DEVELOPMENT OF STIGMA MITIGATION INTERVETIONS IN THE HEALTH SECTOR AND A FAITH BASED ORGANISATION

SUMMARY

BASELINE REPORT

CENTRE FOR THE STUDY OF AIDS,

UNIVERSITY OF PRETORIA

AUGUST 2004

EXECUTIVE SUMMARY
SIYAM'KELA II BASELINE STUDY

1. BACKGROUND

This report is a summary of the findings of a baseline study carried out under the Siyam'kela II project, which developed and tested stigma reduction interventions through careful analysis and strategic partnerships with PLHAs and others in the workplace setting and in a faith-based organization (FBO). The study consisted of two components: a baseline study in each setting, followed by the development and implementation of a stigma-mitigation capacity building interventions.

For 2005, focus will be on developing and refining a Stigma Resource Tool -- a resource document for trainers, opinion leaders, PLHAs, community members and anyone interested in finding out more about HIV/AIDS stigma and how to challenge and address it.

The Siyam'kela Project is a joint project of the USAID funded - POLICY Project, the Chief Directorate: TB, HIV and AIDS, Department of Health and the Centre for the Study of AIDS, University of Pretoria

2. OBJECTIVES

- To conduct an exploratory study in a chosen site within two settings i.e. Faith Based Organization - St. Joseph's Catholic Church - and a Work Place Setting – a Local Municipality Clinic, within a period of six months (April – September 2004).
- Review and refine the indicators developed in Siyam'kela I in 2003 as well as to develop a list of practical and sensitive indicators of stigma.
- Develop a training package and tools for capacity building for education and awareness raising on HIV/AIDS stigma and discrimination, for use in faith-based organisations and government departments.
- Building the capacity of faith-based leaders and clinic staff.

3. PILOT SITE AND SAMPLE SIZE

3.1 Description of site

Eersterus is a predominately coloured township on the east of Pretoria and south of Mamelodi, the biggest, predominantly black township in Pretoria. Eersterus was chosen because it is accessible and because most coloured townships seem to be overlooked when it comes to service provision by non-governmental organizations (NGOs) and government agencies. Furthermore, it is a site that has had minimal research interventions in the past. The population in the area is about 26 074 (Census 2001 – Statistics South Africa).

3.2 Sample size

- Faith-based organization: 176 participants
- Work Place Setting: 15 participants

4. METHODOLOGY

4.1 Faith-based organization

- Focus-group discussions.
- In-depth interviews.
- Structured anonymous questionnaires were used and the total number of respondents was 176. The structured questionnaires were administered during a randomly selected Sunday mass at 08h00, which attracted the highest attendance.
- An analysis of different document including church policies and programmes e.g. minutes of the parish council meetings and HIV/AIDS committee meetings was carried out. The aim was to understand how HIV/AIDS messages are integrated into church policy, statements and programmes.

4.2 Work Place Setting

- Focus-group discussions.
- In-depth interviews.

- Structured anonymous questionnaires were used and the total number of clinic staff who completed the questionnaire was 15. This approach was used to gather sensitive information such as how many health care workers have tested for HIV and what support systems are available for staff members who are HIV positive, and whether they would consider disclosure in the workplace.
- An analysis of HIV/AIDS policy document in the clinic, to assess mainstreaming of HIVAIDS related stigma and programmes

5. FINDINGS

5.1 Exploration of existing HIV/AIDS interventions and organizations for people living with HIV/AIDS (PLHAs) in Eersterus.

- For both the FBO and workplace setting there were no interventions addressing HIV related stigma.
- There were a limited number of NGOs in Eersterus, addressing different issues including poverty, substance abuse and counselling.
- Only one of these NGOs (*Circles of Life)* deals directly with HIV/AIDS. These services include; psychosocial support for those living with and affected by HIV/AIDS, home visits, food parcels, nutritional gardens, income generating programmes.
- There was no NGO addressing human rights issues.
- Some people (very few) reported to be using the services of traditional healers in for various reasons including; divination, and sometimes cures, in conjunction with western traditional medicines.

5.1.1 Addressing the gap

- In an attempt to address the problem of not having sufficient HIV and AIDS focused organizations, the NGOs worked innovatively with limited resources to complement one another and address HIV/AIDS through a system of referring clients to each other.

