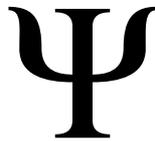




DET PSYKOLOGISKE FAKULTET



The Enigma of HIV/AIDS-related Stigma
*A theoretical exploration of HIV/AIDS-related stigma
in Sub Saharan Africa*

HOVEDOPPGAVE

profesjonsstudiet i psykologi

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Foreword

The epidemic of HIV/AIDS is changing the history of Sub Saharan Africa. Neither words nor statistics can adequately capture the human tragedy caused by HIV/AIDS.

As students of psychology, we completed our internship in clinical psychology at King Edward VIII Hospital in Durban, South Africa. Although we had been interested in working with HIV/AIDS prior to this, coming face to face with the overwhelming impacts of HIV/AIDS fuelled our motivation. Witnessing firsthand the severity of the stigma and the silence that encompasses HIV/AIDS compelled us to choose HIV/AIDS-related stigma as the topic of this thesis.

The writing of this thesis has been an enormous learning-process for both of us, a process neither one of us would want to be without. The continuous cycle of reading writing, and discussing relevant literature has not only increased our knowledge of HIV/AIDS-related stigma. It has also enhanced our awareness and appreciation of the power knowledge has to initiate change. Although the focus of this thesis has been the dismal topic of HIV/AIDS, we have strived to sustain a positive attitude, and to communicate a belief in the capacity to counter HIV/AIDS-related stigma. Sub Saharan Africa is so much more than HIV/AIDS, and despite the tragedy of HIV/AIDS, Sub Saharan Africa shows an awe-inspiring ability to sustain hope. We hope we have been able to mediate this spirit in our thesis.

We would like to thank our supervisor Gro Therese Lie, who with her wealth of knowledge and experience has made significant contributions to our processes of learning. Her ardent involvement in HIV/AIDS-related work in Africa, has been a great source of inspiration.

Special thanks to Pål and Ramón Kristian for patience, much needed sympathy, and technical assistance. We would also like to thank Gunn and Synøve for taking time to read and comment on earlier drafts.

Last, but not least – we give heartfelt thanks to each other. Our friendship and our mutual confidence have made “Our Africa” and this thesis possible.

Oslo, Norway, April 9th, 2003

*Silence and shame
prejudices and fear
it's all capsulated in a name
that is always so painful to hear*

*it is difficult to overcome
challenging to understand
it continues to overwhelm
as we fail to comprehend*

*that it is no enigma
but simply, something called stigma
that is enormously rife
in this process called life*

Anonymous HIV- positive
woman from South Africa

Abstract

29.4 million people are living with HIV/AIDS in Sub Saharan Africa. Despite this high prevalence, HIV/AIDS is a highly stigmatised disease. The United Nations Programme on HIV/AIDS recognize HIV/AIDS-related stigma as one of the greatest barriers to preventing further infections, and to providing adequate treatment, care and support for people living with HIV/AIDS. Stigma, under the slogan “*Live and let live*”, is also the focus of the World AIDS Campaign for 2002-2003.

This thesis provides a conceptual framework for understanding HIV/AIDS-related stigma in Sub Saharan Africa. Based on this framework and its implications, strategies aimed at alleviating and preventing stigma are proposed.

HIV/AIDS-related stigma is understood as a dynamic, multifaceted phenomenon that emerges from the intertwinement of human motivations, social structures, discourses and power relations. This understanding of stigma implies taking a broad approach when responding to stigma, calling attention to the importance of involving all levels of the community. Community psychology and community counselling provide suitable frameworks for such an approach, as they emphasize local adaptation, empowerment and action research. Because the severity of the HIV/AIDS-epidemic requires urgent response, research and action need to be integrated. Ethical and methodological issues pertaining to the understanding, alleviation and prevention of HIV/AIDS-related stigma in Sub Saharan Africa are taken into consideration.

Sammendrag

29.4 millioner mennesker er smittet av HIV/AIDS i Afrika sør for Sahara. Til tross for den store utbredelsen av HIV/AIDS i mange afrikanske land, er sykdommen i stor grad stigmatisert. Stigma anses som ett av de største hindre for effektiv forebygging av HIV/AIDS, og HIV/AIDS-relatert stigma begrenser pleie og omsorg for smittede og berørte. Dette har ført til at HIV/AIDS-relatert stigma har blitt satt på dagsordenen av FNs HIV/AIDS program (UNAIDS). HIV/AIDS-relatert stigma har også blitt lansert som tema for Verdens AIDS kampanje 2002-2003, under slagordet ”Live and let live”. Denne oppgaven gir ett konseptuelt rammeverk for å forstå HIV/AIDS-relatert stigma i Afrika sør for Sahara. Basert på denne forståelsen impliseres mulige tiltak for lindring og forebygging av HIV/AIDS- relatert stigma.

HIV/AIDS-relatert stigma forstås som et dynamisk og komplekst fenomen som springer ut av interaksjonen mellom menneskelige motivasjoner, sosiale strukturer, diskurser og differensierte maktforhold. En slik forståelse krever en bred tilnærming med tanke på forebygging og lindring av HIV/AIDS- relatert stigma. Samfunnspsykologi og samfunnsrådgivning bidrar med egnede metodiske tilnærminger, da lokal tilpasning, lokal styring og aksjonsforskning er viktige mål. Fordi HIV/AIDS- epidemiens omfang krever en umiddelbar innsats, bør forskning og handling integreres. Metodiske og etiske utfordringer knyttet til forståelsen, lindringen og forebyggingen av HIV/AIDS-relatert stigma i Afrika sør for Sahara diskuteres underveis.

ABBREVIATIONS AND DEFINITIONS

AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immunodeficiency Virus
HIV/AIDS	While HIV-infection and AIDS are different conditions, they are both part of the same disease continuum.
HIV/AIDS-related stigma	refers to all unfavourable attitudes, beliefs, behaviours and policies directed at persons who are perceived to be HIV-positive, regardless of whether they are HIV-positive or not.
PLWHA	“people living with HIV/AIDS”. Refers to people infected with, and affected by HIV/AIDS.
PWHA	“people with HIV/AIDS”. Refers to people infected with HIV/AIDS.
SSA	refers to “Sub Saharan Africa” and “Sub Saharan African”.
UNAIDS	Joint United Nations Programme on HIV/AIDS.
West/ Western	used as equivalent to European, North-American and Australian.

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Background and rationale

Recent estimates indicate that 42 million people were living with HIV/AIDS (Human Immunodeficiency Virus/ Acquired Immune Deficiency Syndrome) by the end of 2002. The total of AIDS deaths in 2002 was 3.1 million. No country or region is immune or shielded from the pandemic, though the prevalence rates vary (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2002a).

Sub Saharan Africa (SSA) is the worst affected region, where 29.4 million people are living with HIV/AIDS (UNAIDS, 2002g). 10 million out of these are young people between the ages of 15-24, while 3 million are children under the age of 15 (UNAIDS, 2002a). Overall about twice as many young women as men, aged 15-24, are infected in some SSA countries (UNAIDS, 2002b). Teenage girls are 5 times more likely to be infected than boys, as girls often become infected by older men (United Nations Development Fund for Women [UNIFEM], 2003). Approximately 3.5 million people in SSA became infected with HIV in 2002. In some countries the prevalence amongst the adult population, aged 15-49, has risen higher than expected, exceeding 30% of the population (UNAIDS, 2002a). The number of HIV/AIDS deaths in SSA during 2002, is estimated to 2.4 million (UNAIDS, 2002g). Due to insufficient HIV prevention, treatment, care and support, death stalks the continent and the numbers of deaths are believed to continue rising (UNAIDS, 2002b). Patel et al. (2002, p. 317) put it quite eloquently: “The human costs are, like the distances between stars, impossible for a human being to properly appreciate.”

There are new hopeful signs that the epidemic can be brought under control, as encouraging prevalence trends are visible among younger people, in some SSA countries. Forty countries across the region have completed national strategic HIV/AIDS plans to deal with the epidemic, and nineteen African countries have set up national HIV/AIDS councils or commissions. The local engagement is growing in vigour and number (UNAIDS, 2002b). Brummelhuis and Herdt (1995) point out that the mobilization against HIV/AIDS has been amazing in many African countries. These trends do not, however, offset the severity of the epidemic in these countries. All of them face huge challenges in sustaining and expanding

prevention, treatment, care and support to the millions of people living with HIV/AIDS (PLWHA) (UNAIDS, 2002b).

HIV/AIDS has been given a widely accepted conceptualisation that distinguishes between three phases of the epidemic. The first phase of the epidemic has been the HIV-infection: the epidemic enters every community silently and unnoticed, and without being widely perceived and understood. The second phase has been the epidemic of AIDS itself: the syndrome of infectious diseases that occurs because of the HIV-infection, typically after a delay of a number of years. The third phase of the epidemic has been the most challenging phase, consisting of social, cultural, economic and political responses to HIV/AIDS. This phase has above all been characterised by exceptionally high levels of stigma, discrimination, and at times collective denial that has been said to be as central to the global challenge of HIV/AIDS as the infectious disease itself (Mann, 1987 in Parker & Aggleton, 2003). The third phase will be in focus in this thesis.

Perhaps one of the most complex psychological and sociological HIV/AIDS-related phenomena is that of stigmatisation. In many countries there are well-documented cases of PLWHA being stigmatised due to their HIV-status (Alubo et al., 2002; Bond et al., 2002; Green, 1995; Mill, 2003; Muyinda et al., 1997; UNAIDS, 2001c; UNAIDS 2002c; UNAIDS 2002e; UNAIDS, 2002-2003). People can live with HIV/AIDS for many years, but stigma reduces the life-quality of PLWHA (France, 2001). Stigma can prevent people from attending testing, acknowledging and disclosing their HIV-status, suggesting safe sex, and seeking treatment, care and support (Brown et al., 2001; Goldin, 1994; Muyinda et al., 1997; UNAIDS, 2002c). Stigma thus harms those who are already suffering, and marshals a tendency of silence where ignorance and denial dominate (UNAIDS, 2002-2003). Stigma increases the impact of HIV/AIDS on individuals, families, communities and nations (UNAIDS, 2002c). HIV/AIDS, stigma, ignorance, denial and silence, form in this manner a vicious circle, generating and reinforcing each other, forcing the epidemic out of sight and underground (Bond et al., 2002; UNAIDS, 2002-2003). This facilitates the spread of the disease, and the outcome is fatal (UNAIDS, 2002-2003).

For as long as countries have struggled to respond to the HIV/AIDS-epidemic, the issue of stigma has often been poorly understood and disregarded both conceptually and programmatically (Parker & Aggleton, 2003). Stigma is now regarded as a major obstacle to effective HIV/AIDS prevention and care. The Declaration of Commitment, adopted by the United Nations General Assembly Special Session on HIV/AIDS in 2001, highlights the global consensus on the importance of addressing the stigma and discrimination related to HIV/AIDS. HIV/AIDS-related stigma and discrimination have also been chosen as the theme for the 2002-2003 World AIDS Campaign.

Research the last decade has increased the understanding of many psychological and social aspects of HIV/AIDS (King, 2002; Parker, 1996). However, most of the international HIV/AIDS research resources have been put into sophisticated medical research. Such research is important but has seemingly excluded attempts to confront the many non-medical impacts of HIV/AIDS (Barnett & Blaikie, 1992). Parker and Aggleton (2003) point to how social science research and campaigns mainly have focused on prevention and information, and less on care and support for PLWHA. Documented attempts of challenging HIV/AIDS-related stigma remain relatively rare. Research is urgently needed to identify and exemplify the most effective ways of dealing with this stigma across a range of contexts (UNAIDS, 2002c).

This thesis seeks to explore possible ways to alleviate and prevent HIV/AIDS-related stigma in SSA. In order to do this, stigma as a phenomenon needs to be understood, both in relation to HIV/AIDS, and in the context of SSA. Developing a conceptual framework for understanding stigma in SSA can provide a guideline for possible attempts that can minimize the prevalence and the impacts of HIV/AIDS-related stigma.

Problem formulations

How can one understand the HIV/AIDS-related stigma in Sub Saharan Africa?

What are the potential implications of this understanding for the alleviation and prevention of HIV/AIDS-related stigma?

HIV/AIDS and Sub Saharan Africa

In order to understand and to provide implications for the alleviation and prevention of HIV/AIDS-related stigma in SSA, the nature of HIV/AIDS and the context of SSA need to be taken into consideration. Considering how, and under what conditions HIV/AIDS has spread, and had such an impact on SSA, can provide an understanding of the realities in which HIV/AIDS-related stigma occurs.

With a population of 659 million, divided into 47 countries, SSA is an enormous region (World Bank [WB], 2003), (Appendix I). People differ with regards to ethnicity, language, religion and other important cultural traits. Making generalizations about such a huge and multi-cultural region renders one vulnerable for committing mistakes.

The countries in this region, however, have a range of historical experiences in common such as the structural impacts of colonialism, decades of post-independence and problematic governing, civil and regional wars, unequal trade relations, external powers in politics, rapid class formation and the dept burden resulted from all these factors (Barnett & Blaikie, 1992; Schoepf, 1995). Because SSA is now experiencing the worst impacts of HIV/AIDS worldwide, taking such a broad geographical focus when dealing with HIV/AIDS-related stigma seems justified.

There are three modes of HIV transmission: sexual intercourse, transfusion of infected blood or blood products, and transmission from mother to child (WHO, 1990). In Africa, HIV/AIDS has spread rapidly and mainly through heterosexual sex (UNAIDS, 2002a; UNAIDS 2002g). The various personal, social, economic and cultural factors that facilitate the spread of HIV/AIDS have not yet been adequately studied or explained. In the first years of the global epidemic, attention was mainly focused on people with so-called “high risk behaviour” such as prostitutes, male homosexuals etc. It has, however, become increasingly obvious that many others, who had the false impression that the disease was not a threat to them, have been infected (Lie, 1996; Parker, 1996; United Nations Population Fund [UNFPA], 2000). The fast and “invisible” heterosexual way of transmission in SSA may have contributed to the silence surrounding HIV/AIDS, and the

construction of HIV/AIDS as a “disease of the others”. This is illustrative of how the first phase of the epidemic fuels the third and most devastating phase.

Given that the most common form of HIV transmission is through sexual intercourse, countries that have “conservative” attitudes to sex and sex education can have difficulties with open discussions on HIV/AIDS (Lawson, 1997). Moral and social norms connected to sex, and therefore also to HIV/AIDS, substantiate the taboo of sex, and create a fertile climate for stigma, silence, and the further spread of the disease. HIV/AIDS-related stigma can thus appropriate and reinforce pre-existing sexual stigma associated with sexually transmitted diseases (STDs), sexual practices and sexual identities that differ from the “norm” (Parker & Aggleton, 2002).

The nature of HIV/AIDS makes it distinct from other health problems. There is no cure for HIV/AIDS. Medical advances in developed countries have made it possible to regard HIV/AIDS as a chronic, long term, manageable disease. However, since these anti-retroviral therapies are of limited use, and unaffordable for many developing countries, the majority of people with HIV/AIDS (PWA) on world basis are excluded from possible treatment (Lawson 1997; UNAIDS, 2002a). Living with HIV/AIDS in SSA often means facing the fact of premature death. Because HIV/AIDS is a life threatening disease, it is an illness that people fear, and a disease many equal to an automatic death sentence. The stigma associated with HIV/AIDS thus interacts with pre-existing assumptions and fears about contagion, disease and death.

HIV is a virus with a long latency period. It is therefore possible to be infected without presenting with symptoms, allowing infections to soar undetected (Lawson, 1997; Statens helsetilsyn, 1993). This makes it possible to easily hide one’s status, and to ignore and deny that the disease exists in ones community. The symptoms of HIV/AIDS often present as opportunistic infections and cancers (WHO, 1990), and symptoms can therefore be explained away or concealed. People tend to develop defence mechanisms when symptoms of HIV/AIDS start to occur. Using covering clothes and keeping away from public places are strategies that can be used to avoid stigma (Muyinda et al., 1997).

