

UNVEILING THE SILENCE:
*A Case-Based Analysis of HIV/AIDS Stigma & Discrimination in the
Ndwedwe Sub-district of KwaZulu Natal, South Africa*

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ABBREVIATIONS/ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral (Treatment)
BCC	Behavior Change Campaign
CBO	Community Based Organization
CHC	Community Health Committee
CHW	Community Health Worker
CS	Child Survival
DOH	Department of Health
DOTS	Direct Observation Therapy, Short-Course
HBCV	Home Based Care (Volunteer)
HC	Health Club
HIV	Human Immune-Deficiency Virus
HSPH	Harvard School of Public Health
IEC	Information Education Communication
IMCI	Integrated Management of Childhood Illness
KPC	Knowledge Practice Coverage (Study)
KZN	KwaZulu Natal (Province)
LOE	Level of Effort
MCDI	Medical Care Development International
NAPWA	National Association for People Living with HIV/AIDS
NDCSP	Ndwedwe District Child Survival Project
NGO	Non-Governmental Organization
OI	Opportunistic Infection
PHC	Primary Health Care
PLWA	Persons Living with HIV/AIDS
PMTCT	Preventing mother to child transmission
REACH	Rapid and Effective Approach to Combat HIV/AIDS
RSA	Republic of South Africa
SA	South Africa
SHC	School Health Club
STD	Sexually Transmitted Disease
TBA	Traditional Birth Attendant
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

EXECUTIVE SUMMARY

Background

One of the biggest challenges in addressing the HIV/AIDS epidemic in South Africa is the stigma and discrimination surrounding the disease. While many surveys measure knowledge and attitude towards HIV-related stigma and discrimination, few if any have looked at how they are experienced by those who are infected and affected by HIV/AIDS.

This report describes one such survey conducted by Medical Care Development International (MCDI), a private voluntary organization (PVO) implementing a Child Survival Project in Ndwedwe, a sub-district of the Ilembe District of KwaZulu Natal (KZN) province, South Africa. The aim of the survey was to establish baseline indicators for a Pact/USAID Community REACH Stigma and Discrimination Project in Ndwedwe.

The goal of this report is to provide a picture of how HIV/AIDS-related stigma and discrimination are perceived in the Ndwedwe community using both quantitative and qualitative methods.

Methodology

The three main components of this report are:

- Review of relevant literature
- Quantitative analysis of data collected from a survey (done before our visit by MCDI)
- Qualitative report from observations made in the field

The literature review attempts to synthesize relevant information from the limited library resources available to the team. The baseline survey was conducted from August to September, 2003, by eight members of the Zulu community. Respondents were recruited using convenience sampling in select clinics as well as from the greater community. The interviewers administered questionnaires to a total of 279 respondents, 83 of whom were categorized as HIV positive. Preliminary analysis was completed by MCDI, while members of the Harvard School of Public Health (HSPH) team drafted the final quantitative analysis presented in this report. Qualitative information was collected by the HSPH team from observations made during field visits, group discussions, and community meetings in Ndwedwe from January 6-26, 2004. The qualitative report was compiled using direct and indirect quotes from MCDI staff and community members.

Conclusions and Recommendations

Stigma and Discrimination in Ndwedwe Sub-district

Stigma and discrimination are indeed present in Ndwedwe. This is evidenced by the lag period between diagnosis and disclosure (20% disclosing HIV status only after 6 months) as well as the unexpectedly large number of respondents willing to address stigma and discrimination. The qualitative report also demonstrates the extent of the problem, summed up by one person's declaration: "*I'd rather die than get tested.*"

The literature also reveals that stigma and discrimination abound. It is evident these are experienced as a result of a collective negative reaction towards the disease. It is therefore

imperative to gain the community's trust and involvement both prior to, and in conjunction with, the implementation of a stigma reduction project. Further, support groups, broadly targeted information, education and communication campaign (IEC), and an increase in voluntary, counseling and testing (VCT) centers may aid in this reduction.

It is also important to consider the future impact of antiretroviral drugs (ARVs) once these become available. As an incentive to get tested, ARVs may indirectly aid in the reduction of stigma in the community. The possibility of merging IEC campaigns to reduce stigma and discrimination with those aimed to increase awareness about ARVs should be considered.

Sources and Perpetrators of Stigma

Community and family members are most often mentioned as sources of stigma, so that a broad awareness campaign that targets the larger community should be an essential. It is also essential to mobilize as many stakeholders as possible to maximize such a project.

Awareness of Anti-discriminatory Policies and Legal Rights

Those surveyed appear to be quite knowledgeable about anti-discriminatory policies. However, less than half of those who experienced discrimination actually reported it. Bridging the gap between knowledge about policies and actual reporting of discrimination would be optimal.

