives that are affordable from the point of view of those who have to finance the relevant costs — government and households. Consequently, partnerships with donor bodies and concerned households seem a feasible option. The Cameroon programme assumes this partnership for effective delivery, with household purchase being vital for success. Consequently information on how much patients are willing to pay is important to policy makers, as this will help determine priorities and cost settings. The following is a study on willingness to pay for these drugs in a rural hospital.

Method

The St Martin de Porres Hospital, Njinikom is located in the North West Province of Cameroon. With a capacity of 180 beds and a yearly patient enrollment of over 12 000, the hospital offers health care services to patients coming from distances of over 250 km. The HIV/AIDS pandemic is on the increase — the current prevalence of HIV/AIDS among pregnant women is 12.8%, and local prevalence is conservatively estimated at 16% (Muko & Bangsi, 2002). Thus the hospital, with the help of the British non-governmental organisation Intercare UK located in Leicester, instituted an HIV/AIDS programme geared towards:

- raising awareness and implementing prevention strategies
- reducing mother-to-child transmission using nevirapine
- providing free palliative drugs to HIV/AIDS patients
- providing material and moral support to victims and their families
- instituting life-skill training for youths
- developing a prevention programme with traditional herbalists.

Pre-tested interviewer-administered questionnaires were used for the study, which took place between January and August 2002. The questionnaire with structured and semi-structured, closed and open-ended questions was designed to elicit information with respect to occupation, income earning capacity, marital status, ability to pay for HAART and factors

mitigating against willingness to pay. A discussion with general practitioners (who administered the questionnaire) took place to evaluate tested questionnaires for conformity of content. The desired information was obtained and in almost all cases oral interviews were also carried out. The bidding method was used to elicit the amount the respondents could pay. Patients were followed up for 6 months to determine the proportion of patients still on HAART. In all, 84 patients out of 186 deemed fit for treatment with HAART (based on clinical parameters) in the hospital were involved in the study. Exclusion criteria were children and patients without an independent source of income.

Patients who were sick, attending the hospital and tested HIV-positive were counselled with the intention of initiating HAART. Those deemed clinically qualified for ARV therapy were given information on HAART with respect to: availability, efficacy, administration, costs, adverse effects, side-effects of nevirapine, lamivudine and stavudine as a combination in a single tablet (Triomune). Patients were informed of the payment schedule, which was on a monthly basis. The purpose of the study was explained to patients and their consent obtained, after which the questionnaire was administered. The respondents were asked to bid the maximum amount of money they were prepared to pay for these drugs for a month. Each respondent had a maximum of four bids to make. In-depth interviews were also carried out to clarify patient responses. Income was ascertained indirectly through asking patients' monthly expenditure and determining the source of income for this. Permission for the study was obtained from the hospital administration.

Results

The age group 25 - 50 years featured most prominently in the study, as shown in Table 1. The number of female patients (52%) was slightly more than males (48%). There were more patients in the adult group of above 50 years than in the youth group of less than 25 years. Overall more males (53%) were observed in the age group 36 - 50 years than females (47%); while a greater proportion of females (65%) than males (35%) were found in the most vulnerable age group of less than 35 years. As shown in Table 2, a large proportion of patients had dependants. This included those who were not yet married. Males had a

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TABLE 1. PATIENTS' AGE AND GENDER

Age (years)	Number	Females	Males
< 25	6 (7%)	4 (67%)	2 (33%)
25 - 35	37 (44%)	25 (65%)	12 (35%)
36 - 50	32 (38%)	15 (47%)	17 (53%)
> 50	9 (11%)	1 (11%)	8 (91%)

TABLE 2. FINANCIAL DEPENDANTS OF PATIENTS

Dependants	Number	Females	Males
Less than 3 persons	14 (16%)	6 (43%)	8 (57%)
Between 3 and 6	18 (21%)	8 (45%)	10 (55%)
7 and above	10 (12%)	4 (40%)	6 (60%)
Lost partners	23 (27%)	17 (73%)	6 (27%)
Single	13 (15%)	8 (2%)	5 (38%)

somewhat greater number of dependants than females. The proportion of females who had lost their partners was found to be greater than that of males.

Overall 50% of respondents reportedly had an income of less than \$1 a day, with more women in this category than males, as shown in Table 3. The income earning capacity of males (60% earned above \$1 a day) was observed to be higher than that of females (31%). Over 42% of the women involved in the study had no permanent source of income independent of their husbands. Most of them were housewives, while some were farmers and traders and a few were teachers. This contrasts drastically with the males, most of whom had a source of income. The principal occupations of the males were trading, teaching and working as government officials.

TABLE 3. INCOME EARNING CAPACITY

Income	Number	Male	Female
< \$1/day	42 (50%)	16 (38%)	26 (65%)
\$2 - \$4/day	26 (30%)	15 (58%)	11 (42%)
\$5 - \$6/day	7 (8%)	5 (71%)	2 (3%)
> \$7/day	5 (6%)	4 (80%)	1 (20%)

Table 4 shows the prices which people with HIV/AIDS stated they would be willing to pay for drugs for at least 1 year. Generally patients indicated more willingness to pay at reduced prices (69% at \$1 compared with 22% at \$2 a day and 9% at \$3 a day). Table 5 indicates the actual willingness or ability to

TABLE 4. AMOUNT PATIENTS WERE WILLING TO PAY

Income	Percentages	Male	Female
< \$1/day	57 (69%)	17 (29%)	40 (71%)
\$2/day	19 (22%)	12 (67%)	7 (33%)
\$3/day	8 (9%)	5 (63%)	3 (37%)

TABLE 5. ACTUAL WILLINGNESS TO PAY AFTER 6 MONTHS

Age (years)	Number	Females	Males
< 25	2	2 (100%)	0 (0%)
25 - 35	7	3 (43%)	4 (57%)
36 - 50	9	3 (33%)	6 (66%)

pay, determined from the patients involved in the study who were still consistently taking treatment 6 months later. Overall 22% of patients were still on treatment. A majority (55%) were males. This was higher than the ratio of males to females at the beginning of the survey. More males (55%) were observed in the age range of above 26 years than females (45%).

Table 6 points to some of the factors that militate against willingness to pay for HAART. Of the patients who could not afford to pay for drugs, more than 62% of women linked difficulty in getting money to stigma. This stigma was either perceived (66%), and attributed to the fact that friends and relatives who otherwise could have helped provide money did not want to associate with the victims; or experienced, where 62% of women responded that they felt too ashamed to discuss their status with people who could otherwise have helped them financially. These respondents had either experienced stigma-oriented traits or heard from or met friends who had experienced such traits which made them ashamed of testing positive for HIV, and thus also made disclosure difficult. Of the proportion of respondents who

TABLE 6. FACTORS MILITATING AGAINST WILLINGNESS TO PAY

Difficulty in getting money	43 (66%)
Perceived stigma	43 (66%)
Experienced stigma manifesting as patient ashamed of status	41 (62%)
Disbelief in efficacy of drugs	22 (33%)
Creditors feel patient will die	16 (25%)
Patients feel well	13 (20%)
Side-effects	1 (2%)

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responded to the above factors, the male rate was significantly lower than the female ratio, i.e. 30% and 42% respectively, indicating that more women experienced stigma than men. Other factors observed to militate against willingness to pay included disbelief by patients and relatives about the efficacy of drugs, the fact that creditors who otherwise would have lent money to patients until they recovered and began work again, would not do so because they felt that the patient would die. Furthermore 20% of the patients taking the drugs felt better within 6 months and assumed that they were well.

Discussion

Due to increasing early sexual activity, it is believed that HIV/AIDS prevalence in the age group below 25 years was more than the proportion recorded. Since most of the victims were diagnosed when they were ill, it is likely that infection in the youthful age group could be quite recent and victims were not yet falling ill to HIV/AIDS-related diseases, and consequently did not yet know that they were ill. The fact that more women were found in the younger group is probably because of early sexual exposure with older men. Interestingly few of the victims admitted to being sex workers, although a significant proportion of the spouses of the patients (9%) were members of the forces, which along with sex workers constitute a high-infection group (Bentley, Spratt & Shepherd, 1998). Overall 18% of the victims had lost their jobs as a result of the illness. The fact that the males had more dependants than the females was probably a result of the external family structure, where the man is expected to take care of children of deceased relatives or family where he is an heir. A higher proportion of females had lost their partners. This could be a result of the fact that polygamy is rife in the area of study. In a related study in the area Muko and Bangsi (2002), found an increasing number of orphans, with caregivers having as many as seven orphans in a household. This implies greater expenditure and less money to spend on treatment.

