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HIV/AIDS RELATED STIGMA AND THE PERSUASION OF AT-RISK INDIVIDUALS TO GO FOR VOLUNTARY COUNSELLING, TESTING, AND REFERRAL

Creating a content focused evaluation schema aimed at addressing HIV/AIDS related stigma in written material that tries to persuade at-risk individuals to report for voluntary counselling, testing, and referral

Abstract

This thesis attempts to provide health communicators in South Africa with a content focused evaluation schema aimed at addressing HIV/AIDS related stigma in written material that tries to persuade people to report for voluntary HIV/AIDS counselling, testing, and referral (V HIV/AIDS CTR). A major problem in the area of HIV/AIDS related stigma is the lack of theory-based research on the topic. This lack of sound theory indirectly implies that the (few) interventions aimed at addressing HIV/AIDS related stigma that were launched in South Africa, lack a theoretical backing, and also the effects of these interventions have hardly been measured, which further hampers the promotion of theoretically sound knowledge on the subject.

In order to create a content focused evaluation schema that is grounded in theory, this study first provides a solid theoretical framework on the psycho-social construction of HIV/AIDS related stigma and on the decision-making processes involved in deciding to report for V CTR or not.
Based on this theoretical framework, a set of leads for interventions is created. These leads provide policy makers and health communicators with a holistic approach to the issue of HIV/AIDS related stigma as a determinant of low uptake of V CTR. It is this set of intervention leads which then opens the door for the aforementioned evaluation schema.
To put it briefly: first a theoretical framework is generated on which a set of intervention leads is based, and then the evaluation schema is constructed on the basis of those theoretically sound intervention leads.
After the presentation of the evaluation schema, some suggestions for further research will be discussed briefly.

Contents

Foreword

In the beginning of 2003, I heard about a large-scale project that was being developed by three South African universities (University of Pretoria, University of South Africa, University of Stellenbosch) and three Dutch universities (University of Nijmegen, University of Twente, and University of Tilburg). The project was called the EPIDASA project, and it aimed to analyse and improve the HIV/AIDS public information documents in South Africa. I have to admit that the sheer opportunity to go to Pretoria, South Africa for six months was enough for me to sign up, but at that time I was not sure how to go about writing a thesis on such a complex and broad matter. When I arrived in South Africa, it was prof. Piet Swanepoel who got me interested in the topic of HIV/AIDS related stigma. When I realised the enormous and detrimental impact of HIV/AIDS related stigma on the efforts to fight the epidemic, I was convinced that my choice for this particular topic was the right one.

Today, I am glad to finally be able to present my thesis. I would like to take the opportunity to thank some people that helped me through the process of writing this thesis.
First of all, I would like to thank prof. Piet Swanepoel for pointing me in the right direction, for all of his advice and support, and especially for his enormous patience. Baie dankie Piet!
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Finally, I would like to wish all those who are still involved today in the EPIDASA project the best of luck, and I would like to end by, again, thanking all those that were in one way or another involved in my research, including those whom I have forgotten to mention here. You know who you are!

Abbreviations

AIDS – Acquired Immunodeficiency Syndrome
ARV Therapy – Anti Retroviral Therapy
CTR – Counselling, Testing, and Referral
GPA – Global Programme on AIDS
H/A – HIV/AIDS
HIV – Human Immunodeficiency Virus
IDU – Injecting Drug User
IEC – Information, Education, and Communication
NAPWA – National Association of People living with HIV/AIDS
NGO – Non Governmental Organisation
PLHA – Person Living with HIV or AIDS
PT – Potential tester
TAC – Treatment Action Campaign
V HIV/AIDS CTR – Voluntary HIV/AIDS Counselling, Testing, and Referral
WHO – World Health Organisation

1 INTRODUCTION

"People who are living with HIV/AIDS are one of the most vulnerable groups in our society. Notwithstanding the availability of compelling medical evidence as to how the virus is transmitted, the prejudices and stereotypes against HIV positive people still persist. In view of the prevailing prejudice against HIV positive people, any discrimination against them can, to my mind, be interpreted as a fresh instance of stigmatisation and I consider this to be an assault on their dignity. The impact of discrimination on HIV positive people is devastating."

Justice Ngcobo (Hoffmann v South African Airways)

1.1 HIV/AIDS related stigma and South Africa

The latest estimates are that roughly 5 million South Africans are infected with HIV, and that 20.1% of the South African adults aged between 15 and 49, and thus the labour force, is infected (Human Sciences Research Council 2002). This means that a vast number of people in South Africa could already have experienced some form of discrimination based on their HIV status, and that many more have the potential of becoming vulnerable to stigmatisation, rejection and discrimination once their status becomes known to others. Discrimination could be understood as unfairly disadvantaging a person on the basis of some capacity or quality attributed to that person. Discrimination is a highly subjective phenomenon as it is mostly determined by perceptions and preconceived notions of the person who is discriminating. It does not have to be based on verifiable facts. For example, a person who is merely suspected to have HIV/AIDS can be a target of discrimination just as much as someone who has tested positive and has disclosed his/her status to others.

This chapter aims to briefly show the multifaceted nature of HIV/AIDS related stigma (or simply HIV/AIDS stigma), by showing its manifestations in a variety of contexts. It will also try to explain why and how HIV/AIDS stigma has such a negative impact on all interventions aimed at curbing the spread of the disease. Furthermore, a brief explanation of the construct of stigma is provided, which is then followed by a compressed overview of a number of interventions and their effect, or lack of it, on redressing the problem of HIV/AIDS stigma.

South Africa and the HIV epidemic
At the launch of the South African government's "Partnership Against AIDS" campaign, held on Friday 11 September 1998, there were a number of speakers from the National Association of People Living with HIV and AIDS (NAPWA). Each speaker described their experience as a person with HIV. Each experience contained stories of some form of unfair discrimination and/or human rights abuse. Mention was made of the difficulty of obtaining mortgages, of unfair dismissal from employment and of routine abuse in the health care sector. The complaints of NAPWA members echoed one of the main findings of the extensive Review of the National AIDS Plan that was conducted in 1997: that stigma and discrimination continue to characterise South Africa's response to AIDS. The National AIDS Review found "widespread and systematic abuse of the basic human rights of persons living with HIV/AIDS (PLHAs) in all nine South African provinces. High levels of discrimination and stigma were found both within health services and communities". It recommended that "a concerted effort by all stakeholders needs to be made to protect human rights, counter discrimination and reduce stigmatisation" (Heywood 1998).
Now, HIV/AIDS stigma is certainly not exclusive for South Africa, on the contrary, it can be considered universal. But in South Africa, the problems of HIV/AIDS and the resulting stigmatisation and discrimination are of extraordinary severity, and this can only be explained

when South Africa's historical context and its history of dealing with the epidemic are taken into account;

Two independent HIV epidemics have been identified in South Africa (Medical Research Council 1997). The first epidemic had its origins in 1982, when the first cases of AIDS were identified in gay men. The second epidemic is thought to have started in the mid-1980s amongst heterosexual adults and then their children, infected by mother-to-child transmission of HIV. This classification is based on the molecular make-up of HIV strains and is thus categorised according to medical models.
However, another classification based on social norms is popularly accepted: while AIDS was originally blamed on white gay men, it was steadily transformed to include black Africans - before 1985, the epidemic was characterised as "the Gay Plague", later that year, however, newspapers began reporting black HIV cases in Soweto, and the name of "the Gay Plague" immediately transformed into "the Black Death" -. HIV had thus found the already marginalized or stigmatised in South African society. The apartheid state legislated against and repressed any group not conforming to its norms of being white and heterosexual, thereby creating an oppressive atmosphere in which the AIDS epidemic could flourish. In 1988, the Panos institute observed the following:

"In South Africa, the AIDS virus has already found a situation which provides it with a maximum opportunity: an uprooted, suppressed, materially deprived black population in which infectious disease is already epidemic and among whom distrust of the white authorities in ingrained since birth. Illiteracy promoted by restricted education, and the suspicion with which the use of condoms is greeted (promoted as part of birth control campaigns, they are regarded as a tool of white genocidal aspiration) will ensure the minimum impact of any AIDS information effort led by white officialdom" (Panos Institute 1990).

Although black South Africans are still hardest hit by HIV in terms of percentage, it is alarming to see how fast HIV rates increase in white and coloured South Africans as well, indicating that today AIDS has truly become a problem for the entire population of South Africa, and can no longer be confined to a specific race or age group (Swanepoel 2003).

It is this state of affairs that the new democratic government inherited and it had to forge an innovative response to an epidemic that threatened to engulf the country. While the ANC initially seemed committed to AIDS prevention and education, the transformation process and unstable political conditions in the new South Africa hindered effective engagement with HIV/AIDS. Moreover, the questionable opinions of South Africa's head of state, Thabo Mbeki, who has publicly denied that HIV causes AIDS and contended that anti-retro viral drugs are toxic and dangerous, have lead to added confusion, disbelief and denial.
On these unstable political conditions, Cornell and Heywood (1998) write that "although the principles and proposals for an effective response were firmly established on paper by 1994, the pre- and post-election transformation process proved a debilitating distraction. Politics, violence, and national euphoria strengthened the mood of denial about HIV in which prejudice around HIV issues continued, silencing most people with HIV".

Stigma: present in a variety of contexts
HIV/AIDS related stigmatisation manifests itself in a whole variety of levels and contexts, such as the interpersonal one, the family, the community, the work place, the health care sector, the housing system, insurances, the educational system, and immigration laws. A number of examples of stigmatisation in different contexts is given below (all taken from Heywood 1998);

- "My name is T. I am 32 years old. I tested positive about 7 years ago. I could not tell my family until last month when my sister took me in for a test. I was so scared the family will reject me. And of course my other sister didn't even show up after my elder sister told her. Until they ended up fighting verbally. At work everybody want to know

how come we are both sick with my husband. This has given me so much stress that I have even decided to resign before they find out. I can't talk about it. I have to tell people that I am suffering from Leukaemia so that at least I must be accepted with the society."

- "My name is P. I am 26 years old. I was discriminated against at Techkikon. I was asked to change my career because they said I will contaminate the staff and students. I tried to challenge it but the lecturer's dismissed me."

- M: "I went to hospital for a trial and they took blood samples to check if we qualify. One of the ladies who works at the hospital was not impressed about the whole thing. She was swearing at me telling me that I won't last long. I will die within a few months. This lady was worried about her job, saying that I didn't follow the process well and she is going to lose her job out of useless people who are going to die soon."

- A married women living with HIV approached an attorney to help her with divorce proceedings. In a consultation session with herself and her husband in order to finalise the divorce, the attorney made a number of derogatory remarks. He implied that she was living with a death sentence and expressed surprise that she "could get on a medical scheme". While ignoring his client and her questions completely, he told her husband that he was "very noble to have stayed with her for so long", that if he (the attorney) had met her in a pub and was told of her HIV status that he "would run a mile", as well as that she "will never find Mr. Right with her condition".

As shown in these examples, HIV/AIDS stigma can show up in a whole variety of contexts. The persistent pressure that stigmatisation puts on PLHAs has a devastating effect on openness and disclosure. This was also made clear by the four NAPWA speakers at the "Partnership Against AIDS" campaign mentioned before. None of the speakers were "sick". All were competent and capable young South Africans. Yet all, by one means or another, had been prevented from making a normal contribution to society and to their own families. One immediate consequence of this kind of ostracism is that "disclosure of HIV status in the prevailing political and social climate is difficult for the majority of PLHAs" (Heywood 1998). This constitutes a major problem for all interventions aimed at curbing the spread of the disease. Fear of stigma and discrimination creates an atmosphere of silence and denial, in which openly talking about the disease and its implications becomes hard. This implies for example that negotiating condom use becomes very difficult (thus hampering prevention interventions), that HIV positive tested people refuse to disclose their status out of fear of negative reactions and consequently do not seek care and support (thus hampering care and support interventions), and that people simply refrain from testing for HIV, because they greatly fear the rejection and discrimination brought upon them by a positive test result (thus hampering efforts to persuade people to voluntarily report for HIV/AIDS CTR).

In South Africa, as in most developing countries, there is therefore a general need and urgency to address the problem of HIV/AIDS related stigma and the way it is effecting current interventions to prevent the catastrophic consequences of the HIV/AIDS pandemic on all South Africans.

In this thesis, the focus falls on the role that HIV/AIDS stigma plays in only one of the three types of intervention mentioned above, namely Voluntary HIV/AIDS CTR. Despite the positive attitudes towards V HIV/AIDS CTR indicated in a number of surveys in South Africa, uptake has been very low: it is estimated that only half a million of the estimated 5 million PLHAs know their serostatus (Dept. of Health 2001). Although a number of variables play a role, recent surveys show that fear of HIV/AIDS stigma is a strong predictor of low uptake behaviour (Van Dyk 2003, Van Dyk in press). Van Dyk (2003) conducted a broad empirical study among all ethnic groups in South Africa in order to gain insight into the beliefs and

attitudes that exist among them concerning V HIV/AIDS CTR. Her conclusion was that subjects were in principle not against V CTR, but that there exist a number of barriers for people to go for V CTR. She identified a set of structural barriers (service-related barriers) and a set of psychosocial barriers to V CTR in South Africa;

- *Structural barriers (or service-related barriers)*

  - too limited number of counsellors
  - counselling is often of poor quality
  - lack of privacy
  - long queues for service
  - lack of trust in the health care system or fearing a breach of confidentiality
  - lack of follow-up support after diagnosis

- *Psycho-social barriers*

  - lack of trust in health care professionals to keep results confidential
  - fear of discrimination/rejection by health care professionals, partners or communities
  - fear of disclosure to sex partners
  - concerns about testing without treatment or follow-up options
  - doubts about how to handle the psychological turmoil of knowing one's HIV positive status

When seeking the reasons behind these barriers, we can find that a considerable part of them have to do with the fear that testing for HIV/AIDS will bring about a situation of no return; the result can bring the danger of being diagnosed as HIV positive, and that means the tested individual will be faced with a whole range of negative reactions and consequences which find their origins in HIV/AIDS related stigma.
Reviewing all the barriers, we can try and analyse which ones can be categorised as being caused by HIV/AIDS stigma.
Indeed, some of the barriers mentioned are typical structural barriers; they find their roots in limited budgets and an overloaded health care system, and are not linked to stigma. The very limited amount of counsellors, the poor quality of counselling, and lack of follow-up support are good examples.
Another barrier could be called an "instrumental" one; concerns about testing without the possibility of receiving treatment or follow-up support are totally legitimate. What good is knowing your status if there is nothing that can be done about it and there is no help or support provided? So in this case, it is the lack of hope for treatment that demotivates people to go for CTR, because they no longer see the point in it.
Lack of privacy, long queues for service, and fear of a breach of confidentiality by health care professionals are stigma-related barriers; they all have to do with the fact that people are afraid that others will find out that they went for an HIV test, or even worse, that they tested HIV positive. Why is it that people are so afraid of disclosing their serostatus? It is here where HIV/AIDS stigma plays such a decisive role: people fear that they will be rejected and discriminated against by their family, community, colleagues, etc. And this rejection and discrimination is exactly the result of the stigmatised condition of the disease.
Fear of disclosure to sex partners is also a barrier which is stigma-related; people fear disclosing their serostatus to their partners because they know that this probably means the end of the (sexual) relationship. They fear that their partners will abandon them and spread the news in the community. Why would these partners do that? Why would one leave a loved one that has fallen sick, instead of supporting and helping them? Again, it is to a large extent the extremely stigmatised condition of HIV/AIDS that causes such fierce reactions.
Doubts about how to handle the psychological turmoil of knowing one's HIV positive status can be seen as partly stigma-related; of course, it is perfectly logical that one has doubts about how to handle the disease. Will I feel a lot of pain? How long will I stay alive? These are concerns

that would occur also in the ideal situation where HIV/AIDS would not be a stigmatised condition. But the person that knows his HIV positive status will also have concerns about how to handle the discrimination that awaits him. Will my wife/husband leave me? Will I be able to keep my job? Will I be rejected by the members of my community? These concerns are directly linked to HIV/AIDS stigma, because the discrimination they fear is rooted, again, in the extreme stigmatisation of the disease and its patients.

Overviewing Van Dyk's barriers, we see that the tested individual fears not simply a positive result, but also, and probably even more, the stigmatisation that this result could lead to. The decision to go or not to go for HIV/AIDS CTR will thus be determined in a critical way by the potential tester's knowledge of the manifestations and scope of HIV/AIDS related stigma in his immediate surroundings of family, community and work environment.
Studies (see Herek 1999, Chesney & Smith 1999, etc.) have shown that, throughout different cultures and settings, AIDS stigma manifests itself not only in prejudice against PLHAs, but also in discriminating and threatening behaviour against those considered to be at risk for HIV/AIDS. Stigma and fear of stigma have an extremely negative influence on PLHAs, since it severely inhibits every form of normalization of the disease and of those who suffer from it.

In communities in South Africa where HIV/AIDS stigma is high, fear of HIV/AIDS stigma in fact has lead to a stalemate position with regard to V CTR: given the high levels of HIV/AIDS stigma in some communities, health educators and counsellors are ethically bound to warn clients in messages on HIV/AIDS CTR that testing (positive) could expose them to HIV/AIDS stigma, but at the same time fear of stigma is also one of the main reasons why at-risk individuals do not voluntarily report for CTR. Obviously, this low uptake of HIV/AIDS CTR jeopardizes the benefits of V HIV/AIDS CTR in the fight against the epidemic in South Africa and belittles the South African government's recent attempts to enhance V HIV/AIDS CTR as intervention by up-scaling CTR services. Although a number of other variables also determine uptake behaviour, the strength of fear of HIV/AIDS stigma and the stalemate position it leads to in persuading people at risk for or those living with HIV/AIDS to voluntarily report for HIV/AIDS CTR therefore poses a daunting task for health communicators in South Africa.

1.2 What is stigma?

Now, before elaborating any further on H/A stigma and the South African context, it is of importance to first, briefly, establish what the term 'stigma' stands for, in order to avoid any confusion on this concept.
In ancient Greece, the term 'stigma' referred to a sign, or mark, cut or burned into the body, that designated the bearer as a person who was morally defective and to be avoided – a slave, a criminal or a traitor for example (Goffman, 1963). In the twentieth century, the term stigma was resurrected by sociologist Erving Goffman to refer to an attribute of a person that is deeply discrediting, and reduces him or her 'in our minds from a whole and usual person to a tainted, discounted one' (Goffman, 1963, p.3) Thus, the person who is stigmatised is a person whose social identity, or membership in some social category, calls into question his or her full humanity; the person is devalued, spoiled or flawed in the eyes of others (Jones et al., 1984). Generally, there is nothing objectively wrong with the person, it is those others who supply the label and attach a negative meaning to whatever characteristic the individual possesses. Unfortunately, there is no single feature or even set of defining features that unambiguously signifies that an individual or group is stigmatised (Crocker et al., 1998). The set of conditions that stigmatise can best be thought of as a fuzzy set, with individuals and groups varying in 'family resemblance' to prototypes of a stigmatised group (Cantor & Mischel, 1979). From this perspective, stigmatised groups are likely to share several features, none of which are necessary or sufficient to identify a group as stigmatised. However, if one single defining feature of stigma must be provided, it can be argued that stigmatised individuals posses, or are believed to posses, some attribute or characteristic that conveys a social identity that is devalued in a particular social context (Crocker et al., 1998). In claiming that stigmatised individuals posses,

or are believed to posses, a particular attribute, it is suggested that there is often an objective feature, behaviour or characteristic of the individual that makes him or her vulnerable to being stigmatised. However, it is the belief that the person possesses the attribute, held by either the stigmatised individual or by others, rather than the objective or scientific fact of the matter, that leads to stigmatisation.

HIV/AIDS and stigma
That various medical conditions or diseases and behaviours are stigmatising within society is attested to by numerous early written works, even including the Bible. In the Old Testament, the skin disease leprosy is clearly portrayed as a divine punishment for moral defection and a cause for social isolation. Some conditions appear to have been severely stigmatising in virtually every known culture and time period for which evidence exists (Reingold & Krishnan 2001). And unfortunately, AIDS is a condition that is particularly likely to evoke stigma. As Herek (1999) states in his explanation of the social psychology of AIDS, HIV/AIDS displays a number of characteristics that are especially vulnerable to stigmatisation:

First, stigma is more often attached to a disease whose cause is perceived to be the bearer's responsibility. To the extent that an illness is perceived as having been contracted through voluntary and avoidable behaviours, especially if such behaviours evoke social disapproval, it is likely to be stigmatised and to evoke anger and moralism rather than pity or empathy (Weiner, 1993). Thus, because the primary transmission routes for HIV are behaviours that are widely considered voluntary and immoral (homosexuality, promiscuity, sex with sex workers, injecting drug use etc.) PLHAs are regarded by a significant part of the public as being responsible for their condition and consequently are stigmatised (Herek & Capitanio 1999).
Second, greater stigma is associated with illnesses and conditions that are unalterable or degenerative. Since the earliest days of the epidemic, AIDS has been widely perceived as a fatal condition (Blake & Arkin 1988). Being diagnosed with such a disease is often regarded as equivalent to dying, and those who are diagnosed may represent a reminder, or even a personification, of death and mortality. Although medication is available, there are many PLHAs that do not have access to antiretroviral drugs, and subsequently AIDS will probably continue to be perceived as a fatal disease in the foreseeable future.
Third, greater stigma is associated with diseases or conditions that are perceived to be contagious. Perceptions of dangers and fear of contagion have surrounded AIDS since the beginning of the epidemic (Herek 1990).
Fourth, a condition tends to be more stigmatised when it is readily apparent to others, and disrupts a social interaction or is perceived by others as repulsive, ugly or upsetting. In this regard, the advanced stages of AIDS dramatically affect an individual's physical appearance and stamina, evoking distress and stigma from observers (Klitzman 1997).

When considering these four reasons why AIDS is so likely to evoke stigma, they might provide us with some preliminary, general leads for intervention ideas.
The first notion of greater stigma being attached to a disease whose cause is perceived to be the bearer's responsibility, and thus evokes anger moralism and anger rather than empathy, urges us to think about ways how to change this anger and moralism into a less hostile vision of PLHAs. Herek (1999) provides a clue by describing how campaigns can humanise PLHAs: by showing how they cope with the disease and are living normal lives. PLHAs should not be portrayed as culprits or as helpless victims, but as flesh-and-blood human beings, who live their lives just as the uninfected do. Such messages could point out the human aspect of AIDS and help the public frame AIDS as a virus affecting individuals, not social groups.
The second notion of greater stigma being associated with diseases that are unalterable and fatal, would imply that HIV/AIDS needs to be disassociated from death. Herek (1999) explains that stigma associated with cancer has diminished as chemotherapy has become commonplace. Likewise, H/A stigma could be fought by stressing that HIV/AIDS can be treated with drug therapies, and that HIV infection does not necessarily mean that a person is dying.

Furthermore, the third notion of greater stigma being associated with diseases that are contagious, leads to the idea of clarifying the exact ways of transmission of the disease. This knowledge would then lead to a reduced fear of being infected, and thus a reduced stigmatisation of PLHAs. Unfortunately, it is not as simple as it might seem to reduce people's fear of being infected with HIV just by providing them with knowledge. The problems involved in this process are explained later on in chapter 2.

The fourth and last notion of greater stigma being attached to diseases that are readily apparent to others, leads us to the use of drug therapies. PLHAs who are using anti retroviral drugs, show less apparent signs of illness and thus would be confronted less with H/A stigma. This implies that drug therapies should be widely available to PLHAs, which is obviously not yet the case in South Africa. A more humane drug policy could address this last problem.

After these first, preliminary clues for addressing H/A stigma, an in-depth view on H/A stigma and possible clues for interventions will follow in further chapters. But before turning to this in-depth view on H/A stigma, we would first want to take a look at some already existing efforts to address H/A stigma in South Africa. Overviewing these efforts might provide us with some clues as to what has already been done, and to why these efforts were, or rather were not, effective.

1.3 Motivation

Efforts to address HIV/AIDS stigma

After a brief view on what stigma entails, let us return to the South African context and take a look at a number of interventions that have been launched in South Africa to address the problem of HIV/AIDS stigma. These interventions have been aimed at different target groups and they employ a number of the instruments at hand for health communicators and educators. Given the high levels of HIV/AIDS stigma still prevalent in South Africa (Richter 2001), they have obviously met with relatively low levels of success. Or, as it is put in AIDS Foundation of South Africa (2000), "the result of campaigns and prevention programmes have been largely disappointing". Understanding why interventions to address the problem of HIV/AIDS stigma have failed is a prerequisite for attempts to design effective messages to persuade individuals with high-risk behaviour to voluntarily report for CTR. In this section a brief overview is given of the most prominent HIV/AIDS stigma related interventions that have been carried out so far in South Africa. A division is made into four sections; Information, Education, and Communication-strategies (IEC) aimed at the general population, IEC directed at individuals considering V CTR, the media, and the law as instrument to combat HIV/AIDS stigma.

A. Information, Education, and Communication strategies

1) Strategies aimed at the general population

IEC campaigns aimed at the general population have as their aim to foster compassion in a variety of contexts towards PLHAs and those associated with them. Despite the high levels of HIV/AIDS stigma reported in South Africa, very few attempts have been made to address it by way of IEC campaigns. Two once-off attempts have been;

- A book of testimonials called "Living Openly" as part of the "Beyond Awareness Campaign" (Department of Health 2000a).
  This compilation of personal stories by HIV/AIDS patients about their daily life with the disease is meant to normalise PLHAs. By portraying these PLHAs as human beings who experience happiness, misery, hope, and pain just like other people, an effort is made to generate compassion for these PLHAs, and the idea is that compassionate individuals do not discriminate against PLHAs. The effect of the testimonials has never been researched.

(Note the resemblance of this intervention with Herek's (1999) proposal of humanising PLHAs, as described in the former section.)

