

UNDERSTANDING HIV/AIDS STIGMA

A theoretical and methodological analysis

Funded by the UK Department
of International Development

Harriet Deacon
with Inez Stephney
and Sandra Prosalendis



Compiled by the Social Cohesion and Identity Research Programme in collaboration with the Social Aspects of HIV/AIDS and Health Research Programme, Human Sciences Research Council

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PREFACE

This theoretical and methodological analysis of research on stigma relating to HIV/AIDS is the first phase of a project initiated by the Social Cohesion and Identity Programme of the Human Sciences Research Council (HSRC) in Cape Town in collaboration with the HSRC's Social Aspects of HIV/AIDS and Health Research Programme (SAHA).

Our aim in doing this initial literature review and analysis is to inform our own research and to provide an opening for discussion with other researchers and practitioners in the field of HIV/AIDS stigma in southern Africa. We focused on reviewing the literature on stigma across various disciplines and across different diseases. We tried to cover as much of the literature in as much detail as possible but, because of time constraints, some of our remarks are based on a reading of abstracts rather than the full articles. In Phase II of the project we hope to develop some of these ideas and implement some of the research methodologies in collaboration with other research projects.

The project team is comprised of Harriet Deacon, Sandra Prosalendis and Inez Stephney. The project began in January 2004. Inez Stephney compiled a database in Reference Manager (currently at over 3 000 entries) of recent work on stigma and disease. Harriet Deacon read and analysed the material in the database. Sandra Prosalendis managed the project for the HSRC and contributed her knowledge of educational theory and community-based interventions to the project. Jo Stein reviewed the paper for us with great energy and insight, and Helen Moffett and David le Page commented most helpfully on the paper when proofreading the final draft.

During the course of the project we held discussions with other researchers in the field, among whom we would particularly like to thank Olive Shisana, Leickness Simbayi, Nompumelelo Zungu-Dirwayi, Tilla Pheiffer, Donald Skinner, and Sharon Kleintjes of the HSRC's Social Aspects of HIV/AIDS and Health Research Programme, Leslie Swartz of the HSRC's Child, Youth and Family Development Research Programme, Catherine Campbell of the London School of Economics, Carolyn Wills of the POLICY project, Deborah Posel of the Wits Institute for Social and Economic Research (WISER) and Nicoli Natrass and Brendan Maugham Brown of the Aids and Society Research Unit at UCT. We presented versions of the paper at the Social Aspects of HIV/AIDS Research Alliance (SAHARA) conference in Cape Town in May 2004, at the Aids and Society Research Unit at the University of Cape Town in May 2004, in Pretoria at the HSRC's annual conference in July 2004, and at a seminar at the HSRC in August 2004. We presented the final draft of the paper in Johannesburg at WISER's 'Life and Death in the time of AIDS' symposium in October 2004.

ACRONYMS



ARVs	Antiretrovirals
HAART	Highly Active Antiretroviral Therapy
HDN	Health and Development Networks
HSRC	Human Sciences Research Council
NGO	Non-governmental organisation
PLHA	People living with HIV/AIDS
SAAVI	South African AIDS Vaccine Initiative
SAHA	Social Aspects of HIV/AIDS and Health Research Programme
SAHARA	Social Aspects of HIV/AIDS Research Alliance
SCI	Social Cohesion and Identity Research Programme
STI	Sexually transmitted infection
TAC	Treatment Action Campaign
TB	Tuberculosis
VCT	Voluntary counselling and testing
WHO	World Health Organisation



EXECUTIVE SUMMARY

This theoretical and methodological analysis is the first phase of a project initiated by the Social Cohesion and Identity (SCI) Research Programme of the HSRC in Cape Town, in collaboration with the research programme on the Social Aspects of HIV/AIDS and Health (SAHA). The project aims to develop ideas and test methodologies that can shed light on research on stigma in other contexts and to make recommendations about interventions to reduce the impact of HIV/AIDS-related stigma. We hope to support and inform the work of government and non-governmental organisations (NGOs) in managing the effects of the HIV/AIDS epidemic.

