

## A conceptual model of HIV/AIDS stigma from five African countries

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Accepted for publication 28 November 2006

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HOLZEMER W.L., UYS L., MAKOE L., STEWART A., PHETLHU R., DLAMINI P.S., GREEFF M., KOHI T.W., CHIRWA M., CUCA Y. & NAIDOO J. (2007) A conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing*

doi: 10.1111/j.1365-2648.2007.04244.x

### Abstract

**Title.** A conceptual model of HIV/AIDS stigma from five African countries

**Aim.** This paper is a report on the development of a conceptual model delineating contexts and processes of HIV/AIDS stigma as reported by persons living with HIV/AIDS and nurses from African countries. It is part of a larger study to increase understanding of HIV/AIDS stigma.

**Background.** Researchers have defined stigma, explored determinants and outcomes of stigma and attempted to measure its multiple dimensions. This literature is difficult to synthesize, and often does not distinguish adequately between experiences of stigma and its causes and outcomes.

**Method.** Forty-three focus groups were held with persons living with HIV/AIDS and nurses in five African countries in 2004. Focus group recordings were transcribed and coded. The data were organized into a conceptual model of HIV/AIDS stigma.

**Findings.** Two components were identified in the data: contextual factors – environment, healthcare system, agents – that influence and affect stigma and the stigma process itself. The stigma process included four dimensions: triggers of stigma, stigmatizing behaviours, types of stigma and the outcomes of stigma.

**Conclusion.** A conceptual model is presented that delineates the dynamic nature of stigma as reported by study participants. The model may be used to identify areas appropriate for the design and testing of stigma reduction interventions that have a goal of reducing the burden of HIV/AIDS stigma.

**Keywords:** Africa, focus groups, HIV/AIDS, model, nursing, qualitative research, stigma

### Introduction

Since the 2000 International AIDS Conference in Durban, South Africa, titled *Break the Silence*, stigma has been recognized as a major confounding problem in the HIV/AIDS pandemic. While the body of literature on HIV/AIDS stigma is growing, few attempts have been made to build a conceptual model that identifies and organizes the concepts or variables that affect stigma. Various authors have defined stigma and identified predictors and consequences, but few

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data-based studies have focused on Africa where the burden of stigma is so great. In this paper, we report on the development of a conceptual model of HIV/AIDS stigma which was inductively derived from 43 focus groups held in Lesotho, Malawi, South Africa, Swaziland and Tanzania with persons living with HIV/AIDS (PLWA) and nurses.

## Background

### Definitions of stigma

The famous sociologist Goffman (1963) provided the traditional definition of stigma as a 'significantly discrediting' attribute (p. 3). Weiss *et al.* (1992) discussed the insider's view of stigma as the 'emic' and the outsider's view as the 'etic' perspective. Culture and personal perceptions were viewed as affecting both the person living with the condition and others who were observing it. This early work has influenced greatly the work on HIV/AIDS stigma. Based on Goffman's original definition, Alonzo and Reynolds (1995) defined stigma as 'a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons' (p. 304). Project Siyam'kela (2003) recently supported three types of HIV/AIDS stigma, including received stigma, internal stigma and associated stigma. Received and internal stigma are expansions of Weiss's concepts of emic stigma, and associated stigma relates to etic stigma. Linking to Goffman's original work, the Royal Tropical Institute (2004) recently defined stigma as existing where any two of the three circumstances intersect: low value, exclusion and disadvantage. Their work begins to elucidate the political and community aspect of stigma. Uys *et al.* (2005) reported on the definitions of HIV/AIDS from community members. Stigma is embedded in these definitions, as seen in the songs sung in front of persons with HIV/AIDS and the names they are called by community members.

### Impact of stigma

Stigma may affect many aspects of the lives of people living with HIV/AIDS. Varas-Diaz *et al.* (2005) reported on the importance of understanding the effects of stigma and discrimination among Latinos in Puerto Rico living with HIV/AIDS. The study participants reported that loss of social

support, persecution, isolation, job loss and problems accessing healthcare services resulted from stigma. Duffy (2005) reported on data from an ethnographic study in Zimbabwe, identifying shame, suffering and silence as consequences of HIV/AIDS-related stigma that affected health promotion efforts (Duffy 2005). In yet another example, Poindexter (2004) used narrative analysis to report on a family's experience of stigma as they cared for their HIV-positive daughter at the end of her life. The family experienced healthcare providers' stigmatization of their child, and the narrative also describes how the medical system ultimately failed the daughter. Separately, Poindexter (2005) described her own personal struggle against stigma in caring for her adult son who died of AIDS.

