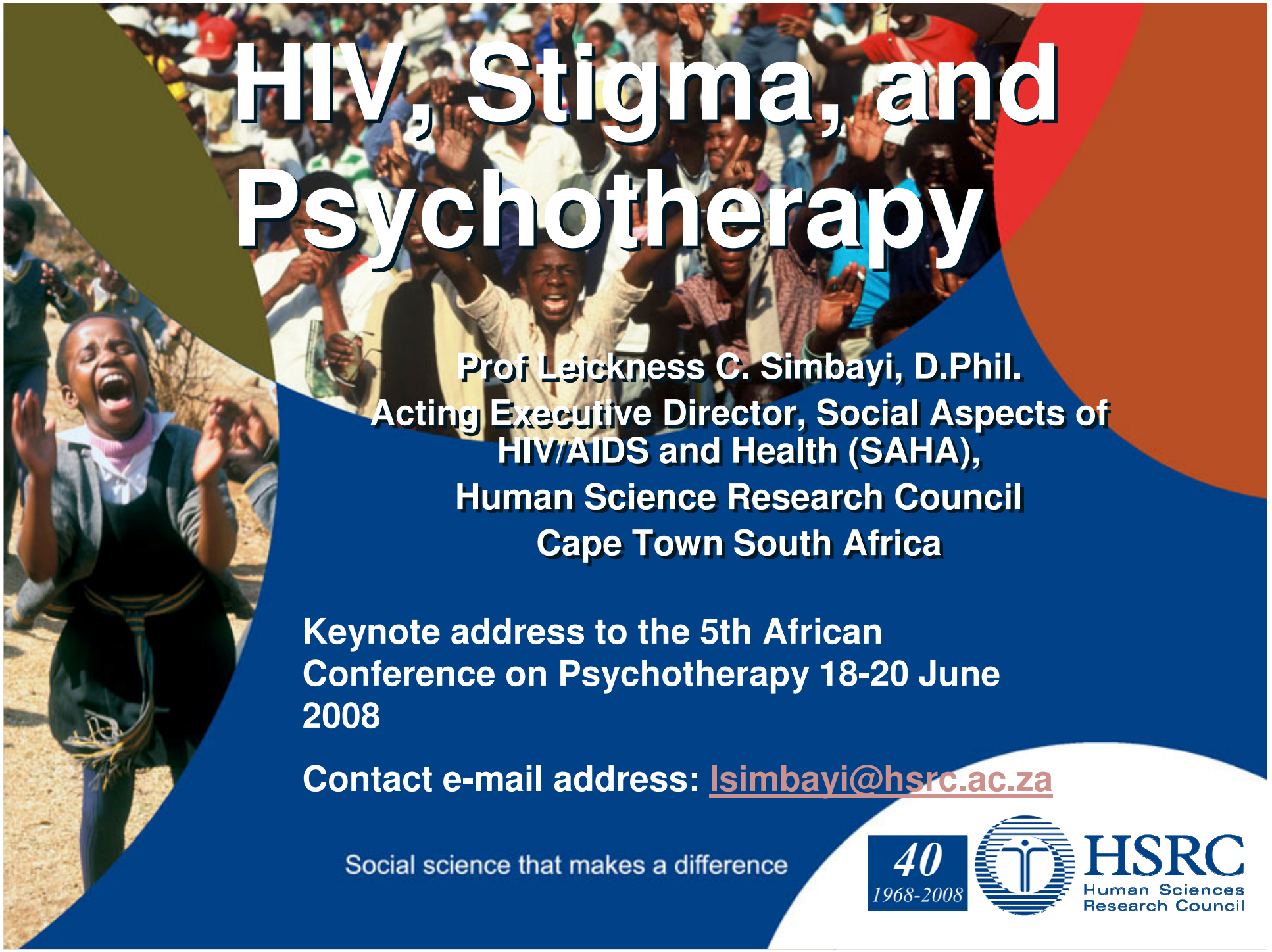

HIV, Stigma, and Psychotherapy

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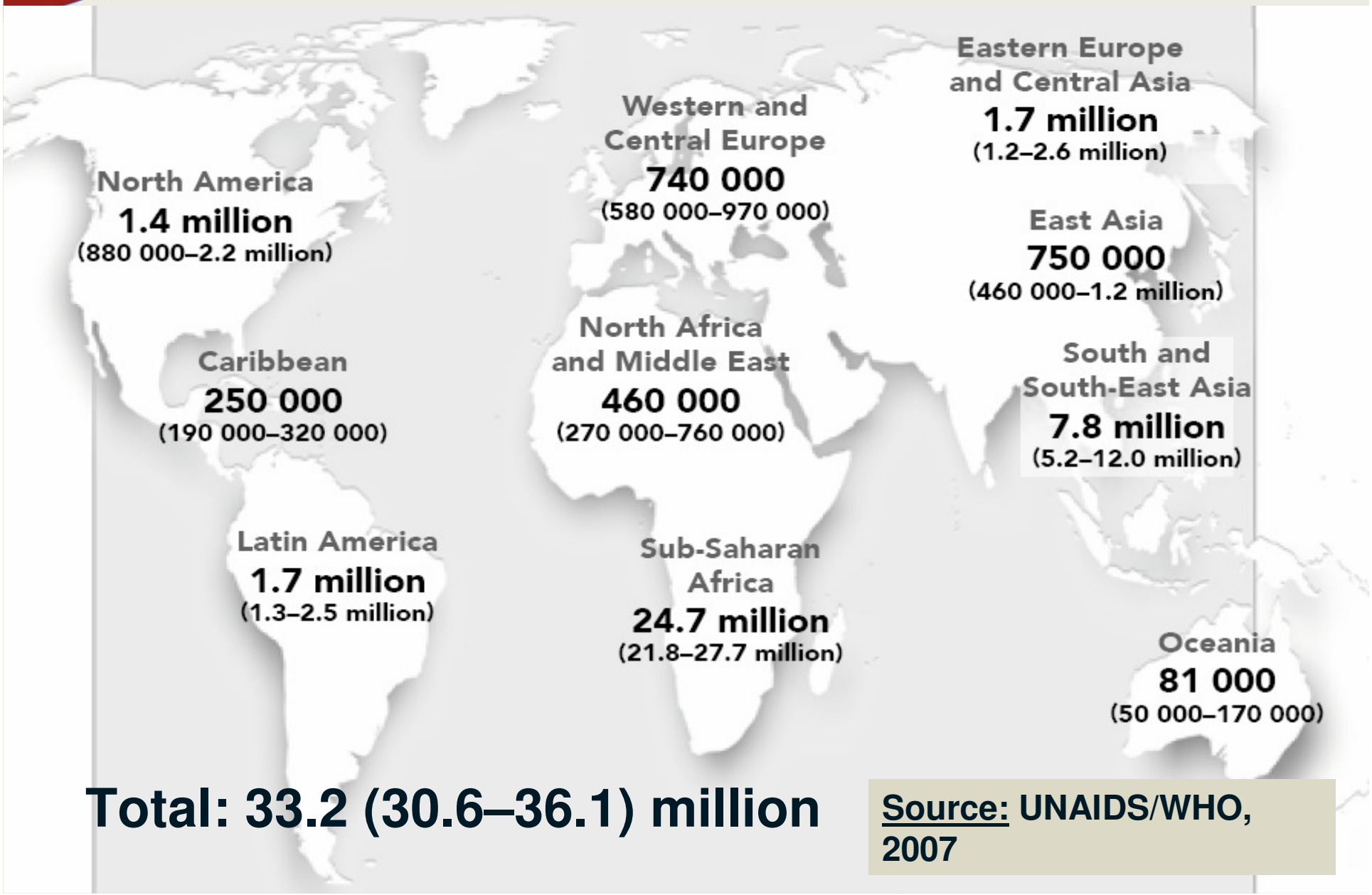
Overview of the presentation

- Background to the HIV /AIDS epidemic in Africa
- HIV/AIDS-related stigma
- A review of some HIV/AIDS-related stigma psychotherapeutic interventions
- Conclusions

Global update on the numbers of adults and children estimated to be living with HIV in 2007



Total: 33.2 (30.6–36.1) million

Source: UNAIDS/WHO, 2007

Background

According to UNAIDS (2007) *AIDS epidemic Update*:

- the total number of people living with HIV/AIDS in the world in 2007 were 33.2 million [30.6–36.1 million]
  - Adults 30.8 million [28.2–33.6 million]
  - Women 15.4 million [13.9–16.6 million]
  - Children under 15 years 2.5 million [2.2–2.6 million]
- People newly infected with HIV in the world in 2007
  - Total 2.5 million [1.8–4.1 million]
  - Adults 2.1 million [1.4–3.6 million]
  - Children under 15 years 420 000 [350 000–540 000]
- AIDS deaths in 2007
  - Total 2.1 million [1.9–2.4 million]
  - Adults 1.7 million [1.6–2.1 million]
  - Children under 15 years 330 000 [310 000–380 000]

Background (contd)

- The majority of those who are infected and affected are Africans, living in Sub-Saharan Africa and especially in the this (Southern Africa) region.