Most of the research on HIV/AIDS stigma has been done in the United States, a country with large research resources, an early epidemic and pronounced stigmatisation of gay men, African-Americans and Haitian immigrants as carriers of HIV/AIDS. Considerable research attention is now being focused on HIV/AIDS research in general in Africa because of the severity of the African epidemic, the politics of the HIV/AIDS issue, and the fact that HIV/AIDS seems to be highly stigmatised in the region. However, the relative 'lack of scientific research on the manifestations of HIV/AIDS-related stigma [in sub-Saharan Africa] presents a serious challenge to the understanding, alleviation and prevention of HIV/AIDS-related stigma' (Lorentzen & Morris 2003:27).

The problem of HIV/AIDS stigma in Africa has been raised in related research: on barriers to testing, treatment, care and adherence; on quality of life; and on social responses to HIV/AIDS. It is important to understand HIV/AIDS stigma in relation to the broader social, political, economic and cultural context, and to address stigma as one of a number of causes of discrimination, reluctance to test, therapeutic non-compliance, and so on. First, however, it is essential to clarify exactly what we mean by stigma, how it arises, and how it operates in order to suggest ways of reducing its negative impact on society. Important recent work on HIV/AIDS stigma in South Africa includes Posel (2004), Kalichman and Simbayi (2003, 2004), Patient and Orr (2003), POLICY project (2003a), Stein (2003a), Shisana and Simbayi (2002) and Jennings, Mulaudzi, Everatt, Heywood and Richter (2002). Research on HIV/AIDS stigma in other African countries includes ICRW (2002), Muyinda, Seeley, Pickering and Barton (1997), Bond, Chase and Aggleton (2002), and several Bergen University theses (Lie [1996 cited in Lorentzen & Morris 2003], Oduroh [2002 cited in Lorentzen & Morris 2003], and Lorentzen & Morris [2003]).

In order to conduct the literature review that forms part of this study, we compiled a database of recent academic work on disease stigma across various disciplines and across different medical conditions (although we focused on HIV/AIDS). We included literature on racism and disability-related stigma. One of the problems we faced was that the large online academic databases we used (such as ISI and EBSCO) often excluded African publications for technical reasons (such as late publication and non-digitisation). In our searches of local sources for the African literature, we focused mostly on southern Africa, where our future research will be based. However, we hope to benefit in future from the Africa-wide networks established by the SAHARA project as we continue to expand the database. Our database (which currently stands at over 3 000 entries) is not yet fully comprehensive, nor yet fully representative of the admittedly meagre amount of current African research, but it provides a good general overview of the available material.

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This paper critically reviews academic literature on disease stigma that can help us to:

- Develop more sophisticated theoretical approaches to understanding stigma in southern Africa;
- Develop research methodologies to better understand the historical and cultural specificity of stigma, and its impact on the treatment and care of people living with HIV/AIDS in southern Africa; and
- Inform the development of better anti-stigma interventions in southern Africa.

Theoretical analysis

Traditional psychological approaches to stigma imply that it is partly or wholly a problem of individual ignorance. This implies that the silence can be broken around HIV/AIDS if people are given the facts. This is the rationale behind educational interventions for the general public to reduce ignorance and increase 'tolerance' of people living with HIV/AIDS. In an attempt to explain why education has not eliminated stigma, a number of researchers have developed a critique of the traditional approach to understanding and researching HIV/AIDS stigma (Fassin 2002; Link & Phelan 2001; Parker & Aggleton 2003; Stein 2003a). They suggest that stigma is instead a complex social process linked to competition for power and tied into existing social mechanisms of exclusion and dominance.

Although this critique of traditional psychological approaches is useful and valid, both theoretical approaches to stigma remain problematic. We need to be able to explain the functions or effects of stigmatisation without resorting to functionalism (defining stigma in terms of discrimination), and we need to be able to understand the role of the individual in stigmatisation without resorting to individualism (defining stigma as a problem of individual ignorance).