The impacts of HIV/AIDS are complex and numeral. HIV/AIDS affects and compromises all aspects of society: personal, social, political, industrial and economical. A diagnosis of HIV/AIDS or suspicion of a possible infection brings with it profound emotional, social, behavioural and medical consequences (WHO, 1990). For the individual, HIV/AIDS cannot be seen as a single crisis or as a stressful event (Dageid, 2002). A transition is a great reconfiguration of one's daily existence, involving redefining one's roles and relations, re-conceptualising one's image and re-planning how to live one's life (Pèrez Blasco, 1998). HIV/AIDS can be thought of as such a transition: an unremitting, uncertain course involving several stressors and challenges pressuring intrapersonal, interpersonal and material resources (Anderson, 1992; Dageid, 2002). A transition, like HIV/AIDS, involves confronting and adapting to distress and potentially negative effects (WHO, 1990). The demanding and tough efforts made in attempt to adapt to the situation can be conceptualised as coping (Pèrez Blasco, 1998). Coping with HIV/AIDS can be understood as a process of trying to maintain, or seeking strategies to maintain, personal identity and integrity (Lie, 1996).

As HIV/AIDS primarily infects the productive part of the population, the epidemic has far greater socio-economic impacts than other diseases (Agadzi, 1989; Lawson, 1997; Lindegger & Wood, 1995; UNAIDS, 2002a; WHO 1990). SSA is now experiencing an increase in mortality, and a reduction in fertility and life expectancy. This affects the social and economic development. The death of an adult can tip vulnerable households into poverty, as the costs of health care and funerals are unaffordable for many families. Reduced levels of nutrition, and even malnutrition can be evident (Agadzi, 1989; Fidjestøl et al., 2000; International Labour Organization [ILO], 2000; UNAIDS, 1998).

As social security systems are scarce, the need for treatment and care for PWHA can require especially women and young girls to stay at home. In order to carry the burden of the disease, leaving school and proper jobs may be necessary. Poverty is a common cause of entry into the sex industry (Lawson, 1997; UNFPA, 2000), and can also force some women to exchange sex for goods (Agadzi 1989; Døhlie, 2000; Fidjestøl et al., 2000; Hankins, 1997; ILO, 2000; Lindegger & Wood, 1995; Mrumbi, 2000; UNAIDS, 1998). The disease leaves behind orphans with an uncertain future, and their rising numbers are

becoming a huge challenge for the extended families and communities (Døhlle, 2000; Fidjestøl et al., 2000; ILO, 2000; Lindegger & Wood, 1995; Mrumbi, 2000; UNAIDS, 1998). No other infectious disease of the modern era has had such a devastating impact on the world's youngest as HIV/AIDS. The total number of AIDS orphans in Africa was estimated to 11 million in 2001. By 2005, the total numbers of AIDS orphans in Africa are believed to exceed 16 million (UNAIDS, 2002i). Due to HIV/AIDS-related stigma, children experience distress and social isolation both before and after the death of their parents (United Nations Children's Funds [UNICEF], 1999).

Due to poverty and high levels of unemployment, adults and children seek better opportunities by migrating. They often migrate to marginalized circumstances and slum areas in the cities, where education and health facilities lack even more than where they came from. Countries and communities with many migrant- and transport- workers are more vulnerable for HIV transmission, as people in these occupations often have precarious family situations. They tend to reside away from home, often in slum areas with bad sanitary conditions and less facilities, have limited social networks and a higher tendency of having many sexual partners (Lawson, 1997; UNFPA, 2000). With migration, social networks fall apart, family dissolution becomes evident, and communities break down (Lindegger & Wood, 1995). All sectors of industry and commerce become affected as the reduction of both quantity and quality of the labour force goes down (Hankins, 1997; Skjelmerud & Tusubira, 1997). The death of workers affects the employers by increasing their costs and reducing their revenues. Recession in the agricultural sector threatens the food production and food security. In the education sector, loss of teachers and the absence of children result in lower level of education and economical growth (Fidjestøl et al., 2000; ILO, 2000; UNAIDS, 1998; UNAIDS, 2002f). Increase of health and social expenditures challenge the health sector, as well as the general official and political activity. In the long run, decreased tax base, use of savings, and decrease in investment further threaten SSA's vulnerability to other challenges (Fidjestøl et al., 2000; ILO, 2000; UNAIDS, 1998). In times of social dislocation such as droughts, famines, and war, poverty becomes even more striking.

Due to the immense personal and socio-economic impacts of HIV/AIDS, being infected can imply becoming a “heavy burden”, rather than a contributor, to ones family and community (Staugård, 1996a). HIV/AIDS challenges the family’s and the community’s capacity to offer support. People, on whom others depend, may be deemed to be guilty, blamed and stigmatised for their resource draining illness. Stigma may, as an example, jeopardize the future of AIDS orphans, as they are carriers of their parents’ burden and often perceived as burdens themselves (Alubo et al., 2002). All this may contribute to HIV/AIDS’ status as a marginalized disease.

The impacts of HIV/AIDS have been worst for families and households from poor communities, reducing their ability to provide food, housing and necessary services even more. At the same time, it is these already disadvantaged people who are the most vulnerable to HIV-infection (Barnett & Blaikie, 1992; Sydnese, 2000). Marginalized countries and communities are those at highest risk of HIV/AIDS due to limited access to education, prevention, health- and recreational- facilities (Barnett & Blaikie, 1992; Lindegger & Wood, 1995). High levels of untreated STDs in poor communities render people biologically more vulnerable to HIV-infection as STDs damage the surface of the genital area and make the body more receptive to the HIV virus. Poor nutrition and frequent exposure to other diseases also make people in poor communities more prone for developing AIDS when first infected with HIV (Lawson, 1997). Poverty increases the vulnerability to HIV/AIDS, which in turn exacerbates poverty – an important factor in the spreading of HIV/AIDS. The relationship between HIV/AIDS and poverty can be seen as bi-directional. Because marginalized communities are most prone to the epidemic and the personal and socio-economic impacts of the epidemic, new forms of social exclusion can have reinforced pre-existing social inequalities and stigmatisation of the poor, homeless, landless and jobless (Parker & Aggleton, 2002).

In many African countries, the low status of women increases their vulnerability to HIV/AIDS and the HIV/AIDS-related stigma. Biological, gender related and socio-economic factors render women less able to protect themselves from HIV-infection (Agadzi, 1989; Dageid, 2002; Hankins, 1997; ILO, 2000; Lawson, 1997; Schoepf, 1995; UNAIDS 2002b; UNFPA, 2000). Women are often discriminated against in terms of access

to education, employment, credit, health care and inheritance. Violence to women and violations of their human rights are often evident. Relationships with men, both formal and commercial, often serve as vital opportunities for economic and social security. Being dependent and subordinates, make it difficult for women to demand fidelity or divorce, and to negotiate safe sex through condom use. In times of armed conflicts, women are also victims of war related violence and rape (Dageid, 2002; Forum for Women and Development [FOKUS], 2001; Hankins, 1997; ILO, 2000; UNAIDS, 2002b; UNFPA, 2000). In similar ways, women are also less able to protect themselves from HIV/AIDS-related stigma because they often have a disadvantaged position and limited right to express themselves due to economic dependency, customs and traditions (Bond et al., 2002; Mill, 2003; Paxton, 2002; UNAIDS, 2002e). In Nigeria, women are frequently blamed for the HIV/AIDS-epidemic, as in many other African countries (Alubo et al., 2002). Comparative studies from India and Uganda show that women are more likely to be blamed for their HIV-status, even when they have been infected by their husbands, in what for them have been monogamous relationships (UNAIDS, 2000). It is a paradox how women are being blamed for HIV/AIDS when they in fact are in a limited position to control their own sexuality. The construction of women as the carriers of the infection may reflect entrenched asymmetrical patterns of power, where dominance and relative impunity are maintained over disempowered and “blameworthy” women (Ratele & Schefer, 2002). HIV/AIDS-related stigma can therefore reinforce pre-existing disadvantages of women (Parker & Aggleton, 2002).

Since HIV/AIDS has become associated with already stigmatised groups, PLWHA can become further devalued through the assumption that PLWHA also belong to such marginalized groups. This augmentation of devaluation can serve as a self-maintaining aspect of stigma. Considering how some contextual factors may have facilitated the spread of HIV/AIDS and the progression of HIV/AIDS-related stigma in SSA can be appreciated as useful epidemiological knowledge. Considering these factors in this section can, however, also enhance a similar form of augmented devaluation through the creation of associations between marginalized groups like the poor and women, and HIV/AIDS.

In summary: HIV/AIDS-related stigma is a result of the interaction between diverse pre-existing social and cultural sources of stigma and the fear of contagion, disease and death. A basic assumption in this thesis is that HIV/AIDS is a disease caused by a virus *and* a socially constructed condition, thus involving both biological and cultural processes. The HIV/AIDS-epidemic is robbing people and countries of their valuable resources and capacities, on which human security and development depend (Barnett & Blaikie, 1992). The impacts of HIV/AIDS function as fertilizers for the further spread of the virus, and also contribute to the strong HIV/AIDS-related stigma, as they invoke sensitive issues of blame and responsibility for self and others. The threatening nature and fear provoking personal and socio-economic impacts of HIV/AIDS presumably gives HIV status as a disregarded “disease that dares not speak its name” (Lie, 1996).

As Professor Alan Whiteside at the University of Natal in South Africa (Lawson, 1997, p. 4) puts it: “AIDS is the end result of an HIV infection and it is a health issue. But HIV/AIDS are both symptoms rather than causes. They are symptomatic of past injustices, dislocations and inequalities. I think when one looks at the AIDS epidemic one has to look both upstream at the causes – like poverty, the violence, the position of women – and downstream at the consequences. So the relationship between AIDS and development is a very complex one”. This also seems to account for the HIV/AIDS-related stigma. PLWHA tend to be stigmatised not only because of their HIV-status, but also due to other qualities ascribed to them like sexuality, poverty and gender. This double and some times triple stigma contributes to an increased burden for PLWHA (Norwegian Church Aid [NCA], 2002).

Understanding stigma

Because HIV/AIDS-related stigmatisation is such a complex psychological and sociological consequence of HIV/AIDS-epidemic, and because it leads to the further spread of the virus at the same time as it complicates care and prevention, the need to understand this phenomenon is of utter importance.

Erving Goffman, a pioneer in stigma research, brought scientific attention to the concept of stigma with his classic book from 1963; “Stigma: notes on a spoiled identity”. He defined stigma as “an attribute which is highly discrediting”. The attribute could be both a physical mark and non-physical characteristics. He also wrote that “by definition we believe the person with a stigma is not quite human” (Goffman, 1963 p.15). This assumption works to justify the discrimination and inhumane treatment of stigmatised people. Crandall and Coleman (1992) noted that stigma legitimise treating stigmatised people less humanely than those with no stigma.

Historically stigma was a physical mark that was burnt or cut into the body. The mark publicly identified the person as deviant from the norms of society, and as one to be avoided (Crawford, 1996). The Star of David that the Jews were forced to wear during WWII is one example. Because HIV/AIDS not necessarily is a visible condition, attempts to make the HIV/AIDS stigma visible have been made. In 1986 W. F. Buckley suggested in the New York Times that everyone detected with AIDS should be tattooed (Herek & Glunt, 1988). In Tanzania, HIV-positive children have reportedly been requested to wear a red ribbon or a red star on their school-uniforms (France, 2001).

Neuberg et al. (2000) say that to stigmatise an individual is to define the individual in terms of a negative attribute, and then to devalue him or her in a manner appropriate to this label. Stigma is a concept that is broad and multidimensional, and its essence centres on the issue of deviance and devaluation (Alonzo & Reynolds, 1995). The stigma itself leads to attributions about the bearer of the mark, in which other aspects of the person are interpreted in terms of the mark. This interpretation can often lead to a global devaluation of the person.

In his book, Goffman noted that stigma is not a static attribute of the person, but something that is attributed to the person in a social interaction. He proposed that the normal and the stigmatised were perspectives, rather than persons. Other theorists after Goffman (e.g. Crocker et al., 1998; Jones et al., 1984; Katz, 1981) have also focused on the contextual and dynamic aspects of stigma, stigma as a relational process, and have made important contributions to the research on stigma.

Dovidio et al. (2000) define stigma as a *process* that leads certain people who satisfy certain criteria to become excluded from various social aspects of life and social interactions. This process itself, and the meaning given to it by its participants, is in turn shaped by the cultural context. Brown et al. (2001) focus on stigma as a dynamic process that arises from the perception that there has been a violation of a set of shared attitudes, beliefs and values.

As illustrated, HIV/AIDS as a disease in itself is something that evokes stigma, but it gains a double stigma from its socially constructed meaning. The need to separate HIV/AIDS from moral and social meanings when dealing with HIV/AIDS-related stigma in SSA has been advocated (UNAIDS, 2001a). The link between HIV/AIDS, mortality and moral is crucial in understanding the social meaning attributed to HIV/AIDS. Many places in SSA, HIV/AIDS has been conceptualised as a shameful disease (Dageid, 2002; Lie, 1996). Therefore, in understanding the HIV/AIDS-related stigma, it is also necessary to look at the representational systems that underlie the social construction of HIV/AIDS itself.

Two central discourses that operate in the construction of HIV/AIDS have been described (Ratele & Shefer, 2002). One is medical and scientific, constructing HIV/AIDS as an epidemic associated with contagion, disease and death. Central to this discourse is the use of military metaphors like “the war against AIDS” (Sontag, 1988), thus creating a context of fear, anxiety and panic. The second discourse centres on HIV/AIDS and its moral and social meanings. Here HIV/AIDS is seen as a result of deviant behaviour, in light of social constructions of sexual and moral behaviour. A central construction here is that of HIV/AIDS as punishment for moral transgressions, fortifying the connection between the psychology of contagious disease and moral impurity. An example of this is how certain aspects of health and moral are closely linked in Tanzania. HIV/AIDS is understood as a consequence of breaking moral and health-related taboos (Lie, 1996). Conforming to the moral rules enforced by society ensures good health, whereas violations of these result in disease.

How HIV/AIDS is locally termed and expressed, can reflect the conceptualisation of HIV/AIDS. Some places in Nigeria, AIDS has been termed “*agolochen*” (separation from

people or isolation) and “*ngu a igba ga*” (person without kinsmen) (Alubo et al., 2002). A common metaphor in Swahili for contracting AIDS is “stepping on the electric fence”(France, 2001). Not only do these terms reflect how HIV/AIDS is conceptualised, they also illustrate how language can contribute to, and maintain, HIV/AIDS-related stigma.

In order to examine the process of stigmatisation, some dimensions of stigma will be considered. The dimensions are important in understanding stigma, because they can have significance for the stigmatisation process by influencing the severity with which people are stigmatised. These dimensions can also influence the quality of interaction, and the process of stigmatisation itself. The dimensions to be presented can elucidate why HIV/AIDS-related stigma is so powerful, and illustrate how it gains its strength from multiple facets. Thereafter, possible functions of stigma will be explored. The dimensions and functions of stigma overlap each other, and the distinction between the two may seem artificial, though necessary for a structured consideration.

It is not without caution that these perspectives are presented. Western perspectives have dominated psychological theory and research in many years, though considerable progress has been recorded (Nsamenang, 1993). The growth of African psychological literature was slow at start, but has increased dramatically since the mid sixties (Gupta, 1995).

Understanding HIV/AIDS-related stigma in the context of SSA has, however, rendered necessary the use of Western theory. Cross-cultural psychology has approved the cross-cultural validation of western theory (Berry et al., 1992). Using theories mainly presented by researchers from the West invites, however, a host of potential pitfalls. Using Western theory to try to understand HIV/AIDS-related stigma in SSA necessitates a culture sensitive stance if a valid understanding is to be obtained. The understanding of stigma, requires an understanding of local, political, social, economic and cultural frameworks (Goldin, 1994). Cultural contextualization of psychological theories is therefore of utter importance when working with global and cross-cultural phenomena such as HIV/AIDS (Dageid, 2002).

Dimensions of stigma

Stigma has the power to discredit the whole moral being of the stigmatised individual. The stigmatised attribute is thought to reveal more underlying and global negative attributes of the person. Several researchers have outlined different dimensions of stigma. These dimensions are attempts of constructing schemas to aid the understanding of stigma and the different conditions under which stigma arises. By defining dimensions of stigma, stigma can be organised into meaningful categories. Some of these dimensions will be used to construct a framework for understanding HIV/AIDS-related stigma.