A majority of respondents indicated a willingness to pay for HAART at reduced prices. This was possibly as a result of the fact that a large proportion of respondents were earning less than \$1 a day. As expected more males than females indicated a willingness to pay for HAART at \$1 a day, possibly because more men had paying jobs than women.

Consequently more men were taking HAART after 6 months than women. This could be attributed to the fact that most women were housewives who could not take an independent decision, with the final decision having to be taken by their spouses who may have been expecting help from other sources which did not materialise. The ability to pay, as observed from patients still paying for their medication 6 months later, was at variance with the indicated willingness to pay. Patients were initially enthusiastic to begin treatment but unfortunately could not get enough money to sustain their therapy.

Furthermore a related study in the area (Muko, Ngwa, Chingang & Meiburg, 2002) showed that, in addition to drug costs, other important costs associated with providing therapy included: HIV tests to establish whether someone is HIV+ and hence eligible for therapy; pre- and post-test counselling; regular outpatient visits to monitor patients for side-effects and to issue supplies of drugs; laboratory tests such as CD4 counts, complete blood counts, viral loads and chemistry panels to monitor patient health status; and outpatient visits/hospitalisations associated with adverse drug effects. These costs in reality may be more than the cost of the HAART drugs. In the health facility used for the study, the costs for laboratory tests done by the patients for full monitoring may be as much as \$80, excluding transportation to laboratory site, accommodation and food estimated at \$20 for each visit. For periodic monitoring after every 6 months, as expected for a sick patient, this translates into a minimum of \$200 a year. The costs of the non-drug components are likely to vary substantially. This problem is aggravated by the fact that approaches to case management are inconsistent in Cameroon. For example, although there are protocols regarding the frequency and type of laboratory tests which would be appropriate, and how often monitoring visits would be required, physicians often do not follow these protocols. This makes costing difficult, since the required resource inputs cannot be clearly identified.

Stigma, both perceived and experienced, was observed to be a prime factor militating against willingness to pay. A comparative analysis of treatment paying schemes (Chingang, 2002) showed that in the area of study, relatives often come to patients' aid in offsetting their costs of treatment. Interestingly even though

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treatment for some diseases, for example tuberculosis, diabetes and hypertension, was identified as being as expensive as the triple therapy, there were higher rates of payment by patients for these than for HAART. This was thought to be because relatives were ashamed to be associated with people with HIV/AIDS, as it is viewed as a moral disease and in certain quarters as a punishment from God. Consequently some victims were perceived as paying for their sins. It is noteworthy that the area in which the study took place is predominantly Christian. Furthermore the fact that victims were not able to share their status with people who otherwise might have helped them, as a result of stigma, further reduced their ability to pay.

Perception of efficacy of therapy is a key issue, as observed from the fact that family members felt that their relatives might not get well. In an area where health insurance schemes are not a priority, not only because of financial implications, but also because an illness is viewed as a misfortune and getting an insurance policy is perceived as wishing for sickness, victims could raise money only from moneylenders and financial institutions. Disbelief in the efficacy of HAART suggested a risky venture on the part of the moneylender, thus making it very difficult for the victim to get treated and regain the energy to work.

As previously mentioned stigma was more strongly experienced by women than men. This could be attributed to the fact that HIV/AIDS is still believed to be associated with prostitutes (women), and in some neighbouring regions of the area of the study it is called 'women's disease'. This is further exacerbated by the fact that it is more socially acceptable for a man to have concubines than for a married woman to have many male sexual partners. Thus it is easier for men not to feel ashamed of their status than for women.

Patients not paying for continued treatment because they were feeling better was perhaps a result of improper counselling and inadequate provision of information. A programme officer for the HIV/AIDS programme Intercare/Njinikom Project Hope reported that the influence of traditional herbalists in this regard could not be overlooked. Promises of effective treatment from herbalists and association with traditional rites as causative factors may be militating against willingness to pay.

Conclusion

Apart from the actual potential to pay for HAART by people with HIV/AIDS, which could be determined easily by their income earning capacity, the above survey shows that other socio-cultural factors are involved. Stigma seems to be a very strong factor in this regard. This is important considering the extended family system in sub-Saharan countries, where it is an obligation for family members to take care of others when in need. Therefore, there is a need for destigmatisation programmes to be put in place with emphasis on educating people on the efficacy of HAART. Misdirected HIV/AIDS prevention messages like 'AIDS has no cure' have to be reoriented, since communities interpret this to mean that treatment cannot really help.

Furthermore, gender roles need to be addressed. Ability to pay has a lot to do with decision making, which can only take place where there is strong female empowerment. With huge benefits shown to be associated with the use of HAART (Alcorn, 1995), both in reduction of transmission and economic benefits, there is a need to address properly the factors militating against its effective implementation in general and willingness to pay for it by patients in particular. Moreover, a portion — perhaps even a majority — of patients will not be able to tolerate the drugs and will suffer adverse effects (Hay, Osmond & Jacobson, 1998), or will refuse to take them at all. This means that the average annual cost of ARV therapy per HIV-infected person may be either more or less than the average annual cost for a patient who tolerates the therapy without any problems. It will be more if the costs of patients suffering adverse effects in a given year exceed the costs of those patients continuing with therapy for that year; and it will be less if the cost of adverse effects is less than the costs which would be incurred were those patients suffering from adverse effects to continue therapy. All avenues for provision of information on awareness creation should be targeted, with special emphasis on traditional herbalists, on whom a majority of the population rely, and who are also highly respected in society.

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Impact of long-term civil disorders and wars on the trajectory of HIV epidemics in sub-Saharan Africa

David Gisselquist

ABSTRACT

From the mid-1970s, seven countries in sub-Saharan Africa have experienced civil disorders and wars lasting for at least 10 years. In two — Sierra Leone during 1991–2002, and Somalia from 1988 and continuing — adult HIV prevalence remained below 1%. In the Democratic Republic of the Congo, HIV prevalence appears to have stabilised during post-1991 civil disorder and war. Limited information from Angola (civil war 1975–2002) and Liberia (civil disorder and war from 1989 and continuing) suggests low HIV prevalence. Mozambique's HIV prevalence was near 1% after its 1975–1992 civil war, but increased dramatically in the first post-war decade. Across African countries with long-term wars, HIV seems to have spread more slowly than in most neighbouring countries at peace. This evidence contributes to the ongoing debate about the factors that explain differential epidemic trajectories, a debate which is crucial to the design of HIV prevention programmes. One possible explanation for slow epidemic growth in wartime is that unsterile health care accounts for an important proportion of HIV transmission during peacetime, but much less when wars disrupt health services. However, other explanations are also possible. The roles of sex and blood exposures in HIV epidemics in war and peace await empirical determination.

Keywords: HIV, epidemiology, Africa, wars, risk factors.

RÉSUMÉ

A partir du milieu des années 1970, sept pays de l'Afrique sous-Sahara ont connu des désordres civils et des guerres qui ont duré au moins 10 ans. Dans deux pays — la Sierra Léone entre 1991 et 2002 et la Somalie depuis 1988 jusque-là — la prédominance du VIH chez des adultes est restée sous 1%. Dans la République Démocratique du Congo, la prédominance du VIH s'est stabilisée après le désordre civil et la guerre de 1991. L'information très limitée de l'Angola (guerre civile 1975–2002) et de Libéria (désordre et guerres civiles depuis 1989) suggère une prédominance du VIH très basse. Au Mozambique, la prédominance du VIH était d'environ 1% après la guerre civile de 1975 à 1992. Cependant, il y a eu une augmentation importante au cours de la première décennie après la guerre. Dans tous les pays africains qui ont subi des guerres à longue durée, le VIH semble se propager plus doucement que dans des pays voisins qui sont en période de paix. Cette preuve contribue au débat actuel portant sur des facteurs responsables aux trajectoires différentielles de l'épidémie. Ce débat est important à la conception des programmes de prévention. Une explication possible de la dissémination lente de l'épidémie durant la guerre est que les soins non-stériles expliquent la proportion importante de transmission de VIH pendant la période de paix. Ce phénomène est encore plus réduit quand les services de santé sont interrompus par la guerre. Néanmoins, il y a d'autres explications possibles. Les rôles que jouent le sexe et la contamination par le sang sur l'épidémie du VIH pendant la guerre et durant la période de paix attendent une détermination empirique.

Mots clés: le VIH, l'épidémiologie, l'Afrique, les guerres, les facteurs de risque.