### Correlates of stigma

Stigma was correlated with basic HIV knowledge by Kalichman and Simbayi (2004), who reported on a survey of 487 men and women living in a black township in Cape Town, South Africa. Eleven per cent of the participants reported that HIV/AIDS is caused by spirits, while 21% reported that they were not sure whether HIV/AIDS is caused by spirits. The relationship between HIV/AIDS-related stigma and the belief that AIDS is caused by spirits disappeared when knowledge of HIV/AIDS was added to the regression model. The authors suggest that continued HIV/AIDS education may be one important strategy in the eradication of HIV/AIDS stigma.

HIV/AIDS stigma has also been correlated with poorer mental health. Bird *et al.* (2004) reported on health-related correlates of perceived stigma in HIV care in the United States of America (USA). Greater stigma was associated with increased depression and severity of HIV-related symptoms and lower levels of adherence to antiretroviral (ARV) treatments. Roeloffs *et al.* (2003) reported on the association between stigma and depression in patients with multiple diagnoses in primary care settings. In an exploration of the

potential differences between HIV and cancer stigma on self-esteem, Fife and Wright (2000) reported that stigma had a statistically significant impact on self-esteem, regardless of the type of life-threatening illness the person had.

Researchers have also noted correlations between stigma and access to care. Letamo (2003) reported on the relationship between willingness to care for a family member with HIV/AIDS and discriminatory attitudes in Botswana. Nurses who had a family member with HIV/AIDS reported feeling less inclined to stigmatize people living with HIV/AIDS than did nurses who had little personal or family level experience with HIV/AIDS. Castro and Farmer (2005) described an anthropological study of HIV/AIDS-related stigma in Haiti. They reported that the increasing access and availability of antiretroviral treatment reduced the prevalence of AIDS-related stigma and resulted in increases in receipt of HIV testing and counselling services. The control that stigma exerts over disclosure of HIV status was extensively reviewed by the Stigma-AIDS eForum discussion (Health and Development Networks, 2006).

### Stigma-reducing interventions

Although some stigma reduction programmes have been developed and implemented, few have been rigorously evaluated. Holzemer and Uys (2004) have discussed the challenge of developing strategies for healthcare workers to assist in managing HIV-related stigma.

### Stigma frameworks

Parker and Aggleton (2003), in their review of research on the topic of stigma, offered a theoretical framework for understanding HIV/AIDS and stigma. They suggested that most research on stigma has focused on how others view the stigmatized person and propose a framework of social inequality as a strategy to understanding stigma:

To move beyond the limitations of current thinking in this area, we need to reframe our understanding of stigmatization and discrimination to conceptualize them as social processes that can only be understood in relation to broader notions of *power* and *domination*. In our view, stigma plays a key role in producing and reproducing relations of power and control. (p. 16)

Parker and Aggleton also urged the recognition of other contextual factors, such as culture and its impact on power relationships, in order to understand stigmatization as a process of social structures.

Campbell *et al.* (2005) studied AIDS-related stigma in a South African community using interviews, focus groups and

fieldworker diaries. Their findings suggest that stigma serves as a form of 'social psychological policing', indicating a close relationship between stigma and power dynamics in social groups. They proposed a framework of the contexts in which stigma occurs: the symbolic context; the economic, political and local community context; and the organizational context of institutions working to address HIV/AIDS (Campbell *et al.* 2005). Collymore (2002) also supported the relationship of AIDS stigma to power relationships and wrote that '[s]tigma related to HIV/AIDS feeds off well-established relations of power within society – those associated with race and ethnicity, economic status, sexual orientation and women's low social status' (p. 2).

Many researchers have proposed definitions of stigma, investigated its impact and correlates, and proposed frameworks for thinking about stigma. None, however, have used a data-based approach to integrate theories on the context and process of stigma. In addition, none have focused on Africa, an area where stigma continues as a major challenge in addressing the HIV/AIDS epidemic.

## The study

### Aim

The aim of the overall study was to increase understanding of HIV/AIDS stigma by (1) developing two culturally appropriate measures of stigma as perceived by people living with HIV/AIDS and by nurses to test how stigma is related to quality of care and quality of work life, and (2) to pilot test a stigma reduction intervention. The study also resulted in the conceptual model reported here. We define a conceptual model in alignment with the writings of Dickoff and James (1968), who state that a conceptual model is a mental image that is for the purpose of describing, relating and predicting a desired situation. The model presented here represents an initial phase of development in describing the dynamics of HIV/AIDS stigma, and further development is needed to continue to clarify the concepts, processes and propositions. The conceptual model is designed to be useful as a guide for practice, education and research.