Goffman distinguished between three different types of stigma. Stigma as

1. abomination of the body
2. blemishes of individual character
3. tribal identity

Abomination of the body refers to disfiguring conditions and physical handicaps.

Blemishes of individual character, refers to individual traits and/or actions that are deemed unacceptable in the culture (e.g. unaccepted sexual practices). Tribal identity refers to group membership in marginal groups, e.g. sex-workers, migrant workers, the poor and women.

HIV/AIDS fits all three of Goffman's stigma types. The progressive nature of HIV/AIDS and the fact that the individual ultimately will succumb to cancers or opportunistic infections is in itself stigmatising, reflecting Goffman's stigma "abomination of the body". The fact that HIV/AIDS primarily is transmitted through heterosexual contact in SSA (UNAIDS, 2002e) coincides with Goffman's dimensions of blemishes of individual character. This modus of transmission can in itself contribute to stigma, since sexuality, as already illustrated, is a sensitive subject and often surrounded by taboo in many contexts in SSA (Lawson, 1997). HIV/AIDS can be understood as proof of sexual promiscuity and is often conceptualised as a "prostitutes disease"(Dageid, 2002). This conceptualisation becomes discernible in the term, "*chilule*", a word often used in Zambia to refer to women

who are perceived as having HIV/AIDS, meaning prostitute (Bond et al., 2002). In SSA, women, sex workers and people living in poverty are, as mentioned, especially at risk for HIV-infection. These are already stigmatised groups, and their “tribal identity” often contributes to multiple stigmas.

Goffman also made a distinction between being “discreditable” and “discredited”. Being discreditable involves having a stigma that can be hidden, and choosing not to disclose it. Being discredited involves having a visible stigma, or having disclosed a stigma that was previously hidden.

The more visible a stigmatising condition is, the greater negative impact it will have on interactions (Crocker et al., 1998; Goffman, 1963; Hebl et al., 2000; Katz, 1981). Even having a hidden stigma can have an impact on interactions, since knowledge of one’s hidden stigma may change the way one behaves, thereby effecting the interaction (Goffman, 1963; Smart & Wegner, 2000) This visibility-concealability dimension is highly relevant with regards to the HIV/AIDS-related stigma, and will soon be illustrated.

Jones et al. (1984) distinguish between other dimensions of stigma. They have presented 6 dimensions that they consider important.

1. concealability
2. course of the mark
3. disruptiveness
4. aesthetics
5. origin
6. peril

Concealability involves the extent to which the stigma is visible, and is associated with Goffman’s distinction between being discreditable and discredited. Course of the mark relates to if and how the attribute changes over time, and what the ultimate outcome is.

Disruptiveness relates to the degree the stigma interferes with social interaction. The dimension of disruptiveness is often present in the definition of stigma, as stigmatisation involves the exclusion of certain individuals that have certain attributes. Aesthetics refers to subjective reactions to the “ugliness” of the stigma. Origin accounts for the circumstances in which the condition originated, and whether the person was responsible for it or not. Peril accounts for the danger that stigma imposes on others, and to how imminent and serious the danger is.

Other researchers have emphasized the same or similar dimensions when looking at stigma. Katz (1981) distinguishes between four dimensions; responsibility, threat, visibility and sympathy. The dimensions that have been presented partly overlap each other, as origin and responsibility are stigma dimensions that refer to controllability, peril and threat make reference to real or perceived danger, and concealability and visibility refer to the degree a stigmatising attribute is observable. To facilitate reading, the terms visibility, responsibility and threat will be used to reflect these overlapping dimensions.

As mentioned, the immense fear of stigma leads many to choose silence. Using Goffman's term, they assume a discreditable “identity”. Psychological literature is abundant with findings of how secrecy and not confiding in significant others pays a toll on both mental and physical health (Pennebaker, 1995; Smart & Wegner, 2000). The fact that HIV/AIDS carries a stigma that potentially can become visible because of illness progression, the individual may, willingly or not, in time assume a discredited identity due to the course of the mark. By choice, or by the potential visibility of the HIV/AIDS stigma, the silence will be broken. When a stigma that has been knowingly concealed from others becomes revealed, the social life of the individual can become further burdened. The psychological distress can be greater when a hidden stigma is revealed, than when a stigma that has not been hidden is revealed (Smart & Wegner, 2000).

Many researchers have pointed out that interactions between stigmatised and non-stigmatised individuals often are characterized by awkwardness (Crocker et al., 1998; Goffman, 1963; Hebl et al., 2000; Katz, 1981). This awkwardness reflects the dimension of disruptiveness. These interactions are frequently uncomfortable and stressful, to both the

stigmatised and non-stigmatised (Crocker et al., 1998). This could pose a threat to social relations, as humans are highly motivated to avoid negative affect (Nathanson, 1992), and provide fuel for the motivation to keep silent about one's HIV-status. The dimensions of visibility and disruptiveness illustrate the complexity of the HIV/AIDS-related stigma. The dilemma of concealing or disclosing one's stigma will be further explored in the section "To tell or not to tell: the dilemma of disclosure".

The dimension of responsibility is important with regards to HIV/AIDS-related stigma, in light of HIV/AIDS' status as a disease. As illustrated, the idea of illness as retribution for sin and moral transgression is often part of the social construction of HIV/AIDS in SSA (Dageid, 2002; Lie, 1996). This coincides with the responsibility dimension of stigma. Since HIV/AIDS often is conceptualised as something that happens to people who engage in immoral and deviant behaviour, the disease can be seen as something deserved. The dimension of responsibility corresponds to the stigma type "blemishes of individual character" presented by Goffman (1963). When HIV/AIDS is conceptualised as punishment for sins committed, the individual is seen as responsible for the condition because it is something that could have been avoided with correct and moral behaviour. This has resulted in the belief that decent people do not become infected with HIV/AIDS (Dageid, 2002). The social construction of HIV/AIDS can lead people to make inferences about responsibility, even if they have no knowledge about the underlying conditions of infection. When people are perceived as responsible for having contracted HIV/AIDS, the negative reactions in form of stigma increase (Hebl & Kleck, 2000). Ascribing responsibility for a stigmatised attribute, can lead to reduction of sympathy. The dimension of sympathy can thus be seen as related to that of responsibility.

The interplay between dimensions can enhance HIV/AIDS-related stigma. Research has shown that stigmatised individuals who are believed to be responsible for their condition (e.g. HIV/AIDS due to assumed sexual promiscuity) are more rejected and disliked, and receive more negative reactions, than individuals with stigmas that are perceived as outside their control (e.g. as HIV/AIDS due to blood transfusion) (Crocker et al., 1998; Jones et al., 1981; Weiner, 1993).

Threat is also a central dimension of the HIV/AIDS-related stigma. HIV/AIDS poses an obvious threat of contagion, disease and death, and is therefore immensely feared (UNAIDS, 2002d). In general, the stigma associated with a contagious disease that poses an obvious threat to others is greater than when there is no obvious threat associated with the stigmatised condition (Alonzo & Reynolds, 1995; Jones et al., 1984; Katz, 1981). With regards to HIV/AIDS-related stigma, threat can be seen as a fundamental dimension.

Katz (1981) proposed that most stigmas probably hold an element of threat. Why others are considered a threat, and how people come to make these judgements are important aspects to take into account. The dimension of threat with regards to the HIV/AIDS-related stigma can be seen on two levels. Firstly, HIV/AIDS is a disease that threatens physical health and life itself. This type of threat has been termed tangible by Stangor and Crandall (2000). Tangible threats are instrumental and threaten concrete and material goods such as health, social position, safety and wealth. Secondly, HIV/AIDS represents a threat to moral, to beliefs and to peoples understanding of how the world works. HIV/AIDS is often conceptualised as something that happens to “others”. Stangor and Crandall (2000) have termed this type of threat symbolical.

A symbolic threat is when values, beliefs and ideologies are threatened. “The others” are seen as individuals or groups who do not oblige to the values of society, in so doing they pose a threat to these values. This corresponds with the definition of stigma provided by Brown et al. (2001) presented earlier, who emphasise stigmatisation as a process that results from the perception that there has been a violation of shared attitudes, beliefs and values. It is not unlikely that threats that originally were tangible can become generalized to be symbolic, due to the social construction of HIV/AIDS. The fact that humans are capable of metaphoric thought facilitates this generalisation. The two discourses operating in the construction of HIV/AIDS described earlier, reflect these dimensions of threat. The medical discourse reflects the tangible threat that HIV/AIDS represents, while the social discourse reflects symbolic threat. Both discourses draw on metaphors in their construction of HIV/AIDS.

The dimension of threat starts to highlight the function of stigmatisation. When perception of threat leads to stigmatisation, stigmatisation can be seen as a way for the stigmatizer to avoid danger. Stangor and Crandall (2000) claim that the perception of threat appears to be a likely foundation for stigma. Thus the avoidance of danger can be seen as a function of stigma, and as a manifestation of the disruptiveness dimension of stigma presented by Jones et al. (1984). When humans are confronted with danger from which they cannot escape, a common response is to try to protect oneself by distancing oneself from the threat, by creating a distinction between “us” and “them” (Gilmore & Somerville, 1994). This can be done on both an instrumental and symbolic level. The relation between HIV/AIDS-related stigma and threat will be further elaborated upon in the sections on the impacts and functions of HIV/AIDS-related stigma.

Felt stigma, enacted stigma and self-stigmatisation

To fully understand the dynamics of stigma it is necessary to look at stigma from the perspective of both the ones who stigmatise, and from the perspective of those who become stigmatised.

From the perspective of the stigmatised, an important distinction has been made between **enacted** stigma and **felt** stigma. Enacted stigma refers to sanctions that are individually or collectively applied to people on the basis of their belonging or perceived belonging to a particular group. Enacted HIV/AIDS-related stigma refers to the discrimination and violation of human rights that PLWHA or people assumed to be infected with HIV/AIDS may experience (Green, 1995). Felt stigma refers to the feelings the individual has about his or her condition, and the fear of how others will react to this condition. Felt stigma can be seen as fear of, or anticipation of, enacted stigma (UNAIDS, 2000a).

Felt stigma can affect PLWHA’s view of themselves, and of their surrounding community. This perception and the fear of enacted stigma, can lead to avoidance behaviour. Felt stigma can be seen as a survival strategy to limit the occurrence of enacted stigma, such as when people deny their risk of infection or fails to disclose their stigma in order to avoid being banished (Brown et al., 2001). Felt stigma disposes individuals in this manner to

conceal their HIV-status. Felt stigma enables individuals to experience the HIV/AIDS-related stigma and suffer its impacts, without having been an actual target of enacted stigma.

Felt stigma and fear of rejection can impair the individual's perception of available support, and the individual can become vulnerable to signs of possible rejection, possibly misinterpreting the behaviour of others as rejecting. Felt stigma can often lead to the individual isolating him- or herself, because he or she anticipates no support and possible rejection, thereby excluding him or herself from social support. Again, the dimension of disruptiveness becomes apparent. Several studies have linked felt stigma to depression and emotional distress. Feelings of shame and embarrassment are components in felt stigma, and may contribute to the inhibition of an individual's adjustment by maintaining focus on negative aspects of the stigmatising condition (Mickelson, 2001).

Both felt and enacted stigma can have serious consequences for the individual. An individual can internalise stigma, resulting not only in the devaluation of one's identity in the eyes of society, but also in the eyes of oneself (Crocker, 1999). Hiding one's stigma can be seen as a defence against enacted stigma, but does not necessarily exclude the experience of the HIV/AIDS-related stigma. The internalisation of society's judgement can be seen as an act of self-stigmatisation, which is defined as an individual's internalisation of perceived or experienced societal attitudes (UNAIDS, 2001a). The negative attitudes of society towards PLWHA are an important source of stigma. Through awareness of cultural representations, PLWHA know that others devalue their social identity. This awareness can function as a strong motivator for keeping one's stigma hidden, and in some cases it can lead to the cultural representations becoming internalised.

Self stigmatisation can be seen as a way of discrediting oneself. Goffmans (1963) term "discreditable" identity – in terms of choosing to keep one's stigma hidden, implies by definition the concept of secrecy and shame. The word shame itself is thought to derive from an Indo-European word meaning "hide" (Macdonald, 1998). Stigma is intimately linked to a sense of shame, and literature on stigma supports the idea of stigma as a cause of shame (Lewis, 1998). The conceptualisation of HIV/AIDS as a shameful disease, and its

link to moral and sexual taboos in many contexts in SSA, contributes to self-stigmatisation and feelings of shame. Self-stigmatisation can lead to depression, withdrawal and feelings of worthlessness (UNAIDS, 2002c), reinforcing shame, stigmatisation and social exclusion.

Self-stigmatisation and felt stigma are examples of how stigma can exist without or outside the interactional context. Anticipation of negative interaction illustrates how the negative impact of HIV/AIDS-related stigma, does not necessarily require actual interaction. The experience of stigma can thus occur in the absence of other people, but not outside a meaning-giving cultural context.

Some dimensions of stigma have now been highlighted. Understanding HIV/AIDS-related stigma, necessitates exploring possible underlying functions of stigmatisation. The functions of stigma are important in understanding why PWHA become stigmatised and the processes through which this happens. Understanding the functions of stigma is particularly important to constructing a framework for the alleviation and prevention of HIV/AIDS-related stigma.

The functions of stigma

The focus of this section will be to examine possible functions of stigma. Threat as a dimension briefly touched in on the function of stigma. Stigma was portrayed as a reaction to both tangible and symbolic threat, involving the avoidance of danger.

Stigma can be observed in every society, across time and cultures. This universality suggests that stigma may serve a function in society (Dovidio et al., 2000). Which attributes that come to be stigmatised, differ with time and between societies. Old age is, as an example, considered a stigma in the U.S., while considered a valued attribute in Japan. There are, however, some attributes that seem to be universally stigmatised (Stangor & Crandall, 2000). Certain sexual identities, handicaps, facial disfigurements and diseases are some examples (Kurzban & Leary, 2001). These universal attributes have certain dimensions in common, some of which were mentioned earlier. HIV/AIDS and the dimensions of HIV/AIDS-related stigma lend strength to the notion of the universality of stigma.

That stigma serves different functions has been well documented (Neuberg et al., 2000). From the perspective of the stigmatizers, some of the proposed functions of stigma have been; enhancement of self-esteem, enhancement of social identity, and justification and validation of social, economic and political world views (Crocker et al., 1998; Gilmore & Somerville, 1994; Neuberg et al., 2000).

Although it is possible that stigma serves these functions, they do not shed light on who becomes stigmatised. According to the dimensions presented earlier, people who are perceived to present a threat are likely to become stigmatised. In presenting theories on the function of stigma, focus will be on the consensual nature of stigma and its function from this perspective, rather than on potential individual goals that can be obtained by stigmatisation. The processes underlying why people within a society generally come to agree upon which groups are to be stigmatised, will be elucidated.

A bio-cultural approach to the functions of stigma will now be presented. Thereafter, the relation between stigma and power will be explored. The functions of stigma presented in the bio-cultural approach, and the relation between stigma and power can be seen as complementary.

Bio-cultural approach to understanding the functions of stigma

Neuberg et al. (2000) argue that stigma has its root in the biological need for humans to live in effective groups. Living in groups characterized by reciprocity can be seen as a primary human survival strategy. People will therefore stigmatise those who threaten the successful functioning of the group to which they belong. They argue that this perspective elucidates the issue of why people stigmatise, whom they stigmatise, when and how.

Group living is adaptive, with the fundamental benefits stemming from the sharing of individual efforts, resources and knowledge (Neuberg et al., 2000). Those who are identified as threats or hinders to group functioning must be dealt with, and stigmatisation serves the function of both identifying and dealing with these individuals. Stigmatisation identifies and excludes individuals who threaten group functioning. At the same time, the group's values and norms are being communicated. Individuals who do not adhere to the

norms and values of the group will also be considered a threat to the group. Stigmatisation thereby preserves effective groups by dealing with both tangible and symbolic threats.

Individuals can threaten group functioning in several ways. The norm of reciprocity can be violated by choice, such as theft, or by for example physical handicaps that make the individual unable to contribute. Individuals with diseases perceived as contagious and thereby threatening to physical health, like HIV/AIDS, will also be considered as threatening to group functioning since individuals need to remain healthy in order to contribute to group functioning.

