

# 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

Funded by the UK Department for International Development

© 2005 Human Sciences Research Council and Harriet Deacon

Published by HSRC Press  
Private Bag X9182, Cape Town, 8000, South Africa  
[www.hsrcpress.ac.za](http://www.hsrcpress.ac.za)

First published 2005

All rights reserved. No part of this book may be reprinted or reproduced or utilised in any form or by any electronic, mechanical, or other means, including photocopying and recording, or in any information storage or retrieval system, without permission in writing from the publishers.

ISBN 0 7969 2104 0

Cover by Flame  
Cover art: *Girl with Orange*, 1943, oil on canvas, 47 x 39.5 cm,  
by Gerard Sekoto. Collection: Johannesburg Art Gallery  
Typesetting by Stacey Gibson  
Print management by ComPress  
Printed by Creda Communications

Distributed in Africa by Blue Weaver Marketing and Distribution  
PO Box 30370, Tokai, Cape Town, 7966, South Africa  
Tel: +27 +21 701-4477  
Fax: +27 +21 701-7302  
email: [orders@blueweaver.co.za](mailto:orders@blueweaver.co.za)

Distributed worldwide, except Africa, by Independent Publishers Group  
814 North Franklin Street, Chicago, IL 60610, USA  
[www.ipgbook.com](http://www.ipgbook.com)  
To order, call toll-free: 1-800-888-4741  
All other inquiries, Tel: +1 +312-337-0747  
Fax: +1 +312-337-5985  
email: [Frontdesk@ipgbook.com](mailto:Frontdesk@ipgbook.com)

# CONTENTS



List of tables and figures	v
Preface	vi
Acronyms	vii
Executive summary	viii
1. INTRODUCTION	1
Conceptual inflation	2
What is the point of quibbling about theory?	3
A review of the literature	4
2. THE LANDSCAPE OF PREJUDICE	7
The risk society	7
The role of biology in the stigmatisation of HIV/AIDS and other medical conditions	8
Racism, sexism and disability-related prejudice	9
Conclusion	12
3. TOWARDS A THEORY OF DISEASE STIGMA	15
Definitions of stigma	15
Understanding functionality without functionalism	16
Separating the analysis of stigma and discrimination	18
Understanding stigmatisation as a process	21
Stigma and power	23
The content of disease stigma	25
Understanding variation	26
Conclusion	29
4. RESPONDING TO STIGMA	31
Self-stigmatisation or internalisation of stigma	33
Expected stigmatisation and discrimination	35
5. STIGMA AND DISCRIMINATION	37
Categorising differential treatment	37
Differential treatment versus discrimination	38
6. INSTRUMENTAL AND SYMBOLIC STIGMA	41
Is the cause of instrumental stigma and symbolic stigma the same?	41
Do instrumental stigma and symbolic stigma perform the same functions?	42
Are the results of instrumental stigma and symbolic stigma the same?	42
Can instrumental stigma and symbolic stigma be ameliorated in the same way?	42
Are instrumental stigma and symbolic stigma both socially constructed?	43
Is ignorance as a cause of instrumental stigma simply a lack of knowledge?	44
Are instrumental stigma and symbolic stigma wrong for the same reasons?	45
Can risk and resource concerns and symbolic stigma usefully be part of the same category (stigma)?	46
Conclusion	47
7. CONCLUDING THE THEORETICAL DISCUSSION	49



8.	DEVELOPING A RESEARCH AGENDA	53
	Existing research agendas	53
	Developing a local research agenda	54
	Questions for southern African research on HIV/AIDS stigma	56
	Conclusion	63
9.	METHODOLOGIES FOR RESEARCHING STIGMA	65
	The survey: problems and possibilities	66
	Qualitative methods for researching stigma	69
	Conducting ethical research	72
	Conclusion	74
10.	DEVELOPING MORE EFFECTIVE INTERVENTIONS: PRELIMINARY THOUGHTS	75
	Removing barriers to treatment and care	77
	Promoting disclosure and protecting confidentiality	77
	Developing and enforcing a rights-based approach	78
	Interventions reducing the impact of stigma on PLHA	78
	Educational interventions	80
	Community projects	81
	Adapting public health messages	82
	Conclusion	83
	GLOSSARY	84
	REFERENCES	86

# LIST OF TABLES AND FIGURES



## Tables

Table 1:	Proposed research questions and methodologies	xi
Table 2:	Features of different kinds of discrimination	10
Table 3:	A numerical analysis of methods used in recent research papers	66
Table 4:	Proposed research questions and methodologies	74

## Figures

Figure 1:	How different kinds of stigma and discrimination relate to each other	20
Figure 2:	Stigma, status loss and discrimination	24
Figure 3:	Responses to stigma	33



# 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.

## EXECUTIVE SUMMARY

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;

## EXECUTIVE SUMMARY

- 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.



# I. INTRODUCTION

This study reviews work in the field of disease stigma and in other disciplines that can help us to:

- Develop more sophisticated theoretical approaches to understanding disease stigma, and specifically HIV/AIDS stigma;
- Develop research methodologies to better understand the historical and cultural specificity of HIV/AIDS stigma in Africa, and its impact on prevention of new infections and the treatment and care of people living with HIV/AIDS (PLHA); and
- Suggest some issues to be considered in developing more effective interventions against HIV/AIDS stigma in Africa.

In the US and Europe, HIV/AIDS was not initially perceived as a threat to the general population because of its association with stigmatised groups (gay men, injecting drug users, commercial sex workers and members of immigrant communities from Haiti and Africa). Activists thus sought political support for combating the disease as a threat to public health in general by showing that the virus 'knows no boundaries' and by highlighting the fact that those with the disease were being unfairly stigmatised (Mann 1996).

In the early years of the pandemic, the scientific and policy literature on HIV/AIDS focused mainly on identifying the disease agents and modes of transmission, and seeking cures or vaccines. Now that HIV-specific medical interventions are available, and HIV affects a growing proportion of the world population, problems such as stigmatisation that create social barriers to implementing prevention and treatment strategies have come into sharper focus. The problem of HIV/AIDS-related stigma has thus been highlighted in recent initiatives by the World Health Organisation (WHO) and other organisations, such as the Red Cross/Red Crescent.<sup>1</sup>

Historically, stigma has been a feature of many diseases, especially those which are sexually transmitted or terminal. The problem is currently being investigated in a wide variety of medical conditions ranging from obesity to stuttering, and including mental illness (Angermeyer & Matschinger 2003; Arboleda-Florez 2003; Corrigan & Penn 1999; Muehrer 2002), sexually transmitted infections (STIs) (for example, Lichtenstein 2003) and tuberculosis (Eastwood & Hill 2004; Westaway & Wolmarans 1994), as well as HIV/AIDS.

Stigma does have a serious effect on the incidence, experience and management of medical conditions today, exacerbating the biological effect of the pandemic (McGrath 1992). It has been used to explain a wide range of different problems. It has been identified as a key reason for reluctance by PLHA to disclose their condition, or come forward for voluntary counselling and testing (VCT) and healthcare; it is also identified as a significant cause of non-adherence to treatments (for example, see Black & Miles 2002; Bond et al. 2002; Chandra, Deepthivarma & Manjula 2003; Kilewo, Massawe, Lyamuya, Semali, Kalokola, Urassa, Giattas, Temu, Karlsson, Mhalu & Biberfeld 2001; Muyinda et al. 1997). It has also been used to explain negative attitudes and discrimination against PLHA in the family, at work, in the community and in healthcare environments (Bollinger 2002; Malcolm, Aggleton, Bronfman, Galvao, Mane & Verall 1998; POLICY project et al. 2003a; Richter 2001).

---

<sup>1</sup> The theme of the 2002–2003 World AIDS Campaign is 'HIV/AIDS-related stigma and discrimination'. The International Council of Nurses theme for 2003 is 'Fighting AIDS stigma: Caring for all'. In May 2002, the Red Cross/Red Crescent launched 'The truth about AIDS. Pass it on...', a campaign to reduce HIV/AIDS-related stigma and discrimination, to educate people about HIV/AIDS and warn against the dangers of stigmatising those who are infected, or their families. In 2001, the WHO also highlighted the need to de-stigmatise mental illness.

Disease stigma is a widespread but highly variable phenomenon with multiple causes and effects. In spite of the acknowledged complexity of the subject, and the breadth of the factors stigma is used to explain, the literature does not use a common or coherent theory of disease stigma. The concept of stigma seems endlessly elastic, an idea that has so much scope it cannot hold its core (Stafford & Scott 1986, cited in Weiss & Ramakrishna 2001).

As one paper commented:

Stigma ... is creaking under the burden of explaining a series of disparate, complex and unrelated processes to such an extent that use of the term is in danger of obscuring as much as it enlightens. (Prior, Wood, Lewis & Pill 2003)

### Conceptual inflation

The tendency to define a concept so that it includes an ever-widening range of phenomena has been dubbed 'conceptual inflation' in work on racism (Miles 1989: 41).<sup>2</sup> Like racism, stigma has suffered from conceptual inflation because much of the research on stigma defines it as something that results in discrimination (see, for example, Link & Phelan 2001), or does not clearly separate the two concepts. Conflating stigma and discrimination is not often perceived as a problem because our major concern about stigma is that it can cause unfair discrimination. Also, the tool we use most often to assess stigma is a questionnaire measuring self-reported beliefs and intended behaviour. In the most common research designs, what people believe (stigma) is measured by what people say they believe, and what people do (discrimination) is measured by what people say they will do. Discrimination is thus measured indirectly rather than directly. Questions about beliefs are used together with questions about intended behaviour to form a 'stigma index'. Such research assumes that stigmatising attitudes and discrimination are interchangeable measures of the 'amount' of stigma because stigma is defined as something that results in discrimination. The stigma index is therefore used to determine how much of a problem stigma is in a society, and this is related to its likely impact.

This approach is problematic for three reasons. Firstly, what people say they do or believe does not translate directly into what they do (neither does it necessarily correspond with what they believe, although we can deduce beliefs from statements and silences [Joffe 1999]). Although some stigmatising ideas lead directly to discrimination, there is no one-to-one relationship between stigmatising ideas (ideology) and discriminatory actions. Not all discrimination arises from stigma, and not all stigmatising ideas lead to, or can be used to justify, discrimination. For example, PLHA may be refused a job because of gender or racial prejudice and not HIV/AIDS stigma. A person who holds stigmatising beliefs towards PLHA might never act on these beliefs. Conflating stigmatising ideology and discrimination forestalls investigation into other causes of discrimination, such as gender or class discrimination, and possibly other avenues for intervention against discrimination.

Secondly, how stigmatised people respond to stigma is not necessarily or directly related to any measure of stigma in the general population. For example, what PLHA choose to do (such as avoiding VCT) cannot be predicted by the degree of actual stigma or discrimination they personally experience. Access to treatment and care by PLHA (just to

---

<sup>2</sup> The concept of 'social control' had also become 'so elastic by the 1980s that it now fits almost every meaning' (Meier 1982: 53). We return to this concept later in the study

take one example) is affected by other factors as well, such as actions taken by PLHA to avoid the kind of discrimination reported by people they know or by the media, the specific meanings associated with HIV/AIDS (for example, that it is caused by bewitchment and not by a virus) and by the degree of confidentiality offered in healthcare environments. The lack of specific research on the relationship between stigmatising ideology, discrimination and their impact on access to treatment and care makes it difficult to target interventions accurately and effectively.

Finally, defining stigma as something that results in discrimination is problematic because it encourages functionalist explanations of stigma (Jennings et al. 2002 have also made this point). Functionalist arguments, in which the effect of something is also defined as its cause or an essential part of its nature, have limitations because they are non-disprovable, circular arguments. For example, let us take the definition of stigma and discrimination ‘as social processes linked to the reproduction of inequality and exclusion’, ‘deployed by concrete and identifiable social actors seeking to legitimize their own dominant status within existing structures of social inequality’ (Parker & Aggleton 2003: 18–19). This could be paraphrased as follows: the need to perpetuate inequality leads to stigma, which leads to the perpetuation of inequality through discrimination. While this argument explains the persistence of stigma better than the idea that stigma arises out of ignorance, it becomes a circular argument if stigma is defined as something that results in discrimination. This circularity blocks debate and tends to hamper investigation of the complexity of how stigma operates and its relationship with discrimination.

### **What is the point of quibbling about theory?**

Some people might argue that we do not need theories of stigma in order to evaluate what works to reduce stigma and discrimination – theorising about it just wastes time that we do not have. However, the few evaluations that have been done on anti-stigma interventions (such as Brown, Trujillo & Macintyre 2001) suggest that the most common interventions (mass media education campaigns) are not particularly effective by themselves. Researchers argue that we need to implement new kinds of anti-stigma interventions within a more holistic and integrated approach (Bollinger 2002), combining educational programmes, for example, with counselling, coping skills acquisition and contact with PLHA (Brown et al. 2001), and encouraging community involvement in anti-stigma programmes, coupling education and awareness programmes with the empowerment of PLHA (Bollinger 2002; Visser 2004). Some of the literature suggests that anti-stigma interventions need to be based on programmes for social advocacy, legal rights protection, and general poverty relief, in association with education programmes (Parker & Aggleton 2003).

It is much more cost-efficient to develop interventions based on careful re-evaluation of the problem than to try out new interventions that repeat the same mistakes. How we define stigma structures our understanding of how it operates and how to address it. Traditional psychological approaches to stigma imply that it is partly or wholly a problem of individual ignorance. This idea implies that the silence can be broken around HIV/AIDS if people are given the facts, and underpins the promotion of educational interventions for the general public to reduce ignorance and increase ‘tolerance’ of PLHA. 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. This approach argues for the importance of exploring issues of power, history and the broad social functions of stigma, and addressing stigma as a problem of social inequality.

Although the latter does have important advantages, both theoretical approaches to stigma are problematic in some way. We need to be able to explain the functions or effects of stigmatisation without resorting to functionalism, and we need to be able to understand the role of the individual in stigmatisation without resorting to individualism. We need to integrate individual and social explanations of stigma in order to develop more holistic interventions (for example, see Fassin 2002). As Campbell has suggested, 'If health and sexuality are indeed shaped by society, culture and history in ways that cannot be apprehended by biomedical or behavioural understandings, we need to develop understandings of the complex dialectic of individual and society which shapes these phenomena' (2001: 6). We also need to understand the process of stigmatisation, the specific context within which it occurs and its effects to help explain the variable nature of stigma and to devise context-specific interventions. Unless we can do this, we will not be able to develop effective interventions.

### **A review of the literature**

Most of the research on HIV/AIDS stigma has been done in the US, 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 politicisation 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 still] 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 VCT, treatment, care and adherence (including Uys 2003; Weiser, Wolfe, Bangsberg, Thior, Gilbert, Makhema, Kebaabetswe, Dickenson, Mompati, Essex & Marlink 2003); on quality of life (for example, see Mast, Kigozi, Wabwire-Mangen, Black, Sewankambo, Serwadda, Gray, Wawer & Wu 2004); and on social responses to HIV/AIDS (for example, Leclerc-Madlala 2002).

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 works, so that we can 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 (2003), Shisana and Simbayi (2002) and Jennings et al. (2002). Research on HIV/AIDS stigma in other African countries includes ICRW 2002, Muyinda et al. 1997, Bond

## INTRODUCTION

---

et al. 2002, and several Bergen University theses – Lie (1996 cited in Lorentzen & Morris 2003), Oduroh (2002 cited in Lorentzen & Morris 2003), and Lorentzen and Morris 2003.

In order to conduct this literature review, 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 some of the 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. While our database (which stands currently at over 3 000 entries) is not yet fully comprehensive or fully representative of the admittedly meagre amount of current African research, it provides a good general overview of the available material.

In writing this study, we used the database to review the large and unwieldy literature on HIV/AIDS stigma, other forms of prejudice, and other disease stigmas to address some of the questions posed in this introductory chapter. In the theoretical chapters that follow, we compare HIV/AIDS stigma to other forms of prejudice, refine current definitions of stigma and develop a process model, discuss ways in which PLHA's responses to stigma affect the impact of stigma, clarify the relationship between stigma and discrimination, and review the distinction drawn between instrumental and symbolic stigma (Herek 1986, 2002). We then develop a research agenda by drawing out issues that require investigation from our theoretical discussion, and suggest a variety of methodological approaches that have been used in the field and could be used in future research. Finally, we offer a few general observations on interventions, noting the need for further research and evaluation before we can make specific recommendations.



## 2. THE LANDSCAPE OF PREJUDICE



Some excellent work has been done on theorising racism that identifies and tries to address the problem of conceptual inflation (Miles 1989). In the next chapter we will discuss the applicability of his ideas to a definition of disease stigma. In this chapter we review part of the social landscape of prejudice, comparing various kinds of prejudice and discrimination associated with physical difference. This will help to highlight some of the key features of disease stigma (specifically, HIV/AIDS-related stigma) that should be dealt with in developing a better theoretical basis for understanding the phenomenon. This also helps to remind us that HIV/AIDS stigma is by no means a unique phenomenon (see Link & Phelan 2001; Weiss & Ramakrishna 2001).

### The risk society

A number of authors (Crawford 1994; Foege 1988; Nelkin & Gilman 1988) have identified a pattern of blaming other groups in discourse about disease that Joffe (1999) has termed the 'not me – others are to blame' phenomenon. Stangor and Crandall (2000 cited in Lorentzen & Morris 2003) argue similarly that the perception of threat appears to be a likely foundation for stigma, whether this threat is tangible (for example, life-threatening) or symbolic (for example, a threat to the moral order). In this study, we have termed this the 'blaming' model of stigma. This phenomenon is evident in responses to a wide variety of risks including disasters and wars as well as disease.

