

## **EXPERIENCES OF HIV/AIDS STIGMA OF PERSONS LIVING WITH HIV/AIDS AND NURSES INVOLVED IN THEIR CARE FROM FIVE AFRICAN COUNTRIES**

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### **ABSTRACT**

The concept of stigma has received significant attention in recent years in the HIV/AIDS literature. Although there is some change towards the positive, AIDS still remains a significantly stigmatized condition. AIDS stigma and discrimination continue to influence people living with and affected by HIV (PLWA), as well as their health-care providers. Unless stigma is conquered, the illness will not be defeated. Due to the burden that HIV/AIDS places on people living in Africa, a five-year project entitled Perceived AIDS Stigma: A Multinational African Study was undertaken. The focus of the first phase of this project was on exploring and describing the meaning and effect of stigma on PLWA from the experiences of PLWA and the nurses involved in their care in five African countries: Lesotho, Swaziland, Malawi, South Africa and Tanzania. An exploratory descriptive qualitative research design was used to explore and describe the experience of stigma through the critical incident method. Purposive voluntary sampling was utilized. Forty-three focus group discussions were held with respondents to relate incidences which they themselves observed, as well as those that they themselves experienced in the community and in families. The transcribed data was analyzed through the technique of open coding using the NVivo 2.0 analysis package. Three types of stigma (received stigma, internal stigma and associated stigma) and several dimensions for each of these types of stigma emerged from the

data. Recommendations were made to pursue these findings further.

**Keywords:** Types of Stigma, Dimensions of stigma, HIV/AIDS, PLWA, Nurses, Africa, experiences, incident.

## INTRODUCTION AND PROBLEM STATEMENT

The concept of stigma has received significant attention in recent years in the HIV/AIDS literature, particularly following the XIII International AIDS meeting held in Durban, South Africa in 2000. Herek, Capitano and Widaman (2002) traced the prevalence of AIDS stigma in the United States from 1991 to 1999. They concluded that although support for extreme punitive measures had decreased, such as putting HIV-positive people in camps, AIDS still remained a significantly stigmatized condition in the United States. Few studies of this kind from Sub-Saharan Africa could be found in the literature. With over 28 million people estimated to be living in Sub-Saharan Africa alone, the impact of HIV and AIDS on communities has been devastating (ACORD, 2004). The five countries with the highest HIV prevalence rates in the world are situated in southern Africa, and South Africa, with an estimated 4.7 million people living with HIV, has more cases of HIV/AIDS than any other country (Connolly, Colvin, Shishana, & Stoker, 2004). Research to understand how stigma manifests in Africa is thus extremely important.

The nature of the stigma may be different in different cultures with regard to what is stigmatized and how stigma manifests itself (Weiss & Ramakrishna, 2001). A study of stigma in the case of people with HIV/AIDS in Uganda demonstrated a strong gender bias (women were more stigmatized than men), rejection of people by their families, increased suspicion and gossip, and isolation in communities. Despite concerted efforts to demystify the disease and enhance awareness and understanding, many people still associate HIV/AIDS with moral decadence and promiscuity (Aggleton, 2000; Aggleton & Tyrer, 2001; Mukasa, Tanga, Nuwagaba, Aggleton & Tyrer, 2001; ACORD, 2004).

In South Africa the purpose of the Siyam'kela research project (2003) was to explore HIV-related stigma and to develop HIV/AIDS stigma indicators that could be used to develop a tool to measure HIV/AIDS stigma mitigation programmes as well as formulate guidelines for developing an HIV/AIDS-supportive environment. The overarching themes common to all forms of external stigma were excluding PLWA, and judging them as less valuable than people who are HIV negative. The various manifestations of internalized stigma included PLWA removing themselves socially and from services, and considering themselves less valuable (Greeff & Phethlu et al., 2006).

In Malawi a study on stigma and discrimination revealed that these aspects serve as barriers to proper care, treatment and support of PLWA, discourage people from seeking voluntary counselling and testing, and hinder the development of an enabling environment that promotes disclosure (MANET, 2003). In studies done in Ethiopia, Tanzania and Zambia it is stated that stigma exists because of a lack of knowledge, fears of death and disease, sexual norms and limited recognition of stigmatizing actions.

The main forms of stigma include physical and social isolation, gossip and voyeurism, and a loss of rights and access to resources. Language is a powerful tool for stigma or support. There is evidence that stigma impedes programmatic efforts around testing, disclosure, prevention, care and support (Nyblade, 2003). De Bruyn (1999) identified factors contributing to the HIV/AIDS stigma, which include the fact that it is life-threatening, that people fear it, that it is associated with behaviours already stigmatized by many societies, (i.e. drug use) and that people themselves are seen as responsible for contracting the disease. The various authors' work demonstrates that stigma is a major problem for PLWA, as well as in the provision of prevention and care for these people in Africa.

Holzemer and Uys (2004) mention that according to anecdotal reports, AIDS stigma and discrimination continue to influence people living with and affected by HIV, as well as their health-care providers, particularly in southern Africa, where the burden of AIDS is so significant. Stigma is perceived as a major limiting factor in primary and secondary HIV/AIDS prevention and care (Weiss & Ramakrishna, 2001). Mill (2003) found that secrecy affected the access of women in Ghana to treatment and financial and emotional support from families. ACORD (2004) mentions that, in studies done in Northern Uganda and Burundi, unless stigma and discrimination are challenged, PLWA are unlikely to access the available life-prolonging drugs. Many health-care workers in South Africa have come to the conclusion that unless stigma is conquered, the illness will not be defeated (Uys, 2000). While limited data are available, numerous testimonials from several countries document the effect that stigma has on reducing access to care.

In the literature, various aspects of stigma is discussed and research reported but not one available source provides an understanding of the meaning and effect of stigma as a whole. No conceptual framework exists that explains the total stigma experience. This five year African project entitled Perceived AIDS Stigma: A Multinational African study (South Africa, Malawi, Swaziland, Lesotho and Tanzania) was undertaken to explore and describe the meaning and effect of the experiences of stigma. The ultimate goal of this study was to develop two validated instruments for PLWA as well as for nurses involved in their care and to explore the stigma profile over time and to develop interventions that could impact on this problem. However, it was important first to understand the meaning and effect of the stigma experience in specifically Africa as seen by PLWA and nurses involved in their care to develop culture-congruent items in these scales as no such data was available. This article focuses on the first phase of this project.

The following research question was posed: What was the meaning and effect of stigma experiences of PLWA for PLWA and nurses involved in their care in Africa?

## **Objectives**

In the first phase of this project the focus of the research was on exploring and describing the meaning and effect of the stigma attached to PLWA from the experiences of persons

living with HIV/AIDS and the nurses involved in their care in five African countries through described incidents of stigma and how this had affected PLWA.

