



Reducing internalized stigma in generalized epidemics

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Outline of presentation

- An overview of the HIV/AIDS epidemic in South Africa
- The problems of HIV/AIDS-related stigma and discrimination in South Africa
- The development and validation of an Internalized AIDS-Related Stigma Scale
- Priorities for future research to reduce internalised stigma in generalized epidemics
- Conclusion

An overview of the HIV/AIDS epidemic in South Africa (1)

- South Africa alone carries the largest burden of HIV/AIDS of any single country in the world
- HIV prevalence in the population two years and older was 10.9% in 2008, not much different from the last two surveys.
- The epidemic has stabilised at this level of nearly 11% and remained so since 2002.

An overview of the HIV/AIDS epidemic in South Africa (2)

- HIV prevalence continues to be high among females compared to males
- The HIV prevalence peaks at ages 25-29 for females earlier than that of males, which occurs at age 30-34.
 - The peak for women remains stubbornly high at 33% for all the three surveys, and for men it peaks at a new high at 25.8%.
- Third, South Africans older than 50 have high HIV prevalence, with 1 in 10 aged 50-54 being HIV positive. This is because HIV programmes may not reach them.

An overview of the HIV/AIDS epidemic in South Africa (3)

- HIV is mainly spread through unprotected heterosexual sex in South Africa
- South Africa has the largest ARV treatment programme in the world with nearly 400 000 PLWHA on treatment, about 50% of those who need treatment.
- Much of the ARV programme is supported through funding received from the USA's President's Emergency Plan for AIDS Relief (PEPFAR) and the rest by the South African government itself.

The problem of HIV/AIDS-related stigma and discrimination in South Africa (4)

- Stigma towards PLWHA manifests itself in two main ways:
 - External (enacted by others towards them)
 - Internal (self-defacing internal representations felt by PLWHA)
- Basically, internalized stigma (or self-stigma) refers the assimilation and internalization of the socially constructed views of AIDS by HIV infected persons.
- Even during the era of HAART, many PLWHA in South Africa still go to their deathbeds without admitting to their friends and relatives that they have HIV/AIDS.
- Many also seek help either under cover of darkness or far way from their homes as they are deeply ashamed of their HIV positive status

The problem of HIV/AIDS-related stigma and discrimination in South Africa (5)

- This is because of the stigma and discrimination experienced by PLWHA which is even fatal at times.

Mother kills kids, herself over Aids rumours

Malungelo Booï and
Lubabalo Ngcukana

A TRANSKEI mother of seven killed herself and her four youngest children after a rumour that she was HIV-positive spread in her village.

Nokuzola Mfiki, 37, a resident of Mtambalala village near Lusikisiki, took her children's lives on Wednesday by feeding them poisoned milk. She then drank it herself.

Her body and those of her two daughters, Phelisa, 8, Phezisa, 5, her sons Alikho, 2, and seven-month old Endinakho Mfiki were later found lying in an open veld less than a kilometre from their home.

All the children had been fathered by the same man.

Mfiki leaves behind her three other children, aged 18, 16 and 14.

Family spokesman Zanele Quwese said Mfiki "was ridiculed, vilified and called by names by some villagers after a woman, who had an affair with the father of her four children, died of an Aids-related illness.

"They (villagers) also believed that she had the disease, and this has been going on for quite a while," Quwese said. She even stopped catching a taxi from her village to town because of the humiliation.

Hours before the killings, Mfiki sat down and wrote 10 letters – eight of them were sealed in light green envelopes and two were open. In the letters she de-

tailed why she had decided to end her life and that of her four children fathered by the same man, alleged to have been having an affair with the HIV-positive woman.

Ntetho Gquwese, who made the gruesome discovery at around 10am that morning, is still battling to come to terms with what he saw.

"All the bodies were covered with a blanket, next to them was an empty container of milk and a knife," he recalled yesterday.

Villagers said people suspected of having HIV were always made to suffer in the village. "They are called by all sorts of names," said resident Solokwane Mambanti.

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The problem of HIV/AIDS-related stigma and discrimination in South Africa (6)

- Unless HIV/AIDS-related stigma is better understood it will continue to be a serious barrier to HIV testing as well as prevention, treatment and care of PLWHA and also the mitigation of impact of the disease in South Africa.
- During the past few years, our research team has been undertaking various studies on both external and internal HIV/AIDS-related stigma.

The development and validation of an Internalized AIDS-Related Stigma Scale (1)

- Previous measures of internalized AIDS stigmas have emphasized the social ramifications of HIV disclosure and public reactions to AIDS.
- Berger, Ferrans, and Lashley (2001), for example, developed a scale that reflected disclosure concerns, perceived public attitudes, social reactions, and interpersonal experiences associated with HIV/AIDS disclosure.
- The scale did not include items to assess self-image and self-perceptions as a person living with HIV/ AIDS.