5.2 Faith Based Organisation

5.2.1 Quantitative

5.2.1.1 In the Faith Based setting, 176 participants were interviewed 106 were female and 58 were male. 18.9% of the participants had tertiary level education, 32% had secondary level education and 36.6% had not completed secondary school.

5.2.1.2 Knowledge of own status -- 87 (54.4%) reported that they knew their HIV status.

5.2.1.3 HIV testing -- more than half 83 (51.2%) of 176 respondents had taken an HIV test. The largest proportion who had been tested (53%) was women.

5.2.1.4 Disclosing of own HIV status – 69 (43.9%) would consider disclosing, 30 (19.1%) would not consider and 69 (43.9%) were not sure.

5.2.1.5 Perception of support from the church community – 158 participants responded to this question. 118, (74.7%) were confident that they would receive support, 5 (3.2%) were negative and 35 (22.2%) were not sure.

5.2.1.6 Support for PLHAs – 149 participants responded to this question, 97 (66.4%) rated the support as average, 36 (24.5%) rated the support as excellent and 13 (10%) reported poor support.

5.2.1.7 Perception of HIV stigma -- 140 participants responded to this question. 48 (34.3%) rated stigma as being very high, 58 (41.4%) rated stigma as average and 34 (24.3%) as low.

5.2.2 Qualitative

5.2.2.1 Fear

"I can talk to those people", meaning the infected people, "As if confessing" she continued, "Aids is a scary disease and most of us are scared".

"As I told you before, we thought by touching a person you could get AIDS, by using one cup…by using toilet…but now we know but still…Fear of infection has created a new set of feeding habits and relationships with friends. I do not eat

beetroot anymore. People are scared for their lives. But with carrots, you can see if there is blood."

A major theme was that of fear of HIV infection by association. This fear derives from inadequate knowledge about transmission and the secrecy that lies with infection. People are not aware who is infected and who is not and as a result suspicion predominates.

5.2.2.2 Prevention and Religion

The majority of participants were aware of available prevention strategies, which include abstinence until marriage and condom use. A challenge faced by girl children is that abstinence is very difficult especially when poverty conflict with social values, in an environment that values success – "the need for money arises and there is this man with "a big car" and is prepared to share resources."

High levels of peer pressure were reported -- *'having sex is cool'*. There was pressure to show your love to your boyfriend.

A pertinent question raised by the research team, would be *"Should mature women, widows, divorcees and married persons with infected partners not use condoms to protect themselves from being infected?"*

5.2.2.3 Morality -- Despite teaching about abstinence, there is a high prevalence of child/teenage and pregnancy and out of wedlock pregnancy, freedom to engage in sex seems to abound in Eersterus and this is true for all ages. This does not imply that if one gets infected with HIV in the process they will readily get acceptance. What it means is that sleeping around seems to be a norm and within various age groups they practice it with little restraint. Those who fall pregnant are neither stigmatised nor discriminated against, as pointed out by participant:

"It is nothing new", the girls reveal. "…Here in Eersterus, a young lady of 14 years gets pregnant. The people never talk about it. The church accepts you, if they don't, they must not accept 40-50 others who have children and are not married."(Harriet)

5.2.2.4 Disclosure

Very few PLHAs are prepared to share their HIV status with their families, the church or the community at large they fear stigmatisation, which comes in the form of rejection and discrimination.

5.2.2.5 Conceptualisation of AIDS

The study found that young people made the following associations;

- Associated the word AIDS, with *"orphanage", "lack of care", "alcohol"* and *"parties."*
- The girls revealed that they think of *"people sleeping around."*
- Despite that, people know of different ways through which HIV is contracted, they continue to associate HIV infection with sexual promiscuity. In all circumstances, they treat AIDS as a disease and not a condition creating a barrier to helping people living with HIV to live normally with the virus.

5.2.2.6 Denial

"People do not want to link AIDS with deaths. One has to die of anything else." (Male respondent)

- The study found that there were high levels of secrecy and denial.