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Impact of long-term civil disorders and wars on the trajectory of HIV epidemics in sub-Saharan Africa

Introduction

During the past several decades, civil disorders and wars have afflicted many countries in sub-Saharan Africa, and at the same time the region's AIDS epidemics have emerged as a major health crisis. Although most early analyses of Africa's AIDS epidemics ignored wars, some experts speculated that wars accelerated HIV transmission. For example, in one of the first AIDS reports from Uganda, Serwadda, Sewankambo, Carswell, Bayley, Tedder, Weiss *et al.* (1985, p. 852) proposed that 'movements of the Tanzanian army in 1980' might have propagated HIV in Uganda. In the mid-1990s, the World Health Organisation (WHO), United Nations High Commission for Refugees (UNHCR) and UNAIDS (1996, p. 6) generalised that 'HIV spreads fastest in conditions of poverty, powerlessness, and social instability - conditions that are often at their most extreme during emergencies'.

However, during the 1990s AIDS epidemic researchers recognised evidence that did not fit these views. Tarantola and Schwartzlander (1997) noted that Mozambique, a country that had suffered a long-term civil war, had lower HIV prevalence than neighbouring countries. Nevertheless, they considered that available information did not demonstrate a causal relationship. Writing several years later, Melo, Beby-Defaux, Faria, Guiraud, Folgosa, Barreto *et al.* (2000, p. 203) hypothesised that 'The isolation of Mozambique during years of the civil war from 1976 to 1992 probably limited the spread of HIV epidemic'. Salama and Dondero (2001, p. S6) discuss migration and other social disruptions 'that may increase HIV transmission in complex emergencies,' but the data they present show relatively low HIV prevalence in many African countries 'affected by major complex emergencies' in the 1990s.

Evidence that Africa's long-term civil disorders and wars are associated with relatively slow epidemic expansion has accumulated in recent years. This paper summarises the evidence and discusses implications for understanding and preventing generalised HIV epidemics. This evidence contributes to an ongoing debate about the factors that explain differential HIV epidemic trajectories (Boerma, Gregson, Nyamukapa & Urassa, 2003; Buve, Caraël, Hayes, Auvert, Ferry, Robinson *et al.*, 2001; Garnett & Fraser, 2003; Gisselquist, Potterat & Brody, 2004). One unresolved issue in this debate — an issue crucial to the design of

HIV prevention programmes — is the contribution of blood exposures during health care to generalised HIV epidemics. One possible explanation for relatively slow epidemic growth during civil wars is that HIV transmission through unsterile health care accounts for an important proportion of HIV transmission during peacetime, but much less when wars disrupt health care delivery. However, other explanations are also possible. Outstanding questions about the role of health care in Africa's HIV epidemics await conclusive empirical resolution.

Methods

During the last several decades, seven countries in sub-Saharan Africa have experienced civil disorders and wars lasting for at least 10 years and interrupting government functions over large areas of the affected countries (Peace Pledge Union Online, 2004a; see below for country-specific references). Moving counterclockwise from west Africa, these seven are Sierra Leone (civil war 1991 - 2002), Liberia (civil war from 1989 and continuing), Democratic Republic of the Congo (DRC; collapse of government functions followed by civil war from 1991 and continuing), Angola (civil war 1976 - 2002), Mozambique (civil war 1975 - 1992), Somalia (civil war from 1988 and continuing), and southern Sudan (civil war from 1983 and continuing). Africans have fought many other shorter or more localised wars in recent decades; however, data on HIV prevalence are generally too weak to convincingly demonstrate an impact on epidemic trends during these more limited events.

For each of the long-term wars, I report evidence on HIV prevalence (including HIV-1 and HIV-2 infections) in adults (usually persons aged 15 - 49 years) before, during, and at the end of the war, or the latest data in continuing wars, and the post-war epidemic trajectory (relevant for Mozambique only). For comparison, I report levels and movements of HIV prevalence in neighbouring countries over time. Long-term trends in HIV prevalence, as considered in this paper, imply matching long-term trends in HIV incidence (although short-term fluctuations in incidence may not be reflected in long-term trends in prevalence).

A major challenge in this study has been to choose the best data to demonstrate levels and movements in HIV prevalence. This is a problem not only in

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countries at war, where data are scarce, but also in neighbouring countries that are at peace. UNAIDS' estimates of country HIV prevalence, which are calculated from HIV prevalence in selected antenatal clinics, have serious problems for this study. Firstly, they are not available before 1994, whereas all wars considered in this paper began no later than 1991. Secondly, they are not comparable across years: country estimates may show large year-to-year fluctuations based on statistical adjustments rather than epidemic realities (e.g. UNAIDS estimated 2.9 million HIV infected Ethiopians in 2000 [UNAIDS, 2000a], but only 1.9 million in 2001 [UNAIDS, 2002a]). And finally, UNAIDS' estimates have an apparent upward bias: comparable estimates of HIV prevalence are available for six African countries from random sample national surveys; UNAIDS' estimates are 0 - 177% (mean of 64%) higher than these survey-based estimates (Table 1).

To avoid overestimating differences between HIV prevalence in countries at war and neighbours at peace, for comparison countries at peace I choose data that are not transparently biased toward the high end. When available, I report adult HIV prevalence from random sample national surveys (Table 2). In most cases, the best available information comes from sentinel surveys in selected antenatal clinics. Since urban clinics tend to report relatively high rates of HIV prevalence that are unrepresentative for the nation, for comparison countries I report medians of

HIV prevalence among all antenatal clinics in the country, or among antenatal clinics 'outside major urban areas'. In exceptional cases, I use other data to characterise HIV prevalence in countries at peace (see notes to Table 2).

For the seven countries with long-term civil disorders or wars, I report data as available from studies before, during, and in several cases after the war. In some cases, I report data from urban centres; since urban data may overestimate HIV prevalence in the country, use of these data tends to underestimate differences between countries at war and their more peaceful neighbours. For six of seven civil wars, I examine the impact on HIV prevalence for the country as a whole; for Sudan, I consider HIV prevalence for the south only, since the impact of the war has been highly concentrated in that region.

Results: trajectory of HIV epidemics during long-term civil wars

Sierra Leone

Sierra Leone entered a period of brutal civil war in 1991, when Revolutionary United Front (RUF) rebels entered from Liberia (United Nations, 2004). During the ensuing decade, the RUF terrorised much of the rural and, at times, urban population while living off profits from diamond mines (Campbell, 2004). The government, even with military assistance from the United Nations (UN) and United Kingdom, was unable to ensure security. Government services were

TABLE 1. COMPARING ESTIMATES OF ADULT HIV PREVALENCE IN AFRICAN COUNTRIES FROM UNAIDS V. RANDOM SAMPLE NATIONAL SURVEYS

Country	UNAIDS' estimate		National survey estimate		UNAIDS' estimate as % of national survey estimate
	Year	Prevalence (%)	Year	Prevalence (%)	
Burundi	2001	8.3	2002	3.0*	277
Kenya	2001	15.0	2003	6.7	223
Mali	2001	1.7	2001	1.7	100
Rwanda	1997	12.8	1997	11.1	115
South Africa	2001	20.1	2002	15.6	129
Zambia	2001	21.5	2001/2	15.4*	140
Zimbabwe	2001	33.7	2001	16.1*†	NA
Mean					164

NA: not applicable.
 * Averages of reported HIV prevalence for men and women.
 † HIV prevalence for persons aged 15 - 29 years.
 Sources: Kenya, Central Bureau of Statistics, 2003; Shisana & Simbayi, 2002; UNAIDS, 2002a; UNAIDS, 1988; WHO/AFRO, 2003; WHO, 2003.