Current government HIV/AIDS policies may inadvertently perpetuate the stigma and discrimination as explained in the qualitative section and these policies should be reviewed to foster a non-threatening, confidential environment for HIV/AIDS testing and disclosure of status.

Cultural Barriers

Male attitude and behavior pervasively present a huge challenge to the prevention and control of HIV/AIDS. Establishing a sub-component in the Reducing Stigma and Discrimination through Innovative and Proven Effective Approaches in Ndwedwe District Project (Stigma and Discrimination Project) specifically targeting men may facilitate their greater participation in addressing the HIV/AIDS problem. A well-designed baseline assessment is essential in the design of a more intensive campaign that targets male behavior and attitude.

It appears that the local culture entails wanting reward or remuneration for an action. Many ask why they should get tested if there is nothing for them in return. These questions highlight the need to explain and emphasize the benefits gained through counseling, testing, and disclosure of status.

Stigma and Discrimination: Best Practice

Very few interventions aiming to reduce HIV-related stigma have been evaluated rigorously to date. MCDI should review local and international programs alike to identify current best practice. It may adopt some aspects of the more successful models (e.g. The Valley Trust's model) and learn from the less successful ones.

Given the relatively new field of stigma reduction interventions, MCDI has a responsibility to contribute to the documentation of best practice and to facilitate the exchange of information and strategies. Thus, in its project, it should incorporate a strong evaluation component that utilizes a

valid and reliable tool. The baseline survey that has been conducted needs to be developed and expanded, so that data collected presents a more comprehensive pre- and post-intervention picture and facilitates the measurement of project indicators and results.

It is important to measure proximal outcomes of the stigma reduction project, rather than solely concentrating on indicators measuring the distal outcome.

Battling HIV/AIDS-related stigma and discrimination entails an enormous information and education campaign targeting all community members. This will be successful if it has community involvement and trust, and if it is complemented by accessible and available social and health services.

INTRODUCTION

“AIDS is not a disgrace. It is a disease... We must fight this stigma.”

-- Thuli Ngidi, MCDI Training Coordinator

An eight-member team from the Harvard School of Public Health (HSPH) visited Kwazulu Natal (KZN), South Africa, from January 6-26, 2004 to participate in a case-based experiential course. Through this course, the team assisted Medical Care Development International (MCDI) in mapping and analyzing the stigma and discrimination situation in Ndwedwe district.

In South Africa (SA), in 2000, it was estimated that 40% of all deaths in the age category 15-49 were due to AIDS.¹ According to the 2001 national sentinel surveillance report, HIV prevalence was highest in the KwaZulu Natal province of South Africa (36.5%).² In response to this public health problem, MCDI is currently implementing a USAID-funded child survival project in Ndwedwe with 30% level of effort directed towards HIV/AIDS.³

Significant barriers in reducing the impact of HIV/AIDS in the community include the widespread stigma and discrimination associated with the disease. Stigma is defined as an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society. Stigmatization is the societal labeling of an individual or group as different or deviant.⁴ Sources of stigma include fear of the illness and its consequences, fear of contagion, fear of death, misconceptions, and erroneous beliefs, and the perception that the disease is associated with unacceptable behavior. Discrimination may be defined as unfair treatment of a person or group on the basis of prejudice. In an attempt to overcome the obstacles presented by stigma and discrimination, MCDI, in partnership with the National Association of People Living with HIV/AIDS (NAPWA), proposes to implement a program that aims to reduce stigma and discrimination related to HIV/AIDS (Reducing Stigma and Discrimination through Innovative and Proven Effective Approaches in Ndwedwe District Project).

This report aims to present an analysis of data collected from a needs assessment survey conducted by the MCDI in August-September 2003. The quantitative data is augmented by information gathered from a review of related literature, as well as qualitative information gleaned from observations made by the team during field visits and group discussions with various community stakeholders (e.g. support groups, community volunteers, health workers). This report also presents a summary of a focus group discussion with the survey interviewers (Appendix 1), which provides insight into their experience and thoughts on the process of administering the survey in their community.

LITERATURE REVIEW

“Stigma is a common human reaction to disease. Throughout history many diseases have carried considerable stigma, including leprosy, tuberculosis, cancer, mental illness, and many sexually transmitted diseases (STDs). HIV/AIDS is only the latest disease to be stigmatized.”⁵ Although fear, misconceptions, and erroneous beliefs have been associated with many diseases including HIV/AIDS, the literature available regarding HIV-related stigma and discrimination is sparse. Little is officially documented or rigorously measured with regards to how stigma and discrimination are experienced by infected and affected individuals.