## **Literature review**

### *The concept of stigma*

The concept of stigma has been well researched and many definitions have been formulated. As an outcome, stigma according to Berger, Ferrans and Lashley (2001) occurs when the negative social meanings attached to the discrediting attribute become linked to the individual. Birenbaum and Sagarin (1976) offer a further useful definition. "When we speak of stigma we are discussing the entire field of people who are regarded negatively, some for having violated ... rules, others just for being the sort of people they are or having traits that are not highly valued." Katz (1979) argues that stigma encompasses a perception of a negative characteristic and a global devaluation of the possessor of the characteristic.

The choice of definitions for stigma in this project was that of Goffman (1963), and the adapted version of this definition by Alonzo and Reynolds (1995). Goffman as early as 1963 defined stigma as an attribute that is deeply discrediting within a particular social interaction. The term stigma as used by Goffman (1963) refers to both a trait and the outcome of being known to possess that particular trait. Alonzo and Reynolds (1995) adapted the definition of Goffman (1963) and refer to stigma as a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons. In general, there is consensus in the stigma literature that stigma represents a construction of deviation from some ideal or expectation (Alonzo & Reynolds, 1995). It is a broad and multidimensional concept whose essence centres on the issue of deviance.

Stigma is also different when viewed from the inside, by those who are stigmatized, than from the outside, by those who stigmatize (Herek et al., 2002). Weiss and Ramakrishna (1992) described the concept of the emic view as being the insider's perspective (personal view) and the etic view as being the outsider's perspective (consequences) of a phenomenon.

Ultimately, stigma creates outsiders and social boundaries between normals and the stigmatized, with the stigmatized doomed to "eternal stigmatization in their own eyes as well as those of society". Thus, the essential meaning of stigma is that the stigmatized are a category of people who are pejoratively regarded by the broader society and who are devalued, shunned or otherwise detrimentally affected in their chances in life and in accessing the humanizing benefit of free and unfettered social intercourse (Alonzo & Reynolds, 1995). Goffman (1963) mentions that if the trait is not immediately apparent to others, the individual is "discreditable" rather than automatically discredited. This

may make it possible to conceal the trait from others in order to “pass” as “normal” (Berger et al., 2001).

### *Types of stigma*

The views of these various authors as well as those of others all imply various types of stigma. The description vary and no consensus exist.

#### \* Stigma as experienced by the person him-/herself

The first type of stigma is referred to as internal, felt or perceived stigma or the emic view. Internal stigma is seen as a complex process that involves internalizing the devaluation from people around the PLWA (Nyblade, 2003). Felt stigma refers to the felt part of stigma, leading to an unwillingness to seek help and to access resources (Siyam’kele, 2003). Perceived stigma refers to an individual’s perceptions of societal attitudes toward people with HIV and his or her personal knowledge of being infected with HIV (Berger et al., 2001; Sandelowski, Lambe & Barroso, 1995).

For the purpose of this study, the concept *internal stigma* was used and redefined as *thoughts and behaviours stemming from the person’s own negative perceptions about him-/herself based on his/her HIV status.*

#### \* Stigma from the people around the person

This type of stigma is referred to as external or enacted stigma, or the etic view of Weiss, Doongaji, Siddhartha, et al. (1992), as discussed earlier. External stigma refers to the enacted aspect of stigma, leading to discrimination on the basis of HIV status or association with someone who is living with HIV/AIDS (Siyam’kele, 2003). Sandelowski et al. (2004) also refer to enacted stigma. Malcolm, Aggleton and Bronfman (1998) state that perceived or “felt” stigma often precedes rather than results from the experience of stigma. They claim many individuals reduce the opportunity for “enacted” stigma in order to protect themselves from discriminatory actions.

For the purpose of this study, the concept was redefined to *received stigma* and refers to *all types of stigmatization behaviour towards a PLWA as experienced and described by themselves or others.*

#### \* Stigma of a person involved with the stigmatized person

The third type of stigma is referred to in the Siyam’kele report (2003), which does not regard this as a type of stigma but rather as an aspect of external stigma.

For the purpose of this study, *associated stigma* was defined as a type of stigma and refers to *incidents that describe stigma against people who work or associate with HIV/AIDS-affected people.*

### *Understanding the divisions made of the various types of stigma*

In the literature some authors make a further division/description under each type of stigma but do not give an explanation as to what this refers to. It gives a better understanding of the behaviour etc. that accompanies the type of stigma. It could be the “language of relationships” that Goffman (in Alonzo & Reynolds, 1995) refers to, as he states that stigma is not merely an attribute. Alonzo and Reynolds (1995) refer to the multidimensionality of stigma. As with the definition of stigma, no consensus about these divisions could be found in the literature. Katz (in Alonzo & Reynolds, 1995) distinguishes four dimensions of stigma: threat, responsibility, visibility and sympathy. Jones (in Alonzo & Reynolds, 1995) distinguishes six dimensions: concealability, course, disruptiveness, aesthetic qualities, origin and peril. The Siyam’kela research project (2003) identified HIV/AIDS-related stigma indicators in South Africa and broadly categorized these indicators under the following two types of stigma: 1) *external or enacted stigma*: avoidance; rejection; moral judgment; stigma by association; unwillingness to invest in PLWA; discrimination; and abuse; and 2) *internal or felt stigma*: self-exclusion from services and opportunities; perception of self; social withdrawal; overcompensation; fear of disclosure.

Weiss et al., (1992) in their proposed conceptual model recognize that there is an insider’s perspective (emic) and an outsider’s perspective (etic) of the consequences of any illness studied: 1) the emic view is rooted in local cultural concepts, reflecting the way people think of their world, themselves, health and health problems; and 2) the etic view relates more to professionally defined consequences, e.g. quality of health and quality of life.

Other authors do not really refer to the finer description according to type but do refer to other aspects that accompany stigma. Herek, Mitnick, Burris, Chesney, Devine, Fullilove, et al. (1998) used the term ‘AIDS-related stigma’ to refer to ‘prejudice, discounting, discrediting, and discrimination that are directed at people perceived as having HIV or AIDS, and at individuals, groups and communities with which they are associated’. Berger et al. (2001) developed an instrument to measure stigma perceived by people with HIV, based on the literature of the time. Four factors emerged from their study: personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes towards people with HIV. Fife and Wright (2000) mention four dimensions of perceived stigmatization: social rejection; financial insecurity; internalized shame; and social isolation. ACORD (2004) refers to rejection, denial, discrediting, disregarding, underrating and social distance. In a report of USAID (2006) they identify four key domains: fear of casual transmission and refusal of contact with PLWA; value- and morality-related attitudes, such as blame, judgement and shame; enacted stigma (discrimination); and disclosure. They suggest ways to begin the process of quantifying and measuring HIV-related stigma in an effort to help practitioners, policymakers and donors evaluate programmes.

