

We demystify behavioural and social aspects of living with HIV and AIDS

HIV and AIDS

It lies in our hands as a nation to change the status of the HIV/AIDS epidemic. The HSRC contributes towards achieving the desired change by undertaking research that leads to a better understanding of HIV/AIDS.

We are home to a multitude of large, policy-relevant research projects on the behavioural and social aspects of the HIV epidemic - from studies that aim at drawing global attention to the need for better policies to address the plight of children, to investigating programmes that may contribute to prevention of infections in the young and in vulnerable groups such as orphans, gays and men who have sex with men (MSM), as well as the health of older people. Our studies also focus on public health systems and how these can be improved.

Our initiatives have resulted in:

- Presenting a plenary paper at the XVII International AIDS Conference in Mexico City;
- Mentoring HIV-positive mothers regarding their wellbeing and that of their babies;
- Understanding the value that HIV sufferers attach to traditional complementary and alternative medicines; and
- Filling the information gap regarding HIV among men who have sex with men.

Plenary on children at International AIDS Conference, Mexico City

For the first time in its existence, the XVII International AIDS Conference invited a South African expert to present a plenary paper on the wellbeing of children affected by HIV and AIDS. The honour fell to Professor Linda Richter of the HSRC who focused her paper on the neglect of children in global responses to the epidemic, on wrong turns taken over the last two decades, and on strong recommendations to move the field forward.

According to Unicef, by 2007 there were an estimated two million children living with HIV - 90% of them in sub-Saharan Africa (see Figure 1).

Richer argued that programmes have failed children in four respects: prevention of HIV infection through parent-to-child-transmission; roll-out of treatment to children that lags significantly behind adult access; an almost exclusive focus on orphans; and neglect of the families and extended kin – many living in extreme poverty – who are largely left to support



affected children with little or no funding, nor assistance from governments.

In particular, the much-used term 'AIDS orphan' has led to considerable confusion. While the term is used in epidemiological and demographic projections to refer to children who have lost one or both parents, 88% of children called orphans have, in fact, a surviving parent.

Professor Linda Richter addresses the plenary of the XVII International AIDS Conference in Mexico City on the wellbeing of children affected by HIV and AIDS. In many cases, this surviving parent is at high risk of being infected, has lost livelihood and social support, and is in critical need of assistance to be able to care for his or her children.

The main recommendations contained in Richter's plenary presentation were:

- Policies, programmes and funding must be redirected to provide support for children through their families.
- A dramatic rethink in policies is needed to develop comprehensive and integrated family-centred services.
- Much greater attention must be given to social protection, given that the backdrop to much of the impact of the AIDS epidemic on children is extreme poverty.
- The use of income transfers, which have demonstrated impressive results in supporting poor and vulnerable families including those affected by HIV and AIDS, should be expanded.

Child, Youth, Family and Social Development programme

Traditional complementary and alternative medicines for HIV patients in KwaZulu-Natal

As many reports have indicated that the use of traditional medicine is common among people with moderate and advanced HIV disease, our Social Aspects of HIV/AIDS and Health (SAHA)



research programme decided to conduct a crosssectional study to assess the use of traditional complementary and alternative medicines (TCAM) for HIV patients before they start using antiretroviral therapy.

Using systematic sampling, we selected and interviewed 618 HIV-positive patients from outpatient departments of three public hospitals in KwaZulu-Natal.

The study found that the use of TCAM was common among study participants with HIV (317, or 51,3%). Some of the participants used only herbal therapies (183, 29,6%). The use of micronutrients (42,9%) was excluded from TCAM since health facilities provided vitamins. Herbal therapies were the most expensive, costing on average R128 (US\$16) per patient per month.

Most participants (90%) indicated that their health care provider was not aware that they were taking herbal therapies for HIV (90%). Herbal therapies were mainly used for pain relief (87,1%) while spiritual practices or prayer were used for stress relief (77,6%).