People gain an illusion of control by the attribution of risk-enhancing behaviour to the 'other', blaming 'outgroups' for being at risk (Foege 1988; Nelkin & Gilman 1988). People articulate their own group identities as different in key risk-reducing ways from groups stigmatised as deviant and 'other', who are then blamed for having risk-enhancing characteristics. A wide variety of groups have been defined as particularly at risk for (and somehow responsible for) contracting HIV/AIDS, including supposedly 'oversexed' black people, white people, 'promiscuous' gay men, commercial sex workers and women in general. Some of these stigmatising discourses become widely accepted because they are supported by powerful groups.

People allocate more blame to those who contract stigmatised diseases that are perceived as controllable and stable than to those who have supposedly less controllable and less stable stigmatised diseases (Weiner, Perry & Magnusson 1998). Attributing stigmatised medical conditions such as obesity or HIV/AIDS to a lack of personal responsibility (such as over-eating) or to the perceived negative characteristics or behaviour of a specific group (such as promiscuity among gay men) helps to distance the 'moral majority' from risk. Risks perceived to be the most serious and the most easily controllable are those that help people to legitimise moral principles (Joffe 1999). STIs form a potent moral vehicle since both disease and sexuality have long been associated with the 'other' (Crawford 1994: 1361).

The 'not me – others are to blame' phenomenon has become particularly prevalent in relation to disease threats in modern society. Crawford (1994) argues that, in America, good health re-emerged in the 1970s as a potent sign of the morally disciplined, conventional self as opposed to the 'unhealthy other', linking concepts of health to social and moral fitness and heightening the tendency to blame people for illness. Projecting of risk onto the 'other' has been particularly prevalent in modern society where we find a high level of risk-awareness coupled with a lack of trust in the experts who might be relied on for protection, forcing people to fall back on their own resources (Joffe 1999: 3).

Many risks are perceived as predictable and therefore controllable because they are considered to be systematically caused and statistically describable (Douglas 1990 in Joffe 1999: 3). Modern society has thus been described as 'the risk society' (Beck 1986, 1992 in Joffe 1999).

### **The role of biology in the stigmatisation of HIV/AIDS and other medical conditions**

In the process of 'othering', disease stigma usually deploys stigmatising content from a wide variety of other forms of prejudice and follows existing patterns of inequality and prejudice. In the case of stigmatisation of HIV/AIDS in the West, these include racism, sexism, and homophobia (see Crawford 1994). According to Nelkin and Gilman:

Categories of blame often reflect deep social-class biases. Illness is frequently associated with poverty and becomes a justification for social inequities ... disease is frequently associated with the 'other', be it the other race, the other class, the other ethnic group. Inevitably the locus of blame is also tied to specific ideological, political and social concerns. (1988: 362–3)

The close relationship between disease stigma, prejudice and social inequality has resulted in some striking similarities in the way different diseases have been stigmatised over time. 'Diseases from hookworm to tuberculosis to cancer, polio, sickle cell anemia and AIDS have been employed as markers of biological and social difference, and also to construct broader notions of danger and inferiority' (Wailoo 2001). Like HIV/AIDS, leprosy in South Africa used to be associated with promiscuity, poverty and blackness (Deacon 1994).

When one moves from sketching broad patterns of 'othering' to understanding the strength and content of stigmatising ideologies, however, considerable variation is evident between diseases (for example, see Hayes et al. 2003; Kelly, Lawrence, Smith, Hood & Cook 1987; Kelly, Raphael, Statham, Ross, Eastwood, McLean, O'Loughlin & Brittain 1996). How can this be explained? Biological factors are often used to explain why HIV/AIDS has attracted more stigma than other diseases in some contexts (for example, Chapman 1998, Hayes et al. 2003 and Kelly et al. 1987 in the US). In this study we are also interested understanding the variability of HIV/AIDS stigma across different cultural boundaries, regions, historical periods and social contexts. Here, biological factors such as the stage of the disease and of the epidemic play a role (for example, Alonzo & Reynolds 1995).

The role of cultural and socio-political factors in creating variability in stigma will be discussed further below. At this stage, it suffices to note that a number of factors, including disease biology and epidemiology, converge to influence how and how much a disease is stigmatised. Jones et al. (1984) identified six biologically-related dimensions of disease – concealability, course/predictability, peril, disruptiveness, aesthetic qualities and origin – that could encourage stigmatisation. Following Jones et al, other researchers have explained that the particularly strong stigma attached to HIV/AIDS in the West is driven by its concealability, the unpredictability of illness onset, its terminal nature, the development of visible and unaesthetic skin conditions such as Kaposi Sarcoma, and its early associations with the gay community and with Africa (Chapman 1998: S180).

We have to be careful of arguments that suggest that the specific nature of the biology of a disease can automatically *produce* stigma. For example, Skinsnes (1964) argued that

leprosy was a specific biological entity that produced stigma because of its visible and horrible effects, progressive physical deterioration and prolonged course, non-fatal and chronic nature (which exposed the sufferer to secondary infections), its slow, insidious onset after infection, high endemicity and limited epidemicity, low incidence rate and association with poor living conditions, apparent incurability and long incubation period.

The idea of social construction – that people construct their reality through socio-cultural processes – underlies most modern understandings of prejudice. Using this approach, Gussow (1989) has suggested that the particularly stigmatising Western reaction to leprosy was not due to anything intrinsic to the biology of the disease, but was created over time in particular socio-historical contexts in order to exclude certain groups (such as Chinese immigrants to the US in the late nineteenth century) or justify prejudice against them. Whether or not we accept Gussow's explanation, it is clear that disease stigma is not determined by biology, but that diseases acquire social meaning (influenced by biological factors) within a specific political and historical context.

We take the position that social constructions of disease are formulated within the framework of the 'biological event' that shapes 'the variety of choices available to societies in developing conceptual and institutional responses to disease'. A disease is a complex intellectual construct, an amalgam of biological state and social definition (Rosenberg 1992: 305–7). David Arnold, for example, has argued of cholera that:

Like any other disease, [it] has in itself no meaning: it is only a micro-organism. It acquires meaning and significance from its human context, from the ways in which it infiltrates the lives of the people, from the reactions it provokes, and from the manner in which it gives expression to cultural and political values. (1986: 151)

Slack (1992: 5–8) has stressed the importance of examining the impact of an epidemic, its social and geographical incidence, the underlying disease environment (background morbidity as well as frequency of epidemics), and the nature of the disease, in building up a historically specific profile of an epidemic. He emphasises the importance of the disease itself here, for although epidemics are 'intellectual constructs' with a 'history, vitality and resilience of their own', they are initiated by a specific micro-organism, the nature of which may affect the social response (Slack 1992: 8).

There are thus both common social processes of 'othering' to distance people from risk, and divergent biological, epidemiological and socio-historical factors that affect the intensity and nature of disease stigma.

### **Racism, sexism and disability-related prejudice**

There is a relationship between HIV/AIDS stigma and other forms of prejudice, in the sense that different negative meanings associated with race, sexuality and so on are also used to stigmatise PLHA. A number of commentators (including Link & Phelan 2001 and Stein 2003a: 5–6) have also pointed out the similarities between definitions of disease stigma and other forms of prejudice. Like HIV/AIDS stigma, racism, sexism and disability-related prejudice all involve the attribution of negative meanings to physical difference. Discrimination may occur on the basis of these prejudicial ideologies, and people may also internalise different forms of prejudice (Fanon [1986] has described this problem in relation to racism). It may therefore be instructive to compare these forms of prejudice (see Table 2).

## UNDERSTANDING HIV/AIDS STIGMA

*Table 2: Features of different kinds of discrimination*

	Racism	HIV/AIDS stigma	Sexism	Disability prejudice
Attributes negative meanings to physical differences	Yes	Yes	Yes	Yes
Internalisation of negative attributions can happen	Yes	Yes	Yes	Yes
When defined	From birth	On testing after infection	From birth	From birth or onset
Correlates with family and group status	Yes, usually	Not necessarily	Not necessarily but most families and groups contain some men and some women	Not necessarily
Physical features used to mark difference	Yes, skin colour etc.	Yes, HIV infection	Yes, different genitals etc.	Yes, loss of leg, blindness, etc.
Secondary markers	Yes, language, accent, culture etc.	Yes, frequent illness, diagnosis of associated illnesses such as TB; and in some contexts, behaviours such as formula feeding	Yes, dress, behaviour, decorative objects, voice	Yes, wheelchairs, guide dogs etc.
Physical features used to mark difference are visible	Yes	Antibodies visible only in a testing lab	Yes, but usually hidden and expressed in clothing or decorative features	Yes, in some cases
Physical differences lead to real disadvantages	Not of themselves, but history of disadvantage may result in poorer health, education etc.	Yes, may lead to premature death. However, the consequences are sometimes exaggerated, (e.g. HIV infection = immediate death)	Differences have real consequences (e.g. men can't get pregnant) but these are not disadvantages except in so far as society structures them as such	Yes, but the consequences are sometimes exaggerated (e.g. shouting at a blind person)

*Source: Adapted from Stein 2003a*

## THE LANDSCAPE OF PREJUDICE

One difference between racism or sexism and HIV/AIDS stigma is that in the case of sexism or racism a person is born with physical features that may mark them as 'black' or 'white', 'male' or 'female'; historical processes of cultural activity, discrimination or migration often create similar circumstances for groups of black or white families, men and women. In the case of HIV/AIDS, biological differentiation usually happens later in life (when HIV/AIDS is contracted) and people living in the same communities or families may not have the same HIV status. People from any family, cultural background and social situation can be infected and then stigmatised, even within their own family. In this regard, HIV/AIDS stigma is most similar to disability-related prejudice, especially if one considers disabilities that are acquired through an external event rather than present at birth or congenital.

PLHA have often been stigmatised more for being part of a specific community or *group* that is already defined negatively ('You acquired HIV through having sex, therefore you must be a prostitute') – than for gaining a new 'deviant' outgroup membership through having HIV. Membership of existing outgroups (such as commercial sex workers) is sometimes considered to be revealed by the diagnosis rather than constructed by it. PLHA may thus be differently stigmatised depending on how the virus was contracted: some HIV-positive people are considered 'innocent' because they contracted HIV through blood transfusions rather than sex. This pattern of differential stigmatisation suggests that HIV/AIDS stigma revolves around the construction of blame and not simply the justification and continuation of existing inequalities between HIV-negative and HIV-positive people.

Racism, sexism and disability prejudice have been challenged by arguing that the physical differences used to mark race, disability or gender do not make a difference (in the case of race) or do not make as much of a difference as has been suggested (in the case of gender or disability). Skin colour, a primary marker of physical difference in racism, does not confer any significant advantage or disadvantage in itself (Stein 2003a: 6). Most gender differences do not carry inherent disadvantages, except in so far as they are constructed as such within a sexist society. For example, the idea that one should not employ women because they might get pregnant is based on an over-estimation of the effects of physical difference: women can work if someone else looks after their babies, just as men have usually done.

Although physical differences based on gender and disability are real, these differences are culturally interpreted and often inflated in the process. The key problem lies in identifying how much differential treatment is actually warranted by the presence of real physical differences, and countering the notion that differential treatment signifies loss of status. For example, most people agree it would be unfair to combine men and women's events at a track and field event, but many other sports are unnecessarily segregated by gender. Most male versions of sports receive better sponsorship, TV coverage and so on, indicating their greater social status. This is also true of sporting events for those with physical disabilities.

Physical differences due to gender, and some kinds of disability, are not always disadvantageous in themselves, even in cases where their presence can justify differential treatment (such as the provision of separate sports teams or additional access facilities). The chief disadvantages experienced by women and some disabled people stem not from physical differences but from the way some societies interpret certain physical differences

negatively and thus celebrate and accommodate only a narrow range of physical abilities. For example, many different people may experience problems with physical access. Hearing aid connections, ramps and Braille signage are ideally required in public sites to aid disabled people, but in many cases making public spaces disabled-friendly also makes them more accessible to the elderly and people with prams.

Unlike race, gender or (in most cases) disability, the physical markers of HIV/AIDS (HIV infection) are not visible (like mental illness, religious affiliation or sexual orientation [see Goffman 1963; Schumacher, Corrigan & Dejong 2003]). Even when someone gets sick, they contract diseases like tuberculosis (TB) that are secondary markers for AIDS; this is because AIDS is not a disease but a syndrome which confers on HIV-positive people a propensity to contract disease. This helps PLHA and others to deny their status (even to themselves) much of the time, and thus to avoid both stigmatisation and self-stigmatisation at a personal level (although apparently convenient in the short term, revealing a hidden stigmatising characteristic causes greater psychological distress [Smart & Wegner 2000 cited in Lorentzen & Morris 2003] and creates problems when PLHA need special treatment or care). At a social level, however, the 'invisibility' of HIV infection exacerbates stigmatisation and encourages people to use secondary markers (such as wasting or the onset of illnesses such as TB) to identify who has the condition. The absence of visible evidence of how large the pool of infected people is, and of who is infected, encourages the idea that HIV/AIDS affects 'other' people.

In contrast to race and gender, there are real health disadvantages conferred by disease, in this case specifically through HIV infection and the development of AIDS. The same is true of some, but not all, kinds of disability. Quite apart from any stigmatisation that might occur, the development of AIDS has undeniable and tangible negative effects on people's lives, including lowered fertility and life expectancy, and higher morbidity.<sup>3</sup> The contagious nature of HIV also makes some kinds of contact with PLHA (for example, contact with bodily fluids) potentially disadvantageous to HIV-negative people, even if they do not stigmatise PLHA (Stein 2003a).

As individuals and as societies we legitimately associate negative meanings with disease syndromes like HIV/AIDS because they have negative effects that we wish to avoid. However, a problem arises when our prejudice against the disease becomes a prejudice against those who have contracted it. This is especially likely, as discussed earlier, in cases where contracting a disease is perceived to be avoidable, where the contraction of a disease is linked to sex or other morally sensitive issues, and where the disease is serious or terminal. This suggests that if effective treatments are found and made widely available, stigma may decrease.

### Conclusion

There are many similarities in the way different forms of prejudice operate. All the forms of prejudice discussed above mark certain physical differences as characteristic of a group, and as negative. According to 'blaming' models of stigma, these prejudices are drawn on in times of crisis or stress as a way of distancing people from risk by associating it with the characteristics of outgroups (Joffe 1999). The content of

---

<sup>3</sup> Comments by J Stein on this study.

## THE LANDSCAPE OF PREJUDICE

---

stigmatising ideologies is often similar because they draw on each other, and the problems faced by those who wish to reduce stigma and related discrimination in these different arenas are also very similar. In the next section, we thus use some theoretical work on racism to critically examine various theories of stigma and to establish the relationship between stigma and discrimination.

There are also differences in the way biology interacts with cultural constructions thereof in structuring stigma in various arenas of prejudice (race, gender, disability, and various diseases or syndromes, including HIV/AIDS). The identification of certain biological differences determines whether some forms of differential treatment are perceived as legitimate or not. While many forms of differential treatment are unfair and are labelled as discrimination by those concerned with the protection of human rights, the contagiousness and seriousness of HIV and its consequences do justify some forms of redress and limited forms of differential treatment in order to retard the spread of HIV (for example, the exclusion of blood from HIV-positive donors) (Weiss & Ramakrishna 2001).

We have to recognise the existence of differences where they are relevant: they should not be underplayed in the interests of 'integration' (Sayce 2003). The key problem here, as with accommodating special needs of women and those with disabilities, is how to ensure that differential treatment is not based on an *inflated* sense of risk or difference. In the case of HIV/AIDS, differential treatment should only be justified if it reduces the risk of infection with HIV without further stigmatising PLHA or taking away any human rights to which they are entitled. We do therefore need to distinguish between discrimination based on stigma and ignorance and differential treatment based on rational assessment of risk.



### 3. TOWARDS A THEORY OF DISEASE STIGMA



As we have seen, there are problems with current theories of disease stigma. The literature on HIV/AIDS stigma tends to conflate the causes, functions and effects of stigma and reveals a continuing tension between individual and social explanations for the phenomenon. The conceptual inflation of stigma has resulted in a conflation of cause and effect – of stigma and discrimination. Also, the focus on finding generic ‘social control’<sup>4</sup> explanations for stigma in the sociological literature, or on measuring the ‘amount’ of stigma through some generic measure in the psychological literature, have distracted us from the task of understanding the diversity of stigma in different contexts. To address these problems, we use theoretical work drawn from studies of racism and from ‘blaming’ models of disease stigma to define the concept more rigorously and to provide a means of understanding how stigmatisation operates as a process and how variation might occur. This will help us to research and address HIV/AIDS stigma and discrimination more effectively.

#### Definitions of stigma

Definitions are important because they structure how we think about a phenomenon – they are critical tools in our theoretical toolbox. If we compare disease stigma definitions, the first thing we notice is the lack of common ground: the definitions show wide variation (Link & Phelan 2001: 364) and reveal considerable polarisation between individualistic psychological explanations, ‘social control’ explanations in the sociological tradition and ‘blaming’ models of stigma. In addition, many authors do not clearly separate ideology and discriminatory practice in defining disease stigma. Herek (2002: 595) perhaps comes closest to doing so when he distinguishes between stigma, prejudice (an individual’s negative attitude towards a social group, which can only be termed stigma when it matches the negative evaluations of society towards the attributes held by that group), and discrimination (behaviour or actions that are differentiated according to membership of a specific group, which only becomes a manifestation of stigma when society defends or encourages it).