### Design

A qualitative methodology, focus groups, was used to capture PLWA and nurses' perceptions of stigma related events, and data were collected in 2004. The first step in the research process was a series of 43 focus groups held in the five participating African countries. Results from the focus groups were then used as the basis for the two stigma measures,

(Holzemer *et al.*, in press). The results were also used in the development of a conceptual model of HIV/AIDS stigma, reported here. While we were aware of the existing literature and definitions of stigma, the conceptual model presented here was based upon the data from the respondents. Our findings coincide with the literature as presented by Fife and Wright (2000), Collymore (2002) and Parker and Aggleton (2003), but this comparison was made after textual analysis of the coded statements was complete.

### Settings and participants

This project was a collaboration among nurse-scientists at seven universities in six countries. Data were collected in Lesotho, Malawi, South Africa, Swaziland and Tanzania. Initially, the countries were selected because of the collaborative working relationships among the investigators and the high disease burden in each nation from HIV/AIDS.

In Lesotho and Swaziland, the focus groups included participants from all regions of the country. In Malawi, South Africa and Tanzania, one region with a relatively homogeneous population, participated. In Malawi, participants were from Lilongwe. In South Africa, the Potchefstroom urban area and Kayakulu rural area were included. In Tanzania, urban participants were from Dar-es-Salaam and rural participants from Mbeya. Country investigators had worked with nursing groups and PLWA groups before and therefore already had established relationships with the potential study participants.

People living with HIV/AIDS were recruited mainly through community-based HIV/AIDS organizations. Nurses were mainly recruited from area hospitals or clinics, or based on their membership in the national nursing association. Because of the importance of community-based volunteers in the care of people living with AIDS, four focus groups were conducted with volunteers. It is highly possible that some of the nurses and volunteers were also HIV-positive, but we did not ask about this. To the extent possible, the convenience sample of participants was balanced in terms of urban/rural settings and male/female participants.

**Table 1** Participants by groups, sex and age combined by country

Groups	Number of groups	Men	Women	Total sample	Mean age
People living with HIV/AIDS	19	52	59	111	36.8
Nurses	20	5	109	114	42.7
Volunteers	4	11	15	26	34.3
Totals	43	68	173	251	39.9

Forty-three focus groups were conducted with a total of 251 individuals (Table 1). Participants included people living with HIV/AIDS (44%,  $n = 111$ ), nurses and nurse managers (45%,  $n = 114$ ) and volunteers/youth groups (10%,  $n = 26$ ). The mean age of participants was 39.9 years. Women were 53.1% of the sample of people living with HIV/AIDS, 95.1% of the nurses and 58% of the volunteers. Fifty-six per cent of the focus groups were carried out in urban areas, and 44.2% were conducted in rural areas. The total sample included approximately equal numbers of participants from each of the five countries (Kohi *et al.* 2006).

### Data collection

Data were collected by the country investigators, all of whom were doctorally qualified nurse researchers. In some cases, a Master's degree-holding co-investigator participated in the data collection. The focus groups were conducted in convenient locations in one of the main cities or a rural area. Lunch was provided and the respondents were reimbursed for their travel expenses. All participants completed a brief demographic questionnaire before the focus groups began.

In the focus groups, the investigators asked two main 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?' For each incident mentioned, the investigator used additional probes to draw out further details about the circumstances, the specific stigma action, whether something prompted the incident and, if so, what that was and the reaction that the incident elicited.

Participants, including the nurses, were most comfortable speaking in their local languages, and so each discussion was conducted in that particular language. In South Africa, the co-investigator simultaneously communicated with participants in Afrikaans, English, Tswana, Sotho and Zulu. The other country investigators conducted the focus group discussions in English and Chichewa in Malawi, Sotho in Lesotho, Swazi in Swaziland and Kiswahili in Tanzania. The discussions were tape-recorded, transcribed and translated into English by the country investigators, all of whom spoke English fluently. In South Africa, the recordings were translated into English during the transcription process.

### Ethical considerations

The institutional review boards or ethical committees of each of the seven universities involved in the study approved the protocol. Where necessary, the country investigators also

received permission from government authorities. Before enrolling in the study, each person was given background information about the project and notified that participation was completely voluntary and that they could withdraw at any time. We also assured them of the confidentiality of the information gathered. After this, people who agreed to participate in the study signed a consent form.