One approach to the function of stigma that also emphasizes disease, is that of Kurzban and Leary (2001). They present an evolutionary approach to the function of stigma, and argue that the desire for social distance is predicted by instrumental concerns such as avoiding parasitic infections. How the personal and socio-economic impacts of HIV/AIDS also can be threatening by robbing families and communities for valuable resources, has been illustrated. Since the spread of a disease, like HIV/AIDS, will lead to a decrease in the group's efficiency, the spread must be hindered. This may be achieved through the process of stigmatisation, and reflects a reaction to tangible threat.

For a group to be effective, there must exist a consensus among the group members as to which norms and values they shall abide by. As we have seen, a common social construction of HIV/AIDS is that it is retribution for moral transgressions. In the same manner that a contagious disease can threaten the functioning of the group, so can violation of the group norms and moral codes. Hence, the symbolic threat of HIV/AIDS can also be seen as a threat to group functioning, and therefore also as a foundation for stigma.

Stigmatisation creates a barrier between the healthy and the unhealthy, the good and the bad, those who conform and those who do not. This is the well known "us" - "them" barrier, which is meant to ensure the continuation of the healthy, effective group. This distancing strategy seems to be an integral part of stigmatisation (Ratele & Shefer, 2002). How the HIV/AIDS-related stigma has been seen as a way of reinforcing pre-existing

social inequalities, illustrates how stigma can strengthen the distancing process between “us” and “them” through multiple stigma.

Research in social psychology has shown that humans have a tendency to favour the group to which they belong, and that they have an almost innate scepticism and mistrust to other groups. This preference for the so-called “in-group” is so strong, that random assignment to a group is enough for individuals to act favourably to in-group members. In-group preference is present even in the absence of competition and conflict between groups (Neuberg et al., 2000). This highlights the biological need to belong to groups as well as the innate disposition humans seemingly have to engage in stigmatising processes. In later sections, the need to belong will again be highlighted. We will move beyond the biological perspective presented by Neuberg et al. (2000), and examine the need to belong as a fundamental human motivation. The aim will be to enhance the understanding of how HIV/AIDS-related stigma affects the individual.

When stigmatisation serves the function of ensuring the group’s functioning because it is a reaction to a real or perceived threat, on a tangible or symbolic level, the stigmatisation itself becomes justifiable. The perception of threat can also be escalated, e.g. through negative media propaganda. In many African countries, the media has associated HIV/AIDS with e.g. non-acceptable sexual behaviour and death, and thus contributed to the production, maintenance and the legitimisation of HIV/AIDS-related stigma (UNAIDS, 2002-2003). Doing the opposite, reinterpreting the perceived threat of HIV/AIDS, could reduce stigmatisation. This is important to keep in mind with regards to the alleviation and prevention of HIV/AIDS-related stigma, and will be considered later.

Stigma and power

Approaches to the function of stigma, indirectly highlight power aspects of stigma. Stigmatisation requires power, as one cannot stigmatise without having the power to do so. Stigma is linked to power and has its origin in the structure of society. Power is essential in the social production of stigma (Link & Phelan, 2001).

Stigma creates and is in turn reinforced by social inequality. Stigmatisation is thus an exercise of power over certain people, underlining and reinforcing the differences between powerful and powerless, rendering the stigmatised disempowered (Gilmore & Somerville, 1994). Parker and Aggleton (2003) highlight how stigma can be used to marginalize, to exclude and to control individuals who, through the process of stigmatisation, are labelled as deviant, representing symbolic or tangible threats.

Contrasting those who are “normal” to those who are deviant, those who contribute to those who do not, enhances group functioning and creates order and conformity. Stigma can thus be used to strengthen a community’s values and functioning by metaphorically or actually excluding, or threatening to exclude, those who are different or unwanted (Gilmore & Somerville, 1994). The boundaries between “us” and “them” thus contribute to the order, structure and functioning of the community.

The fact that HIV/AIDS-related stigma is closely related to other stigmatised attributes such as sexuality, poverty and gender shows how HIV/AIDS-related stigma contributes to the reinforcement of social inequality. How PLWHA represents as both symbolic and tangible threats in the social and medical discourse of HIV/AIDS has also been illustrated.

Manifestations of stigma in Sub Saharan Africa

As illustrated in earlier sections, stigma is a complex and multifaceted phenomenon that can take many forms. Stigma and discrimination can occur everywhere; in the family and in the community, in the education sector and the workplace, in the health care setting, in the religious sector, the media and in the political and judicial system (UNAIDS, 2001c; UNAIDS, 2002e; UNAIDS, 2002-2003).

There are widespread cases of stigmatisation and discrimination of PLWHA in SSA (Alubo et al., 2002; Bond et al., 2002; Mill, 2003; Muyinda et al., 1997; UNAIDS, 2001c; UNAIDS, 2002e; UNAIDS, 2002-2003). The following sections will illustrate how HIV/AIDS-related stigma can manifest itself in SSA. The examples below are, however, not exhaustive and only represent as a limited synopsis.

Some of the reported cases obtained for use in this thesis, have serious limitations with regards to their scientific and empirical quality. The information that has been collected on HIV/AIDS-related stigmatisation is often of an anecdotal quality, and presents as “grey literature” with a limited scientific utility. Parker & Aggleton (2002) point to how these limitations can be due to the unavailability and/or inadequacy of theoretical and methodological tools.

The lack of scientific research on the manifestations of HIV/AIDS-related stigma in SSA presents a serious challenge to the understanding, alleviation and prevention of HIV/AIDS-related stigma. As mentioned, understanding HIV/AIDS-related stigma is essential because it lays the foundation for effective and successful ways of dealing with HIV/AIDS-related stigma. It is with an awareness of these limitations that we present some of the existing material on the manifestations of HIV/AIDS-related stigma in SSA. The material is of limited amount, and is solely meant to be illustrative. Stigma manifests itself with great variation, both within the regions and the communities of SSA. The following presentation is not sufficient to allow any general assumptions or generalisations to be made about how the HIV/ADS-related stigma manifests itself in SSA.

Stigma often leads people to do things, or omit to do things, that harm others or denies them services or entitlements (UNAIDS, 2002c). In this manner stigma often leads to discrimination and becomes evident through negative special treatment. Discrimination with regards to HIV/AIDS occurs when negative thoughts and emotions lead people or institutions to take action that treat PLWHA unfairly and unjustly on the basis of their presumed or actual HIV-status. Because of the stigma associated with HIV/AIDS, and the discrimination that may follow from this, the human rights of PLWHA are frequently violated (UNAIDS, 2002c; UNAIDS 2002-2003).

Individuals can stigmatise and discriminate both in their personal and professional capacities. Systems and institutions can stigmatise and discriminate through practices and policies (UNAIDS, 2002-2003). Data collection in Ethiopia, Tanzania and Zambia indicate that people are largely unaware that their attitudes and actions are stigmatising

(International Center for Research On Women, [ICRW], 2002). This highlights the need to put HIV/AIDS-related stigma on the agenda.

The family and the community

The family is the main source of care and support for PLWHA in most SSA countries (Parker & Aggleton, 2002). Obligations to care for family-members with HIV/AIDS have been documented in Uganda (Muyinda et al., 1997). Amongst Zambian women, safe disclosure has been considered to imply telling their mothers about their HIV-status (Bond et al., 2002). This may illustrate the importance of family as a source of support for PLWHA. A recent study from Ghana indicates a willingness amongst family-members to offer PLWHA care and support, though stigma also is evident (Mill, 2003). In Nigeria, family-members express an obligation to take care of family-members with HIV/AIDS, though they mostly accept the status within themselves and tend to shamefully shield them away from the community (Alubo et al., 2002). Research from Tanzania has indicated that even when PWHA have been cared for by their family-members, they have experienced stigma and felt that love has been withdrawn from them (Lie, 1996).

Negative family responses to PWHA are also common (Horizons, 2002). When a family learns that one of its members is HIV-positive, a tendency may be to isolate or to chase that person away. HIV/AIDS brings shame upon the entire family, and in many cases the family rejects family-members with HIV/AIDS (UNAIDS, 2002e). In Nigeria, as an example, whole families have been labelled “AIDS family”, and the children of PWHA have regularly been taunted as having an “AIDS mama or papa” (Alubo et al., 2002). It is not only PWHA who are affected by the HIV/AIDS-related stigma, but also people affiliated to them. The contagiousness of stigma has been conceptualised as “courtesy stigma” (Goffman, 1963). Courtesy stigma has also been reported in Uganda (Muyinda et al., 1997).

When PWHA bring shame upon their families, members of the family tend to stigmatise them, treat them with hostility and as less valuable members of the family. In many cases PWHA often experience stigmatisation at home and in the community through blame,

rejection, abandonment, neglect, unjust treatment and punishment (Parker & Aggleton, 2002). Expulsions, separation, confiscation of property, and death threats have been documented (UNAIDS, 2002e). Several women in a Ghanaian study reported that their families no longer were willing to share meals with them after disclosure, and some were told not to touch anything belonging to family-members (Mill, 2003). In Uganda, PWHA have been blamed for domestic instability, and been given insufficient care and treatment (Muyinda et al., 1997). In Zambia, women have also reported experiencing blame, rejection, bitterness, anger, insufficient treatment and neglect (Bond et al., 2002).

In Nigeria, community members have encouraged family-members of PWHA not to waste time or money on them, since the disease cannot be cured anyway (Alubo et al., 2002). Communities may shun, mock, and gossip about those who have, or are perceived to have HIV/AIDS, and stigma may manifest itself in form of violence and murder (Parker & Aggleton, 2002). Common forms of stigma in Zambia are gossip, verbal abuse, name-calling and public ridicule. People avoid sitting close to PWHA, and avoid contact with items they have used (Bond et al., 2002). In a review of disclosure amongst women in Ghana, negative outcomes were experienced in the forms of being avoided and isolated (Mill, 2003). In Nigeria, community members have reportedly been treating PWHA as if they were already dead, staring blankly at them, sitting far away, not paying them visits, spitting at them and not wanting to eat together or share pit latrines with them (Alubo et al., 2002). In Uganda, people have avoided places where PWHA have been. It has also been reported that community members have stopped buying produce from PWHA (Muyinda et al., 1997). In Tanzania, people have also avoided purchasing profitable goods from PWHA (Biswalo & Lie, 1995). PLWHA often find themselves in a position of weakness, abandonment and extreme isolation in the community, a situation that is difficult to deal with (UNAIDS, 2002e).

The education sector and the workplace

In the education sector PLWHA have been refused to enrol or gain access to education facilities. Schools and universities have excluded and expelled pupils and students perceived to be HIV-positive. They have received negative treatment by both peers and

teachers, through teasing and violence (Parker & Aggleton, 2002). In Zambia, AIDS orphans have been taunted and called disparaging names, and sending HIV-positive children to school has been considered unsafe (Bond et al., 2002). Students and school-children have also been segregated within the classroom and been refused to attend medical appointments (UNAIDS, 2002-2003). Besides women, children have been cited as particularly vulnerable to HIV/AIDS-related stigma in Botswana, Tanzania and South Africa, due to stigmatisation in the education sector (France, 2001). In a study from Zambia, the stigmatisation of teachers also became evident, as leave was imposed upon them, making their illness visible (Bond et al., 2002).

In the workplace, HIV/AIDS-related stigma manifests itself through negative interaction, unjust hiring and firing, unfair payment and benefits, limited employment security and health insurance, denial of medical absence and leave, and inconsistent promotion and training (UNAIDS, 2002-2003). Prohibitions to enter certain occupations, and mandatory HIV testing as a requirement to obtain work permits have also been documented (Parker & Aggleton, 2002). Employees have reportedly been treated poorly and harassed by both business leaders and co-workers. Co-workers have refused to work next to PWHA (Parker & Aggleton, 2002). In Botswana, private companies have tested employees for HIV during regular health-checks without informing them it was a HIV test. If test results were positive, they were subsequently fired (Lie et al., 1996).

The health care setting

In many instances, the institutions where one expects to obtain care and support is the first place where people experience HIV/AIDS-related stigma (UNAIDS, 2002-2003). Health care settings have been identified as the most frequently cited context for experiencing HIV/AIDS-related stigma in SSA (UNAIDS, 2001a). In health care settings, stigma may be expressed in lesser standard of medical care, restricted access to facilities, or denial of drugs and treatment. Conditional treatment, name tagging, lack of confidentiality and negative attitudes and interaction of health workers are some documented incidents (UNAIDS, 2002-2003). In Zambia, patients have reportedly been segregated, isolated, left in the corridors, been dealt with last, been called disparaging names, and been discharged to

go home or to go to traditional healers so that “other” diseases could have the hospital beds (Bond et al., 2002; UNAIDS, 2002e). In some hospitals, HIV test results have not been communicated to patients, and testing has been conducted without any pre- or post-test counselling (UNAIDS, 2002e). In a Ghanaian study, women reported that information about their own HIV-status and their partner’s cause of death had been withheld from them (Mill, 2003). In health care settings, medical research on HIV/AIDS has also been conducted inappropriately and unethically. Research has been performed without informed consent and confidentiality. Some patients have been discriminatory selected and misused for research projects, and non-equitable access to information and benefits of research have been given (UNAIDS, 2002e).

HIV/AIDS-related stigma in health care settings poses a serious threat to HIV/AIDS prevention and care. HIV/AIDS-related stigma in health care settings can directly prevent people from attending HIV/AIDS testing, seeking treatment, care and support (France, 2001). Health care personnel have both a responsibility and a unique opportunity to deal with stigma within their professions and workplaces (Health and Development Networks [HDN], 2001). The role of health care workers in dealing with HIV/AIDS-related stigma will be discussed in the section on alleviation and prevention.

The religious sector

In some instances the religious sector (churches, mosques, religious schools, lay groups, and religious community-based organizations) reinforce stigmatisation of PLWHA through acting upon their attitudes towards sexuality, the use of contraceptives, multiple sexual partnerships and the notion that HIV/AIDS is a punishment by God (UNAIDS, 2002-2003). Some religious leaders and religious organizations have used their power to maintain status quo, rather than to challenge and modify negative attitudes towards PLWHA. How religious doctrines, moral and ethical positions have contributed to the perception that PWHA have sinned and deserve their “punishment”, has been noted by the African Regional Forum of Religious Health Organizations (Parker & Aggleton, 2002). Such attitudes promote silence and stigma, and can make finding solace and support in religion difficult for PWHA.

In the religious sector, PLWHA have been excluded, abandoned, condemned, and treated as “witches”. People have been denied spiritual assistance, and have been blamed for their HIV-status (UNAIDS, 2001a). In a Zambian study, some churches were reported to impose mandatory testing before allowing marriage, and said to refuse to discuss realistic HIV/AIDS prevention strategies (Bond et al., 2002). In Nigeria, PWHA have been given different funeral rites. The mourning period has been shorter than for “normal deaths”, and it has been suggested that the graves of people who have died from AIDS should be much deeper than others’ to guard against any possibility of post-burial infection (Alubo et al., 2002). Quick and non-traditional funeral ceremonies for people that have died of AIDS have reportedly been conducted in Ghana (Mill, 2003). PWHA have also been promised miraculous healing, and have in this manner been taken advantage of in mendacious propagandas (UNAIDS, 2001a).

The media

The media is a useful canal for campaigns communicating information on HIV/AIDS and HIV/AIDS-related stigma. From an international perspective, Garcia Gonzalez (2000) highlights how HIV/AIDS-related campaigns can be fear-arousing and based on cognitive rationale messages that tend to produce anxiety and confusion, rather than changing behaviour or social norms. In many African countries the media has succeeded in associating HIV/AIDS with sexual promiscuity, death and minority groups like sex workers and homosexuals. The media does not always have the necessary knowledge and background information when reporting on situations regarding HIV/AIDS and PLWHA. This can lead to inappropriate and negative journalism, which can include improper comments, the use of negative terminology and, sensationalism. The use of terms like “innocent AIDS victims” implies that there are guilty ones responsible for their condition. The media has also violated confidentiality when reporting on PLWHA (UNAIDS, 2002-2003).