- The "Flu/AIDS advertisement" (Department of Health 2000b).
  In this advertisement, a comparison is made between the flu and HIV/AIDS. The message of the advertisement is that "you wouldn't throw a loved one with the flu out on the street, so why do it to a loved one with HIV?". What they do is to take a disease that is not stigmatised at all (the flu), and compare it to a disease that is highly stigmatised (HIV/AIDS), with the aim that the public will start to treat PLHAs the same way as they would treat someone with the flu, that is without prejudice and discrimination.
  This concept of comparison poses some problems if viewed from the perspective of several risk theories (see Holtgrave et al 1995). These theories state that comparing a disease like the flu with a disease like HIV/AIDS is impossible. It is what they call an "incomparable risk"; whereas the flu is a disease which is practically harmless, HIV/AIDS is considered highly fatal. The associations with and reactions to these two diseases are thus completely different, and they cannot be compared. The creators of the advertisement try to make an appeal to the idea of "general compassion for someone that is ill", but the way they try to achieve this is not backed by understanding of how stigma works. Coulson (2002) observes that the effect of this advertisement has never been established.

Most other attempts directed at the general population were very implicit and probably unintentionally aimed at fighting HIV/AIDS stigma; in particular some brochures with information about the ways of transmission of HIV, which were set in the context of care for PLHAs. These brochures tried to reduce fear of personal contact with PLHAs by explaining the exact ways of transmission of the virus.

However, very few of them have been in fact launched on a broad scale and very few have met with success. The main reason being our lack of theoretical understanding of HIV/AIDS stigma itself, which has hampered the development of theoretically sound IEC campaigns. The phenomenon of stigma itself is undertheorised, i.e. there have been few attempts at theoretically clarifying and understanding stigma and it's various manifestations in different contexts. Those that did come up with theories on stigma (see Herek 1999, Pryor and Reeder 1993, Fiske 1998, Smith 1993, Pryor et al 1999, etc.) have mainly focused on certain aspects of stigma, but did not create an integrated, overall theory in which stigma is dealt with as a complex social and individual phenomenon, and in which the numerous variables that determine the possible dimensions of stigma are taken into account. And with regard to V HIV/AIDS CTR, we still lack a theoretical understanding of how fear of stigma/discrimination impacts on the processes of deciding to report for V CTR or not.
Theoretical models to foster our understanding of H/A stigma are, however, needed not only for interventions aimed at the general public, but also for all groups equally affected by stigma: PLHAs and those associated with them, all individuals at risk for HIV/AIDS, and of course those considering V CTR.

2 Strategies aimed at individuals considering Voluntary Counselling, Testing, and Referral

In IEC campaigns directed at persuading high-risk individuals to voluntarily report for CTR, two types of interventions must be discerned: those initiated by NGO's specifically concerned with human rights and legislation with regard to HIV/AIDS, and those aimed at the general public. (The former is discussed below under 'C'). With regard to the latter a number of brochures and pamphlets have been produced by governmental and nongovernmental agencies and widely distributed in South Africa (such as the loveLife campaigns 2002, the Department of Health's "AIDS Helpline" brochures 2000, etc.).

Despite the fact that fear of H/A stigma is indicated as a strong negative indicator of uptake of V CTR, very few of the concerns of potential testers are in fact addressed in the brochures themselves. Very few if any, for example,

- refer to current legislation with regard to issues of confidentiality and informed consent
- mention or discuss the possibility of experiencing H/A stigma related negative attitudes and behaviours under the possible disadvantages of testing (positive)
- provide information (as an incentive to test) on how current legislation prohibits discrimination against PLHAs in a variety of contexts.

In South Africa, no studies have been done on the effectiveness of text-mediated interventions to persuade people to voluntarily report for CTR. Nor have in-depth studies been launched to be able to develop theory and databased interventions to persuade people with high-risk behaviours to voluntarily report for CTR (Bartholomew et al 2001). None of these brochures, for example, pay systematic attention to the number of H/A stigma related variables that determine V CTR uptake behaviour, as mentioned by Van Dyk (2003) for instance.

Beside theories to understand H/A stigma and data on H/A stigma related variables that determine uptake behaviour, we also need theories of how these variables determine peoples decisions whether to test or not (Burris 1997). In HIV/AIDS interventions the focus has almost exclusively been on a theoretical understanding of the determinants of unsafe sex practices and hardly any attention has been given to the determinants of the decision processes involved in CTR uptake behaviour and in developing coherent analytical, explanatory and predictive theoretical models of these processes.

B. The mass media
A number of studies have been done on the way the mass media portray PLHAs and the way in which the media's portrayal of PLHAs both supports the general public's stigmatising attitudes and behaviours and shapes the identities forced on PLHAs and their attitudes and behaviours towards people that stigmatise them.

In decisions whether to test or not, potential testers in fact have to assess whether or not they will be subjected to H/A stigma related negative attitudes and behaviours. Since the mass media both shape and portray the general public's image of PLHAs, they are important sources of the construction of these attitudes and behaviours.

The media of course do not have an easy part to play in covering the epidemic. On one hand they have to come up with something new and spectacular every time, whilst still meeting editors' deadlines, and on the other hand most reporters would like to make some sort of contribution to fighting the HIV/AIDS epidemic, instead of merely covering it (Soal 2003). Critics say that the media "are generally shockingly inept in reporting the worst crisis our nation has ever faced. They are either alarmist, most do no research, and they rely on often repeated 'truths', they do very little focussing on positive interventions or community work, they give people no idea how to manage the virus, or they take political stances instead of the only one that counts - a people oriented stance...we should be doing more research, relying less on the internet and more on going out into the field and meeting the researchers and scientists, and people infected and affected" (Smith 2003). The often poor reporting on the epidemic might imply that also reporters and editors have to be educated on the issue. Efforts to address the role that the mass media play in fostering H/A stigma include advocacy activities to sensitise the media to their portrayal of PLHAs and the way this influences the public's perceptions and attitudes towards PLHAs. In South Africa, these efforts have been backed up by a booklet produced and distributed by Soul City (2002) for use by media practitioners and health reporters that have to cover HIV/AIDS related topics.

However, as far as could be ascertained, no studies have been done -most probably given the methodological problems involved- on how effective these interventions have been in either sensitising reporters in their coverage and reporting of PLHAs, or the effect it has had on the general public's perceptions of PLHAs and/or in reducing HIV/AIDS stigma.

C. The law as an instrument to combat HIV/AIDS stigma

Following best practices in developed countries, a number of laws have been promulgated in South Africa that pertain to human rights and HIV/AIDS. Most of these directly address stigma as determinant of low uptake behaviour of CTR and were in fact instigated to directly address the negative effect of H/A stigma on intervention efforts (Burris 1997):

- legislation regulating HIV testing, including the right to confidentiality and informed consent
- legislation that prohibits unfair discrimination against PLHAs in a number of contexts

This legislation finds its roots in Chapter 2 of the South African Constitution, which contains a list of fundamental human rights that everyone is entitled to. This is commonly called the "Bill of Rights". These rights are important because they protect everyone from being treated unfairly and in ways that damage their dignity. There are a number of human rights in the Bill of Rights that are of particular importance to PLHAs:

- Human Dignity
- Freedom and Security of the Person
- Privacy
- Freedom of Expression
- Freedom of Association
- Freedom of Movement and Residence
- Freedom of Trade, Occupation and Profession
- Right to fair Labour Practices
- Housing
- Health Care, Food, Water and Social Security
- Education

These rights protect PLHAs in a whole range of contexts; in the workplace, in schools and universities, in insurances, in the health care system, in the housing system, at home, etc.

The possibilities that the law provides to take action against unfair discrimination of PLHAs have been backed up in South Africa by IEC text-mediated campaigns such as that of the recent and quite innovating Current Law & Policy Pamphlet Series by the Wits Aids Law Project (2002), which is aimed at various target groups:

- people considering V CTR (informing them of the advantages and disadvantages of testing; informing them of their right to confidentiality, their right to consent and current legislation prohibiting unfair discrimination against PLHAs)
- employees and employers (informing them of current legislation prohibiting unfair discrimination against PLHAs in the workplace)
- PLHAs (informing them of their rights)

These Current Law and Policy Pamphlets provide us with an interesting idea, namely empowering people to enforce their human rights even though they are HIV infected. A brief overview of the content of these pamphlets is given below;

"The Current Law & Policy Pamphlets" *(The Wits AIDS Law Project)*

The Wits AIDS Law Project has come up with a series of pamphlets that aim to educate and inform people about the protection that the law provides against unfair discrimination based on HIV infection. Every pamphlet is aimed at a different target group in a specific context, and tries to clarify exactly how people can enforce their rights within these contexts. We will take a closer look at the pamphlets aimed at the three groups mentioned above;

- *people considering V CTR.*
  This pamphlet describes the rules for HIV testing. It states the benefits (being able to avoid infection of partners, possible early uptake of medication, and slowing down the epidemic in general) as well as the risks (vulnerability to stigma and discrimination, decreased life expectation) of knowing one's HIV status, and explains key concepts concerning testing such as the window-period. It then continues with stating several contexts prone to HIV/AIDS related discrimination such as the workplace, medical aid schemes, health care, etc. It then proceeds with describing the exact process of HIV testing (pre-test counselling, test, post-test counselling) and shows how to tackle any acts of unfair treatment that can occur anywhere in this process. This is done by providing and explaining the laws and policies which apply to these circumstances, for example;
  the rule of "informed consent", which means that no person can be forced to take an HIV test and that no person should take an HIV test without a) knowing what the test is all about and being offered pre- and post-counselling, and b) his/her agreement. This policy finds its roots in the Bill of Rights, and more specifically in the Right to Freedom and Security of the person. The pamphlet then also shows how numerous people have successfully fought unfair discrimination by going to court or laying complaint.

- *employees and employers.*
  This pamphlet starts off with a description of the disease itself, and explains the difference and relation between HIV and AIDS. It then gives some examples of common acts of unfair discrimination in the workplace. Following this, the laws and policies that have been put in place to protect workers and their rights are introduced. An elaborate description of all these laws and policies is given, intertwined with numerous successful cases of fighting unfair acts by means of the law. For example, the pamphlet refers to the Employment Equity Act, which states that no one may unfairly discriminate against a PLHA at work, or when applying for a job. Immediately following this, a case is presented in which a PLHA successfully sued a company for not hiring him only because of his HIV status (Hoffmann v SAA 2001). Furthermore, it provides advise for both employees and employers on how to protect workers with HIV/AIDS from unfair discrimination and victimization. Finally, it clearly describes the different steps one can undertake to fight unfair acts legally.

- *PLHAs*
  This pamphlet aims to make PLHAs aware of all the possibilities to prevent and fight unfair discrimination that the law provides them with. It gives a detailed overview of all the laws and policies protecting them, such as the Bill of Rights, the Promotion of Equality and Prevention of Unfair Discrimination Act, Labour Law, Medical Schemes Act, etc. The final section consists of a meticulous description of how to enforce the rights that are protected by these laws and policies. All the options are given, such as civil claims, equality courts, the South African Human Rights Commission, etc.

For this study, especially the pamphlet aimed at people considering CTR is of course very interesting. The main target of the pamphlet is of importance to us, namely to support the

propagated behaviour (i.e. to go for CTR in spite of the threat of potential stigmatisation) by explaining how the law protects PLHAs against unfair discrimination.

In principle, informing potential testers of how confidentiality and issues of consent are enshrined in legislation and how unfair discrimination against them in a variety of contexts, should they test positive, is not allowed, could be seen as strong arguments to support a decision to report for CTR. Despite the Wits AIDS Law Project and other similar projects, negative attitudes and behaviours towards PLHAs and those associated with them are still widespread across South Africa in the contexts regulated by current legislation (Heywood 1998), and as Van Dyk's (2003) study indicates, still remains a primary determinant of the low uptake of CTR.

This raises a number of questions with regard to the efficacy of projects like the Wits AIDS Law Project. Why do they fail to address at least those concerns potential testers have with the negative attitudes and behaviours of H/A stigma that is addressed by current legislation? Burris (1997) provides a number of reasons why the law in itself is not a sufficient instrument to combat stigma: the law cannot be enforced in those contexts in which HIV/AIDS stigma is most acutely felt, namely the interpersonal and social level, where interpersonal, social and cultural norms guide interpersonal interactions. Furthermore, for the law to become a real tool in fighting stigma and discrimination, the potential tester, or PLHA, has to be aware of the law and the possibilities it provides him/her with. But mere awareness of the law is not enough, because the individual's perception of certain aspects of the law influences the actions the individual will take; Burris (1997) identified these perceptions as a) the perceived right to legal protection, b) the perceived access to a legal remedy, and c) the perceived effectiveness of law. If the individual's perceptions are positive, then the option of law as an instrument in fighting H/A stigma and discrimination becomes a reality.

Crucial for this thesis, however, is also the fact that:

- despite the existence of human rights and HIV/AIDS legislation that enforces certain practices in the testing procedure (confidentiality, consent) and laws that prohibit discriminatory behaviour towards PLHAs in a variety of contexts, and
- despite the fact that people may well be aware of the existence of these laws,

people considering CTR may still site lack of confidentiality and fear of the negative consequences of testing positive as one of the main reasons for not voluntarily taking up CTR.

This problem once again points out one of the major shortcomings of interventions aimed at promoting CTR, viz. the lack of theoretical models to guide our understanding of the psychological processes involved in deciding whether or not to voluntarily report for CTR (Burris 1997). Besides a proper theoretical understanding of stigma itself, a theoretical understanding of these decision-making processes involved in deciding whether or not to test is therefore of equal importance in designing effective IEC campaigns to persuade those at risk for HIV to report for V CTR. Therefore, the following chapter will be dedicated to the theoretical perspectives on stigma in the mind of the stigmatiser as well as in the mind of the stigmatised, and to theory on decision-making processes involved in deciding whether or not to go for an HIV antibody test.

1.4 Research goals

The ultimate goal of the research at hand is to come up with a set of evaluative heuristics that help health communicators to better address the problem of stigma as a behavioural determinant of low uptake behaviour. These heuristics then are meant to be used for the

evaluation of written material in South Africa aimed at persuading PTs to go for V HIV/AIDS CTR. This set of heuristics will be based upon the intervention leads that are identified in the preceding chapters. It is of importance to emphasize that these intervention leads do not consist of tailor-made and detailed descriptions of interventions, but they are meant as leads to what kind of information is required for addressing H/A stigma, i.e. they focus exclusively on content. As such, the set of heuristics will also focus on content and is intended to evaluate if sufficient and proper attention in written material has been devoted to a number of essential topics regarding the issue of H/A stigma in persuading people to report for V CTR. Issues such as format, wording, and structure of the written material are not discussed.

In order to be able to form a solid and reliable set of heuristics, we need to know much more about what stigma is and how it works, about theoretical perspectives on stigma and on decision-making processes involved in going for a test, about the specific South African context, and about the success and failure of interventions that already have been undertaken. After having reviewed all these issues, we will come up with a range of intervention leads or clues that could be useful in fighting HIV/AIDS stigma. Keeping in mind that many attempted interventions aimed at addressing stigma were and are not solidly based in theory (Swanepoel 2003), we will try to fit these intervention leads into theoretical models of decision-making processes and into models of the way stigma works socio-psychologically.
Based on these theory driven intervention leads, we will finally present the earlier mentioned set of evaluative heuristics. Implications for further research, such as the empirical testing of the set of heuristics presented in this study, are also provided.

Structure
The content of this thesis is structured as follows;

Chapter 1 is meant as an introduction into the issue of AIDS in South Africa in general. It explains the history of the AIDS epidemic, and provides numerous examples of how PLHAs are stigmatised and discriminated against in different contexts. It is made salient that PTs do not just fear a positive result, but also greatly fear the consequences of such a positive result: stigma and discrimination. This implies that stigma has a distinct negative impact on all interventions aimed at curbing the spread of the disease: HIV/AIDS stigma triggers fear and denial, which in turn leads people to engage PLHAs in a negative or even overtly hostile manner, and PLHAs in their turn accordingly hide their HIV status and avoid testing for HIV. In general, stigma leads to a hostile atmosphere surrounding the disease in which openly talking about it becomes very difficult. After having established the negative impact of stigma, a brief theoretical concept of the term 'stigma' is provided. We then continue with a short overview of recent attempts in South Africa to address HIV/AIDS stigma. It will be shown, that many of these attempts lack a theoretical base, and that lack of theory could therefore form a motivation for this research; coming up with interventions leads, and finally heuristics, that are indeed theoretically sound.

Chapter 2 is completely dedicated to the formation of a theoretical framework on the concept of stigma and on the decision-making processes involved in deciding whether or not to go for a test. Special emphasis will be placed upon Smith's (1993) analysis of threatened identities, appraisals, emotions and action, on Pryor's et al (1999) two-stage model of how people react to HIV-related stigma, and on Fishbein and Yzer's (2003) integrative model of behavioural prediction.

Chapter 3 entails a brief overview of two rather large programmes that explored the issue of HIV/AIDS stigma and discrimination. First, the UNAIDS (2000) programme held in India and Uganda is reviewed, followed by the Horizons Programme (1999) which was conducted throughout Southeast Asia. Findings and implications of these studies need to be integrated in the set of intervention leads which will be established in chapter 4.

Chapter 4 then provides us with a broad set of interventions leads. These leads are all backed up by theories that were introduced in chapter two.

Chapter 5 finally entails the actual set of heuristics, based upon the findings from the preceding chapter. Also some suggestions for further research will be discussed briefly.

2 HIV/AIDS RELATED STIGMA : A THEORETICAL FRAMEWORK

As established in chapter 1, the design of effective interventions aimed at HIV/AIDS stigma is being impaired by the lack of theoretical development on stigma and the still rather small quantity of action research/basic empirical research. Equally important in order to be able to design effective interventions aimed at addressing H/A stigma in potential testers (PTs), is theory on the decision-making processes that a PT goes through. Consequently, this chapter will be dedicated to the development of a theoretical framework of the construct of stigma, and to a behavioural prediction model. In the end, this broad framework then can provide us with leads for interventions aimed at potential testers (that is, a theoretical framework will be developed with a heuristic goal).

As explained in chapter one, we adopt several ways of looking at H/A stigma. In order to be able to better understand the problems faced by the potential tester, it is not enough to simply focus on these potential testers. As stigma is a broad societal phenomenon, we need to first portray a more holistic view of stigma before returning to the more specific view of the potential tester. So in this chapter, this multidimensional view will be adopted and H/A stigma will be discussed with regard to the stigmatisers, the stigmatised, and finally our focus group, the potential testers.

2.1 Stigma in the mind of the stigmatiser

Merely mentioning the word 'AIDS' can elicit a whole range of feelings in people such as fear, revulsion, anger, contempt, sympathy, shame, and pity. Moreover, these feelings are usually not limited to the disease itself but are also linked to those who contracted the disease and those with whom the AIDS label has come to be most closely associated (Devine et al. 1999). The AIDS label is stigmatising. This pattern of prejudice can take the form of negative attitudes and stereotypes about the disease and its victims, as well as hostile and avoidant behaviours directed towards PLHAs. That means that PLHAs are not only coping with a life-threatening disease, but have also fallen victim to discrimination: they have been driven from their homes, fired from jobs, socially isolated, and even attacked and murdered (Herek & Cogan 1995). Several researchers have indicated that negative reactions could be expected towards any epidemic of a fatal disease (Herek 1990). However, the nature of reactions and stigma associated with HIV/AIDS goes far beyond realistic fear about infection and reflects instead the nature of H/A related stigma as a social phenomenon. HIV/AIDS stigma is socially constructed, and in different regions of the world, the stigmatisation varies according to the groups that are most affected (for example in Africa heterosexuals and injecting drug users (IDUs) are most affected, in the US homosexuals, IDUs, Blacks, and Hispanics). So, AIDS stigma is both a personal phenomenon that reflects a potential threat to physical well-being (i.e. to one's identity as a healthy person), and a social phenomenon, reflecting a threat to core values involving sexual behaviour, morality, and religion.

For a clear understanding of the theory that will follow, it is imperative to first get a better grip on the two phenomena mentioned here: the threat to an individual's well-being, and the threat to social, core values. The first one could be described as 'instrumental stigma', while the second one could be characterised as 'symbolic stigma':

Instrumental stigma
Instrumental stigma actually represents an obvious reason why people are reluctant to associate with PLHAs (Perloff 2001); they are afraid that they will contract the disease, even though they know that AIDS cannot be transmitted through casual contact. Psychologists term this the instrumental basis of a negative attitude toward AIDS. According to this view, people

stigmatise PLHAs because they are afraid that they or their loved ones will contract HIV through casual contact, and there is evidence that this kind of fear can contribute to AIDS stigma (Bishop et al 1991). Thus, one reason why people stigmatise PLHAs is the fear of being infected, and some of this is understandable; a natural reaction to a strange and deadly disease. However, this fear of contagion is not completely rational. It may also reflect a belief in what is called a magical law of contagion (Rozin et al 1992, Perloff 2001). According to this view, people adhere to some sort of primitive belief that when two objects come into contact, they pass properties to each other and will continue to influence each other from that point on (Perloff 2001). This fear also has a more rational component; there are people that think that medical experts might not already have found out all of the transmission routes for the virus, and that they might get infected through ways that will only later be discovered.

The fact that magical contagion is part of how people think of AIDS as a disease and of an PLHA clearly indicates that it is not only based on the biomedical facts but typically a social-cognitive construct of a disease, often termed an illness schema', of which the context can consist of all kinds of 'myths' or cultural 'beliefs'.

Symbolic stigma

Symbolic stigma emphasizes associations between AIDS and social objects (Perloff 2001; Herek 1999; Pryor et al 1999). As Herek (1999) explains: 'it represents the use of the disease as a vehicle for expressing a variety of attitudes, especially attitudes towards the groups perceived to be at risk for AIDS and the behaviours that transmit HIV'. In other words, this symbolic view stresses the connection people make between AIDS and groups they don't like (and which are often already stigmatised). Pryor and Reeder (1993) put it like this:

'HIV/AIDS may have acquired a symbolic meaning in our culture. As a symbol or a metaphor, it represents things like homosexual promiscuity, moral decadence, and the wrath of God for moral transgressions…So when people react negatively to someone with AIDS or HIV, they may be expressing their feelings about the symbol'.

More formally, Pryor and Reeder argue that we learn to represent people and ideas in certain ways in our minds. A person with AIDS (who they call a 'person node') is not a neutral entity but is connected with al sorts of other ideas and emotions that come to mind when we think about AIDS. HIV or AIDS may be associated in an individual's mind with IDUs, homosexuals, hedonism, minorities, promiscuous sex, sex with sex workers, even death. All of these items are charged with emotions or affect. These emotions become powerfully associated with a PLHA (see Fig. 1). If someone thinks of HIV/AIDS as a disease involving homosexuality for example and despises homosexuals, then AIDS, homosexuality and hate will mesh into a unified cognition and will come to mind when PLHAs are discussed (Pryor et al 1999). As mentioned earlier, it is important to bear in mind that this network of associations is strongly determined by one's cultural environment, i.e. the network of associations is culture specific and determined by the specific epidemiology of HIV/AIDS in a community. For example, in Western, industrialized countries the ratio of infected men to women is about 16:1. The dominant means of transmission have been unprotected homosexual intercourse and sharing of unsterilised hypodermic needles. In sub-Saharan Africa, the sex ratio is closer to 1:1 and the dominant means of transmission is unprotected heterosexual intercourse (Pryor & Reeder 1993). These different cultural experiences create different collections of associations to HIV/AIDS.
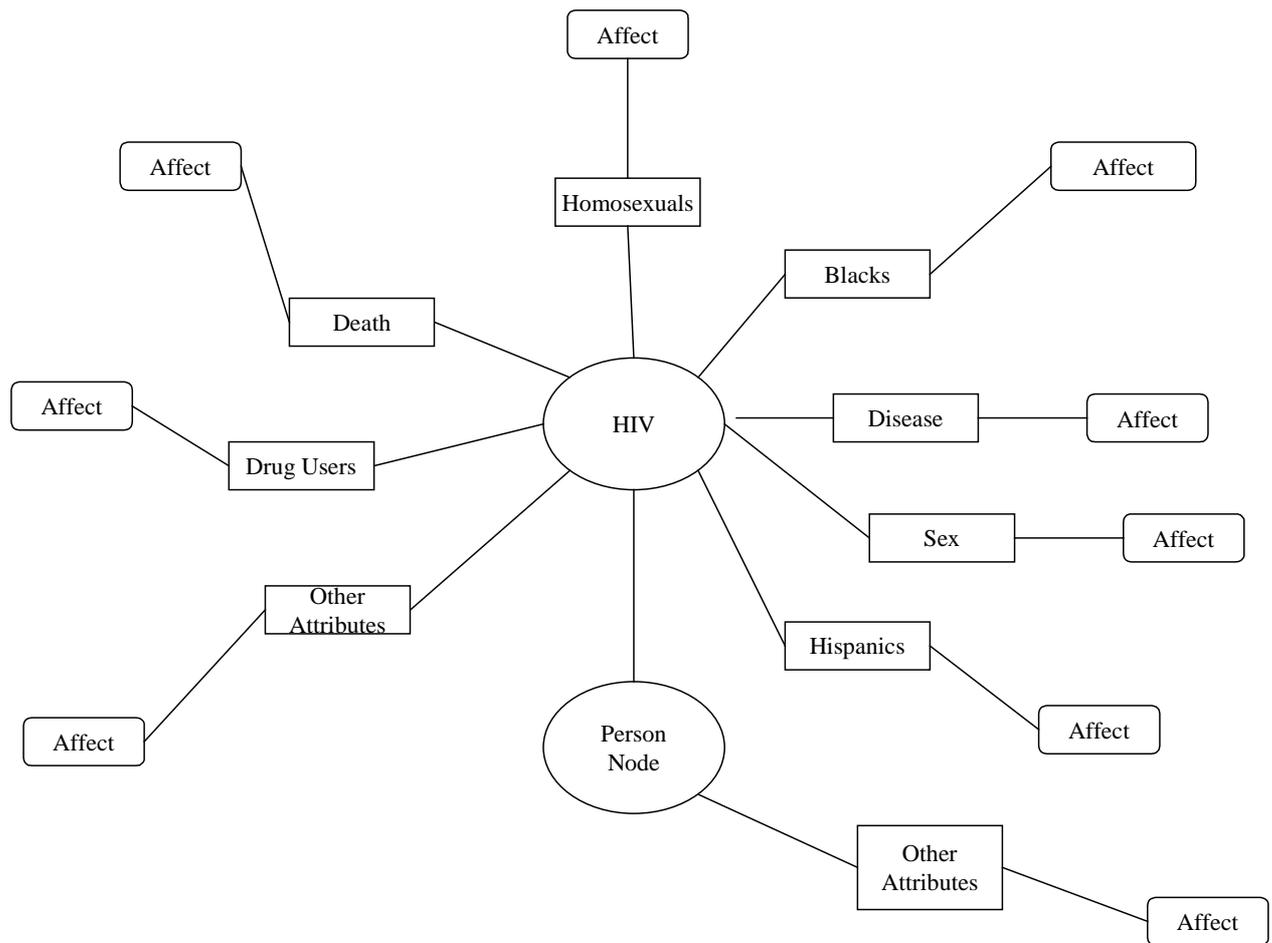
Figure 1. An associative network representation of a person with HIV. (Pryor & Reeder 1993)

Now, after having reviewed these two basic phenomena of stigma, we can begin to try and get to the roots of stigmatisation.