The modern understanding of disease stigma owes much to Goffman (1963), who suggested that people who possess a characteristic defined as socially undesirable (HIV/AIDS in this case) acquire a ‘spoiled identity’ which then leads to social devaluation and discrimination. Following this interpretation, Herek (2002) defines HIV/AIDS stigma as an enduring attribute of an individual infected with HIV that is negatively valued by society and thus disadvantages PLHA. Various authors have challenged the tendency in much psychological work to see HIV/AIDS stigma (or, indeed, any disease stigma) in individual psychological terms (for example, Link & Phelan 2001; Parker & Aggleton 2003).<sup>5</sup> Alonzo and Reynolds (1995), for example, provide a more complex reading of Goffman, suggesting that stigma is not merely an attribute, but represents a language of relationships, as labelling one person as deviant reaffirms the normalcy of the person doing the labelling (Goffman 1963: 3 in Alonzo & Reynolds 1995: 304).

<sup>4</sup> We use ‘social control’ in this study to describe an approach dominant in sociological work that understands human behaviour as being regulated by social controls (for example, institutions, practices, beliefs) to perform activities fulfilling social needs, sometimes at the expense of individual needs (Davis cited in Janowitz 1975: 98). Control does not have to be directly coercive, but can operate through the creation of ‘conforming subjects’ (Foucault 1977 in Parker & Aggleton 2003: 17). As sociologists have become more critical of society, they have understood social control as operating to the advantage of dominant members of society (for example, by perpetuating social inequalities [see Parker & Aggleton 2003]).

<sup>5</sup> Parker and Aggleton have perhaps been unfairly critical of Herek in this regard, since he does not nod towards social processes of exclusion in his definition of stigma as a socially widespread belief.

In other areas of HIV/AIDS work, and in work on racism, much early work also conceptualised prejudice as a problem of individual ignorance. Campbell (2001, 2002) argued that individualistic biomedical and behavioural theories have dominated in the field of HIV/AIDS prevention research. In much of the sociological and psychological literature racism was also initially seen as a 'bad-apple' problem, that is, one originating in the ignorance of isolated individuals. This meant that the social and political aspects of racism were only fully recognised much later (Miles 1989).

We need to understand stigma as a social process (constantly changing and often resisted) rather than as an individual attribute. However, in an attempt to recognise the social and political aspects of stigma, researchers have tended to define stigma primarily with reference to its discriminatory effects. Alonzo and Reynolds, for example, define stigmatised people in terms of discrimination:

[They] are a category of people who are pejoratively regarded by the broader society and who are devalued, shunned or otherwise lessened in their life chances and in access to the humanizing benefit of free and unfettered social intercourse. (1995: 304)

Many researchers in the sociological tradition adopt the view that stigma is defined by its discriminatory result (for example, Link & Phelan 2001), and believe that stigma is a social process that functions to constantly reinforce existing social inequalities (Parker & Aggleton 2003), thus acting as an agent of social control. This approach avoids the problem of individualism (that is, explaining stigma solely as an individual attribute) but may fall into the trap of functionalism, if the outcome of some stigmatising processes (that is, discrimination that follows the lines of existing social inequalities) is used to explain why all stigmatisation happens.

We need to seek a broader explanation of the processes by which stigma arises, why some people stigmatise and not others, and how different forms of stigma could emerge for different diseases in the same social contexts. Before we develop a better definition of stigma to address these questions, we need to address the problem of functionalism in greater detail.

### **Understanding functionality without functionalism**

The assumption underlying many traditional definitions of stigma (as with racism) was that stigma and discrimination were traits of dysfunctional and ignorant individuals – rotten apples – and could be 'weeded out' through education, leaving the rest of society intact. The systematic reproduction of stigma in large numbers of people, and the difficulty of addressing the problem through education, has challenged this assumption. Drawing from sociological theory, which often has to explain why people act against their own interests, some researchers have suggested that stigma persists in spite of education programmes because it helps to maintain social control (for example, Link & Phelan 2001; Parker & Aggleton 2003).

Parker and Aggleton suggest that stigma and discrimination should be understood as 'part of the political economy of social exclusion present in the contemporary world' (2003: 19; see also Paiva, Filipe, Santos, Lima & Segurado 2003: 92). HIV/AIDS stigma exacerbates social divisions by stereotyping marginalised or disempowered groups (such as poor

Africans, women and commercial sex workers) as responsible for the illness and its spread. Because stigma which leads to discrimination has the effect of reproducing relations of social inequality that are advantageous to the dominant class, these forms of stigmatisation are functional in the sense that they help to maintain the socio-political status quo.

However, it is not clear how stigma specifically contributes to the reproduction of social inequalities, because even without stigmatisation, the HIV/AIDS pandemic would exacerbate existing inequalities.<sup>6</sup> Heywood shows how, in South Africa, social inequality aids the spread of HIV, and how the pandemic widens the division between rich and poor, white and black, in society:

First, HIV takes advantage of entrenched fault lines in society, of the inequities and inequalities, in order to spread. Second, HIV makes these fault lines far, far wider. This is very apparent in 'post-apartheid' South Africa, where the people who have access to advanced medical care (including anti-retroviral medicines) are predominantly white and where the people who have access to sub-standard care are black. Thus does HIV, and other causes of illness, widen the divisions that already exist. (2002: 3)

There are some effects of stigma and discrimination that happen to be useful to certain powerful sectors within our society, although there are other causes of social inequality besides stigma. If we see stigma as being an agent of social control, however, we need to explain away the fact that the lines drawn by stigmatising beliefs do not always follow the fault lines of existing social inequalities, nor does stigmatisation always perpetuate inequalities. Some stigma does not lead to discrimination, but leads to other negative effects, such as self-stigmatisation; some discrimination is caused by other factors; and not all stigma or discrimination actually supports the status quo. Stigmatisation could for example form a springboard for activism.

Functionalist arguments have in the past been used to explain the relationship between prejudice and social power. For example, in the 1970s, revisionist historians of South Africa suggested that apartheid racial discrimination was functional to capitalism: this was later challenged for its functionalism (Posel 1983). A similar criticism of social control theories has been made in other disciplinary contexts (see for example, Ignatieff 1985; Meier 1982; Van Krieken 1991). The social control model focuses too much on the big picture, ignoring individual agency, imputing social functionality from the weak stigma-discrimination-inequality chain, and defining stigma as only that which leads to discrimination and fosters social inequality. Focusing on a very broad effect of stigmatisation (the maintenance of social inequality) as its *raison d'être* does not help us to understand the specific impacts of stigma on PLHA, for example, in reducing access to treatment and care. It also tends to focus on stigmatisation that targets groups that are already otherwise marginalised, which is useful because these groups may not be in a position to challenge related discrimination. But we also need to understand stigmatisation that targets dominant groups, and, even more important, stigmatisation of family members and other peer groups.

Both Parker and Aggleton (2003) and Link and Phelan (2001) have recognised this problem, but provide no clear solution. Instead of explaining it away with a caveat, we should go back to the drawing board and avoid defining stigma as something that automatically leads to discrimination and therefore inequality. We are not denying that

---

<sup>6</sup> Comments by J Stein on this study.

stigma may sometimes reinforce existing inequalities. But, because there is no direct, one-to-one relationship between stigma and discrimination, it may be better to speak of effects of stigma that are useful to the dominant class, rather than of functions which imply that discrimination and the exacerbation of inequalities are automatic, desired, or intended effects of stigmatisation.

We can begin to avoid these problems by separating our analysis of stigma from an analysis of its effects (which do include discrimination). As we explained in Chapter 2, there is research (such as Joffe 1999; Crawford 1994) that provides an alternative argument for the persistence of stigma: the 'blaming' model. In this model, stigma is a fundamental emotional response to danger that helps people feel safer by projecting controllable risk, and therefore blame, onto outgroups. Stigmatisation thus helps to create a sense of control and immunity from danger at an individual and a group level. These socially constructed representations only result in discrimination and the reproduction of structural inequalities when other enabling circumstances (such as the power and opportunity to discriminate) come into play (Joffe 1999).

Of course, the functionality of stigma to individuals as a means of distancing risk is a short-term phenomenon, because feeling invulnerable to HIV infection reduces the incentive to protect oneself (for example, by practising safer sex with other members of the ingroup). Nevertheless, the benefits of anxiety reduction may be sufficient to reproduce stigmatising behaviour, along with the social processes of 'anchoring' – in which new events are explained within existing models – and 'objectification' and 'symbolisation' – in which new problems are represented by comparison with the tangible and the known, using shared symbolic representations (Joffe 1999: 75).

How does this argument avoid conceptual inflation, functionalism and individualism? First, it is not suggesting that stigma has to result in discrimination to reduce individual and group anxiety. Second, the individual-level effect of stigma is both (unconsciously) desired by the person who expresses it and universal, making it reasonable to term it a function rather than an effect. Third, although Joffe (1999) focuses on the individual as the agent of stigma, she avoids excessive individualism by viewing individuals as social beings, who draw on social representations to formulate stigmatising beliefs. Those who stigmatise others on a specific issue are doing so not because they are isolated 'splitters', but because their reaction to that specific issue and its specific social circumstances awakens the splitting tendency that is latent in everyone.

The blaming model of stigma thus provides an alternative approach to the social control model. The main challenge lies in using this model to help understand the relationship between stigma, discrimination and power, and how to change the way people respond to risk. If we can reduce the fear surrounding the risk of contracting HIV/AIDS, or its effects, will we be able to reduce stigma? Clearly, some degree of fear of infection, coupled with knowledge about what is likely to transmit the disease and how to prevent this, is important in maintaining people's ability to prevent themselves from being infected.<sup>7</sup>

### **Separating the analysis of stigma and discrimination**

As we have seen above, disease stigma definitions do not generally separate stigmatising beliefs from discriminatory actions for analytical purposes and some define and explain

---

<sup>7</sup> Comments by J Stein on this study.

stigma by its effects (see Jennings et al. 2002: 9–10 and Miles 1989). This reduces the analytical power of the concept of stigma and thus our ability to understand the complexity of the phenomenon. In this section we will propose ways of addressing these problems.

For clarification and comparison, let us examine the way in which Miles (1989) has addressed a similar problem in the field of racism theory. A 1967 Unesco statement defined racism as all ‘beliefs and acts’ that justify discrimination on biological grounds (Montague 1972: 158 in Miles 1989: 50). This definition of racism could include acts of discrimination that are based on class distinctions rather than racist ideology, as well as prejudice or discrimination based on gender, or even HIV-positive status.

Miles (1989: 50) criticised the Unesco definition and others like it on the grounds that defining racism in terms of inequality or discrimination is unnecessarily limiting, as this excludes those claims of difference that are not meant to, or do not explicitly, justify or result in inequality of treatment. Inflating the concept of racism to include actions as well as ideology makes it especially vulnerable to a functionalist analysis in which the result of the action is treated as its rationale. Miles emphasises that what he calls ‘exclusionary practices’ (1989: 78) may have several causes besides racism, whose discriminatory effects may not all be intentional.

Miles therefore suggested using a narrow definition of racism, defining it as an ideology that differentiates and devalues a group, but which need not explicitly justify or result in discriminatory action in order to qualify as racism. Such an ideology would change over time, but show a certain historical continuity (1989: 54). He describes this minimal continuity as follows: Firstly, ‘racialisation’ occurs, a process in which certain biological characteristics are ‘signified’ in order to identify a group whose origins are supposedly natural and unchanging. No strict biological hierarchy is evoked yet. Next, other, negative characteristics (cultural or biological) are attributed to individuals in the group (1989: 79): this process could be called ‘stacking’. Racism thus explicitly devalues the outgroup, and those exclusionary practices that can be historically proven to have arisen out of racist ideology intentionally discriminate on this basis.

In the field of HIV/AIDS stigma, the link between stigmatising attitudes and discriminatory actions is often treated as seamless, and discrimination against PLHA (or any failure to access treatment) is frequently attributed to HIV/AIDS stigma without actually investigating whether this is the case. Relatively little research has been done to determine the relative importance of HIV/AIDS stigma in comparison to other barriers to treatment and care, or other sources of discrimination. Jennings et al. (2002: 22) suggest that a number of different factors (for example, class position, gender, education or HIV status) can heighten the level of discrimination experienced.

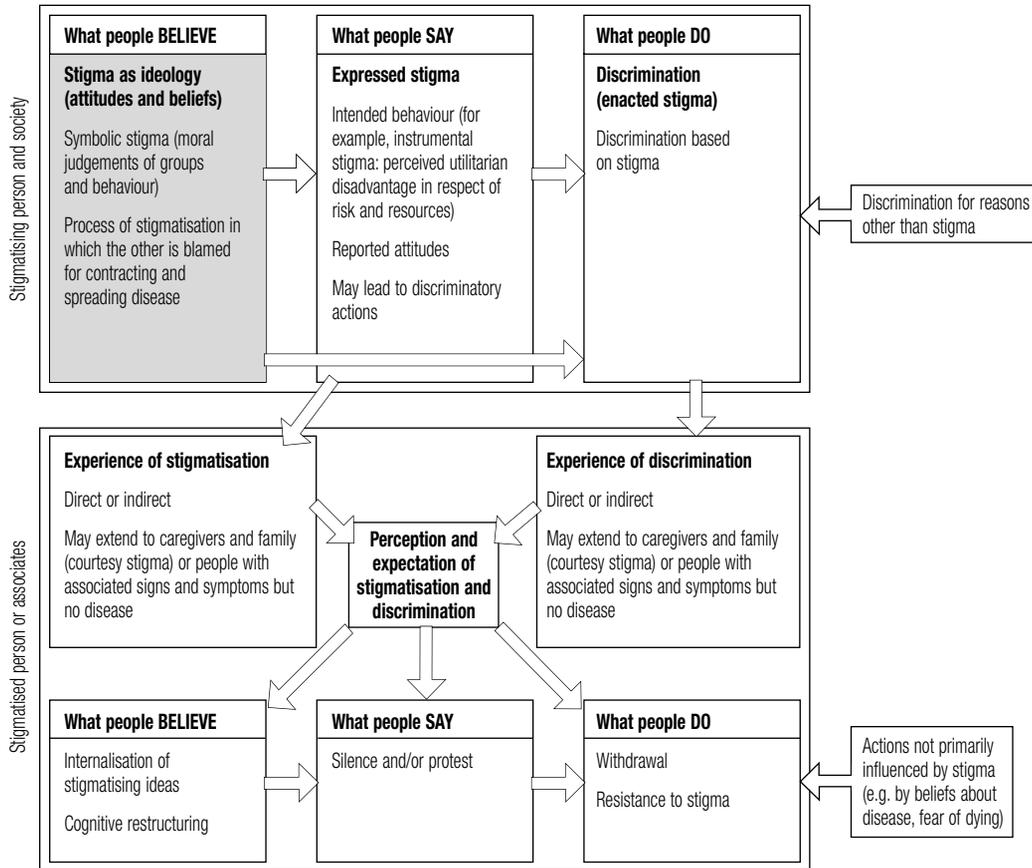
We therefore propose to define disease stigma initially as follows:

***Proposition 1 – a definition of disease stigma***

*Disease stigma can be defined as an ideology that claims that people with a specific disease are different from ‘normal’ society, more than simply through their infection with a disease agent. This ideology links the presence of a biological disease agent (or any physical signs of a disease) to negatively-defined behaviours or groups in society. Disease stigma is thus negative social ‘baggage’ associated with a disease.*

## UNDERSTANDING HIV/AIDS STIGMA

Figure 1: How different kinds of stigma and discrimination relate to each other



Note: The shaded section represents the aspects of stigma covered by the proposed definition. Arrows represent lines of influence or causality

Figure 1 illustrates the relationship between our proposed definition and the current psychological literature on stigma. The three columns represent what people believe (stigma), what they say, and what they do (discrimination, withdrawal, activism). The rows represent what stigmatising people believe, say or do, and what stigmatised people experience, believe, say and do. Notice that most of this research does not adequately theorise the interaction between individuals and the social domain. Also, most of the studies of stigma and discrimination (what people believe and do, respectively) utilise survey questionnaires that directly measure only what people say (that is, what they say they believe and what they say they will do or have done in the past). This latter problem will be addressed in the methodology section below.

The shaded section in Figure 1 represents those aspects of stigma covered by the proposed definition. What has been referred to in the literature as 'enacted stigma' would be defined as discrimination according to our definition. Figure 1 suggests that there is a considerable difference in, on the one hand, understanding the process of stigmatising others and, on the other hand, the process of being stigmatised oneself and reacting to this. Responses to stigmatisation by PLHA (self-stigmatisation and perceived stigma) are thus not included in our definition of stigma *per se*. Internalisation of stigma may result from

the same cognitive and emotional processes that lead to stigmatisation, but crucially, it is imposed on the self rather than the 'other'. In Chapter 6, we will distinguish the secondary process of self-stigmatisation or internalisation from stigmatisation itself. We will also expand the analysis of what has been called 'perceived stigma' to include both expected stigmatisation and discrimination. Actions springing from stigmatising ideas, such as withdrawal from certain situations or activism against stigma, would also not fall under our definition of disease stigma, but would be classified as reactions to stigma and/or discrimination.

In this study we will use the term 'expressed stigma' to describe stigmatising beliefs that are enunciated (verbally, in writing, and so on), although this term is sometimes used in the literature as a synonym for discrimination. What people say is the only way we have of inferring beliefs, but we do not have to read beliefs directly off people's statements: silences and statements should be interpreted (Joffe 1999). In drawing a distinction between what people believe, say and do, we recognise the difficulty of distinguishing between the latter two, since saying is a form of doing. However, for both theoretical and methodological reasons we feel it is useful to sustain the distinction at this stage. We need to have a way of categorising beliefs that are expressed, but not acted upon, and discriminatory actions that are intended, but not acted upon. We will use the term 'intended discrimination' to describe discriminatory actions that are intended (articulated or expressed) but not necessarily acted upon.