Link and Phelan (2001) proposed that stigma contains the following five elements. First, differences are identified and labelled. Second, human differences (labels) are linked to undesirable attributes. Third, a segregation of “them” and “us” occurs. Fourth, the resulting status loss and discrimination lead to devaluation, rejection, exclusion and blame, which Fife and Wright (2000) described as social rejection, financial insecurity, internalized shame and social isolation. Fifth, this process can only occur if a group has the power to enforce the stigma. Breaking down the process of stigmatization into these steps provides a framework for a better understanding of the concept. They (Link and Phelan, 2001) further articulate three mechanisms of stigma. One is direct discrimination at a person-to-person level, where actions devalue, reject, exclude or blame the other person. A second is structural discrimination in which social contexts, such as a sign identifying an HIV/AIDS clinic, enforce stigma without person-to-person actions. The third mechanism is self-stigmatization, a socio-psychological process that operates through the stigmatized person. Stigmatized persons apply labels to themselves, believe in these labels, and live accordingly.

From this literature review it becomes clear that there are many perceptions or descriptions of stigma with no real consensus, although similar aspects are described or identified.

## **Methodology**

The methodology describes the first phase of the five-year project, from which two other articles have already been published, one focusing on words and phrases people use to refer to HIV/AIDS and to PLWA (Uys, Chirwa, Dlamini, Greeff, Kohi, Holzemer, Makoe, Naidoo & Phetlhu, 2005) and the other on the violation of human rights (Kohi, Makoe, Chirwa, Holzemer, Phetlhu, Uys, Naidoo, Dlamini & Greeff, 2006). A further article on disclosure is in the process of publication (Greeff, Phetlhu, Makoe, Dlamini, Holzemer, Naidoo, Kohi, Uys & Chirwa, 2006).

## **Research Design**

An exploratory descriptive qualitative research design was used to explore and describe the meaning and effect of the experience of HIV/AIDS stigma of people living with HIV or AIDS and nurses involved in their care. Focus group discussions were held with respondents to capture an emic view of PLWA, and an etic and emic view that nurses have of stigma and discrimination (Weiss et al., 1992). The critical incident method was used. Respondents were asked to relate incidences which they themselves observed as well as those that they themselves experienced in the community and in families. Respondents were also asked to define their own understanding of what stigma and discrimination meant.

## Settings

The study was conducted in the five above-mentioned African countries. In Lesotho and Swaziland focus groups involved people from all administrative regions of the country. In South Africa, Malawi and Tanzania only one geographical area with a more-or-less homogeneous population was included. In South Africa the setting was the Potchefstroom urban area and the Kayakulu rural area, both in the North West Province. In Malawi, Lilongwe was used, and in Tanzania the urban setting was Dar Es Salaam and the rural setting Mbeya.

## Sample

Purposive voluntary sampling was utilized. 43 focus groups were conducted, which included a total of 251 respondents (see Table 1). The duration of the focus groups varied between an hour and an hour and a half. The groups only met once. The respondents were persons living with HIV/AIDS (44%, n=111), nurses and nurse managers (45%, n=114), and volunteers/youth groups (10%, n=26). The PLWA were recruited through support groups and care-givers providing home-based care. Nurses and nurse managers were recruited through senior nurse managers in the various countries. The mean age of respondents was 39.9 years. Women constituted 53.1% of PLWA, 95.1% of the nurses and 58% of the volunteers. Of the focus groups, 55.8% were conducted in urban settings and 44.2% in rural settings. The sample was approximately equally divided amongst the five countries.

**Table 1:** Participants by groups, gender and age combined over country

Groups	# Groups	Men	Women	Total Sample	Mean Age	Urban Group	Rural Group
PWLA	19	52	59	111	36.8	9	10
Nurses	20	5	109	114	42.7	12	8
Volunteers	4	11	15	26	34.3	3	1
Totals	43	68	173	251	39.9	24	19

## Data Collection

Respondents were invited to meet at a central place in one of the main cities or to a specific place in a rural area, where focus group discussions were conducted. Respondents were reimbursed for transport and lunch was provided.

A brief demographic questionnaire was completed by all respondents. A focus group discussion guide covered the following two questions: “How do people you know refer to people living with HIV/AIDS?”, and “Can you share an example of stigma or

discrimination directed toward a person living with HIV/AIDS, their family members, or nurses who care for them?” Probes were used to elicit further details of the incidents described.

Focus group discussions were conducted in the local languages of the five countries, since all the respondents, including the nurses, were more comfortable expressing themselves in the local language. In South Africa respondents used Afrikaans, English, Setswana, Sesotho and isiZulu. The co-researcher simultaneously communicated with respondents across these languages. The following languages were used in the other countries: in Malawi, English and Chichewa; in Lesotho, Sesotho; in Swaziland, Seswati; and in Tanzania, Swahili.

The focus group discussions were audio-recorded, transcribed verbatim and translated into English. In South Africa, the focus group discussions were translated into English during the transcribing process. The Nvivo™ software was used to code demographic attributes (country, type of participant, gender) and themes.

After each focus group, field notes were written reflecting observations, methodology and perceptions.

### ***Protection of Human Subjects***

The research protocol was approved by all seven the universities involved (see author list), providing protection of human subjects. Permission to conduct the study was also obtained from the relevant local and central government authorities.

Respondents were provided with information about the background of the study, informed that participation was voluntary and that they could withdraw from participation at any time. Respondents were also assured of confidentiality of information obtained. Following this explanation, respondents each signed a written consent form.

### ***Data Analysis***

The textual data from the focus groups in the five countries were analyzed separately for each country, using a qualitative data analysis package, NVivo 2.0. Five transcripts, one from each country, were analyzed by the research team using the open coding technique of Tesch (Creswell, 1994). Several free nodes (of the NVivo 2.0 system) were identified, e.g. self stigma, nurse stigma, other health-care stigma, family stigma, community stigma, outcomes, disclosure, descriptions of PLWA, help-seeking behaviour, meaning of stigma, patterns of distress and other incidents.

Consensus discussions were held during a meeting attended by all five countries. It was then decided that the results reflect definite types of stigma and that each type had specific dimensions. Subsequently, it was decided first to classify the data into three broad *categories of stigma*, namely *received stigma*, *internal stigma* and *associated*

stigma. These categories were adapted from the Siyam'kela report (2003), which described two types, namely external and internal stigma. They classified 'stigma by association' as one of the themes under external stigma. However, stigma by association proved to be of much greater significance in this research and was used as a third type of stigma.