A recent review looked at 21 interventions targeted at reducing stigma and discrimination.⁶ It found that all 21 were successful, independent of the type of intervention. However, the authors suggest a possible bias towards positive results and note that the lack of rigorous evaluation of the majority of interventions surfaced as a major weakness. Nevertheless, the review does reveal a significant need to address the problem of stigma around HIV/AIDS. Although not complete, the following discussion looks at issues around HIV-related stigma and discrimination that have been highlighted in the current literature.

Forms of Stigma and Discrimination

While fear and misconceptions (as noted above) are often the root cause of stigma and discrimination, the literature also suggests that gender discrimination and disregard for women’s rights are significant sources of stigma and discrimination, with women bearing the brunt of the stigma associated with HIV/AIDS, as well as the greatest burden of disease.⁷ The literature also reveals that stigma and discrimination result in those at risk often refusing to test, and those who are HIV positive refusing to disclose their status. Many will avoid being tested for fear of actually having the disease and living with its consequences.⁸ There is a very real perception in the community that an HIV diagnosis is tantamount to a death sentence, coupled with a strong sentiment that coping mechanisms to tackle the “mental burden” of having HIV/AIDS are lacking.⁹ The fear of social, financial and personal loss, as well as the lack of perceived benefit (i.e., available treatment), inhibits many from getting tested. Many ignore the issue of HIV/AIDS until they, or the individual they are caring for, are very sick and desperately in need of care.¹⁰

The literature also reveals that disclosure of one’s status is the big hurdle that follows testing. A 2003 survey of 726 HIV positive individuals at two different sites in the Ndwedwe, found that 65% and 92% of respondents had not disclosed their status to anyone for fear of stigma, discrimination, blame, and collective denial.¹¹ The fear of rejection from a partner, family, community, or religious group is a strong incentive to remain quiet about one’s status.¹² For example, men will often desert their female partners when the latter disclose their status. Furthermore, in 2000, the Knowledge Practice Coverage (KPC) survey found that only 26% of respondents were willing to look after a relative who was sick with AIDS.¹³ The 2001 KPC findings also revealed that only 68.3% of mothers interviewed would allow their child to play with an HIV positive child, or the child of an HIV positive parent.¹⁴

Finally, there is also a reluctance to openly discuss HIV stigma and discrimination even in a clinic setting. In a recent KZN Department of Health survey, investigators found that during pretest counseling, Voluntary Counseling and Testing (VCT) for the client was discussed in 80% of sessions, but VCT for the partners of the clients in only 48% of the sessions, while the issue of

stigma and discrimination was discussed in only 32% of the sessions. In this same survey, the fear of violence upon disclosure was discussed in only 21% of the clinic sessions.¹⁵ Thus, both staff and clients are reluctant to discuss stigma and discrimination.

Implications for the South African Population

The literature clearly shows that stigma and discrimination remain integral parts of the barriers faced in fighting the HIV/AIDS pandemic. One of their main impacts is the continued and uncontrolled spread of the disease. In a population whose prevalence is overall estimated to be around 35% and rising, the consequences of this are multifold.

The social architecture is being disrupted by families refusing close contact or to live with HIV-infected family members.¹⁶ Parents are dying, leaving orphans and vulnerable children in need of costly foster care, often putting an unsustainable strain on very low-income families. Where there were once whole families, there are now increasing numbers of child heads of household. Subsistence then takes place by any means available, often at the cost of the children's education and/or healthcare. As these children remain vulnerable, there is also an increase in child abuse rates, as there is still a belief that coitus with virgins will cure the sufferer from HIV.¹⁷

The subject of HIV/AIDS remains taboo, even at funerals where it is known or suspected to be the cause of death. Reverend Davey said: "We hate the sin but we love the sinner. We must be careful to state that people with AIDS must be loved and we all make mistakes. Perhaps it is something that is not said enough."¹⁸

Lastly, there is a widening rift between the discriminated (those afraid to test or disclose) and those who are the perpetrators of discrimination.¹⁹ Even with regards to receiving treatment in the hospital, patients who have or who are suspected of having HIV receive worse treatment and are often neglected by staff.²⁰

Implications for Policy Making

Faced with the existing literature, policy makers cannot neglect the facts. In the Republic of South Africa Policy Guidelines for Youth and Adolescent Health, it is stipulated that a non-discriminatory environment, adequate shelter and nutrition, treatment of opportunistic infection, and support from friends, family, schools, teachers, employers, and co-workers should be ensured for all persons living with HIV.²¹ New policies must, and do, include legislation and efforts toward improvements to promote safe and supportive environments.²²