### **Understanding stigmatisation as a process**

It is not sufficient to explain stigma simply as negative meanings associated with disease (as Proposition 1 does). Proposition 1 avoids the problem of conceptual inflation but it fails to address why and how stigmatisation occurs, the relationship between stigmatisation, discrimination and social power relations, what the role of the individual is, and whether it matters who stigmatises whom. Also, it seems to include any negative beliefs about disease.

We thus need to develop a better model of stigmatisation. Using a process model not only helps us to distinguish causes, functions and effects of stigma more easily, it also shows how significant variation in the content of stigma will occur.

Miles (1989) argues that the articulation of racism involves signification of difference, then stacking of negative meanings. Miles' model has influenced later work but his attempt to distinguish racism from discrimination has not been followed in process models of disease stigma. Gilmore and Somerville (1994 cited in Malcolm et al. 1998) identified four features of stigmatisation: the problem; the identification of the person or group to be targeted; the assignment of stigma to that person or group; and the development of a response to the stigmatised person or group that tackles the problem. Taking a similar line, Link and Phelan define disease stigma as a convergence of four processes:

Stigma exists when the following interrelated components converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labeled persons to undesirable characteristics – to negative stereotypes. In the third, labeled persons are placed in distinct categories so as to accomplish some degree of separation of 'us' from 'them'. In the fourth, labeled persons experience status loss and discrimination that lead to unequal outcomes.

Stigmatization is entirely contingent on access to social, economic and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination. Thus we apply the term stigma when elements of labeling, stereotyping, separation, status loss and discrimination co-occur in a power situation that allows them to unfold. (2001: 367)

Our main objection to Link and Phelan's model is that, like the definitions discussed above, it not only fails to separate stigma from discrimination, but defines something as stigma only if it leads to discrimination. It also fails to illustrate the highly derivative character of disease stigma in relation to other forms of prejudice and the fact that disease stigma can be defined as quite distinct from descriptions that refer to actual negative effects of some diseases (for example, premature death).

Sayce suggests that Link and Phelan should use 'discrimination' to describe their process 'because of the confusion of using one term to describe both the act of discrimination and the personal experience of being labelled' (2003: 628). Sayce contends that the term 'discrimination' is preferable because:

It directs attention to the power of perpetrators, which is essential to any effective change strategy. It can stand as the over-arching concept for all the processes that Link & Phelan outline – discrimination does involve distinguishing ('discriminating') between human differences, conferring negative value on some types of difference and treating people unjustly as a result by drawing on social and economic power.

We have noted, however, that discrimination may result from other causes than stigma (Miles 1989). Sayce's definition of discrimination would therefore only refer to discrimination resulting directly from stigma. We feel that it is important to understand, and hopefully address, all sources of discrimination, as well as other effects of expressed stigma such as self-stigmatisation. We therefore argue that it is worth developing a process model of stigma that does not overlap with discrimination, allows us to investigate responses to stigma outside of the framework of discrimination, and, while focusing only on the process of labelling and status loss, does not retreat into individualism.

The blaming model of stigma suggests that negative meanings are associated with disease, and people who contract it, in order to allay anxiety about risk of infection (Crawford 1994; Gilman 1985; Joffe 1999). Joffe (1999) uses some of the psychological literature to explain the process by which this occurs in an individual. She suggests that people's responses to danger draw on fundamental human defence mechanisms known as splitting and projection – separating bad from good and rejecting the bad by projecting it onto the 'other'. Klein identified splitting as a key mechanism by which infants reduce anxiety, of which traces remain in later life, and can be deployed by adults in times of crisis or stress (see Joffe 1999: Chapter 5). Joffe goes on to argue that HIV/AIDS stigma is a process in which people use splitting of the 'good' and the 'bad' to forge 'protected' identities by projecting risk and deviance onto outgroups. This allows people to highlight characteristics which would increase risk of contracting the disease in representations of existing outgroups, and then blame outgroups for having those characteristics, and thus contracting or spreading the disease.

The blaming model of stigma helps us to understand both why people stigmatise, and how common and shared stigmatising representations are linked to existing representational systems. It thus helps us to understand how individuals are active agents in creating stigma, and that stigmatisation is a fundamentally social process.

We therefore propose the following process model to explain stigmatisation:

***Proposition 2 – a process model***

*Disease stigmatisation can be defined as a social process by which people use shared social representations to distance themselves and their ingroup from the risk of contracting a disease by: (a) constructing it as preventable or controllable; (b) identifying ‘immoral’ behaviours causing the disease; (c) associating these behaviours with ‘carriers’ of the disease in other groups; and (d) thus blaming certain people for their own infection and justifying punitive action against them.*

### **Stigma and power**

As we have explained, the main aim of social control models of stigma is to understand the relationship between stigma and power. However, the blaming model of stigma explains the politics of stigma without resorting to a functionalist definition of stigma. The process of stigmatisation helps to create a sense of control and immunity from danger at an individual and a group level, as it distances people (and their ingroups) emotionally from risk. The choice of who is identified as the outgroup depends on personal identities and historical power relations, and is thus highly variable. For example, Joffe’s work has shown that some black South Africans blame Western scientists for HIV/AIDS, while some white heterosexual British men blame black Africans for it (1999: 27,103).

These socially constructed representations are all functional to the individual in distancing him or her from risk and thus reducing anxiety, but they only result in discrimination and the reproduction of structural inequalities when other enabling circumstances (such as the power and opportunity to discriminate) come into play. The status loss ascribed to the stigmatised by the stigmatiser may (note, not *will*) lead to discrimination against stigmatised people depending on the existence of power differentials and an enabling context. It may also result in internalisation of stigma. When a particular group of stigmatising ideas is validated by a powerful person or group (in the media, in communities and so on) and deployed as part of broader power struggles, it becomes pervasive, entrenched and very difficult to shift. The powerful nature of dominant group ‘othering’ in a society can override other representations and even cause widespread self-stigmatisation.

In applying the blaming model to our purposes here, we do face a problem akin to the one we mentioned earlier in relation to the distinction between saying and doing in Figure 1. Link and Phelan’s (2001) model introduces the concept of status loss, which is similar to the notion of social death. A question this raises for the development of a better process model is whether status loss is a form of discrimination (action), whether it only occurs once stigma has been expressed, or whether it is an automatic consequence of stigmatisation (ideology). We propose following the latter approach, because loss of status seems to be intrinsic to the allocation of negative meanings. However, it is important to note that status loss in respect of the stigmatised person only occurs automatically in the view of the stigmatiser; it is not necessarily internalised by the stigmatised person, nor

## UNDERSTANDING HIV/AIDS STIGMA

does it necessarily lead to discrimination. If stigma is expressed, it may result in status loss on the part of the stigmatised person.

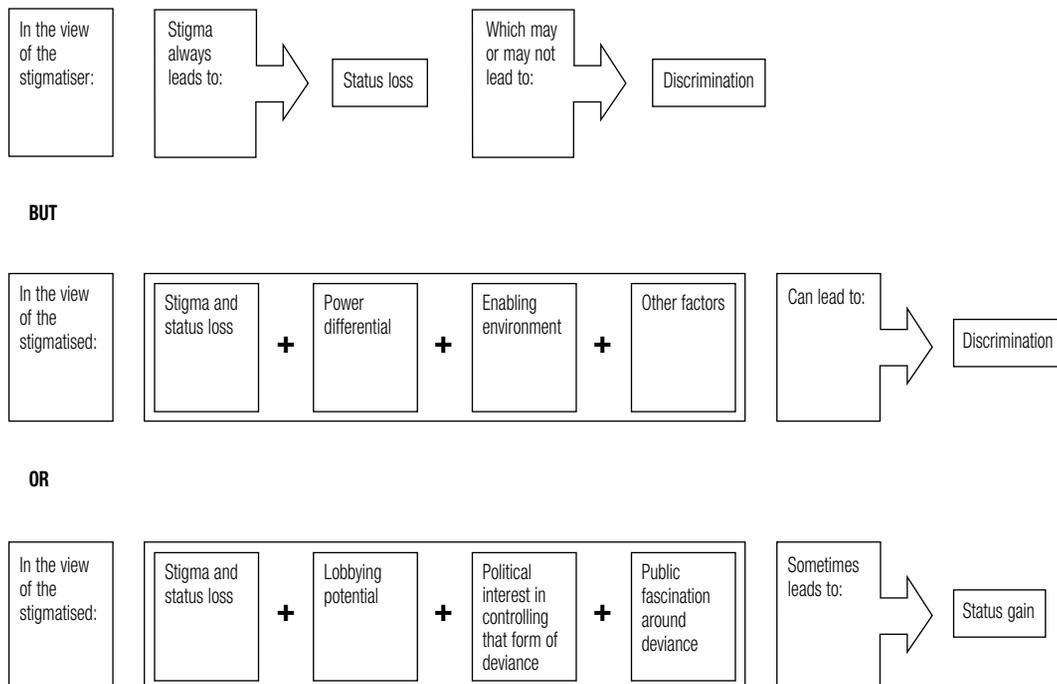
In some contexts expressed stigma actually leads to status gain, although this may be as a result of initial status loss. Stigmatised status forms the basis for many minority group identities and establishes their legitimacy in lobbying for state recognition (Berbrier 2002). People may gain status if they 'come out' about a stigmatised characteristic and if they become legitimate spokespeople for minority or marginalised groups in the process. Botnick (2000) suggests that this phenomenon has created a rift between HIV-positive and HIV-negative people in the US gay community, as HIV-positive members have become the most prominent representatives of the gay community in lobbying for funds and recognition. Botnick suggests that in the gay community in the US, being gay has, ironically, become synonymous for many with being HIV-positive.

Klingemann suggests that, in certain contexts, stigmatisation can actually confer some cachet:

How society and professionals perceive individuals with a history of stigma varies from complete rejection to admiration or recognition of usefulness. This assessment depends on such factors as degree of political and scientific interest in controlling, changing, and detecting hidden deviant populations, as well as public fascination with 'authentic' deviants, combined with increasing scepticism about conventional expert knowledge. (1999: 1505)

It should be emphasised, however, that stigmatisation and status loss result in discrimination far more often than they result in status gain.

*Figure 2: Stigma, status loss and discrimination*



### The content of disease stigma

Very little of the stigma research focuses on the content of stigmatising beliefs, either because these beliefs are seen as contrary to correct medical knowledge (in much of the psychological literature) or because they are seen as crude justifications for reinforcing social inequality (in the sociological literature).

Disease stigmatisation associates negatively-defined behaviours or attributes (for example, promiscuity or lack of cleanliness) with people who have a specific disease (Katz in Alonzo & Reynolds 1995: 304), thus 'stacking' meanings and values onto a biological phenomenon like disease. But the process often happens in reverse, with existing negatively-defined groups being represented as disease carriers (for example, commercial sex workers and gay men). Disease stigmas draw heavily on existing negative definitions of the 'other' and other social representations. In dominant group representations, which usually gain greater currency in society, these definitions often identify and blame existing marginalised groups in society, following existing lines of inequality. This association is often given credence by the fact that existing social inequalities can affect the epidemiology of disease, making marginalised groups more vulnerable to disease and less able to find (private) treatment.

HIV/AIDS stigmatisation relies heavily on existing prejudice and social stereotypes. The relationship between disease stigma and other forms of prejudice has been called multiple stigmatisation, double (or even triple) stigmatisation (Grossman 1991; Hergovich, Ratky & Stollreiter 2003), following a trend in racism and gender studies in which it is argued that different kinds of prejudice are added together. But disease stigmatisation operates in a slightly different way. Disease stigmatisation does link diseases with negative meanings, but often by suggesting that already-defined outgroups are somehow responsible for the disease because of certain negatively-valued traits or behaviours, rather than representing all people with a particular disease in the same way. For example, some PLHA are perceived as innocent victims (those who contracted HIV through blood transfusions or childbirth), while others are considered blameworthy because they contracted it through 'deviant' behaviour (sex that is considered immoral) that demonstrates their membership of already marginalised communities (such as commercial sex workers, gay men and so forth).

Earlier in this chapter, we noted that HIV/AIDS stigma cannot be defined to include any and all negative meanings associated with disease. For example, the term 'stigma' cannot legitimately be used to describe statements like, 'HIV-infection could result in higher susceptibility to diseases like TB'. A more important, and perhaps controversial, question to ask would be whether one can include negative beliefs like, 'HIV is easily transmitted by shaking hands' or 'HIV-positive people will consume more resources because they get sick more easily' in the definition of stigma. In Chapter 6, we will suggest that these beliefs (defined as instrumental stigma by Herek 1986, 2002) do not constitute HIV/AIDS stigma unless they form part of a general set of beliefs that help to differentiate and blame PLHA for their disease.

If we are going to limit the content of stigma in this way, we need to understand exactly how to categorise secondary stigmatisations associated with HIV/AIDS. Secondary stigmatisations of various illnesses, treatments and behaviours associated with HIV/AIDS widen the frame of reference for stigma and thus increase its potential impact. In the case

of HIV/AIDS, secondary stigmatisation has occurred with contraction of TB, the use of formula feeding and the use of condoms. These are read as markers for HIV/AIDS and are thereby stigmatised by association (Godfrey-Fausset & Ayles 2003; Leclerc Madala 1997). For example, a school feeding scheme was recently placed in jeopardy because the cereal used was labelled 'AIDS-porridge' (due to its use by AIDS patients), with the result that learners refused to eat it. Secondary stigmatisation can also involve people associated with PLHA. The mental illness literature has coined the term 'courtesy stigma' to describe the stigmatisation of families of affected individuals (Angermeyer & Matschinger 2003, on schizophrenia). Stigma by association may also include people who care for those with HIV/AIDS.

Initially, then, HIV/AIDS was stigmatised in relation to existing outgroups, PLHA were then stigmatised as a category in their own right (although some were excluded from this because they were 'innocent victims'), and a highly variable, but nevertheless distinctive, discursive field<sup>8</sup> finally coalesced around the disease, stigmatising related disease (such as TB) and activities (such as the use of formula milk) by association. Secondary stigmatisation does not always feed directly into the process of blaming PLHA for the disease (which may justify discrimination): it may feed into the earlier process of identifying and differentiating PLHA from other people. More work needs to be done in this area to understand the way in which the content of stigmatisation leads to differentiation and blaming, and what criteria can be used to identify stigmatising beliefs.

### Understanding variation

Studies attempting to generalise across research sites tend to try and find commonalities rather than differences in understanding patterns of stigma. While the content of HIV/AIDS stigmatisation does reveal some common global patterns, the politics of which are worthy of investigation, it also shows considerable local variation as stigma is influenced by a number of local social, political, historical and cultural factors. Understanding the different cultural meanings associated with HIV/AIDS has been found to be essential in developing effective HIV/AIDS interventions (Rakotonanahary, Rafransoa & Bensaid 2002). Yet very little of the stigma literature actually investigates variation in the content of stigmatising beliefs about HIV/AIDS, or indeed investigates how specific local content is constructed (exceptions with regard to southern Africa include Campbell, Foulis, Maimane & Sibiyi. 2005, Dowling 2002 and Leclerc-Madala 1997; with regard to America, see Eliason 1993).

Patient and Orr (2003) suggest that a series of shared beliefs underlie much of the stigma against PLHA in southern Africa. These beliefs are often unconscious and contradictory, but help to justify and create discriminatory behaviour against PLHAs. They are as follows:

- (1) 'If you have HIV you're going to die, so I won't invest resources in you' (*AIDS=death*).
- (2) 'HIV/AIDS is a punishment for sin' (*AIDS=sex=sin*).
- (3) 'We cannot change the way we do things' – for example, condoms challenge cultural norms about procreation, and culture and tradition cannot be challenged (*AIDS=condoms=contraception=cultural taboo*).

---

<sup>8</sup> We use the term 'discursive field' to describe a set of beliefs or statements that are commonly used in association with HIV/AIDS in a specific socio-historical context. An example of a discursive field could be the three beliefs cited here by Patient and Orr (2003).

A critical aspect of the stigmatising process can be illustrated by (3) above, in which condoms and their use (like other materials, behaviours and attributes associated with a disease) may suffer from secondary stigmatisation, that is, stigmatisation by association with a stigmatised disease.

In exploring why the content of stigma varies, one of the questions that has attracted most attention in the literature has been that of variability in the strength of stigmatising ideologies concerning different diseases (for example, Alonzo & Reynolds 1995; Chapman 1998; Dilger 2001; Hayes et al. 2003; Jones et al. 1984; Kelly et al. 1996; Kelly et al. 1987). In this process, various factors that affect the extent to which a disease is stigmatised have been identified. These same factors can also influence how the same disease is stigmatised in different places and within different communities.