### Data analysis

NVivo<sup>TM</sup> software (QSR International, Cambridge, MA, USA) was used to code demographic attributes, including country, type of participant, sex and stigma-related themes. The three types of stigma proposed by the Siyam'kela (2003) Project (received, internal, associated) served as the origin for coding the data. Using the open coding technique (Corbin & Strauss 1990), the investigators reviewed one identical transcript from one focus group from each country to identify themes, develop definitions of themes and sub-themes and explore agreement among the investigators as to what consisted of an incident of stigma. Based upon agreed definitions, each researcher independently coded several sections of transcripts from several focus groups to refine the coding categories. The discrepancies in the coding were then discussed, resulting in more clear definitions and distinctions between the themes and sub-themes. A second round of coding and discussion was carried out to finalize the definitions. For purposes of consistency, one researcher then coded all the transcripts using the comments from the full research team. Finally, each country investigator reviewed the coding of the transcripts for each country and provided feedback to the one coder where appropriate.

The resulting codes were the basis of the research team's efforts to develop a conceptual model of HIV/AIDS-related stigma. To foster the creation of a conceptual model, the codes were logically organized through a group process of examining the codes and linkages among the codes from the transcripts. Finally, the team developed a diagrammatic representation of the themes and codes and this framework with definitions and relational statements is presented here.

### Rigor

Lincoln and Guba (1985) proposed that qualitative research should be tested against four constructs to enhance rigor, including credibility, transferability, dependability and confirmability. To ensure the credibility of our data analysis, we reviewed and coded the data, compared and discussed differences between coding and then clarified

the codes further. Two rounds of this coding and discussion were used to develop clear definitions of categories. Transferability was ensured by using data not only from PLWA in five countries, but also from nurses and volunteers working in affected settings, some of whom may also have been living with HIV/AIDS. Dependability was ensured by careful transcription and analysis of the data with appropriate software, and also by careful description of the decisions made during analysis of the data. Confirmability was enhanced by openness to the creation of new themes as these emerged from the data.

### Results

In the process of coding the textual data, it became apparent that stigma might be best conceptualized as a process occurring within a context of the environment, healthcare system and different agents or people. Based on the data and personal experiences of working with HIV clients, we conceptualized the stigma process to include triggers of stigma, stigmatizing behaviours, types of stigma and outcomes of stigma. While they are represented in a linear format suggesting a causal order, this conceptual model is a heuristic and iterative, interactive process where outcomes become triggers. We then combined the stigma process with the context of stigma and created a Conceptual Model of HIV/AIDS Stigma (Figure 1).

### Context of stigma

The stigma process is conceived to occur within three contextual factors: the environment, the healthcare system and the agent. These factors are described below.

Environmental factors include cultural, economic, political, legal and policy environment (Castro & Farmer 2005). Politics, in the sense of power relationships, may play a role in the approach taken towards people living with HIV/AIDS in the cultural, economic, legal and policy environments. There may be secondary gain for those involved in stigmatizing people living with HIV/AIDS, and this might lead to them using their power to stigmatize. The very process of stigmatizing might also increase their perceived power. It should be noted that the legal and policy environments are usually secondary to the culture, politics and economics influencing the response to an illness. The environment of stigma has been described anecdotally, but there is limited understanding about which elements increase and which decrease stigma. For instance, under the guise of public health measures, some countries have laws and policies that