There are also extensive mass media public health and anti-stigma awareness campaigns involving TV, radio, movies, flyers (e.g. one poster reads, "My friend with AIDS is still my friend"), newspapers, puppetry, live theatre (e.g. DramAidE), magazines, videos, internet, dance and photo novellas.²³ Different types of interventions can be used, including information-based, coping skills acquisition, counseling approaches, and contact with affected groups.²⁴ These campaigns attempt to establish social norms and cultural practices with the hope of disseminating realistic messages that the public can relate to. Accessibility of key opportunities and commodities, such as tutoring, available condoms, health services or recreation, is a key

factor for the success of these prevention campaigns. Unfortunately, a lack of financial resources is a very real obstacle in the way of achieving this goal.²⁵

Going Forward

This literature review has revealed suggestions and recommendations toward reducing the stigma and discrimination surrounding HIV/AIDS in South Africa. The first is to incorporate HIV/AIDS into the Integrated Management of Childhood Illness (IMCI).²⁶ An increase in the provision of information, counseling, skill building, and access to health services is also recommended.²⁷

Intervention settings in school, home, health facilities, work place, community-based organizations, residential centers, and in the street are being established and need to be reinforced.²⁸

Further research is needed in the area of HIV/AIDS-related stigma and discrimination. The overall emphasis needs to focus on assessing the impact of implemented change in a measurable and rigorous evaluation.²⁹ Conclusions in the literature suggest that most interventions do work, even if in the short term and on small scale. The extent of this, however, is not yet known. More research is needed and efforts to combat stigma need to be amplified. Stigma and discrimination still remain one of the biggest hurdles for the international community to overcome in the fight against HIV/AIDS.³⁰

QUALITATIVE REPORT

Stigma and discrimination associated with a person's HIV status influence how affected and infected individuals, as well as the larger community and other stakeholders, react to and choose to address issues pertaining to HIV/AIDS, from prevention and care to policy and societal response. We are looking at five areas in which stigma and discrimination are expressed in the daily life of an HIV positive person. These areas are interconnected and often reinforce each other to create an environment that negates effective HIV/AIDS program development or clinical intervention. This section presents some observations and case vignettes gathered by the team during field visits and interviews with various community stakeholders.

Family and Community

Ostracism

"I was not allowed to use the same eating utensils as the rest of my family. My own son would have nothing to do with me."

Stigma and discrimination towards HIV/AIDS are major barriers to prevention and treatment of the disease in that people are afraid to go for testing. It is evident that many beliefs and myths exist about how HIV is transmitted from one person to another. HIV positive clients are not willing to disclose their status for fear of social isolation. Ostracism is often experienced at the family level, as illustrated by the excerpt below from a Ndwedwe HIV support group meeting. A member of the support group reported that members of her family had ostracized her. It was subsequently decided that three members of the support group visit the family to assure them that they cannot contract HIV just from social association with an HIV positive person.

Community perception and stigmatization of HIV/AIDS are also strong determinants of whether an HIV positive individual will disclose his or her HIV status. In the minds of people, HIV is most often associated with extramarital sex, promiscuity, and prostitution- an association that is only gradually and very slowly being changed. A teenage girl tells the following story:

Delinquency

"I am HIV positive and have a 9-month old child. I live with my aunt and my sister. I do not know my father, and my mother died of AIDS-related tuberculosis. All my family members know that I am HIV positive, but I do not want people in the community to know about my HIV status, as they will think of me as delinquent or a prostitute."

The stigma and discrimination associated with HIV/AIDS appears to have resulted in a highly defensive attitude in the community, especially among the youth. During a road show (an information campaign using drama), a young man introduced himself with the statement "*I am innocent,*" perhaps trying to emphasize that he attended the road show because of general interest, but that his HIV status was negative. This illustrates further that being HIV positive is often associated with guilt and shame. Terms like 'guilt' and 'innocence' are coupled with positive or negative HIV status, underpinning the common belief that HIV comes about through socially unacceptable behavior.

HIV positive individuals are not the only ones affected by the existing stigma and discrimination towards HIV/AIDS. Children rapidly adopt the perceptions of adults and make them their own, thus perpetuating stigma across generations. A father shares the following:

Your Mother or Father is “Bad”

“... if one or both of the parents are HIV positive, their children are stigmatized and discriminated against. Other children will not play with them because their parents have AIDS and are considered to be “bad”. Some people who are HIV positive have been separated and isolated from their families, including their children. They are not allowed to live in the same house as their children and are not allowed to eat together with them.”

Due to the large number of adults dying from AIDS-related illnesses, children are being orphaned at an alarming rate, leaving an increasing number of them to fend for themselves. A woman discloses that:

What Will My Daughter Think?