2.1.1 Social identity theory and HIV/AIDS stigma

Essential for the construct of stigma is the social identity conception, a theory that was first outlined by Tajfel (1981). The theory's starting point is that important group memberships form a fundamental part of people's identities or 'self-concepts'. Secondly, it suggests that people are motivated to establish and maintain their self-esteem, and that various group memberships have positive implications. Social identity theory indicates that several psychological processes concerning the promoting of self-esteem result from the act of categorizing oneself and others into groups. For example, group categorization leads to an accentuation of differences between one's own group and other groups.

In addition, group categorization leads to a series of social comparison processes. Tajfel and Turner (1986) argue that positive self-esteem is achieved and maintained through intergroup comparisons along characteristics that favour the in-group. That is, people search for intercategory differences that favour the group to which they belong or with which they identify. This competitive orientation leads to perceptual biases and discriminatory behaviour, which functions as attempts to differentiate between the in-group and the out-group in a manner favouring the in-group. As a result, differences favouring the in-group are exaggerated, while differences favouring the out-group are minimized or ignored. Tajfel and Turner (1986) further argue that these categorization processes produce affective and motivational outcomes. That is, when people feel they belong to a certain social group, they can be expected to experience positive affect on behalf of the in-group and be moved to act toward in-group goals. Similarly, negative emotions can be directed toward the out-group. Such emotions, experienced in

response to group-based outcomes, can be considered social, as apposed to personal emotions (Smith 1993).

HIV/AIDS related stigma seems to be completely intertwined with social identities and the motivation to maintain positive social identities. A great deal of negativity toward PLHA's arises out of uninfected people's need to protect their identity as healthy and nondeviant. Interactions with PLHA's simultaneously define and threaten social identities that involve personally important moral and/or religious values. Thus, stigmatising PLHAs has a major social function of protecting the in-group members by derogating the out group members. As the development of the epidemic makes clear, a variety of factors conspired to facilitate the perception of PLHAs in the early stages of the epidemic as different and deviant. In what follows, a brief overview is given of this development in the context of social identity theory and the motivation to perceive the in-group as different and better than the stigmatised out-group.

The general public versus risk groups

HIV/AIDS was first identified in the United States in 1981 among homosexual men. The idea that the mysterious disease only affected gay men, created a sense of security among the uninfected, because the disease seemed safely contained among a subgroup of the population. Then, when later the disease was also found in IDUs and Haitian immigrants, it became clear that it no longer was exclusive for the gay community, and immediately questions arose about who exactly was at risk and how the disease was transmitted (Devine et al. 1999). While scientists worked to understand the ways of transmission of this deadly virus, fear started to escalate in the general public. In an effort to reduce this fear, the Centre for Disease Control (CDC) used the notion of 'risk groups' to differentiate between those who were initially the common victims of the disease (homosexual men, IDUs, and black and coloured minorities) and everyone else. This use of the term risk groups promoted collective perceptions rather than individualised perceptions of PLHAs, and thus the public was encouraged to think about AIDS in terms of social groups and not individual persons (Herek 1990). The term risk group serves both to stigmatise those who are members of the so-called risk groups, and to insulate people who are not members of those groups from a sense of personal risk for the illness. It is striking how the term risk group has been contrasted throughout the epidemic with the term 'general public' – as if members of the disease's risk groups were not also members of a wider social population (Chao Gunther 1995).

As an illustration, consider what Margreth Heckler, Secretary of the US Department of Health and Human Services under President Ronald Reagan, said in a speech delivered to the International Conference on AIDS in 1985:

"We must conquer AIDS before it affects the heterosexual population and the general population...We have a very strong public interest in stopping AIDS before it spreads outside the risk groups, before it becomes an overwhelming problem".

This kind of distinct classification will obviously clear the path for stigmatisation of particular groups in society.

On top of this, what has been uniquely disastrous about the course that the AIDS virus chose to follow is the fact that it initially affected groups that were already widely stigmatised in society, namely the earlier mentioned homosexual men, ethnic minorities, and IDUs (Herek 1990). Research has indicated how the unique epidemiological progression of AIDS made it especially easy for those who had particular fears and anxieties around the epidemic to shift blame to the members of the populations most affected by the disease. Because many individuals could place responsibility for the disease on already stigmatised members of so-called risk groups – and not themselves or their loved ones – the process of HIV/AIDS related stigma could develop so rapidly. Moreover, the identification of AIDS with specific populations meant that members of groups that were already marginalized within society became doubly stigmatised through

their association with HIV/AIDS. This means that even uninfected homosexual men or IDUs can suffer from H/A stigma.

According to the social identity theory, out-group members can be perceived by in-group members as a threat to in-group social identities (Tajfel 1981). These threats can elicit 'social emotions' from in-group members that can range from contempt to disregard (Herek & Cogan 1995). When it became clear that the disease spread outside the defined risk groups, a need for protection arose among the uninfected. Thus, their concern derived not from worry about the well-being of those infected with the disease (who were generally perceived as dirty and immoral), but rather from fear of the disease's potential to affect the general public (perceived as clean, acceptable and moral). Viewed as such, the disease endangered both the health and the social identities of the (so-called) general public. The out-group now was not only different, but also threatening.

Blame and the risk groups
When finding out that a person is HIV positive, many uninfected individuals are interested in knowing more about the ways that a person acquired the virus, whether out of a desire to know how to avoid the disease, a need to judge others or distance themselves from the infected, or simply out of curiosity (Weiner 1993). Unfortunately, knowledge of this particular attribution often facilitates a very insidious aspect of H/A stigma: blame (Devine et al 1989). As mentioned before, a PLHA is morally suspect, because the stereotype implies that he or she has done something 'bad' that lead to the infection (i.e. homosexual sex, promiscuous heterosexual sex, drug use, etc.), and therefore the PLHA is ultimately to blame for his/her circumstances. This further serves to protect the uninfected person's in-group status as a nonpromiscuous, non-drug using, and moral heterosexual.
Blame helps to make what is incomprehensible somehow explicable and potentially controllable. In premodern times, and even to this day, disease was and is often explained by the wrath of God (or gods). According to Cadwell (1991), in the case of AIDS, attributing blame "is an attempt to make the locus of risk outside oneself in the other". Only when outcomes are controllable can blame be attributed, and with blame then comes responsibility. Indeed, a substantial number of people still see AIDS as deserved punishment for offensive and immoral behaviour (Herek & Capitanio 1998).
Perceived responsibility for being HIV positive is an important factor not only in understanding how uninfected people think about PLHAs, but also in determining how they react to PLHAs. Weiner (1993) studied the concept of sin and sickness, and he argues that AIDS is considered by many to be a sin in addition to a sickness because of the attributions made about the personal responsibility of PLHAs for their illness. Weiner states that with perceived controllability come attributions of responsibility and blame, and that these attributions determine the type of affect directed toward the person or group in question. Note that affect here is proposed to be the necessary antecedent of attitudes and behaviours directed toward stigmatised others.
Weiner (1993) proposes a model to account for attitudes toward others who are being stigmatised by 'failures' (failure should be regarded in our case as contracting the AIDS virus). According to this model, failure due to lack of effort evokes more intolerance than failure due to lack of ability. The model can be represented as a chart beginning with perceptions of controllable causality for another's stigmatised condition or failure (see Fig. 2). When PLHAs are perceived as having control over the means by which they contracted HIV (e.g. homosexual or promiscuous sex, drug use, etc.), they are held responsible for their condition. Perceived responsibility elicits anger from the uninfected and leads to neglect and rejection. On the other hand, when PLHAs are perceived as not having control over the means by which they contracted HIV (e.g. blood transfusion, babies born with HIV), they are not held responsible for their condition. Perceived lack of responsibility elicits sympathy from the uninfected others and leads to positive, helping behaviour.
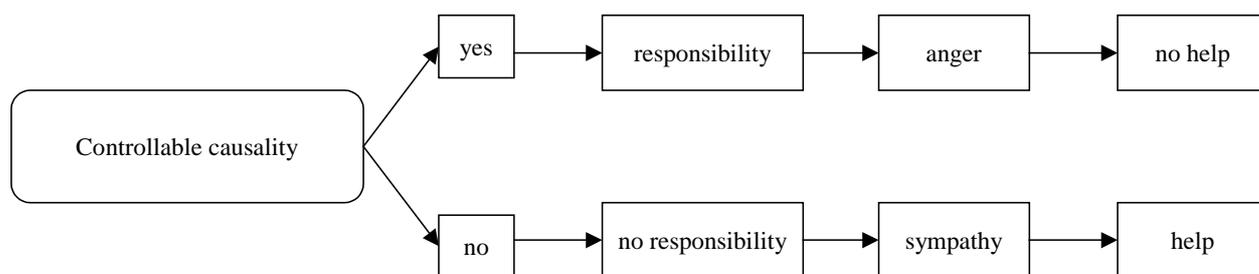
Controllable causality → yes → responsibility → anger → no help

Controllable causality → no → no responsibility → sympathy → help

Fig 2. Model for Reactions to Other's Stigmatised Condition or Failure (Weiner 1993).

Weiner (1993) further proposes that there are cognitive connections to the perceived causes of AIDS that result in different affective reactions. AIDS and its most commonly perceived causes -homosexuality, promiscuous sex, and drug use- are regarded by many as controllable, deviant, morally wrong, and dangerous. When coming into contact with a PLHA, any of these cognitive connections may be activated. Each leads to specific and different affective consequences. For example, the idea that AIDS is contagious elicits fear and anger, while the conception that promiscuous sex, a perceived source of HIV infection, is morally wrong elicits feelings of disgust (Weiner 1993). These different affective reactions are likely to lead to different behavioural tendencies ranging from altruistic help to neglect or even aggression (see also Smith 1993). Smith (1993) elaborated further on affective reactions and behavioural tendencies, and his findings will be discussed in the next section.

HIV/AIDS and symbolic reactions
Smith (1993) argues that the traditional social-psychological conceptions of stereotypes, prejudice, and discrimination as beliefs, attitudes and behaviour may be inadequate to explain the complex nature of reactions to out group members. Before discussing Smith's work any further, it seems sensible to first take a closer look at this traditional conception, in order to be able to distinguish the added value Smith (1993) has brought to this research area.

Basically, the traditional conception of the way that stigma works psycho-socially, is an analysis in terms of three constructs: stereotyping, prejudice and discrimination. Following a traditional division of attitudes (Eagly & Chaiken, 1998), stereotyping is taken as the most cognitive component (beliefs), prejudice as the most affective component (attitudes), and discrimination as the most behavioural component (behaviour) of category-based reactions and stigmatisation. Accordingly, stigma is analysed as a set of behaviours (discrimination) based on certain specific beliefs (stereotypes) and associated attitudes (prejudice/bias) (see Fig. 3). The actual process in the mind would then boil down to discriminating behaviour emanating from the attitudes (prejudice) the individual holds, which are in turn a result from the individuals' beliefs (stereotypes) he has accumulated throughout his lifetime.

Stigma

Values		
Stereotyping (beliefs)	*Prejudice (attitudes)*	*Discrimination (behaviour)*
All homosexuals are sexually promiscuous and have anal sex. They are at great risk of getting AIDS.	*So, someone with AIDS is promiscuous and immoral, and it's his own fault that he contracted the disease*	*That is why I do not wish to have anything to do with PLHAs*

*Figure 3. Stereotyping, prejudice, and discrimination.*

Smith (1993) specifically argues that prejudice-as-attitude models like the one shown above focus too narrowly on the evaluative nature (like vs dislike) of stereotypes and attitudes. This prejudice-as-attitude conception cannot effectively account for the variety of distinct emotional reactions to outgroups, such as hatred, fear, contempt, and disgust, because it does not account for situational specificity in ingroup members' reactions to outgroup members (i.e. the fact that people respond to members of an outgroup differently in different situations.) To address the complexity of stigma, Smith offers an alternative conceptualisation in terms of appraisals, emotions, and action tendencies, based on the perceiver's social identities. He proposes that when people are in intergroup interactions, their social identities become apparent and appraisals are made of outgroup members in the context of these social identities. Smith's model, which is conceptual somewhat similar to Weiner's analysis reviewed earlier, contends that people's cognitions or appraisals regarding stigmatised others lead to the particular emotional reaction that they experience in response to these others. This emotional reaction in turn determines the type of behaviour ultimately exhibited toward the stigmatised other. Whereas Weiner's (1993) model revolves around the emotional reactions of anger vs sympathy, Smith's model allows for greater complexity in emotional reactions, depending on the appraisals made and the specific social identities threatened. Given the fact that AIDS stigma is multifaceted because AIDS and PLHAs can threaten so many different social identities, Smith's analysis may provide a very useful framework. HIV-negative people may make completely different appraisals of PLHAs based on whatever social identity has been made apparent, and their emotional reactions toward PLHAs can include in turn not only anger and sympathy, but fear, disgust, contempt and a variety of other emotional reactions. Table 4 provides a diverse sampling of threatened social identities and appraisals that may be made regarding PLHAs, and the emotions and action tendencies that may be expected to be associated with each.

Table 4. Examples of threatened identities, appraisals, emotions, and action tendencies of the uninfected toward PLHAs (Smith 1993).

Threatened Identity	Appraisal	Emotion	Action Tendencies
Instrumental			
Self as a healthy person	PLHA is contagious	Fear	active avoidance
Symbolic			
Self as a moral heterosexual	PLHA violates moral values (e.g. promiscuous sex)	Disgust	neglect/discrimination
Self as virtuous and conscientious	PLHA is morally weak (e.g. drug user)	Contempt	neglect/discrimination
Self as careful and avoiding danger	PLHA has aquired a controllable disease	Anger	discrimination

Put into a flow chart, table 4 would look like this:

Existing symbolic network
of associations on PLHA

Appraisals → Emotions → Behaviour

Threatened social identity
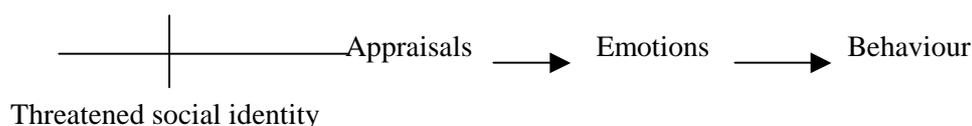
Traditional approaches are not equipped conceptually to address such complexities in reactions to PLHAs. It is not enough to talk about the positivity or negativity of an uninfected

individual's reaction to PLHAs, but we also need to know which value, rule, or norm has been violated (Smith 1993). For example, a PLHA may be viewed as a threat to one's social identity as a conservative and religious heterosexual. The PLHA, particularly if homosexual, will be viewed as morally weak and as breaking codes of behaviour. This appraisal may result in feelings of disgust and anger, which in turn leads to avoidance and rejection of the PLHA. Disgust and anger, however, are only two of the possible emotions that may be experienced as a result of different appraisals regarding PLHAs, and it is important to note that the appraisals are not mutually exclusive. That is, a person can be viewed as violating more than one value (e.g. a homosexual may be viewed as violating religious values, as promiscuous, and as reckless). In such cases, it is expected that the emotional reactions elicited in response to that person are also multifaceted. Recognizing the complex nature of people's emotional reactions may help us to understand the breadth of their negative action tendencies (Smith 1993).

Reviewing the theory above, it can be established that the pattern of attribution, affect, and action serves to protect HIV negative people's social identities as healthy, moral and safe. By making attributions of blame, uninfected individuals can decrease their sense of vulnerability and increase their sense of control. To improve uninfected people's attitudes towards PLHAs, it will be vital to create persuasive appeals to fit their appraisal and emotional reaction (Devine et al. 1999). Trying to decrease fear in reaction to AIDS, as is often done with educational material (Pryor et al. 1999), does nothing to reduce the anger and disgust resulting from feeling that one's moral codes of behaviour have been violated. Oversimplifying what is involved in changing attitudes related to cherished social identities will lead to a failure in reducing stigma toward PLHAs.
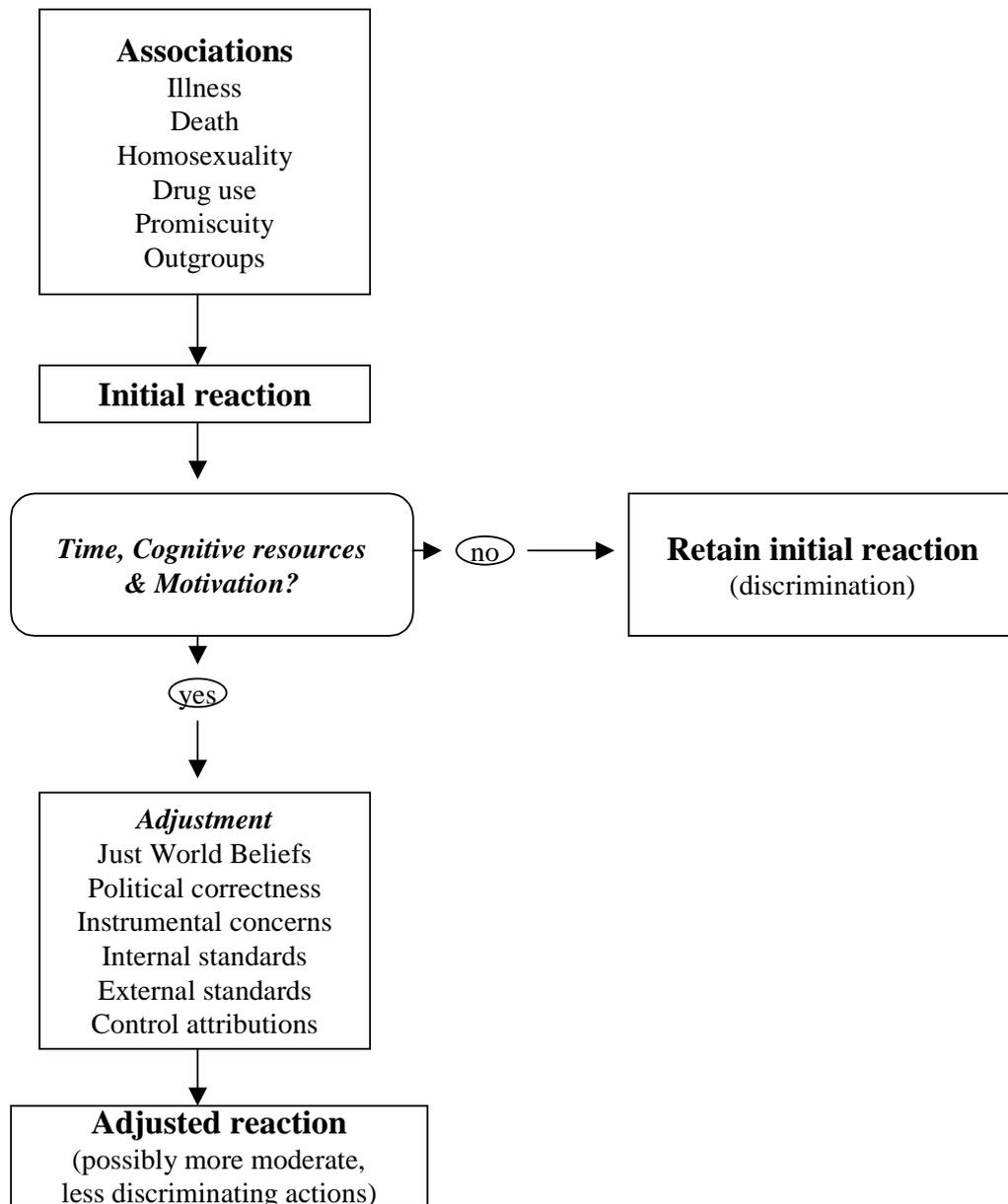
Using social identity theory in order to try and identify possible leads to interventions aimed to reduce H/A stigma, Perloff (2001) points out that stressing the virtues of displaying compassion for PLHAs might be of importance. Devine et al (1999) note that "if campaigns are created in which tolerance for PLHAs is portrayed as part of a positive social identity that is held by the majority, behavioural change could be facilitated in both the short and long term". Persuasion could be used to encourage people to take note of the incongruence between their view of themselves as kind, decent and tolerant people and their prejudice against PLHAs. This discrepancy could motivate attitude change. Viewed in the context of Smith's (1993) model, this means that an individual is now much more aware of the positive values he holds in his different social identities; he now is not only a faithful heterosexual for example, but a faithful *and tolerant* heterosexual. The underlining of this positive value in his social identity will now make for a change in the according appraisal, because this positive value will somehow be reflected in that appraisal. So, if more positive social identities can be stimulated, the appraisals made on the basis of these identities will also reflect more postive images.

2.1.2 Stigma in action
Pryor et al. (1999) take Smith's (1993) theory one step further, and provide us with a complete behavioural model of what happens when people are confronted with a PLHA. In their study, they speak of a two-factor theory of stigma. Just as Herek (1999) did, they try to explain stigma using the instrumental and symbolic components of stigma. This means that people's reactions to PLHAs are related to a thoughtful consideration of the pros and cons of interacting with a PLHA (the instrumental component), and to the network of associations they have concerning the disease and those who suffer from it (the symbolic component). These two components constitute people's beliefs about PLHAs. Then, according to Smith (1993), depending on the perceived threatened identity, people form appraisals, leading to certain emotions which finally lead to a certain behaviour. But now Pryor and his colleagues take this explanation a step further by adding a second stage in the process of processing information and stimuli.
They suggest that, when confronted with PLHAs, people's initial reaction is characterised by a relatively automatic negative affect. Then, given time, cognitive resources, and motivation, this initial negative response can be adjusted. The result is that this adjustment will often result in a more moderate or less negative reaction to the stigmatised person. So then we have two stages

in processing stimuli (hence the name two-factor theory) : an initial, almost automatic (usually negative) reaction and an adjustment of that initial reaction through thoughtful consideration, based on things as the intention not to react in a prejudiced way, political correctness, just world beliefs, etc. Figure 5 schematically shows how these processes might unfold in responses to a person suffering from H/A stigma.

Figure 5. Pryor et al (1999, p.1203) A Two-Stage Model of How People React to HIV-related stigma

Associations
Illness
Death
Homosexuality
Drug use
Promiscuity
Outgroups

↓

Initial reaction

↓

Time, Cognitive resources & Motivation? → no → **Retain initial reaction** (discrimination)

↓ yes

Adjustment
Just World Beliefs
Political correctness
Instrumental concerns
Internal standards
External standards
Control attributions

↓

Adjusted reaction
(possibly more moderate, less discriminating actions)

There are many possible empirical implications inherent in this conceptual model, which has recently been subjected to empirical scrutiny (see Reeder & Pryor, in press). First, if the first phase is relatively automatic, then it should be generally unaffected by processing demands, time considerations, and the like. The second phase where people edit and make adjustments, however, should be highly vulnerable to factors that would stress the information processing capabilities of the person. So, time constraints and other factors that reduce the opportunities for adjustment should have more impact on the second phase than on the first.

Second, the degree to which people adjust their initial reactions to stigma should be subject to the type of stigma involved and individual differences in people's motivations to control stigmatised reactions. Essentially, the adjustment phase entails a thoughtful and reasoned response, and reactions to some kinds of stigma, although automatic and very negative, may seem highly appropriate even after thoughtful consideration. For example, a very conservative and religious person may feel that AIDS is God's just punishment for sinners, and may still feel that way even after thoughtful consideration.

The essence of Pryor's et al. (1999) message is that people manifest immediate affective responses to PLHAs (and other kinds of stigma). Rozin et al. (1992) suggest that the emotional response to many types of stigma may be one reflecting disgust. It is possible that other emotional reactions are automatically evoked in other forms of prejudice. However, immediate reactions are only part of the story. As shown in Figure 5, people are sometimes not satisfied with their initial reactions. These reactions may be edited or adjusted to reflect a person's convictions that prejudicial reactions are wrong. Monteith (1993) found that people sometimes experience considerable guilt when they think they have reacted to someone in a prejudicial way. And this is exactly when the adjustment phase can lead to a more moderate and less negative reaction to stigmatised individuals.

Considering Pryor's et al. (1999) ideas, we could try and identify possible indications for interventions aimed at addressing H/A stigma. We have seen that time considerations and processing demands do not influence the first phase, since it is relatively an automatic phase. And when a process is an automatic one, it is extremely hard to influence. The second phase, however, is not an automatic process, and when individuals should dispose of sufficient time, cognitive resources, etc., an adjustment of their initial reaction is possible. In order for this second phase to have any positive impact, it is essential that people fall back on positive convictions concerning human rights, tolerance, decency, etc. Therefore, changing certain social norms in society by educating the public about human rights, tolerance, and political correctness might enhance people's behaviour toward PLHAs, because this could allow for a more serious and positive adjustment phase and thus reduce stigmatising behaviour.

2.2 The effect of AIDS stigma on the stigmatised

Now that we have considered the motivations that may explain the phenomena of stigma and some of the ways in which stigma works psycho-socially in nonstigmatised individuals, we will focus on the predicaments of the stigmatised individuals. In this section, an attempt is made to clarify the phenomenological experience of the stigmatised individual. Four aspects of this experience are particularly important (Crocker et al 1998):

• experiences with prejudice and discrimination,
• awareness of the devalued quality of one's social identity,
• stereotype threat,
• attributional ambiguity.

The first of these predicaments presents an aspect of the objective reality of PLHAs: they must confront, sometimes on a daily basis, experiences with insults, rejections, or even overt hostility. The other three predicaments represent the states of mind that the experience of stigmatisation may create in PLHAs. Although the predicaments that function as states of mind may be powerful influences on how stigmatised individuals feel, and on what they think and do, it is of importance to bear in mind that these states of mind have their grounding in the realities of stereotypes, prejudice and discrimination.