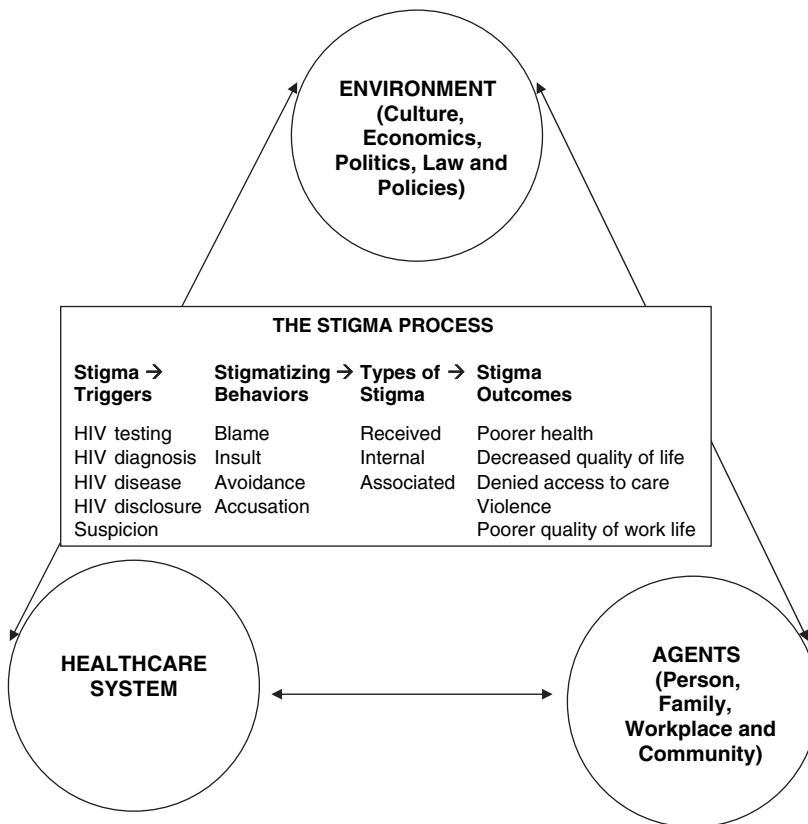


Figure 1. Model of the dynamics of HIV/AIDS stigma.

discriminate against PLWA (Tomasevski 1992). Examples of textual data from focus group participants related to the context of the environment that reflect legal issues include the following:

‘Sometimes the patient is denied the right health care simply because he/she is infected with the HIV virus.’ (Tanzania Urban Administrative Nurse)

‘If it happens that you are HIV positive and your partners in a group know, you would not get a loan. So when they are required to guarantee you so that you get a loan they would give excuses.’ (Tanzania Female PLWA)

‘After being found that he was HIV positive, he was sacked from work.’ (Malawi Urban Administrative Nurse)

‘When someone is to be employed he/she has to undergo medical examination. If she/he is found to be HIV positive, he/she will not be employed while employment is her/his right.’ (Tanzania Rural Administrative Nurse)

The healthcare system includes settings such as hospitals, clinics and home-based care settings and healthcare workers such as physicians, nurses and others (Aujoulat *et al.* 2002). Health service delivery settings are noted as a context for

stigma, since they are primary settings in which stigma can be triggered and also where stigma can manifest. In our study, as in others, informants reported healthcare workers as a source of stigmatization (Bird *et al.* 2004). Although the healthcare system can be seen as a setting for stigma as well as an influencing factor, it was given independent status in our model because of its importance in health care and as a potential site for anti-stigma interventions. Examples of textual data from focus group participants related to the context of the healthcare system include the following:

‘I went to the clinic, where I explained my status and the prescribed treatment. They said: ‘Oh! No, no, you want to infect us.’ (Lesotho Rural Female PLWA)

‘They would skip his bed and go to the other patients, and the nurses, they would just come there and give him the drugs but he said that he had noticed the change in the care. It was not like the way it had been before he was diagnosed HIV positive.’ (Malawi Urban Administrative Nurse)

‘The one girl, she was sixteen years old, she came to me and said she said they were chasing her away from the clinics in town.’ (South Africa Nurse)

'Because we take care of people with HIV...that's why they stigmatise against us.' (Malawi Female Volunteer)

Agents of stigma, as identified both in the literature and the study data, include the individual who may self-stigmatize, family members, work colleagues and community members (Fife & Wright 2000, Varas-Diaz *et al.* 2005). Data from focus group participants related to the agents can be found in the following quotations:

'I used to dislike myself before people disliked me. I refrained from going anywhere because I thought that everybody could see my status. I was ruled by fear. I hated going to town.' (Lesotho Urban Female PLWA)

'They pretend as if I am dead and not alive. Even when they go to work in the fields they do not tell me even when they are going to do something they do not tell me.' (Swaziland Rural Female PLWA)

'[T]hey think that because we work with those with AIDS we should be infected too, so they put us in the same group with those that are sick. Ummh! They even point fingers at us and say we cannot help them we are only fit for the AIDS patients and that we also look sick.' (Malawi Rural Nurse)

## The stigma process

The Stigma Process takes place within these contexts and is proposed to include four elements: stigma triggers, stigmatizing behaviours, types of stigma and stigma outcomes. Our informants discussed stigma-related actions that triggered stigmatizing behaviours on the part of others that were interpreted as stigma, and this stigma affected health-related outcomes.

### *Triggers of stigma*

The stigma process can be triggered or activated by a variety of factors, such as an HIV diagnosis or disclosure of HIV status. A trigger is any action that allows people to label themselves or others as HIV-positive. In the view of many authors, the trigger includes an element of 'a marker of difference' (Royal Tropical Institute 2004). Received stigma can be triggered by, for example, disclosure. Associated stigma can be triggered by continued association with a person(s) who is either suspected of being HIV-positive or having AIDS, or definitely infected. Internal stigma can be triggered by the suspicion of being infected, or the confirmation of an HIV-positive diagnosis. This duality (fact or suspicion) also activates received and associated stigma. Many persons living with and affected by HIV/AIDS indicate that the suspicion of being HIV-positive is enough to trigger stigma. Such

suspicions can be created by a person's behaviour, such as attending a particular clinic, or a symptom, such as losing weight, and can lead to a stigmatizing behaviour often described as 'pestering', a continual questioning of the PLWA about their diagnosis or behaviour. PLWAs tend to avoid stigma triggers, if at all possible.