Stigma has come to mean almost anything people do or say that stands in the way of rational responses to public health campaigns on HIV/AIDS, or that restricts the access of people living with HIV/AIDS to employment, treatment and care, testing and a reasonable quality of life. We have used Miles' (1989) term 'conceptual inflation' to describe this. HIV/AIDS stigma cannot describe the entire range of barriers to dealing with HIV/AIDS – making the concept too elastic does not help us to understand what causes these very different barriers, or to develop interventions to address them.

In this study, we suggest that it is vital to distinguish between what we can call HIV/AIDS stigma (negative things people believe about HIV/AIDS and people living with HIV/AIDS), and what we should call discrimination (what people do to unfairly disadvantage people living with HIV/AIDS). Stigma does not always have to result in discrimination to have a negative impact, because people may internalise stigma or expect to be stigmatised or discriminated against, and may not come forward for testing or treatment, or enjoy a good quality of life as a result. Discrimination can result from stigma but could also stem from resource concerns, fear of infection, racism, sexism, and so on. All forms of unfair discrimination are unacceptable and need to be addressed, but we may need to tackle them in different ways.

Instead of defining HIV/AIDS stigma simply as something that results in discrimination, we therefore define it as an *ideology* that identifies and links the presence of a biological disease agent (or any physical signs of a disease) to negatively-defined behaviours or

groups in society. In short, disease stigma is negative social 'baggage' associated with a disease. However, disease stigma does not consist of all negative beliefs about a disease because infection with a disease agent does have some demonstrably negative effects (such as higher morbidity and mortality). Disease stigma does not include all medically-unjustifiable negative beliefs about a disease either. It consists of beliefs that are part of a social process of stigmatisation, differentiating those with a disease in negative social as well as biological terms, and projecting risk of contracting the disease onto other groups.

Understanding stigma as a problem of fear and blame, rather than as a problem of ignorance or a mechanism of social control, helps us to understand the stigmatisation process without resorting to individualism or functionalism. This model suggests that people often blame social groups other than their own for being affected by diseases and conditions like HIV/AIDS, and for putting society at risk of infection (for example, Joffe 1999). This emotional (rather than cognitive), and often unconscious, response to danger helps people to feel they are less at risk of contracting serious diseases, but it has many negative effects. The association between disease, negatively-defined behaviours or characteristics, and certain groups of people, results in stigmatisation of the disease and most of the people infected by it. Some stigmatising ideas have a very powerful hold on society because of the way in which they fit into existing prejudices and power alliances. While more powerful groups in society may be able to express stigmatising beliefs more widely or discriminate more on the basis of their stigmatising beliefs, stigmatisation can occur across the social spectrum in many different ways, and varies widely in different contexts.

Methodological analysis

Internationally, much of the socio-medical research on HIV/AIDS stigma catalogues and measures stigmatising attitudes and knowledge about HIV/AIDS through public opinion polls and surveys. However, measuring the general amount of stigma in a region will not really shed light on its specific local or situational forms, impacts and effects. This blunts the effectiveness of anti-stigma interventions. We need to review the kinds of findings we seek from survey methods and redesign the surveys accordingly.

Extensive qualitative research is being done on stigma, but it is generally not combined with quantitative surveys (except to inform their design). Qualitative research on HIV/AIDS stigma draws mainly from psychological case-study models, anthropological models (using participant observation, grounded theory methods) and discourse analysis. These qualitative studies generally rely heavily on interviews and media analysis. We need to use a wider range of qualitative methods and to aim for far more integrated qualitative and quantitative measures in research (as the ICRW 2002 study has done). The South African AIDS Vaccine Initiative (SAAVI) is a good example of collaborative, multi-disciplinary research on HIV/AIDS.