The political and judicial system

HIV/AIDS-related stigma can be manifested in the forms of laws, policies, regulations and administrative procedures, which are justified as necessary to protect the general population (Parker & Aggleton, 2002). In some instances stigma has been manifested through compulsory examination and screening, compulsory testing and treatment, compulsory notification of HIV/AIDS cases, restrictions of the right to anonymity etc. Due to their HIV-status, PWHA have had problems obtaining insurance contracts and bank credits (UNAIDS, 2002e). Many countries have introduced policies restricting travelling and migration for PWHA, because they are seen to represent a danger for public health or health budgets in the host country (Parker & Aggleton, 2002). Denial of entry and deportation, thereby restraining people's freedom of movement, has been evident in West- and Central- Africa (UNAIDS, 2002e).

In many countries, laws, policies, regulations and administrative procedures have contributed to a more supportive environment for PLWHA. Despite the existence of a supportive judicial system, lack of law enforcement contributes to stigma and discrimination. Documentation of discrimination is limited. Executive inaction further legitimises stigmatisation (Parker & Aggleton, 2002; UNAIDS, 2002-2003).

The many ways HIV/AIDS-related stigma manifests itself within the society illustrate the complexity of HIV/AIDS-related stigma. This complexity renders it difficult to generalize about HIV/AIDS-related stigma as a phenomenon, at the same time as it poses a challenge to attempts aimed at alleviating and preventing HIV/AIDS-related stigma.

The impacts of HIV/AIDS-related stigmatisation on the individual

The pervasive and devastating impacts of HIV/AIDS-related stigma have already been illustrated. To enable a more detailed exploration and understanding of the impacts of HIV/AIDS-related stigmatisation on PLWHA, a theory of fundamental human motivation will be presented.

Baumeister and Leary (1995) have proposed that **the need to belong** is a fundamental human motivation. This theory elucidates the impact stigmatisation can have on individuals, at the same time as it coincides with perspectives presented earlier, on the functions of stigma. Because stigma affects and disrupts relations, this theory can be used as a framework for understanding the impacts HIV/AIDS-related stigma can have on PLWHA. How stigma can lead to social exclusion of PLWHA, or PLWHA withdrawing themselves from society because of fear of stigma or self-stigmatisation has been illustrated. The impacts this can have on PLWHA can be understood in light of the need to belong as a fundamental human motivation.

The need to belong

Empirical research supports the postulation that the need to belong is a fundamental human motivation (Baumeister & Leary, 1995). For a need to be a fundamental human motivation, certain criteria need to be fulfilled. Amongst these are that it must be universal, operate in a variety of settings, affect a broad variety of behaviours and have implications that go beyond immediate functioning. A motivation can only be fundamental if health, adjustment or well-being requires that it be satisfied (Baumeister & Leary, 1995). This implies that if the need to belong is not fulfilled, the individual can suffer severe psychological distress.

Baumeister and Leary (1995) have reviewed the existing empirical evidence in order to evaluate the validity of the need to belong as a fundamental motivation, and conclude that the evidence supports the need to belong as a fundamental motivation.

Baumeister and Leary (1995) propose that the need to belong has two central features: **frequency** and **quality** of interactions and relations. People need to have frequent contacts or interactions with other people, and these need to be seen as stable, continuous and marked by affective concern. Thus, to satisfy the need to belong, the person must perceive the other as one who cares for and is concerned about his or her welfare, and the interactions and contact should be of a certain frequency. The need to belong as a fundamental motivation can therefore not elucidate the impact of stigma on the individual

in all cases. The need to belong can only elucidate the impacts of stigma in those situations where stigma disrupts relations based on frequent, stable, continuous and affective contact.

As the need to belong is a fundamental motivation, loss of frequent affective care should provoke aversive reactions in the individual that go beyond negative affect. Disruption and fear of disruption of important relationships are major stressors for humans, negatively effecting psychological and physical well-being. The tendency for human beings to respond with distress and protest to the end of a valued relationship is nearly universal, even across cultures and across the age span (Baumeister and Leary, 1995). Anxiety and distress at separation from important others can be seen already during infancy (Mahler et al., 1975). Social exclusion may be the most common and important cause of anxiety, and depression is linked to the degree to which one feels included and accepted by others (Baumeister & Leary, 1995). Changes in one's belongingness status will produce emotional responses, with positive emotions linked to increases in belonging, and negative emotions linked to decrease in belonging. Many people even resist dissolving relationships that are harmful and destructive (Baumeister & Leary, 1995). This illustrates how important the need to belong can be, and how motivated humans are to maintain affective relations.

General well-being and happiness in life seems to depend on having some close social ties. The connection between social support and psychological health is consistent in psychology (Orford, 1992). Social support is relevant to the need to belong because social support is based on positive relationships and interactions with others. Social support is both health promoting and can function as a buffer against stressful life events (Orford, 1992). People facing the challenge of coping with a life threatening disease, like HIV/AIDS, are thus further burdened by the potential disruption of social relationships and the potential loss of social support. When PLWHA is at the most in need of social support and belongingness, this very need is threatened by the HIV/AIDS-related stigma. AIDS orphans are especially vulnerable. Due to their status as orphans, they may become overwhelmed by lack of belongingness (Mrumbi, 2000).

How people isolate themselves because of shame and felt stigma, or are abandoned and rejected because of enacted stigma, have been illustrated. In both instances stigma disrupts

important relations (Crandall & Coleman, 1992). Rejection of PLWHA and the withdrawal of love from PLWHA can be seen as violations of their basic human need to belong. This violation may be one of the gravest consequences of HIV/AIDS-related stigma.

Research on HIV/AIDS-related stigma carried out in Tanzania found that the experience of spouse stigma was predictive of depression, guilt and feelings of not having meaningful relationships (Lie, 1996). Research has shown that depression renders people more susceptible to illness and infection, as it negatively affects the functioning of the immune system and its ability to combat physical disorders (Gilbert, 1992). This illustrates the cyclic dynamics of the HIV/AIDS-related stigma, mental and physical health.

To tell or not to tell; the dilemma of disclosure

The conceptualisation of HIV/AIDS as a disease of shame, sexual promiscuity and immorality has consequences for disclosure and help-seeking behaviour. The fear of HIV/AIDS-related stigma and its negative impacts force many PWHA to face the dilemma of whether to disclose their status or not.

The need to belong, and the impacts of getting this need satisfied or not, has just been reviewed. In this section we wish to explore the potential consequences of disclosure, keeping one's HIV-status hidden or not. The main focus here will be on the price of silence.

Some people choose to disclose their HIV-status to one or a few significant others, while others yet again go fully public. Some people choose to tell no one. These choices all have their different and varying consequences. The fears people have in connection with disclosure of their HIV-status have been identified as the manifestations of felt stigma (Bharat et al., 2001). As illustrated, behaviour motivated by felt stigma, like avoidance and withdrawal, can turn into self-fulfilling prophecies. Trying to avoid the impacts of enacted stigma, felt stigma can thus create and reinforce both felt and enacted stigma (UNAIDS, 2001a). This enhances the dilemma of disclosure.

Disclosure may be necessary to obtain social support. Some HIV-positive people who disclose reveal a supportive network by so doing, gaining both emotional and instrumental support. Others become abandoned as a result of their disclosure. One cannot always know for sure what the reactions to disclosure will be, making the dilemma whether or not to disclose painstaking.

The many examples of the negative consequences of disclosure are abundant, e.g. in Durban, South Africa, AIDS activist Gugu Dlamini was beaten and died of the injuries after revealing her HIV-positive status during a commemoration of World AIDS day in 1998 (UNAIDS, 1999). Episodes like this spread fear and shape perceptions and ideas of what will happen if PWHA disclose. The many ways in which HIV/AIDS-related stigma can manifest and harm PLWHA has already been illustrated. Wanting to protect significant others from worry is also a motivation for not disclosing one's HIV-status (Muyinda et al., 1997). A current and extensive dilemma facing many HIV-positive parents is whether or not to tell their children, and if how and when to do so (Lie, 2000).

Goffman (1963) noted how information control becomes very important to the individual who chooses to keep his or her stigma hidden. Individuals who try to keep their stigmas hidden, can become obsessively preoccupied with thoughts around their stigma. This can be explained by Lane and Wegners' theory of the "preoccupation model of secrecy", that proposes that attempts at secrecy activate cognitive processes that lead to obsessive thinking about the secret (Smart & Wegner, 2000). The constant monitoring of the interaction, steering it in the direction that will best facilitate concealment of the stigma and the cognitive capacity this requires, is bound to influence how one interacts in the relationship. Again the dimension of disruptiveness becomes evident.

The effort and strain that secrecy requires can take its toll on both the psychological and physical well-being of the individual. Crandall & Coleman (1992) have found that PWHA who do not disclose their status to significant others are likely to become more isolated, more depressed and more anxious than those who selectively confide in people they feel they can trust. Keeping one's HIV-positive status hidden from significant others can influence the quality of that relationship. As previously noted in the section about the need

to belong as a universal human motivation, the need to belong is seen as central to functioning. Humans need caring and enduring relations to significant others. Withholding personal information about oneself, such as one's HIV-status, can affect both the quality of affective relationships and the pattern of interaction.

In summary, it is often fear of rejection that leads PWHA to choose silence. This can leave them to live in constant fear of their status being revealed, and the perceived or real consequences disclosure could have. The constant risk of discovery can turn in to a major stress factor, creating a considerable amount of psychological distress, and negative impacts on the physical condition. Choosing silence thus burdens the individual with secrecy, at the same time as it deprives the individual of potential sources of social support (Miller & Major, 2000). As illustrated, neither keeping ones stigma hidden, nor disclosing it comes without a price. However, disclosure has the potential to be beneficial both for PWHA and the society. How disclosure can be used as a tool for dealing with HIV/AIDS-related stigma will be discussed in the section on alleviation and prevention.

Alleviation and prevention of HIV/AIDS-related stigma in Sub Saharan Africa

The tremendous impacts of HIV/AIDS-related stigma, at both individual and societal levels, call for immediate actions aimed at alleviating and preventing HIV/AIDS-related stigma. This section will employ the conceptual framework for understanding HIV/AIDS-related stigma presented above, to devise strategies to alleviate and prevent HIV/AIDS-related stigma in SSA.

HIV/AIDS-related stigmatisation has for long been regarded mainly as an individual phenomenon, as expressions of personal attitudes. Awareness raising and attitude-change campaigns, together with educative strategies based on behavioural psychological models, have therefore consequently dominated the attempts that have been carried out to counter HIV/AIDS-related stigma. Understanding stigma as a phenomenon linked to group processes and functioning, to the production and reproduction of structural inequalities, and as central to the constitution of social order, has major implications for how stigma and

stigmatisation should be investigated and responded to (Parker & Aggleton, 2003). This understanding of HIV/AIDS-related stigma therefore calls for a redefinition of stigma, and for putting greater emphasis on the broader social, cultural, political and economic forces that facilitate the production and maintenance of HIV/AIDS-related stigma (Agadzi 1989; Garcia Gonzalez, 2000; Parker & Aggleton, 2003). Taking a broader focus implies dealing with the social structures and power relations that allow stigma to prosper. Attitudes, misconceptions and fear associated with HIV/AIDS should also be challenged, at the same time as the impacts of HIV/AIDS-related stigma must be reduced by providing care and support for PLWHA (Parker & Aggleton, 2003). These areas for dealing with HIV/AIDS-related stigma will be brought further into focus. Addressing some or all of these areas have been emphasised by other researchers (Brown et al., 2001; Muyinda et al., 1997; Parker & Aggleton, 2002; Patel et al., 2002; ICRW, 2002; UNAIDS, 2000; UNAIDS, 2001b; UNAIDS, 2002c; UNAIDS 2002-2003).

Even though universal aspects of stigma have been emphasised, stigma is still socially constructed and can manifest itself differently across many settings. This poses ethical and methodological challenges. No universal or correct way for understanding, alleviating and preventing HIV/AIDS-related stigma exists. Nor can attempts to deal with stigma be conducted properly, applying universal, standardized and stable concepts of understanding. Before implicating ways to alleviate and prevent HIV/AIDS-related stigma in SSA, some methodological and ethical perspectives need to be taken into consideration. In dealing with HIV/AIDS-related challenges, researchers have to some degree agreed upon which perspectives that can be appropriate. Because these perspectives are to be related to the HIV/AIDS-related stigma, and its alleviation and prevention, a discussion of these perspectives seems warranted.

Ethical and methodological perspectives

Based on the presented understanding of HIV/AIDS-related stigma in SSA, cultural sensitivity, empowerment and action research emerge as important components in any attempt to deal with HIV/AIDS-related stigma in SSA. Taking these perspectives into consideration has been emphasised by other researchers working with HIV/AIDS-related

challenges (Beeker et al., 1998; Dageid, 2002, France 2001; Krantz & Staugård, 1996; Lie, 1996; Lie, 2000; Parker, 1996; Patel et al., 2002; Rakotonanahary et al., 2002; Shoepf, 1995; Skjelmerud & Tusubira, 1997; United Nations Development Programme [UNDP], 2000; Wang, 1992).

Cultural sensitivity

In order to understand how people and communities contribute to mental health suffering, like that of HIV/AIDS-related stigma, and to be able to offer appropriate mental health services, cultural factors must be studied (Brummelhuis & Herdt, 1995; Swartz, 1998; Triandis, 1990). Cultural sensitivity refers to a professional's knowledge of culture and cultural differences. Knowledge of culture involves knowledge of how culture evolves, what constitutes culture, and how culture can change. It also implies an acceptance of diversity and a willingness to take culture into account when seeking to understand how others think, feel and behave within a certain context (Brislin, 1993; Sue & Sue, 1999). Gausett (2001) highlights how one should not disregard African systems of belief that do not fit into Western discourses, but rather assimilate them when working with HIV/AIDS-related challenges.

Before any alleviative or preventive strategies can be planned or implemented, the assessment of the stakeholders' needs, priorities, and cultural standards is necessary (Swartz, 1998). Acquiring cultural sensitivity with regards to HIV/AIDS-related stigma means striving to take new patterns of thought and explanations for the phenomenon into consideration.

It is important to keep in mind that people do not always behave according to the cultural standards. Taking a culture sensitive stance is therefore not sufficient in dealing with HIV/AIDS-related stigma in SSA. One must also strive to be sensitive to each and every individual. In this regard, phenomenological psychology holds an important point of view. Phenomenological psychology stresses people's understanding of the self and one's surrounding world as explanatory for reactions and behaviours. From the perspective of some phenomenologists, no objective or universal reality exists (Creswell, 1998; Egidius,

2000; Graham, 1986). People's understanding is based upon their own reality, as it is lived and experienced. This reality, however, is instituted in a cultural context. Both these perspectives are important to keep in mind when working in the cultural diversity of SSA.

Empowerment

Empowerment is both a value orientation for creating social change in the community, and a theoretical model for understanding attempts to exert control and influence over decisions that affects one's life, at individual, organizational and community level (Zimmerman, 2000). Essential aspects of empowerment are participation, control and critical awareness. The implicit assumption in empowerment is that people are believed to benefit psychologically from more awareness, participation and control (Zimmermann, 2000). People who have self-knowledge are believed to be more effective in making decisions in their lives, and education is therefore a critical component of empowerment (Swift, 1992). In empowerment, opposition to the status quo becomes accepted, and generates objectives of change that expand to an ever-widening circle of self-induced change (Parker, 1996; Swift, 1992). Freire (1970) calls for a related collaborating approach involving liberating learning through co-generative dialogues. In such a process the professional change-agent assists, interacts and cooperates with the stakeholders in developing self-awareness. Such self-awareness can serve as a base for problem-definitions, goals and actions, and make change come into being. Through co-generative dialogues, empowerment activities have the potential to transform communities into positive circles of self-help and greater fulfilment (Swift, 1992).

Garcia Gonzalez (2000) believes that the HIV/AIDS-epidemic will lead us to discover the importance of combining empowerment as a health promoting strategy with traditional prevention strategies. Empowerment as a health promoting strategy is a dialectic model. The goal is a generative spiral of never ending empowering processes, as change is carried out through a holistic unit of analysis, interactively both in persons and environments. Swift (1992) stresses the importance of seeking the causes behind the causes in preventive work. Combined prevention and empowerment strategies can address both the critical dangers

threatening the wellness of society and the flaws and structures of society inhibiting positive transformation (Swift, 1992).