### *Stigmatizing behaviour*

Triggers lead to stigmatizing behaviours that harm, isolate, exclude or identify the person in a negative way. The level of stigmatizing behaviour varies from very limited, such as asking a person to use special eating utensils, to extremely serious, such as chasing such a person out of their home.

### *Types of stigma*

Three types of stigma were identified from the data: received, internal and associated. Their definitions and data examples from the transcripts are presented in Table 2.

Received stigma refers to all types of stigmatizing behaviour towards a person living with HIV/AIDS, as experienced or described by themselves or others. It is similar to the concept of the etic view of the world, where others direct stigma-related remarks or actions to the person living with HIV/AIDS (Weiss *et al.* 1992). Sub-categories of received stigma include neglecting, fearing contagion, avoiding, rejecting, labelling, pestering, negating, abusing and gossiping.

Internal stigma is thoughts and behaviours stemming from the person's own negative perceptions about themselves based on their HIV status. It is similar to the concept of the emic view of stigma, or the person's perceived or self-interpreted view of stigma (Weiss *et al.* 1992). Sub-categories of internal stigma include perception of self, social withdrawal, self-exclusion and fear of disclosure.

Associated stigma involves examples of stigma that result from a person's association with someone living with, working with or otherwise associated with people living with HIV/AIDS. This can include, for example, having a family member who is HIV-positive, or working with people who are HIV-positive.

### *Outcomes*

Focus group participants reported on the consequences of stigma. These consequences for PLWA were grouped under the categories of general health, violence, poor quality of life and reduced access to care. It is important to note that poor health as an outcome of stigma is not restricted to physical health, but also includes mental health, since social exclusion, rejection, high stress due to stigma and economic pressures may lead to stress-related mental illness.