'Affluent families are notorious for denials. Their argument is that "the poor should get AIDS not us, the elite die of problems such as cardiac failure" and not anything to do with AIDS" (Respondent)

5.2.2.7 Judging

According to one respondent, AIDS is seen to be *"affecting promiscuous people"* and revealing ones status could be seen as admission of promiscuity. Even religious teachers such as Father Gilbert commented that AIDS related illness results from *"relationships lacking of commitment."* The boys noted that if one is infected with HIV whilst young, one is considered a sinner since *"sex before marriage is a sin"*.

5.2.2.8 Shame

"People do not trust - those that know about their status will not talk". (Male congregant)

"If I came out and said I had AIDS I would feel like an outcast. They will talk about you, they will gossip and avoid discussing AIDS during your presence. They know you did not get AIDS from holding hands." (Young female (teenage) respondent)

The study noted persistently high levels of shame associated with HIV infection, which affects their willingness to disclose.

5.2.2.9 Rejection

There is labeling of people who reveal their HIV status, as well as isolation within families and rejection by peers.

5.2.2.10 The role of the church

- Both a beneficial and a retrogressive role as far as HIV/AIDS and its transmission is concerned.
- Its dogma or it's scriptures exacerbate stigmatization as there is an element of being judgmental with regards the understanding of HIV infection, and therefore PLHAs continue to be marginalized.
- As long as the church does not appreciate the use of condoms, its prevention efforts remain undermined by HIV, for members will continue to become HIV positive.

5.2.2.11 Morality, Shame, and Blame are closely related to HIV- related Stigma

"The Catholic approach to sex and sexuality…is to capacitate love. (The purpose of the) sexual act is to express the love, in the context of a committed relationship of two persons, male and female that have committed themselves before the church, the leadership of the church, and made public in marriage. If you have to act it outside that context it is not moral"

5.3 Work Place Setting

5.3.1 Quantitative

5.3.1.1 In the workplace setting, 15 participants were interviewed, 14 of which were women. 46.2% of the participants had tertiary level education, 46.2% had secondary level education and 7.7% had not completed secondary school.

5.3.1.2 Knowledge of own HIV status -- 9 (60%) knew about their HIV status.

5.3.1.3 Disclosing of HIV status -- 6 (40%) would consider disclosing, 3 (10%) would not and 6 (40 %) were not sure.

5.3.1.4 Perception of support from the clinic -- 7 (46.7%), of respondents were confident that they would receive support from the clinic, 3 (20.0%) did not think they would get support from clinic and 5 (33.3%) were not sure whether the clinic staff would support them.

5.3.1.5 Giving support -- 7 (46%), rated average support and 2 (22.2%) rated poor support. Although there were indications and reports by staff members that institutional support for staff members was important, responses to this question suggest that respondents did not seem to think it was important for them to offer support to others.

5.3.1.6 Perception of stigma towards PLHAs -- 50% indicated that the levels of stigma towards PLHA were very high, 37.5% indicated that the levels of stigma at the clinic towards PLHA were average, and 12.5% reported low levels of HIV related stigma towards PLHAs.

5.3.2 Qualitative

5.3.2.1 Institutional response to staff members thought to be living with HIV/AIDS

"One nurse was hospitalised at Santa Hospital. Her salary *was stopped and when she passed away I had to collect money to bury her. Management, the medical insurance and all deserted her" (Sister Rooney).*

This type of institutional response to HIV/AIDS is likely to drive the epidemic underground. It creates an environment of fear, having a long-term negative impact on those who might be living with HIV/AIDS in this particular work place. This case presents a number of ethical and human rights issues, e.g.

- Breaching of confidentiality,
- Withholding access to employment benefits,
- Basic rights at work – Employment Equity Act.
- Psychosocial support.

5.3.2.2 Revelation and discrimination

"A matron came to me at the clinic and said these three are very sick, I do not think they will be able to work anymore, here are the forms, give it to them and give it to the doctor and they must 'be bought out'."

At the institutional level the rights of those living with HIV/AIDS should be respected and upheld. The above-mentioned quote highlights coercive public health approach where staff members' right to privacy and autonomy are violated. Based on the matron's perception the three staff members lost their right to dignity.