The essence of each of these predicaments is the threat it poses to the self-worth of the stigmatised individual. The aspect of self-worth that is threatened may be one's personal self-esteem, based on regard for one's individual characteristics, skills, abilities, or value as an

individual; or it may be one's social or collective self-esteem, based on the attributes of one's social group and the value placed on that group (Luhtanen & Crocker 1992).

Experiences with prejudice and discrimination
One of the essential features of the experience of being stigmatised is the ever-present possibility that one could be the target of prejudice and discrimination (Jones et al 1984). This is the reality that defines the experience of H/A stigma. The extent to which these experiences have their impact on the lives of the stigmatised may easily be underestimated by the nonstigmatised. The experience of others with prejudice and discrimination may also profoundly influence one's sense of vulnerability to these phenomena. Personal experiences with prejudice and discrimination might be relatively rare or quite common, but nonetheless, the stigmatised are never entirely free of the possibility of encountering prejudice in others (Crocker et al 1998).
Prejudice and discrimination threaten PLHAs on multiple levels. On a practical level, they create barriers to obtaining resources such as employment, housing and so on, and failure to obtain these resources may threaten or compromise the physical well-being and comfort of the stigmatised. On a more psychological level, prejudice and discrimination communicate lack of regard for one's social identity (see also Smith 1993), and by implication, for one's worth as a person (Tyler & Lind 1992). Consequently, being the target of prejudice and discrimination may threaten both personal and collective self-esteem.
One major consequence of the ever-present possibility of encountering prejudice is that many PLHAs feel the need to be constantly alert, or "on guard", in many settings (Crocker et al 1998). That is, in interactions with nonstigmatised persons, the stigmatised may feel the need to be alert, or mindful of the possibility that the other person is prejudiced (Frable et al 1990). Furthermore, in view of the discrepancy between expressed attitudes and behaviour frequently observed in the nonstigmatised, stigmatised persons may be mistrustful of claims by the nonstigmatised that they are unprejudiced and well-intentioned (Major & Crocker 1993).

Awareness of the devalued quality of one's social identity
In general, stigmatised persons seem to be aware of the negative connotations of their social identity in the eyes of others. For example, D'Emilio (1983) found that homosexuals are aware of the negative consequences of their label, as are the blind (Scott 1969), the obese (Harris et al 1990) and the mentally ill (Link 1987). PLHAs will also feel this awareness of the negative aspects of their social identity in the eyes of others (see Smith 1993).
Crocker et al (1998) argue that awareness that one's social identity is devalued in the eyes of others poses a threat to both personal and collective self-esteem. Knowing that others evaluate one's social identity as negative raises the possibility that they are right – that one's social group or collective identity is, in fact, less worthwhile, deserving or valuable than other social groups. Furthermore, if one's social identity is devalued by others, one's personal sense of self-worth may also be threatened. If one's social identity is an important aspect of the self, and that identity is questioned by others, then one's personal sense of self-worth may, by implication, be questioned (Crocker & Major 1989).

Some theories of the self-concept and self-esteem suggest that the threat to self-concept posed by possessing a social identity that is devalued by others will inevitably and directly lead to having low personal or collective self-esteem. For example, the perspective of the 'looking-glass self' and the notion of 'reflected appraisals' advocated by sociologists such as Cooley (1956) argue that the self-concept develops through interactions with others and is a reflection of those others' appraisals of oneself. Cooley (1956) argued that the self-concept consists of the 'imagination of our appearance to the other person, the imagination of his judgement of that appearance, and some sort of self-feeling, such as pride or mortification'.
However, more recent evidence suggests that although having a negative social identity may threaten both collective and personal self-esteem, it does not inevitably lead to low personal or collective self-esteem (Crocker & Major 1989; Tajfel 1982). In contrast to the view that people more or less passively incorporate the views that others hold of them into the self-concept,

considerable research over the past two decades has documented that people use a wide variety of strategies to maintain, protect and enhance their self-esteem, both personal (Blaine & Crocker 1993) and collective (Crocker, Blaine and Luhtanen 1993).

Stereotype threat
In addition to knowing that their social identity is generally devalued by others, PLHAs are likely to be aware of the specific stereotypes that others hold of their social groups. Because these stereotypes are sometimes spread throughout a culture, it may be inevitable that members of these social groups know the content of those stereotypes (Devine 1989). That is not to say that stigmatised individuals inevitably accept the validity of these stereotypes. Rather, stigmatised persons are aware of the accusations against them that are contained in those stereotypes. PLHAs, therefore, are likely to be well aware that stereotypes accuse them of being promiscuis, unmoral, homosexual, etc.
Awareness of the negative stereotypes associated with the PLHA's social identity creates a predicament for this PLHA, a predicament that Steele and Aronson (1995) call "stereotype threat". Stereotype threat occurs when important negative stereotypes about a group are known to the targets of those stereotypes and provide a framework for interpreting the target's behaviour. This awareness that one may be judged and treated stereotypically, and might even confirm the stereotype in one's behaviour, creates a state of stereotype threat (Steele & Aronson 1995).

Attributional Ambiguity
Although in many cases PLHAs may realise that the treatment they receive from others reflects prejudice and discrimination, sometimes they may feel considerable uncertainty; they may often be in doubt whether a reaction they reveive is based on their personal merit or lack of it, or that this reaction is based on prejudice concerning their stigmatised condition. The causes of events in one's life may be ambiguous for anyone (Snyder & Wicklund 1981), but Crocker and Major (1989) have argued that the causes of reactions from others are likely to be particularly ambiguous for stigmatised individuals, because of the role their devalued social identity may play in those reactions. Both positive and negative reactions may be attributionally ambiguous for the stigmatised person. Negative reactions from others could be due to one's lack of merit, inferior qualifications, poor performance, or other shortcomings such as physical appearance. But alternatively, they could just as well be due to prejudice and discrimination based on one's devalued social identity.
Less obviously, positive reactions may also be attributionally ambiguous for the stigmatised. Positive reactions recveived from others can reflect one's merit. As Kelley (1972) states, "the personal significance of positive reactions might even be augmented for the stigmatised because they occur despite one's devalued social identity". And alternatively, such reactions could be discounted if the stigmatised believe that these reactions were obtained because of their membership in a stigmatised group. Why would the stigmatised have this suspicion? Studies have found that responses towards the stigmatised are sometimes more positive than responses towards nonstigmatised. These exaggerated responses may result from genuine feelings of admiration and respect (Carver, Glass & Katz 1977), from ambivalence which amplifies both positive and negative responses (Katz 1981), from the wish to avoid the appearance of being prejudiced (Carver, Glass & Katz 1977), or from the desire to demonstrate one's nonprejudiced and egalitarian values (Gaertner & Dovidio 1986).

So, both positive and negative reactions can be atributionally ambiguous for stigmatised persons. Now, this attributional ambiguity creates a predicament for the stigmatised because it poses a threat to self-esteem (Crocker & Major 1989). When positive reactions could be due to one's stigmatised identity rather than to one's personal merits, it is more difficult for stigmatised individuals to "own" or to take credit for those reactions (Crocker et al 1991). Such negative effects of positive reactions may occur when the stigmatised receive unwanted, and often unneeded, help from a nonstigmatised person. Such 'assumptive' help, even though well intentioned, implies that the stigmatised individual is inferior. Research demonstrates that

unsolicited help from the nonstigmatised to the stigmatised can have negative consequences for the recipients' self-esteem (Schneider et al 1996), as well as spoil their identity in the eyes of an observer (Gilbert & Silvera 1996).

Attributional ambiguity may have a variety of additional negative consequences for PLHAs. For example, when the reactions or evaluations one receives from others are attributionally ambiguous, it may be difficult to assess one's abilities and potential (Major & Crocker 1993). Should an HIV infected, black female student who is told by an uninfected, white male teacher that she doesn't belong in graduate school accept that evaluation as being true and accordingly drop out, or should she write it off as an act of discrimination? This added difficulty in assessing one's skills and abilities may make it difficult to determine appropriate goals and career choices. Ambiguity about the causes of important events might use up "cognitive resources", as the stigmatised person engages in an analysis of why the particular reaction was received (Weary et al 1993). It might also undermine motivation if it weakens the perceived link between personal efforts and outcomes (Major & Crocker 1993). Finally, attributional ambiguity may lead to suspicion and mistrust in relationships.
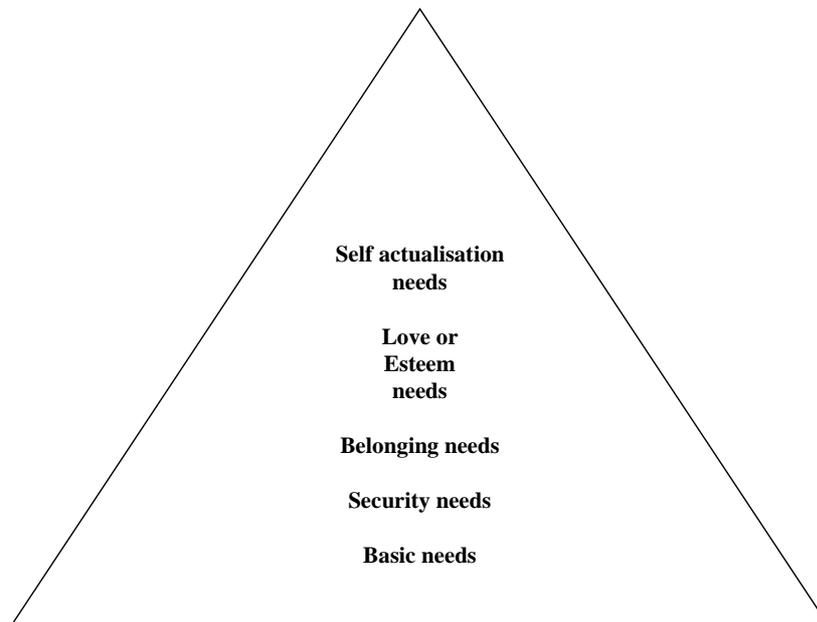
Because both stereotype threat and attributional ambiguity are relatively new concepts in stigma literature, it could be useful to articulate the similarities and differences between these two ideas. Both constructs refer to the ways in which stigma, or membership in a stigmatised group, may provide a framework for interpreting events or outcomes in one's life. Attributional ambiguity refers specifically to reactions that are determined or influenced by another person, who might or might not be prejudiced. The ambiguity concerns whether the reaction was determined by one's personal qualities or by reactions to one's stigmatised status. Stereotype threat, on the other hand, occurs in situations where negative stereotypes about one's group apply. In this case, negative stereotypes relevant to the behaviour raise the possibility that one could be judged or treated stereotypically or that one could confirm the stereotype through one's behaviour. Both attributional ambiguity and stereotype threat can be self-threatening, but in different circumstances. Attributional ambiguity is self-threatening when positive events occur, or when negative events that were caused by prejudice cannot easily be attributed to prejudice. Stereotype threat is self-threatening when the stigmatised person behaves in the domain in which the negative group stereotype applies. Often, however, a single situation may contain elements of both constructs.

One common theme to the predicaments posed by being stigmatised is the threat they pose to personal and collective self-esteem. Being the target of prejudice and discrimination, having a devalued social identity, experiencing stereotype threat, and feeling attributional ambiguity all challenge the self-worth of the individual, and worth of the social group. Thus, each of the identified predicaments places the stigmatised individual at risk of losing self-esteem and self-regard, or esteem and regard from others, or both. Since going for V HIV/AIDS CTR can well place an individual in each and everyone of these predicaments, it becomes understandable that people have difficulties deciding whether to go or not to go for CTR; a decision to go for CTR can have severe negative consequences for one's personal and social identity, while a decision not to go will maintain the individual's current identity and status.

Maslow's pyramid of needs
With regard to the predicaments of the stigmatised, Maslow's pyramid of needs offers a further understanding of the consequences of stigmatisation for the stigmatised individual. Abraham Maslow, a well-known psychologist, created a starting point for examining major need levels. He noted that people have various kinds of needs which can be placed in order of 'strength' (Maslow 1954). In his pyramid of needs (Figure 6) the lower levels represent the stronger needs and the higher levels represent the weaker needs. Remember that the pyramid is only a model and that the lines between needs are not as distinct as the picture suggests. Also note that higher

needs are not superior to lower ones. They are just different and less likely to emerge until stronger needs are met (Maslow 1954).

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                    Self actualisation
                         needs

                       Love or
                       Esteem
                        needs

                   Belonging needs

                   Security needs

                    Basic needs
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Figure 6. Maslow's pyramid of needs

The pyramid shows an upward dynamic of needs; Maslow (1954) states that as more powerful needs are met, less potent needs emerge. As time passes the earlier emerge again as they are or are not met. For example, the need for food or water emerges and then recedes as we eat or drink, and later re-emerges as we feel hungry again. Maslow (1954) argued that these needs have a so called "prepotency", that is, they are tied together so that weaker needs, such as ones for self-respect, emerge only after stronger needs, like ones for food, have been filled.

Basic needs
On the bottom level are the strongest needs we have, the basic needs. These are the physiological needs of each human being. We need regular access to air, food, water, sex, sleep and elimination of wastes. Until these needs are met, we cannot concern ourselves with other, higher needs. The basic needs are too strong to be forgotten in favour of other needs, and people will go to great lengths to fulfil these basic needs.

Security needs
The second level of the pyramid contains our needs for security. There are several ways of looking at these needs. We may want to feel secure in our ability to satisfy our basic needs; we want a secure job and we may want to save money for hard times. This is one kind of security. At the same time, we might look at this need level in another light. We could for example also experience some sort of personal insecurity (and spend money on mouth wash, deodorant and hair transplants), social insecurity (and install a burglar alarm system) or political insecurity (and vote for a particular political party) (Toffler 1980).

Belonging needs
Once our security needs are met, at least in part, we become aware of needs on the third level: belonging, or association, needs. A number of options are open to us in meeting our needs for association. We may choose to fulfil these needs in our immediate family. But usually, individuals seek further than their family to fill this need. They become member of groups such as soccer teams, churches, golf clubs or service groups.

Like basic and security needs, the need to belong often interacts with these other needs and continues to re-emerge throughout our lives. Also, what fulfils our belonging needs differs at various points of our lives. But the need to belong will always be with us (Maslow 1954).

Love or esteem needs
Once we satisfy belonging needs, we will feel the emergence of needs in level four of Maslow's model: the needs for love or esteem. Once we are part of a group, we want to feel that the group, be it family, colleagues or soccer team, values us as a member. We want to feel wanted and valued as human beings. This need is also a re-emerging need. That is, if we find that we are needed and esteemed and loved by our family, our need for esteem does not fade away. Instead, its focus shifts. We now want to feel needed and loved by our boss, our colleagues and our friends. The more we get this kind of esteem, the less compelling the need becomes. However, it is never completely satisfied, and we try to seek other circumstances in which we can achieve status and rank.

Self-actualisation needs
Once all levels of the pyramid have been satisfied, we arrive at the top of the pyramid, which Maslow called the level of self-actualisation. Once we have access to the basic needs, feel secure, feel ourselves belonging to a certain group and feel loved,we can begin to live up to our own potential. This means that we can then maximize our personal development. Note that Maslow later added that self-actualisation can also be seen in terms of peak-experiences; events in which people can enjoy themselves, learn about themselves, or experience something they have only dreamed of before. As Jackson Lears (1983) puts it for example, a person who goes out in the wilderness and learns to be self-reliant and to overcome fear of isolation, has enjoyed a peak, or self-actualising, experience.

Putting this information in relation to the stigmatised individual, and looking at the threat which stigmatisation poses to this individual's needs, it becomes obvious that stigmatisation has an extremely negative influence on all the levels of the pyramid;
once a person is tested HIV-positive, the problem of stigmatisation will soon come into play. The problem which stigma then causes is that it deprives the PLHA of a psychosocial environment to fulfil the needs as articulated by Maslow (1954). The discrimination and rejection resulting from stigma, threatens needs on all levels; a PLHA may be fired or have trouble finding a job threatening his capability to provide for himself, he may be rejected as a sex partner, he may be cut off socially, be refused to enter groups or clubs, may be looked down on or made fun off, may be seen as dangerous and immoral and thus be avoided, etc. If we take a look at Maslow's pyramid, we can establish that all levels are affected by stigmatisation in one way or another, and especially the levels that have to do with human interaction (the third and fourth) are severely threatened.
The bottom line of the problem is that ostracism, resulting from HIV/AIDS related stigma, cuts off the stigmatised individual from his social framework, whilst it is this social framework that is of vital importance for satisfying his needs.

The issue of coping: coming to grips with a positive test result and its consequences
As mentioned earlier, rejection of PLHAs, or those who are thought to have HIV/AIDS, occurs within a wide range of contexts and settings. Experiencing such discrimination, and even experiencing the mere threat of possible discrimination, can be emotionally, socially, and physically devastating.
When looking for possible stigma intervention leads on the side of the stigmatised, or the PLHAs, it is of major importance to bear in memory that making sure that PLHAs keep being active and keep interacting socially is of essential meaning in promoting acceptance, and thus destigmatisation (Schietinger 1998). Helping PLHAs remaining visible and socially active and preventing them from withdrawing from social life and turning to isolation is therefore of great interest. As a way of combating the emotional, social, and physical devastation caused by stigma and discrimination, Danziger (1994) stresses the importance of providing psychosocial

support for the stigmatised. Psychosocial support aims to rebuild and maintain a positive self-image where discrimination and stigma have had their negative impact on confidence and sense of self-worth. It is essential to enable PLHAs to continue functioning in contexts that were once safe but are now hostile (Schietinger 1998).

This psychosocial support can be considered an essential part of offering PLHAs a way of coping with their situation. To briefly clarify the concept of coping in our context, it seems useful to consider Lazarus and Folkman's (1984) notion on coping. Lazarus and Folkman (1984) argue that coping strategies are formed in response to a source of stress (in our case how to cope with possible discrimination due to HIV/AIDS stigma). When facing a source of stress, people first make a primary appraisal, which entails the process of perceiving a threat to oneself. Then, a secondary appraisal is made, which consists of the process of bringing to mind a potential response to the threat. And coping then is the process of executing that response. Although these processes are described as linear, Lazarus and Folkman (1984) emphasize that they do not occur in an unbroken, linear way. Fact is that an outcome of one process may reinvoke a preceding process. For instance, realising that an adequate coping response is available, may cause a person to reappraise a threat as less threatening. Or, as another example, if a coping response turns out to be not very effective, a person could reappraise the level of threat or reappraise what coping strategy is appropriate.
What seems of particular importance, to this study, is the indication resulting from Lazarus and Folkman's (1984) theory, that a decent coping tool may cause a person to reappraise a threat as less threatening. This directly implies that, when armed with a coping strategy, PLHAs would experience less fear in social settings where they may be discriminated against, and that their sense of self-worth would be improved.

There is widespread agreement among experts and institutions around the world, that psychosocial support is an essential aspect of HIV/AIDS counseling, in particular with respect to assisting individuals in coping with a positive test result and the consequences (WHO 1995). According to the World Health Organisation's Global Programme on AIDS (WHO/GPA), psychosocial support is one of the two main components of HIV/AIDS counseling sessions. The other is an assessment of risk and planning for risk reduction (WHO 1995).

The type and intensity of psychosocial support that is needed, varies with the circumstances faced by each individual. But such support could entail physical, emotional, and spiritual elements. Mechanism to provide this type of support include support groups, volunteers who visit in the home and hospital, hospital outpatient clinics, pastoral counseling, peer groups, home care programmes, etc.

Another, additional, interesting lead on providing PLHAs with coping tools, is provided by Sullivan (1999). Sullivan views the issue from the opposite direction than usual and that is why it fits well into this section: it aims to target the attitudes of PLHAs, rather than those of the uninfected. The idea is that PLHAs deflect prejudicial comments made by others through consideration of their origins. This view is of interest because it empowers PLHAs by reminding them that they can control how they respond to people's prejudices. By turning the problem around, PLHAs are offered a strategy for coping with other people's hate.

2.3 The potential tester: deciding to test or not

After having reviewed the theory on stigma from the viewpoint of the stigmatisers as well as that of the stigmatised, we have come to our central issue of the potential tester and his decision to go for a test or not. With the above mentioned theory in mind, it is of importance to bear in memory that the potential tester is actually a person like anyone else, who may just as well foster negative attitudes and behaviours towards PLHAs, and thus could be called a stigmatiser, or who could already be stigmatised for another reason than having HIV/AIDS (such as being

homosexual, belonging to an ethnic minority, being obese, etc.), or in some cases, the potential tester could even be both a stigmatiser and a stigmatised person at the same time; as Burris (1997) explained, people who are being stigmatised themselves, can still foster a whole variety of prejudices and negative appraisals of other social groups and even of their own group (Burris gives an example of HIV/AIDS patients who felt their dentist was in his right to refuse them as his patients). The fact is that potential testers' attitudes, appraisals, and behaviours will vary enormously, just as they would within a whole population. But although the potential tester may not be a specific person with specific ideas, the predicament he faces does show certain specific aspects. All potential testers will have to weigh the positive and the negative consequences of a positive result, and they will have to seriously consider if and how they are going to cope with this result and the consequences. So, the potential tester will have to make an essential decision that could alter his entire life, and in order for interventions aimed at the potential tester to be effective, our understanding of the psychological processes involved in deciding whether or not to voluntarily report for CTR needs to be improved. In order to get a better grip on these processes, we need theoretical guidance of the decision-making processes and the variables involved.

The Integrative Model of Behavioral Prediction
A model that fits extremely well into the subject of deciding to go for a test or not, is the Integrative Model of Behavioral Prediction (Fishbein & Yzer 2003). This model may be considered an integrative model, since it integrates three separate well-known and widely accepted theories on decision-making processes and health behaviour, namely the Health Belief Model (Rosenstock 1974), Social Cognitive Theory (Bandura 1977), and the Theory of Reasoned Action (Fishbein & Azjen 1975). As a build-up to the unifying, integrative model, each of the three separate theories will be briefly discussed.

Health Belief Model
The health belief model is in fact a cost-benefit model. This entails that a person will weigh the costs and the benefits of a certain recommended behaviour, and when the benefits outweigh the costs the recommended behaviour is likely to be performed. As a condition for this process of weighing costs and benefits to take place, the health belief model emphasizes that first the person must feel he is at risk for a serious negative health consequence. When this is not the case, the process of weighing costs and benefits will not be activated.
Translating the health belief model to our situation, we could come to the following; a PT who feels he is at serious risk of being infected with HIV, will weigh the costs and benefits of going for a test. When he feels the benefits would outweigh the costs of such a test, that would simply imply that this person will go for a test. Unfortunately, the process of deciding to test is much more complicated, and the health belief model is not well enough equipped to overcome all the implications. If we look a bit further into the matter of the person that is weighing the costs and benefits of going for a test, we can establish that testing negative could clearly be considered a benefit, and this would have little further implications. Testing positive, however, does have severe implications. The PT will now be faced with the question: 'What are the results of a positive test result?'. Among the numerous answers to this question, our topic of interest can surely be found: potential exposure to HIV/AIDS stigma. When faced with the numerous implications of a positive test result, simply weighing costs and benefits is not enough. According to further research in this area (see Bandura 1977, Fishbein & Azjen 1975) the evaluation of this weighing costs and benefits, will now in its turn be weighed against the perceived pressure from others to go for a test (social norms), and against the notion of being able or not to cope with the negative consequences of a positive test result (self-efficacy), in particular with the potential exposure to stigma. The Health Belief Model does not provide for these important issues, which is not to say that it would therefore become obsolete. In its basics, it is an excellent model, it simply needs specific additions to answer to the complicated issue of HIV/AIDS testing.

Social Cognitive Theory.
Again, this theory can be considered a costs-benefits model in its basics. According to the theory, a person must be convinced that the benefits of the recommended health behaviour outweigh the costs. An important addition in this theory, is the concept of self-efficacy, as mentioned above. For the person to be able to perform the recommended behaviour, he will need to have "a certain sense of personal agency" or self-efficacy with respect to performing the behaviour (Fishbein & Yzer 2003). This means that the person must feel that he is physically and mentally able to perform the recommended behaviour, even when he encounters certain environmental barriers. As explained above, this perception of self-efficacy is of importance when in the process of deciding to go for a test, because a person that does not feel empowered or able to perform a certain behaviour, will not likely be persuaded to perform that behaviour. In our case of HIV/AIDS related stigma, self-efficacy should be regarded as "being able to cope with the possible stigmatisation as a consequence of testing", and not just simply as "being able to go for testing", as this last conception implies a wide range of possible problematical determinants, while we are trying to focus on stigma.

Theory of Reasoned Action
The Theory of Reasoned Action is not simply a costs-benefits model. It argues that the performance of a recommended behaviour is directly linked to the person's intention to perform that behaviour. The intention to go for a test is thus a critical factor in actually going for a test. According to the Theory of Reasoned Action, intention is formed by two factors: the person's attitude towards performing the recommended behaviour, and/or the person's perception of what others think of the recommended behaviour (the subjective norms) (Fishbein & Yzer 2003).
In their turn, the two factors attitude and subjective norm are formed through given beliefs. As Fishbein and Yzer (2003) put it: "Attitudes are a function of behavioural beliefs (i.e. beliefs that performing the behaviour will lead to certain outcomes) and their evaluative aspects (i.e. the evaluation of those outcomes); subjective norms are viewed as a function of normative beliefs (i.e. beliefs that a specific individual or group has regarding whether one should or should not perform the behaviour in question) and motivation to comply (i.e. the degree to which, in general, one wants to do what the referent thinks one should do)".

Put together, the three mentioned theories have put forward three important proximal determinants of testing behaviour; in order for a person to go for a test, he needs to believe that the benefits of testing outweigh the costs of testing. This believe will then be the basis of his attitude toward testing. What's more, is that for the person to be convinced to go for a test, he has to believe that his significant others support the performance of the recommended behaviour, or may already be performing that behaviour. And finally, what's also critical in the process of deciding to go for a test, is the person's perception that he is physically and mentally able to perform the recommended behaviour, even when faced with certain barriers. All of these determinants have been incorporated in the already mentioned Integrative Model of Behavioral Prediction (Figure 7).