Using work by Goffman (1963), Katz (1979), Alonzo and Reynolds (1995) and others, we can identify a number of factors affecting the intensity and content of HIV/AIDS stigmatisation:

- *Definitions of the other*: the nature of specific cultural associations between the disease and particular groups (for example, gay men) or with behaviours already labelled as deviant because they transgress moral codes (for example, homosexuality, female promiscuity and unfaithfulness in marriage);
- *Other cultural associations*: these could include associations with other historically stigmatised diseases, such as syphilis, leprosy or TB;
- *Individual responsibility*: culturally-mediated assessments of the role and responsibility of the individual in contracting the disease (Mantler, Schellenberg & Page [2003] rank controllability, responsibility and blame into an attributional hierarchy in which blame is the final step);
- *Disease biology*: culturally-mediated assessments of the biological nature of the disease in each of its phases, and interpretations thereof (visibility, severity, speed of progress, aesthetic effects, contagiousness);
- *Course of the epidemic*: culturally-mediated assessments of the epidemiological nature of a specific epidemic (origin identified in certain groups, its differential prevalence in certain groups, its severity);
- *Medical knowledge*: the degree of uncertainty, level of knowledge and efficacy of treatments associated with the disease in lay and medical contexts (Brashers, Neidig, Reynolds & Haas 1998);
- *Situational context*: stigmatisation (both actual and perceived) varies according to social context and distribution of power (Jennings et al. 2002; Malcolm et al. 1998: 365; Worthington & Myers 2003);
- *The social acceptability of expressing stigmatising beliefs towards a specific group*: this can be determined by cultural or community norms as well as mass media, politicians and other social and religious leaders;
- *Legal and regulatory environment*: even where implementation of the law is not the norm, legal recognition of the rights of PLHA and the extent of knowledge about this will affect what public reactions are considered acceptable (Parker & Aggleton 2003); and
- *Socio-economic context*: In certain resource-poor contexts where there is little state support, some beliefs about PLHA will have greater impact (for example, 'they will be a drain on resources') and create more of a focus for stigmatising ideology (Patient & Orr 2003).

As we discussed in Chapter 2, the biology of a disease is an important variable that influences the strength and nature of its stigmatisation, but the meanings associated with biological phenomena are always culturally mediated. Changes in knowledge about biological processes are thus also of interest. Crandall and Glor (1997) suggest that knowledge about the severity, contagiousness and treatability of a disease are significant determinants of instrumental stigma. As we will see, knowledge about a disease does not necessarily filter directly from medical experts to the lay public, especially if there is a cultural mismatch or public distrust of medical experts. We will return to the relationship between stigma and all the factors mentioned above later in our discussion of instrumental and symbolic stigma.

Biology is a vital factor in understanding variations in the strength and content of stigma within a disease. Stigmatisation can change as an epidemic, or the disease itself, progresses through various biological stages. These changes can affect how stigma is experienced by PLHA. Alonzo and Reynolds (1995: 303) suggest that in different phases of HIV/AIDS, PLHA experience stigma differently. They describe this changing experience of stigmatisation as a 'stigma trajectory' with four phases: '(1) at risk: pre-stigma and the worried well; (2) diagnosis: confronting an altered identity; (3) latent: living between illness and health; and (4) manifest: passage to social and physical death'. They argue that we need to 'conceptualize how individuals with HIV/AIDS experience stigma and to demonstrate how these experiences are affected by changes in the biophysical dimensions of HIV/AIDS' (see also Taylor 2001).

Brashers et al. (1998) have used this biopsychosocial model to show how uncertainty about the impact of the disease changes in the four different phases of the HIV illness trajectory identified by Alonzo and Reynolds (1995). They argue that: 'Uncertainty is a chronic and pervasive source of psychological distress for persons living with HIV. Numerous sources of heightened uncertainty, including complex changing treatments, ambiguous symptom patterns, and fears of ostracizing social response, play a critical role in the experience of HIV-positive persons and are linked with negative perceptions of quality of life and poor psychological adjustment' (Alonzo & Reynolds 1995: 66). Uncertainty in medical knowledge of a disease, and in the lack of a cure, could thus both increase stigma by others and independently increase anxiety and fear among PLHA in different phases of the disease.

The successful introduction of anti-retroviral (ARV) therapies since 1996 that have helped HIV/AIDS to be recast as a chronic illness in the West may have flattened the stigma trajectory and reduced uncertainty over treatments. Bos, Kok and Dijker offer evidence from the Netherlands suggesting that 'knowledge about HAART is related to lower risk perceptions, a positive attitude toward homosexuals, less fear, and more willingness to have personal contact with people with HIV/AIDS' (2001: 219). By comparison, in the southern African context, there is greater mistrust of allopathic medicine, greater poverty (which hampers access to healthcare even if it is free), and considerable politicisation of the ARV treatment rollout and the debate over the efficacy of ARVs.

It is important to investigate what the impact of the ARV treatment rollout might be on stigma and willingness to test and receive treatment for HIV. Day's work on mineworkers in South Africa suggests that the 'impact ART has had on life expectancy of those living with HIV in industrialized nations may eventually change the perception of HIV/AIDS as

“a killer disease” in areas where it is widely available’ (2003: 671). However, the fact that ARVs cannot cure HIV/AIDS, the lack of knowledge about ARVs among PLHA, the lack of easy access to the drugs, and the absence of an anonymous, convenient VCT service may hamper this process (Day 2003). At present, the impact of the rollout is patchy.

### Conclusion

We need a theory of stigma to explain why and how stigmatisation happens, what its functions and effects might be, whether it matters who stigmatises whom, what constitutes stigmatising beliefs, and how the specific content of stigma is influenced by different factors.

Work in HIV/AIDS stigma generally shows a polarisation between psychological explanations that ignore the socially-constructed nature of stigma and ‘social control’ explanations that downplay the role of the individual as an agent of stigma. Current definitions of disease stigma also tend to define stigma to include its effects (conceptual inflation), which often leads to using the definition of stigma to explain it (functionalism). We need to understand the causes of stigma separately from its effects, as not all stigmatisation leads to actual discrimination and not all discrimination is caused by stigma (see Miles 1989 on racism).

Understanding stigma as a largely emotional process, in which people distance themselves from risk by projecting risk onto outgroups using existing social representations (Joffe 1999), accommodates both individual and social levels of explanation and does not define stigma in terms of discrimination. It also explains why education has a limited effect on the reduction of stigma – stigmatisation is not a rational, cognitive process.

Understanding stigmatisation as a social process involving differentiation and blaming of outgroups for disease directs our attention towards understanding more about the content of stigma – not all negative beliefs associated with HIV/AIDS can be attributed to stigma. We will return to this debate in Chapter 6, but further work is required. Understanding stigma as a social process also focuses our attention on understanding the politics of stigma. Using the blaming model of stigma, and Miles (1989), we can develop more sophisticated understandings of the relationship between stigma, discrimination and power that do not rely on social control theory. Conceptualising stigmatisation as a social process also enables us to understand stigma as something that is constantly re-enacted or re-created in different situations. Understanding how a process interacts with an environment to produce certain forms of stigma is essential in understanding how to research stigma in specific contexts to provide effective local intervention programmes.

In this section we have chosen to define stigmatisation by focusing on the stigmatiser rather than the stigmatised. In the next section we examine stigma from the perspective of the stigmatised.



## 4. RESPONDING TO STIGMA



The specific social context within which people live materially affects their experience of a chronic illness like HIV/AIDS and their treatment needs (Sankar & Luborsky 2003; Schrimshaw & Siegel 2003). Social contexts can be shaped by socio-economic factors, the political environment, and culturally-mediated ideas about gender, age, sexuality, and illness in general. The socio-economic context could even affect access to treatment, and therefore whether people experience HIV/AIDS as a chronic illness or as a terminal one. As discussed above, many of these social factors often also affect the nature and strength of stigmatisation of HIV/AIDS. In this chapter, we focus particularly on how responses to social stigmatisation affect the impact of stigma, but we note that research on stigma and discrimination needs to be part of a broader understanding of people's experiences of, and responses to, the illness within their everyday lives.

Most of the disease stigma literature examines the process and functions of stigmatisation from the perspective of the stigmatiser rather than the stigmatised (Link & Phelan 2001; Schulze & Angermeyer 2003, on schizophrenia). This is appropriate to some extent given that stigma is initiated by those who stigmatise, and perpetuated, to some extent, by entrenched social patterns of exclusion. Understanding how PLHA experience and respond to stigmatisation is no less important, however, because the way people respond to stigmatisation is an important determinant of the impact of stigma. Work as early as Goffman (1963) emphasised the importance of understanding self-stigmatisation. Stigmatised people may, for example, suffer disadvantage without experiencing any direct discrimination by avoiding situations that they think will be discriminatory. Stigma can also be internalised, leading to self-doubt, lower self-esteem, depression, immunosuppression and even premature death (see for example, Santana & Dancy 2000).

The experience of (and response to) stigma by PLHA is thus worthy of special investigation. Scambler, a sociologist working on epilepsy stigma, was one of the first to distinguish between felt (internal) and enacted (external) stigma (Scambler 1989 cited in Herek 2002). Ritsher, Otilingam and Grajales (2003) subsequently developed a measure of perceived stigma for mental illness and Berger, Ferrans and Lashley (2001) have developed an instrument to measure the stigma perceived by PLHA. Research has also been conducted on PLHA's experiences of stigma in hospitalisation (Surlis & Hyde 2001), the effect of stigma on PLHA's experiences of treatment and care (Songwathana & Manderson 2001), quality of life (Sowell et al. 1997) and self-esteem (Berger et al. 2001; Fife & Wright 2000).

Internal stigma has often been seen in the literature as a 'type' of stigma. As discussed in the previous chapter, we wish to explain internal stigma (specifically, self-stigmatisation and perceived stigma) as responses to stigma rather than as a type of stigma. We also believe that self-stigmatisation and perceived stigma are linked processes rather than distinct kinds of internal stigma. Self-stigmatisation, or internalisation of stigma, involves accepting some of the negative social judgements of one's identity; and perceived stigma is the stigma people expect from others should they be known to be HIV-positive (see Bharat, Aggleton & Tyrer 2001 cited in Bond et al. 2002). When others express stigmatising ideologies, PLHA experience the status loss and moral judgements projected onto them: this may be direct (when a person expresses stigma directly to them) or indirect (when a person living with HIV/AIDS reads a newspaper in which stigmatising views are expressed). When discrimination occurs, PLHA may also suffer disadvantage directly or indirectly. In this chapter, we are concerned with the way in which PLHA act

as a result of projecting their direct or indirect experiences of stigmatisation or discrimination into the future.

Under existing definitions of stigma, perceived stigma includes perceived discrimination. Because we have chosen to define stigma as ideology that may not necessarily result in action (discrimination), we have separated stigma and discrimination analytically. However, in some cases we may need to investigate their interrelationships; researching not only 'perceived stigma' but also expected discrimination. PLHAs may use perceptions of both to plan their actions, and many will act on the basis that stigma generally leads to discrimination. In regard to terminology, since we do not wish to suggest that PLHAs necessarily perceive something that is not there, a better term for perceived stigma is 'expected stigma'. We can therefore best describe this kind of investigation as research into expected stigma and discrimination. This approach does not negate the usefulness of separating stigma and discrimination in our theoretical definitions. We sometimes need to research them separately, and sometimes we need to research their close relationships, or how responses to both could be similar.

Theoretical work done on coping with stressors is relevant to understanding how stigmatised people respond to stigmatisation (Miller & Kaiser 2001: 87–88; Steele & Aronson 1995 cited in Link & Phelan 2001). Miller and Kaiser (2001) suggest that a transactional, process-oriented model is useful in explaining that people respond in a number of ways to stigma and other stressors, and that feedback from one response alters other responses (Lazarus & Folkman 1984 cited in Miller & Kaiser 2001). Moneyham, Seals, Sowell, Cohen and Guillory have also used this model to show that 'how HIV-positive women think about HIV-related stressors is an important factor that may account for individual variability in the ability to maintain a sense of subjective well-being in the face of a devastating fatal disease' (1996: 125).

As we can see in Figure 3, responses to stigmatisation by people who have been stigmatised may be voluntary or involuntary, and involve both engagement and disengagement. Not all responses to stigmatisation are maladaptive – they may also represent positive ways of coping with the stressor (Miller & Kaiser 2001). Shih (2004), for example, identifies the following positive responses to stigma: compensation; strategic interpretations of the social environment, focusing on multiple identities; and the adoption of an empowerment model rather than a coping model.

Responses to stigmatisation may be considered maladaptive or adaptive depending on circumstances and on who is making the judgement. Although avoidance-coping mechanisms are generally thought of as maladaptive in the literature, PLHA in a South African study (Stein 1996) derived benefit from some forms of avoidance coping such as non-disclosure and repudiation of negative ideas about HIV and about their HIV-positive status. These coping mechanisms do not necessarily constitute denial of HIV-positive status, but an attempt to reject its stigmatising connotations. Stein (1996) argues that non-disclosure of HIV-positive status may be functional to the affected individual's privacy and peace of mind, but it may also be seen as a maladaptive response because it is not an 'active' working through and acceptance of the illness (and in the absence of safer sex practices, non-disclosure to sexual partners may also put them at greater risk of infection).

## RESPONDING TO STIGMA

Instead of blaming PLHA (yet again) for failing to respond in the best way to stigma, it may be better to focus on finding out what responses people find most useful and why, and directing our attention towards addressing key areas of risk rather than tarring all avoidance-coping mechanisms with the same brush.

Figure 3: Responses to stigma

### Voluntary coping

<table border="1"> <tr> <td><b>Disengagement</b></td> </tr> <tr> <td>Avoidance Denial of discrimination/stigma Wishful thinking</td> </tr> </table>	<b>Disengagement</b>	Avoidance Denial of discrimination/stigma Wishful thinking	<table border="1"> <tr> <td colspan="2"><b>Engagement <sup>1</sup></b></td> </tr> <tr> <td><b>Primary</b> – aiming to change the situation</td> <td><b>Secondary</b> – aiming to adapt to the situation</td> </tr> <tr> <td> <ul style="list-style-type: none"> <li>• Problem-solving</li> <li>• Containing emotions</li> <li>• Expressing emotions</li> </ul> <p>(Groups can also use these strategies)</p> </td> <td> <ul style="list-style-type: none"> <li>• Distraction</li> <li>• Cognitive restructuring (reframing negative attributions, devaluing of stereotyped domains)</li> <li>• Acceptance (this has however been linked with rapid mortality in PLHA)</li> </ul> </td> </tr> </table>	<b>Engagement <sup>1</sup></b>		<b>Primary</b> – aiming to change the situation	<b>Secondary</b> – aiming to adapt to the situation	<ul style="list-style-type: none"> <li>• Problem-solving</li> <li>• Containing emotions</li> <li>• Expressing emotions</li> </ul> <p>(Groups can also use these strategies)</p>	<ul style="list-style-type: none"> <li>• Distraction</li> <li>• Cognitive restructuring (reframing negative attributions, devaluing of stereotyped domains)</li> <li>• Acceptance (this has however been linked with rapid mortality in PLHA)</li> </ul>
<b>Disengagement</b>									
Avoidance Denial of discrimination/stigma Wishful thinking									
<b>Engagement <sup>1</sup></b>									
<b>Primary</b> – aiming to change the situation	<b>Secondary</b> – aiming to adapt to the situation								
<ul style="list-style-type: none"> <li>• Problem-solving</li> <li>• Containing emotions</li> <li>• Expressing emotions</li> </ul> <p>(Groups can also use these strategies)</p>	<ul style="list-style-type: none"> <li>• Distraction</li> <li>• Cognitive restructuring (reframing negative attributions, devaluing of stereotyped domains)</li> <li>• Acceptance (this has however been linked with rapid mortality in PLHA)</li> </ul>								

### Involuntary coping

<table border="1"> <tr> <td><b>Disengagement</b></td> </tr> <tr> <td>Avoidance (this is more adaptive if it is involuntary rather than deliberate)</td> </tr> </table>	<b>Disengagement</b>	Avoidance (this is more adaptive if it is involuntary rather than deliberate)	<table border="1"> <tr> <td><b>Engagement <sup>2</sup></b></td> </tr> <tr> <td> <ul style="list-style-type: none"> <li>• Cardiovascular activation</li> <li>• Emotional arousal</li> <li>• Intrusive thoughts</li> <li>• Rumination about the problem</li> </ul> </td> </tr> </table>	<b>Engagement <sup>2</sup></b>	<ul style="list-style-type: none"> <li>• Cardiovascular activation</li> <li>• Emotional arousal</li> <li>• Intrusive thoughts</li> <li>• Rumination about the problem</li> </ul>
<b>Disengagement</b>					
Avoidance (this is more adaptive if it is involuntary rather than deliberate)					
<b>Engagement <sup>2</sup></b>					
<ul style="list-style-type: none"> <li>• Cardiovascular activation</li> <li>• Emotional arousal</li> <li>• Intrusive thoughts</li> <li>• Rumination about the problem</li> </ul>					

Source: Derived from the theoretical review in Miller & Kaiser 2001

#### Notes

1. Some responses to stigma, such as seeking social support, can serve a number of these functions at the same time (for example, problem solving, expression of emotion, cognitive restructuring).
2. Thinking about negative stereotypes may lead to depression and psychological distress, but emotional and physiological arousal, as a result of prejudice or discrimination, may alert and motivate better coping responses. Immediate reactions, such as exclamations, may serve as a kind of protest.

Individuals react differently to different kinds of stressors and in different circumstances. Sometimes groups of people with a history of stigmatisation develop common coping mechanisms over time (Miller & Kaiser 2001: 88–89). We should also beware of explaining all behaviour of PLHA in terms of HIV or related stigma. People's problems, identities and behaviours are influenced by a number of factors, not just their stigmatised status (see Fine & Asch 1988 cited in Link & Phelan 2001: 365–66 on this issue as it relates to disability). PLHA often complain that people assume that who they are and what they do are solely determined by 'the virus' (for example, POLICY Project et al. 2003a).

### Self-stigmatisation or internalisation of stigma

We now look more closely at self-stigmatisation as a response by PLHA to stigmatisation. This is essentially an ideological process that need not depend on the existence of discrimination. Since people generally know how society stigmatises them, they react by

conforming to or resisting this framework (Steele & Aronson 1995 cited in Link & Phelan 2001). Conforming involves self-stigmatisation or accepting society's negative judgement of one's identity as HIV-positive. This is psychologically very damaging because it reduces the self-esteem of the stigmatised person, which will in turn affect the way they respond to the illness, reducing the incentive to challenge stigmatisation or discrimination. This has further negative consequences both for the individual and for public health programmes, reducing self-esteem, discouraging testing, disclosure and treatment-seeking.