Van Uchelen (2000) points out how psychological theory is dominated by individualistic, rather than collectivistic perspectives. Although empowerment is a multilevel phenomenon that spans the community level of analysis, it still reflects an individualistic ideology of personal power and control as independent and ideal. A critical analysis of power and control is therefore necessary before the initiation of empowering processes. Seeing the self as linked to relations, settings and inter-human realms may need to be emphasized when working with collectivistic cultures (Van Uchelen, 2000). Since the relative emphasis is often said to be towards collectivism in Africa (Lie, 1996; Triandis, 1990), a critical awareness of empowerment as a method and value is necessary when dealing with HIV/AIDS-related stigma in SSA. Misinterpreting the local concepts of participation, control and critical awareness could result in incomplete, inaccurate and insensitive representations of HIV/AIDS-related stigma as a phenomenon.

Emphasising empowering processes in dealing with HIV/AIDS-related stigma in SSA means promoting people's knowledge of HIV/AIDS and awareness of HIV/AIDS-related stigma. Through co-generative dialogues thoughts on how to deal with the HIV/AIDS-related stigma can be generated and reinforced through the constant creation of objectives for change.

Action research

Action research is a research method originated by Kurt Lewin (1948). Action research is a method directly related to solving systemic, real life challenges in given social contexts (Lewin, 1948). HIV/AIDS-related stigma can be regarded as such a challenge. Action research reflects Freire's learning processes used in training for transformation (Freire, 1970), and can illustratively generate critical reflection and group action for social change. Action research is a cycle of diagnosis, action and evaluation, in which the stakeholders are encouraged to use knowledge as it is generated (Greenwood & Levin, 2000). In action research knowledge of human activity is acquired through aiming at changing it, and

current problems of major importance to local stakeholders are solved through democratic inquiry in collaboration with professional change-agents (Greenwood & Levin, 2000). People are believed to both create and change their social reality, and the responsibility for this reality is emphasized in problem-solving processes (Mc Kenna, 2000). The belief that professional change-agents and stakeholders have things to learn and experience from each other is crucial in such people-oriented research (Denzin, 1989). Overall action research has the effect of giving the stakeholders the opportunity to analyse solutions, gain insight and develop and implement own solutions to challenging phenomena (Mc Kenna, 2000). Action research enables researchers to combine theoretical concerns with a humanist concern for the survival and the empowerment of individuals and communities. Action research is in this manner a concrete method for oppressed people to reclaim their identity and power (Schoepf, 1995).

Action research seems appropriate in dealing with HIV/AIDS-related stigma, as it stresses cultural sensitivity through the acquisition of local knowledge, collaboration with and involvement of local stakeholders in an empowering way. Using action research in dealing with HIV/AIDS-related stigma means mobilizing the community, involving locals in all phases of alleviation and prevention: addressing stigma, planning, implementing and evaluating attempts of change. Action research can be seen as a gateway to a more just society, in which stigmatisation no longer will be tolerated.

A theoretical framework for alleviation and prevention

Empirical studies on empowerment and social mobilization have demonstrated that the most effective and powerful ways to deal with HIV/AIDS have taken place when affected communities have mobilized themselves to deal with stigmatisation and discrimination (Parker & Aggleton, 2003). Models of community mobilization, advocacy and social change, constitute an important basis for the development of responses aimed at dealing with HIV/AIDS-related stigma (Parker & Aggleton, 2003). The fact that community-based approaches are the most used in SSA can be seen as a reflection of the understanding that stigma must be dealt with at both a collective and individual level (Brown et al., 2001). In SSA, HIV/AIDS-related stigma concerns everyone, because everyone is at risk. Models of

community mobilization appear highly relevant in SSA, because strategies directed at the individual level never can be scaled up in a manner required for an efficient response throughout Africa, due to financial and academic constraints (Parker & Aggleton, 2003).

When environmental and social factors have powerful impacts on the well-being of people, such as with HIV/AIDS-related stigma, problems need to be addressed through systemic strategies directed at all levels of society (Lewis et al., 1998). The ecological model of human development, developed by Bronfenbrenner (1979), provides a structure in which strategies to alleviate and prevent HIV/AIDS-related stigma can be located. Bronfenbrenner defines four systemic levels of interpersonal relations, where change in one level will affect the other levels. These systemic levels are referred to as micro, meso, exo, and macro systems.

Community psychology provides a scientific framework for the development of community-specific attempts aimed at countering HIV/AIDS-related stigma, both on individual and community levels (Lindegger & Wood, 1995). Garcia Gonzalez (2000) points to how the HIV/AIDS-epidemic poses a huge challenge to community psychology, as it is necessary to work creatively and systemically in order to deal with HIV/AIDS-related issues. Changing the social discourses on HIV/AIDS can be seen as the superior objective in countering HIV/AIDS-related stigma.

Community approaches see the causes of problems as social interactions between persons, settings and systems, analyse all levels of the community, emphasise prevention rather than treatment, and are methodologically flexible. Community approaches mobilize communities, and address broader socio-political and developmental issues. Community-based approaches encourage multidisciplinary collaboration, including non-professionals and self-help, and is a cultural sensitive approach (Orford, 1992).

Based on the understanding of HIV/AIDS-related stigma in SSA, and the ethical and methodological perspectives considered above, community psychology appears to be an appropriate framework for the alleviation and prevention of HIV/AIDS-related stigma.

The community counselling model appears to be applicable for countering HIV/AIDS-related stigma. This model is based on ecological theories, and assumes that people share a universal drive to belong to some sort of community. The experience people have within the community affect psychological health and well-being, through either nurturing or limiting them (Lewis et al., 1998).

The community counselling model

The community counselling model consists of four comprehensive and complementary components that constitute a framework for bringing about changes in the community. These are; **preventive education, outreach and counselling for vulnerable populations, advocacy and consultation**, as well as **systemic changes and attempts to change public policy**. Community counsellors can be seen as professional change-agents working along two dimensions. Direct services assist individuals in developing knowledge and skills that may enhance their well-being. Indirect services address the social surroundings that affect people's life. Client services are aimed at people identified as needing active assistance. Community services are aimed at providing assistance to larger numbers of people who have not yet been identified as having any problems (Lewis et al., 1998).

Implementation of the community counselling model in Sub Saharan Africa

The necessity of taking a broad focus in order to counter HIV/AIDS-related stigma has been stressed. This section will use the community counselling model to illustrate how different strategies to counter HIV/AIDS-related stigma can be carried out in SSA. When employed in the alleviation and prevention of HIV/AIDS-related stigma, the four components that constitute the model overlap and mutually influence each other. However, systemic changes and attempts to change public policy are primarily aimed at addressing social structures and power relations. Attitudes, misconceptions and fear related to HIV/AIDS can be challenged through preventive education. The impacts of HIV/AIDS-related stigma on PLWHA can primarily be reduced by providing care and support, advocacy and consultation (Parker & Aggleton, 2003).

The four components of the community counselling model can be used in a variety of agencies and institutions. Based on Bronfenbrenner's model of human development, one can see community counselling directed at all systemic levels of interpersonal relations. This means that the model addresses individuals, families, education settings, workplaces, health care settings, religious sectors, the media, the political and judicial system, and subsequently all cultural aspects that influence practices in SSA.

Preventive education

Direct community services provide educational experiences to the community as a whole. This is typically accomplished through education, training and direct experiences that assist people to help themselves. Seminars, courses, presentations, workshops, and other activities are some possible strategies, but the opportunities are endless (Lewis et al., 1998).

Learning can be liberating (Freire, 1970). Increasing knowledge and awareness about HIV/AIDS is perhaps the most crucial component in dealing with HIV/AIDS-related stigma. Education is a key component in empowerment, as well as in any strategy to alleviate and prevent HIV/AIDS-related stigma. Earlier sections have illustrated how myths, misconceptions and negative conceptualisations of HIV/AIDS contribute to stigma. Changing these myths and misconceptions are crucial elements in the alleviation and prevention of HIV/AIDS-related stigma, and important steps towards creating objectives of change.

Preventive education can lead to changes in the negative social discourses that encompass HIV/AIDS, and importantly provide a positive framework for thinking about and coping with HIV/AIDS. Increasing knowledge and awareness about HIV/AIDS and HIV/AIDS-related stigma can reduce real and perceived threats at both tangible and symbolic levels.

Knowledge about HIV/AIDS has shown to reduce stigma (Oduroh, 2002), and information-based approaches for reducing stigma have demonstrated positive effects (Brown et al., 2001). People often do not know that a word, an action or a belief can be perceived as stigmatising, and are often unaware of the impacts stigma can have on the individual and the community. Despite correct knowledge about transmission, fear of HIV/AIDS often

persists. This could be due to people feeling compelled to adopt extraordinary risk-averse behaviours, or to seek alternative explanations for the high prevalence of HIV/AIDS (ICRW, 2002). As mentioned, such alternative explanations, especially when based on fear, operate to maintain HIV/AIDS-related stigma. Preventive education must therefore address and minimize the gap that exists between knowledge, attitudes and behaviour change, by creating a deeper knowledge and awareness that is relevant to people's lives.

Preventive education can be applied in many ways. Using the media is one way to promote education and increase knowledge about HIV/AIDS. As exemplified earlier, the media plays an important role in shaping the social discourses on HIV/AIDS. In the same manner that the media can contribute to HIV/AIDS-related stigma, the media can be used in attempts to reduce HIV/AIDS-related stigma.

An example of the use of media in preventive education has been the introduction of an HIV-positive muppet in the South African version of Sesame Street, Takalani Sesame Street. The muppet is a 5 year-old orphan girl, and the aim of introducing this muppet in the show is the promotion of positive attitudes towards PWHA. As a part of the community, the muppet is respected and appreciated by her fellow muppets, thereby modelling compassion and respect for PWHA. This strategy reflects Bandura's social learning theory, and the concept of observational learning (Bandura, 1977). It is also hoped that the introduction of this muppet will help dispel the denial and ignorance that surrounds HIV/AIDS, and encourage openness and prompt discussions about HIV/AIDS (Lim, 2002). This is an example of using an innovative approach in raising awareness and knowledge about HIV/AIDS. By creating a popular culture in which open and informed dialogues can take place, communication between people is encouraged, and the silence can be broken.

However, not all people can be reached by means of such medias, and providing vital information about HIV/AIDS to all communities must take this into consideration. A study from Tanzania indicated that stigma can have a tendency to be more prevalent in rural areas and amongst the uneducated (Oduroh, 2002). Because medias such as television, radio and the printed press can be inaccessible to people residing in rural areas, preventive education

must employ strategies that are specifically adapted to the community at which it is directed.

Schoepf (1995) emphasises how active, participatory learning methods can be used to provide information to PLWHA in SSA, in ways that are relevant to their lives. Active and participatory learning methods include the utilisation of short dramas, role-plays, puppet performances, comic sketches, and pictures that tell stories in readily understood metaphors. Such active, participatory learning methods encourage dialogues. Providing top down information does not promote dialogues, self-awareness and self-induced change.

The use of participatory theatre in Tanzania to create knowledge and awareness, and to deal with the reluctance to talk about HIV/AIDS in communities is another example of the innovative use of preventive education. This method moves beyond message delivery, and towards grassroot mobilization, involving whole communities (Patel et al., 2002). Because the community members participate in the production of the theatre, ownership and empowerment are enhanced. Countering HIV/AIDS-related stigma necessitates social change, not only individual change (Parker, 1996). Through active participation, people feel a collective responsibility in addressing the challenge of HIV/AIDS-related stigma and for making changes in their communities. Participatory theatre has been very successful in stimulating communities to discuss sensitive issues (Patel et al., 2002).

According to social learning theory people learn by observing the behaviour of others. People who have an admired status, are perceived to be similar to those who observe, and are perceived as competent tend to function as role models (Bandura, 1977). In this manner, people with a certain status and proficiency can serve as role models. It is important to involve people who have the power to function as role models, when providing preventive education.

As mentioned in the section on manifestations of stigma, the health care setting is one area where stigma is prevalent, and where the consequences can be especially devastating. The causes and consequences of stigma in this setting are both general, and specific to the health care setting. Fear of contagion, disease and death has clear negative effects on health

care workers' attitudes towards and treatment of PLWHA (Brown et al., 2001). Because of the specific repercussions stigma has in this setting, education of health care workers needs to be prioritised. In capacity of their professions and positions, health care workers can function as role models. Their professional status, code of ethics and conduct, social and professional authority, and ability to act as educating role models for their communities, place them under the obligation to be change-agents for reducing stigma (HDN, 2001). Health care workers serve as models capable of eliciting behavioural change in certain other people. If health care workers are observed treating PLWHA with compassion and respect, this can set the mode for others. On the other hand, when health care workers are observed treating HIV/AIDS patients in a stigmatising manner, this observation can model behaviour for others, and serve to justify and maintain stigmatisation and discrimination of PLWHA.

Attempts to address the specific challenges faced in the health care sector have been carried out through promoting knowledge and skills amongst health care workers in Zambia (Bond et al., 2002). The Zambian Nurses Association has in collaboration with WHO and UNICEF conducted workshops for nurses and midwives. These workshops are to be combined with an interactive radio programme, a quarterly newsletter and support groups for nurses (Bond, et al., 2002). This strategy utilises principles of participation, collaboration and empowerment, and is an example of how different education methods can be combined in the provision of preventive education. Peer education is one of them.

Peer education is one of the most widely used strategies in countering the HIV/AIDS-epidemic. Peer education typically involves training and supporting members of a given group (or community) to effect change among members of the same group. Peer education is used to effect changes in knowledge, attitudes, beliefs and behaviours on the individual level, but can also create change at the societal level (Horizons, 1999).

PLWHA can play an important role as peer educators with regards to countering HIV/AIDS-related stigma. As peer educators, PLWHA can also function as role models for others. Their stories of stigmatisation and discrimination need to be heard, reflected upon and internalised by the general public. By sharing their experiences, PLWHA can

demonstrate how HIV/AIDS and its related stigma impinge upon their lives, yet illustrate the possibility of living positively with HIV/AIDS. Not unlike the mechanisms of support groups, PLWHA as peer educators have the power to model positive coping. Such modelling can perhaps address people's fear of HIV/AIDS and HIV/AIDS-related stigma more than traditional education and provision of information. The involvement of PLWHA is also considered to be important because disclosure and involvement give PLWHA a unique possibility to build up their morale. However, involving PLWHA in countering HIV/AIDS-related stigma is not a method to be used unconditionally, nor is it always appropriate or ethically correct. One reason for this is that it requires disclosure on behalf of PWHA.

Breaking the silence; disclosure as a tool against stigma

Although disclosure can have positive effects on the individual, certain conditions need to be fulfilled for these positive effects to occur. Positive response and social support are essential if disclosure is to be beneficial. The individual also needs to be prepared to disclose, it must not be a decision that is rushed or forced. Psychological preparedness is therefore a critical factor in beneficial disclosing (France, 2001). Full and unconditional disclosure for all PWHA is cautioned.

Disclosure can take place on varying levels, each requiring different strategies. The first level is confiding in a significant other, like a near friend or relative. This is disclosure on an intimate level, and can serve to lessen the burden of living with HIV/AIDS. Research from Tanzania has shown that having a trusting relationship characterised by confidentiality are central factors when choosing to disclose, and to whom to disclose to (Lie, 1996). Disclosing on the intimate level can also be beneficial to both psychological well-being and physical health, because the burden of secrecy is unloaded (Pennebaker, 1990). The second level of disclosure is disclosure that is necessary in order to access social, spiritual or health-related care. The last level is public disclosure. On this level PWHA go fully public, and can function as peer educators and role models in the alleviation and prevention of HIV/AIDS-related stigma.

On all levels of disclosure, the significant factor is how the disclosure is received. For it to be beneficial, the reactions need to be supportive and accepting. One cannot promote disclosure, when individuals or communities are unable to deal with the information disclosed. The setting for disclosure has to be prepared and enabled, just like the individual needs to be psychologically prepared. Only then can disclosure be seen as an appropriate tool against stigma. This aspect of disclosure points to perhaps the most crucial aspect of dealing with HIV/AIDS-related stigma, and that is the need to enable people and communities to deal openly and constructively with HIV/AIDS.

As illustrated, prevention campaigns can reinforce already existing misconceptions and negative social discourses surrounding HIV/AIDS. A central challenge in preventive education aimed at reducing HIV/AIDS-related stigma, is the need to communicate openly and frankly about sex. Open discussion on sex is something that communities can sanction as socially unacceptable behaviour (ICRW, 2002). When constructing campaigns aimed at the alleviation and prevention of HIV/AIDS-related stigma, it is therefore necessary to explore possible unwanted and unintended effects.