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Table 2. HIV PREVALENCE IN COUNTRIES WITH LONG-TERM CIVIL DISORDER AND SELECTED NEIGHBOURING COUNTRIES

Region, country	Population (millions)	% adult literacy	1985-86	1987-88	1989-90	1991-92	1993-94	1995-96	1997-98	1999-00	2001-02	2003-04
West												
Guinea	8.2	36			OW: 0.7			OW: 1.4			NW: 2.8	
Sierra Leone	4.6	31			UW: 0.8		UW: 2.0				NA: 0.9	
Liberia	3.1	55		NA 0.0		UW: 3.7	UW: 4.0				NW: 4.3	
Côte d'Ivoire	16.1	50		OW: 2.6					OW: 9.8	OW: 8.8	NW: 7.3	
Central/Southwest												
CAR	3.8	48			OW: 6.5	OW: 5	OW: 10	OW: 14			NW: 15	
DRC	59.8	63	UW: 6.0	UW: 7.1	UW: 4.7	UW: 5.9	UW: 5.4	UW: 3.2	UW: 3	UW: 4.1	UW: 3.0	
Rwanda	8.1	68	NA: 3			OW: 2.5		OW: 8.8	NA: 11		NW: 4.2	
Angola	12.8	43	UW: 0.3			UW: 0.7		UW: 1.2			NW: 2.4	
Zambia	10.6	79			OW: 17	OW: 10	OW: 14		OW: 13		NA: 15	
Namibia	1.9	83				OW: 3.4	OW: 8.2	OW: 17	OW: 15	OW: 17	NW: 23	
Southeast												
South Africa	44.4	86			NW: 0.8	NW: 2.7	NW: 7.6	NW: 14	NW: 23	NW: 22	NA: 16	
Zimbabwe	12.8	89			OW: 16	OW: 19	OW: 24	OW: 31	OW: 29	OW: 33	NW: 30	
Mozambique	18.2	45		UW: 0.4	UW: 0.6	UW: 1.2	UW: 2.7	UW: 5.8	UW: 11	OW: 11	NW: 14	
Malawi	11.6	61		UW: 8.2	UW: 17	OW: 5.5	OW: 16	OW: 16	OW: 18	OW: 22	NW: 17	
Northeast												
Kenya	31.1	83			OW: 3.2	OW: 7.9	OW: 8.9	OW: 11	OW: 14	OW: 23	NW: 6.5	NA: 6.7
Somalia	9.1	24							OW: 2.0	OW: 0.7		
Ethiopia	67.3	40				OW: 4.9	OW: 4.3	OW: 9.2			NW: 11	
Southern Sudan	11.1	nd						UW: 3.0	UW: 3.5			RA: <1
Uganda	24.2	68			OW: 11	OW: 13	OW: 8.7	OW: 8.4	OW: 9.3	OW: 5.2	NW: 5.6	

nd: no data; DRC: Democratic Republic of the Congo, CAR: Central African Republic; NA, RA: national or rural adult HIV prevalence; UW, OW, NW: HIV prevalence in antenatal women in urban areas, outside major urban areas, or nationally (medians among antenatal clinics, omitting medians based on one clinic only; where medians are available for 2 years, the Table 2 shows the one based on the most clinics; exceptions are described in the following notes on sources by country).

Sources: Population and adult literacy (15 years and older) in 2001 are from United Nations Development Programme (2003) except for population in southern Sudan (which is estimated as 34% of Sudan's 2001 population [Prunier & Gisselquist, 2003]), and adult literacy for Guinea, Sierra Leone, and Angola in 1995 (from UNAIDS, 2000a).

Sources for HIV prevalence in each country:

Guinea: medians from five and six rural clinics in 1990 and 1996, respectively (UNAIDS, 2000f); 2001 survey of antenatal women (USAID, 2004).

Sierra Leone: 1990 and 1992 from one urban clinic (UNAIDS, 2000i); 2002 from a national survey of youth and adults aged 12-49 years (Kaiser *et al.*, no date).

Liberia: 1987 from multiple studies of healthy individuals and blood donors (US Census Bureau, 2003); 1992-93 from one urban clinic (UNAIDS, 2000g); 2002 from national antenatal women (sampling and weighting not clear) (WHO/AFRO, 2003).

Côte d'Ivoire: 1987 - 2000 medians from 4 - 9 clinics outside major urban areas (UNAIDS, 2002b); 2002 national median of 28 clinics (WHO/AFRO, 2003).

CAR: 1990 - 96 medians from 3 - 10 clinics outside major urban areas (UNAIDS, 2000c); 2002 national median of 48 clinics (WHO/AFRO, 2003).

DRC: 1986 - 99 medians from 2 - 6 urban clinics (UNAIDS, 2000d); 2002 antenatal women in Kinshasa (WHO/AFRO, 2003).

Rwanda: 1986 and 1997 adult HIV prevalence from national surveys (Bizimungu, Ntilivamunda, Tshimana, Nzaramba, Busingo, Ndikuyezu *et al.* 1989; WHO/AFRO, 2003); 1991 and 1996 medians from 6-10 clinics outside major urban areas (UNAIDS, 2000h); 2002 national median of 24 clinics (WHO/AFRO, 2003).

Angola: 1986 - 95 from one clinic in Luanda (UNAIDS, 2000b); 2002 median of clinics from 6 provinces (WHO/AFRO, 2003).

Zambia: 1990 - 98 medians of 4 - 22 clinics outside major urban areas (UNAIDS, 2002k); 2001/2 from a national Demographic and Health Survey of adults aged 15-49 years (WHO, 2003).

Namibia: 1992 - 2000 medians of 5 - 16 clinics outside major urban areas (UNAIDS, 2002g); 2002 national median of 21 clinics (WHO/AFRO, 2003).

South Africa: 1990 - 99 estimates for national antenatal women (Laurence, 2000); 2002 for adults 15 - 49 years from a national survey (Shisana & Simbayi, 2002).

Zimbabwe: 1990 - 2000 medians of 3-30 clinics outside major urban areas (Table 2 shows reported median prevalence of 19% for 1991 rather than 0% for 1992) (UNAIDS, 2002i); 2001 national median of 19 clinics (WHO/AFRO, 2003).

Mozambique: 1986 - 98 from Maputo clinics, and 2000 median of 18 clinics outside major urban areas (UNAIDS, 2002f); 2002 national median of 37 clinics (WHO/AFRO, 2003).

Malawi: 1987 - 89 medians of 2 urban clinics, and 1992-99 medians of 10 - 16 clinics outside major urban areas (UNAIDS, 2002e); 2001 national median of 19 clinics (WHO/AFRO, 2003).

Kenya: 1990 - 2000 medians from 11 - 25 clinics outside major urban areas (UNAIDS, 2002d); 2002 national median of 34 clinics (WHO/AFRO, 2003); 2003 from a national Demographic and Health Survey of adults aged 15 - 49 years (Kenya, Central Bureau of Statistics, 2003).

Somalia: 1997 - 99 medians of 2 - 3 clinics outside major urban areas (UNAIDS, 2002h).

Ethiopia: 1991 - 98 medians from 2 - 10 clinics outside major urban areas (UNAIDS, 2000e); 2001 national median of 34 clinics (WHO/AFRO, 2003). Southern Sudan: 1995 and 1998 from an antenatal clinic in Juba, a city in southern Sudan (UNAIDS, 2002j); 2003 from 2002-03 surveys in a rural area near Yei town and in Rumbek, a small southern town (Kaiser *et al.* 2004).

Uganda: 1990 - 2000 medians of 6 - 23 clinics outside major urban areas (UNAIDS, 2002j); 2001 national median of 17 clinics (WHO/AFRO, 2003).

minimal to non-existent. After an agreement with the rebels, the UN declared in January 2002 that the war was over (Peace Pledge Union Online, 2004b). In a national survey shortly after the end of the war, 0.6% of men and women aged 12 - 49 years reported a war-related amputated limb, 9.4% of youth aged 12 - 17 years reported one or both parents killed or missing, and 6% of women aged 12 - 49 years

reported forced sex with someone other than their regular partner in the last 12 months (Kaiser, Spiegel, Salama, Brady, Bell, Bond *et al.*, no date). The country is extremely poor; according to recent estimates, only 45% of adult men and 18% of adult women are literate, and life expectancy is below 40 years (UNAIDS, 2000a).

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At the beginning of Sierra Leone's civil war, HIV prevalence was low in the general population; for example, 0.8% among urban antenatal women and 0.4% among army recruits in 1990 (United States [US] Census Bureau, 2000). However, higher prevalence was found in some groups, e.g. 6.7% in Freetown blood donors in 1987 - 89 (US Census Bureau, 2000), and 4.7% in sexually transmitted disease (STD) patients in 1990 (Kosia, Makiu, Mansaray & Koker, 1992). During the war, UNAIDS (2002a) estimated 7.0% adult HIV prevalence in 2001, which was a significant over-estimate. Within months after the war ended in early 2002, a national serosurvey assisted by the US Centers for Disease Control and Prevention (CDC) found only 0.9% HIV prevalence in youth and adults aged 12 - 49 years, which was a weighted average of 0.6% HIV prevalence in rural areas and 2.1% in Freetown. The survey covered an estimated 79% of the population (Kaiser *et al.*, no date).

Sierra Leone is bounded by Guinea and Liberia. The best recent estimate of HIV prevalence in Guinea is 2.8% from a national survey of antenatal women in 2001 (WHO, Regional Office for Africa [WHO/AFRO], 2003), which is triple the HIV prevalence in Sierra Leone. Information on HIV in Liberia is too limited to make any sound comparisons with the situation in Sierra Leone (see below).