“... I have not divulged my status to my daughter because I am afraid she will think badly of me or encounter problems in the community. She is my only daughter, and my partner left me when I disclosed my status. I know I contracted the virus from him, but there is nothing I can do about it. I know I will die. I am concerned about the future of my daughter and I want her to receive an education, so that she can survive without me.”

In general, there appears to be no or only minimal incentive for voluntary counseling and testing, and for disclosure of one’s HIV status. The burden of stigma and discrimination far outweighs the personal benefits that a potential HIV positive individual can gain through disclosure. HIV positive individuals have everything to lose (partner, job, family, and friends) upon disclosure, and there are few financial benefits from the government, so that many people see very little advantage in HIV testing and disclosure.

A strong element of denial exists with people refusing to face up to the reality they know deep down is inevitable and unavoidable. It is interesting to note that an AIDS counselor has a totally different perspective on the community’s attitude to HIV/AIDS. According to him:

“People living with HIV/AIDS are generally accepted in the community. People are aware of the various routes of transmission and that the virus is not only transmitted through sex. Men who are HIV positive are not ostracized among their peers, but rarely attend HIV support groups because they are ashamed of their predicament. It is generally migrant male laborers that contract the virus and bring it to the rural community, where their womenfolk become infected.”

The Male Sphere

Male behavior is a huge barrier to HIV prevention. In many cases, the male partner infects the woman, but then denies responsibility and the woman has to face the consequences of the disease on her own. In general terms, it is the women who become outcasts while men are the spreaders. This problem is further compounded by the mobility of the male population in its search for employment.

It is common to hear of men deserting their female partners when they learn of her HIV positive status. An HIV positive woman who recently gave birth has not divulged her HIV status to her partner for fear of him deserting her and discontinuing support for their baby. Some of the women in the support group had disclosed their status to their intimate partner. The partners, in denial, often left the woman as a result. Among those who had not disclosed their status, fear of their partner leaving them was the key reason for not disclosing. When the group was asked about how the issue of male responsibility could be addressed, one woman defiantly stated that she was going to leave her partner regardless of the consequences. Another woman started to cry and said:

The Man Takes Off

“My partner denied responsibility and left me after I confronted him with my test result.”

It is commonly felt that knowing your status by taking a test brings no benefit and that testing triggers a set of negative societal responses. One of the road show actors, who has a girlfriend and son, gives us a glimpse of the existing attitudes of men towards HIV status and testing. He says:

“Very few people get tested because they do not want to know the result. If the result is positive, they will die and be subject to the scorn of the community. I have had sex with at least ten women, but I still do not want to take the test. If I do and the test is positive, I will suffer like the others. I have not asked my girlfriend to take the test because I trust her.”

Church

Stigma and discrimination towards HIV/AIDS are also present in the religious arena. There is a rejection of HIV positive individuals by certain churches, and there is a widespread belief that HIV positive individuals are sinners even though the illness may have been acquired through no fault of one's own (e.g. faithful wife but promiscuous husband). The following vignette illustrates the attitude of a religious leader towards an HIV positive woman who was a member of his own family:

A “Dirty” Grave

“My sister recently died from AIDS. I was very traumatized by the way my father, who is a minister in the Zionist church, ill-treated my sister during her long period of illness. He would not allow anybody to help her with her washing when she had uncontrollable diarrhea and no energy. When she ultimately died, my father refused to have her buried close to the other members of my family because she was considered “dirty”. Her grave is located far from the graves of the other members of our family.”

Culture

The country’s history and culture may have played a role in developing and propagating stigma and discrimination towards HIV/AIDS. According to an MCDI staff member:

“Given the history of South Africa, there is real sensitivity around black/white discriminating behavior. Many blacks believe that revealing their HIV status may be just another way for whites to discriminate against them.”

Blacks are infected at much higher rates than whites, and some believe that the HIV/AIDS epidemic therefore may be an instrument to inflict revenge or control on the black population after democracy was introduced. While South Africa has made great strides in racial integration, some mistrust remains between the races and greatly influences perceptions and beliefs.

There are strong societal and cultural expectations around a woman’s fertility. Women are expected to bear children and those who are barren are frowned upon by the rest of the community. The husband’s family generally expects a “return” on the lobola, a dowry paid by the latter when the couple marries. If the couple does not produce any offspring within a reasonable time after getting married, pressure by the husband’s parents grows and becomes a strain on the couple. If the couple chooses to use contraceptives because one or both of them are HIV positive, it is often impossible to explain this choice to the rest of the family. As a result, the women may feel forced to become pregnant even if she knows it will be detrimental to her health, or may leave orphan children behind.