- Although Sub-Saharan Africa has about 10% of the world's population:
  - More than two out of three (68%) adults and nearly 90% of children infected with HIV in the world live in this region,
  - More than three in four (76%) AIDS deaths in 2007 in the world occurred in the region
  - More than two thirds of all new infections in 2007 in the world also occurred in the region.

Background (contd)

- South Africa alone carries the largest burden of any single country in the world with an estimated 5.5 million PLWHA (14% of the global burden) with a prevalence rate of 16% among adults aged 15-49 years of age
  - This represents about 20% of the African total
  - One out of every six PLWHA in the world

- [Swaziland, which is one of South Africa's neighbours, has the highest prevalence rate in the world at an estimated 25% in the adult population aged 15-49 years].

Background (contd)

- During the past 5 years there have been some concerted efforts by individual African nations in the fight against HIV/AIDS which have been supported by various international initiatives such as
  - The Global Fund to fight AIDS, Tuberculosis and Malaria,
  - The United States of America's President's Emergency Plan for AIDS Relief (PEPFAR), and the World Health Organisation's (WHO) and
  - the Joint United Nations Programme on HIV/AIDS (UNAIDS) '3X5' plan (WHO, 2006).
  - More recently, this process has been further supported by the Clinton Foundation which has championed the cause to encourage a further drop in ARV drug prices and more rapid availability of generic forms of some of the drugs.

Background (contd)

- This is expected to improve both availability and access to ARV treatment over the next few years especially in developing and transitional countries including South Africa.
- There is some anecdotal evidence that the wider availability of ARV treatment is helping to reduce the levels of HIV/AIDS-related stigma in several African countries.
- According to a new report *The World Bank's Commitment to HIV/AIDS in Africa: Our Agenda for Action, 2007-2011* launched in Washington DC on 14 May 2008, for every infected African starting antiretroviral therapy (ART) for the first time, another four to six become newly infected, even as regional figures show falling prevalence in countries such as Kenya, and parts of Botswana, Côte d'Ivoire, Malawi, and Zimbabwe.

Background (contd)

- The foregoing information suggests that Sub-Saharan African countries including South Africa must continue to champion HIV prevention efforts to slow and reverse the rate of new HIV infections otherwise all the recent modest gains in improving access to and use of ARVs in the region shall be in vain.

- In the rest of this presentation, I will focus on the following two issues:
  - HIV/AIDS-related stigma
  - A review of some psychotherapeutic interventions which address HIV/AIDS-related stigma

HIV/AIDS-related stigma

- HIV/AIDS has been described as both a medical and a social disease.
- It is clearly a predominantly debilitating physical disease, albeit now considered as a chronic illness among those receiving ARV treatment.
- It is a social disease primarily because of stigma which is one of the most serious obstacles in the fight against HIV/AIDS.
- Indeed, HIV/AIDS is perhaps the most stigmatized medical condition in the world.
- Stigma towards people living with HIV/AIDS (PLWHA) manifests itself in two main ways:
  - internal (felt by PLWHA)
  - external (enacted by others towards them)

HIV/AIDS-related stigma: Internalized stigma

- Socially constructed views of AIDS can be assimilated and internalized by infected persons.
- Internalized AIDS stigmas have the potential for adverse behavioral and emotional ramifications including:
  - not seeking treatment and care services,
  - engaging in unsafe sex practices
  - fostering a sense of isolation and emotional distress, and
  - self-hatred.

HIV/AIDS-related stigma: Internalized stigma (contd)

- In a study designed to assess the impact of internalized AIDS stigmas in the USA, Lee, Kochman, and Sikkema (2002) found that 63% of HIV-positive persons sampled in two US cities indicated that they were embarrassed by their HIV infection and 74% stated that it is difficult for them to tell others that they are HIV positive.

- In a recent survey conducted by my research team in Cape Town South Africa among 1063 male and female PLWHA , we found that 40% of persons with HIV/AIDS had experienced discrimination resulting from having HIV infection and one in five had lost a place to stay or a job because of their HIV status (Simbayi et al., 2007).

- More importantly, more than one in three participants indicated feeling dirty, ashamed, or guilty because of their HIV status.

HIV/AIDS-related stigma: externalized stigma (contd)

- The social stigma surrounding the disease is mostly due to the fact that HIV infection is widely perceived as an outcome of sexual excess and low moral character.