Coding was done using sections of the text that were labelled by the coder as an incident. An incident was defined as 'a narrated event, including the circumstances, what happened, the actions taken, and feelings of respondents and then the results of the incidents. It could be as short as several sentences or as long as several paragraphs discussed'. Five transcripts, one from each country, were once again carefully studied by the research team to see whether the broader classification for the types of stigma would work. The number of times an item from each category was mentioned or coded was explored to assess if there were any differences between the countries or in the urban and rural focus groups. No significant differences were found and it was decided to pool the data of all the countries and only mention the differences, should there be any. It was found that one incident could include several dimensions of stigma.

After the incidents had been coded as types of stigma, a second phase of coding took place, involving the isolation and coding of the dimensions of stigma within each incident in order to refine the coding protocol. This was reflected as passages. One transcript of each country was once again coded independently by each member of the team. Initial definitions of the types of stigma and the various dimensions of stigma were developed, based on the verbal responses of the respondents. Discrepancies were discussed until unambiguous categories and explicit definitions were agreed upon. One researcher then coded all the transcripts. However, the coded country-level data were finally checked by the country investigator.

Three *types of stigma* were identified, with nine dimensions of *received stigma* (neglecting, fearing contagion, avoiding, rejecting, labelling, pestering, negating, abusing and gossiping), and four dimensions for *internal stigma* (perceptions of self, social withdrawal, self-exclusion and fear of disclosure). Two dimensions were identified for associated *stigma* (family/spouse and health-care workers). The dimensions emerged as sub-categories. Two *additional themes*, not related to types of stigma, were identified through an endeavour to understand the context of stigma: results of stigma, and disclosure.

### **Trustworthiness**

Rigor was ensured in this research using the model of Guba (in Krefting, 1991) to assess the trustworthiness of the qualitative data. Truth value, applicability, consistency and neutrality were used as criteria to assess the value of the findings.

## Results

Three main categories and several subcategories emerged from the data. The main categories were labelled types of stigma and the subcategories as various dimensions of each type of stigma. A clear conceptual framework for understanding the meaning and effect of stigma experiences of PLWA and nurses involved in their care became evident during data analysis. The results are discussed by first focusing on the three types of stigma (received, internal and associated stigma) as they manifested in selected *incidents* described by respondents. The focus is on the incident as a whole and not on the various dimensions. A discussion of the *dimensions* of various types of stigma follows the discussion mentioned, using verbal accounts (passages) of the respondents. The latter is focused on a better understanding of each dimension. See table 2 and 3 for a summary of the structure that guides the discussion, as well as for an indication of the number of passages for the various countries. As mentioned above, the results of the five countries were pooled as no significant differences were found among the various countries and the results therefore reflect an African perspective.

**Table 2:** Types and dimensions of HIV/AIDS stigma

Types and dimensions of HIV/AIDS stigma	Number of passages per country					
	Lesotho	Malawi	Swaziland	South Africa	Tanzania	TOTAL
<b>Received stigma (Etic view) = 1409 total passages</b>						
All types of stigma behaviour towards a person living with HIV/AIDS as experienced or described by themselves or others						
Neglecting	32	31	57	14	73	207
Fearing contagion	72	58	72	16	87	305
Avoiding	35	41	26	16	41	159
Rejecting	6	27	47	14	48	142
Labelling	28	43	34	28	9	142
Pestering	19	13	19	14	26	91
Negating	8	17	29	7	57	118
Abusing	11	16	22	10	17	76
Gossiping	22	33	48	36	29	168
<b>Total</b>						<b>1409</b>

<b>Internal stigma (Emic view) = 301 passages</b> Thoughts and behaviours stemming from the person's own negative perceptions about him-/ herself based on his/her HIV status						
	<b>Lesotho</b>	<b>Malawi</b>	<b>Swaziland</b>	<b>South Africa</b>	<b>Tanzania</b>	<b>TOTAL</b>
Perceptions of self	30	20	15	8	52	125
Social withdrawal	15	12	15	20	26	88
Self-exclusion	13	10	8	15	18	64
Fear of disclosure	26	31	29	85	53	224
<b>Total 301</b>						
<b>Associated stigma = 69 passages</b> Incidents that describe stigma against people who work or associate with HIV/AIDS-affected people.						
	<b>Lesotho</b>	<b>Malawi</b>	<b>Swaziland</b>	<b>South Africa</b>	<b>Tanzania</b>	<b>TOTAL</b>
Family/spouse	8	19	12	12	18	69
Health-care workers						
<b>Total 69</b>						

**Table 3:** Additional themes not directly related to stigma

<b>Types and dimensions of HIV/AIDS stigma</b>	<b>Number of passages per country</b>					
	<b>Lesotho</b>	<b>Malawi</b>	<b>Swaziland</b>	<b>South Africa</b>	<b>Tanzania</b>	<b>TOTAL</b>
Results of stigma	13	38	49	18	56	174
Disclosure	83	58	85	76	130	432
<b>Total 506</b>						

## Types of stigma

As indicated under the discussion of the analysis of the data, three main types of stigma were identified: *received stigma*, *internal stigma* and *associated stigma*.

### *Received stigma*

The definition of received stigma that was formulated for this research after interpretation of the verbal responses is as follows:

**Received stigma** refers to *all types of stigmatization behaviour towards a person living with HIV/AIDS as experienced or described by themselves or others.*

It is similar to external or enacted stigma described by the Siyam’kela research project (2003) and refers to the etic or outsiders’ view of Weiss et al. (1992).

Received stigma became evident from the following and other incidents which described various behaviours directed at an HIV-infected person and quoted directly from a transcript of one of the focus groups:

*“This friend of mine ... she went around and people started laughing at her. You know she was a very up and going person, much like a ... loose type of person. When she ended up being sick, even at her home, especially her younger sister, chased her away, saying that she is sick and things like that. It ended up that she went to the clinic. I don’t know which one but she told the social workers. They came to her home. To talk to them at home, that they should treat her well. This person is sick. She doesn’t do it purposely. They should treat her just like each and everybody, just like a normal person. So if they isolate her, who do they expect from outside to pick her up and treat her well. So she started losing hope there ... with ... the relationship at home. She saw that the atmosphere was tense at home. It is impossible. She started losing hope.”*

### **Internal stigma**

The second type of stigma that was identified was internal stigma. It became clear in this incident and others that internal stigma is stigma that one brings onto oneself. From the findings the following definition was formulated:

**Internal stigma** refers to *thoughts and behaviours stemming from the person’s own negative perceptions about him-/herself based on his/her HIV status.*

Internal stigma is also referred to as internal or felt stigma mentioned by the Siyam’kela research project (2003) and the emic or insider’s perspective of Weiss et al. (1992).