**Table 2** Types of stigma, definitions and textual data from participants

Received stigma (etic view) – All types of stigmatizing behaviour towards a person living with HIV/AIDS as experienced or described by themselves or others.
<p><i>Neglecting – Offering or giving less care than is expected in a situation.</i></p> <p>‘No one spoke to her or washed her or fed her. No one bothered to see that she had food or not. No one cared replacing the dirty beddings while she had a running stomach.’ (Tanzania Rural Administrative Nurse)</p> <p><i>Fearing contagion – Behaviour that shows a fear of close or direct contact with a PLWA or things (clothing) he/she has used</i></p> <p>‘[W]hen the person is with you in the same house, and you people are suspicious in the same family, you will see if the person uses a mug to drink water, I will take another mug to drink water, I do not use the same spoon the person uses. We start showing the person. ...All such thing and finally the person becomes aware of the fact that he is not well accepted.’ (South Africa Rural Volunteer)</p> <p><i>Avoiding – Deliberately limiting social contact with PLWA</i></p> <p>‘Sometimes it’s like before they started seeing the symptoms in the patient, they were very close with him/her, they were working together but then when rumours start circulating that this person is infected the friends begin to keep a distance. Instead of working together you’d find the others working in this corner and the patient in the other corner. Sometimes when it is time for tea others say ‘this is my sup and no one should use.’ (Malawi Male Rural Nurse)</p> <p><i>Rejecting – Behaviour that humiliates or breaks off relationships; separates PLWA from group; isolates PLWA</i></p> <p>‘When his parents heard that he was HIV positive, because he and his family were staying with his parents, they chased him they said go and rent a house but his disease got worse and he went back to his parents’ house and stayed in a kitchen together with his wife. Then his mother and father chased him away again.’ (Malawi Female Rural PWLA)</p> <p><i>Labelling – Attaching an identifying or negative term or sign to a PLWA; linking cause of infection to behaviour of the PLWA; blaming PLWA for their behaviour</i></p> <p>‘Very often I have heard people use words such as ‘people with no morals or people who are wild like horses.’ (Lesotho Male Rural)</p> <p><i>Pestering – Persistent questioning of the PLWA about their behaviour and or illness</i></p> <p>‘In these rural areas they like to show their kids the homes where there is the problem or show off about the people that came out to say they are positive. Once they know you have disclosed when you become ill, you become a laughing stock of the community or you become what they can gossip about.’ (Swaziland Male Rural PLWA)</p> <p><i>Negating – Disallowing access to services and opportunities based on the PLWA status</i></p> <p>‘Some patients come to Outpatient Department to see the doctor during the week-end. When the doctor arrives, on seeing the patient he suspects the patient is HIV positive, he becomes upset and says, ‘Why do you call me for an AIDS person?’ Then he refuses to see the patient.’ (Lesotho Urban Nurse)</p> <p><i>Abusing – Verbal or physical behaviour intended to harm the PLWA</i></p> <p>‘[W]hen my husband’s relatives saw me thy (sic) came where I was and began to poke me with their fingers like this saying ‘you are an AIDS patient you are going to die.’ (Malawi Female PLWA)</p> <p><i>Gossiping – Spreading rumours and talking inappropriately to others about the PLWA and their illness, without permission, uncaring, in public</i></p> <p>‘In my home area they started gossiping about her. Sometimes in the shop, they would talk about her stating how ill and skinny she was.’ (Swaziland Male Rural PLWA)</p>
Internal stigma (emic view) Thoughts and behaviours stemming from the person’s own negative perceptions about him or herself based on their HIV status
<p><i>Perception of self – Negative evaluation of self based on HIV-positive status</i></p> <p>‘Fear and self stigmatization prevailed with me since I pictured myself as being different from other people. That I do not deserve to live anymore; I am simply waiting to die.’ (Tanzania Female Rural PLWA)</p> <p><i>Social withdrawal – Person withdraws from sexual and or loving relationships to protect self from discrimination</i></p> <p>‘Because you know your HIV status, you no longer want to meet with people, you want to be alone even in the family setting.’ (Lesotho Female Rural PLWA)</p> <p><i>Self exclusion – The process by which the person decides not to use the services due to being HIV-positive and fear of discrimination</i></p> <p>‘There was a certain patient..., and we had decided that volunteers and we nurses would be visiting him. When we told him about this he did not respond immediately. He later called us and told us that his house was near the community taps where a lot of people go to draw water, now when these people see that the nurses and volunteers are going to the house they will know that there is something wrong and he will be the talk of the town. He was afraid that people will start to discriminate him and all eyes will be on him.’ (Malawi Rural Nurse)</p> <p><i>Fear of disclosure – All behaviours related to revealing HIV status</i></p> <p>‘It is because people who have this disease have their own secret. They not want to disclose now how will they go to the doctor. In the clinic you have to explain your illness.’ (Malawi Rural Male Nurse)</p>
Associated stigma – Incidents that describe stigma against people who work or associate with HIV/AIDS affected people.
<p><i>Family/Spouse – Incidents directed at family members of a person living with HIV/AIDS</i></p> <p>‘Something that caused me great pain was the way my children were being treated at school. People at school were saying that their father has AIDS even their mother (my wife) is dead because of AIDS. This stressed my children, they were no longer walking or playing together with other children, they kept to themselves...’ (Lesotho Male Rural PLWA)</p>



Table 2 (Continued)

*Healthcare workers – Incidents directed at healthcare worker who cares for people living with HIV/AIDS*

'They say, 'aaah, is that a job, where you touch and wash people with HIV? Is that a job? What problem do you have for you to be doing that?' We are really stigmatized. Such that for us to explain to some of our friends about our job, they say, 'aaah, there is nothing that you can tell me I know quite well about your job.' (Malawi Female Volunteer)

PLWA, Person living with HIV/AIDS.

## Discussion

The development of a conceptual model of this sort has limitations. First, the data were from five different countries and, although some of them share languages and cultures, they were different in many ways. The research team, however, included representatives from each country and the USA, and their input, along with the diverse data, has resulted in a model that is relevant in southern Africa. The fact that the model also coincides with theories and related models developed in other settings supports the conclusion that this model may have international relevance.

A second limitation of the study is that the data describing the etic or outsider's perspective of stigma comes only from nurses and volunteers rather than from the wider community. During the focus groups with nurses and volunteers, however, discussion was not limited to the hospital/clinic setting. Nurses and volunteers are also part of the communities in which they live, and therefore described incidents that occurred not only in the workplaces but also in their communities.

The types of stigma that emerged from the data correspond with existing frameworks and definitions. These types of stigma – received, internal and associated – are similar to those outlined in the Siyam'kela (2003) Report.