- At the time when those infected really need social support the most, PLWHA who reveal their status are often subjugated to victimisation and discrimination.
  - This happens everywhere starting from their own homes and within the communities they live in as well as at work.

External HIV/AIDS-related stigma: externalized stigma (contd)

- Consequently, there is a strong culture of silence by PLWHA because of fear of rejection and ostracism (or isolation) from both close relatives and the community at large.

- Families themselves also suffer from ostracism through association with PLWHA.

- It discourages disclosure of PLWHA's HIV status to spouses/partners and members of the family as well as the community.

External HIV/AIDS-related stigma: externalized stigma (contd)

- The stigma is particularly more severe for women than for men.
- Stigma also prevents members of the general population from finding out about their HIV status by undergoing VCT.
- Externalized stigma is also experienced with health providers in health care settings which in turn discourages PLWHA from seeking help from available HIV/AIDS-related services including from health care centres .

External HIV/AIDS-related stigma: externalized stigma (contd)

- Although still prevalent, AIDS stigmas appear to be declining somewhat in Southern Africa.
- The national HIV/AIDS household survey in South Africa in 2005 showed that endorsements of AIDS stigmatizing beliefs had declined from the previous household survey reported in 2003 (Shisana et al., 2005).
- Nevertheless, 29% of South Africans stated that they would not buy food from a vendor who has HIV and 20% stated that HIVpositive children should be kept separate from other children to prevent infection (Shisana et al., 2005).

External HIV/AIDS-related stigma: externalized stigma (contd)

- Studies have shown that people living in Cape Town, South Africa frequently endorse AIDS stigmatizing beliefs (Kalichman & Simbayi, 2003; Kalichman, Simbayi et al., 2005).

- For example, Kalichman, Simbayi et al. (2005) found that
  - 43% of people surveyed in local townships and neighborhoods stated that people living with HIV/AIDS should not be allowed to work with children, and
  - 41% felt that people with HIV/AIDS should expect to have restrictions placed on their freedom.

Impact of internalized AIDS stigmas on the health and mental health of infected persons.

- In their 2002 study in the USA, Lee and colleagues further showed that
  - internalized AIDS stigmas accounted for a significant and unique proportion of the variance in depression symptoms among people living with HIV/AIDS;
  - internalized stigma was related to depression over and above demographic characteristics, health status, symptoms of grief, and coping responses.

Impact of AIDS stigmas on the health and mental health of infected persons (contd).

- Similar findings were found when a hierarchical regression model was fitted to our Cape Town data that included demographic characteristics, health and treatment status, social support, substance use, and internalized stigma significantly predicted cognitive–affective depression (Simbayi et al., 2007).

- Internalized stigma accounted for 4.8% of the variance in cognitive–affective depression scores over and above the other variables.

- Both Lee et al's (2002) and our findings suggest that internalized AIDS stigmas may play a crucial role in the emotional reactions and distress experienced by many people living with HIV/AIDS.

Impact of AIDS stigmas on the health and mental health of infected persons (contd).

- In another study by our research team conducted among people living with HIV/AIDS in Cape Town South Africa (n = 1068), Mbabane Swaziland (n = 1090), and Atlanta USA (n = 239) (see Kalichman, Simbayi et al., 2008), we found that across the three countries, internalized stigma was positively associated with depression and inversely related to social support.

- All the above findings suggest that internalized AIDS stigmas may play a crucial role in the emotional reactions and distress experienced by many people living with HIV/AIDS.

Interventions to minimize the ill effects of internalized HIV/AIDS-related stigma (contd)

- Interventions are needed to minimize the ill effects of internalized stigma.
- We need more interventions to reduce the impact of internalised stigma on PLWHA (e.g., support groups).
- Rights-based interventions are essential not only because they may reduce discrimination but also because they may reduce discrimination expected by PLWHA.
- We need to mitigate the stigmatising consequences of disclosure before we can expect people to disclose their status/

- both in the West and in Sub-Saharan Africa support groups which are mostly run by lay counselors rather than mental health professionals have also been found to be effective in improving coping styles and psychosocial adjustment of PLWHA. While these psychotherapeutic approaches have addressed the emotional well-being and distress experienced by many PLWHA who know their status, it should be highlighted that only 10% of the estimated 33.2 million [30.6–36.1 million] PLWHA globally know their status. It is also important to note that one major glaring gap in the provision of HIV-related mental health services in many countries in the world is the apparent continued neglect of the impact of HIV/AIDS-related stigma amongst friends and relatives including spouses and/or partners of PLWHA who themselves also suffer from a similar impact of the HIV-positive diagnosis of the actual individual person living with HIV/AIDS as well as experience some secondary social stigma as a result of their social or kinship relation. Therefore, there is a need to serious consider training professional counselors to provide both individual and group psychotherapy to deal with the mental health concerns of both PLWHA themselves and their friends and relatives including spouses and/or partners especially to address the adverse effects on their health including mental health due to HIV/AIDS-related stigma.