The following incident enhances an understanding of internal stigma:

*“Okay ... I started to be stressed for that period only. The child was still alive ... After the child died, that stress came back ... I pictured her; I thought, I am coming ... I am going to follow her. I am going to die, such things. So I told myself that ... The nurse called me and counselled me. I told myself that you know what, it doesn't help. Let me ... let me give up because when I give myself much stress, I lose weight. Mmm ... to think about a lot of things I will end up mad. So since the nurse started to counsel me, I became all right. And always she is on my side, she is on my side. You know she has never been negative towards me. So I told myself that it is useless to go places, and exposing myself among people. Let me focus on her ... ”*

### **Associated stigma**

The third and last type of stigma is associated stigma. This means that the mere fact that a person is associated with a PLWA leads to the stigmatization of that person. The findings led to the following formulation:

**Associated stigma** is defined as incidents that describe stigma against people who work or associate with HIV/AIDS-affected people.

It is similar to associated stigma as described in the Siyam'kela research project, but was categorized as a theme on its own and not as a theme under external stigma.

Associated stigma was expressed through the following incidents:

*“What happen is most of the time, when we (nurses) go to a community; people can see you there with a certain company, so we're thinking maybe they have formulated a connotation about nurses who work with HIV. Also with the Condor. When they stop with the Condor outside, they relate that to HIV.”*

*“Our colleagues look at us as if this one ... is something wrong...so there it's like a shadow over your head, and they think you might also even have it, why otherwise will you be so ...”*

*“Both the parents died of AIDS. The children are now all alone. The grandparents are chasing away the six children so there is nobody at home to look after them.”*

### **Dimensions of the three types of stigma**

It was found that each of the three types of stigma has its own dimensions. The dimensions will be discussed in detail and illustrated with quotations (derived from the passages) from the transcripts. A discussion of each dimension follows, giving verbal quotations (passages) from each country to illustrate the discussion. All dimensions were identified by all five the countries. In some instances the respondents were more vocal about a specific dimension, which led to more passages being coded.

## ***Dimensions of received stigma***

The respondents were most vocal about these dimensions. 1409 passages were coded. Nine dimensions of received stigma namely *neglecting, fearing contagion, avoiding, rejecting, labelling, pestering, negating, abusing and gossiping* emerged from the data. Definitions of these dimensions originated from the verbal responses of the various respondents in the focus groups and were achieved through consensus discussions amongst the various researchers.

- Neglecting (207 passages): *Neglecting is seen as offering or giving less care than expected in a situation.*

This dimension was the second highest amongst the dimensions of received stigma. Although the specific behaviour differed in each country, it became clear that PLWA was denied certain things, e.g. a bed wash, physical care or contact, or not doing things for the person leading to neglect.

Some direct verbal quotations from the focus groups follow to enhance the understanding of this dimension.

“I remember one day I found his mattress wet because he was incontinent. ‘Look at how my mattress is! Please get out of bed.’ He was unable to get out of bed.”

“Why do you call me for an AIDS person? Then he (the doctor) refuses to see the see the patient.”

(Lesotho – 32 passages)

“As soon as I tested HIV pos my relatives started stigmatizing me. They no longer washed me or helped me, not giving me food, even porridge.”

(Malawi – 31 passages)

“His own mother also left the home and left him with his grandmother. The grandmother also had a problem of not taking good care of him.”

The child had a discharging rash. The nurses will tell this child to sit far away and use the tissue to wipe her discharge.”

(Swaziland – 57 passages)

“The one girl, she was 16, she came to me and she said they were chasing her away from the clinic.”

“So when I went there one of the patients were crying only to find that the patient was neglected – stinking and was mixed up.”

(South Africa – 14 passages)

“The HIV/AIDS victims are not given priority in treatment, as the service providers are afraid of being infected by touching the patient.”

“No one spoke to her or washed or fed her.”

(Tanzania – 73 passages)

- **Fearing contagion (305 passages):** *This dimension is defined as behaviour that shows a fear of close or direct contact with a PLWA or things (clothing) he/she has used.*

Of the nine dimensions the respondents were most vocal about this dimension, as can be seen from the 305 passages. Various forms of possible contagion were feared, e.g. coughing, using the same utensils, touching either the person or an item of the person, and playing with the affected children.

“You are here coughing all the time, do not use our utensils for eating. We do not want to use them.”

“One day they took him to the community court because they said his child was playing with their and the child could infect their children.”

(Lesotho – 72 passages)

“I was just thinking that this must be AIDS. Uhhh, so I really tried not to get in contact with her plate.”

“When I met them and wanted to shake their hands they would just answer verbally.”

(Malawi – 58 passages)

“Whenever we checked on him, the family members will ask and say ‘do you see some of his girlfriends by any chance?’”

“Even when I am sick she jokes and says what you are suffering from kills.”

(Swaziland – 72 passages)

“You see the person using a mug. I will take another mug to drink water.”

“If we were sharing a bed then you start not to share a bed with him.”

(South Africa – 16 passages)

“The way the nurse touches the HIV/AIDS patient or his/her clothes or bedding. It shows that the nurse is afraid of the patient.”

“It means that if I stay close, share same bedroom or touch his/her clothes I will be infected with HIV.”

(Tanzania – 87 passages)

- **Avoiding (159 passages):** *This dimension is defined as the deliberate limiting of social contact with PLWA.*

Avoidance took various forms e.g. to stop going to the house, not going near the PLWA or inviting that person.

“People stopped going to her house, including those who were very close to her.”

“When the community heard they tried to isolate him.”

(Lesotho – 35 passages)

“Stigmatizing is there in the places we stay. Our fiends whom we used to chat with previously no longer chat with us.”  
(Malawi – 41 passages)

“We are not going to come closer to her.”  
“So the easiest thing parents tell their children is that they must not visit this homestead.”  
(Swaziland – 26 passages)

“This person was your friend. When people see that person has ... sort of, they start moving away from him. They do not want to associate with him.”  
(South Africa – 16 passages)

“We felt that if we come close to him we could be infected.”  
“When he developed coughing his sister would never come near him.”  
(Tanzania – 41 passages)

- *Rejecting (142 passages): This dimension refers to behaviour that humiliates or breaks off relationships with PLWA, separates PLWA from groups, and that isolates PLWA.*

Rejection was either verbal or physical. People would shout and chase the PLWA away, not take the PLWA anywhere, or exclude the PLWA from religious or social activities.

“When we told the students in the high school that we are living with AIDS they screamed and yelled at us until we felt bad and inferior. They kept on jeering at us until we left.”