Liberia

Liberia's civil war began in 1989 when Charles Taylor's National Patriotic Front of Liberia entered from Côte d'Ivoire. Taylor seized power in 1990, but for years competing armed factions controlled parts of the country. Despite a peace agreement and elections in 1997, fighting continued. In 2003, as part of another peace agreement, Taylor resigned as President and moved to Nigeria, but 'fighting and marauding ...has continued' (International Crisis Group, 2004, p. 1). In early 2004, the UN Mission in Liberia increased troop levels, with plans to demobilise and disarm warring factions (Europaworld, 2004).

HIV was present in Liberia at low levels at the beginning of the civil war. Studies in 1987 - 89 reported 1 - 4% HIV prevalence in tuberculosis patients, 0 - 0.6% in blood donors, and 0 - 0.7% in visa applicants (US Census Bureau, 2003). Other studies in 1988 reported no HIV in 30 prostitutes, 35 STD patients, or 941 healthy individuals (US Census

Bureau, 2003). From 1995, rates of HIV prevalence in multiple studies of inpatients, outpatients, and tuberculosis patients range upward from 11.3% (US Census Bureau, 2003), pointing to an expanding pool of infected people in the non-patient population. UNAIDS (2000a) estimated 2.8% adult HIV prevalence nationally in 2000, but the basis for that estimate is unclear. WHO/AFRO (2003) reported 4.3% HIV prevalence for women attending antenatal clinics throughout Liberia in 2002. However, it is not clear how representative this is for all women.

Liberia shares borders with Sierra Leone and Côte d'Ivoire. As already stated, a national survey in 2002 reported 0.9% HIV prevalence in Sierra Leone (Kaiser, Spiegel *et al.*, no date). Côte d'Ivoire has consistently reported the highest levels of HIV prevalence in the region: in 2002, the median HIV prevalence in 28 sentinel antenatal clinics was 7.3% (WHO/AFRO, 2003).

DRC

As President Mobutu aged and aid to the DRC faltered at the end of the cold war, government mismanagement led in the early 1990s to a collapse of services and cessation of many aid projects. In September 1991, soldiers protesting low pay rioted in Kinshasa; as others joined, rioting and looting spread to other cities. French and Belgian soldiers entered Kinshasa to protect and evacuate expatriates; foreign staff of Project SIDA, a major US and Belgian-funded AIDS research project, left Kinshasa at this time, and the project soon closed (Cohen, 1997). In 1993, soldiers protesting low pay instigated a second episode of urban riots. Civil disorder gave way to civil war in 1996 as Laurent Kabila, with assistance from Uganda and Rwanda, drove from eastern DRC to overthrow Mobutu in 1997. Civil war resumed in 1998 with the additional involvement of troops from Angola, Zimbabwe, Namibia and Sudan. Since Joseph Kabila replaced his assassinated father in 2001, fighting has subsided (Peace Pledge Union Online, 2004c), but as of early 2004, civil order and government services have yet to be restored in much of the country.

AIDS is an old epidemic in the DRC. Sequencing of HIV collected in 1997 found many samples that did not cluster with known clades (Vidal, Peeters, Mulanga-Kabeya, Nzilambi, Robertson, Ilunga *et al.*, 2000), indicating that HIV was spreading in the DRC not long after the most recent common ancestor,

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which has been dated to 1931 (95% confidence interval: 1915 - 1941) (Korber, Muldoon, Theiler, Gao, Gupta, Lapedes *et al.*, 2000). The oldest known HIV was isolated from a blood sample collected in or near Kinshasa in 1959 (Nahmias, Weiss, Yao, Lee, Kotsi, Schanfield *et al.*, 1986). Blood collected in rural Equateur Province (northwest DRC) in 1976 and 1986 showed a stable 0.8% HIV prevalence over a decade (Nzilambi, De Cock, Forthal, Francis, Ryder, Malebe *et al.*, 1988). In the early 1980s, the DRC was one of the first countries in Africa in which AIDS was recognised.

During 1984 - 91, multiple studies found HIV prevalence around 5% in low-risk adults in Kinshasa. A 1984 survey of health workers found 8.1% of women and 5.2% of men with HIV infection (Mann, Francis, Quinn, Bila, Asila, Bosenge *et al.*, 1986). In 1987 - 88, HIV prevalence among men working at a bank and their wives was 5.8% and 5.7%, respectively, somewhat higher than the 2.8% and 3.3% found among men working at a textile factor and their wives (Ryder, Ndilu, Hassig, Kamenga, Sequeira, Kashamuka *et al.*, 1990). In this, as in many other early studies in Africa, higher status and income was associated with higher HIV prevalence. During 1986 - 91, median HIV prevalence in urban antenatal clinics ranged from 4.7% to 7.1% and outside major urban areas from 1.1% to 3.8% (omitting years with only one clinic reporting in a category) (UNAIDS, 2000d).

From the mid-to-late 1980s, evidence suggests stable or declining HIV prevalence in the DRC. After a 1997 study of HIV in antenatal women, blood donors, tuberculosis patients, commercial sex workers, and STD patients in three locations (Kinshasa, Mbuyi-Mayi, a south-central city, and Bwamanda, a northern town), the study team reported that 'Despite the social disruption, the rapid decline in health-care provision, and the decrease in funding in health education programmes, our results show that the HIV seroprevalence rates remain relatively low and stable in DRC' (Mulanga-Kabeya, Nzilambi, Edidi, Minlangu, Tshimpaka, Kambembo *et al.*, 1998, p. 908). The median HIV prevalence in three urban antenatal clinics in 1997 was 3% and in 14 clinics outside major areas it was 3.7% (UNAIDS, 2000d). In 2002, HIV prevalence among antenatal women in Kinshasa was 3.0%. Moreover, WHO/AFRO (2003, vol. 2, p. 124) assessed that 'available data suggest a stabilization of the trend in some parts of the country', but also noted

evidence of rising HIV prevalence in Lubumbashi (near Zambia). HIV testing in rural areas with presumably lower prevalence has been limited.

In the early 2000s, HIV prevalence in the DRC appears to be lower than in most if not all neighbours. A 2001/2 national survey in Zambia found 15% HIV prevalence among adults (WHO, 2003); the median from 48 antenatal clinics across the Central African Republic (CAR) in 2002 was 15% (WHO/AFRO, 2003); median HIV prevalence in 24 Tanzanian antenatal clinics was 8.1% in 2002 (WHO/AFRO, 2003); a 1997 national survey in Rwanda reported 11% adult HIV prevalence (though prevalence seems to have fallen in recent years); and median HIV prevalence in 17 antenatal clinics across Uganda in 2001 was 5.6% (WHO/AFRO, 2003). On the other hand, a 2002 national survey in Burundi reported 3% adult HIV prevalence (WHO, 2003), Congo's 2002 median HIV prevalence across antenatal clinics was 4.3% (WHO/AFRO, 2003), and HIV prevalence in Angola is also low (see below).

Angola

From Angola's independence in 1975, the government faced civil war with União Nacional para Independência Total de Angola (UNITA) rebels led by Savimbi. War continued with occasional truces until Savimbi's death in 2002. Agreements and ceremonies in August 2002 marked the end of the war. Over 27 years an estimated 600 000 Angolans were killed and a third of the population displaced by fighting (Peace Pledge Union Online, 2004d).

In the mid-to-late 1980s, after more than 10 years of civil war, HIV was found in Angola at low rates, with differences across provinces. A 1986 study found 0.3% of antenatal women, 4% of inpatients, and 1% of tuberculosis patients in Luanda, the capital, to be HIV-positive (Bottinger, Palme, da Costa, Dias & Biberfeld, 1988). In 1987 - 88 another study confirmed low prevalence in Luanda, but found higher prevalence in other provinces, including Lunda Norte (22% in blood donors, 12% in urban healthy persons, 22% among tuberculosis patients), Huambo, Zaire province of Angola, and Kuando-Kubango (Santos-Ferreira, Cohen, Lourenço, Almeida, Chamaret & Montagnier, 1990). In 1992, HIV prevalence was 1.7% in 11 333 blood donors from nine provinces (US Census Bureau, 2000).

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In the last decade of the war to 2002, evidence suggests a minor increase in HIV prevalence. As of 2001, UNAIDS (2002a) estimated adult HIV prevalence at 5.5% for Angola, but this may be high. Prevalence was 3.2% among military personnel in Luanda in 2001, and in 2002 the median HIV prevalence in antenatal clinics in six provinces was 2.4%. Angola's Cabinda enclave, which borders Congo and the DRC, has had somewhat higher HIV prevalence, i.e. 6.8 – 8.5% among women at the one reporting antenatal clinic during 1992 – 96 (UNAIDS, 2000b), but falling to 3.3% in 2002 (WHO/AFRO, 2003).