GROUP-BASED INTERVENTIONS

- groups offer a forum of peer support, a sense of universalism or shared experience, and an opportunity to learn from others who are facing similar challenges
- peer support and modelling may contribute to new coping resources and self-efficacy, perhaps more effectively than is possible in individual based interventions.
- participants began to derive hope by witnessing others face the challenge of living with HIV participants in their groups experienced renewed self-worth by helping others who were doing poorly than they were for example through downward and upward social comparison processes
- groups as less stigmatising and cost effective

SUPPORT GROUPS

- Support groups can be composed of men, women, heterosexuals, homosexuals, or people at various stages of HIV disease, and be directed at individuals, couples, or families or they can be mixed.
- Leaders of support groups can be other PLWHA, lay counsellors or professionals.

- Studies evaluating the effectiveness of support groups have mostly conducted in more industrialised western countries.
- Several studies have shown that support groups are effective in reducing psychological distress in both in PLWHA and in other chronic illnesses
  - A 12-session support group program reported greater reductions in stress and depression (Heckman, 2003).
  - Long-term support group significantly resulted to a reduction in depression (Kalichman et al, 2001; Nunes, Raymond, Nicholas, Leuner, & Webster,1995)
  - In the Kalichman et al. (2001) study, support group attendees endorsed the strategy of seeking social support as a coping mechanism, while the non-attendees used avoidant coping, for example avoiding being with people and refusing to believe and accept their HIV positive status,

- Support groups have also been found to be effective in improving coping styles and psychosocial adjustment of PLWHA.
  - the participants' level of social support, and coping increased and group members viewed their participation as beneficial to their well being (Wiener, 1998, Greenberg & Johnson, 1996; Weisthut, 1997).
- An association between support group attendance participants' ability to work through their day-to-day difficulties of living with HIV was also found.
  - the support group was able to assist its members in working through their difficulties associated with being HIV positive, provided an opportunity for the participants to give and receive meaningful support (Sikkema, 2002)

- there is a paucity of empirical studies on the effectiveness of such groups in reducing psychological distress of PLWHA. In South Africa
- informal support groups led by HIV-positive lay counsellors who were trained by NGOs became active in providing the needed emotional support for PLWHAs (Department of Health 2005).
- Many support groups in South Africa make use of very little resources. A review of community-based HIV/AIDS care and support programmes in South Africa revealed that the typical community support group system provided informal, emotional support groups and counselling, education and often income generating activities (Russel & Schneider, 2000).

- In a study among female PLWHA in South Africa using the support group approach led by uninfected clinical psychology masters students it helped the women to make friendships, gain support and self-acceptance, learned to talk about their problems and how to cope with them, gained confidence (Visser, de Villiers, Sikkema, & Jeffery, 2005)
- In a similar study among women in Zimbabwe it was found that support groups led by uninfected lay counsellors provided a place in which members were able to share feelings and discuss the practicalities of their daily living with HIV, develop friendships that reduced feelings of loneliness (Krabbendam, Kuijper, Wolfers, & Drew, 1998).

Differences and similarities of HIV-support groups in more industrialized and less industrialized countries

- Studies conducted in more industrialized countries have shown that support groups are effective in reducing depressive symptoms in HIV-infected persons. These studies were mostly conducted with homosexual men, lacked in randomisation, and were not utilising control groups. Most of these studies also used small samples of relatively affluent participants.
- The difference between HIV-support groups in more industrialized countries and less industrialized countries was that most of such groups were usually conducted by other HIV-infected individuals in less industrialized countries and by uninfected professionals in more industrialized countries.
- An important similarity between research on support groups and HIV-infected persons in more industrialized countries and in less industrialized countries was the ability of the groups to provide a feeling of mutual support and of not being alone in its participants. These feelings were found to be contributing factors in reducing depressive symptoms, anxiety, and psychological distress PLWHA, both in more industrialized countries and in Africa.

cognitive behavioural therapy

- There is abundant evidence of the effectiveness of CBT in enhancing mood states, coping styles, and psycho-social adjustment of PLWHA

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