“His brother expelled me from their home, so I went back to my home.”  
(Lesotho – 6 passages)

“So I chased my husband away since he is the one who got tested first.”  
“Once he was discharged from hospital, I chased him away from my house.”  
(Malawi – 27 passages)

“It turned out that the in-laws suspected that she was HIV positive then they chased her away from their home.”  
“She no longer has anyone to support her and no one wants to stay with her.”  
(Swaziland – 47 passages)

“Finally they said they were going to leave her out and they were going to take her anywhere.”  
(South Africa – 14 passages)

“Then the HIV/AIDS victim is isolated or left to stay alone.”  
“The church decided to discriminate or isolate or excommunicate any person said to be

HIV positive because he/she committed adultery or fornication.”  
(Tanzania – 48 passages)

- Labelling (142 passages): *This is defined as attaching an identifying or negative term or sign to a PLWA, linking cause of infection to behaviour of PLWA or blaming PLWA for their behaviour.*

Low morals were quiet often mentioned, as well as labels assigned to the PLWA to identify him/her e.g. hangers, stick animals, etc. They were also labelled for using certain services.

“Very often I have head people use words such as ‘people with no morals or people who are wild like horses’.”  
(Lesotho – 28 passages)

“They would jeer at me.”  
“When other people see you blowing your nose, walking slowly, they say ‘sjee, that one has swallowed a paper’.”  
“They say you look as thin as a hanger.”  
(Malawi – 43 passages)

“Sometimes you hear them say she is suffering from the nation’s killer.”  
“She used to live a loose life.”  
(Swaziland – 34 passages)

“If someone comes from the counselling room they call it the AIDS room. It means there is something with him.”  
“She was very thin. As she passed they said this one goes with Nkosi Johnson (well-known AIDS victim).”  
(South Africa – 28 passages)

“For those who believe adultery or fornication is a sin, hence they tend to think an HIV/AIDS victim was infected through adultery or fornication.”  
“What I don’t understand is those who are infected are regarded as the most sinful group.”  
(Tanzania – 9 passages)

- Pestering (91 passages): *This dimension refers to persistent questioning of a PLWA about his/her behaviour and illness.*

If people suspected a PLWA of being infected they would repeatedly question him/her. Even if the diagnosis is known they would constantly ask questions on various aspects.

“People who knew my hair well used to express their disappointment at its miserable state and say: ‘why have you let the bat to pull out your hair?’”

“When we get back to people they ask: ‘Where are your AIDS things?’”

(Lesotho – 19 passages)

“Every time I visited my friend, his mother would say that I am visiting a dying person, someone who will never recover.”

“Every morning the children would say get away from us you have HIV. You just want to pass it on.”

(Malawi – 13 passages)

“At times the family would ask him and say: ‘what did you do exactly?’”

“In the rural areas they like to show their kids the homes where there is the problem.”

(Swaziland – 19 passages)

“Yes, her granny who used to take care of her, every time when she reprimanded her she would say: ‘By the way they say this thing has AIDS.’”

(South Africa – 14 passages)

“My wife is compelled to explain to me how she contracted the disease.”

“At the place where I am staying, every time I cough, they tell me: ‘Go to Angaza and test.’ This kind of talk for about a month!”

(Tanzania – 26 passages)

- **Negating (118 passages):** *This dimension is defined as denying PLWA access to services and opportunities based on the PLWA's health status.*

Because the status of PLWAs is known, they were denied opportunities like cook for the family or be part of community activities. They were also denied access to health services.

“They were also not allowed to cook in their own homes because of their status. They were starving.”

(Lesotho – 8 passages)

“But when she arrived nobody attended to the patient, not even the nurses. He was told that there were no drugs for treatment of opportunistic infections.”

“I cannot participate in the ‘Food for Work Programme’. This is sad because this could have helped some of us to live longer.”

(Malawi – 17 passages)

“As nurses we normally do work together, but in this case the patients who are HIV positive or AIDS suffering normally have to wait for the home-based care nurse.”

“Anyone could have helped her, but this lady had to wait until I came back.”

(Swaziland – 29 passages)

“Because this poor child, she was crying, because she was so ill and nobody wanted to help her.”

“No use sending the patient to the hospital. He will die anyway.”

(South Africa – 7 passages)

“So when he/she is admitted to hospital seriously ill and needs spiritual attendance, he/she is denied of the service as he/she is judged that he is a sinner.”

“Due to this the husband was very angry with the wife hence he neglected her to high extent.”

(Tanzania – 57 passages)

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| <ul style="list-style-type: none"><li>• <b>Abusing (76 passages):</b> <i>This refers to verbal or physical behaviour intended to harm the PLWA.</i></li></ul> |
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Both verbal and physical abuse of PLWA occurred. PLWA were insulted, degraded and screamed at. Physical abuse varied from a poke with a finger to pinching or assault.

“Don’t you realize that you have sores and lacerations in your mouth? Are you intending to cross-infect my child? Stop it!”

““Don’t you realize you have AIDS? Look at your symptoms.’ It was very painful to hear him speak that way.”

“Used to insult me daily, saying: ‘You are a prostitute now you have brought AIDS to my home.’”

(Lesotho – 11 passages)

“Nobody came to see me (in hospital). Instead they were saying in the places where I used to drink beer, they were singing funeral songs.”

“Get lost. What do you want me to do with that stench of yours?”

“Poke me with their fingers and say: ‘You are and AIDS patient and are going to die.’”

“Came to bed and began to beat me.”

(Malawi – 16 passages)

“They indeed pinched him while cleaning him.”

“At times they would talk in front of her and she would come home crying.”

(Swaziland – 22 passages)

“She was badly beaten up by her own family, her children actually.”

“The doctor was not calm with her. He said: ‘Did they tell you, you are going to die?’”

(South Africa – 10 passages)

“Every time she entered her in-laws’ house her sister in law said: ‘you will die from Ngoma (HIV).’ She was told this by everyone at home.”

“Look at your uncle, he has no brain, he is HIV positive.”

(Tanzania – 17 passages)

- **Gossiping (168 passages):** *This dimension is defined as spreading rumours and talking inappropriately to others about PLWAs and their illness, without permission, uncaring, and in public.*

Gossiping was ranked very high in regard to the amount of verbal responses uttered by respondents. It was very difficult for PLWA when people spoke about them behind their backs and spread rumours by talking with others. It became even more difficult if other people close to them were affected by the gossip.

“She goes around telling people that me and my family suffer from AIDS.”

“Something that caused me great pain was the way my children were treated at school. People were saying that their father has AIDS even their mother (my wife) is dead because of AIDS.”

(Lesotho – 22 passages)

“She was telling her friends that. That boy was found HIV positive.”