The study concluded that outpatients on HIV treatment at public health facilities commonly used traditional herbal therapies and TCAM. Healthcare providers should routinely screen patients for use of TCAM when initiating ART and also during follow-up and monitoring, keeping in mind that these patients may not fully disclose other therapies.

The study was done in collaboration with the Centre for the Study of Sexual Health and HIV at the Homerton University Hospital's NHS Foundation Trust in London, UK, and the HIV/ AIDS Pharmaceutical Care.

Project Accept shifts access

Project Accept, a large scale, four-country community randomised trial funded by the National Institutes of Mental health, is completing almost three years of intervention, delivering mobile voluntary counselling and testing services, coupled with community mobilisation and post-test psycho-social support to communities in a rural community just outside Pietermaritzburg.

Close to 10 000 people in four intervention communities have been tested so far.

Significantly, 77% of those we've tested are between 16 and 32 years of age, with 47% being male and 53% female (read further under Demonstration Projects on page 83).

Child, Youth, Family and Social Development programme

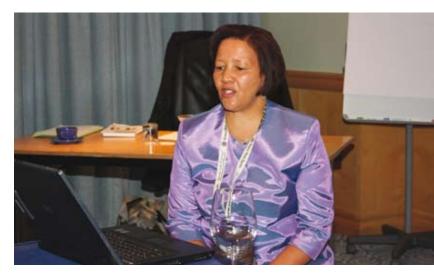
Mentor mothers programme (Masihambisane)

Project *Masihambisane* is a randomised clinic trial to test the effectiveness of health information materials and a clinic-based peer-support and mentoring intervention to improve the health and wellbeing of HIV-positive mothers and their babies during pregnancy and the early post partum period.

This HSRC study is funded by a grant from the National Institute of Health (NIH).

Masihambisane focuses on teaching HIV sufferers how to disclose their status and the importance of making such disclosure. Data from the current sample suggests that about 40% of the women (239 of 565) feel that they are able to tell someone their HIV status. (read further under Demonstration Projects on page 84).

Child, Youth, Family and Social Development programme



Johannesburg/eThekwini's Men's Study

The Johannesburg/eThekwini's Men's Study (JEMS) study was one of three groundbreaking studies carried out in South Africa to provide preliminary information on the epidemiology of HIV among men who have sex with men (MSM). JEMS focused on men living in Johannesburg and eThekwini (Durban), and also reviewed the availability of health programmes and services for MSM at these two major cities.

The study used respondent-driven sampling to recruit 285 men from Johannesburg and Durban for the survey. Those who consented to participate completed a questionnaire and provided blood specimens for anonymous HIV testing in a laboratory. Participants who did not know their HIV status were offered free onsite voluntary counselling and testing (VCT). The survey was also complemented with qualitative interviews with 32 key informants and approximately 150 men who participated in focus group discussions.

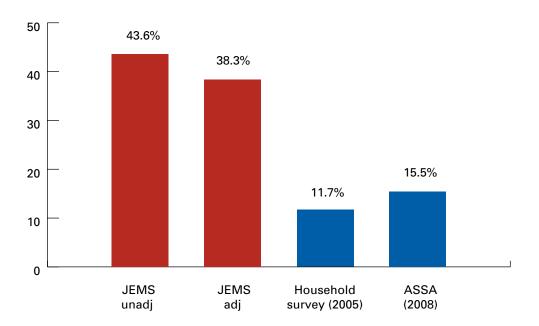
The study found that all men in the survey had had sex with at least one other man in the previous year. Their ages ranged from 18 years to 61 years, with an average age of 24 years; the majority were black Africans (88%), under 25 years of age (67%) and identified as being homosexual or gay (78%). Of the 266 men tested for HIV in the survey, 44% were HIV-positive.

Professor Laetitia Rispel, former executive director of the Social Aspects of HIV/AIDS and Health programme at the HSRC, presents the findings of the Johannesburg/ eThekwini's Men's Study (JEMS) study on men who have sex with men at a breakfast meeting at the 4th South African AIDS Conference in Durban.

