HIV/AIDS, MENTAL HEALTH AND QUALITY OF LIFE

International Society for Quality of Life Conference,

Grahamstown, South Africa, 20 July 2006

PLEASE DO NOT CITE

Kevin Kelly, CADRE, Rhodes University

RHODES UNIVERSITY
Where leaders learn

CADRE
CENTRE FOR AIDS DEVELOPMENT, RESEARCH AND EVALUATION

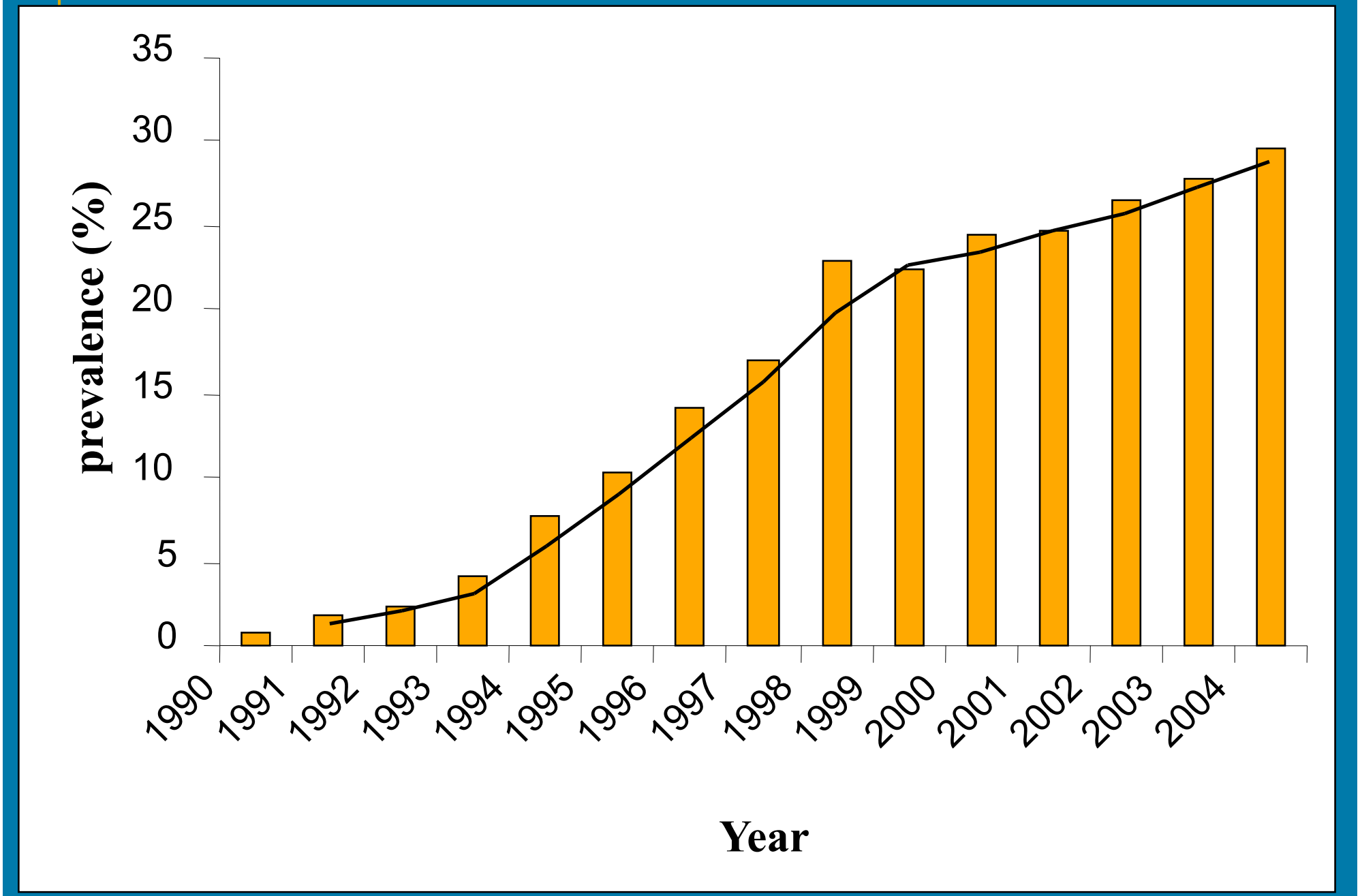
Background

- The current situation: HIV epidemic and its impacts
- The response
- The outlook

Current situation at a glance

- 1 in 9 South Africans over the age of 2 are HIV positive
- 14.4% (1 in 7) children between the age of 2 and 18 have lost a mother, father or both. 1 in 50 have lost both mother and father.
- About 1 in 6 public school educators are HIV+ve. In some districts as many as 1 in 3.
- A similar situation prevails in the health sector.