Participants in the Research Workshop on Health-related Stigma and Discrimination (Royal Tropical Institute 2004) defined stigma as existing where any two of the three circumstances of low value, exclusion and disadvantage intersect. These circumstances are all reflected in the definitions of the sub-types of received, internal and associated stigma presented in Table 2. Low value is captured with terms such as humiliation, verbal abuse and spreading rumours. Exclusion is expressed in terms such as offering less care than expected, disallowing and withdrawal. Disadvantage is reflected in descriptions such as choosing not to use services, stigma by association and negative self-evaluation, in addition to the fact that people living with HIV/AIDS in these settings had few economic resources.

The proposed model has a process component, but also identifies structural elements. This addresses the points made by Parker and Aggleton (2003) that stigma is a process and

not a thing, but also identifies the social structures that form the arena of stigma and anti-stigma interventions. It is unlikely that the process will change unless the structural elements support such a change.

Portions of the model are not yet fully developed and should receive more attention. Very little is known, for instance, about the healthcare system factors that influence stigma. The organizational climate of the hospital – whether it advocates for tolerance generally – may play a major role in how it deals with HIV and AIDS. Is there more stigma in smaller services or in larger services? In urban or in rural services? Amongst certain healthcare workers? In poorer or in better equipped services? In government or religious or private health services? Do separate and dedicated services for people living with HIV/AIDS result in increased or decreased stigma? Such questions need to be answered in order to target stigma interventions effectively.

The context of stigma elaborated in our model correlates with the 'antecedent factors' identified by the models group of the Research Workshop on Health-related Stigma and Discrimination (Royal Tropical Institute 2004). They made the point that different illness conditions involve different features of stigma, and that this should be given attention when addressing stigma in relation to a specific condition. They identified the following variables as part of the context of stigma: class structure (with which class is the illness associated?), social/cultural/ethnic/race/language group, global and local political and economic factors, the history of the illness, gender roles in society, religion, education, occupation, media representations and age. They also include healthcare encounters and the conception of the body and illness. All of these factors are included in our proposed model under the categories of culture, economics, law, politics and policies.

Poku *et al.* (2005), explored the differential impact of HIV/AIDS on two groups of men (African-American and Ghanaian), which they ascribe to the difference in culture. They described how HIV/AIDS stigma as linked to perceptions of 'bad death' as defined in Ghana, as well as the level of knowledge about the disease, illustrating the impact of the context on HIV and AIDS stigma. The outcomes of stigma have been demonstrated mainly in qualitative studies (Skinner &

### What is already known about this topic

- A significant amount of literature on HIV/AIDS stigma is primarily testimonial and provides support for stigma's negative effect on people's lives.
- Researchers have defined, measured and examined the correlates of stigma without using a coherent conceptual model.
- Researchers have not synthesized a model that links the context and process of stigma.

### What this paper adds

- A conceptual model of HIV/AIDS stigma identifying contextual factors which influence the stigma process.
- Articulation of the stigma process as a four-part iterative process.
- A conceptual model which may be used to identify potential areas for stigma reduction interventions.

Mfecane 2004, Campbell *et al.* 2005). However, Poku *et al.* (2005) measured the impact of HIV and AIDS quantitatively, measuring social rejection, financial insecurity, internalized shame and social isolation. Their findings indicated that Ghanaians experienced a greater amount of both stigma and negative self-perception than their USA counterparts.

### Conclusion

In this conceptual model, we have attempted to articulate and visualize the comments from the focus group participants about the context within which stigma occurs and the stigma process itself. Each component of this conceptual model could become a target for stigma-reduction interventions. For example, work could be done to change legal conditions in work environments, create awareness campaigns in hospital and clinic settings of the impact of stigma on patients, and work directly with people who are affected by HIV/AIDS. The framework and the data are being used as the basis for developing items for two instruments to measure stigma, in order to understand it more fully. Developing a greater understanding of the stigma process may also provide insight as to how stigma is initiated, the related negative behaviours, the types of stigma experienced and the negative outcomes of the stigma experience.

### Acknowledgements

This project is supported by a grant from the National Institutes of Health's Fogarty International Center, R01 TW006395 (PI: Holzemer; Co-PI: Uys), and partially support-

ted by the National Institute of Mental Health and the Health Resources and Services Administration, U.S. Government.

### Author contributions

WLH, LU, LM, RP, PD, MG, TK, MC, YC and JN were responsible for the study conception and design. WLH and LU were responsible for the drafting of the manuscript. LM, RP, PD, MG, TK and MC performed the data collection. WLH, LU, LM, AS, RP, PD, MG, TK, MC and JN performed the data analysis. WLH and LU obtained funding. YC and JN provided administrative support. WLH, LU, LM, AS, RP, PD, MG, TK, MC, YC and JN made critical revisions to the paper. WLH and LU supervised the study.

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