This is more than double the estimates of HIV prevalence estimates among men in the general population (Figure 2). Of those men who were

HIV positive, 80% reported that they had never had sex with a woman.

Figure 2: Unadjusted and adjusted HIV prevalence estimates among JEMS participants (on left) compared to HIV prevalence estimates for men in the general population (on right)



Although the study results cannot be generalised to all MSM in South Africa or in the two cities, the findings raise concern that there is a 'hidden epidemic' of HIV among MSM in South Africa, as is the case in many other countries with generalised HIV epidemics. The findings suggest that MSM in South Africa may be experiencing an HIV epidemic in parallel with the HIV epidemic in the general population, with limited overlap between the two epidemics. The preponderance of black Africans in the survey dispels the misconception that men having sex with men is a white Western practice and that it is 'unAfrican'.

The JEMS results address an information gap noted in the *National Strategic Plan on HIV&AIDS* and STIs, 2007 – 2011. Using the experience gained from JEMS, HSRC researchers are planning a larger national study of HIV among MSM, in consultation with senior government officials as well as with key stakeholders in the lesbian, gay, bisexual, and transgender (LGBT) sector.

The findings are also being used to help motivate for funding to increase HIV prevention, care and support services and programmes for MSM.

The study was conducted by the HSRC in collaboration with the Medical Research Council and the Centre for Health Policy at the University of the Witwatersrand.

Social Aspects of HIV/AIDS and Health programme

The Joint Learning Initiative on Children and AIDS (JLICA)

The HSRC is a founding member of the JLICA, a global network of policy-makers, practitioners, community leaders, researchers, and people living with HIV that meet and work to mobilise research and discussion on children affected by HIV/AIDS.

The activities of JLICA are divided into four groups: strengthening families; community action; expanding access to services and

protecting human rights; and social and economic policies.

In February 2009, JLICA released a comprehensive report – supported by four integrated learning group reports and more than 50 detailed systematic reviews - on its activities and findings.

The world's leading general medical journal *The Lancet* carried an editorial describing the report as laying out a new agenda for children affected by HIV and AIDS.

Since the launch of the final report, members of the JLICA steering committee have participated in a number of dissemination activities, including:

- presenting JLICA recommendations to UNAIDS and its partners the Unicef, WHO, and the Global Fund;
- briefing congress in Washington;
- addressing the African First Ladies health summit held in Los Angeles;
- addressing a symposium on the impact of HIV/AIDS and poverty on children in sub-Saharan Africa held at Stanford University; and
- addressing the annual meeting of the Dutch Working Group on Children Affected by AIDS held in Amsterdam, in the Netherlands.

A South African launch of the report is being planned jointly with Unicef, South Africa.

Child, Youth, Family and Social Development programme

Evaluation of psychosocial needs of caregivers in South Africa

The HSRC carried out an evaluation of the psychosocial needs of community-based people who care for orphans, vulnerable children (OVC) and people living with HIV/AIDS.

This was one of the first projects to concentrate on the psychological, social and other needs of



volunteers who deal with ill and dying people on a daily basis.

One of the most significant findings was that most caregivers felt they were getting the necessary help and instructions to cope with their caring tasks for people with chronic illnesses (78,4%), including HIV/AIDS. A total 73% said they were getting instruction or education about caring for people's medical conditions, treatment, medication and other needs.

Against expectations, about 83% of carers said they had freedom to interact with friends and family on a social level, and 81,5% said they were able to have peace of mind - described as freedom from excessive anxiety about the people they cared for.

As Table 1 shows, participants felt they were they were being valued and respected as individuals (75,7%) and the same proportion said they had a sense of shared responsibility, both practically and emotionally.

When it came to a question of whether they had a sense of satisfaction or achievement, 74,5% agreed; 73% said they were informed, prepared, confident, skilled, equipped, or trained for the caring task; and 68,3% said their care-giving needs and expertise were being recognised.