The US Agency for International Development (USAID) (2003, p. 1) noted that 'Angola's HIV prevalence has remained significantly lower' than in neighbouring countries, and speculated that this is 'perhaps due to the initially isolating effects of civil war...' In 2002, the median HIV prevalence in 21 antenatal clinics across Namibia, Angola's southern neighbour, was 23% (WHO/AFRO, 2003). As already discussed, a 2002 national survey in Zambia found 15% adult HIV prevalence (WHO, 2003), while prevalence in the DRC is low and may be comparable with Angola's.

Mozambique

Mozambique's civil war during 1976 – 92 devastated much of the country. South Africa supported the Resistência Nacional de Moçambique (RENAMO) to destabilise Mozambique's government and to block its support for South Africa's African National Congress. RENAMO rebels attacked government facilities; among other damage, 46% of clinics and health posts were looted, destroyed, or closed through 1988 (Finnegan, 1992). The peace agreement in 1992 led to multiparty elections in 1994, demobilisation, and extension of government services with donor support.

To the end of the war, Mozambique's HIV prevalence remained low. Among antenatal women in Maputo, HIV prevalence was 1.2% in 1992 (UNAIDS, 2002f). Prevalence was also low in regions of the country that had suffered intensively from rebel attacks. A 1992 – 93 survey of antenatal attendees among displaced persons (mean duration of displacement 5 years; only 1% had left Mozambique) in Zambezia Province, which borders Malawi, found 26 (1.5%) of 1 728 women to be HIV-positive. One hundred and forty-five women (8%) had been raped (half more than once), of whom

4 were HIV-positive (Cossa, Gloyd, Vaz, Folgosa, Simbine, Diniz *et al.* 1994). A 1991 – 92 study of antenatal women and STD patients in Inhambane Province in southern Mozambique found no HIV among antenatal women, although 51% had one or more STD; while among 155 men and women with STD-related complaints, three men (2%) were HIV-positive (Vuylsteke, Bastos, Barreto, Crucitti, Folgosa, Mondlane *et al.*, 1993). A 1990 – 91 survey of 1 338 prisoners in Maputo found 0.6% HIV prevalence (Vaz, Gloyd, Folgosa, & Kreiss, 1995). On the other hand, a 1990 survey of displaced persons on Inhaca Island near Maputo found 10 (4.7%) of 216 volunteers with HIV infection (Fernandes, Vaz, Esteves & Noya, 1992).

From 1992, rates of HIV prevalence in Mozambique began a sharp increase. In Maputo, prevalence in antenatal women rose from 1.2% in 1992 to 5.8% in 1996 (UNAIDS, 2002f) and 18% in 2002 (WHO/AFRO, 2003). In 2002, the national median HIV prevalence across 36 antenatal clinics was 13.7%; prevalence was lower in the north than in the centre and south (WHO/AFRO, 2003). In Chimoio, a city along the Beira corridor to Zimbabwe in the centre of the country, HIV prevalence among blood donors increased to 21% (49% in military donors, and 16% in others) in 1999 (Newman, Miguel, Jemusse, Macome & Newman, 2001). These rates may be compared with 0% prevalence among blood donors in Chimoio in 1987 (Barreto, Ingold, De La Cruz, Jorge, De Sousa, Leandro *et al.*, 1988), and less than 4% among soldiers in Tete in 1987 and Pemba in 1990 (US Census Bureau, 2000). A study of post-war HIV prevalence in Mozambique (Melo *et al.*, 2000, p. 203) speculated that 'the opening of the borders, the return of refugees, and widespread prostitution have contributed to a dramatic increase in HIV prevalence'.

HIV prevalence in Mozambique was far below most of its neighbours at the end of the war. In 1991 – 92, when antenatal prevalence in Maputo was 1.2%, median HIV prevalence in antenatal clinics outside major urban areas was 8% in Tanzania (UNAIDS, 2000j), 19% in Zimbabwe (UNAIDS, 2002l), 10% in Zambia (UNAIDS, 2002k), and 5.5% in Malawi (UNAIDS, 2002e), while estimated national HIV prevalence in antenatal women in South Africa was 2.7% (Laurence, 2000). In the first decade after the war, Mozambique's HIV prevalence soared. Among antenatal women in sentinel surveys, rates of HIV prevalence are now higher in Mozambique than in

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Tanzania, are comparable with Malawi's, and remain somewhat lower than in Zambia, Zimbabwe, and South Africa (WHO/AFRO, 2003). However, unmeasured HIV prevalence may be lower in rural populations.

Somalia

Somalia's civil war began in the north in 1988 with a rebellion that led to the secession of Somaliland in 1991 (which has not been recognised by the international community). In 1991, armed militias overthrew the central government (Peace Pledge Union Online, 2004e). From 1991, militias have successfully rejected a new central government, and intermittent civil war continues (as of early 2004).

Somalia had few HIV infections up to the end of the 1980s. Three studies during 1985 - 89 found no HIV in prostitutes, STD patients, or tuberculosis patients in Mogadishu and two southern cities (Burans, Fox, Omar, Farah, Abbass, Yusef *et al.*, 1990; Jama, Grillner, Biberfeld, Osman, Isse, Abdirahman *et al.*, 1987; Scott, Corwin, Constantine, Omar, Guled, Yusuf *et al.*, 1991). In 1990, HIV appeared at low levels in prostitutes (5 of 245) and military personnel (1 of 79) in Mogadishu and two southern cities, and none of 80 STD patients or 43 tuberculosis patients was infected (Watts, Corwin, Omar & Hyams, 1994). In 1995, a study in Mogadishu found no HIV infection among 157 blood donors, 57 inpatient adults, and 42 inpatient children (Nur, Groen, Elmi, Ott & Osterhaus, 2000). The authors observe that 'during the civil war in Somalia, no evidence of an increase in HIV-1 infections was found (p. 137)'. The latest information on antenatal women in Mogadishu showed no HIV infections in 1998 (UNAIDS, 2002h). However, in northern Somalia (Somaliland), HIV has been found at low levels in the general population: a 1999 study in three cities reported 0.9% HIV prevalence in antenatal clinics and 4.6% among 314 tuberculosis patients (Abokor, 2000).

HIV prevalence in Somalia has been much lower than in neighbouring countries. Kenya's and Ethiopia's HIV epidemics reached double-digit rates of infection in at least one urban antenatal clinic by 1990 - 91 (UNAIDS, 2002d; UNAIDS, 2000e). A Demographic and Health Survey in Kenya in 2003 reported 6.7% adult HIV prevalence (Kenya, Central Bureau of Statistics, 2003). In Ethiopia, the median HIV prevalence among 34 antenatal clinics nationally was

11% in 2001 (WHO/AFRO, 2003). In Djibouti, the latest data from antenatal clinics showed 2.9% HIV prevalence in 1996, while 17.2% of tuberculosis patients were HIV-positive in 1998 (UNAIDS, 2002c).

Southern Sudan

Rebel armies in Sudan's southern regions have fought for autonomy or secession for decades. The first civil war began when Sudan became independent in 1956 and lasted 16 years. The second began in 1983 with a rebellion led by the Sudan People's Liberation Movement/Army (SPLM/A). From 1991, a split within the rebel movement led to additional fighting. Up to 2002, an estimated two million Sudanese had died during the second civil war, four million had been internally displaced, and 400 000 had sought refuge in neighbouring countries (Prunier & Gisselquist, 2003). Despite progress in talks, fighting continues in early 2004.

In 1986, a study of 130 inpatients with fever in Juba, a southern city, found HIV in two, a prisoner and a Ugandan soldier (Woodruff, Morrill, Burans, Hyams & Woody, 1988). Three years later, another study in Juba identified HIV in 3% of outpatients, 19% of tuberculosis inpatients, and 16% of prostitutes (McCarthy & El Hag, 1990). Subsequent surveys in an antenatal clinic in Juba reported 3% and 3.5% HIV prevalence in 1995 and 1998 respectively (UNAIDS, 2002i). HIV prevalence in Juba, which has been under central government control, may not be characteristic for surrounding contested and rebel-held territory. In 2002 and 2003, random sample surveys in southern Sudan (assisted by the US CDC) reported adult HIV prevalence around 4% in Yei town near Sudan's border with Uganda, less than 1% in rural areas near Yei town, and less than 0.5% in Rumbek, a small town further north from the border (Kaiser, Kebedamo, Lane, Kessia, Handzel, Downing *et al.*, 2004). Figures for rural Yei and Rumbek may be the best indicators of HIV prevalence in rural southern Sudan.