Prevalence HIV - antenatal care attendees in South Africa, 1990- 2004



Epidemic trends in South Africa

- Fewer than 3 in 100 South Africans aged 10-14 years are infected with HIV.
- At current infection rates more than 20 in 100 will be infected by the time they turn 25
- However, infection rates have leveled among young people, although not in all provinces
- 25-40 year olds have not responded well
- Mother to child transmission a continuing problem with less than 50% uptake so this technically manageable risk is proving difficult to control
- Elsewhere: Zimbabwe – infection rates on the retreat.

Why is it so bad?

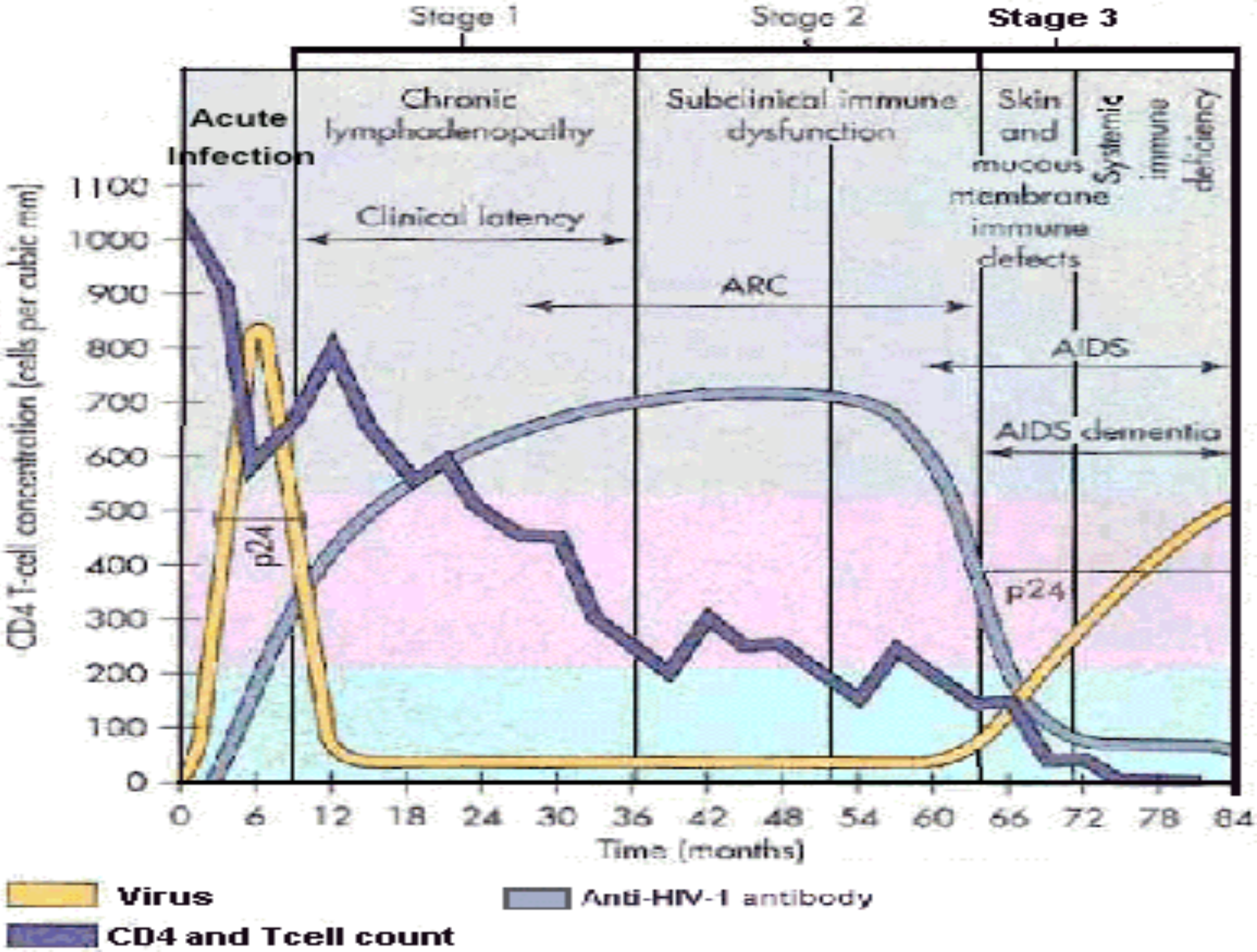
- Two main behavioural factors
- Concurrency
- Age differentials in sexual relationships
- Many non-behavioural factors, notably active herpes, untreated sexually transmitted infections