Hiding a stigmatised status can be very damaging too. Goffman (1963) distinguishes between being discreditable (that is, having an attribute that will be stigmatised if it were revealed, but choosing not to disclose it) and being discredited (that is, having a visible stigma, or having disclosed a stigmatising attribute). Hiding or revealing a previously hidden stigma causes greater psychological distress than revealing a stigma that has not been, or cannot be, hidden (Smart & Wegner 2000 and Pennebaker 1995 cited in Lorentzen & Morris 2003: 17). In work on eating disorders, Smart and Wegner (1999), for example, argue that people who try and hide their status experience greater anxiety than those who reveal it. The same may be true for PLHA.

Stigmatisation thus influences the way people negotiate their own identity, and the way they behave, whether or not their status is revealed to others. In research on disability, Taub et al. found that disabled women negotiated their status with able-bodied others, either downplaying or claiming their disability status 'depending on the type of stigma (discredited or discreditable), the nature of the relationship with the audience (personal or formal), and the perceived reaction of the audience (accepting or questioning the legitimacy of the disability)' (2004: 169).

Internalisation of stigma is generally considered a maladaptive response to stigma (Miller & Kaiser 2001). But if self-stigmatisation is so damaging, why do people do it to themselves? Freund and McGuire (1991 cited in Alonzo & Reynolds 1995: 304) suggest that self-stigmatisation is a consequence of repressed anger as a result of being stigmatised. But this is not a very useful way of understanding how it happens because it ignores the social dimension – specifically, the fact that people are socialised prior to self-stigmatisation.

Link and Phelan (2001: 373–4) suggest that prior internalisation of stereotypes about a disease may result in internalisation once people acquire that disease. In the absence of alternative frameworks that are publicly supported by society, people may be unable to reconceptualise their status as non-stigmatising. Continuing to accept society's definition of deviance (even if this means being temporarily defined as deviant) may also be important in reinforcing people's sense of belonging within a society – if they 'repent' or 'reform' they may be accepted once again.

In an effort to resist self-stigmatisation PLHA may deploy an overly positive identity that leaves too little room for dealing with illness and distress. Soskolne, Stein & Gibson (2003: 14) show how HIV-positive women working with the Memory Box project at UCT cultivated a positive identity that emphasised their wellness and 'projected contagion and irresponsibility, key elements of a stigmatised HIV identity' onto other people: those who did not know their HIV status. The decision by many PLHA to adopt a strongly positive identity was influenced not only by the psychological need to evade anxiety about their condition, but also by social factors (Soskolne, Stein & Gibson 2003: 21). These include

the extreme negativity projected by society onto PLHA, and the resultant need for the broad promotion of a positive HIV identity in strong individuals as part of an attempt to minimise the threat of HIV-positive people to society by emphasising that HIV-positive people can take care of themselves.

Soskolne et al. (2003: 21) suggest that a strongly positive HIV identity has particular appeal in South Africa where the widespread nature of the epidemic makes it difficult to limit risk to marginalised outgroups. Because of the nature of the illness, which almost always leads to illness and premature death in the absence of effective treatments, there are difficulties inherent in maintaining a wholly positive view of HIV-positive status that focuses on strength and good health. Such an identity does not leave space for speaking about distress and sickness associated with the disease or for preparing for the phase of ill-health and later death, even where people do have access to treatment. It can also cause anxiety as PLHA feel they have to appear healthy even when they may not be. Soskolne et al. (2003: 22) therefore suggest the importance of integrating some of the negative and painful aspects of life with HIV/AIDS within a more nuanced identity as a PLHA.

### **Expected stigmatisation and discrimination**

The second issue concerning PLHA's responses to stigma is perceived (or expected) stigma and discrimination. Stigmatised people do experience stigma and discrimination directly, but their perceptions of stigma are influenced by how they identify themselves (for example, as members of a stigmatised group) and how they perceive others (for example, as stigmatising) (see Shelton 2003 on racial stigma). The amount of stigma and discrimination people have already experienced, read about or heard of, affects their perception of how much it is going to affect them in the future.

The literature suggests that levels of expected stigmatisation and discrimination materially affect the self-esteem and behaviour of PLHA. Fife and Wright (2000) suggest that individuals' perceptions of stigma account for the significant differences seen in the impact of an illness on the self. Clark, Lindner, Armistead & Austin (2003) show that higher perceived stigma reduced the likelihood of disclosure of HIV-positive status in African-American women in the US. Perceived levels of stigma may also have a negative effect on willingness to present for VCT and treatment (Lichtenstein 2003).

Some research also suggests that levels of stigma perceived by PLHA tend to be higher than 'actual' levels of stigma (Green 1995 and Green & Rademan 1997). Media exposure of minority stigmatisation of PLHA raised PLHA's perceptions of generalised stigmatisation in the UK. In a survey in Scotland, Green (1995) found that HIV-positive people generally had more liberal attitudes towards PLHA than the general public, but felt that attitudes towards them were far less liberal than reported by the general public. Clark et al. (2003) reported a similar finding for the US. Their research showed a difference between perceptions of stigma by HIV-positive and HIV-negative women, with the former group believing that the public expressed a much higher level of stigma against PLHA than the latter group. These findings will have to be tested in the southern African context. In a South African study, Visser (2004) has, for example, found that perceived stigma played a larger role in determining HIV-positive women's experience of community stigma than did enacted stigma or community support.

It is dangerous to assume that there is necessarily less stigma and discrimination 'out there' than PLHA think, because it is very difficult to measure the amount of likely stigma and discrimination in the public sphere. The mismatch between perceived and reported stigma could instead indicate that the general public significantly under-reports stigma against PLHA, a factor that could explain the very low reported levels of stigma in the Nelson Mandela/HSRC study undertaken in South Africa (Shisana & Simbayi 2002).

Instead of focusing only on the negative impact of high levels of expected stigmatisation and discrimination on necessary public health goals such as persuading members of the public to present for VCT and treatment and to disclose their status, we need to examine the situation from the perspective of PLHA. For example, PLHA might choose to hide their HIV-positive status to avoid discrimination: simply asking people to disclose without providing extra support or an effective barrier to discrimination will not remove this disincentive.<sup>9</sup> In focusing on the experience of stigma by stigmatised people we need to be careful that research is not used to 'blame' stigmatised people for seeing stigma and discrimination that does not really exist, or to pathologise them for not confronting it (for example, through disclosure of HIV status).<sup>10</sup>

We cannot understand the impact of stigmatisation simply by measuring what supposedly HIV-negative people say they think about PLHA, or how they intend to act towards them. Because PLHA respond to stigma and discrimination based not only on their own experiences, but also on what they encounter in the media and hear from others, expected stigmatisation and discrimination could be an even greater barrier to PLHA accessing treatment and support than levels of reported or actual stigma or discrimination might suggest. Expected stigma and discrimination is thus an important but under-researched area in the stigma literature.

---

<sup>9</sup> Comments by J Stein on this study.

<sup>10</sup> Comments by J Stein on this study.

## 5. STIGMA AND DISCRIMINATION



Discrimination is the basis for most of our concerns about stigma. A focus on discrimination 'directs attention to the power of perpetrators, which is essential to any effective change strategy' (Sayce 2003). In this chapter we consider the relationship between stigma and discrimination.<sup>11</sup> We also distinguish positive and protective kinds of differential treatment from unfair discrimination because this forms the basis for our discussion of 'instrumental' and 'symbolic' stigma (Herek 1986, 2002) in the next chapter.

Because of the conflation of stigma and discrimination, existing research generally measures intended discrimination – what people say they will do – as an index of stigma. All unfair discrimination against PLHA is usually attributed to stigma. As we have suggested above, it is important to avoid defining stigma in terms of discrimination or discrimination solely in terms of stigma because discrimination is not always caused by stigma and is not a good measure of the impact of stigma. Stigmatisation may have negative effects (for example, increasing expected stigmatisation and discrimination) without actually resulting in discrimination. In combating the effects of stigma, we need to distinguish between situations in which stigma directly causes discrimination, and in which discrimination is caused by other factors such as sexism, racism or resource concerns. In researching discrimination, we therefore need to find out more about why people intend to discriminate, and how intended discrimination relates to action.<sup>12</sup>

### Categorising differential treatment

Based on our reading of the literature, we suggest that differential treatment can be categorised according to four aims:

#### (1) Redress

Where disadvantages have been conferred on a group of people by physical differences or cultural prejudice, societies sometimes feel the obligation of redress. In the race, gender and disability fields, for example, the existence of historical discrimination and the effects of physical differences have on occasion been addressed by employment equity programmes, and by providing women with guaranteed maternity leave, or women and those with physical disabilities with separate track and field events. PLHA or disabled people may at times receive disability benefits to offset loss of income or meet specific additional needs. The main problem with providing disability grants on the basis of illness is that, in an environment of grinding poverty and high unemployment such as in South Africa, it provides a perverse incentive to stay sick, and possibly even to get sick (Nattrass 2004).

#### (2) Preventing infection

Medical science validates some kinds of differential treatment for PLHA (for example, rejection of their blood products for transfusions) and invalidates others (for example, refusal to shake their hands). Ignorance of scientifically validated modes of HIV transmission may result in unfair discrimination (we will suggest in the following chapter that this is not always due to stigma). Even if they are likely to be effective, measures to prevent infection nevertheless have to be balanced against other factors, such as cost and human rights issues.

<sup>11</sup> The term discrimination generally implies unfair differential treatment, but in some cases we have used the term 'unfair discrimination' to underline the point.

<sup>12</sup> See, for example, the work of the AIDS Law Project (<http://www.alp.org.za>).

### **(3) Social distancing**

Where PLHA are judged to be promiscuous or immoral they may experience varying kinds and degrees of status loss and discrimination, for example, being excluded from a religious community. This form of discrimination is a direct consequence of stigmatisation that helps to affirm risk-free identities by projecting negatively-defined characteristics and risky behaviours onto other groups.

### **(4) Balancing social contributions**

Certain kinds of discrimination (such as loss of the right to medical aid, pension and life insurance benefits, education and so on) have been based on (or justified by) lower expected contributions to society by PLHA and higher expected burdens on the family or the public purse. Such discrimination has been challenged because it violates the human rights of PLHA.

### **Differential treatment versus discrimination**

As we have noted above, HIV infection (or any other illness) confers a material disadvantage on people. Because HIV can be transmitted through bodily fluids it is legitimate, and advisable, to recommend the use of condoms when having sex with someone who is infected, or to prevent contact with their body fluids when caring for them. Because it is difficult to know who might be infected, and because body fluids also transmit other disease agents, protective measures have generally been recommended for any contact with body fluids.

However, given the long history of using biological differences based on race, gender and disability to justify unfair discrimination we should be very careful when determining what differential treatment is actually warranted by the threat of infection. Discrimination aimed at preventing infection is sometimes based not on actual risk of HIV infection but on incorrect scientific knowledge or on an overestimation of the potential risk. For example, at first, HIV-positive patients in US hospitals were treated as though the condition was an Ebola-type virus that was highly infectious, and some people still think that HIV can be transmitted through ordinary social contact such as touching, sharing eating implements and bathrooms, and so on. This phenomenon, which Herek (1986, 2002) calls 'instrumental stigma', will be discussed in the next chapter.

In understanding whether differential treatment is fair or unfair (that is, discriminatory) we have to recognise that there is a difference between judging public health discourses and related public health measures on the one hand, and judging individual discourses and actions on the other (Stein 2003a: 1). In the personal sphere it is acceptable to make personal choices to meet personal needs and reduce personal risk, and few public health professionals would consider it to be unfair discrimination if an individual refused to have sex with a person openly living with HIV/AIDS (with or without a condom) because they wished to avoid any risk of contracting the virus (Stein 2003a) or, indeed, wished to avoid increasing their own viral load if HIV-positive themselves. The same would be true regarding individual sexual decision-making in the presence of other sexually transmitted diseases. Unfair discrimination, however, would involve unnecessary measures to reduce risk (such as refusing to shake hands) or moral judgements (for example, claiming that someone was promiscuous because they had HIV).

Public health strategies to combat the spread of the HIV/AIDS pandemic, on the other hand, generally avoid singling out PLHA because this would further stigmatise them, contravene their human rights, and discourage public co-operation, VCT and disclosure. In the public health context, equality of treatment is a critical gauge of the acceptability of public health measures, even where these are designed to reduce the chances of some people infecting others. The public health message is thus 'if you have sex, use a condom' rather than 'don't have sex with PLHA'.

Even if differential treatment is aimed at redress or the prevention of infection, it may have adverse consequences within a stigmatising society. The main problem with current public health programmes in relation to stigma and discrimination is not that they single out PLHA for special treatment (generally, they don't), but that guidance concerning how to remain HIV-negative (for example, abstain, be faithful) seems to support the stigmatising notion that people who have HIV are promiscuous. It is true that the more sexual partners people have, the more likely they are to contract HIV from someone (epidemiological risk), but it is equally true that HIV can be contracted from a single sexual encounter with a HIV-positive person, even if that person happens to be one's only sexual partner (individual risk). HIV is not caused by promiscuity – it simply happens to be transmitted sexually, as well as in other ways (see Davenport-Hines 1990: 7 and Crewe 1992). The promotion of condoms as a means of protection against HIV infection has also helped, paradoxically, to stigmatise condom use ('people who use condoms are people who have slept around or who think their partner has slept around'). Where public health measures do single out PLHA for special services (for example, special ARV clinics, provision of formula feeds for HIV-positive mothers, or the provision of certain medicines), these often become markers of HIV-positive status and are stigmatised (Skinner 2002).

There are thus unintended stigmatising and potentially discriminatory consequences of the conflation of epidemiological risk and causes of infection in society's reception of public health messages – quite apart from the fact that scientific models are often themselves a morally-charged reading of the medical evidence – as well as the impact of the provision of special services for PLHA. In understanding the impact of stigma, therefore, we need to conduct research not only on unfair discrimination and on PLHA's perceptions of stigma and discrimination, but also on the unintended consequences of legitimate forms of differential treatment in public health programmes and campaigns.

In researching discrimination we also need to be very clear about what forms of differential treatment constitute discrimination, why they are unfair, and whether, in specific cases, they are caused by stigma or other factors. HIV/AIDS activists and others have helped to expand the notion of discrimination to include transgressions of the human rights of PLHA. For example, this would include refusal of employment to a PLHA on the grounds that a HIV-positive person is likely to die sooner than a HIV-negative person. This particular example would not just be unfair because it transgresses the human rights of a HIV-positive person, it would also be unfair because other diseases such as cancer are less easily detected in their early stages and may be equally detrimental to someone's career.

In our categorisation of differential treatment above, where we mentioned discrimination aimed at balancing social contributions, we gave the example of insurance discrimination against PLHA. However, there are other more controversial examples. Hospitals routinely

make judgements about whom to treat first, based on prognosis for likely recovery (this is called triage), especially in resource-constrained situations like public hospitals. The denial of treatment to people in public hospitals on the basis of resource constraints has been validated by the South African Constitutional Court, in spite of the fact that the Constitution contains a 'right to life' clause (Klaaren 2004).

The issue of human rights raises an interesting question concerning the role of the household in sustaining a person living with HIV/AIDS. Decision-makers in households make triage-like calculations about, for example, how likely a sick household member is to recover and how much it is costing to treat and feed them relative to household income. It would be very dangerous to suggest that such discrimination would be legitimate, since the household is supposed to be the one place where people are cared for unconditionally. However, discrimination of this kind (for example, withholding of food) happens quite frequently, especially in resource-poor situations where even free treatment is too expensive or difficult to access and the financial benefit of receiving a disability grant while a sick person is alive is weighed against the cost of special food for the invalid and the potential income from life insurance or funeral benefits on death (Le Marcis 2004).

The fact that HIV/AIDS can be viewed as a chronic disease in better-resourced environments makes this form of discrimination not only unfair, but unnecessary, should treatment and proper support be made more accessible. In understanding what to do about discrimination, based on resource concerns, at the household level, we need to determine whether it would be amenable to better-designed treatment or benefit programmes for carers, or whether it is an expression of stigma (discrimination based on resource concerns is included in Herek's definition of 'instrumental stigma'). Are people who have died a social death through stigmatisation helped to die a physical death more quickly? Stigma does sometimes play a role in this, but resource concerns may also cause discrimination quite independently. In the next chapter we will therefore debate whether or not to include 'instrumental stigma' in our definition of stigma.

In this chapter we have suggested that discrimination is an important area of investigation that has been somewhat under-researched because of the conflation of stigma and discrimination in the literature and the use of survey data on intended discrimination as a measure of both. We have described four main categories of differential treatment, aimed at redress, prevention of infection, social distancing, and balancing social contributions. All these forms of differential treatment are worthy of investigation, both to help us distinguish between fair and unfair differential treatment, and to understand the potentially negative impact of certain well-meaning public health programmes and campaigns within a stigmatising society. A matter of particularly pressing concern is the discrimination directed at PLHA because of resource concerns at a household level.

## 6. INSTRUMENTAL AND SYMBOLIC STIGMA



Herek and Capitanio (1998) and Herek (1986, 2002) use the term 'instrumental stigma' to describe intended discrimination based on an inflated fear of contracting HIV, as well as intended discrimination based on resource concerns due to judgements about the likely social contribution of a person living with HIV/AIDS (see also Stein 2003a). This might include not wanting to shake hands with such a person, for example, or refusing to care for or support financially a family member living with HIV/AIDS. Herek and Capitanio use the term 'symbolic stigma' to describe the kinds of moral judgements that may cause a third kind of discrimination, such as refusing to provide the same treatment for intravenous drug users and 'innocent victims' of HIV/AIDS because the former are judged to be more blameworthy for contracting the disease, or not allowing PLHA to serve on a school board because they are judged as immoral.