Fertility Pressures

“I am HIV positive, and it is quite likely that my wife is HIV positive too, but she has not tested yet. She is taking a lot of pressure from my parents because we have been married for more than two years without having any children. It is because we are both HIV positive and choose to use condoms. A pregnancy would be very risky for her because all HIV positive women deteriorate after a pregnancy, and both of us would increase our viral loads by unprotected sex. We don’t know how to deal with my parents, and we cannot tell them about our situation. They would simply not understand and would blame her.”

Government & Providers

HIV/AIDS is a significant challenge currently facing the community. The early government reaction to this illness may have contributed to the negative attitude of the population towards HIV/AIDS. According to a hospital worker:

“The government should have intervened when the first cases of AIDS appeared in the late eighties and early nineties. Instead, it was tardy and suppressed the issue in a manner that contributed to the subsequent pervasive stigmatization of people living with HIV/AIDS. The government’s voluntary disclosure law has contributed to stigma, because the fact that people have the right to opt not to test or disclose their status has created a situation in which, by implication, it is understood that the condition carries a stigma.”

Existing legal rights promoted by the government may also exacerbate the stigma and discrimination towards HIV/AIDS, thus hindering progress in the prevention of the illness. An MCDI staff member explains:

“... South Africans are well aware of their legal rights protecting them against disclosure of their HIV status. This is in part due to a mass media campaign to educate the public about these rights by the government. The laws of confidentiality serve to increase stigma. Because physicians may be sued if a person’s HIV status is disclosed, they tend to be restrictive in using HIV and AIDS as classifications for statistical purposes. This is a prime reason why physicians do not enter AIDS as cause of death on death certificates, but rather other diseases, such as pneumonia or tuberculosis. Physicians are afraid of being held responsible for disclosing someone’s status.”

HIV/AIDS is likely to become the all-pervasive challenge to the South African health care system in the near future. According to a hospital worker, the impact of HIV/AIDS will overburden the existing health facilities in terms of hospital bed capacity, personnel, budget, and other physical resources within the next few years. In the past year alone, 60% of in-patients at one hospital who consented to HIV testing were found to be positive. Also, hospital facilities continue to face the impact of stigma against AIDS in that patients admitted with HIV-related illnesses refuse to be tested, thus putting hospital staff at risk and adding to clinical costs.

Several government stakeholders have acknowledged that there is a need for partnership between the government health system and NGOs in combating HIV/AIDS, including the associated stigma and discrimination. An official from the provincial Department of Health (DOH) stated that, given the limited capacity of the government health care system, the Department’s role in this partnership would be to act as a funding agency, while the NGOs would complement the health service delivery component as implementers and service providers. In support of this view, a hospital worker remarked that NGOs may play a significant role in community outreach and mobilization that will complement existing government programs.

GOING FORWARD

Conclusions and Recommendations

The preceding discussion offers a brief look at the issues of HIV/AIDS-related stigma and discrimination. Although not exhaustive, it conceptualizes both stigma and discrimination in light of relevant literature and a quantitative analysis, and is complemented by a qualitative report of stories from the field. A summary of conclusions and recommendations generated by the report follows as it pertains to the Reducing Stigma and Discrimination through Innovative and Proven Effective Approaches in Ndwedwe District Project (Stigma and Discrimination Project).

Stigma and Discrimination in Ndwedwe Sub-district

The baseline survey results reveal that self-reported HIV positive respondents were more likely to experience stigma and discrimination compared to HIV-affected respondents. A lag period between diagnosis and disclosure also exists, with 20% disclosing only after one month, and a further 20% disclosing only after six months, which may be indicative of the fear of stigma and discrimination surrounding HIV/AIDS. The unexpectedly large number of survey participants who were willing to address stigma and discrimination suggests the gravity and magnitude of these problems, which may escalate out of control if left unchecked. The above trends are backed by people's accounts of their own experiences that may be summed up in one person's declaration: *"I'd rather die than get tested!"*

The needs assessment results and qualitative field observations from Ndwedwe demonstrate that HIV/AIDS-related stigma and discrimination are major challenges in controlling the HIV/AIDS epidemic. Awareness of HIV/AIDS is high, but misconceptions and erroneous beliefs abound. The pervasive stigma and discrimination towards HIV/AIDS, coupled with the perception that there is very little to gain in knowing one's status present stumbling blocks in both the prevention and control of HIV/AIDS. It is evident that HIV-related stigma and discrimination are experienced as a result of a collective negative reaction towards the disease, and it is therefore imperative to gain the community's trust and encourage the people's involvement and participation both prior to and in conjunction with the implementation of a stigma reduction project. Support groups may serve as a starting point for de-stigmatizing HIV/AIDS in that these sessions provide a good venue for allowing HIV positive individuals to disclose their status and talk freely about their experiences, thereby promoting greater openness about the disease and its consequences. There is a strong need for an intensive and comprehensive information and education campaign (IEC) that will increase the knowledge about the disease, its methods of transmission, and its consequences. In addition, the IEC campaign needs to clarify and emphasize the benefits and incentives that can be gained from VCT, knowing one's status and disclosure of status. Using HIV positive individuals as educators will help further in reducing the stigma and discrimination towards HIV/AIDS.