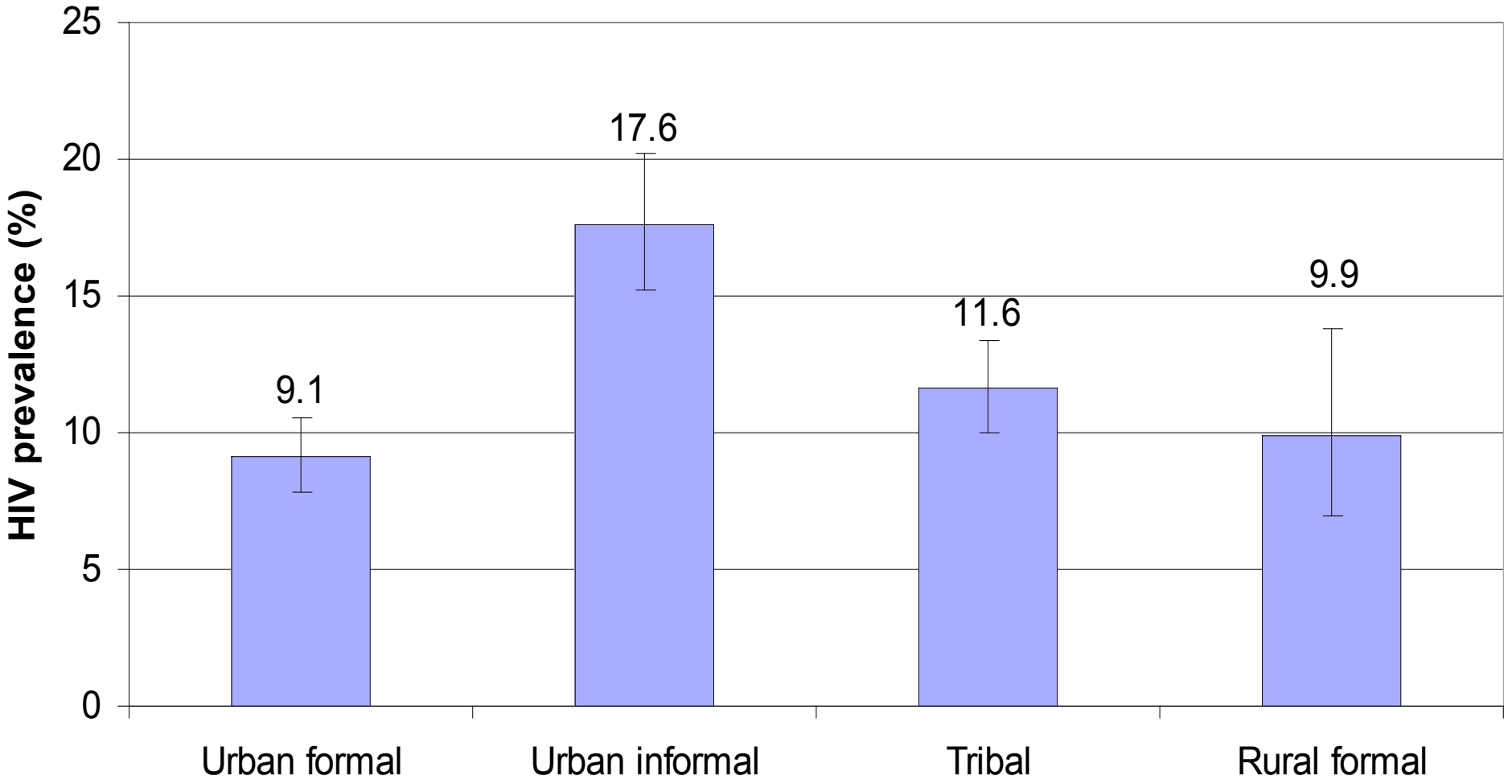
Concurrency - New infections are driving the epidemic

- Concurrency refers to maintaining relationships with more than one sexual partner such that the partners overlap in time. Concurrent relationships include regular or non-regular partners in short or long-standing relationships.
- It has been convincingly shown that in two populations in which individuals have the same average number of partners in a given period, HIV spreads more rapidly in the population in which partnerships are concurrent than in the population in which partnerships occur sequentially.