One last note on the determinants of health behaviour as provided in the three theories; Fishbein and Yzer (2003) point out that there is sufficient evidence that attitude, subjective norms, and self-efficacy can be considered as proximal determinants of intention and behaviour. However, the same cannot be said of risk perception. The role of risk perception is, at best, inconsistent (Fishbein & Yzer 2003), and available research suggests that perceived risk is more likely to be a "distal" rather than a "proximal" predictor of intention and behaviour (see also Fig. 7).
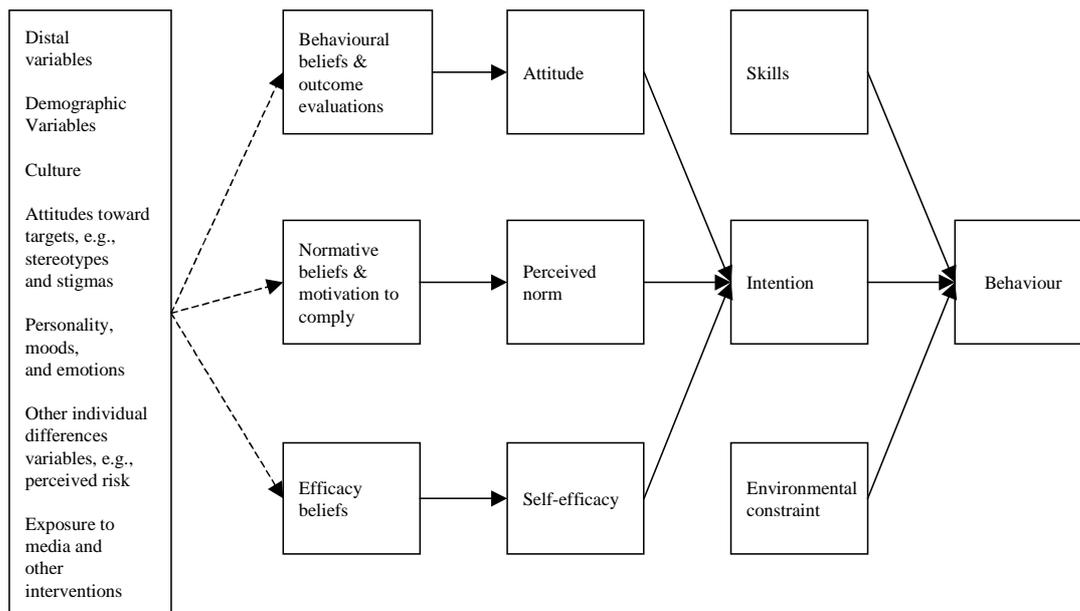
Distal variables

Demographic Variables

Culture

Attitudes toward targets, e.g., stereotypes and stigmas

Personality, moods, and emotions

Other individual differences variables, e.g., perceived risk

Exposure to media and other interventions

Behavioural beliefs & outcome evaluations → Attitude

Normative beliefs & motivation to comply → Perceived norm

Efficacy beliefs → Self-efficacy

Skills

Intention

Environmental constraint

Behaviour

Figure 7. Fishbein and Yzer's (2003) Integrative Model of Behavioral Prediction.

Looking over the model, we can establish that the intention to perform a certain behaviour is critical for the actual performance of that behaviour. Also skills and environmental constraints are directly linked to performance of the behaviour. This logically leads us to the conclusion that people have to form strong intentions, need the necessary skills, and be able to overcome environmental barriers in order to perform the recommended behaviour. So what needs to be done, is to establish what intentions, if any, are formed concerning the recommended behaviour, what skills are needed to perform the behaviour, and what environmental constraints are standing in the way of performing the behaviour, and then to create interventions that address these specific issues; creating more positive intentions toward the recommended behaviour, building skills, and removing or helping people to overcome environmental constraints (Fishbein & Yzer 2003).

Now, in order to identify the influence of HIV/AIDS stigma on the determinants in the IMBP, we need to start on the left side of the model, or with the distal variables. But before starting, we need to firmly establish what our recommended behaviour should be. In our study, the recommended behaviour is articulated as such : "to report for V HIV/AIDS CTR". It is of importance to keep in mind that this study is only concerned with the specific role that stigma plays in the process of deciding to test or not, and none of the other distal variables that influence the recommended behaviour will be investigated. We also need to define a target group, which should meet some specific requirements. We are looking for people that may have had previous unsafe sexual encounters, who have not yet been tested positive, and who are able to read brochures and education material. In view of the age of sexual activity, we could set the target age at 10 years of age and older. Furthermore, Fishbein and Yzer (2003) also recommend to set up a time frame for the performance of the propagated behaviour. In view of the serious threat HIV/AIDS poses in South Africa, the time frame should be as brief as possible. We would think that a reasonable time frame in our case could be two months; after the impact of the intervention, a PT needs time to consider all the beneficial and the negative consequences of reporting for CTR for his own specific situation, but we do not want this time to be exceedingly long, since unnecessary delaying the decision could well lead to loss of a sense of urgency.

So, summarizing the above mentioned objectives, we would come to the following:

Recommended behaviour: 'to report for V HIV/AIDS CTR.'
Target group: 'South Africans older than 10 years of age, who have engaged in unsafe sexual encounters, who have not yet been tested positive, and who are able to read brochures and education material.'
Time frame: '2 months.'

Having established our objectives, we can go and try to work our way through the IMBP. When overlooking the distal variables at the left of the model, we can identify stigma as being one of them. So what this implies, is that stigma has a, somewhat indirect, influence on the final recommended behaviour at the extreme right of the model. More precisely, stigma has a direct influence on various beliefs, which in turn influence attitude, perceived norm, and self-efficacy, which then in their turn influence intention. And as we have seen, intention is a critical issue in the actual performance of the behaviour. So, stigma's influence on behaviour thus becomes a reality.

So, now let us go through the model step by step in order to establish the impact HIV/AIDS stigma has on the determinants. Afterwards, this analysis could provide us with possibilities for intervention leads.
According to IMBP, stigma influences beliefs; behavioural beliefs, normative beliefs, and efficacy beliefs.
The behavioural beliefs a person holds in combination with the according outcome evaluations concerning a specific behaviour could be simply described as the beliefs on which an estimate of the costs and benefits of that specific recommended behaviour is based. That is, when an individual is invited to perform a certain behaviour, i.e. going for a test, he will try to 'calculate' the benefits of that behaviour versus the costs. In the case where this person perceives that the behaviour will lead to 'good' outcomes and prevent 'bad' outcomes, his attitude towards performing the behaviour will be a favourable one. Of course, the opposite also applies; if a person feels that the recommended behaviour will have negative consequences for him, his attitude will most likely be not very favourable toward performing the behaviour.
Now, in our case of HIV testing, the PT will weigh the benefits of going for a test against the negative consequences. Then the PT will have to take H/A stigma as a negative result of testing positive into account, and as long as there is no real hope for treatment and support, the costs (rejection and discrimination due to H/A stigma) will most probably outweigh the benefits (slim chance of treatment and support). A likely behavioural belief and according outcome evaluation could then be: "If I go for a test, there is always a chance that the result could come out as positive, and that means that I would be exposed to stigma and discrimination, whilst there are hardly any options for treatment and support. I find it very disturbing to be rejected or discriminated against. I will not report for V CTR because that simply rules out the option of being diagnosed as HIV positive, and thus also the related stigma and discrimination". Clearly, the result of this particular behavioural belief and outcome evaluation, is an attitude that is negative toward the recommended behaviour.
As for stigma's influence on normative beliefs, we have established on several occasions in this research that people often decline an HIV antibody test out of fear of being rejected and discriminated against by their significant others, even including their loved ones. The reason that these significant others react in such a destructive way toward the person who has tested positive, is that they feel that this person brings shame and disgrace on the family and/or community. So, then the perception of the norm would become that the significant others would not accept a positive test result, since that would damage the reputation and honour of the family and/or community. This conception now strongly stimulates the following reasoning: "If going for a test inextricably brings about the risk of being tested positive, and if my significant others would consider this positive result as damaging to their reputation and honour and hence reject me, it would be wiser not to go for a test at all". Now, the relative importance that a PT will attach to the opinion of these others is what has been called the motivation to comply. It is

likely to assume that in a rather collectivistic society such as South Africa, the motivation to comply is high. This high motivation to comply will only strengthen the negative reasoning mentioned above, and the normative belief and according motivation to comply then form a destructive combination: "Going for a test always implies a risk of being tested positive, and a positive result will be severely punished by my significant others. I attach great value to the opinion of my family and/or community, and I would never want to bring shame on them. Not going for a test rules out the option of testing positive, and thus the option of bringing shame on my loved ones, so I will not report for VCTR". This underlines that the normative belief that the recommended behaviour is not supported by the significant others, in combination with a high motivation to comply, will lead to a negatively perceived norm, and accordingly to a negative attitude.

Then we come to the efficacy beliefs. The negative influence of stigma on efficacy beliefs, entails the fear that people experience when they think of the discrimination and rejection they could well encounter after being tested positive. These fears can be so overwhelming, that coping with these problems might seem extremely hard, or even impossible. The belief that one will not be able to cope with the possible stigma and discrimination resulting from a positive test result will then make for a negative perception of one's self-efficacy, and thus for a negative attitude.

Since intention is formed through attitude, perceived norm, and self-efficacy, it then becomes obvious that no intention at all, or a negative intention, will be formed toward going for an HIV test. In addition to this lack of intention, many people in South Africa could use some form of skills building (information on how the test procedure works, informed consent, etc.), and they could also use help in overcoming environmental constraints (transportation to clinics, more hospital capacity, etc.).

After having moved through the IMBP step by step, the pervasiveness of the problem of stigma is again attested to. Since stigma has a negative impact on all three belief categories (behavioral, normative, and efficacy beliefs), and therefore on attitude, perceived norm, and self-efficacy, no intention to go for HIV testing is formed. In addition to this, many people in South Africa lack the skills to decide to go for a test or not (they lack information on test procedures, do not know about informed consent, do not know how to enforce their rights, etc.), and there are a great number of environmental constraints standing in the way of testing (long distances to the clinics and only few means of transport, too little capacity in hospitals, etc.). Therefore, a set of intervention leads needs to be created that includes all of these issues. It is simply not enough to offer people skills building, when they have formed no intentions at all to go for testing. Similarly, it is not helpful to try and create more positive intentions towards testing, while people may be unable to overcome certain environmental constraints. In South Africa, we are faced with a situation where the problem of stigmatisation is extremely severe, while the economic and social situation is far from ideal, and a holistic approach of the problems seems the only way forward. In chapter 4, the IMBP will be applied, and leads for interventions will be generated.

3 EXISTING INTERVENTIONS: WHAT CAN WE LEARN?

Now, before going into the matter of creating intervention leads within the theoretical framework that has been set up in chapter 2, it seems like a sensible idea to first look at the very few programmes aimed at reducing H/A stigma that already exist. As we have portrayed in chapter 1 only a very small number of interventions aimed at addressing stigma are known, and interventions specifically aimed at potential testers are practically not available at all. Given this lack of theory based action research, it might seem all the more important to take a closer look at those few interventions that do exist. Studying their impact and implications could provide us with leads and ideas on how to tackle stigma related issues.

When reviewing the literature on H/A stigma interventions, two large programmes seem of interest to the study here at hand. One is a programme under the auspices of the World Health Organisation which was started in 1994 (UNAIDS 2000), the other entails a broad review of challenging H/A stigma in Southeast Asia by the Horizons programme (Horizons 1999).

A. Research studies from India and Uganda (UNAIDS 2000)

In 1994, in name of the the World Health Organisation's Global Programme on AIDS, some first steps were undertaken to develop a research protocol to explore the issue of H/A stigma and discrimination in some depth (WHO 1994). After consultation with the WHO's regional offices, India and Uganda had both the capacity and the willingness to undertake extended rapid assessments according to the outlines in the general research protocol. Moreover, these countries experienced the seriousness of the epidemic among their population, which warranted the commisioning of such work. Potential investigators from each country were subsequently invited to prepare local research proposals based on the general research protocol and to submit these to WHO/GPA for scientific evaluation and approval. Two studies undertaken by the Tata Institute of Social Sciences in India, and by TASO in Uganda were then funded. With the support of UNAIDS the work started in 1997, and it was completed in late 1998.

In India, in-depth work was conducted in two locations: Greater Mumbai, a fast growing city in the state of Maharashtra, and Bangalore, a metropolis with a cosmopolitan population in the state of Karnataka. In Uganda, the study took place in two contrasting locations: Kampala District, the largest urban area in Uganda, and Mbarara District, a rural area that is relatively homogeneous with respect to population and culture. The general research protocol identified the appropriateness of several different methods in the investigation of relevant issues. These included both primary and secondary approaches to data collection and analysis. The primary approaches included in-depth interviews with PLHAs and those associated with them, focus groups in settings affected by H/A stigmatisation, and observation in workplace, health care and community settings where H/A stigma might manifest itself. Secondary approaches included the analysis of existing sources of information such as television, radio, and newspapers, legal records and case notes relating to relevant court cases, and national and local policies relating to H/A related stigmatisation.

A detailed and exact description of these specific methods of research would not be of practical use in this context, but what is of significant importance are the main observations and the consequental implications that were identified during these studies concerning H/A stigma. Many of these observations are in a general sense already established in the former chapters as they are also mentioned in existing theory on H/A stigma, but in this case the findings come directly from the UNAIDS study at hand, and thus ought to be mentioned here.

As for the observations that were made, a number of themes recur throughout both of the studies:
First, it is important to recognise that H/A stigma can appear in a variety of forms, levels, and contexts (see chapter 1). The problem of H/A stigma is not limited to certain specific contexts,

but PLHAs can encounter stigmatisation in their complete social framework (e,g, at home, in the workplace, in the health care sector, in their community, in prison, etc.).

Second, pre-existing local cultural practices and beliefs are both determinants and legitimators of H/A stigma. These beliefs frequently establish categories of persons or types of behaviour that are likely to be stigmatised (sexually promiscuous individuals, sex workers, drug users, homosexuals, etc.). This often means that PLHAs become stigmatised in a multiple way, as belonging to a certain devalued group, and as having HIV/AIDS (see chapter 2).

Third, stigmatising responses, or the mere fear of such responses, causes PLHAs to deny or conceal their serostatus, and to experience anxiety about telling others (see chapters 1 & 2). It prevents PLHAs from publicly acknowledging their serostatus, and thus contributes to the atmosphere of silence and denial.

Finally, socioeconomic status, financial security and education level can influence the stigmatisation process. It appears that (relative) wealthy families are better able to manage the flow of information relating to HIV/AIDS and it's impact on the family, have better access to the law (see also Burris 1997), and better access to private medical facilities.

In the UNAIDS study, the researchers come up with several implications for interventions, generally based upon the observations mentioned above. The following, rather general, points are made:

- A supportive legal framework is a prerequisite for effective interventions aimed at H/A stigma. Without the backup of such a framework, efforts to address H/A related stigmatisation and discrimination are doomed to fail.
- Even if such laws exist (as is the case in South Africa), it is of importance to challenge popular stereotypes, judgements and myths that feed H/A stigma. Intervention programmes should foster tolerance and social solidarity.
- In both employment and in health care, discriminatory policy needs to be developed to protect the employment and health care rights of PLHAs. Central to this must be principles of confidentiality and respect for human rights.
- Interventions and activities should aim to move from providing only information to providing services and social support aimed at countering the prejudices about HIV/AIDS that seemingly justify stigmatisation.

B. The Horizons Programme (1999)

The Horizons Programme aims to review the successes and failures of a number of interventions throughout Southeast Asia. Most interventions identified through this review are not 'stigma projects' as such, but this angle was often added when it became apparent that project objectives could not be achieved without paying attention to the barriers posed by pervasive stigma. The aim of the programme is to collect and analyse the intervention material that already exists in order to be able to begin to systematically and comprehensively address H/A stigma. This can then serve as an effective base for future initiatives in this important area of research.

The Horizons Programme looks at these interventions in a contextual kind of order; that is, the interventions are reviewed per context, such as the family, the workplace, etc. Again, as with the UNAIDS studies, it would not be practical nor necessary to exactly describe methods of research used, but what interests us most are the useful findings and implications of the review. Following the division of the original programme, findings will be presented in contextual order.

Family and community
Interventions that aim to reduce stigma at the level of the family or most immediate community generally rely on 'outreach activities' that actively demonstrate how casual and close contacts

do not carry the risk of HIV transmission. For example, home care teams in Cambodia visit PLHAs on a weekly basis and train primary caregivers on how to relieve specific symptoms. By performing treatments in the home that involve touch and close contact with the PLHAs, the members of the team reinforce educational messages about what activities do or do not carry risk of transmission.

Another interesting intervention is focused on what is called 'mainstreaming the HIV experience'. This entails a programme which aims to highlight that PLHAs can remain economically productive for years, and involves PLHAs in work on chicken farms, fish farms, etc. At the same time, participatory education techniques are provided within the community. The approach is to refer to the legacy of compassionate family care in society and to point out that in about 98 percent of cases, the symptoms experienced by PLHAs are no different from those of other terminal or chronic illnesses.

Workplace

The main projects reviewed that focused on the workplace adopted a two-step approach. First, they target instances of dicrimination that occur at the level of workplace policy, such as mandatory testing for applicants or employess or HIV related dismissal. Workshops are given in which is demonstrated that PLHAs can remain productive employees for years and that, in fact, respecting human rights ultimately makes 'good business sense' as it saves constant re-training costs and delays caused by hiring replacements. Second, these programmes take advantage of the access to large communities that the workplace offers. Existing work groups are also an audience with whom training, workshops, and education sessions can be conducted. Furthermore, addressing stigma that exists within the same physical environment helps to connect educational messages to daily reality.

Health Care

As mentioned in Chapter 1, Van Dyk (2002a/b) established a number of barriers that deter people from testing and seeking help from health care workers. Some of these barriers had to do with the context of the health care sector; if people feel that they will receive an unwelcome reception from health care workers, or that their confidentiality will not be respected, they might well refrain from seeking care. Sensitivity of health providers towards PLHAs remains a critical issue of effective medical services within the response to HIV/AIDS.

Findings from the Horizons Review attested that, at the very least, health personnel need a thorough understanding of how HIV is transmitted, familiarity with universal precautions, and awareness of the importance of confidentiality. Ideally, health providers should have a grounding in counselling and support skills, an appreciation for the wider socio-cultural issues related to HIV, and the ability to refer PLHAs to a variety of psycho-social, welfare, and care services.

One specific project in the Philippines made education materials availabale for health workers in their own dialect. In addition to seminars and training, this project provided ongoing support and technical assistance to both governmental and private providers of care as they increasingly encounter HIV patients.

Another approach to changing the often negative reaction of medical personnel toward HIV/AIDS is to strenghten the capacity of PLHAs to seek appropriate care. The Thai Red Cross initiated a support and empowerment group for PLHAs, with the focus of challenging traditional views of the health services. PLHAs are encouraged to become involved in their own treatment. Requesting additional information, keeping informed about available options, and taking an active rather than passive role in interactions with medical personnel is emphasized.

Religion

In the Horizon Programme, it is suggested that the impact of HIV/AIDS messages can be greater when they are brought by revered members of the community. When the impact also carries the additional authority of an accepted ethical system, it could even be further augmented. This then calls upon spiritual leaders to engage themselves in the fight against H/A

related stigma and discrimination, because messages provided by such leaders could be more readily accepted. In Thailand, a project was started that involved the cooperation of local monks. They invited PLHAs to assist them with work and other activities, gave welfare assistance, and visited PLHAs in their homes. As it is put in the Horizons Programme Review, "for the HIV/AIDS patients and their families, what is probably even more important than material support is perhaps the moral embrace offered by those they highly respect".
The mobilisation of spirtual leaders to involve them in prevention and advocacy works could therefore form a positive step in the fight against H/A stigma.

After having identified some of the succesfull components of already existing H/A stigma interventions, we come to the point where these components need to be integrated in our planned set of intervention leads (or recommendations) for chapter 4. As mentioned before, the above discussed interventions and findings were not always part of anti stigma programmes, and what is more, they never were exclusively aimed at persuading PTs to go for V CTR. Moreover, as positive, praiseworthy, and sometimes even effective these existing interventions and their findings may be, few of them have been backed up or were based upon relevant theories on stigma. In creating a set of possible intervention leads for chapter 4, we try to back this set up by the theories mentioned in chapter 2.

4 INTERVENTION LEADS

As shown numerous times in previous chapters, potential testers have to make various evaluations when in a situation where they have to decide whether to test or not: they have to assess whether and in what contexts H/A stigma exists in their communities, i.e. who the stigmatisers and who the stigmatised are and how they interact. In other words we can say that the potential testers seek for information in their own environment, or 'frame of reference', which then consists of the manifestations of H/A stigma in one's own community and societal networks, both on the side of the stigmatisers and on the side of the stigmatised. Furthermore, they have to evaluate their own position should they test positive, i.e. they should adopt the view of the stigmatised.

Existing interventions against stigma are mainly aimed at the stigmatisers, some have focused on the stigmatised PLHAs, but next to none have focused on the potential testers. The assumption seems to be that to reduce a potential tester's fear of stigma, interventions should primarily be aimed at the stigmatisers, in order to create an environment that is less hostile to PLHAs, thus making it easier for people to get tested. However, when considering the testing behaviour of people at risk for HIV/AIDS, specific interventions are needed to address the potential tester's fear of stigma. To be able to develop effective interventions one would therefore have to consider the specific predicaments of the potential tester as well. So in addition to the interventions aimed at the stigmatisers and the stigmatised, there is also the need for interventions aimed at the potential tester in order to create a broader and more effective manner of getting these potential testers to overcome their fear of H/A stigma and actually going for a test. See Figure 8 for a visualisation of this notion.

Figure 8
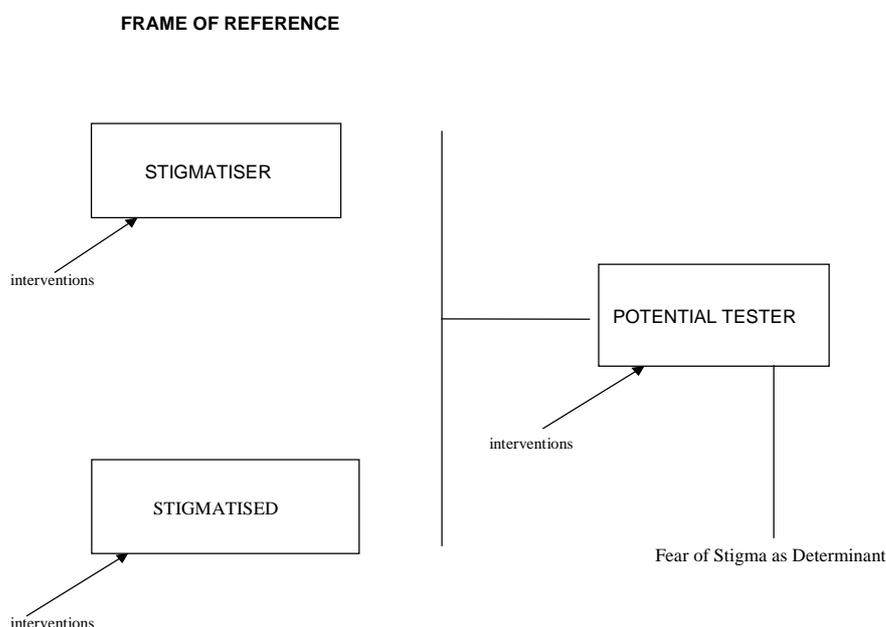
FRAME OF REFERENCE

So what this chapter aims to accomplish, is to first come up with intervention leads aimed at the PTs' frame of reference, which consists of the stigmatisers and the stigmatised, followed by a set of intervention leads aimed at the specific situation of the PTs themselves.

4.1 INTERVENTION LEADS AIMED AT THE PT'S FRAME OF REFERENCE

4.1.1 The stigmatisers

A Turning negative affects associated with HIV/AIDS into more positive ones
A prominent feature of the previous theory on stigma in the stigmatiser's mind was the fact that HIV/AIDS elicits a whole range of feelings in people, such as hatred, fear, anger, etc., and that these feelings are not limited to the disease itself but are also linked to those who contracted it and those with whom the AIDS label has become closely associated (Devine et al 1999). In addition to a natural fear of being infected with HIV, there are also a number of symbolic associations that come to peoples' minds when they are confronted with a PLHA, and these are usually distinctively negative; things like promiscuous sex, injecting drug use, homosexuality, or death are commonly associated with HIV/AIDS and are disapproved of or feared by the majority of people (Pryor and Reeder 1993). Moreover, we have seen that HIV/AIDS has been portrayed by government and health agencies as well as by the media as a disease that affects certain groups in society. The use of the term 'risk groups' promoted collective perceptions rather than individualised perceptions of PLHAs, and thus the public was encouraged to think about AIDS in terms of social groups and not individual persons (Herek 1990).
Adding to the disaster, is the fact that these so-called risk groups were largely already stigmatised groups within society, such as ethnic minorities, IDUs, homosexual men, etc., making it very easy for people to shift blame to the members of these groups (who then became doubly stigmatised). All these factors, among others, contributed to the highly stigmatised condition of HIV/AIDS and those who suffer from it.

Several researchers came forward with specific theoretical notions of how stigma works in the stigmatiser's mind, and the most interesting have been discussed. Smith (1993) contended that the various distinct emotional reactions associated with HIV/AIDS, such as fear, disgust, and hatred, all need to be taken into account in order to do justice to the complexity of H/A stigma. In contrast to Weiner (1993), who reduced the emotional reactions to PLHAs to a narrowly focused evaluative (like vs dislike) model, Smith (1993) offers an alternative conceptualisation in terms of appraisals, emotions, and action tendencies, based on the perceiver's social identities. This conceptualisation maintains that when people are in intergroup relations, their social identities become apparent and appraisals are made of outgroup members in the context of these social identities. Accordingly, these appraisals regarding outgroup members (in our case PLHAs) lead to a particular emotional reaction that they experience. This emotional reaction in turn determines the type of behaviour ultimately exhibited toward PLHAs.
Pryor and Reeder (1999) take Smith's ideas one step further by adding a second stage in the process of what happens when an uninfected individual is confronted with a PLHA. They suggest that people's initial reaction is characterised by a relatively automatic negative affect. Then, given time, cognitive resources, and motivation, this initial response can be adjusted (the second stage in the process) on the basis of people's internal standards, just world beliefs, (religious) values, etc. This adjustment then should facilitate a more moderate and less negative reaction toward PLHAs.