“They thought that I had not heard what they were saying at the office.”

“When rumours start circulating that this person is infected the friends begin to keep a distance.”

(Malawi – 33 passages)

“What happened was that one of the ladies who overheard this went and told some people at the nearest market place.”

(Swaziland – 48 passages)

“They say they go about talking about our illness.”

“The spouse died and everybody was assuming that it was HIV/AIDS.”

“As the person got thin people were speculating. You know it was hearsay.”

(South Africa – 36 passages)

“One worker asked to be transferred from the ward as she suspected her colleagues were telling the patients that she is HIV/AIDS victim.”

“So those people who owed me used to go behind me saying why should they pay the debts when I am HIV positive and soon will die.”

(Tanzania – 29 passages)

### ***Dimensions of internal stigma***

Four dimensions of internal stigma were identified: perceptions of self, social withdrawal, self-exclusion and fear of disclosure. 301 verbal responses were received in regard to the various dimensions of internal stigma.

- **Perceptions of self (125 passages):** *This dimension is defined as the negative evaluation of oneself based on one’s HIV-positive status.*

Most of the perceptions about the self occurred before the community was aware of the PLWA's status because they feared stigma. Self-blame and feelings of guilt, fear, sadness and futility were verbalized.

"I felt she was going to blame me because I was the one who was diagnosed and this also meant I had shortened my life."

"I feared that people would talk about me and my status and that my wife would desert me."

(Lesotho – 30 passages)

"I thought that from that time I would be sick all the time or I could fall sick anytime or die."

When I thought of the way I will get home and the way I will live my life.... aah... it was saddening."

(Malawi – 20 passages)

"He felt no one thinks of him."

"She showed that she was not at ease with us since she thought we will gossip about her."

(Swaziland – 15 passages)

"I wasted my time and I also hurt my father because I was sick."

"My worry was why I have become thin so much. Because even people see it."

"After the child died, that stress came back. I pictured her, I thought, I am coming... I am going to die."

(South Africa – 8 passages)

"Even the HIV/AIDS victim tends to feel that he/she is dead while alive and feels isolated from others."

"He says: 'Let me die anyway I am going to die. If you continue to pressing me for testing, I will commit suicide.'"

(Tanzania – 52 passages)

- Social withdrawal (88 passages): *This refers to persons withdrawing from sexual and/or loving relationships to protect themselves from discrimination.*

This specific behaviour took place because the PLWA made the choice to withdraw and not because the community isolated them. The PLWA isolate and keep to themselves or deny others access to their homes.

"The colleague who is sick usually feels bad, withdraws and fears mixing with other people."

"He left that family and even as of now he does not visit anymore."

"I stigmatized myself because I felt I had to avoid attending any social gatherings. I

feared sharing utensils with other people.”  
(Lesotho – 15 passages)

“I was not living happily. I liked to keep to myself.”  
“Right now I have moved into my own house. The children do not come to my house.”  
(Malawi – 12 passages)

“The child was also isolating herself. She was not able to talk nor sit next to other children.”  
“She decided to leave her in-laws for her parental home.”  
(Swaziland – 15 passages)

“She would stay in the house and not go outside.”  
“She did not want us to touch or play with the baby.”  
“She does not want to communicate with anyone in the family.”  
(South Africa – 20 passages)

“When I tried to console her for losing her child, she told me that she could not stay in Dar due to the tortures she was getting from her sister in law and everybody in that home.”  
“Since then he started isolating himself from his relatives, instead of being discriminated against.”  
(Tanzania – 26 passages)

- Self-exclusion (64 passages): *This dimension is defined as the process by which a person decides not to use services due to being HIV-positive and fearing discrimination or attend community activities.*

This behaviour was seen in a social context by PLWA not attending community activities but also excluding themselves from health services.

“I would do my best to get myself away from people.”  
“When we attend funerals we sometimes shy away from taking plates when we remember our status.”  
“I disliked myself before people disliked me.”  
(Lesotho – 13 passages)

“He told me he could not come because he was afraid of what people would say since he was popular in the community.”  
“I left the hospital without taking the letter.”  
“Some patients say only a nurse and not a volunteer should go to their house.”  
(Malawi – 10 passages)

“He got angry and told him that it is better for him to go home because he is not getting assistance here.”

“He does not want anything. In other words he did not want anyone to come near him.”

(Swaziland – 8 passages)

“If they have a boyfriend they decide they do not want the boyfriend anymore.”

“She was very downhearted and she didn’t want to go back to that place.”

(South Africa – 15 passages)

“He says: ‘Let me die, anyway, I am going to die.’”

“I felt very bad and I just told her, ‘No thank you dear but I won’t be at home.’”

(Tanzania – 18 passages)

- Fear of disclosure (224 passages): *This refers to all behaviour related to revealing the HIV status of the person.*

This was the second highest subcategory verbalized by the respondents. They set many barriers to disclose that varied from denial, keeping it a secret, fear of the community’s reaction as well as to whom, when and what to disclose.

“When we got home he only mentioned TB and did not disclose the HIV status.”

“Even our parents are not happy to be seen talking to us in the streets because we will be showing people that you know her.”

“I did not know how to disclose to my wife. I was worried.”

(Lesotho – 26 passages)

“My wife was the first to go for a blood test. She went secretly.”

“I did not do anything or speak to anybody as I went on my way. I was confused.”

(Malawi – 31 passages)

“This man stated that he was afraid the nurses in the company will disclose their illness to the employer and they would then lose their jobs.”

“You have to find a hidden place to ask the patient about his tablets. The patient first looks around about his tablets. It is his secret.”

(Swaziland – 29 passages)

“She kept it a secret. She even refused to tell her mother at home.”

“They didn’t tell, they have a denial.”

“They are afraid to disclose to tell them at home that they have been places and now I am sick.”

(South Africa – 85 passages)

“She started feeling sick in 1999 but did not inform anyone about her sickness. She kept quiet until she was very sick.”

(Tanzania – 53 passages)

## ***Dimensions of associated stigma***

The dimensions of associated stigma were not coded separately for spouse/children/family and health-care workers. This division became evident at a later stage. The total number of passages was 69. The number of passages per country was as follows: Lesotho – 8; Malawi – 19; Swaziland – 12; South Africa – 12; and Tanzania – 18.

- *Spouse/children/family: This refers to incidents directed at the spouse, children or family of a person living with HIV/AIDS.*

The mere fact that a spouse, child or family member was related and associated with the PLWA led to their also being stigmatized, e.g. such as people who do not allow children to play with the children of PLWAs or minimizing contact with affected people.

“One day they took him to the community court because they said his child was playing with their children and this child could infect theirs.”  
(Lesotho)

“The grandparents are chasing away the six children so there is nobody at home to look after them.”