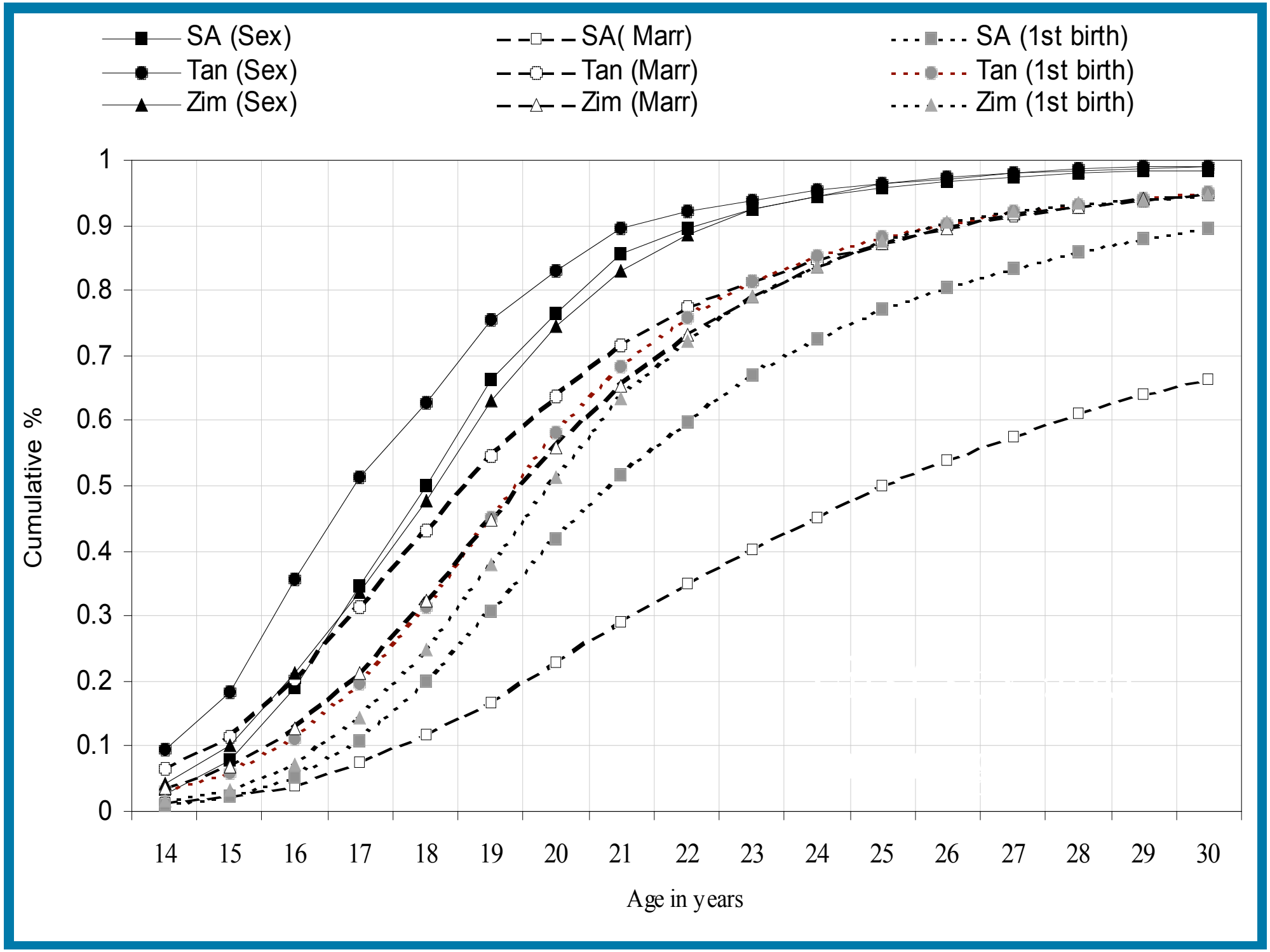
Viraemia and infectivity

- Individuals are hyper-infectious from before the onset of the acute retroviral syndrome – which typically occurs three weeks after infection and precedes sero-conversion by 10 to 21 days
- Peak viraemia occurs at 20 days from infection.
- Hyper-infectiousness continues for approximately 6 weeks after the onset of acute retroviral syndrome.
- On average men there would be 7-24% infection of sex partners during the first 2 months of infection.
- After this period passes the risk is relatively low, with estimates that in the absence of sexually transmitted infections, aggregated across sexes, the chances of becoming infected in an unprotected sexual act with an infected partner are 1 in 1000 per sexual act.
- May explain sero-discordance in couples.