Outreach and counselling for vulnerable populations

Direct client services include outreach and counselling for vulnerable populations, and addresses the immediate needs of distressed people and people at risk. Direct client services aim at helping people to develop buffers that can protect their well-being in stressful situations, and includes general counselling and treatment services (Lewis et al., 1998).

PLWHA are confronted by a multitude of complex problems, and are often in need of emotional and practical support in order to cope with the many impacts of HIV/AIDS and HIV/AIDS-related stigma (World Health Organization [WHO], 1990). This section will explore how HIV/AIDS counselling and the treatment of HIV/AIDS-related symptoms can work to alleviate and prevent HIV/AIDS-related stigma.

HIV/AIDS-related stigma is a barrier that can prevent people from attending HIV/AIDS testing, seeking treatment, care, and support (Brown et al., 200; Goldin, 1994; Meursing & Sibindi, 2000; Myinda, 1997; Painter, 2001; UNAIDS, 2000b; UNAIDS 2002c). It is,

however, hoped that as increasing numbers of PLWHA participate in counselling, this can have the effect of reducing stigma and enhancing acceptance of PLWHA (Oberzaucher & Baggaley, 2002). Since seeking counselling may be difficult for many PLWHA, it is important to reach out to the communities and offer counselling actively rather than awaiting arrival of clients (Painter, 2001). There is increasing evidence that HIV/AIDS counselling is feasible to implement in developing countries, despite the existing scientific and economic constraints (Campbell et al., 1997; Lie & Biswalo, 1996; Meursing & Sibindi, 2000; UNAIDS, 2000b). HIV/AIDS counselling can take place in any setting where there is, or could be, a discussion about HIV/AIDS (WHO, 1990).

HIV/AIDS counselling has been described as a confidential dialogue between PLWHA and a care provider, aimed at enabling PLWHA to cope with stress and make personal decisions related to HIV/AIDS (UNAIDS, 2002b). Counselling is based on the belief that people need to confront and come to terms with HIV/AIDS if they are to cope effectively (Dageid, 2002). WHO's Global Programme on AIDS has suggested that the objective of HIV/AIDS-related counselling is to enhance PLWHA's quality of life through encouragement of self-determination, enhancement of self-confidence and the improvement of family and community relations. Prevention of HIV/AIDS transmission and psychosocial support to PLWHA are thus the two main objectives of counselling, and they can be seen as complementary processes (WHO, 1990). Counselling provides a useful opportunity for PLWHA to address HIV/AIDS-related stigma, and to receive psychosocial support, which is of great relevance for dealing with the impacts of HIV/AIDS-related stigma.

Pre- and post- test counselling should be seen as a beginning and a minimum of necessary services (Meursing & Sibindi, 2000), and as an entry point to prevention, care and support for PLWHA (UNAIDS, 2000b). The manner in which positive test results are delivered can influence reactions, and proper counselling in the test situation can have an impact on PLWHA's well-being and ability to deal with HIV/AIDS (Dageid, 2002). Follow-up counselling focusing on extended psychosocial support should ideally be a service to all PLWHA. In SSA, the physical and social needs of PLWHA have often been overshadowed by long term psychological needs in counselling (Kaaya & Smith Fawzi, 1999; Meursing & Sibindi, 2000). The communication of test results and health advice are woefully

inadequate in helping people to deal constructively with HIV/AIDS (Meursing & Sibindi, 2000).

Based on our understanding of HIV/AIDS-related stigma in SSA, both information and psychosocial support for PLWHA appear to be fundamental components of counselling aimed at alleviating and preventing HIV/AIDS-related stigma. Psychosocial support directly helps PLWHA to live fully and productive lives. Counselling should address stigma directly, by focusing on the ways in which a client may fear or actually experience stigma. France (2001) calls attention to how helping PLWHA to deal with self-stigma may empower them to cope with familial and societal stigma. Counselling should address how stigma affects the clients' choice with regards to disclosure, treatment seeking behaviour, care and support. Counsellors need to be sensitive to the stigma-related fear, as PWHA often will present with fear of blame and fear of rejection related to disclosure (Kaaya & Smith Fawzi, 1999). Counselling that promotes a safe environment for possible disclosure and a maximal use of confidants in coping and prevention activities is called for.

Effective counselling needs to take into account the culture in which it takes place (Campbell et al., 1997; Kaaya & Smith Fawzi, 1999; Lie & Biswalo, 1995; Lie & Biswalo, 1996; Lindegger & Wood, 1995; Meursing & Sibindi, 2000; Oberzaucher & Baggaley, 2002). Empirical data from Tanzania support the need for a client-centred counselling approach, similar to Western client-centred therapy. Providing factual information should be balanced with a person-centred approach. Exploring the client's concerns, like that of HIV/AIDS-related stigma, and assisting to identify significant others in the client's network who are able to give further psychosocial support, have been considered important factors in effective counselling (Lie & Biswalo, 1995).

With the consent of the client, and where this is appropriate, counselling can be extended to encompass partners, family-members and friends (UNAIDS, 2000b). This can be of particular importance when dealing with HIV/AIDS-related stigma, due to the emotional and moral reactions HIV/AIDS causes. In SSA, involving families in the counselling process has been acknowledged (Lindegger & Wood, 1995; Kaya & Smith Fawzi, 1999). People who receive testing and counselling may be left vulnerable and unsupported if they

are unable to share their HIV-status and concerns with anyone (Oberzaucher & Baggaley, 2002). How disclosure of HIV-status may be an initial and important step in dealing with the reactions to HIV/AIDS has been considered in the above section. Counselling models should move beyond the individual, and towards the family and the wider community to ensure the development of sustainable support for PLWHA (Kaaya & Smith Fawzi, 1999). In both marital and family relationships, the presence of a counsellor may facilitate discussions about sensitive issues, which are of relevance for the production and maintenance of HIV/AIDS-related stigma.

The fact that addressing HIV/AIDS in SSA is difficult due to sexual taboos, that the main transmission mode of HIV is sexual intercourse, and that women often occupy disadvantaged positions limiting their possibility to express themselves, calls for an approach sensitive to these issues. Couple counselling is one such approach. Painter (2001) has advocated that couple counselling be recognised and practiced more widely in Africa. Couple counselling can lead to more effective prevention of HIV/AIDS, and enhanced care and support for PLWHA (Oberzaucher & Baggaley, 2002; Painter, 2001). Counselling for couples can enhance openness and communication, address challenging HIV/AIDS-related emotions, decrease denial, facilitate disclosure, and increase the acceptance of, and support for PLWHA. Painter (2001) sees the reduction of HIV/AIDS-related stigma as a secondary effect, and a desirable social impact, of couple counselling.

By taking a couple- and family perspective, counsellors can function as “relay stations” in organizing comprehensive care that is adjusted to the changing needs of the client. This can be achieved by bringing PLWHA in contact with the appropriate sources of support in the community and the health care system such as the family, hospital services, and community-based organisations (Meursing & Sibindi, 2000).

How HIV/AIDS-related stigma can be countered by reducing the real and perceived threat of HIV/AIDS has already been mentioned. Sontag (1988) writes that as the scientific knowledge increases with regards to HIV/AIDS, and when treatment is available, the stigmatisation should decrease. Reduction in real or perceived threat could therefore reduce the extent to which a group or individual becomes stigmatised. Tangible resources such as

drugs and medical treatment can be essential in improving the lives of PLWHA, by reducing the threat of HIV/AIDS. Minimizing the impacts of HIV/AIDS-related stigma through the treatment of HIV/AIDS-related symptoms, cancers, and opportunistic infections can minimize feelings of helplessness, and strengthen the belief that it is possible to live positively with HIV/AIDS (Meursing & Sibindi, 2000). In order to deal with HIV/AIDS-related stigma, France (2001) claims that HIV/AIDS should be normalised, and not separated from other diseases. A study from Zimbabwe illustrated how successful treatment of HIV/AIDS-related illnesses boosted patient's confidence, by challenging the belief that HIV/AIDS as a disease equals imminent death (Meursing & Sibindi, 2000). The role of antiretroviral therapy in the normalisation of HIV/AIDS could be of importance, as it can transform HIV/AIDS from being a fatal disease, to a chronic, manageable disease. Fear can be reduced when people see that having HIV/AIDS is not equal to an automatic death sentence (UNAIDS, 2002h). Research from Zambia suggests that treatment can reduce HIV/AIDS-related stigma, as hope and decreased fear of disclosure can make people more willing to seek testing, treatment, care and support (Integrated Regional Information Networks [IRIN], 2003). However, the concerns and shortcomings related to antiretroviral therapies need serious consideration if they are to be evaluated as a way of dealing with HIV/AIDS-related stigma. A serious controversy exists with regards to the use of antiretroviral therapies in developing countries. Problems with quality control and adherence to treatment due to increased resistance, side effects, the lack of regulation, information and expertise in antiretroviral therapies, are some of the obstacles (International HIV/AIDS Alliance, 2002; Taegtmeyer & Chebet, 2002; Weidle et al., 2002).

Advocacy and consultation

Client advocacy and consultation aimed at creating new helping networks are components in indirect client services. These programs intervene in the environment of specific individuals or groups, allowing their special needs to be met. Creating conditions that lead to the empowerment of vulnerable persons through speaking up on their behalf and defending their rights, is essential. Encouraging clients to help themselves and boosting

their functioning through available community resources is important. Informing about, and arranging for participation in grassroots initiated helping networks like traditional healing, and community-based organisations are of great relevance (Lewis et al., 1998).

In this section the establishment and mobilization of grassroots initiated helping networks will be given some consideration. How advocacy and consultation activities can serve to alleviate and prevent HIV/AIDS-related stigma through the promotion of traditional healing systems, and community-based organisations like non-governmental organisations and self-help groups will be elucidated. Self-help groups can also be regarded as direct client services, as they provide outreach and counselling for vulnerable populations. This illustrates how the different components of community counselling overlap.

Globally, grassroots action is needed to cover the shortage of overburdened health systems and inconsiderate governments (Garcia Gonzalez, 2000). In SSA, where HIV/AIDS prevalence is high and health resources often are scarce and ineffective, an alleviative and preventive pluralism of strategies to deal with HIV/AIDS-related challenges needs to be considered (Chipfakacha, 1997; King, 2002; King & Homsy, 1997). Grassroots initiated involvement also bring to light the sensitive issues, and the specific localized resources that are needed to confront HIV/AIDS-related stigma (Chipfakacha, 1997). Grassroots action also reflects empowerment and action research, as people themselves take responsibility, in their own environments. Grassroots action implies that people own both their problems and the solutions. These factors are of great relevance in change-promotion (Skjelmerud & Tsubira, 1997).

Because sources of treatment, care and support are limited for many PLWHA in SSA, the roles of traditional healing systems have been more acknowledged (Chipfakacha, 1997). A number of community-based organisations have also been founded (UNAIDS, 2002b).

One way stigmatised people can benefit from advocacy and consultation activities is through getting their label put in perspective as only one part of their total being (Lewis et al., 1998). Studying how people attribute effects to causes and the consequences of these attributions has been an active pursuit in social psychology. The internal attribution of

negative attributes, has tended to be less desirable for people's well-being than external attribution (Hewstone et al., 1996). When HIV/AIDS-related stigma is internalised, PLWHA may attribute negative reactions to their stigma, rather than to other people's intolerance. How PLWHA attribute HIV/AIDS-related stigmatisation can be detrimental with regards to the impacts of stigma. External attributions will most likely be less distressing. Lewis et al., (1998) argue that advocacy and consultation can decrease self-stigmatisation by including the stigmatised in social interactions, thereby increasing their belief in own ability and motivation to stand up for themselves.

The possibility of collaboration between modern health practices and traditional healing systems is one existing community resource that should be taken advantage of in SSA (Chipfakacha, 1997; King & Homsy, 1997). Traditional healers and modern formal health practitioners have demonstrated great enthusiasm for collaboration in dealing with HIV/AIDS-related challenges in SSA, and research from numeral African countries verifies that such a collaboration is possible (Burnett et al., 1999; Chipfakacha, 1997; King 2000; King, 2002; King & Homsy,1997).

Ever since the existence of humans, all societies and cultural groups have developed their own explanations of human problems and distress, and how to deal with this. Such age old forms of health related wisdom constitute traditional healing systems (Sue & Sue, 1999). Traditional healers represent a broad range of practitioners including herbalists, spiritualists, diviners, priests and faith healers. They all mirror the great variety of cultures and belief systems that exist in SSA, and possess equally heterogeneous experiences, training and educational backgrounds (King, 2000; King 2002; King & Homsy, 1997). The term traditional healer is therefore a notable oversimplification of a complex range of practices.

In many African countries, traditional healing is part of the health practices of individuals and communities: a form of private practice outside the formal health care system (Chipfakacha, 1997; Pitt, 1996). WHO has recognised the importance of traditional healing in HIV/AIDS-related health care (King, 2002; King & Homsy, 1997). Unfortunately,

collaboration between modern health services and traditional healers has rarely been carried out in SSA (King, 2000; King, 2002).

Traditional healers remain the majority of preferred and accessible health care providers in Africa (Chipfakacha, 1997; King, 2000; King, 2002; King & Homsy, 1997; Moss, 1999; Pitt, 1996). Traditional healers are usually well distributed throughout SSA, they are affordable to consult and receive respect, esteem and recognition in their communities (Chipfakacha, 1997; King, 2000; King, 2002; Pitt, 1996; Staugård, 1996b). Traditional healers often feel a responsibility for the health of their communities, as they are trusted and called upon for assistance in a variety of proficiencies (King, 2002). Traditional healers are at the frontline of the struggle to prevent and cure diseases and distress. They have acquired considerable knowledge about the community, and are well placed to understand the dynamics of health in relation to people and their total environment. Their sheer numerical strength, and their already well integration into the communities make them an essential resource for delivering health care (Chipfakacka, 1997; King, 2002; Staugård, 1996b). With their ability to understand the dynamics of local phenomena, traditional healers should be desired partners in the alleviation and prevention of HIV/AIDS-related stigma. If traditional healers are excluded from attempts to deal with HIV/AIDS, factors such as stigma, that contribute to the HIV/AIDS-epidemic, may not be eliminated (King & Homsy, 1997).

The approach of traditional healers is usually holistic and deals with all aspects of client's life, e.g. relations to other people, the natural environment, the supernatural forces as well as any physical or psychological symptom. The philosophy is restoration of spiritual balance, the unity of spirit, mind and matter (Chipfakacha, 1997; Sue & Sue, 1999). Traditional healers provide client-centred, personalized health care that is tailored to meet the needs and expectations of their clients. This approach makes traditional healers strong communication agents for health- and social issues, like that of HIV/AIDS-related stigma (King 2000; King, 2002). Counselling is probably one of the fundamental services traditional healers have provided to their clients (King 2000; King & Homsy, 1997). Their approach also reflects the approach desired for effective HIV/AIDS counselling, as exemplified by Lie (1996). Traditional healers often see their clients in the presence of

clients' family-members, and play an important role in providing family counselling (King, 2000). Implying client-centred and systemic community work, traditional healing seems highly relevant in the alleviation and prevention of HIV/AIDS-related stigma.

Traditional healers are also able to offer remedial treatment for HIV/AIDS symptoms and opportunistic infections. Traditional healers are thus able to educate, empower, care for and support PLWHA (King 2002; King & Homsy, 1997; Pitt, 1996). Traditional healers are capable of performing outreach and counselling to vulnerable populations, an approach already considered as essential in dealing with HIV/AIDS-related stigma in SSA. France (2001) points to how traditional healers can provide hope for PLWHA. Studies from Kenya, Tanzania and Uganda have demonstrated that HIV/AIDS-related stigma has been significantly reduced when traditional healers have become champions of the cause, contributing to changes in attitudes, behaviours and practices with regards to HIV/AIDS and PLWHA (King, 2002).

The involvement of traditional healers in dealing with HIV/AIDS-related stigma is, however, not an unproblematic endeavour. The gap between African and modern approaches to illness and disease need extensive incorporation to be bridged (Kaaya & Smith Fawzi, 1999; King, 2000; King & Homsy, 1997). Misconceptions about HIV/AIDS and harmful practices have also been revealed in traditional health care settings (Burnett et al., 1999; Chipfakacha, 1997; King, 2000). Involving traditional healers as educators and counsellors in the alleviation and prevention of HIV/AIDS-related stigma can therefore imply training and quality assurance.