Professor Linda Richter (left), team leader of learning group 1: strengthening families, of the Joint Learning Initiative on Children and HIV/AIDS (JLICA) at the preparation phase of the project. On the right is Dr Scott Drimie, a group member.

Our study concluded that, in general, there was a low level of psychosocial distress among carers and a great passion for the care-giving role.

Caregivers and stakeholders indicated that their wellbeing could be improved if they were given transport to patients who stay far away; if their stipend was standardised to at least R1 000 per month; if they received structured and consistent training and re-fresher courses; if they were given psychosocial support through professional counsellors who do not necessarily work in

the same organisation; and protection against exposure to infectious diseases.

The findings of this study will contribute to the new government policy on task shifting in the health and HIV/AIDS sector, which is being discussed at the South African National AIDS Council (SANAC).

The South African Red Cross Society collaborated in the research and funded the study.

Social Aspects of HIV/AIDS and Health programme

Table 1: Psychosocial needs of carers in South Africa

PSS needs	Percent
Getting help with caring tasks for people with chronic illnesses, including HIV/AIDS	78,4
Getting instruction or education about the care for people's medical conditions, care needs, treatment and medication	73
Getting help with household tasks as a care giver	57,1
Have freedom to interact with friends and family on a social level	83
I have peace of mind (freedom from excessive anxiety about the people cared for)	81,5
Received information on emergency telephone numbers for ambulance, hospital and other services where you can refer your patients	80,3
In trying to achieve quality of life, have positive morale, emotional and mental health	79,5
I am being valued and respected as an individual	75,7
I have a sense of shared responsibility, both practically and emotionally, with services including	75,7
emergency access to help	75,7
I have a sense of satisfaction or achievement in providing care to others	74,5
I am informed, prepared, confident, skilled, equipped, or trained for the caring task	73,0
My care-giving needs and expertise are being recognised	68,3

Health Systems

Our research also focuses on public health systems and how these can be improved for the benefit of the entire South African population.

Our initiatives have resulted in:

- Developing and evaluating the efficacy of interventions for HIV/AIDS and sexually transmitted infections (STIs); and
- Better understanding of the health status of South Africa's older population.

Men, wisen up

Over the past seven years, the HSRC has been running a series of studies into theory-based behavioural interventions, known as *Phaphama* (meaning 'wisen up' or 'be wise').

Our studies aim to reduce the risk of sexually transmitted infections (STIs) and/or HIV infection among various target groups such as both male and female patients with repeat STIs at public health care clinics (original *Phaphama*, *Phaphama* 1 Alcohol and *Phaphama* 2); men who engage in gender-based violence (*Phaphama* Men); both men and women who drink in informal alcohol serving establishments such as shebeens (*Phaphama* Community Alcohol); and people living with HIV/AIDS who are aware of their HIV-positive status (*Phaphama* positive prevention).

The National Strategic Plan for HIV/AIDS and sexually transmitted infections (STIs) has highlighted the need of such evidence-based interventions as a national priority.

Indeed, the HSRC's Social Aspects of HIV/ AIDS and Health programme is among the few research programmes in South Africa that have been developing and evaluating the efficacy of such interventions. Phaphama Men is a community-based gender violence and HIV prevention intervention for men in their social networks. It is based on Social Action Theory, the concept of intervention, and advocacy-skills training.

A quasi-experimental field-intervention trial to determine efficacy, found that the intervention reduced negative attitudes toward women in the short term (see Table 2) and reduced violence against women in the longer term.

Men in the intervention group also increased discussions with sex partners about condoms and were more likely to undergo HIV testing. There were, however, few differences in risk-reducing behavioural outcomes such as condom use and number of sexual partners.

This is one of the few South African studies that demonstrate a high level of efficacy in changing some gender social norms. Further research will examine the potential synergistic effects of alcohol use, gender violence, and HIV-prevention interventions.