“There is nobody who is taking care of the children everybody is rejecting them.”  
(Malawi)

“When the neighbours’ children ask why you do not come and play with us, they say our parents said we must not come to your place.”  
(Swaziland)

“But the mother afterwards said that nobody visits her anymore after his death.”  
(South Africa)

“I was discriminated against when my husband died. My best friend had her door opposite mine blocked by bricks and used the other door.”  
(Tanzania)

- *Health-care workers: This refers to incidents directed at health-care workers who care for people living with HIV/AIDS.*

The health-care workers were also stigmatized for working with PLWA by their own families, the community or even colleagues, e.g. people fearing that health-care workers will contaminate them, or people visiting health-care workers less.

“Husband feared that the wife would bring the virus from the work.”  
“Oh I know you, I don’t want to talk to you. You are a lady from AIDS.”  
(Lesotho)

“They say: ‘Aah is that job where you touch and wash people with HIV. What problem do you have for doing that job?’  
(Malawi)

“It stresses me. Such that I always wish I could change the workplace.”  
“Since no one volunteered I had to come back from my off day to go with World Vision to collect their patients.”  
“Since I started working in that office colleagues are no longer close to me.”  
(Swaziland)

“They talk about her as the AIDS nurse and horrible things they have mentioned and this really got to her. Very badly.”  
“The patients said people say sisters will only work with AIDS patients if they have AIDS themselves.”  
(South Africa)

“Where are you working? Ward ten? I feel sorry for you.”  
“Whenever they see a car they know those are vengeance. Therefore those visiting the homes of the infected people are referred to as vengeance.”  
(Tanzania)

### *Additional themes not directly related to stigma*

Two *additional themes*, not related to types or dimensions of stigma, were identified through an endeavour to understand the context of stigma: results of stigma, and disclosure.

- Results of stigma (174 passages): *This theme refers to the outcomes of stigma and can be described in many ways. Some measurable outcomes, however, are quality of life, quality of work life, access to health care and health behaviour.*

Having been stigmatized led to specific consequences or outcomes for PLWA. It refers to several aspects impacting on PLWA’s quality of life, quality of work life and access to care, but also on their own choices in health behaviour.

“We called a village gathering.”  
“Following that, there were quite a few people who came for voluntary testing.”  
“Nobody ate the potato salad I made.”  
“People became supportive.”  
(Lesotho – 13 passages)

“When my husband was sick in hospital, uhm, when he was tested to have the virus, I wanted to run away from him.”  
“I joined my group as a volunteer.”

“I asked a friend to help me with the issue.”  
(Malawi – 38 passages)

“We tried to talk to them, that a HIV positive person still belongs to them, they have to love and care for the person.”  
“I referred her to the hospital to be attended by the doctor.”  
“I tried to teach him about HIV/AIDS.”  
(Swaziland – 49 passages)

“The sister came and started me with food parcels.”  
“Patient went back to the clinic and they sorted things out.”  
(South Africa -18 passages)

“The first thing was to let the family know that their sister is a sick person just like others.”  
“She went to STI clinic where she was tested and recovered.”  
“We educated our people that the patients feel bad if we attended to them differently.”  
(Tanzania – 56 passages)

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| <ul style="list-style-type: none"><li>• Disclosure (432 passages): <i>This refers to statements relating to disclosure or fears of disclosure of HIV status.</i></li></ul> |
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432 passages were coded, which indicates that this is a significant dimension of the stigma experience of PLWA. The content of these responses led to three additional themes being identified: experiences before the disclosure; the process of disclosing; and lastly responses during and after disclosure. Because of its significance, this theme will be covered in detail in an article on “Disclosure of HIV status: Experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in five African countries” (Greeff et al., 2006).

“After the death of his wife, he accepted and went public.”  
“He disclosed to his family and began to separate his dishes.”  
“After disclosing my HIV status I experienced very unpleasant words about my status.”  
(Lesotho – 83 passages)

“A woman stood up to tell them she was HIV positive.”  
“Why do I need to check for it since people already say I am positive.”  
(Swaziland – 58 passages)

“That is why I voluntarily offered to talk on TV Malawi. I wanted people to understand.”  
“Yes he realized because we showed each other the letters from the hospital the time we both were found to have HIV.”  
“He came out in the open to say I am HIV positive.”  
(Malawi – 85 passages)

“She said she is HIV positive and she wants milk for the baby.”  
 “They have all reported and four of them disclosed to the family.”  
 “My people at home all know.”  
 (South Africa – 76 passages)

“After the burial ceremony of the child the wife told her husband that it was confirmed that the late child and herself were found HIV positive.”  
 “She told us not to bother because she had tested already and found that she was positive.”  
 (Tanzania – 130 passages)

## Conclusion

The unique nature of HIV/AIDS with its at risk, diagnosis, latent and manifest phases, lends itself to many dynamic and demanding changes in the manner in which the individual and others must address issues of stigma construction and management (Alonzo & Reynolds, 1995). The findings confirm that stigma is a highly discrediting and traumatic experience. A clear conceptual framework for stigma became evident through the three types of stigma (received, internal and associated stigma) and the various dimensions for each type that was identified (see table 4). Clear descriptions for each of these types and dimensions were formulated, which could in future provide a better understanding of stigma experience as a whole.

**Table 4:** Conceptual framework for stigma types and dimensions

Types of stigma			
	Received stigma	Internal stigma	Associated stigma
<b>Dimensions</b>	Neglecting	Perceptions of self	Spouse/child/family
	Fearing contagion	Social withdrawal	Health-care worker
	Avoiding	Self-exclusion	
	Rejecting	Fear of disclosure	
	Labelling		
	Pestering		
	Negating		
	Abusing		
	Gossiping		

## Recommendations

The following recommendations could enhance the findings of this first phase of the study:

- If health-care workers are themselves a reservoir of perceived stigma from the patient's perspective, research strategies are necessary to understand the phenomenon better, and intervention strategies are necessary to eliminate it from practice (Holzemer & Uys, 2004).
- Part of the challenge of AIDS stigma is to recognize its impact on patients and caregivers alike and to develop strategies for mitigating its effects (Holzemer & Uys, 2004).
- It could be meaningful to develop and validate an instrument to measure stigma experiences for both PLWA and nurses, including all the types and dimensions of stigma identified in this research.
- The findings of this research should be developed into a conceptual model of HIV/AIDS stigma.

This project is supported by R01 TW06395 Fogarty International Center, National Institutes of Health. This study was partially supported by the Health Resources and Services Administration's Global HIV/AIDS Program, U.S. Government (PI: Holzemer, Co-PI: Uys).

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