Considering the development of H/A stigma and the theory mentioned above, we can try and extract the basics for intervention leads aimed at changing negative affects associated with HIV/AIDS and PLHAs into more positive ones. As some exploring ideas of Herek (1990) suggested, these basic issues could centre around:

- disassociating AIDS from death, and
- disassociating AIDS from certain groups in society.

Disassociating HIV/AIDS from death – the importance of access to treatment.
As Herek (1999) explained, greater stigma is associated with diseases that are considered untreatable and fatal. Likewise, a lot of the stigma that has attached itself to HIV comes from a fear of something that is perceived to be untreatable and associated with death.
A very interesting clue as to what improved access to treatment could potentially mean for the destigmatisation of HIV/AIDS comes from a judge of the Supreme Court of Appeal in South Africa, Edwin Cameron. Cameron first publicly stated his HIV positive status in 1999, and he explained how this public statement had been made possible by his economic security that shielded him from common acts of unfair discrimination. But later, he repeatedly argued that his experience since his public statement that he was HIV positive has been one where his access to treatment, and antiretroviral medicines in particular, has changed attitudes towards him and normalised his HIV infection in the eyes of other people. In 2001, Cameron stated: "Beneficent social effects have come with the medical breakthrough. The social meaning of the new drugs is that the equation between AIDS and death is no longer inevitable." (Cameron 2001).
In another speech he pointed out how "treatment has irreversibly broken the equation between AIDS and death. By this breakthrough, we can begin to undo the social stigma and phobias that make prevention and care so difficult to talk about frankly, and to practice effectively" (Cameron 2000).

These experiences suggest that access to treatment could be a crucial strategy for destigmatising HIV and advancing toward equality for PLHAs. Unfortunately, access to treatment in South Africa has been problematic for a long period of time. Because of this, better access to antiretroviral therapy became a crucial issue for certain organisations in South Africa, in particular for the TAC (Treatment Action Campaign), which was formed in 1998. Main objective for this movement is try and obtain antiretroviral drug therapies for the "third world". Only a few months ago, in November 2003, the TAC attained one of their greatest victories so far; the South African government passed a treatment plan in which free antiretroviral drugs will be made available for PLHAs in South Africa within the next five years (TAC 2003). This indeed means a major step forward in the direction of normalising HIV/AIDS. Greater numbers of people on treatment, and consequently fewer deaths, will lead to the erosion of perceptions of HIV/AIDS as an incurable illness. This in term will hopefully lead to a less stigmatised condition of HIV/AIDS, and to an increased willingness amongst South Africans to consider going for CTR (see further down in this section for the theoretical embedding of this notion).

Disassociating HIV/AIDS from certain groups in society.
Unfortunately, HIV/AIDS exhibits many aspects that are extremely vulnerable to stigmatisation. In general, Herek (1999) put forward that several conditions tend to invoke greater stigma on a disease; greater stigma is assigned to diseases in which individuals are seen as being in some way responsible for contracting it, to diseases that are particularly virulent and fatal, to diseases that are considered to be contagious, and to diseases that cause visible physical symptoms that could be shocking (patients in later stages of AIDS often manifest certain shocking physical symptoms such as a gaunt appearance resulting from HIV wasting syndrome, and spotting on the skin caused by Kaposi's sarcoma.). As demonstrated throughout this study, HIV/AIDS shares all of the characteristics mentioned above, and is therefore extremely prone to stigma.
Adding to this already negative connotation of HIV/AIDS, is the fact that the AIDS virus initially choose the unfortunate path of mostly affecting those that belonged to already stigmatised groups in society, in particular homosexual men, sex workers, IDUs, blacks, etc. The idea took hold that the virus was well contained within these groups, and that those that did not belong to these groups were not at risk of being infected. HIV/AIDS became closely associated with particular groups in society, and when the disease later appeared not to remain confined to these groups, they were largely blamed for the threat HIV posed to society as a whole.

The concept of 'risk groups' cleared the way for stigmatisation of particular groups in society, and even today, HIV/AIDS is often viewed as a disease hat afflicts groups rather than individuals. Chao Gunther (1995) concluded that because of the fact that responsibility for the disease could be placed on already stigmatised members of the so-called risk groups, the process of H/A stigma could take hold so rapidly and fiercely.

Interventions are urgently needed to break down the strong associations between AIDS and the so-called risk groups, because the negative affects people experience when they are confronted with PLHAs originate largely from these associations, and are preventing them from engaging PLHAs in a positive manner. Changing the negative affects arising from the risk group conception, could focus on the following issues:

- humanising PLHAs,
- value confrontation, and
- promotion of human rights.

Humanising PLHAs
Portraying PLHAs as ordinary people with their hopes, dreams, and problems just like the next person, instead of portraying them as culprits or victims who live a life of misery, could facilitate a more honest and humane view of PLHAs. It becomes increasingly difficult for people to hold on to their stereotypes when the objects of those stereotypes suddenly become human beings just like themselves. This could allow for greater compassion and less judgmental reactions toward PLHAs (later in this section the theoretical embedding of this notion will be provided).

Value confrontation
As demonstrated in Smith's (1993) theory described in chapter 2, it is not enough to simply look at the positivity or negativity of an uninfected individual's reaction toward PLHAs. It is of importance to consider what value or norm the PLHA violates in the eyes of that person. For example, a PLHA might be considered a threat to a person's social identity as a faithful husband. The PLHA could then be viewed as a promiscuous person which makes him morally suspect in the eyes of that person. This appraisal could then result in feelings of disgust, which in turn leads to avoidance or rejection of the PLHA. It is of interest to note that a PLHA can threaten different social identities and based on whatever social identity is threatened, people form different appraisals. Now, in order to influence this process of appraisal formation, we could try and address certain positive values most people hold. People generally feel positive about values such as integrity, kindness, forgiveness, tolerance, decency, etc., and most people think they possess at least some of these positive values. Behavioural change could be attained by encouraging people to take note of the incongruence between that positive view of themselves and their prejudices against PLHAs (Devine et al. 1999). What could be done is to create campaigns that portray compassion, tolerance, kindness, and understanding as part of a positive social identity that is held by the majority. This could lead to a less hostile and more tolerant perception of PLHAs. The example mentioned above, could now be transformed into the following; the person now views himself as a faithful, tolerant, and kind husband. The PLHA now comes across as less threatening to his social identity and could be viewed as a person who has had bad luck or who has made an unfortunate mistake just like anyone else could have done, and who nevertheless still is a valuable person. This appraisal could then result in feelings of compassion, which then leads to supportive behaviour (see further down in this section for the theoretical embedding of this notion).

Promotion of human rights
In order to help people understand the unfairness and unjustness of H/A stigmatisation and discrimination, an approach of human rights could offer some useful options. Freedom from discrimination is a fundamental human right, founded on principles of justice that are considered universal. International human rights instruments prohibit discrimination based on

race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, or other status. It is this last term, 'other status', of which the United Nations Commission on Human Rights (2002/47) has declared that it should be interpreted to cover health status, including HIV/AIDS. Discrimination of PLHAs is therefore a clear violation of their human rights. It is important to note that, since freedom from discrimination is a human right, there already are existing frameworks for 'responsibility and accountability of action' (UNAIDS 2002/43E). Human rights derive from the relationship between the individual and the State (government). States are responsible and accountable not only for violating rights but also for ensuring that individuals can realise their rights. So states have the obligation to respect, protect, and fulfil human rights.

A human rights framework provides possibilities for people who suffer discrimination on the basis of their HIV status to make use of procedural and institutional mechanisms. Since HIV/AIDS related discrimination forms a violation of human rights, persons who discriminate are accountable by law.

But there is more than legal redress. It is of great importance to create a sense of non-tolerance for stigma and discrimination among the public. Public information campaigns should focus on the unfairness of stigma and discrimination. Interventions such as education programmes, implementation of policy, programmes promoting greater involvement with PLHAs, etc., could all contribute to a change in individual and social attitudes.

As mentioned earlier, we will try to back our intervention leads up with relevant theories from chapter 2. This section deals with the side of the stigmatisers, and most relevant theories linked to this subject are Smith's (1993) theory on threatened identities, and Pryor's et al. (1999) two-stage model. By fitting our intervention leads into these theoretical principles, we can better understand their usefulness and effect.

After every section of proposed leads for interventions we will try to fit them into the according theories.

Looking at the intervention leads above, we will start off with the disassociation of AIDS from death.

Concerning Smith's (1993) model of threatened identities, it is obvious that death constitutes a major threat to the identity of the self as a healthy person. If HIV/AIDS were to be disassociated from death, a lot of the fear concerning the disease and PLHAs (i.e. the natural fear of death) would be eliminated. If one does no longer associate AIDS with death, then the social identity of the healthy person is less vulnerable. This could then allow for a more positive appraisal of the PLHA.

Applying the above to the model, we would then come to the following;

Threatened Identity	Appraisal	Emotion	Action Tendencies
Self as a healthy person	PLHA is ill, but can still live a decent and productive life, and does not necessarily have to die soon	Acceptance, understanding	Support

Table 9. Disassociation of AIDS from death in Smith's (1993) model.

As for Pryor's (1999) model, the disassociation of AIDS from death could have a two-way effect (see fig. 10). Clearly, it would have it's effect on the 'associations' section in top of the model; the negative association of death is replaced by the association of AIDS as a serious affliction, but one that does not directly imply that one will lead a useless life and die soon. Also the association of 'illness' can change; drug therapies can alleviate serious and visible symptoms, therefore making it a less shocking experience to engage with a PLHA. Of course,

AIDS will still be considered a very serious disease, but the association becomes less negative because of the less shocking appearance of the PLHA (just like treatment for cancer decreased the stigma surrounding that affliction).

Furthermore, the disassociation of AIDS from death can also have its impact on the 'adjustment' section. If one does not think of death when confronted with a PLHA, this person's instrumental concerns will be reduced. When death is no longer an automatic aspect of HIV/AIDS, the fear of interacting with PLHAs can begin to diminish.

Fig. 10 Visualisation of the proposed intervention leads in Pryor's et al. (1999) model (Proposed intervention leads are displayed in grey shaded sections.)
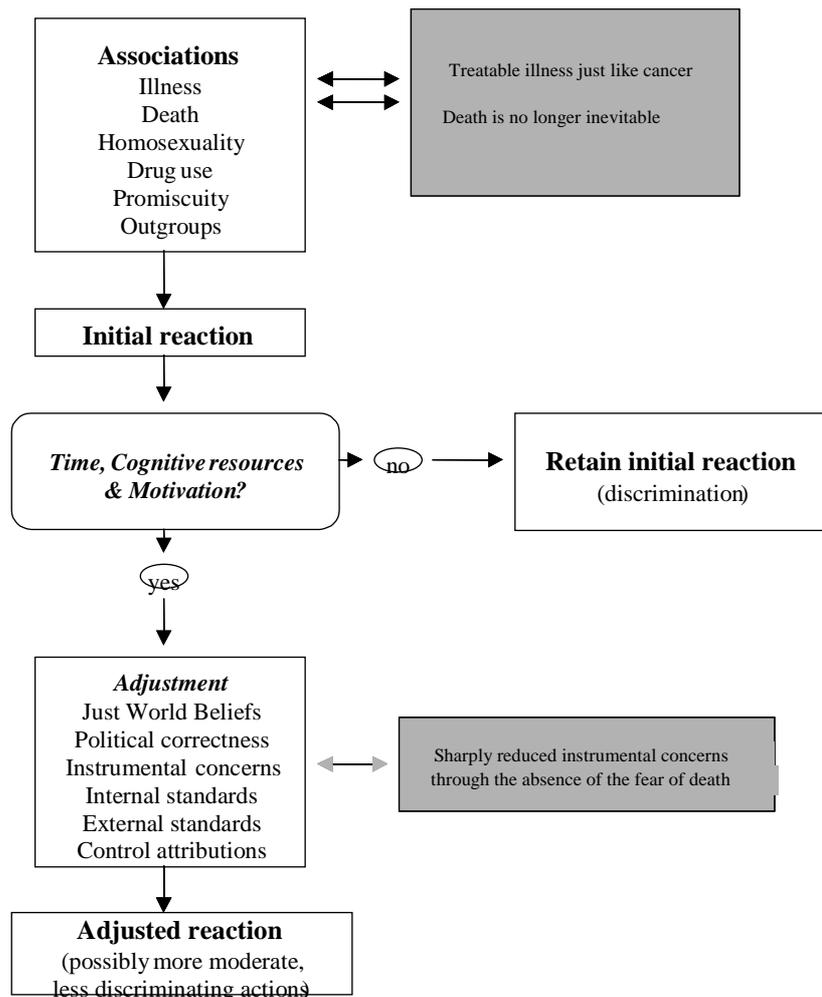
Then, the disassociation of HIV/AIDS and certain groups in society needs to be addressed theoretically. The three proposed ways through which this objective could be attained (namely humanising PLHAs, value confrontation, and human rights promotion), boil down to the following;

- by presenting the PLHAs as real human beings, holding on to stereotypes becomes harder;
- by addressing people's positive social identities, chances of a more positive appraisal formation are improved;
- by presenting these positive social identities as being held by the majority, and by creating a sense of non-tolerance for stigma and discrimination, people could feel some sort of pressure to act in a less negative way.

Looking at our theoretical models, the proposed leads for interventions could now be inserted. Smith's (1993) model as shown in chapter 2, could then be transformed to look like this;

Threatened Identity	Appraisal	Emotion	Action Tendencies
Self as a moral, *decent* heterosexual	PLHA may have violated moral values, but is not to be condemned by me	Forgiveness	Support
Self as virtuous, conscientious and *compassionate*	PLHA may have given in to temptation, but I am not perfect either	Compassion, understanding	Support
Self as careful, *toleran*t, and avoiding danger	PLHA has acquired a disease through natural behaviour that we all exhibit (sex)	Understanding, acceptance	Support

Table 11. Disassociation of AIDS from certain groups in Smith's (1993) model.

As for Pryor's et al (1999) model, a number of issues can be addressed through our proposed intervention leads (see fig. 12). In the 'associations' section on top of the model, we are able to address several associations. In the former section 'illness' and 'death' were addressed through disassociating AIDS from death. Now, we come to the other associations in this section, i.e. 'homosexuality', 'drug use', 'promiscuity', and 'outgroups'. Our proposed leads do not pretend to have the power to eradicate these associations, but they provide a better way of dealing with them; by bringing PLHAs closer to one's own world, by stressing more positive elements of people's social identities, and by creating an environment that does no longer tolerate stigma and discrimination, we aim to foster positive attitudes that can overcome the negative associations attached to HIV/AIDS. So, directly eradicating these negative associations seems next to impossible due to the pervasive stigma, but when PLHAs are no longer distant 'objects', and when constant appeals are made on people's positive social identities, the first steps can be undertaken toward breaking down negative associations in terms of presumed adherence to certain social groups.

In the 'adjustments' section, there are also a number of issues that can be addressed by means of our proposed leads for interventions, in particular the issues of 'political correctness', 'internal standards', and 'external standards' (see also fig. 12).
By raising the issue of human rights, a certain sense of 'what is right' or political correctness could be installed. Stressing of positive virtues in people's social identities could lead to an increased sense of value of these virtues, in the sense that they will then start to dominate over the negative associations that were dictating their actions beforehand. Furthermore, the 'pressure' of an environment that no longer seems to tolerate stigma and discrimination could well have a positive effect on what Pryor et al (1999) have called the 'external standards': if people feel that tolerance for PLHAs is what the majority thinks is right, they will be motivated to comply with that opinion and act accordingly.
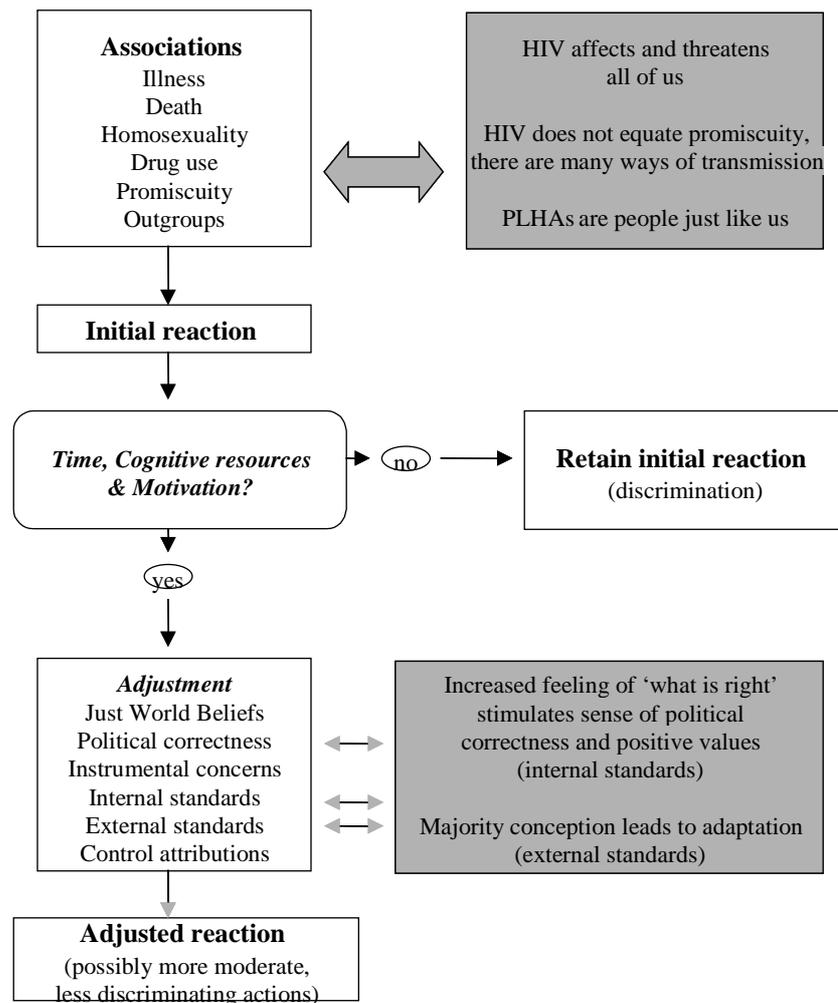
Associations
Illness
Death
Homosexuality
Drug use
Promiscuity
Outgroups

⟷

HIV affects and threatens
all of us

HIV does not equate promiscuity,
there are many ways of transmission

PLHAs are people just like us

↓

Initial reaction

↓

Time, Cognitive resources & Motivation? → no → **Retain initial reaction**
(discrimination)

↓ yes

Adjustment
Just World Beliefs
Political correctness
Instrumental concerns
Internal standards
External standards
Control attributions

⟷ Increased feeling of 'what is right'
stimulates sense of political
correctness and positive values
(internal standards)

⟷ Majority conception leads to adaptation
(external standards)

↓

Adjusted reaction
(possibly more moderate,
less discriminating actions)

Fig. 12. Visualisation of the proposed intervention leads in Pryor's et al. (1999) model

B Reducing instrumental concerns

Since the early 1990's, several organisations, both governmental and non-governmental, have been involved in educating the public about HIV/AIDS. The routes of transmission and the ways how to prevent infection were central issues in these campaigns. Nowadays, the majority of the South Africans seem to be well aware of the fact that HIV/AIDS constitutes a real threat (ALP 2001), but awareness is not the same as accurate knowledge and understanding. Many people still do not seem to understand what HIV does to the human immune system and that there are drugs to fight the virus. Still, many South Africans keep displaying riskful behaviour when it comes to sexual practices, and this risk behaviour needs to be addressed incessantly. Two issues concerning risk behaviours still displayed might be addressed, and will be accordingly discussed;
First, emphasis should be placed on the importance of always using a condom when both or one of the partners have not been tested. It often happens that partners soon think they know each other well enough to have unprotected sex, but they might underestimate their previous sexual encounters. Of course, as we have already seen, H/A stigma makes talking openly about these issues very hard, and that is why it cannot be seen separately from the set of intervention leads as a whole. It is an unfortunate fact that stigma hampers the effort to improve people's sexual practices, and at the same time the continuous unsafe sexual practices increase the number of infections and with it the accompanying stigma. Constantly educating people about the risks of unprotected sex seems therefore necessary, as part of a greater set of interventions.

Second, there are a lot of common myths in South Africa that contradict with healthy sexual behaviour. As Van Dyk (2001) describes, there are many cultural barriers to having protected sex. Beliefs that oppose the practice of safe sex, such as the belief that condoms are not to be used because they prevent the 'gift of self', need to be properly addressed and incorporated in the HIV/AIDS educating efforts. These beliefs cannot just simply be denounced since they constitute essential beliefs within South African societies, but an effort could be made to try and adapt these beliefs to healthier ways of sexual practice (see Van Dyk 2001).

By spreading factual knowledge about transmission routes of the virus, and by addressing myths and specific customs, a better understanding of HIV/AIDS is promoted. This is necessary in order to be able to address the instrumental concerns people have about infection. People that truly understand how infection can occur are less vulnerable to fear and anxiety concerning PLHAs. They will be more likely to engage PLHAs without fear of infection, and will thus attribute to destigmatising HIV/AIDS because of their visible interaction with PLHAs.

When reviewing our theoretical models, we can establish the following;
Smith's (1993) model provides us with a very clear and distinct option for incorporating our lead of reducing instrumental concerns in his theory. By reducing people's fear of getting infected, we clear the path for much less negative action tendencies (see table 13).

Threatened Identity	Appraisal	Emotion	Action Tendencies
Self as a healthy person	PLHA is not contagious when in casual contact	Openness	Neutral or supportive action

Table 13. Reducing instrumental concerns in Smith's (1993) model.

As for Pryor's et al (1999) model, we can identify the following implications; in the 'associations' section, the meaning of the association of illness could well change. When the conception of 'contagious illness' changes to a notion of a disease that has very specific ways of transmission, and can never be transmitted through casual contact, a lot of fear can be taken away. As such, HIV/AIDS can be seen more and more along the lines of a disease like cancer for example.
In the 'adjustment' section, the instrumental concerns are the main issue. Reduced instrumental concerns can allow for a more open and fearless reaction toward PLHAs (see fig.14).
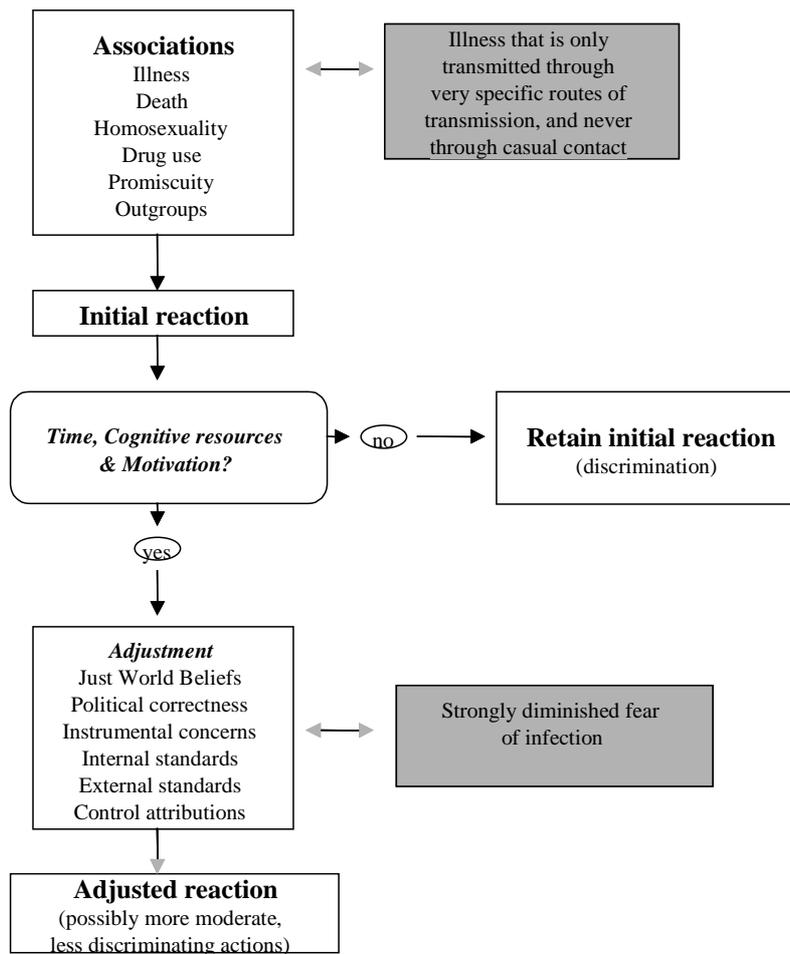
```
  ┌─────────────────────┐           ┌────────────────────────┐
  │   Associations      │◄─ ─ ─ ─ ─►│  Illness that is only  │
  │   Illness           │           │  transmitted through   │
  │   Death             │           │  very specific routes of│
  │   Homosexuality     │           │  transmission, and never│
  │   Drug use          │           │  through casual contact │
  │   Promiscuity       │           └────────────────────────┘
  │   Outgroups         │
  └─────────────────────┘
            │
            ▼
  ┌─────────────────────┐
  │   Initial reaction  │
  └─────────────────────┘
            │
            ▼
  ╭─────────────────────╮                        ┌───────────────────────┐
  │ Time, Cognitive     │── no ──►                │  Retain initial reaction│
  │ resources &         │                         │  (discrimination)     │
  │ Motivation?         │                         └───────────────────────┘
  ╰─────────────────────╯
            │ yes
            ▼
  ┌─────────────────────┐
  │    Adjustment       │
  │ Just World Beliefs  │           ┌────────────────────────┐
  │ Political correctness│◄─ ─ ─ ─ ─►│  Strongly diminished fear│
  │ Instrumental concerns│          │  of infection           │
  │ Internal standards  │           └────────────────────────┘
  │ External standards  │
  │ Control attributions│
  └─────────────────────┘
            │
            ▼
  ┌─────────────────────┐
  │  Adjusted reaction  │
  │ (possibly more moderate,│
  │ less discriminating actions)│
  └─────────────────────┘
```

Fig. 14. Visualisation of the proposed intervention leads in Pryor's et al. (1999) model

C The Law

In support of the spread of knowledge about HIV/AIDS and the creation of a less hostile and more understanding environment, the law could also play an important role in this process. In bringing about a change in mentality, the law could be viewed as a means of pressure; enforcing laws and acts on discrimination could set a deterring example for people. Of course, simply pressuring people in the right direction through sheer force of law will never succeed, but again, the issue of law should be regarded as an integrative part of the broader proposed set of interventions.