The HSRC has been conducting this work in collaboration with the University of Connecticut at Storrs, in the USA, and the University of the Western Cape.

Table 2: Comparison of intervention communities on behaviours in the previous month

Variable	Gender Vi	Alcoh	Alcohol & HIV/AIDS		
	N	%	N	%	OR
Did not lose temper with a woman among	men who had	at basline			
1-month	53	23	27	13	0.5**
3-month	43	18	32	15	0.7
6-month	52	23	29	14	0.5**
Hit or pushed a woman in the past month					
1-month	54	23	40	19	1.3
3-month	84	36	62	29	1.2
6-month	72	31	124	61	0.3**

Note: All analyses were controlling for age and baseline scores, *p<.05, **p,.01

Survey on global ageing and health (SAGE study)

South Africa has a higher proportion of older people in its population than any other sub-Saharan African country. Our older population rate also grows at a much faster tempo (2,60%) than the total population (1,28%). The projected increase of the number of people 50 years and older is 14,3% (6.8 million) in 2005 to 18,4% (8.9 million) by 2025, and those 60 years and older from 6.8 (3.2 million) in 2005 to 11,5% (5.6 million) by the year 2025 (UN Population Division, 2005).

The survey on global ageing and health (SAGE) study, initiated by WHO in selected countries (South Africa, China, Ghana, India, Mexico and Russian Federation), intended to get an empirical understanding of the health state of older people's morbidity and mortality, and an equitable system to address their needs. The countries were selected to give a broad representation across different regions, taking into consideration population and health characteristics in South Africa to allow cross-country comparisons.

The goals of SAGE were to promote a better understanding of the effects of ageing on wellbeing, to examine the health status of individuals aged 50 years and older, and the changes, trends and patterns that occured over time.

Over the past two years, the HSRC's Social Aspects of HIV/AIDS and Health research programme has been conducting South Africa's first ever nationally representative study on ageing and health. Our study involved 5 044 participants (558 individuals aged 18-49 years and 3 838 individuals aged 50+ years).

An important groundbreaking methodological contribution was the use of direct health examinations (anthropometric and performance measures) to determine the health status of the elderly population and then cross-validate the self-reported information by objective measurements. The measurements included height, weight, and body-mass index.

Our study indicated that there was a need for health promotion to improve the health status of the elderly, especially in addressing obesity and the associated risk factors.

Table 3: Percentage of underweight, overweight and obese respondents by age, sex, u/r, marital status

Characteristics		Prevalence of	Normal	Mean BMI		
	Underweight (%)	Overweight (%)	Obesity (%)	nutritional status (%)		
Sex						
Male	6,0	61,5	33,1	29,0	29,0	
Female	4,3	73,9	47,4	32,6	32,6	
Age group						
18-49	5,9	62,2	35,1	30,5	30,5	
50-59	4,0	71,6	44,5	31,9	31,9	
60-69	4,7	70,6	46,1	31,2	31,2	
70+	6,4	68,0	36,9	30,3	30,3	
Residence						
Urban	4,7	72,8	44,9	31,7	31,7	
Rural	5,6	63,5	35,5	30,1	30,1	
Characteristics	Mean systolic blood pressure	Mean diastolic blood	Mean pulse Rate	No. of resp	oondents	
		pressure				
Sex						
N 4 1						
Male	141.61	94.46	74.94		1231	
Female	141.61 146.96	94.46 95.16	74.94 77.12		1231 2224	
Female						
Female Age group	146.96	95.16	77.12		2224	
Female Age group 18-49	146.96 132.01	95.16 89.98	77.12 76.49		2224	
Female Age group 18-49 50-59	146.96 132.01 142.71	95.16 89.98 96.37	77.12 76.49 77.12		2224 401 1356	
Female Age group 18-49 50-59 60-69	146.96 132.01 142.71 147.21	95.16 89.98 96.37 95.90	77.12 76.49 77.12 75.99		2224 401 1356 989	
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