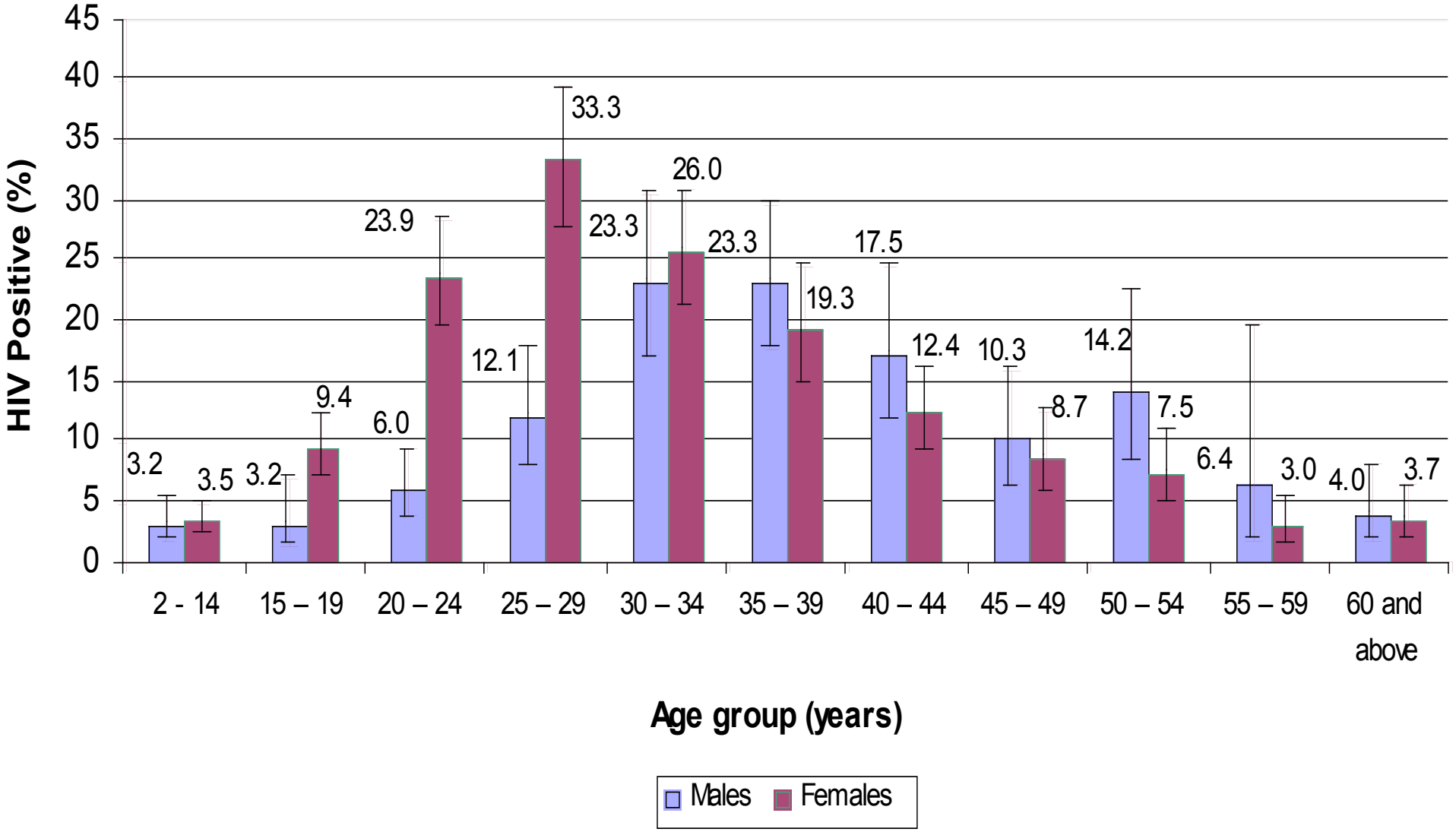

Stage 1
Stage 2
Stage 3
Acute Infection
Chronic lymphadenopathy
Subclinical immune dysfunction
Skin and mucous membrane immune defects
Systemic immune deficiency
Clinical latency
ARC
AIDS
AIDS dementia
p24
p24
CD4 T-cell concentration (cells per cubic mm)
1100
1000
900
800
700
600
500
400
300
200
100
0
0 6 12 18 24 30 36 42 48 54 60 66 72 78 84
Time (months)
Virus
Anti-HIV-1 antibody
CD4 and Tcell count



HIV prevalence by geotype: South Africans older than 2: 2005


SA (Sex)
Tan (Sex)
Zim (Sex)
SA(Marr)
Tan (Marr)
Zim (Marr)
SA (1st birth)
Tan (1st birth)
Zim (1st birth)
Cumulative %
0
0.1
0.2
0.3
0.4
0.5
0.6
0.7
0.8
0.9
1
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
Age in years

HIV prevalence by sex and age: 2005



Age and sex

- There is directionality to HIV infection. Infected populations infect…uninfected populations are infected.
- Young people are not so much infected by each other as by older people
- Poorer non-traditional communities have higher age differentials at sexual debut throughout the world
- When living in sight of wealth there are high expectations and high vulnerability to various forms of coercion and ‘transactional sex’

Responses

- Nevirapine uptake less than 50% in 2005
- ART probably reaching above one third of those that need it
- Condom uptake good, but problems associated with consistent use
- Need to connect prevention with VCT
- STI infections considerably reduced
- Looking promising…outcomes of intervention likely to show much more strongly in 2-3 years time
- Widespread social mobilisation. Massive growth of NGO and FBO activity
- Poor management, weak coordination, little systematisation
- Major human resource and knowledge management challenges

An HIV-positive mother of five in rural KwaZulu-Natal explains the steps she has gone through to apply for a disability grant

'In August of 2005…I went to the doctor and told him that I am a person who is always sleeping and can't wake up. I asked the doctor to make a letter for pension [disability grant] since I'm not working and my kids are not working….
When they gave me the letter at eShowe, I then took it to eSikhawini. When I arrived at eSikhawini, they gave me another form and asked me where I was staying. I told them Obanjeni. Then they said I must go to Dr K------.