Most stigma research also focuses on identifying incorrect beliefs about HIV/AIDS and people living with HIV/AIDS, and/or how these support the status quo. The narrow range of the literature suggests that we need to expand the range of questions we ask around stigma to include:

- How stigmatising beliefs form part of other social discourses;
- How stigmatising beliefs have a local history and politics;

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- The nature and impact of stigmatising beliefs expressed by the educated (including doctors and nurses) and the wealthy, as well as by the poor and less formally educated;
- How people living with HIV/AIDS experience and respond to stigma; and
- The different impact of stigma in different contexts, and whether or under what circumstances stigmatising beliefs are translated into discrimination.

In order to do this, we need to expand our range of qualitative methodologies beyond content analyses of interviews and discourse analyses of media coverage or policy, although these methods will continue to be very useful. We need to make more use of historical analysis for understanding the history and politics of stigmatising beliefs, and of participant observation for understanding the impact of stigma. Innovative techniques such as diaries kept by people living with HIV/AIDS, body maps and stigma mapping could be more widely used.

We therefore propose the research agenda outlined in Table 1:

Table 1: Proposed research questions and methodologies

Research question	Methodologies
What is the content of local beliefs around HIV/AIDS?	Participant observation, interviews, linguistic analysis
What are the histories and politics of stigmatising ideologies?	Documentary historical analysis, current political analysis, interviews, media analysis
What is the impact of stigma on people living with HIV/AIDS, and how do they respond to it?	Interviews, surveys, participant observation, diaries, stigma mapping, body maps
What are the effects of stigma?	Participant observation, surveys, interviews, legal case studies, stigma mapping
What are the barriers to treatment and care?	Participant observation of interactions in clinics and homes, surveys, interviews, history and policy overviews of health care systems, synthesis of qualitative and quantitative data
What are the barriers to testing and disclosure?	Participant observation of interactions in clinics and homes, surveys, interviews, history and policy overviews of health care systems, synthesis of qualitative and quantitative data
How can our theoretical models of stigma be improved?	Theoretical work in conjunction with grassroots observation and consultation

We also need to design ethical research projects that give something back to respondents and their communities. In this regard, we recommend careful consideration of what research projects can give back to communities, whether this involves counselling provided as part of the research, donations to related local projects, or the provision of

specialised advice office services that network with support services and non-governmental organisations to help address problems faced by individuals and families affected by HIV/AIDS.

Interventions

There seems to be a gap between the relatively large body of research on what stigma is and the relatively small body of research on what to do about it. Because we have not fully researched the question of interventions, our comments here remain preliminary. Like racism or sexism, stigma is extremely difficult to eliminate. Education is not enough in dealing with stigma: we need to use legal measures and activism to challenge the power relationships that sustain stigma and discrimination. We need to monitor the nature and extent of stigma very carefully to identify and understand reasons for change, and thus to maximise the impact of interventions in reducing stigma.

We need more evaluations of interventions, and an understanding of how public health messages are interpreted in local contexts. Identifying key levers for change in specific contexts is a crucial step in developing more effective interventions. We need to focus on the main problems facing us in relation to HIV/AIDS: barriers to prevention, treatment and care; discrimination against people living with HIV/AIDS; and the difficulties (and occasional opportunities) posed by living with HIV/AIDS in a stigmatising, and increasingly poor and divided, society.

Instead of simply addressing stigma and discrimination in a general sense, we need to focus on reducing the most critical, negative impacts of stigmatisation, discrimination and other factors on prevention, treatment and care. This means that, while we can promote effective responses to stigmatisation by people living with the virus (and other challenges posed by the social and medical context of HIV/AIDS) that challenge stigma and/or mediate its effects, the focus will be on removing as many barriers to prevention, treatment and care as we can (such as confidentiality), rather than always blaming lack of access on maladaptive responses to stigmatisation. We can focus on reducing opportunities for discrimination against people living with HIV/AIDS, and on reducing the impact of discrimination when it occurs, whatever its cause.