5.3.2.3 Lack of Knowledge and awareness of appropriate management of PLHAs

"My colleagues in the ward, if they see an HIV positive patient, they are so scared to attend to that person. And even if it is not a patient… maybe if it is your colleague, it happened that some of them used to distance themselves from the colleague saying that 'she has got HIV/AIDS and how are we to handle her." (Sister Mildred)

"Most health professional people used to keep quiet even if they knew their status, because they never had anybody to talk to or maybe a place where they can go to and be counseled". (Sister Mildred)

"I think AIDS is seen as the bad sickness people are very naïve about HIV/AIDS. I think most people just assume we getting sexual intercourse and because of that you almost like punished for having it. But with cancer people it is seen differently. It is more accepted unlike the HIV/AIDS people."

Lack of knowledge was identified as a key barrier to disclosure and to stigma mitigation. The assumption that was generally held – was that nurses are well informed about HIV/AIDS by mere fact that they are health professionals – "*workshops on awareness were held everywhere else and not in clinics and hospitals"*, one staff member lamented.

As a result of health professionals not having sufficient and appropriate knowledge on HIV/AIDS they lacked skills in managing the care of PLHAs. In addition, HIV/AIDS was perceived to be a disease of sex, morality, shame and blame.

5.3.2.4 Modes of infection

A general perception was that HIV is spread predominantly through sexual encounters; despite the fact that nurses are vulnerable to HIV infection through injuries on duty e.g. a needle prick or blood spill into a nurse's eye.

5.3.2.5 Lack of intervention

Information and intervention were said to be 'piece meal' as they were either from *individuals who volunteered by going beyond the call of duty* e.g. one participant (a nurse counsellor, Sister Mildred) volunteered to educate her colleagues on basic HIV information.

External organisations e.g. DENOSA, a national union for nurses, supported by external funding organisations undertook to train 18 nurses who would then participate in the training of their colleagues at provincial level.

An analysis of documents at the clinic revealed that: there was no mainstreaming of HIV/AIDS or HIVAIDS related stigma.

No implementation of available programmes at the time of the study.

6.0 SUMMARY OF OVERARCHING THEMES RELATING TO THE WORKPLACE AND FAITH BASED ORGANISATION SETTINGS

For both the FBO and Workplace Settings, there were striking overarching themes within the two settings themes with a few but significant nuances specific to FBO and Workplace setting, as reflected under 5.2.

- People are not aware that their attitudes and behaviour are stigmatising,
- Stigma is expressed through the use of language,
- HIV/AIDS is still perceived as the disease of others,
- Rejection, verbal abuse and avoidance of people living with HIV/AIDS by family and community is still a matter of serious concern,
- The church runs care and support programmes through an HIV/AIDS committee but the HIV/AIDS committee lacks the capacity to lead an effective, stigma sensitive and expanded programme over and above their care and support programme,
- Although general knowledge on HIV/AIDS was satisfactory, certain attitudes and actions are still informed by myths and misconceptions about HIV/AIDS.

7. CONCLUSION

7.1 Stigma Indicators

The process of reviewing the indicators revealed one additional indicator:

- Uptake into Voluntary Counselling and Testing Programmes and/ or Prevention of Mother to Child Transmission Programmes.

Some ideas have emerged that will be useful for policy & programme managers wanting to monitor and evaluate the progress they are making in mitigating stigma.

7.2 Internal Indicators of Stigma

From the process of this research it can be said that measuring internal stigma would depend on knowledge by leaders or managers living with HIV. From this study it is difficult to make recommendations on internal indicators of stigma because of a lack of data (or access to PLHAs). It would appear that these indicators would only be useful in contexts or programmes that have existing programmes for PLHAs.

7.3 External indicators of Stigma

This was easier to review in that the researchers had access to the perceptions and views of participants. All the indicators emerged as key themes in the data, indicating that they

would be useful markers of whether stigma is increasing or decreasing in any context. A particularly central theme was that of avoidance.

8. RECOMMENDATIONS

- Implement the stigma mitigation training programme that has been developed for implementation in both settings.
- Disseminate findings of the report with relevant stakeholders e.g. other organisations in the community, and to Tshwane metro and DENOSA.
- Conduct a study that would evaluate the capacity building process.

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