[He said] did they ever take blood from me, then I said no. I never did it.… Then I went to Nsingweni and then I took it [blood test]. They said I should come back after two weeks to fetch the letter for results. Then I find out what was the problem.

The time I was fetching it, they gave me two letters. They said the one I should go with it to Salvage, the hospital, and the other one I should take to the doctor. Then the doctor photocopied it and stamped it and said I should take it to eSikhawini. My form is in eSikhawini.'

-

‘The major problems that we encounter are that mothers die without ID documents. So when we have to apply for birth certificates for the children, we really do not know where to start. And if we go to Home Affairs they need lots of things – questions like: ‘Where do you know the child from and from when do you know the child?’

- CBO in Vosloorus

‘It hurt us terrible….These sick people don’t get sick because they want to, so you just tell yourself that you should continue to give help, because what you are doing is really needed….[There is] a person who calls me a ‘faeces remover.’ This person who insults me just stands on the road and doesn’t work. He is like us [silence] … As I’m coming from afar, he always says, ‘You come from afar to bring AIDS from across.’…But I go there because I need to work with sick people. Tomorrow, the same ‘faeces remover’ will be needed by that person. When the person can’t wake up, I won’t be called ‘faeces remover’ – instead, my help will be appreciated. The insults won’t be used anymore. If I had a hard heart, I would remind the patient of those things. That wouldn’t be good. That’s why I say [the] person is in the darkness without being aware of what he is doing.’

--Caregiver from Obanjeni, KwaZulu-Natal

The need for contextual approaches

- “We are wet but we inside our house. You cannot say I must use a raincoat.”
- Gender, marriage relations, children’s rights, rape, rapid urbanisation

The outlook? …it depends

- Need to review prevention
- Connect prevention with VCT
- Expect continuing upscaling of treatment and thus distigmatisation
- Expect increasing visibility of AIDS
- Expect problems in adherence down the line
- Expect more high profile deaths
- Don't expect miracles, but slow-moving change
- The situation has many determinants, some of which are deeply ingrained in the fabric of the society. They won't simply wash out.
- We are in it for the long haul

Mental health?