South African law provides abundant protection for PLHAs. As already mentioned in chapter 2, the South African Constitution contains many stipulations that are of particular importance to the protection of PLHAs against stigma and discrimination (such as the principles on Human Dignity, Privacy, Freedom and Security of the Person, etc.). These issues are firmly enshrined in the Constitution, which is in fact the highest law in South Africa.
In addition to the Constitution, there are also many acts and policies that also aim to guarantee PLHAs a fair and equal treatment. Important examples are the Employment Equity Act (Act 55 of 1998), which specifically prohibits unfair discrimination on the grounds of HIV infection, while section 7 (2) of this act prohibits mandatory HIV testing of employees, the National Education Policy Act (Act 27 of 1996), which prohibits unfair discrimination against learners, students and educators living with HIV/AIDS, and the Medical Schemes Act (act 131 0f 1998),

which prevents medical aid providers from discriminating on the grounds of state of health. Many more of these acts and policies exist in South Africa, of which most have been installed in the last decade. What is clear is that the South African law provides enough possibilities to act firmly against H/A related stigma and discrimination.

In practice, more and more cases concerning HIV/AIDS related discrimination are being brought to court, and are subsequently won. Recent cases are proof of this, for example the case of Hoffmann vs South African Airways (2001). The Constitutional Court ruled in this case that SAA had infringed Hoffmann's rights not to be unfairly discriminated against as a PLHA and violated his right to equality, dignity, and fair labour practices. The court held that SAA unfairly discriminated against Hoffmann when they refused him a job of cabin attendant when the HIV test they required from him came out as positive.

Cases like this obviously strengthen PLHAs in their notion that HIV/AIDS stigma and discrimination can be fought (which will be discussed in section 4.1.2), but what is of importance for this section on stigmatisers, is that the stigmatisers are more and more confronted with the fact that HIV/AIDS related stigma and discrimination are no longer tolerated and can in fact be punished quite severely. This then could well motivate behaviour change, because stigmatisers now start to realise that their actions are unacceptable and illegal, and that these actions could cause them to be convicted in court. Of course, this motivation to avoid stigmatisation and discrimination could be called an extrinsic one (external standard), and as such it should be regarded as an added value to the intrinsic change in mentality and knowledge.

When embedding the law issue into theory, we first consider Smith's (1993) model of social identities. It might be argued that there is such a thing as the "law abiding identity", which comes down to a person regarding himself as acting within the bounds of law, and as not being a criminal. This social identity then can be maintained by not discriminating against a PLHA (see table 15).

Threatened Identity	Appraisal	Emotion	Action Tendencies
Self as a law abiding person	Discrimination against PLHAs is illegal	Fear of judicial repercussions	No discriminatory actions

Table 15. The law in Smith's (1993) model

Next is Pryor's et al (1999) model. Considering the nature of the law issue (punishment after a discriminatory action) it is likely to fit this issue into the 'adjustment' section; when considering one's initial reaction, one might then start to wonder what legal consequences that initial and discriminatory reaction may have.

Accordingly, the law might influence the external standards and people's just world beliefs (see figure 16).

Fig. 16. Visualisation of the proposed intervention leads in Pryor's et al. (1999) model
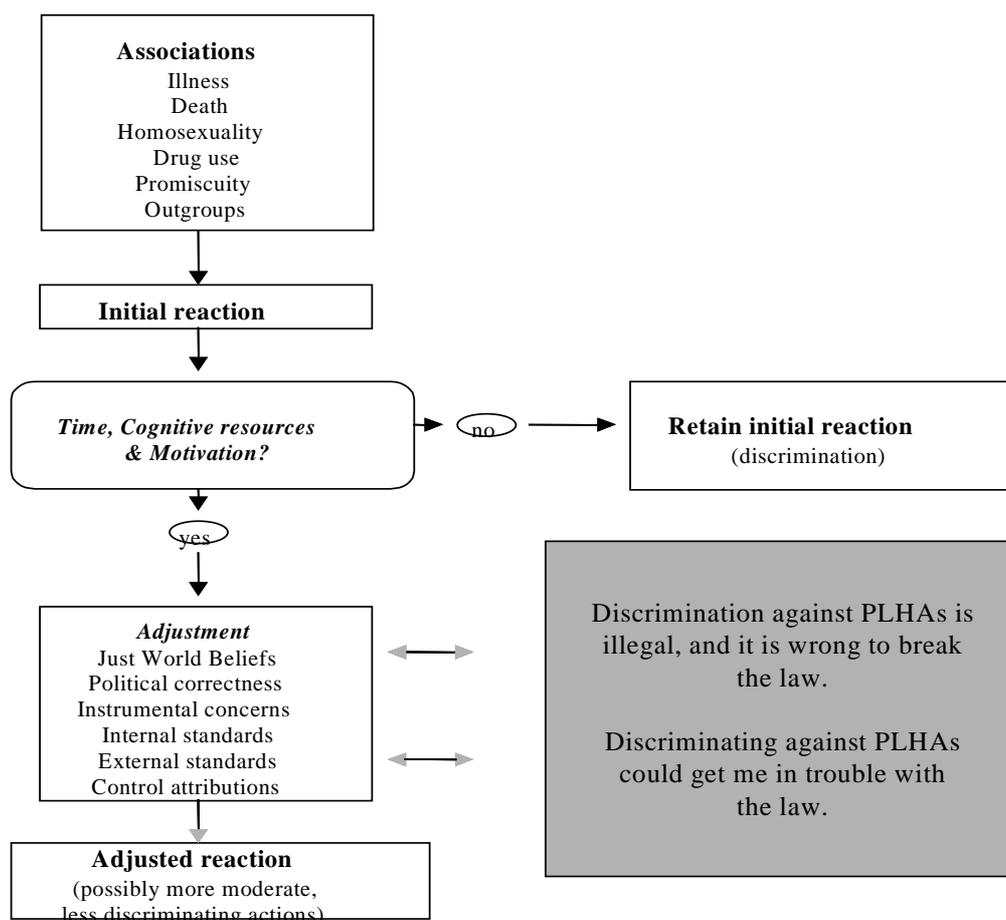
D Media, politics, and religion

When trying to address the causes of H/A stigma, the highest level on which public policy is created cannot go by unnoticed. It is here that policy is made that can influence the entire population's view on HIV/AIDS, because public policy has its effects on all levels in society. In South Africa, public policy has not been one of decisive and firm action against the spread of the disease and its accompanied stigma. Obviously, if the president himself, Thabo Mbeki, publicly announces that HIV does not cause AIDS but poverty does, then doubt and disbelief will be passed down to many levels in society.
However, the South African government recently seems to become more aware of the daunting scenario that awaits if they do not start taking appropriate action. The most recent example of that is the official intention announced by the government, to make a serious effort to provide drug therapies freely to all those infected within the next five years.
Clarity is what is needed from the government. Clear intentions concerning things such as providing drug therapies, passing and enforcing of firm anti-discrimination laws, support of PLHAs speaking out publicly, etc., will lead the way to social change in relation to HIV/AIDS.

Very closely linked to public policy, is the role of the media. We could argue that the media have a two-way direction of influence; they do not merely cover the policy that is made by the government, they also have a considerable influence on what the policy will consist of. It is no secret that when the media give a lot of attention to a certain topic, public policy makers will try to act on that. So the media do not just have the role of 'covering the news', they also contribute to the making of that very same policy.

Obviously, the role of the mass media nowadays is one that has a major impact. Daily newspapers, television, and radio can determine to a large extent what is considered acceptable and what is not. So far, South African media have focused too much on sensationalism and 'news value' when it comes to the HIV/AIDS epidemic (Stein 2002). Wallack and Dorfman (2001) argue that the mass media should take on an active advocacy role, which means that they should focus on promoting collective action and policy change. This advocacy role includes more than educating the public about appropriate individual behaviour; it includes the promotion of social change and collective action more specifically, it includes the promotion of large scale policy implementation which facilitates an environment conducive to behavioural change and to managing the impact of HIV/AIDS in the long run. This new way of covering HIV/AIDS and all it's related problems might well be a firm step in the right direction.

Just as political leaders and the media, religious leaders also take a considerable part in shaping beliefs and attitudes concerning HIV/AIDS in the South African society. Considering that a large part of the South African population regularly visits church meetings or otherwise religiously organised meetings, it then becomes a reality that what is told at such meetings by these religious leaders, could be of great impact on the social construction of HIV/AIDS stigma. Muller (2002) writes that religious leaders, too often, take a moralistic stance concerning the disease, which only has the detrimental effect of deepening the silence and the denial. What is needed from these leaders is a shift from a moralistic point of view towards an understanding and caring point of view. Only such a message will lead people to the conviction that HIV/AIDS is something that can be spoken about openly, without feelings of shame, revulsion, or contempt. It is this path toward an understanding and caring point of view that leaders need to follow in order to contribute to the destigmatisation of HIV/AIDS.

Overlooking the above, we can establish that the government, the media, and the religious leaders constitute entities that are closely linked, and that they have a major influence on the social construction of HIV/AIDS. So far, many of their actions have only led to further stigmatisation of the disease and those who suffer from it, but a change seems to have been put in motion. In general, we can argue that the main tasks these three entities face would consist of the following;

- implementing, or advocating the implementation of effective policy on HIV/AIDS (such as access to ARV therapies);
- sensitising the public to the epidemic and PLHAs in order to create a less hostile and more supportive environment;
- breaking the silence on the subject by leading the way to open discussion;
- further educating the public about HIV/AIDS.

Framing the above in our theoretical models, we can identify the many implications that these proposals have.
Considering Smith's (1993) model of social identities, we can argue that a sensitised and educated individual who finds himself in a society that speaks openly about the disease, and where the government states clear and effective policy to fight it, would make for a completely different idea of identities in the model. It could then look like the following (see table 17).

Threatened Identity	Appraisal	Emotion	Action Tendencies
Self as a healthy and educated person	PLHA is not contagious (education) and deserves my respect (sensitising), and can still live a productive life (access to drug therapy)	Understanding	Support

Table 17 Public policy, media, and religion in Smith's (1993) model.

Pryor's et al (1999) model also provides opportunities for these issues to be framed. The issues of effective policy and education will have their immediate impact on people's associations with the disease. The notions of illness, death, and contagiousness are bound to change in a positive direction. Moreover, the enhanced education will also lead to a decreased instrumental concern in the 'adjustment' section. The issues of sensitising the public and breaking the silence can influence both the section of 'associations' and 'adjustments'; a sensitised individual in an atmosphere of openness will be less likely to immediately associate HIV with certain groups in society, and his increased sense of political correctness and internal standards will allow for a more positive adjustment phase (see figure 18).
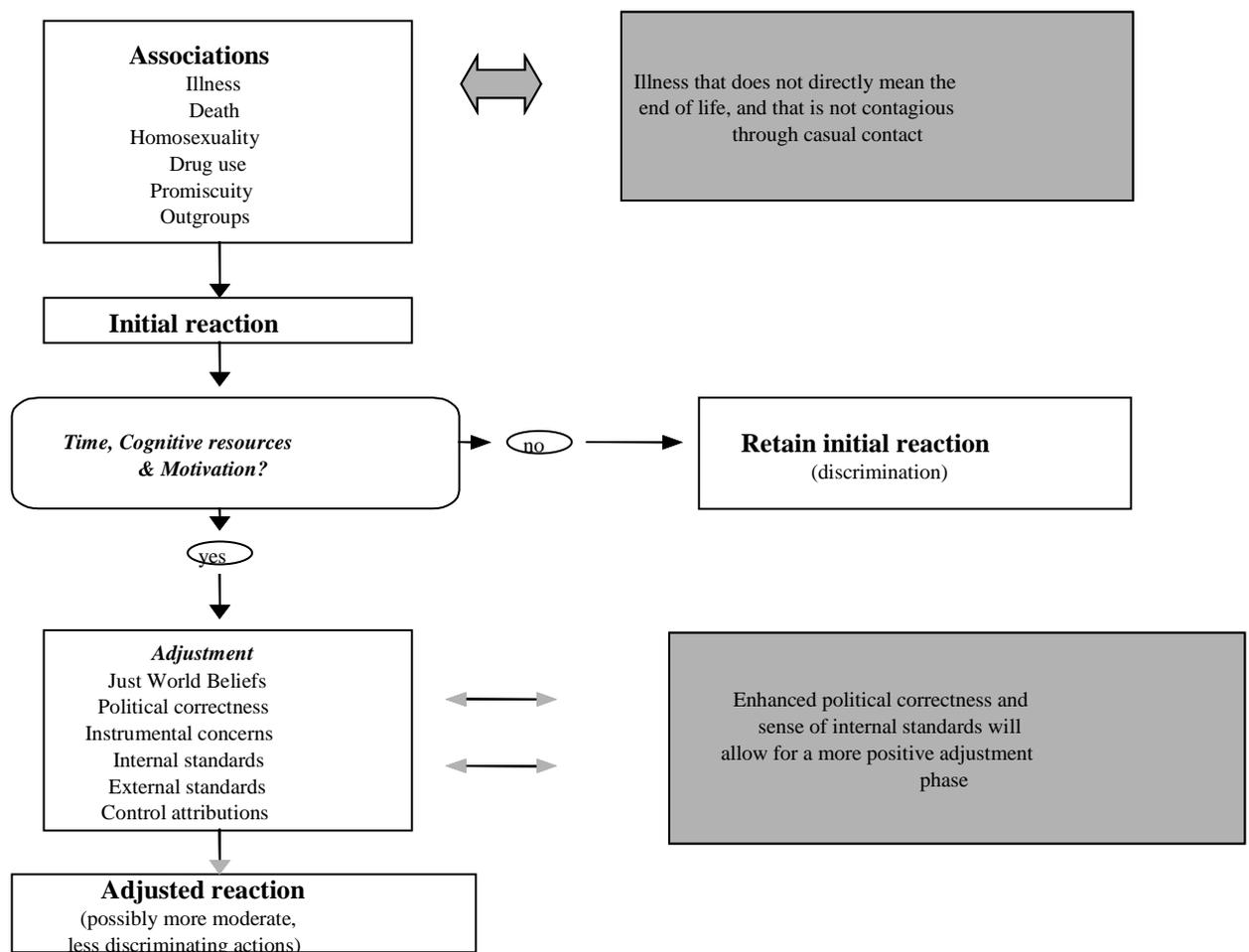

Fig. 18. Visualisation of the proposed intervention leads in Pryor's et al. (1999) model

4.1.2 The stigmatised: empowering PLHAs

As established in the discussion on the predicaments of the stigmatised in chapter 2, there is a common theme to the predicaments of being stigmatised; the threat to personal and collective self-esteem. Furthermore, Maslow's (1954) pyramid of needs demonstrated how a PLHA is cut off from his social framework, and that this social framework is just what he needs in order to satisfy his needs.
Although PLHAs face these serious threats of challenged self-worth and ostracism, they are by no means powerless to counteract these threats posed by H/A stigma. What is important is how a PLHA handles the predicaments that he faces both practically and mentally. This handling is what we have termed 'coping' in chapter 2. Enhanced coping skills is what many PLHAs could well use in their struggle against H/A stigma.

Enhanced coping skills can cover a wide range of issues aimed at different settings. In this section, we have selected the following essential elements for our intervention leads:
* the law
* improved access to drug therapies
* psychosocial support

A The Law
Many of the origins and benefits of the law as a tool in fighting stigma have already been mentioned in a former section, where the law was described in light of the stigmatiser's side of the story. Actually, all the statements made in that section could be considered equally valid for this section, accept for the fact that now the point of view shifts from the stigmatiser to the stigmatised. Whereas in the section about the stigmatisers the emphasis was put on the preventive effect of the law, in the sense that the expected punishment will deter people from acting in a discriminatory way, the focus now shifts to the enormous strengthening of heart that PLHAs can experience in their fight against stigma as a result of the options that the law offers them.
As demonstrated before, PLHAs have many options to bring matters of discrimination to court. The rights of PLHAs are enshrined in both the Constitution and in many acts and policies. Recently, more and more cases of HIV/AIDS related discrimination are being won by PLHAs (see for example Hoffmann vs SAA 2001), which will only strengthen the idea that the law really can provide ways to fight H/A stigma and discrimination.

It is of significance to note that law use cannot simply be assumed to form a natural tool for everyone in fighting H/A stigma. Burris (1997) states that for law use to become a real option, people's 'social capital' is of crucial meaning. By the term social capital Burris (1997) means "any tradable asset in a particular social setting", which could materialise in things such as economic wealth, the possession of prestige arising from a social respect for wealth, educational credentials which may be traded for social or economic advancement, etc. (Burris 1997). Burris (1997) poses that greater sources of social capital lead to a more positive perception of the law and the possibilities it provides to counter H/A stigma.

In asserting whether or not to seek legal advice, Burris (1997) identified four issues that greatly influence the individual decision. These four issues entail:

* awareness of law
* perceived access to law
* perceived rights to legal protection
* perceived effectiveness of law

Actual awareness of protective law is a baseline issue in the process of deciding to turn to law as a way of fighting H/A stigma. Awareness should be broadly defined to include a range of degrees of legal knowledge, and should be understood to be strongly mediated by the source of knowledge. Obviously, a greater awareness of law leads to an improved conception of the possibilities it can offer (Burris 1997).

An individual is more likely to rely on law if he believes that the advantages are truly available. However, the skills to identify relevant legal rules and invoke them in relationships with others are not evenly distributed throughout society (Burris 1997). A decision to use law in managing H/A stigma would reflect some more or less conscious evaluation of one's capacity in this respect. Greater social capital would in this respect lead to a higher perception of access to a legal remedy (Burris 1997).

For a person to decide to rely on law, he must believe that the loss he perceives would be an injury, and that it can be seen as well as a wrong, unjustified imposition. If, for example, an individual is afraid of losing his job if he should test positive, he may conceptualise his firing as an inevitable side effect of his own behaviour rather than as an injury from which he is entitled to immunity.

To place serious reliance on law, one presumably must believe that law will be effective in the uses to which it is put. This means that the law has to be strictly enforced by the government and private litigants, and that punishment for discriminatory acts should be severe enough to be taken seriously. Like this, the legal system's commitment to PLHAs is underlined, and it is made clear that law is indeed a serious and effective form of recourse.

Considering these issues that influence an individual's decision of whether or not to make use of the law as a tool in fighting stigma, we can now start to identify several intervention leads, that aim to promote a greater use of law.

In order to improve the awareness of law as a realistic tool in fighting H/A stigma, investments should be made in educating the public about the possibilities that the law provides them with. Particularly in hard-hit regions such as South Africa this kind of education could have beneficial effects. As for perceived access to a legal remedy, it is clear that especially those that do not dispose of a large social capital need to be convinced that the law is also accessible to them. Again, education and additional help from legal institutions that provide free legal counselling are the answer.

In order to improve people's ideas about their rights to legal protection, they must be convinced that any act of H/A related discrimination is illegal and immoral. HIV infection should never be considered a justification for discriminatory behaviour. Education backed up by an ever-growing number of convictions and penalties for discriminatory behaviour could be a way forward. This ever-growing number of convictions will also improve people's notion of the law's effectiveness; if the law is strictly enforced by the authorities, people will start to see the legal system as an ally which can help them fight injustice.

As for the theoretical side of the issue of the stigmatised, the ideas of Maslow (1954) and Lazarus and Folkman (1984) as mentioned in chapter 2 are of interest. From the point of view of the PLHAs' needs, as meant by Maslow (1954), the law could contribute to a counterbalance to ostracism; through fighting injustice by means of law, one could regain power and respect from the self and from others around the self, and one could again satisfy needs on the different levels of the pyramid (for example, by fighting dismissal on the grounds of HIV infection, one regains the ability to provide for oneself (basic needs) and one restores confidence and respect from others that might have been lost (social needs).

As for Lazarus and Folkman (1984), we can argue that the whole issue of awareness, access, and effectiveness of law, can be regarded as an improvement of coping skills. As such, the law can improve a PLHAs sense of self-worth because according to their theory, an improvement in coping skills may cause a person to reappraise a threat as less threatening.

In conclusion we can argue that the law is a major tool for PLHAs that suffered from discrimination to take their fate into their own hands again and fight the injustice that they encountered.

B Improved access to drug therapies

As established in the former section of disassociating AIDS from death, we have seen that better access and provision of drug therapies can normalise, in the eyes of others, the disease and those living with it. From the point of view of the PLHAs themselves, drug therapies form the essential issue in continuing a normal and productive life. Access to drug therapies will keep many PLHAs able to continue their life as before, and as such they become walking ambassadors of the fact that HIV/AIDS is not necessarily a fatal disease that reduces a human life to sheer misery. A possibility of treatment is what can keep many PLHAs hopeful and positive, and in that state of mind they are much better able to defend themselves against the prevailing stigma. Drug therapies are crucial in the sense that they keep PLHAs active and visible, and allow them to keep playing important and respectable roles in society, which in turn will maintain their sense of self-worth.

Obviously, drug therapies are effecting all of Maslow's (1954) levels, simply because they keep the PLHA alive and therefore maintain the individual's needs. One could argue that drugs allow the PLHA to keep trying to fulfil all of his needs, including the self-actualisation need, which generally constitutes a form of ultimate vindication for an individual, and by effectively fighting the disease with drug therapies, one could well experience such a sense of vindication. As for Lazarus and Folkman's (1984) theory, it can be argued that drug therapies form an essential coping tool for PLHAs. Armed with this powerful coping tool, the PLHA will, most probably, reappraise the threat of H/A stigma as less threatening, and will assume a much more positive outlook on the situation.

C Psychosocial support for PLHAs

Psychosocial support is considered an essential element of providing care for PLHAs (Sanei 1998). It includes a range of interventions that enable individuals (and families) to cope with the circumstances caused by HIV infection. In our case, these circumstances entail the stigma and discrimination that surround HIV/AIDS. Psychosocial support is essential to enable victims of discrimination and rejection to continue functioning in settings that used to be safe but are now hostile (Schietinger 1998). The support can rebuild and maintain a positive sense of self-worth in PLHAs. Furthermore, psychosocial support is an important aspect of programs that assist people whose human rights have been violated (Danziger 1994).

The type and intensity of psychosocial care and support that is needed varies with the circumstances faced by each individual or family, but such support can entail physical, emotional, and spiritual elements. Mechanisms to provide this type of psychosocial support can include support groups, volunteers who visit at home and in the hospital, hospital outpatient clinics, pastoral counselling, and homecare programs. The support can be provided by professionals and non-professionals, such as physicians, nurses, social workers, health educators, religious leaders, traditional healers, family, and friends.

Psychosocial support can encompass a wide range of activities, including:

- formal activities designed to provide counselling, psychological care, and social and spiritual support, such as individual counselling, group counselling, and pastoral care
- formal medical activities, such as taking a medical history or conducting a physical exam, and making home care visits to assist with daily activities
- informal activities with a more general character, including instrumental support (help in caring for children, agri-cultural work, etc.) and emotional support.

Looking at psychosocial support through the perspective of Maslow's (1954) theory on needs, it is particularly the levels of belonging needs and love or esteem needs that can be enhanced. Providing support for a PLHA can make him feel better about himself and the situation, and can help him feel wanted and appreciated again. Especially group support can provide a sense of belonging in a PLHA.

Since psychosocial support can be considered a way of improved coping with the threat of stigma, it will therefore, according to Lazarus and Folkman (1984) lead to a reappraisal of the threat as less threatening and PLHAs who are less intimidated by the perspective of encountering H/A stigma will have a more positive attitude and are less likely to give in to depression and fear.

4.2 INTERVENTION LEADS AIMED AT THE PT

After having reviewed some possible intervention leads for the PT's frame of reference, which consists of both the stigmatisers and the stigmatised, it is now time to address the specific situation in which a PT finds himself. Of course, a PT's conception of H/A stigma is strongly influenced by his environment, or frame of reference, which is the reason why we identified several options in the former section to improve that environment. This is important since a more positive frame of reference concerning H/A stigma will have its influence on the PT's conception of the issue of testing. But now, we need to address the specific problematic issues that are withholding PTs from testing, and these cannot simply be properly addressed by trying to improve the frame of reference. Since the decision process of whether or not going for a test is a complicated social-cognitive process, we will need to guide our set of intervention leads by a decent model on the decision making process, and for this purpose, the Integrative Model of Behavioural Prediction (IMBP) by Fishbein and Yzer (2003) is of great value.
Since the IMBP provides us with a holistic view of determinants that influence the decision making process in people's minds, it can be considered highly appropriate for our issue of testing, because a whole range of different determinants are involved in the process of deciding to go for a test or not.