It is also important to consider the future impact of antiretroviral drugs (ARVs) once these become available. As an incentive to get tested, ARVs may indirectly aid in the reduction of stigma in the community. Given this potential, and to maximize available resources, the project could take into account the possibility of merging IEC campaigns to reduce stigma and discrimination with those aimed to increase awareness about ARVs.

Sources and Perpetrators of Stigma

In order to combat stigma and discrimination, it is imperative to identify the sources as well as the perpetrators. There appears to be a trend that neighborhood members and the community are most feared as perpetrators of stigma. Similarly, the family and community were most often mentioned as sources of stigma and discrimination experienced by HIV positive individuals during field visits. A broader awareness campaign that targets the larger community should therefore be an essential component of the program.

Churches and religious leaders are major social institutions in the community, and have a strong influence on the community's perception of HIV/AIDS. These institutions have played a role in the perpetration of stigma and discrimination. MCDI has had positive experience with the Diakonia Council of Churches, a multi-denominational group that coordinates church activities in the Durban area, and it may be helpful to target an IEC campaign towards an expanded group of religious leaders, with the aims of increasing knowledge, changing behavior, and possibly establishing church-based support groups for HIV/AIDS-infected and HIV/AIDS-affected individuals.

Due to the widespread nature of stigma and discrimination in Ndwedwe, it is necessary to mobilize as many stakeholders as possible. In addition to church leaders, traditional healers, teachers, health workers, village chiefs and other political leaders should be pursued as sources of support. This is particularly important if they are highly respected in the community. For example, traditional healers are often the first to be consulted at onset of illness. Although familiar with the signs and symptoms of HIV/AIDS, due to erroneous beliefs and fear, many will claim their patient has "bad blood" or "bad spirits." By educating the traditional healers, their patients are also indirectly educated. The partnership between government institutions and community-based NGOs, as well as interagency collaboration, should be strengthened in order to reach all levels of society.

Awareness of Anti-discriminatory Policies and Legal Rights

The participants surveyed appear to be quite knowledgeable about anti-discriminatory policies. However, less than half of those who experienced discrimination actually reported it to anyone. Future efforts should attempt to bridge the gap between knowledge about policies and reporting discrimination.

Current government HIV/AIDS policies may inadvertently perpetuate the stigma and discrimination as explained in the qualitative section and these policies should be reviewed. There may be a need to develop new policies to create a non-threatening environment for HIV/AIDS testing and disclosure of status without sacrificing the patient's right to confidentiality.

Cultural Barriers

Male attitude and behavior present a huge challenge to the prevention and control of HIV/AIDS in Ndwedwe. Establishing a sub-component in the Stigma and Discrimination Project that specifically targets men may facilitate their greater participation in addressing the HIV/AIDS

problem. Further review of the knowledge, attitudes and practices of men on HIV/AIDS, through a well-designed baseline assessment is essential in the design of a more intensive campaign that targets male behavior and attitude.

It appears that the local culture entails wanting or expecting a reward or remuneration for an action. Many people often ask why they should get tested if there is nothing for them in return. During the survey, people wondered whether they might be able to access treatment in turn for their participation. These commonly encountered questions highlight the need to clarify and emphasize the benefits and incentives to be gained through counseling, testing, and disclosure of status. The expectation of gain, in the context of high unemployment rates in the area, is an important factor to consider in formulating the project components. It may even be necessary to include a component on livelihood and income-generating activities or skills development in the project in order to facilitate and encourage the participation of the people in fighting against HIV/AIDS and the stigma and discrimination associated with the disease.

Stigma and Discrimination: Best Practice

Interventions that aim to reduce HIV-related stigma have been implemented in quite a number of countries to date, but very few have been evaluated rigorously. MCDI should review local and international programs alike to identify current best practice. In developing further its Stigma and Discrimination Project, MCDI may adopt some aspects of the more successful models (e.g. The Valley Trust's documentary video and discussion workshops) and learn from the less successful ones.