The definition of instrumental and symbolic stigma rests on a distinction between two different causes of discrimination (resource concerns and ignorance of risk on the one hand, and moral judgements on the other). As we have argued earlier, it is problematic to assume a direct relationship between stigma, intended discrimination and discrimination in all cases, although some stigma may directly cause discrimination. In this chapter, we debate whether we should include instrumental stigma in our definition of stigma. Is it possible to distinguish instrumental from symbolic stigma? What makes resource concerns and ignorance of risk qualify as stigma? It might be necessary to change the definition of stigma in order to accommodate instrumental stigma. Alternatively, we could redefine instrumental stigma as intended discrimination based on inflated risk of infection or on resource concerns. This kind of intended discrimination could be expressed alongside symbolic stigma in the same individual, as Herek and Capitanio (1998) suggest. In this case, we could simply redefine instrumental stigma as intended discrimination instead of stigma.

We will conduct the debate by means of a series of questions.

### **Is the cause of instrumental stigma and symbolic stigma the same?**

The instrumental/symbolic distinction is based on a distinction made in the psychology literature between ways of thinking in individuals: evaluative (based on instrumental concerns about personal risk or infection) and expressive (based on a need to affirm one's self-concept by expressing personal values). These ideas were drawn from the literature on racial prejudice (Bobo 1983 and Sniderman & Piazza 1993 in Herek 2002). Herek and Capitanio suggest that holding evaluative attitudes leads to instrumental stigma, while holding expressive attitudes leads to symbolic stigma. People may hold both kinds of attitudes simultaneously.

Herek and Capitanio (1998) showed that attitudes towards gay men did not predict attitudes towards PLHA among heterosexuals with predominantly *evaluative* attitudes. Attitudes towards homosexuals did predict attitudes towards PLHA among heterosexuals with predominantly *expressive* attitudes. In other words, people in the evaluative group who were judgemental about homosexuals were not necessarily judgemental about PLHA, while people in the expressive group tended to feel the same way about both PLHA and homosexuals. In both expressive and evaluative groups, people's beliefs about contagion predicted their behavioural intentions to avoid PLHA. In other words, if people held the (medically validated) belief that shaking hands would not transmit HIV, they would report an intention to shake the hand of a PLHA, and *vice versa*, whether or not they were prejudiced in other ways against PLHA.

Herek conflates stigmatising ideology and intended discrimination in his research design, which helps him to define both as stigma. His model, however, suggests that instrumental and symbolic stigma have different psychological origins and may therefore require separate consideration.

### **Do instrumental stigma and symbolic stigma perform the same functions?**

We have to be careful in answering this question because the fact that they may in many cases both lead to discrimination or increased social inequality does not make them both stigma. Stein argues, however, that both instrumental stigma and symbolic stigma perform the same 'distancing of risk' function (2003a: 8). According to Proposition 2, distancing from risk by 'othering' is a key element of our definition of stigma. However, instrumental stigma distances people from risk not by 'othering' and projection of negative characteristics, but by suggesting the need for physical distance due to the risk of infection. The fact that instrumental stigma proposes greater physical distance than is required by biomedical knowledge about the disease qualifies this as (intended) unfair discrimination, rather than best practice in public health.

### **Are the results of instrumental stigma and symbolic stigma the same?**

One could argue that the instrumental-symbolic framework is particularly important for understanding HIV/AIDS stigma and discrimination. This is because the joint effect of symbolic stigma (the links drawn between HIV/AIDS and, for example, promiscuity) and instrumental stigma (biological factors like severity, contagiousness and treatability) has made HIV/AIDS more stigmatised than diseases such as cancer or hepatitis (Crandall & Glor 1997; Crawford 1994), at least in the absence of widely available ARVs. Biological factors and uncertainty in medical knowledge about a disease certainly affect the nature and strength of symbolic stigma. They would also influence intended or actual discrimination caused by ignorance or resource concerns, if we redefine instrumental stigma in this way. Both instrumental and symbolic stigma could result in discrimination but we do not need to define everything affecting PLHA as stigma in order to explain the highly discriminatory environment they face.

All negative beliefs about or actions towards PLHA are not caused by HIV/AIDS stigma as we have defined it in Chapter 3. Some negative beliefs may be associated with ignorance of risk (that is, instrumental stigma, which may not qualify as stigma under our definition), the individual characteristics of a person (for example, personality traits or behaviour unconnected with their disease status), linked to other identities that person has which are not stigmatised as AIDS-related, or linked primarily to the circumstances of a household (for example, poverty and unemployment) rather than to HIV/AIDS itself. This, together with multiple stigmatisation, helps to explain why not all PLHA experience the same kinds of stigma and discrimination.

### **Can instrumental stigma and symbolic stigma be ameliorated in the same way?**

Educational campaigns have had an important but limited effect in reducing stigma against PLHA (Bond et al. 2002: 352; Brown et al. 2001: 2; Visser 2004). Herek (2002: 600)

explains this by suggesting that instrumental stigma carries less social baggage, is based on an evaluation of knowledge, and is therefore more easily shifted than stigma based on moral judgements (see also Crandall et al. 1997: 97). Symbolic stigma is more entrenched because it is tied into existing forms of stigmatisation and discrimination in society (for example, race and gender stigmatisation), existing power relationships and the reduction of ingroup anxiety through differentiation and blaming of PLHA as 'other'.

But the reason why we see a reduction in 'stigma' after educational campaigns is that research that measures stigma usually includes measures of intended discrimination in the definition of stigma. However, we have argued in this study that intended discrimination need not be defined as, or caused by, stigma. It may be easier to develop anti-discrimination measures by focusing separately on symbolic stigma (or stigma proper, as we have defined it) and on other causes of intended or actual discrimination such as ignorance or resource concerns. It is not necessary to define them as stigma simply to justify addressing their discriminatory effects.

### **Are instrumental stigma and symbolic stigma both socially constructed?**

We already know that an inflated perception of risk of infection (instrumental stigma) is defined with reference to a body of accepted medical knowledge concerning the biological nature of the disease. According to Herek (2002) and Stein (2003a), instrumental stigma also includes negative attitudes or intended discrimination based on resource concerns as a result of medical and social assumptions about people's biological incapacity through the effects of disease. At first glance, symbolic stigma seems to be a much more culturally mediated concept, which relies on a cultural association between PLHA and other stigmatised groups and behaviours (homosexuality, promiscuity). Symbolic stigma might gain credibility from a 'working misunderstanding' that associates epidemiological prevalence with causation ('if more gay men have AIDS then AIDS must be caused by gay sex' [Herek 2002: 600]).

Biomedical knowledge is however socially constructed.<sup>13</sup> Western biomedical knowledge is thus part of a Western value system (see Good 1994). Biomedical 'knowledge' about HIV/AIDS in particular contains a moralising dimension, particularly in epidemiological research and public health messages (see Joffe 1999 and Stein 2003a). For example, the conventional medical fraternity supported the identification of risk groups (the 4 H approach, or homosexuals, Haitians, heroin addicts and whores) at the beginning of the epidemic, and continues to identify risky behaviours (for example, promiscuity) in defining who is at greatest risk of contracting the disease.

At an individual level, someone who always carefully practices safer sex, whether promiscuous or not, is at lesser risk of contracting HIV than someone who has a single unprotected sexual encounter with an HIV-positive person (Crewe 1992). Promiscuity is nonetheless perceived as problematic from a public health perspective because, as one study has suggested, most people do not put on condoms early enough during intercourse to protect themselves against STIs (De Visser & Smith 2000), and because promiscuous behaviour will, on average, expose people to a higher number of HIV-

---

<sup>13</sup> See, for example, Epstein 1996 on the social construction of medical knowledge of HIV/AIDS – there is a huge literature on the social construction of science in general.

positive partners. This concern ties in with religious moral objections to the practice of sex outside marriage, hence the emphasis on abstinence in the 'Abstain, Be Faithful, Condomise' (ABC) campaign (Stein 2003a). Another socially-constructed aspect of prevention campaigns is the assumption that sexual encounters are mutually consensual and that men and women negotiate sex and condom use from an equal footing of power and choice.

### **Is ignorance as a cause of instrumental stigma simply a lack of knowledge?**

The literature on HIV/AIDS stigma takes a very simplistic view of knowledge and ignorance. Stigma is not usually conceptualised as part of a knowledge-power nexus (Parker & Aggleton 2003 are an exception). Ignorance of biomedical knowledge as reported in research on stigma may not simply be due to a lack of information – it could instead be due to a lack of trust in the source of information, a preference for alternative explanations, and a fear of stigmatisation or bad luck ensuing from being knowledgeable, or even talking about, a taboo subject.

Professing ignorance about HIV/AIDS carries literal, ideological and contextual social meanings (Gee 1988). For example, some people do not want to appear too knowledgeable about a stigmatised disease because they fear being associated with the disease in some way or bringing bad luck upon themselves. In some circumstances, people may maintain or report ignorance about modes of transmission to avoid expressing stigmatising beliefs – for example, that they should not associate with PLHA for moral reasons or claiming to avoid PLHA to avoid infection rather than openly admitting to avoiding PLHA because they regard them as morally suspect. In such cases, instrumental stigma is used as a more 'acceptable' excuse or justification for discrimination that is really based on symbolic stigma.

Information is like a seed – it needs to fall on fertile ground in order to grow into knowledge. One of the factors that can fertilise the ground is trust in the source of information. The historical, political and cultural context of information sources makes people more or less likely to trust it. Herek and Capitanio have suggested that 'AIDS educational programmes can be effective only to the extent that they are perceived as credible by their target audiences' (1994: 365). They found that even with similar levels of exposure to AIDS information, 'African-Americans were more likely than whites to express distrust of doctors and scientists concerning HIV transmission through casual contact, to believe that AIDS is being used as a form of genocide against minority groups, and to believe that information about AIDS is being withheld from the public'. Lower trust was associated with inaccurate beliefs about HIV transmission and greater willingness to avoid and stigmatise people with AIDS. Keogh, Beardsell and Sigma Research (1997: 233–4) suggest that HIV-positive gay men in London do not trust information about sex that they receive from medical professionals, preferring to rely on gay community sources and the gay media.

Lack of trust in the source of biomedical information (Herek & Capitanio 1994) or beliefs in alternative medical models (Prior et al. 2003) can thus affect the uptake of information about how HIV/AIDS is transmitted and how it should be treated. In Africa, both distrust of biomedical models of disease that underlie HIV 'knowledge' and established alternative

explanatory frameworks for illness (which may also have moralising dimensions) are widespread (Kalichman & Simbayi 2004; Malala 2001). For example, nearly 20 per cent of the population in South Africa are open to the idea that HIV/AIDS may have supernatural causes (Kalichman & Simbayi 2004; Shisana & Simbayi 2002). Although ignorance of HIV transmission, rather than belief in supernatural causes, explained most of the variation in stigmatising views on PLHA in Kalichman and Simbayi's (2004) study, ignorance about transmission modes was nevertheless most common among those who believed in supernatural causes of HIV/AIDS. This may be a result of a lack of trust in biomedical explanations and suggests that in providing educational material for HIV/AIDS, great care needs to be taken to ensure that messages grounded in a biomedical view of HIV/AIDS do not exclude that sector of the population which does not subscribe to this model.

Heald (2002: 1) shows how the HIV/AIDS epidemic in Botswana has been 'interpreted by traditional healers as a manifestation of old "Tswana" diseases, acquiring new virulence because of the increasing disrespect for the mores of traditional culture, or as a result of "old" diseases mutating as they have "mixed together".' The fact that 'official Health Education programmes and policy have been couched exclusively in biomedical terms, and in apparent ignorance of other conceptualisations, has been detrimental to public education and understanding'. This 'has encouraged the development of a powerful and coherent counter discourse, based in the common understandings of Tswana society and cosmology'. In plural healthcare systems like those found in southern Africa, different epistemological traditions coincide with entrenched social divisions, so 'educational interventions carry an inevitable political load, operating to locate the Government and its spokespeople on one or other side of the social (and epistemological) divide' (Heald 2002: 1).

Given that biomedical 'knowledge' about a disease is part of a Western value system, responses to PLHA based on the biology of a medical condition or its material effects must also be culturally mediated. But even if these responses are culturally mediated, this does not mean they necessarily constitute stigma.

### **Are instrumental stigma and symbolic stigma wrong for the same reasons?**

Instrumental stigma based on fear of infection is usually considered wrong because the risk of infection is inflated when measured against public health guidelines and the current state of biomedical knowledge. Instrumental stigma based on resource concerns is wrong because it violates people's human rights: for example, calculation of likely resource consumption by PLHA is not a morally appropriate way of deciding whether to care for someone or not in a family context (although the private and public health services do this all the time), or whether or not to employ someone and train them. Symbolic stigma is usually considered wrong because there is no direct causative link between membership of outgroups such as gay men or commercial sex workers and the contraction of HIV, so gay men cannot be blamed for contracting HIV because they are gay (see Proposition 2). But symbolic stigma is also wrong because the association of various negative beliefs with a medical condition (AIDS = death, AIDS = sex = sin, and so on) tends to inflate or distort the true negative impact thereof (Proposition 1).

Are resource concerns necessarily inaccurate? It would be difficult to assess the accuracy of predictive models of consumption and income used for household decision-making.

Resource concerns may be based on miscalculations, but with increasing numbers of AIDS-related deaths, people in southern Africa have already become adept at making such calculations, based on the resource capacities of households and benefit structures for PLHA. The impact of any sick, economically active adult on a poor household's income and expenditure is severe. It would be interesting to see whether resource-based decisions at a household level are systematically skewed against PLHA, and whether this has any gender or age dimensions. The provision of free VCT and ARV treatment does provide PLHA with opportunities to remain productive for a long time, and disability benefits reduce their burden on the household. But even on ARV therapy, HIV-positive people may die prematurely after a period of illness. The more advanced the illness at the point at which people are diagnosed as having HIV/AIDS, the less of an impact treatment is going to have (see for example, Sliep, Poggenpoel & Gmeiner 2001 on Malawi).

### **Can risk and resource concerns and symbolic stigma usefully be part of the same category (stigma)?**

As we have shown above, the analytical categories of instrumental and symbolic stigma rely on culturally-mediated concepts (biomedical knowledge and social morality respectively) that change over time in different ways. What is morally acceptable within the human rights discourse is a political construct that does change over time and varies in different contexts – but generally more slowly than medical knowledge changes. This would affect what is defined as resource-based and symbolic stigma. Definitions of what constitutes instrumental stigma based on risk of infection would have to change as scientific knowledge or the nature of the disease changes. At present, an understanding of HIV/AIDS based on ignorance of the current scientifically identified ways in which HIV is transmitted is termed 'stigma'. An understanding of HIV/AIDS, supported by current scientific knowledge, is termed 'knowledge'. Should a mutation of the virus make it more easily transmissible, or should medical science discover new modes of transmission, some of what has been termed 'instrumental stigma' could become 'sensible precautions' against contraction of the disease. With new treatments that could significantly reduce the viral load, the risk of transmission through sex could also drop to such an extent that currently necessary public health measures for safer sex would be recast as instrumental stigma.

In the research literature, instrumental stigma is usually measured by self-reported intended behaviour in surveys, while symbolic stigma is measured by attitudinal scales or interviews that reveal people's beliefs. Although infection and resource concerns (instrumental stigma) can be attributed to quite different socio-psychological processes from HIV/AIDS stigma (symbolic stigma), they can also become part of the negative group definition of PLHA articulated by HIV/AIDS stigma. Risk and resource concerns can also be trotted out as an excuse or justification for discrimination based on symbolic stigma.

In order to establish whether something is instrumental or symbolic stigma we need to determine whether actions taken to avoid a perceived risk of infection, for example, are related to evaluations of incorrect knowledge (that is, instrumental stigma based on fear of infection), or have become part of the differentiation and blaming of PLHA (that is, symbolic stigma). In the case of resources as a trigger or justification for stigma, to what extent is the fear that PLHA will be a drain on financial resources based on an assessment of household costs which would be equally applied to other household members (instrumental stigma)? Or is this fear based on the idea that PLHA are by definition always

## INSTRUMENTAL AND SYMBOLIC STIGMA

incapable, unproductive and will die a terrible, costly and lingering death soon after diagnosis because they are being punished for sin (symbolic stigma)?

These are critical distinctions because they determine how easily discriminatory behaviour based on these beliefs can be changed. Providing PLHA with a disability grant might more easily ameliorate discrimination based on the lack of income than discrimination based on a stigmatising view of PLHA as immoral wasters. However, in very poor communities the provision of benefits may have unintended consequences, especially in the context of high unemployment. For example, providing a disability grant for severely affected PLHA might make some of them stop taking medication so that they remain seriously ill and therefore eligible for the grant. In the absence of other household income, there is also no guarantee that the money will be spent on medical supplies for PLHA and on transport for getting to the clinic rather than on household costs in general, so a disability grant may not actually increase access to treatment and care. Thus, even where resource concerns rather than stigma lie behind discriminatory behaviour towards PLHA, it is not a simple matter to eliminate such discrimination through the provision of benefits.

In addressing discrimination against PLHA, it is as important to tackle resource concerns and ignorance, as it is to tackle symbolic stigma. Instrumental and symbolic stigma will change over time in different ways and respond to different kinds of interventions, even though at an ideological level they are also sometimes intertwined. This discussion suggests that symbolic stigma, risk and resource concerns should not be part of the same analytical category if we wish to focus on research that is directed towards improving interventions. It is easier to understand this complex terrain using several different analytical tools (for example, definitions of evaluative and expressive attitudes, and an understanding of different origins of discrimination), than stretching a single concept to encompass everything.