- Remarkably little known
- AIDS has neuropsychiatric implications. AIDS dementia long been known about.
- Much less known about other psychiatric morbidity

A mental disorders epidemiological survey

- Composite International Diagnostic Interview for the assessment of mental disorder.
- Conducted with 900 HIV positive South Africans recruited in AIDS support centres and public health clinics in five provinces.

Age in years	**18–25**	**26–35**	**36–45**	**46 and older**
N = 900	**16%**	**51%**	**26%**	**6%**

Respondent characteristics

- Most had some schooling, but did not complete high school (74%). Only 5% had a post school qualification.
- 77% currently not working for income. Amongst employed 14% had only part time or piece work.
- Poverty levels high with 98% saying that they either did not have enough money for basic things such as food and clothes or had money for these basics but had no resources beyond seeing to basic needs.
- 78%had children.

HIV status characteristics

- 11% had found out that they were HIV positive within the 4 months prior to the interview.
- 31% had known between 4 months & 1 year, 31% between 1 & 3 years and 27% had been diagnosed positive for longer than 3 years.
- The majority believed that they had been infected by a regular partner (62%), while 21% said it had been through sex with a casual partner, 2% had been raped and 12% did not know how they had been infected.
- 3% percent believed they had been infected through other means such as blood transfusions or drug use.

HIV status characteristics cont.

- 52% found out their status after falling ill, 19% following routine antenatal testing or after disclosure of a positive status by a partner (12%). Only 11% found out that they were positive simply because they were concerned and went for testing.
- Staging of the disease and the CD4 count was obtained from patient records and was available for 80% and 40% of people respectively.
- 30% were in stage 1 (asymptomatic-normal activity)
- 37% in stage 2 (symptomatic-normal activity),
- 22% in stage 3 (bedridden <50% during last month)
- 17% in stage 4 (bedridden >50% during last month).
- Fifty six percent of people where CD4 count was available had counts above 200 while 44% had counts below 200.
- 18% were enrolled in ART programmes.

Findings 1

- **Previous studies in SA 10%–25% prevalence of mental disorder in the general population. Our study of HIV positive people finds 43.7% with mental disorder**
- **Males were more likely than females to experience a mental disorder. This is a reflection of higher levels of alcohol abuse as in all other categories of mental disorder there was no significant gender difference.**
- **Unemployed people were more likely to experience any mental disorder and have particular susceptibility to depression and alcohol abuse compared to their employed counterparts.**

Findings 2

- **Those with children were more likely to experience mental disorder, but having children is not related to the presence of any particular disorder.**
- **Respondents who did not know how they were infected were more likely to suffer from depression than those who knew – no matter how they were infected.**
- **A diagnosis of alcohol abuse was associated with having been infected by a casual partner.**
- **Way of learning about status was related to alcohol abuse only. Respondents who fell ill and went for care were more likely to have alcohol abuse disorder than those who found out from other means.**

Findings 3

- While in stages one and two mental disorder differences were minimal (39 ·8% and 37 ·2% respectively), at stage three 49 ·7% of respondents had identifiable psychiatric diagnoses and at stage four 68 ·8% of respondents were diagnosed with mental disorder.

	Male	Female	Total
Major depressive disorder	10·2%	11.%	11·1%
Minor depressive disorder	28·1%	30.5%	29·9%
Alcohol dependence	5·5%	2%	2·9%
Alcohol abuse disorder	23%	8·8%	12·4%
Drug dependence	1·3%	0%	0·3%
Drug abuse	5·1%	0·8%	1·9%
General anxiety disorder	0·8%	0·3%	0·4%
PTSD (event HIV)	5·1%	3·9%	4·2%
Panic disorder	0%	0·2%	0·1%
Social Phobia	0·9%	0·9%	0·9%
Intermitt. explosive disorder	3·8%	3·9%	3·9%%
Agoraphopia	0%	0%	0%
Any mental disorder	49·4%	41·5%	43·7%

Variables associated with mental disorder

	Presence of any disorder	Depression	Alcohol abuse
Gender	0·023		0·000
Employment status	0·001	0·012	0·022
Whether have children	0·018		
How infected		0·015	0·001
How status discovered			0·002
Clinical stage of the disease	0·000	0·000	