Populations in southern Sudan affected by war have experienced later and fewer HIV infections than populations in neighbouring countries. Southern Sudan borders Ethiopia, Kenya, Uganda, DRC, CAR and Chad. By 1992, median HIV prevalence in antenatal clinics outside major urban areas had been reported as high as 4.9% in Ethiopia (UNAIDS, 2000e), 7.9% in Kenya (UNAIDS, 2002d), 11% in Uganda (UNAIDS, 2002j), and 6.5% in CAR

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(UNAIDS, 2000c). Antenatal HIV prevalence in Gulu District in northern Uganda was reported at 27% in 1993 (UNAIDS, 2002j).

A note on other wars

Accounts of HIV epidemics in Tanzania, Uganda, and Guinea Bissau have speculated on a role for civil disorder and wars. Hooper (2000) proposed that Tutsi refugees fleeing ethnic violence in Rwanda introduced HIV into northwest Tanzania and southwest Uganda around 1960. In the early 1960s, medical authorities in Uganda and Tanzania recorded unusual cases among recent Rwandan immigrants of Kaposi's sarcoma and other diseases now recognised as opportunistic infections associated with AIDS. This timing is plausible: from genetic evidence, HIV was circulating in central Africa well before 1950 (Korber *et al.*, 2000; Vidal *et al.*, 2000). One hypothesis that fits this evidence is that immunodeficiency viruses crossed from chimpanzees to humans through a cut hunter, and then spread through unsterile health care, including especially intensive programmes to find and treat trypanosomiasis in French and Belgian colonies in central Africa during 1930 - 1950 (Gisselquist, 2004). However, Hooper's (2000) hypothesis that oral polio vaccines introduced HIV into Rwanda in the 1950s does not fit the genetic evidence. The regions of Tanzania and Uganda where Tutsi refugees settled around 1960 were recognised over 20 years later with high HIV prevalence. Hence, ethnic violence in Rwanda may have spread HIV to neighbouring countries through refugee resettlement.

Serwadda *et al.* (1985) and Hooper (2000) speculate that Uganda's 1978-79 war with Tanzania contributed to Uganda's HIV epidemic. In October 1978, Ugandan soldiers crossed the border with Tanzania west of Lake Victoria and occupied over 1 000 km², and then withdrew several weeks later. Tanzanian troops assembled in northwest Tanzania from November 1978, invaded Uganda in January 1979, and took Kampala in April (Kasozi, 1999). While the occupied area in Tanzania and invasion routes through southwest Uganda were later found to have high HIV prevalence, large groups of soldiers spent no more than a few months in these regions. This was probably too little time for more than about 1% to have become HIV-infected, which in turn limited their potential role as vectors for HIV transmission (cf. in five studies of African men in serodiscordant couples in which many men were unaware of their wife's HIV

status, their unweighted average HIV incidence was 7.1 per 100 person years (PYs) [Gisselquist & Potterat, 2003]; other studies report HIV incidence of 6.6 per 100 PYs among Kenyan truckers [Martin, Jackson, Mandaliya, Bwayo, Rakwar, Nyange *et al.*, 1994] and 2.0 per 100 PYs among Tanzanian policemen [Bakari, Lyamuya, Mugusi, Aris, Chale, Magao *et al.*, 2000]). Hence, it seems more likely that high HIV prevalence in border regions built up over time, both before and after the war, and that peacetime commerce and travel contributed more than troop movements to the spread of HIV to other parts of Uganda and Tanzania.

Several authors have hypothesised that Guinea-Bissau's liberation war in 1963 - 74 contributed to the spread of HIV-2 through increases in sexual and health care exposures (Hooper, 2000; Poulsen, Aaby, Jensen & Dias, 2000). A variety of evidence supports this hypothesis, but also fits patterns of peacetime, urban-centered HIV epidemic growth common in Africa. Genetic analyses of HIV-2 samples collected in Guinea-Bissau in 1989 - 92 suggest a transition around 1955 - 70 from no growth to 20% annual epidemic growth (Lemey, Pybus, Wang, Saksena, Salemi & Vandamme, 2003). According to this evidence, whether or not growth began during the war, it continued for 15 years after the war. The geographic distribution of infections in 1980 was centered on Bissau, the capital (Piedade, Venenno, Prieto, Albuquerque, Esteves, Parreira *et al.*, 2000). Many of those found infected in samples collected during 1980 - 92 were too old or too young to have been involved in much sexual transmission during the war (Poulsen, Aaby, Jensen & Dias, 2000; Wilkins, Ricard, Todd, Whittle, Dias & Da Silva, 1993). Moreover, assumptions about the survival of persons with HIV-2 infections are required to interpret this data.

Discussion

This paper describes levels and changes in HIV prevalence in seven African countries experiencing long-term civil disorders or wars over the last several decades. In one country (DRC), adult HIV prevalence appears to have stabilised; in two (Sierra Leone and Somalia), it increased from near zero to less than 1%; in three (Angola, Mozambique, and southern Sudan), it increased from near zero to undetermined but low rates; and in Liberia, adult HIV prevalence increased from near zero, but current rates are unknown. In Mozambique, the one country where post-war

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movements in HIV prevalence have been observed, prevalence appears to have increased by more than 10% (from roughly 1% to 14%) over the decade from 1992 (UNAIDS, 2002f). Only a handful of countries in southern Africa have experienced greater increases in HIV prevalence over a decade.

These findings are relevant to ongoing research and debate to identify factors that explain differential epidemic trajectories, as well as related debates about what to include in HIV prevention programmes. Some key conclusions are discussed below.

Communities with HIV prevention programmes often do no better than communities at war, with no prevention programmes

Observed trends in HIV prevalence in countries with long-term civil wars may be compared with UNAIDS' (2002a) estimate of 9% adult HIV prevalence in sub-Saharan Africa in 2001. Allowing for some overestimate, this suggests an average increase in adult HIV prevalence of 3 - 4% per decade from 1980 to 2000, which exceeds what has been observed in countries with long-term civil wars. On the other hand, a number of African countries at peace have demonstrated low or falling HIV prevalence that compares favourably with what has been observed in countries with long-term civil wars. Senegal and Madagascar have maintained adult HIV prevalence below 1% (UNAIDS, 2000a). Declining HIV prevalence in Uganda from 1990 has been widely recognised (Green, 2003). Less well known are comparable declines suggested by some evidence in Burundi (WHO, 2003), Rwanda (WHO/AFRO, 2003), Kagera District in Tanzania (Kwesigabo, 2001), and possibly other countries and communities as well.

During civil disorders and wars, WHO, UNHCR & UNAIDS (1996, p. 6) recognise 'a strong likelihood that AIDS control activities, whether undertaken by national governments or NGOs, will have been severely disrupted or have broken down altogether'. Hence, it is noteworthy that epidemic trajectories in countries at war compare favourably with what is observed in many countries at peace. Although there is no question that HIV prevention programmes do prevent some HIV transmission (e.g. providing condoms to men who would otherwise contract or spread HIV), the failure to outperform consistently the 'no programme' option observed in countries at war demonstrates that these positive impacts are often

outweighed by other factors. However, with few exceptions, even the lowest rates of HIV prevalence in African countries at war or peace are high on a world scale, and represent a failure to prevent spread of HIV beyond high-risk groups such as men who have sex with men, injection drug users, and their sexual partners. Prostitute women are also often a high-risk group in Africa and Asia (which may be due to unsterile health care [Packard & Epstein, 1991] as well as sexual exposures), although not in Europe, where 'prevalence is generally less than 2%, except in settings where most HIV-infected prostitutes seem to be injecting drug users' (Hamers & Downs, 2004, p. 89).