As already mentioned in chapter 2, the IMBP (see figure 19) demonstrates that the intention to perform a certain behaviour is essential for the actual performance. Together with skills and environmental constraints, intention has a decisive influence on the performance of the propagated behaviour. So what obviously needs to be accomplished, is to establish what intentions, if any, are formed concerning the recommended behaviour, what skills are needed to perform the behaviour, and what environmental constraints are standing in the way of performing the behaviour, and then to create intervention leads that address these specific issues; creating more positive intentions toward the recommended behaviour, building skills, and removing or helping people to overcome environmental constraints.
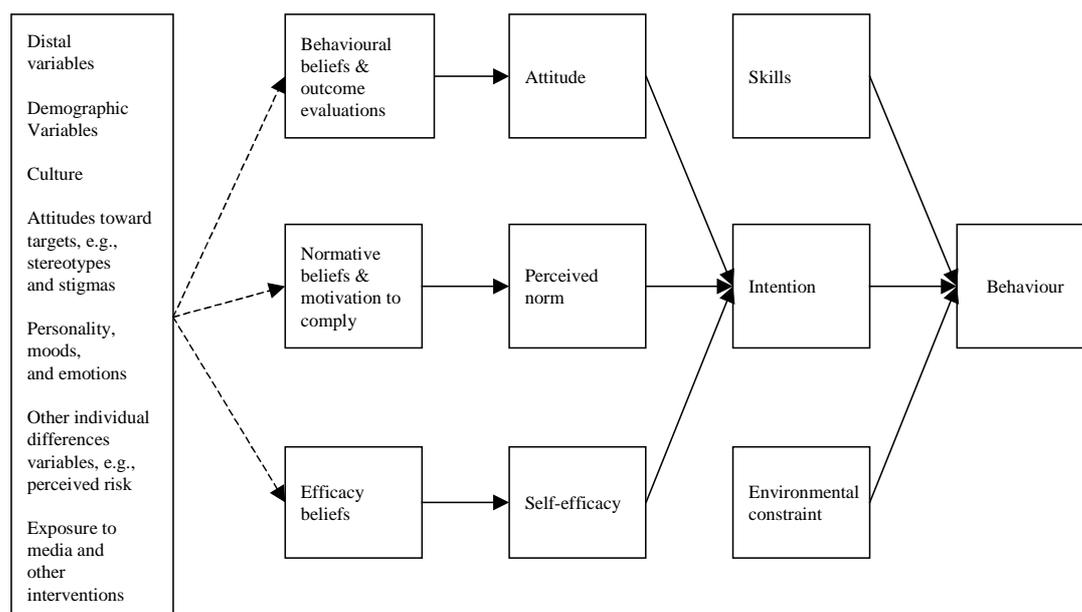

Fig. 19. The Integrative Model of Behavioural Prediction (Fishbein & Yzer 2003)

IMBP in action
When looking at the model, we can establish that stigma is classified as a distal variable of behaviour. It has a close impact on beliefs held by an individual, i.e. on behavioural beliefs and outcome evaluations, on normative beliefs and motivation to comply, and on efficacy beliefs. These belief structures then influence attitude, perceived norm, and self-efficacy, which in turn are critical factors in the formation of an intention toward a certain behaviour. And then finally, intention, together with skills and environmental constraints, determine the actual behaviour which is displayed.

We will try to analyse the impact of stigma on all three belief categories, that is behavioural beliefs and outcome evaluations, normative beliefs and motivation to comply, and efficacy beliefs.
Now, before the model can be applied, it is of vital importance to clearly establish certain conditions concerning the final recommended behaviour. That is, we need to define the behaviour and the target group, and also a time frame in which the behaviour should be performed. As already clearly defined in chapter 2, the recommended behaviour is to report for V HIV/AIDS CTR, the target group is defined as South Africans aged older than 10 who have engaged in unsafe sexual practices, who have not yet tested positive, and who are able to read brochures and education material, and the time frame is set at two months (time from the impact of the intervention(s) until the actual performance of the recommended behaviour, i.e. reporting for CTR). With these specifications in mind, we can now go and apply the model step by step.

Behavioural beliefs, outcome evaluations, and attitude
The behavioural beliefs a person holds in combination with the according outcome evaluations concerning a specific behaviour could be simply described as the beliefs on which an estimate of the costs and benefits of that specific recommended behaviour is based. That is, when an individual is invited to perform a certain behaviour, i.e. going for a test, he will try to 'calculate' the benefits of that behaviour versus the costs. In the case where this person perceives that the behaviour will lead to 'good' outcomes and prevent 'bad' outcomes, his attitude towards performing the behaviour will be a favourable one. Of course, the opposite also applies; if a person feels that the recommended behaviour will have negative consequences for him, his attitude will most likely be not very favourable toward performing the behaviour.

For our case of HIV testing, we need to understand the impact of stigma on the behavioural beliefs and outcome evaluations. As demonstrated on numerous occasions throughout this thesis (see chapter 1 and 2), the fear of stigma, discrimination, and rejection is a strong negative indicator of CTR uptake. When a person beliefs that a positive test result will cause him to be discriminated against and rejected, while the chances of receiving treatment and support are slim, then the costs of the recommended behaviour seem to outweigh the benefits of it. The outcome evaluation of the behavioural belief then becomes a destructive one: "If I go for a test, there is always a chance that the result could come out as positive, and that means that I would be exposed to stigma and discrimination, whilst there are hardly any options for treatment and support. I find it very disturbing to be rejected or discriminated against. I will not report for V CTR because that simply rules out the option of being diagnosed as HIV positive, and thus also the related stigma and discrimination".
Clearly, this kind of belief and evaluation will undoubtedly lead to a negative attitude toward going for V CTR. Intervention leads that aim to address the negative impact of stigma on behavioural beliefs and attitude will be developed in section 4.2.1.

Normative beliefs, motivation to comply, and perceived norm
The issue of normative beliefs and motivation to comply has to do with the PT's perception of what specific others think of the recommended behaviour, and the motivation to comply with those specific others. In South Africa, example cases of PLHAs who have been discriminated

against, rejected, or even physically attacked by family members and close members of the community are abundant (see chapter 1). The reason that these significant others react in such a destructive way toward the person who has tested positive, is that they feel that this person brings shame and disgrace on the family and/or community. So, then the perception of the norm would become that the significant others would not accept a positive test result, since that would damage the reputation and honour of the family and/or community. This conception now strongly stimulates the following reasoning: "If going for a test inextricably brings about the risk of being tested positive, and if my significant others would consider this positive result as damaging to their reputation and honour and hence reject me, it would be wiser not to go for a test at all". Now, the relative importance that a PT will attach to the opinion of these others is what has been called the motivation to comply. It is likely to assume that in a rather collectivistic society such as South Africa, the motivation to comply is high. This high motivation to comply will only strengthen the negative reasoning mentioned above, and the normative belief and according motivation to comply then form a destructive combination: "Going for a test always implies a risk of being tested positive, and a positive result will be severely punished by my significant others. I attach great value to the opinion of my family and/or community, and I would never want to bring shame on them. Not going for a test rules out the option of testing positive, and thus the option of bringing shame on my loved ones, so I will not report for V CTR". This underlines that the normative belief that the recommended behaviour is not supported by the significant others, in combination with a high motivation to comply, will lead to a negatively perceived norm, and accordingly to a negative attitude.

In opposition to the relationships mentioned above, there is another form of relationship in which often a more positive view is adapted, i.e. in a sexual relationship. People in a sexual relationship may have doubts about the sexual history of their partner and thus worry about their own health. That is why they could be interested in the sero status of the partner. But even though the PT's close sexual partner would stimulate him/her to be tested, and even if the PT really values this partner's opinion, it is still very doubtful whether this motivation to comply with the sexual partner weighs up against the motivation to comply with the family and community. On top of that, there are numerous examples in South Africa of partners that broke up the marriage or relationship as soon as it turned out that the other was HIV positive, which of course does not promote the uptake of CTR. So, the importance of the close sexual partner's opinion will be weighed against the fear of the consequences of a positive test result, and in the current South African situation it is not illogical to assume that most PTs will then opt for the 'safe' option of not reporting for CTR.

With respect to this issue of sexual partners, it is of importance to understand the gender inequality in African society. Most African women are not in a position to negotiate condom use or HIV testing because they are highly subordinate to men (Human Rights Watch 2003). Many women see themselves powerless to change their partner's view on sexuality, and they are not in a position to make demands concerning sexuality. So, this implies that the whole issue of testing within the sexual relationship is mostly a male determined issue, in which women have little or no say.

As for the conception of the perceived norm, which influences the intention, it is obvious that negative normative beliefs, as portrayed above, in combination with a high motivation to comply, will lead to a negatively perceived norm. Intervention leads aimed at changing the perceived norm will follow in section 4.2.1.

Efficacy beliefs and self-efficacy
Efficacy beliefs are beliefs that have to do with the PT's beliefs that he in fact is able to perform the recommended behaviour. In our case, we need to take on a broad view on the recommended behaviour, in the sense that we do not just look at the ability of a PT to undergo a test, but especially the abilities of a PT of dealing with a positive test result. That is, a PT can have such strong fears about the negative consequences of a positive test result, that coping with these consequences might seem impossible. This belief then constructs a negative

perception of one's self-efficacy: "I am not able to cope with the possible stigmatisation emanating from a positive test result", which will obviously lead to a negative intention toward V CTR.

Intervention leads aimed at increasing the PT's coping abilities will follow in section 4.2.1.

The above section has shown that all three determinants that together form the intention, i.e. attitude, perceived norm, and self-efficacy, are negatively influenced by H/A stigma. As such, this implies that the intention toward the recommended behaviour is also a negative one, or it may even be non-existent. In order to improve the PT's intention toward CTR, intervention leads need to be provided that improve the three determinants of intention, and thus also intention itself.

4.2.1 Creating a more positive intention toward CTR

Attitude

In order to come to a more positive attitude toward testing, the underlying behavioural beliefs and outcome evaluations need to be addressed. The PT needs to be convinced that going for a test will lead to 'good' outcomes and that not going for CTR will lead to 'bad' outcomes. This means that the benefits of testing need to outweigh the costs. Giving more weight to the benefits of testing is obviously achieved best by providing people with real hope that they will be treated with drug therapies (ARV therapies). This directly implies that access to drug therapies needs to be dramatically improved. When people feel that they have a real chance of being treated after they test positive, they will perceive the testing procedure as more useful, because the following treatment will help them stay healthy and alive. This chance for treatment can now act as reality in counterbalancing the negative effect of stigma. The fact that going for a test could now mean that one's life can be saved should convince many PTs that this is worth challenging the prevailing stigma by actually reporting for CTR.

In addition, the process of CTR would greatly benefit from strictly enforced conditions of confidentiality regarding test results. As demonstrated in chapter 1, confidentiality issues deter people from seeking help, because they fear that a positive test result will be leaked to third parties. Van Dyk and Van Dyk (2003) demonstrate that these fears are actually based in reality, since leaking of test results by health care workers occurs on a regular basis in South Africa. But if confidentiality regulations would be strictly upheld then this fear could begin to diminish. So in order to provide these confidential circumstances, health personnel needs to be educated about the enormous importance of respecting confidentiality regarding the testing procedures, and boards of direction of clinics and hospitals should also adopt strict regulations regarding this issue with severe penalties for a breach of confidentiality.

Now, when a combination of a real option for treatment together with strict confidentiality regulations is provided, a powerful argument is created for people to overcome their fear of stigma when considering V CTR. Backed by these intervention leads, the new outcome evaluation could now look like this: "testing could save my life since a proper treatment is provided afterwards, and the procedure is strictly confidential so no one needs to know about it. I do not want to die, and going for a test will have no negative consequences because of the strict confidentiality regulations. I will report for CTR."

This favourable outcome evaluation will now make for a positive attitude toward reporting for V CTR.

Perceived norm

To improve the second determinant of intention, the perceived norm, the underlying normative beliefs and the motivation to comply need to be addressed. As portrayed in the section about intervention leads aimed at the PT's frame of reference, the beliefs regarding HIV/AIDS held by societies can change through ways of disassociating HIV/AIDS from death and from certain groups in society, through use of law, through reducing instrumental concerns, etc. These interventions would then lead to a less hostile, and more understanding and supportive view on PLHAs, which directly implies that a PT would probably feel more support from his significant

others to report for V CTR. Now, when talking about specific interventions aimed at convincing PTs to report for CTR, we need to take in account that in a collectivistic society such as South Africa, the perceived norm is highly valued, i.e. people attach great value to what they think the community would want them to do. That means that we could both try and sensitise the PT's community, and that we try and increase the PT's sense of independence from the community.

Sensitising the PT's frame of reference is what we have described in a former section, but specific intervention leads aimed at a PT's community also need to be adapted here, since the issue of perceived norm draws heavily on inter-group relations; it is about what a PT thinks that his significant others think he should do, and thus the relationship between them becomes a reality. As demonstrated by the Horizons Programme (1999), community based education and 'outreach' activities can contribute to decreasing H/A stigma. Community based education involves the entire community, which means that all members of the particular community receive education about the disease, about the importance of testing in stopping it, and about how stigma hampers these efforts. 'Outreach' activities such as homecare, can contribute to a better understanding of what activities do or not carry the risk of transmission. The goal of this participatory education is to appeal to a sense of compassionate family care in the community, which would lead to a sensitised opinion about PLHAs within that community. In such a climate, PTs will feel more support from their significant others in their decision to report for CTR.

A different approach, which should not be seen separately from the one above but as an addition to it, is to sharply increase the confidentiality regulations surrounding HIV testing. Just like in the section before, it is again of vital importance in this respect that people can test anonymously, and that their results will be kept strictly confidential. If the conception of total confidentiality regarding HIV testing can be realised, then PTs would become in fact more independent from their communities. That is, if a PT feels he can go for a test without anyone in his community finding out about it, he will experience greater freedom in his decision, since the fear of being rejected by his significant others is now ruled out.

If both the community based education and the confidentiality issue can be realised, a much more positively perceived norm can now be expected, which will strengthen the intention to report for CTR.

Self-efficacy
The third and last determinant of intention, self-efficacy, needs to be addressed by improving the PT's efficacy beliefs. This means that a PT must be convinced of his ability to cope with the possible stigmatisation resulting from a positive test result.

An essential element in strengthening PTs against stigma and discrimination is the issue of 'coping'. A PT needs to be taught about the ways of coping with stigma that are available to him. This comes down to close personal counselling of those that tested positive. In these counselling sessions it is of major importance that the PT is convinced that he is not alone in fighting the disease and the accompanying stigma. Assistance in partner notification, peer group counselling sessions, close medical care, and free judicial assistance can all contribute to a sense of support. If a PT is aware of all the supportive action that awaits him should he test positive, then the option of testing will come across as less threatening.

The option of law as a tool in fighting stigma can also play a major role in improving efficacy beliefs. As shown in chapter 1, South Africa disposes of a well-developed legislation prohibiting any form of discrimination of PLHAs. But as Burris (1997) notes, the mere existence of anti-discrimination legislation alone is not enough to convince people that this legislation is of any use to them personal. Burris (1997) indicates that the individual's perception of the law influences the actions that this individual will take. He identifies these perceptions as the perceived right to legal protection, the perceived access to a legal remedy, and the perceived effectiveness of law. This directly implies that interventions need not just refer to the law as an option in fighting stigma, but need to very clearly state that the law is a real, affordable, and effective way of fighting HIV/AIDS related discrimination. Education

about the law needs to be incorporated in counselling sessions and free judicial assistance should be easily available for all those that decide to report for CTR.

By improving the beliefs a PT has about his efficacy, the self-efficacy component will become one that is viewed upon as positive; if a PT feels he is supported by a number of people from different backgrounds and by the law, he will feel much more able to cope with a positive test result than if he were to fight the disease and its stigma on his own.

Now, the three determinants of intention have been addressed. According to IMBP, we should now have created a positive intention among PTs toward going for CTR; a positive attitude, a positively perceived norm, and a high sense of self-efficacy have been created, which in their turn lead to a positive intention toward CTR.

Looking at the IMBP, we can see that behaviour is constructed by three determinants, i.e. intention, which we have already addressed, skills, and environmental constraints. So that leaves skills and environmental constraints to be further investigated.

4.2.2 Improving skills

Besides a PT's intention toward reporting for CTR, he also needs to feel that he has the necessary skills to actually go and do it. In our case of H/A stigma, this does not simply mean that the PT needs the skills to simply report for CTR, but he also needs skills to be able to cope with a positive test result. Both issues will be reviewed in the following.

In order to give a PT the idea that he can truly comprehend the testing procedure and feel that he is able to report for it, information on how the procedure works is a prerequisite. PTs need substantial information on how the procedure works, on what happens after their results come in, on their rights within and after the procedure, on the issue of informed consent, etc. If the clarification of the procedure can be installed as a standard measure before a PT is allowed to take a test, then much of the ignorance and fear surrounding the testing procedure can be eliminated. Information can provide PTs with a better understanding of what will happen and thus make them feel more confident about their abilities to perform the HIV test.

Furthermore, as was also the case in the section of self-efficacy, we need to provide the PTs with skills that will help them to overcome the possible stigma and discrimination following a positive test result. These 'coping skills' need to be offered as standard procedure in the counselling sessions preceding and following the test. PTs have to be made aware of the fact that, should they test positive, they will be assisted in numerous ways in order to cope with the disease and the accompanying stigma. Again, peer group sessions, partner notification assistance, and close medical and judicial assistance all contribute to the sense of the PT that, in spite of many obstacles, he will be able to cope with a positive result.

4.2.3 Removing environmental constraints

Last of the three determinants of behaviour is the issue of environmental constraints, which could be described as the most practical issue of all. If one has the intention and the necessary skills to go and report for CTR, but one cannot afford the three hour bus ride to the clinic, then it will simply be impossible to perform the recommended behaviour.

These so called environmental constraints can only be overcome by a substantial up scaling of testing facilities, clinics, counselling and treatment facilities, and public transport. If people have to travel long distances to clinics, they will often feel that reporting for CTR is too much of a burden on their time and budget. When testing facilities are brought closer to the communities, especially in rural areas, then these practical issues could be overcome. The up scaling of all the mentioned facilities will require a substantial investment from the South African government, but it is an investment that is urgently needed if the AIDS epidemic is to be brought to an end.

This last section completes the step-by-step route through the IMBP. We identified the problematic sides of every determinant in the model, and by addressing them one by one, we now have a theoretically sound set of intervention leads. Figure 20 provides a summarized

visualisation of the IMBP and all the proposed intervention leads for the problematic sides of the determinants.

Now, in the following and last section, a set of evaluation heuristics will be developed, based on all of the intervention leads identified in this chapter.

Fig. 20. Summarized visualisation of all proposed intervention leads
(Proposed intervention leads are displayed in grey shaded sections.)
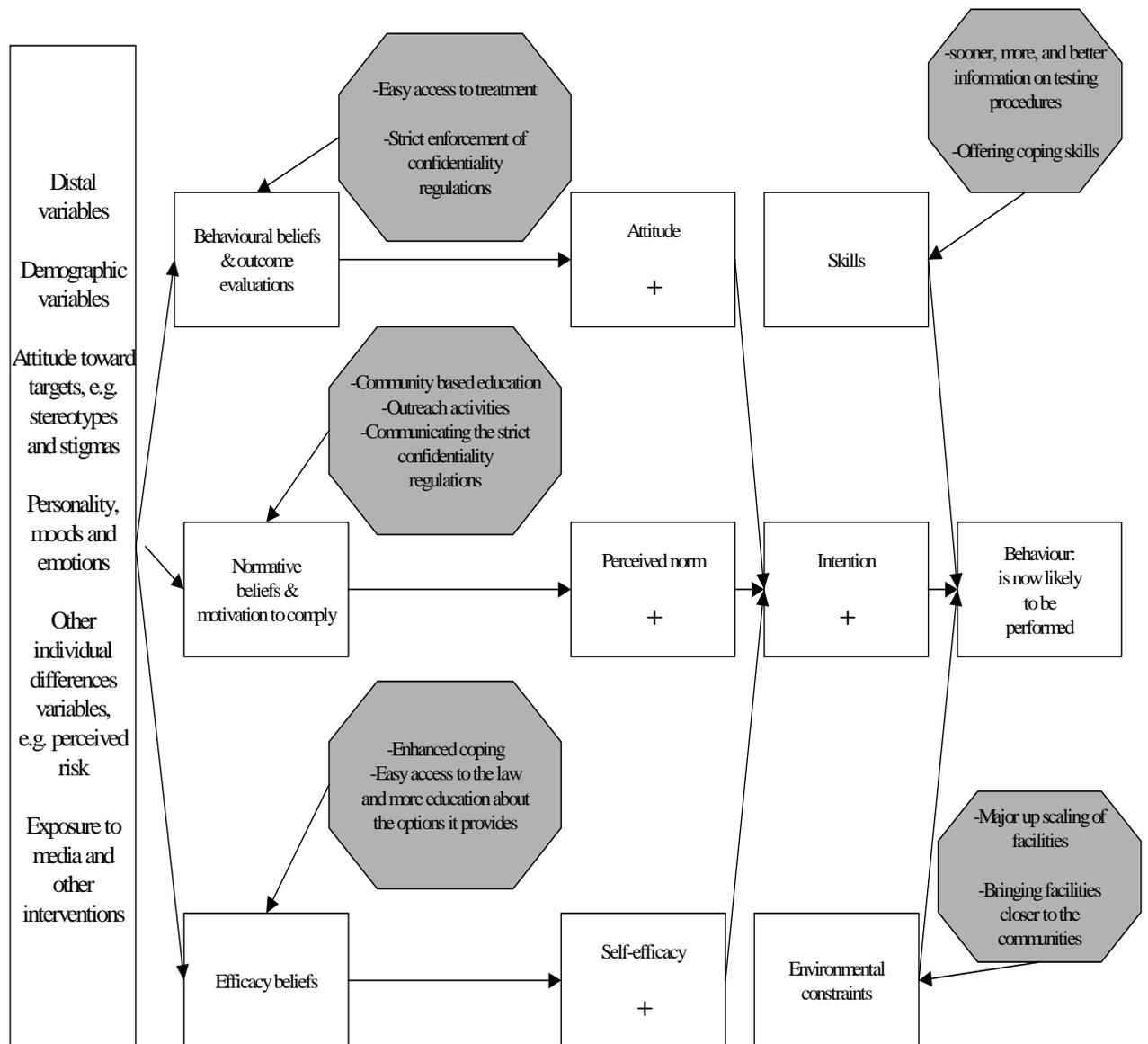
5 DESIGNING AN EVALUATION SCHEMA

After having discussed the problems that are posed by HIV/AIDS stigma, its theoretical framework, and some possible intervention leads, we have now come to our ultimate goal, i.e. the design of an evaluation schema. This evaluation schema in meant to assist health communicators who want to address HIV/AIDS stigma in written material that aims to persuade people to report for V CTR.

Now, in chapter 4 we have identified numerous intervention leads of which some were aimed at the PTs' frame of reference, and others at the specific situation of the PTs themselves. It is of importance to note that the evaluation schema is aimed strictly at the PTs, and that the PTs' frame of reference is not a target in the schema. This does not mean that the intervention leads aimed at the PTs' frame of reference as presented in chapter 4 are no longer of interest to us. On the contrary, they are very important in the whole context of addressing the problem of HIV/AIDS stigma, and they are an integrative element of the total package of intervention leads. But as our evaluation schema is focused strictly on written material that aims to persuade PTs to report for V CTR, they are of no direct use in that written material, and thus in our schema. The intervention leads aimed at the PTs' frame of reference should then be regarded as the surrounding conditions that are to be met in order for the intervention leads aimed at the specific situation of the PTs to be effective.

Another important issue with regard to the evaluation schema is the fact hat the heuristics can only be effective when their content is based in reality. That is, a recommendation made in the evaluation schema can only be of significant effect when it is backed up by the actual, real situation, otherwise credibility will be at stake. For example, when a recommendation is made to underline the options that the law offers in fighting HIV/AIDS stigma and discrimination, it can only be of any true effect when in reality people have easy access to legal assistance. And many more of the proposed recommendations obviously imply a substantial investment from the South African government, and without these investments the fight against HIV/AIDS and its related stigma will surely be lost. So what it comes down to is that this evaluation schema, which is meant as a tool for health communicators to improve their written material aimed at addressing HIV/AIDS stigma in PTs, has distinct implications for South African policy; only when the urgently needed proper investments and policy changes will have been realised, can we begin to effectively communicate them.

As a final remark we would like to emphasize that the following evaluation schema does by no means pretend to be exclusive. Instead, it merely reflects the issues that are considered essential by the author.

THE TEXT EVALUATION SCHEMA AIMED AT ADDRESSING HIV/AIDS STIGMA IN WRITTEN MATERIAL THAT AIMS TO PERSUADE PEOPLE TO REPORT FOR V CTR.

General (section 1.1)
- Is any explanation provided on what HIV/AIDS stigma exactly is?
- Are the benefits of reporting for V CTR clearly stated?
- Is HIV/AIDS stigma mentioned as a possible negative consequence of reporting for V CTR?

Risk of infection (sectiopn 4.1.1)
- Is sufficient and clear information provided about when an individual has been at risk of contracting HIV?
- Are the ways that do not carry the risk of infection, but are often thought to be riskful, clearly indicated?
- Are myths and cultural beliefs regarding sexual behaviour refuted?

Clarity about the testing procedure (4.2.2)

- Is any explanation about the actual, medical routine of testing provided?
- Is the issue of informed consent clearly explained?
- Is any mention made of pre- and post test counselling, and is the purpose and content of these counselling sessions indicated?
- Are the rights of the PT during the total procedure stated?
- Is any attention given to the strict confidentiality regulations surrounding the test?
- Is any mention made of the coping skills that are offered should the PT test positive?

Drug therapies (section 4.2.1)
- Are the hopeful options and benefits that drug therapies provide mentioned?
- Is any information given on the easy access to treatment?
- Is explicitly mentioned that these therapies are meant for everyone and that they are free of charge?

Confidentiality (section 4.2.1)
- Is any mention made of the strict confidentiality regulations concerning CTR?
- Is any relation stated between these strict regulations and the options they provide to go for V CTR without anyone knowing about it?

The Law (section 4.2.1 & 4.2.2)
- Is any attention given to the fact that HIV/AIDS related discrimination is prohibited by law?
- Is any legislation concerning confidentiality issues mentioned?
- Are the ways of access to the law clearly stated?
- Is indicated that anyone can call on the law free of charge?
- Is clearly indicated that the law is there to help PLHAs, and not those that are behaving in discriminatory ways (such as employers for example)?
- Are any successful court cases mentioned?

Coping (section 4.2.1 & 4.2.2)
- Is clearly stated that persons who test positive will not be on their own in fighting the disease and its related stigma, but that there are many organisations and individuals that will help them?
- Is the option of help in partner notification mentioned?
- Are peer group counselling sessions mentioned?
- Is any mention made of the close medical care that the PLHA will receive?
- Is clearly explained that the PLHA will have easy and free access to judicial assistance?

Facilities (section 4.2.3)
- Is any mention made of the fact that hospital and clinic facilities have been substantially up scaled?
- Is any information given on the discrete procedures and strict confidentiality regulations in hospitals and clinics?
- Is any information provided on how to best cover long distances to clinics?

As some suggestions for further research, we would like to underline the need for the empirical testing of the evaluation schema generated in this thesis. Future studies could focus on testing the evaluation schema in an experimental research. And as our evaluation schema is strictly content focused, further studies could also attempt to identify the most attractive ways of presenting the written material for which the evaluation schema was designed. Further studies could investigate structure, wording and format which is considered most appealing by the target audience.

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