Association of disorder and services

- It was found that having had pre- and post-test counseling or not was not significantly related to presence of a mental disorder.
- Nor were the number of sessions, the professional status of the counsellor and perceived helpfulness of counseling related to mental disorder.
- Being in an HIV support group was significantly related to presence of a mental disorder, although the frequency of attendance was not significantly related.
- This suggests that experience of availability of support may be a more significant prognosticator of mental disorder than learning gained in a support group context.
- Although most of those who disclosed their HIV status found the experience helpful there was a significant positive association between presence of a mental disorder and having disclosed HIV positive status.
- Although being a member of an association for people with HIV/AIDS and being religious was perceived as helpful it was not statistically associated with the presence of mental disorder.
- Discrimination by community and family and isolation, were strongly related to mental disorder.
- Death of a significant other due to AIDS was strongly related to mental disorder
- Whereas death associated with other causes was not. The findings suggest a strong need for provision of psychiatric care as part of AIDS care as well as strengthening of support services.

Death of a significant other

- More than half the respondents (57%) had had someone close to them die of AIDS. Those that had had a close person die from AIDS were significantly more likely to have a mental disorder than those that did not ($p<0.01$).
- Seven percent had had a child die, 20.5% a friend, 1.6% a parent, 10.3% a partner, 12.2% another relative and 18% a sibling. Twenty six percent of respondents had experienced other major losses due to non-AIDS related deaths in the year prior to the interview. This included deaths of children, spouses, parents, siblings and friends. Deaths due to other causes did not correlate with the presence of a mental disorder.

ART

- Eighteen percent of respondents were receiving ART. Receiving ART was not associated with differences in prevalence of mental disorder.

Support groups

- Being part of a support group was the only service-related factor that had a significant association with mental disorder.
- Being part of a group may be protective for individuals vis-à-vis mental disorder. A substantial number of people returned to support groups and 65% of those who started in a group attended 10 or more sessions further attesting to perceived value. Over 90% of attendees felt the groups had been either very or somewhat helpful in coping with their positive status.
- The number of times a support group was attended was not related to mental disorder, suggesting that it may be the perception of an available supportive context that has the primary mitigating effect, rather than the actual learning derived from the support group.

Disclosure

Notwithstanding the fact that a high percentage of people found disclosure to be very helpful in all categories and 92% of people that had fully disclosed their status felt it had been very helpful to do so, those that had disclosed their status were significantly more likely to have a mental disorder than those who had not disclosed ($p < 0.05$).

Involvement in organisation

- Twenty two percent of respondents were part of an organisation of people living with HIV/AIDS and/or an activist group advocating for PLHAs. Ninety three percent of those that were part of such an organisation found that this was very helpful in coping with their positive HIV status, however there was no statistically significant association with mental disorder.

Religion

- Self-rated levels of religiosity were not related to diagnosis of mental disorder. However, seventy percent said that their faith had been very helpful in helping them to cope with their status, 15% found it to be somewhat helpful, 8.4% said it helped a little, 4.4% found religion no help at all and 2.3% said that religion had made things worse for them.

Discrimination

- Twenty three percent of respondents said that they had been discriminated against or had had negative reactions due to their positive status.
- This correlated strongly with the presence of mental disorder ($p<0.000$). The discrimination mainly took the form of being blamed for the infection and name calling by members of the community and family. Twelve percent of respondents said that they had been isolated as a result of their positive status. This too was significantly related to mental disorder ($p<0.001$).

Adherence

- Research shows that psychological, psychosocial and psychiatric factors play a significant role in how well PLWHA comply with treatment.
- Variables such as satisfaction with social support and ability to cope are significantly correlated with treatment adherence, while dimensions like hopelessness, loss of motivation and poor coping skills are indicative of noncompliance.
- Additional research has found that "age, education, employment, religious support, and perceived quality of life" are not specifically correlated with adherence to drug treatments, but adaptive coping ability and level of depression are.
- Depressed subjects with poor support adhere to drug treatments only about half as frequently as non-depressed subjects with good social support.

Implications

- **This research provides compelling reason to include mental health treatment in ART programmes.**
- **Because of the strong correlation between mental health disorders and noncompliance with treatments, addressing mental disorders within the HIV epidemic is critical for preventing drug-resistance.**
- **It is of course also critical to improving quality of life.**