The development and validation of an Internalized AIDS-Related Stigma Scale (2)

- Although interpersonal and public reactions to HIV/AIDS indirectly reflect the stained social identity dimension of Goffman's (1963) theory, it is likely that self-defacing internal representations of being a person living with HIV/AIDS are important in predicting long-term adjustment and coping with HIV infection.

The development and validation of an Internalized AIDS-Related Stigma Scale (3)

- Items for this scale were adapted from a reliable and valid measure of community-held AIDS-related stigmas in the South African general population
- We selected six items from the AIDS-Related Stigma Scale (Kalichman et al., 2005) and reframed the wording to represent negative self-perceptions and self-abasement in relation to being a person living with HIV/AIDS
- The items included in the scale reflect Goffman's (1963) dimensions of stigma and focus on self-blame and concealment of HIV status

The development and validation of an Internalized AIDS-Related Stigma Scale (4)

1. It is difficult to tell people about my HIV infection;
2. Being HIV positive makes me feel dirty;
3. I feel guilty that I am HIV positive;
4. I am ashamed that I am HIV positive;
5. I sometimes feel worthless because I am HIV positive;
6. I hide my HIV status from others

To simplify administration, the items were responded to dichotomously, 1=Agree, 0=Disagree; with higher scores representing greater internalized stigma

The development and validation of an Internalized AIDS-Related Stigma Scale (5)

- Data were collected among 1068 PLWHA from Cape Town in South Africa, 1090 PLWHA from Swaziland and 239 PLWHA from Atlanta USA (Kalichman, S.C et al., 2009)
- Internalized stigma was positively correlated with depression scores in all three countries, higher internalized stigma scores were related to greater depression symptoms

The development and validation of an Internalized AIDS-Related Stigma Scale (6)

- For participants in both Cape Town and Atlanta, individuals who indicated that they have been treated differently since disclosing their HIV status endorsed significantly greater internalized stigma.
- For all three cities/countries, individuals who indicated that they have not discussed their HIV status due to fear of the consequences of disclosure endorsed greater internalized AIDS stigma.
- It was concluded that the Internalized AIDS-Related Stigma Scale appears reliable and valid and may be useful for research and evaluation with HIV positive populations across Southern African and North American cultures.

Study Limitations

- None of the samples included in the scale development are representative of people living with HIV/ AIDS in any of the three cities/countries although samples of people living with HIV/AIDS were drawn from multiple regions of Swaziland.
- It should also be noted that we were only able to obtain test - retest correlations for Cape Town and Atlanta.
- With the above limitations in mind, we conclude that the Internalized AIDS Related Stigma Scale demonstrated good evidence for its reliability and validity in three countries.

Priorities for future research to reduce internalised stigma in generalized epidemics

- . There is a need to investigate the impact of the following:
 - Legal and policy interventions such as outlawing discrimination at work and in all walks of life (e.g., challenges to SADF & SAA in South Africa using EEA legislation).
 - Activism and advocacy by human rights organizations such as the Treatment Action Campaign in South Africa.
 - ARV literacy and treatment such as the scaling up of treatment
 - Theory-based behavior change interventions linked to adherence and/or positive prevention such as Healthy Relationships which addresses both disclosure and risk reduction among PLWHA who know their status (which has been packaged and disseminated as part of CDC's Replication Project [REP] currently be in implemented throughout the USA as part of the Dissemination of Evidence-Based Interventions [DEBI] initiative).

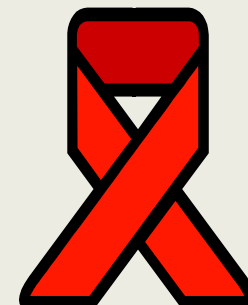
Conclusions (1)

- Internalized stigma is likely an important construct in the mental health and adjustment of people living with HIV/ AIDS.
- Additional studies are needed to confirm the psychometric properties of the Internalized AIDS-Related Stigma Scale and to expand the number of constructs examined for convergent and discriminant validity.
- The Internalized AIDS-Related Stigma Scale developed by Kalichman, Simbayi et al. (2005, in press) appears to be most promising tool - it is reliable and valid and may be useful for research and evaluation with HIV positive populations across Southern African with generalized epidemics (as well as among some North American cultures with concentrated epidemics).

Conclusions (2)

- These results indicate an urgent need for social reform to reduce AIDS stigmas and the design of interventions to assist PLWHA to adjust and adapt to the social conditions of AIDS in South Africa.
- Stigma is a complex social process dependent on specific cultural contexts (Maughan-Brown; 2006; Parker & Aggleton, 2003)

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