Given the relatively new field of stigma reduction interventions, MCDI has a responsibility to contribute to the documentation of best practice and to facilitate the exchange of information and strategies. Thus, the Ndwedwe Stigma and Discrimination Project should incorporate a strong evaluation component that utilizes a tool that is both valid and reliable. Clearly, the baseline survey that has been conducted needs to be developed further, and even expanded, so that data collected will present a more comprehensive picture pre- and post-intervention. This will better facilitate the measurement of project indicators and results.

Finally, it is important to consider measuring proximal outcomes of the stigma reduction project (such as knowledge, attitudes and practices of HIV/AIDS educators) rather than solely concentrating indicators measuring the distal outcome and impact on the target population. How effective will a peer educator be in reducing stigma and discrimination if s/he has never been tested?

It is clear that battling against HIV/AIDS-related stigma and discrimination entails an enormous information and education campaign that will target all members of the community. Such a campaign will only be successful if it is founded on community involvement and trust, and if it is complemented by social and health services that are easily accessible and readily available to everyone in the community.

APPENDIX I: FOCUS GROUP SUMMARY

Introduction

After reviewing the draft summary of the stigma and discrimination baseline survey, we felt it would be helpful to supplement these results with some qualitative information from the interviewers themselves. Our aim was to gain insight into their experience and thoughts on the process of administering the survey in their community.

We developed a focus group plan and arranged for a 1.5 hour discussion to take place at the MCDI office in Durban on 16 January 2004. There were 3 male and 4 female focus group participants (former interviewers) in addition to MCDI staff person and two HSPH team members. After group introductions and stating the focus group agenda and objectives, we began our discussion.

Introductions were made in English, and the rest of the discussion was conducted in Zulu with English interpretation by the MCDI staff person after each comment and question. This method worked well, and conversation flowed smoothly. Most of the participants were open and active throughout the discussion, though one of the men did not contribute anything after his self-introduction.

After reviewing the transcript of the focus group session, we identified three main themes occurring during the discussion. These were: interviewer issues, interviewee issues, and general perceptions of stigma and discrimination.

Interviewer Issues

There were three sub-themes related to the interviewer. First, we noted that interviewers often acted as informal counselors to the respondents particularly if s/he was HIV positive. For example, interviewers reported giving advice such as informing respondents of other neighborhoods where they could talk about their status more freely. Additionally, if a respondent was upset or needed consoling, the interviewer tried to soothe and allay fears and worry. Oftentimes, this occurred during informal conversations prior to administering the questionnaire. Several interviewers said this enabled better rapport and trust.

A second theme was related to increasing awareness around stigma and discrimination through the questionnaire. Focus group participants reported increased knowledge and awareness in addition to positive behavior change towards stigma and discrimination. For instance, while administering the questionnaire, one interviewer witnessed a family with one HIV positive and one HIV negative child where the parents prevented the two children from playing with each other. Some time later, the interviewer noticed the children were now playing together suggesting that the questionnaire may have increased awareness around stigma and discrimination (in addition to other factors). Furthermore, some interviewers reported increased testing and disclosure within their community post-survey.

Finally, some of the HIV positive interviewers also felt comfort in discovering that there were many other HIV positive people in their community throughout the interviewing process. One woman said she “no longer feels alone.”

Interviewee Issues

We noted two sub-themes related to the interviewee. Many focus group participants noted that respondents expected something in return for their time such as support and assistance to access treatment. Secondly, many respondents were fearful of disclosure due to issues regarding confidentiality. They were suspicious of how the information collected was going to be used. For example, some respondents thought that their status would be disclosed to their community or family. Others did not admit to knowing their status even if they did. However, interviewers did their best to reassure them that all questionnaires were anonymous and confidential.

General perceptions of stigma and discrimination

It appeared that focus group participants were knowledgeable about general definitions of stigma and discrimination, yet when asked to define the terms, they found it difficult to explain. In addition, one participant felt that stigma and discrimination was not at all present in some areas of the community. Interestingly, when posed the question: “Have you personally experienced stigma and discrimination?” the response was unanimously: “Never.” It was unclear whether or not this response came from lack of trust between us and them or a difference in how each of them perceived stigma and discrimination.

Conclusion

In conclusion, it appears that the interviewing process benefited both interviewers and interviewees as described above. One focus group participant reported seeing a greater acceptance of HIV/AIDS in the community, as evidenced, for example, by the formation of support groups. However, in probing further about their own perceptions of stigma and discrimination, participants were reluctant to disclose personal experiences and thoughts, though it is unclear why this was.

The focus group allowed a more complete picture of the data collection process as well as the impact the questionnaire had on the interviewers relative to their attitudes and beliefs towards stigma and discrimination.

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