Low risk for HIV in war zones corresponds to low risk in remote rural populations and in persons with low socioeconomic status

Within African countries at peace, HIV is associated with residence in or convenient access to cities or towns. In a 1987 survey in Tanzania, adult HIV prevalence in Bukoba town was 24%, dropping to 10%, 4.5%, and 0.4% in progressively more remote rural wards (Killewo, Dahlgren & Sandstrom, 1994; Killewo, Nyamuryekunge, Sandstrom, Bredberg-Raden, Wall, Mhalu *et al.*, 1990). At maternity units in Kimpete, DRC, during 1988 - 91, HIV prevalence was 11.7% in women from large cities, 4.3% from small towns, 3.7% from villages within 1.7 kilometers from a main road, and 1.7% from more remote villages (Green, Mokili, Nganzi, Davies, Hardy, Jackson *et al.*, 1992). In Hlabisa, South Africa, in 1997, HIV prevalence in 11 antenatal clinics varied inversely according to the isolation of the population in each clinic's catchment area (measured as the mean distance from homesteads to a primary or secondary road). Thus, across clinics, HIV prevalence fell roughly 2% per kilometer ($r = 0.66$, $p = 0.002$) (Tanser, LeSueur, Solarsh & Wilkinson, 2000). In a rural district in Malawi in 1987 - 90, HIV prevalence in antenatal women living more than 8 km from a clinic was 4.7% compared with 8.4% for those living closer. In the same study, 17% of women with more than 10 years of education were HIV-positive, compared with 8% with less than four years (Slutsker, Cabeza, Wirima & Steketee, 1994). In a 1989 - 93 study in Rwanda, HIV incidence was 8.6 times greater among urban than rural women (Bulterys, Chao, Habimana, Dushimimana, Nawrocki & Saah, 1994). Botswana is an exception to this pattern, with comparable levels of

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HIV prevalence in urban and rural antenatal clinics (WHO/AFRO, 1993).

Within urban and rural African communities, HIV is often associated with more education and other measures of high socioeconomic status. A recent review of evidence from published studies found that Africans with more years of schooling were often at higher risk for HIV-positivity. Moreover, the association between education and HIV was comparable in men and women, and stronger in rural populations and older cohorts (Hargreaves & Glynn, 2002). In a study of urban antenatal women in Malawi in 1989–90, having more compared with less than 8 years of education more than doubled the woman's risk for prevalent HIV infection. Similarly, having a husband with more compared with less than 8 years of education more than doubled the woman's risk for HIV, but reduced her risk for STDs (Dallabetta, Miotti, Chipangwi, Saah, Liomba, Odaka *et al.*, 1993). In Lusaka in 1985, HIV prevalence ranged from 8% in adults with 0–4 years of education to 33% in those with more than 14 years (Melbye, Njelesani, Bayley, Mukelabai, Manuwele, Bowa *et al.*, 1986). However, associations between education — and more generally, higher socioeconomic status — and HIV are weaker or even reversed in some recent studies. For example, a 1996 study in Kisumu, Kenya, reported higher socioeconomic status associated positively or negatively with HIV for various age and sex cohorts (Hargreaves, Morison, Chege, Rutenberg, Kahindo, Weiss *et al.*, 2002).

Alternate views on the importance of HIV transmission through unsterile health care lead to alternate hypotheses for slow spread of HIV during civil wars

Since the late 1980s, most AIDS experts have accepted the hypothesis that sexual transmission accounts for almost all HIV infections among African adults. From this viewpoint, differences in sexual risk factors should explain differences in HIV epidemic trajectories across countries. Although hundreds of studies find that sexual behaviour and biological variables are personal risks for HIV infection, research to date has been unable to identify even one such variable that is consistently more common in countries with high compared with low HIV prevalence (Gisselquist *et al.*, 2004). For example, a recent African study found adults in cities with high HIV prevalence not to have more syphilis, gonorrhoea, chlamydia, and non-marital

and concurrent sexual partners than adults in cities with low HIV prevalence (Buve *et al.*, 2001). In other studies, differences in prevalence of herpes simplex virus 2 (Orroth, Korenromp, White, Changalucha, de Vlas, Gray *et al.*, 2003) and lack of male circumcision (Boerma *et al.*, 2003) across communities do not correlate with differences in HIV prevalence. Hence, the view that sex accounts for almost all HIV transmission to African adults remains an hypothesis in search of evidence.

A competing hypothesis proposes that differences in HIV transmission through blood exposures — particularly during unsterile health care — drive epidemics in countries where HIV is not concentrated among men who have sex with men, injection drug users, and their sexual partners (Gisselquist & Potterat, 2003; Gisselquist, 2004). From this perspective, HIV prevention in countries with generalised epidemics should address health care transmission along with sexual risks. Between these two views, there are many possible compromise positions, with health care accounting for more than 5% to 10% of infections, but not enough to drive generalised epidemics. In countries with generalised epidemics, there are to date no reliable estimates of the proportions of HIV infections from sexual and health care exposures, so it is not yet possible to end the debate with an empirical resolution.

Experts who accept the view that sex explains most HIV infections in Africa have tried to explain observed low HIV prevalence during wars as due to low rates of sexual transmission. For example, Mulanga-Kabeya *et al.* (1998, p. 909) suggest for DRC that 'the high degree of poverty experienced in the country as a result of the political and socio-economic crisis could have contributed in the change of sexual behavior.' For Mozambique, Barreto, Liljestrand, De Sousa, Bergstrom, Bottinger, Biberfeld *et al.* (1993, p. 687) suppose that 'closed roads and isolation from neighboring countries' limited HIV entry. Although war may reduce the frequency of HIV-infected truck-drivers copulating with sex workers, the level of HIV infection in soldiers and rebels and their sexual activities must be considered as well. It is not at all obvious that civil wars cause a net reduction in sexual risk. WHO, UNHCR & UNAIDS (1996) speculate that wars increase sexual risks (abuse of women and boys, earlier sexual activity, and prostitution) as well as

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non-sexual risks (injection drug use and transfusion of untested blood).

On the other hand, if one supposes that unsterile health care accounts for an important proportion of HIV infections in countries with generalised epidemics, then slower epidemic growth during wars may be explained by wars reducing exposures to unsterile health care. Health care services diminish as aid and government health expenditures collapse, and violence drives away health workers and destroys facilities. Lack of access to health care in southern Sudan is demonstrated by a finding of 0% of common pathogens (*pneumococci*, *S. pyogenes*, *H. influenzae*) resistant to common antibiotics in samples collected in 2000 in a rural hospital that had been isolated by civil war for 18 years (Doczeova, Liskova & Kremery Jr., 2003).

In what might be a macabre parallel to wartime conditions reducing public access to health care and HIV transmission, Seale (1986, p. 123) explains the spread and end of the Ebola outbreak in Yambuka, DRC, in 1976: 'Once the hospital closed on 28 September because of the death of three-quarters of the hospital staff, the epidemic vanished as abruptly as it started, leaving 280 people dead... The cause, and amplifier, of this particularly explosive epidemic was traced by the international team to five hypodermic needles and syringes, the daily allocation for the nurses for use on all ward patients in the 120-bed hospital and on all 400 outpatients per day... [T]he five hypodermics...were never sterilised between use all day.'

Evidence for slow growth of HIV epidemics during long-term civil wars may be easier to correlate with wartime reductions in health care exposures than with unknown differences in sexual exposures. If so, the evidence would seem to favour the view that unsterile health care accounts for an important proportion of HIV transmission in Africa. However, alternate interpretations are possible, so that evidence is suggestive, not decisive. Further research in early post-war populations might help to characterise better wartime sexual and blood exposures as risks for HIV infections.

Conclusion

In African communities subject to civil disorder and war, people are impoverished and cut off from

government services. Setting aside war-related violence, these wartime conditions are approximated in peacetime among remote rural populations with low socioeconomic status. Factors that explain relatively low HIV prevalence in countries after long-term civil wars may help to explain much of the diversity in HIV epidemic trajectories across African countries and communities. Identifying what those factors might be (e.g. more or different sexual or medical exposures in peacetime than in war) may lead to more effective prevention programmes that will consistently outperform the 'no programme' option.

Acknowledgements

I thank Anthony Okwuosah, John J Potterat, Garance Upham, Reinhard Kaiser, Stuart Brody and anonymous reviewers for comments on earlier drafts.

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The journal publishes contributions in English and French from all fields of social aspects of HIV/AIDS (care, support, behaviour change, behavioural surveillance, counselling, impact, mitigation, stigma, discrimination, prevention, treatment, adherence, culture, faith-based approaches, evidence-based intervention, health communication, structural and environmental intervention, financing, policy, media, etc.). While the emphasis is on empirical research (qualitative and quantitative), the journal also accepts theoretical and methodological papers, and review articles, which should not be longer than 8 000 to 10 000 words, as well as, short communications, letters, commentaries and book reviews. Priority is given to articles which are relevant to Africa and the developing world and which address social issues related to HIV and AIDS. Special issues may deal with a specific topic, region or country. Submission of papers presented at the biannual international conferences of HIV/AIDS and STI in Africa and biannual Social Aspects of HIV/AIDS Research Alliance (SAHARA) conferences are especially invited.

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