As illustrated earlier, HIV/AIDS counselling can encourage peer-support, self-help and voluntary work. Non-governmental organisations and self-help groups are types of community-based organizations that can provide individuals with opportunities for involvement, personal care and psychosocial support that may not be available elsewhere (WHO, 1990). Community-based organizations can therefore be seen as advocacy groups that have the potential of defending and speaking up on the behalf of PLWHA, at the same time as providing consultation services where these are needed.

There are four different ways PLWHA can become involved in community-based organisations. They can take part through accessing services as beneficiaries or users of services, such as medical care, counselling or training. PLWHA can also be involved by supporting staff and volunteers in activities without any formal training. PLWHA can participate actively, and deliver HIV/AIDS-related services on a formal regular basis, as employees or as volunteers with expertise. The most advanced stage of involvement is when PLWHA take part in management, policymaking and strategic planning of community-based organisations (Horizons, 2002). This pluralistic way of involvement in community-based organisations makes it possible for people with different motives, and at different stages in their process of coping with HIV/AIDS to become involved. Community-based organisations can in this manner provide flexible offers to PLWHA, and possibly stand as an alternative source of health care for many PLWHA. Such optional involvement is probably an advantage given the HIV/AIDS-related stigma and the challenge of disclosing HIV-status, as involvement does not necessitate public disclosure and visibility.

A comparative study conducted in Burkina Faso, Zambia, Ecuador, and India indicates that any type of involvement in community-based organisations can have a therapeutic effect. It is assumed that the degree of effect will depend on the type of involvement. Improved psychological health as a result of increased knowledge, increased peer support, improved physical health, and decreased isolation has been evident. The same study indicated that greater involvement of PLWHA in prevention, treatment, care and support can lead to improved access to care and support, thereby reducing levels of HIV/AIDS-related stigma and discrimination (Horizons, 2002).

In community-based organisations that are organised as self-help groups, people with a common ideology dealing with common issues or problems meet one another, provide mutual support and have the opportunity to both seek and offer assistance. This sharing of common interests and social support has shown to give people a sense of understanding and encouragement to carry on despite major life stress, like that of HIV/AIDS (Lewis et al., 1998).

Some issues are often best dealt with through self-help groups consisting of PLWHA, such as learning to live with HIV/AIDS as many involved already has gone through the process. Members of self-help groups can describe the medical and psychological problems they have experienced, and the strategies they have found most useful for coping with HIV/AIDS and its related stigma. Conflicts related to emotional distress can be discussed, reduced and avoided. Self-help groups can also assist people on how to best talk about HIV/AIDS, and fears related to disclosing can be explored. Self-help groups can also assist significant others to handle the pressures of living with sick or distressed people, as significant others often suffer psychological distress similar to that of PWHA (WHO, 1990). Providing significant others with the strength to care and support for PWHA is crucial in the alleviation and prevention of HIV/AIDS-related stigma.

In Uganda, contact with community-based organizations has shown to mitigate the HIV/AIDS-related stigma. The AIDS support organization TASO is amongst the responses to the epidemic that has been organized in Uganda (Hogle, 2002; UNAIDS, 2000a). As the first community-based organization to respond to the needs of PLWHA in Africa, TASO is recognized around the world as a leader and innovator in the field of HIV/AIDS care and support. TASO services include education, skills training, counselling, support activities and medical care for HIV/AIDS-related symptoms. As of March 2001, more than 65 000 clients have received care and support through TASO. TASO's effective advocacy program has shown to decrease stigma and discrimination, and support the development of governmental policies and programs for PLWHA (The United States Agency for International Development [USAID], 2002).

Systemic changes and public policy

Indirect community services include attempts aimed at promoting systemic changes and influencing public policy. These are aimed at making the social environment more responsive to the needs of the population as a whole, which has been emphasized as a crucial element in countering HIV/AIDS-related stigma. Negotiating and promoting positive changes in political, economic, social and cultural structures is necessary, as these are the very structures that render the existence of HIV/AIDS-related possible. Raising a

general awareness of issues, gaining support from policy makers and encouraging positive community interaction through cooperation with administrators and leaders is essential (Lewis et al., 1998).

All attempts to counter HIV/AIDS-related stigma have the power to indirectly influence public policy, and to contribute to systemic changes that can create a more supportive community by placing HIV/AIDS on the political and social agenda. The public policy on HIV/AIDS needs to address HIV/AIDS-related stigma and its impacts, and this requires governmental and institutional involvement. By passing and enforcing laws that protect the rights and the needs of PLWHA, important messages and values are communicated to society. Government action is required to protect human rights.

Brislin (1993) has emphasised the importance of engaging highly respected community members in introducing and maintaining programmes, strategies, and attempts to counter HIV/AIDS-related stigma, as their involvement can promote attention and acceptance for these programmes. Without the cooperation of leaders, and without a public policy that acknowledges the gravity of HIV/AIDS-related stigma, attempts to alleviate and prevent stigma will be seriously hampered. Lack of political will and commitment to talk about HIV/AIDS is a significant factor fuelling HIV/AIDS-related stigma, by maintaining silence, denial and ignorance.

Focusing on the human and judicial rights of PLWHA and making these explicitly known, can contribute to a public policy that supports openness about HIV/AIDS and enhances support for PLWHA. Societal exclusion, unequal distribution of power, social inequality and oppression of already marginalized groups have been highlighted as mechanisms operating in the stigmatisation process. Attempts to alleviate and prevent stigma therefore need to focus on the structural aspects in society that render stigmatisation possible. In the same manner as it requires power to stigmatise, power is needed to deal with stigma. In order to change the social structures that facilitate stigmatisation, it is necessary to involve people with power and who have the ability to change these structures. Grassroot initiatives and community-based organisations are also important in this manner, as they represent the power of the people.

Uganda has set an example of how HIV/AIDS can be dealt with openly on both community and national levels. Strategies to reduce HIV/AIDS prevalence and the impacts of HIV/AIDS have been firmly supported by the government, including the personal involvement of the president, Yoweri Museveni. Religious and traditional leaders, community groups and all sectors of the society have also been involved. These initiatives have involved PLWHA at all levels. The Ugandan national policy on HIV/AIDS states that all Ugandans have an individual and collective responsibility for dealing with HIV/AIDS and its impacts (UNAIDS, 2000a). Uganda has managed to reduce its HIV/AIDS prevalence, while prevalence rates in the same region continue soaring, and the decline in prevalence is unique worldwide (Hogle, 2002). This united approach seems to have created a community that is enabled and committed to counter the HIV/AIDS-epidemic.

The South African government, and president Thabo Mbeki's stance on HIV/AIDS, is an example of how leaders and policy makers can impede such attempts. Mbeki, who questioned the relation between HIV and AIDS, caused immense confusion among the public, thereby contributing to misconceptions and increased denial (Frafjord Johnson, 2000). The former president, Nelson Mandela, publicly opposed Mbeki's stance on HIV/AIDS, as it was proving to be a serious setback in dealing with HIV/AIDS. Mbeki's position on HIV/AIDS can be seen as related to the phase of denial mentioned by Mann (Parker & Aggleton, 2003), resulting in silence and the strengthening of the already existing stigma. Dealing effectively with HIV/AIDS-related stigma requires unity.

Constructive thinking about HIV/AIDS and how to deal with its impacts through laws and policies need to become part of the social discourses surrounding HIV/AIDS. Education, care and support, provided through campaigns and services need to be reinforced by respected community members who demonstrate in words and in action this thinking. Lee et al. (2002) claim that effective community mobilisation and good community ownership is characterized by the involvement of traditional and political leaders, schools, police and churches.

Summary and concluding comments

HIV/AIDS-related stigma can be understood as a multifaceted phenomenon that emerges from the intertwining of human motivations, social structures and discourses, and power relations. Countering HIV/AIDS-related stigma therefore implies addressing the context within which individuals and communities respond to HIV/AIDS. In exploring HIV/AIDS-related stigma, it has become apparent that issues related to HIV/AIDS are closely interwoven with issues such as power, gender, sexuality, and poverty. Addressing HIV/AIDS-related stigma is therefore not sufficient without also addressing these issues. Only when all aspects of stigma are understood, can it possibly be dealt with constructively. This understanding of stigma implicates a need to take a broad approach in attempts to alleviate and prevent HIV/AIDS-related stigma in SSA.

The conceptual framework for understanding stigma in SSA can provide a guideline for constructing strategies to alleviate and prevent HIV/AIDS-related stigma. However, there are no simple answers or easy solutions on how to deal with the challenges of HIV/AIDS-related stigma in SSA. Multifaceted challenges require multifaceted solutions. Based on the conceptual framework for understanding stigma, and the strategies this understanding seems to implicate, suggestions for alleviation and prevention of HIV/AIDS-related stigma in SSA have been presented. The suggestions presented will have to be regarded as superficial, as the cultural diversity of SSA will lead to a diversity of stigma-manifestations. Local adaptations will always be necessary in attempts to understand, alleviate and prevent HIV/AIDS-related stigma in SSA.

Through its provision of knowledge and awareness regarding HIV/AIDS-related stigma, this thesis can be regarded as one step forward in an empowering process. It is hoped that raising awareness and understanding of HIV/AIDS-related stigma will contribute to a more tolerant society. As a small step in this direction, and as an attempt to mould the social discourses on HIV/AIDS in a direction that allows for more tolerance, the use of words with negative connotations has been avoided. Negative laden words such as *combat*, *fight*, *plague* and *war* have not been used in association with HIV/AIDS and its related stigma. Such words can provoke fear, anxiety and negative associations, complicating the

transformation of HIV/AIDS from a stigmatised disease to a more normal and accepted disease. To constructively communicate a belief in PLWHA's own power and ability to deal with stigma, words such as *victim*, *intervention* and *undergo* have been avoided. Everyone involved in HIV/AIDS-related work, and any medium that addresses HIV/AIDS and its related stigma should reflect upon and discuss how they themselves might contribute to the maintenance or mitigation of stigma. HIV/AIDS researchers should perhaps be especially aware of this, as they are important contributors to both the form and content of the social discourses on HIV/AIDS. The scientific and empirical literature obtained for use in this thesis did not always reflect such awareness. This could perhaps be seen as a reflection of how entrenched social discourses can be, and how they easily can elude reflection.

Neither the conceptual framework presented for understanding HIV/AIDS-related stigma in SSA, nor the approaches proposed for its alleviation and prevention are without limitations. Dealing with such limitations is an integral part of any concrete strategy aimed at alleviating and preventing HIV/AIDS-related stigma in SSA. Attempts to alleviate and prevent stigma can have unintended and potentially negative effects, with the worst-case scenario being attempts that inadvertently contribute to HIV/AIDS-related stigmatisation. That is why a thorough understanding of stigma, and of the factors that fuel it, is essential to effectively reduce stigma.

Cultural sensitivity

This thesis has stressed the importance of taking a culture sensitive stance when countering HIV/AIDS-related stigma in SSA. The complexity of SSA, lack of scientific material, and limited African literature has complicated reaching an understanding of HIV/AIDS-related stigma that can be regarded as deep, complementary and valid.

Sustaining a culture sensitive stance can be seriously complicated when confronted with cultural practices that facilitate HIV/AIDS-related stigma, or increase the probability of HIV-infection. Culture can in this manner become an obstacle, as beliefs and traditions that are harmful, or in opposition to human rights, need to be challenged. Having a thorough,

yet flexible and reflected stance to cultural sensitivity is therefore necessary. Cultural aspects that can be regarded as obstacles should not be opposed or disregarded, but rather be dealt with through sensitive promotion of education and self-awareness. The alleviation and prevention of HIV/AIDS-related stigma requires amongst many things, open dialogues on sexual issues. Such open dialogues can imply breaking cultural taboos, as open discussion of sex is a taboo in many countries in SSA. This poses a dilemma with regards to cultural sensitivity, as confronting the taboo implies considering and deciding on whose values, norms and standards to adhere to.

The reinforcement of cultural beliefs that mitigate stigma should be emphasised as a component in culture sensitivity. One should not undermine or subvert already existing cultural aspects that seem useful in the alleviation and prevention of HIV/AIDS-related stigma. Seeking out, assessing and mobilizing the community's own coping mechanisms and effective strategies for countering HIV/AIDS-related stigma should be strived for. The need to counter HIV/AIDS-related stigma is urgent, and one cannot afford to risk compromising any possible contributions, despite the cultural challenges they may pose.

The need for evaluation

Because the severity of the HIV/AIDS-epidemic requires urgent action, research and attempts to counter the epidemic and its stigma need to be integrated. Evaluations of attempts are crucial, as it is essential to know what works, and what does not, when planning strategies to reduce HIV/AIDS-related stigma. This points to the necessity of evaluating attempts of alleviating and preventing HIV/AIDS-related stigma. Empowering processes and action research have been presented as suitable approaches for the alleviation and prevention of HIV/AIDS-related stigma. These approaches strongly emphasize evaluation as part of their change processes. This poses a challenge to the implicated attempts to alleviate and prevent HIV/AIDS-related stigma. In order to measure change, one must have clearly defined objectives. This requires a thorough understanding of stigma, as well as an operational definition of stigma as a phenomenon. Evaluation also raises questions pertaining to what is perceived as satisfactory change.

Methods and tools are needed to evaluate whether HIV/AIDS-related stigma has been reduced, and such methodological and theoretical tools for conducting research on stigma are lacking. Due to the complexity, various manifestations, and subtle forms, measuring HIV/AIDS-related stigma is complicated and challenging. This poses an impediment to the alleviation and prevention of HIV/AIDS-related stigma, as it is crucial to know whether the effects achieved are short-lived or persistent. Another challenge is how to differentiate between stigma and discrimination. Although stigma and discrimination are related, effective countering of HIV/AIDS-related stigma necessitates distinguishing between the two phenomena. More research is urgently needed to identify and demonstrate which strategies are effective for countering HIV/AIDS-related stigma across different contexts.

The need for cooperation

The inclusion of stakeholders has proven to be an important component in strategies to reduce HIV/AIDS-related stigma. Still, the process of inclusion needs to be critically examined.

Strategies aimed at changing the social discourses surrounding HIV/AIDS can lead to recognition of its oppressive and stigmatising nature. This could entail the possibility of the inadvertently assignment of blame. Cooperating at the same time as pointing to flaws and inappropriate power structures can be challenging. It is important to keep in mind that stigma can be seen as common human reaction to threat. Creating an awareness of the fact that people themselves stigmatise and contribute to the impacts of stigma, can have the power to change such discourses in constructive ways.

Stakeholders that are included in strategies to counter HIV/AIDS-related stigma, are not necessarily representative of the community. The process of inclusion can unwillingly become selective and biased towards more socially affluent and active members of the community. Power relations can hinder fulfilment of rights, access to support and to privileges in society, such as knowledge. In SSA, this applies especially for women, and can in many ways exclude them from active involvement. An awareness of factors such as

these can ensure unbiased inclusion of stakeholders, as selective exclusion contradicts the fundamental idea of empowerment.

When implementing strategies aimed at alleviating and preventing HIV/AIDS-related stigma, one is also confronted with ethical dilemmas pertaining to the selection of individuals and communities for programme-participation. Involvement in programmes can provide the participants with advantages others miss out on, both on short- and long term levels, as follow-ups or further care might be a part of such programmes. The selection of participants may therefore imply some sort of cost-benefit analysis, where people seen as more deserving are selected for participation, inevitably at the expense of others who also are in need of assistance. On the other hand, being selected for programmes can also entail the risk of increased stigmatisation, as such involvement can lead to visibility, and the creation of boundaries between those being helped, and those not being helped. Ethical guidelines for stigma-related work could reduce these dilemmas, and future work with HIV/AIDS-related stigma should include the provision of such guidelines.

Although understanding, alleviating and preventing HIV/AIDS-related stigma in SSA is an endeavor that poses enormous ethical, methodological, theoretical, and economical challenges, these challenges should not discourage attempts to counter HIV/AIDS-related stigma in SSA. Research has shown that HIV/AIDS-related stigma can be reduced. This provides hope. Where there is hope, there is life.

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