### Conclusion

Although both instrumental stigma and symbolic stigma are socially constructed and may lead to discrimination against PLHA, it is not really useful to try and define them both as stigma as they do not originate from the same social, cognitive or emotional processes nor respond to the same kinds of interventions. While instrumental stigma and symbolic stigma could both lead to discrimination, instrumental stigma does not employ 'othering' and projection to distance people from risk. The instrumental-symbolic distinction relies on differentiating between different causes of discrimination rather than different kinds of stigma, and thus blurs the distinction between stigma and discrimination. We therefore propose redefining instrumental stigma as intended discrimination based on risk or resource concerns, and not as stigma. For similar reasons, it is not particularly useful to include both risk and resource concerns in the same analytical category.

This raises an important question for our definition of stigma: should the term stigma include any (biologically unjustified) negative beliefs about a disease, or only those negative beliefs used to differentiate or blame PLHA as a group for the disease? We have argued in this chapter that not all unjustifiably negative beliefs about a disease (for example, the belief that HIV/AIDS is highly contagious) constitute stigma. Some beliefs can be characterised as incorrect understandings of the biomedical consensus rather than as stigmatising moral judgements.

In some cases, however, both risk or resource concerns may become part of broader stigmatising beliefs. Simply believing that 'shaking hands with PLHA will transfer HIV' is not stigma, but resource or risk concerns may form part of stigmatising representations of PLHA as intrinsically different, 'greedy, draining' or 'contaminating'. Ignorance can also be used as an excuse for less acceptable prejudices: perhaps the best test of this is whether people change their beliefs when given appropriate educational material. Curiously, some people use moral judgements to justify discrimination that is actually based on resource concerns.<sup>14</sup>

The debate on instrumental and symbolic stigma has key implications for how one designs interventions. We need to address discrimination based on moral judgments, risk and resource concerns in different ways. Symbolic stigma is an emotional problem based on fear that draws on broader prejudices, identities and power relations in society. It is difficult to eliminate. It may be easier to address risk and resource concerns by, for example, providing educational and financial assistance, but it is also clear that the provision of information and money will not simply eliminate ignorance or unfair resource allocations. Education can help to change perceptions about likely risks of infection from PLHA, and thus reduce discrimination. However, we need to move away from the simplistic notion of education as a transfer of correct information to the ignorant. There is a sophisticated literature on educational theory that can be used to understand learning and the relationship between knowledge and power more fully (for example, Freire 1970; Gee 1988, 1989). Further work is needed on this issue.

---

<sup>14</sup> Comments by Bond on this study.

## 7. CONCLUDING THE THEORETICAL DISCUSSION



Current use of the term HIV/AIDS stigma suffers from conceptual inflation because stigma is defined as something that results in discrimination (and perpetuates existing inequalities), and is thus blamed for a wide range of social barriers to dealing with HIV/AIDS. We should be wary of assuming that a direct link always exists between stigma and discrimination, because this is precisely the relationship that needs to be understood in all its complexity. Although stigma often leads directly to discrimination, it is important to avoid defining stigma *in terms of* discrimination.

Disease stigma can thus be better defined as *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. Disease stigma is negative social ‘baggage’ associated with a disease. This approach separates what people believe (stigma) from what people do (which may include discrimination). Researching stigmatising beliefs helps us to understand effects of stigmatisation other than discrimination: how people respond to risk in the case of HIV/AIDS (feeling invulnerable, they ignore risk), and responses to infection with HIV (possible internalisation of stigma). This approach also helps us to investigate possible causes of discrimination against PLHA other than HIV/AIDS stigma (for example, resource concerns unrelated to stigma), and to research barriers to prevention, treatment and care in all their complexity.

Recent work on stigma has helped us to refine the above definition of disease stigma further. Infection with a disease agent does have some demonstrably negative effects (for example, higher morbidity and mortality) that do not constitute stigma. In the previous chapter we concluded that disease stigma does not necessarily include concerns about resources and risk of infection either, although these concerns may lead to unfair discrimination. It consists of beliefs that are part of a social process of stigmatisation, differentiating people who have a specific disease from the self, projecting risk of contracting disease onto other groups, and blaming them for having the characteristics that increase their risk of being both infected and infectious.

Holding the (medically incorrect) belief that HIV/AIDS is highly contagious is not necessarily linked to a judgemental ‘othering’ process – it may simply be a result of ignorance. Herek’s category of ‘instrumental stigma’ (1986, 2002) is thus probably better described as intended discrimination based on risk perceptions or resource concerns rather than as stigma *per se* because it originates from evaluative rather than expressive psychological processes, and does not employ ‘othering’ and projection to distance people from risk. In some cases, however, resource concerns or risk perceptions become part of stigmatising representations of PLHA as intrinsically greedy, draining or contaminating.

Although HIV/AIDS stigma may result from a psychological need to distance the self and the ingroup from risk of contracting a medical condition like HIV/AIDS, the process of stigmatisation is profoundly social and operates within existing social power relationships. Representations of the ‘other’ are constructed with reference to existing social representations. In dominant group representations, which usually gain greater currency in society, these definitions often identify and blame already marginalised groups in society, following existing lines of inequality. This association is often given credence by the fact that existing social inequalities can affect the epidemiology of disease, making marginalised groups more vulnerable to disease and less able to find treatment.

Stigmatisation is a process that cannot be defined by, and does not automatically result in, discrimination, but its translation into discrimination is one of the reasons we need to address the phenomenon. Stigmatising beliefs and related discrimination are more likely to be expressed or acted on in enabling legal, social and economic environments where power differentials exist between the stigmatiser and the stigmatised. The mapping of HIV/AIDS stigma onto marginalised groups can further marginalise them through status loss, internalisation and the justification and encouragement of discrimination.

Social inequalities thus create the framework within which HIV/AIDS stigmatisation is shaped and discrimination is permitted to happen. However, it is too simplistic to assume that stigma is a servant of the dominant class, always reinforcing social inequality. Stigmatisation is not a hegemonic process: people can resist both stigmatisation and self-stigmatisation (Link & Phelan 2001). According to our definition, stigma does not need to result in discrimination to qualify as stigma. Marginalised people can stigmatise each other and dominant groups (Joffe 1999). Thus stigmatisation and discrimination occur within families and peer groups (although unequally, because of other power relations such as gender) just as easily as they occur between the powerful and the marginalised. While more powerful groups in society may be able to express stigma more widely and effect more discrimination on the basis of stigma, stigmatisation can happen across the social spectrum in many different ways.

Using 'blaming' models of stigma helps us to understand the role of individuals in constructing and perpetuating stigma without resorting to individualistic 'rotten apple' theories. It emphasises the need to understand the social context of stigmatising beliefs, and allows us to explore the complex effects of stigmatisation, without restricting ourselves to those that support the existing status quo. We can thus understand stigma's functions at the individual level without resorting to individualism, and we can understand the politics of stigma without resorting to functionalism.

Very little of the research on HIV/AIDS stigma focuses in sufficient detail on the content and discursive context of stigmatising beliefs, either because these beliefs are constructed as the opposite of correct medical knowledge (in much of the psychological literature) or dismissed as simple justifications for reinforcing social inequality (in the sociological literature). Stigmatisation is, however, a social process that is constantly changing and being reformulated in different social contexts. This poses a challenge to researchers in the field who wish to help develop interventions to improve public health programmes. We need this kind of information to develop locally-appropriate HIV/AIDS programmes (Rakotonanahary et al. 2002).

Definitions of the 'other', and therefore the content of HIV/AIDS stigma, vary according to who is doing the stigmatising. Different cultural, biological, situational, social or political contexts also influence the content and intensity of stigmatising beliefs. These include perceptions about the cause and origins of the disease, the extent of individual responsibility for contracting it, the nature of disease biology, the course of the epidemic or the disease in a specific individual, the level of uncertainty in lay and medical knowledge, the situational context of an interaction, and broader legal, social and economic factors. Different behaviours, diseases and treatments are stigmatised by association with HIV/AIDS as the epidemic proceeds and different treatments are made available. Understanding the variability of stigmatising beliefs helps to target research so that we can update and improve existing HIV/AIDS programmes.

## CONCLUDING THE THEORETICAL DISCUSSION

---

The literature on HIV/AIDS stigma does not focus sufficiently on the perspective of the stigmatised. Yet the way stigmatised people respond to stigma can materially affect the impact of stigma on society, whatever the extent of actual discrimination based on stigma. Where attention has been paid to this issue, many PLHA's responses to stigma have been defined as maladaptive (internalisation of stigma, avoidance, denial) or simply incorrect (expectations of higher levels of stigma compared to those reported by the general public). Yet many people continue to suffer abuse and face death for doing what public health programmes recommend (for example, accepting the disease, disclosing positive status). We need to do more research about why people choose different responses to stigmatisation and how useful these responses are to them and to public health goals.<sup>15</sup>

In conclusion, then, we believe it is important to avoid conflating the causes and effects of stigma, and to theorise and research variations in the strength and content of stigma in a more structured way. We also need to focus more attention on understanding the impact of stigma: both the experience of stigma from the perspective of the stigmatised, and the relationship between stigma and discrimination. Research into stigma and anti-stigma interventions needs to take these issues into account. We can use the gaps identified in the preceding discussion and in an examination of our research database to develop a research agenda and to suggest methodologies most appropriate to this research. We can use the theoretical analysis and new research on stigma to help us develop appropriate anti-stigma interventions, moving away from purely educational programmes and targeting interventions to fit specific local circumstances. These are the issues we will discuss in the remainder of this study.

---

<sup>15</sup> Comments by J Stein on this study.



# 8. DEVELOPING A RESEARCH AGENDA



This chapter reviews the literature on HIV/AIDS stigma in the southern African context in relation to questions raised in preceding chapters in order to develop several specific questions for a local research agenda on HIV/AIDS stigma. We apologise in advance for any repetition the reader might encounter, as some of the key points from the preceding chapters have been summarised here for those who wish to focus only on the research and implementation chapters.

## Existing research agendas

In the last decade, the main players in the HIV/AIDS stigma research field have each presented a research agenda for the field (Herek, Mitnick, Burris, Chesney, Devine, Fullilove M, Fullilove R, Gunther, Levi, Michaels, Novick, Pryor, Snyder & Sweeney 1996; Parker & Aggleton 2003). They have emphasised the importance of doing 'action' research – research that informs interventions against stigma. We endorse this approach.

Herek et al. (1996) suggested the following areas of research:

### (1) The cultural context of HIV/AIDS stigma

- Law: the effects of anti-stigma laws on different sectors of the population.
- Mass media: how are HIV/AIDS presented, and how does this affect stigma?
- Religion: what are effective responses to HIV/AIDS?
- Workplace: what are effective programmes for addressing PLHA needs?
- Healthcare: how to ensure that healthcare workers do not stigmatise.

### (2) Targets of HIV/AIDS stigma

- How does stigma affect PLHA?
- How does stigma change over time?
- How do we mitigate the effects of stigma?
- How does stigma affect people caring for PLHA?

### (3) Perpetrators of HIV/AIDS stigma

- Prevalence of stigmatising beliefs;
- Social psychological processes influencing stigma (for example, personal contact);
- Time course of psychological reactions to PLHA;
- Interaction with other kinds of stigma (for example, racism);
- Interaction with fear for personal well-being; and
- How public health messages can communicate personal responsibility without encouraging blame.

In 2003, Parker and Aggleton published a paper that was meant to directly counter Herek et al.'s focus on psychological research. They proposed the following research agenda (2003: 19ff.):

- Conceptual studies: theoretical work that encompasses social, economic and political aspects of stigma;
- New investigative studies: context-specific studies of the social processes involved in HIV/AIDS stigma conducted alongside broader comparative work; and
- Strategic and policy-oriented research: identifying the elements that contribute to success or failure of anti-stigma programmes (policy context, actors involved, ideological context, combinations of programmes and so on).

As discussed above, we need to combine individual-level analysis with social-level analysis of stigma rather than interpreting the choice as a mutually exclusive one. But we may need to ask slightly different questions in surveys of individuals if the focus is no longer only on identifying areas of ignorance. We may also need to ask questions about the social environment of stigma that go beyond mapping the relationship between the effects of stigmatisation and the maintenance of the status quo.

Do we also need a comparative research agenda for HIV/AIDS stigma? Weiss and Ramakrishna suggest that we need to '[compare] stigma for different conditions and in different health system[s], social, and cultural settings, and [evaluate] practical approaches for intervention programmes' (2001: 1). This broad comparative investigation may be realisable in the longer term, but the severity of the problem and the relative lack of research on HIV/AIDS stigma in sub-Saharan Africa (Lorentzen & Morris 2003: 27) suggest that there is a short-term need to focus on developing African research on stigma.

### **Developing a local research agenda**

Prioritisation and careful methodological consideration are necessary to draft research agendas for specific regional contexts. In the next two chapters, we pose two questions for HIV/AIDS stigma research in southern Africa:

- What are the most important questions we should be asking, based on the local context and existing research?
- What are the most effective methods we should be using to get answers to these questions?

In 2001, Health and Development Networks (HDN) and the UNAIDS Intercountry Team for East and Southern Africa facilitated the development of an operational research agenda on stigma and HIV/AIDS in Africa (HDN & UNAIDS 2001). This document, derived largely from the discussion paper for the meeting (France 2001), outlines key questions in six areas of interest: definition and context; the healthcare sector; PLHA; the religious sector; communication; and indicators to measure stigma. This research agenda includes ideas for interventions, placing it firmly in the arena of action research, and it combines measures of individual attitudes with research questions around the social, political and cultural context of stigma. It is an excellent building block for further research on stigma in southern Africa.

The main issues to consider in developing this research agenda further are, firstly, whether our theoretical review in Chapters 1 to 7 suggests any general questions that have been neglected and, secondly, which of these questions require particular attention given the spread of existing literature?

There has been immense pressure on HIV/AIDS stigma researchers to find a general pattern of stigma so that general solutions can be implemented by international public health agencies. Using the same intervention in different contexts has not worked very well in HIV/AIDS prevention programmes, as a result of different local issues and meanings associated with the disease (Rakotonanahary et al. 2002), and it is unlikely to work well in anti-stigma programmes either. We need to focus on understanding variations as well as commonalities in researching stigma to make more effective interventions. On a more general theoretical level, studying continuity and variation in

## DEVELOPING A RESEARCH AGENDA

stigmatisation can help to identify factors that influence, change or entrench stigma and assess their relative impact in different contexts.

The HDN and UNAIDS research agenda for Africa recognises both commonality and variation in stigmatisation across Africa, the importance of researching the impact of stigma on PLHA (including internalisation), and on carers or family of PLHA, and the need to understand the situational nature of stigma. There is, however, a persistent emphasis on developing an index of the amount of stigma. We do need to know how big the problem is in order to direct funding appropriately, but it is very important to measure it in a way that is useful in directing funding towards the most effective interventions.

South African research that shows relatively low levels of reported stigma in attitudinal surveys does not prove that stigma is not a problem (for example, Shisana & Simbayi 2002; Whiteside, Mattes, Willan & Manning 2002). We may need to revisit the way we measure the amount of stigma. Because of the notion that research on stigma can identify misconceptions correctable through educational programmes, most of the research into the content of stigmatising beliefs focuses on documenting incorrect beliefs that can be challenged by science. Measuring the 'level' of stigma in this way will not help to design appropriate interventions if we do not understand the nature, politics and effects of stigmatising beliefs in the local context.

Some stigmatising ideas have a very powerful hold on society because of the way in which they fit into existing prejudices and power alliances. We do need to identify and challenge these beliefs (see Patient & Orr 2003), but we also need to understand the way that stigma is expressed and discrimination is enacted within families at the household level as well as in the media and in government. We cannot only focus on identifying beliefs that support the status quo (as Link & Phelan 2001 and Parker & Aggleton 2003 suggest we should) or have some general currency across national and cultural boundaries. We need to explore the entire discursive field around HIV/AIDS. The unit of analysis for such work should not be too large. For example, the paper by Malcolm et al. (1998) discusses the metaphors associated with HIV/AIDS in some detail, but it ranges over such a wide spectrum of countries that we lose sight of how different local interpretations affect the stigmatisation process.

The HDN and UNAIDS (2001) research agenda suggests that instead of simply measuring the number of people who hold stigmatising attitudes, we need to measure the *impact* of stigma and discrimination on public health goals, for example, VCT and disclosure. Because much of the early stigma research focused on prevention issues, current research into stigma needs to address access to testing and treatment as well; access to vaccine trials is also becoming an issue. The development of recent programmes for delivering ARV treatment in southern Africa makes this research a matter of local urgency. If stigma becomes less of a barrier to prevention, treatment and care, but other barriers remain, we need to find out what these barriers might be, and what to do about them. Methodologically, instead of relying only on self-reporting of stigmatising attitudes and intended discrimination in surveys, we need to use more participant observation and detailed analysis of interviews.

Existing research on stigma generally focuses on the stigmatisers in the 'general population' so that they can be taught not to stigmatise. This is important, but, as we suggest in Chapter 4, there is no direct correspondence between the amount of stigma or

intended discrimination HIV-negative (or untested) people admit to expressing and the amount of stigmatisation or discrimination HIV-positive people expect to face. Expected stigmatisation and discrimination are crucial determinants of health-seeking behaviour by PLHA. We therefore need to understand PLHA's expectations of stigma and discrimination in specific social or healthcare contexts, then investigate what factors affect these expectations and how they can best be addressed.

Having covered these general points, we now consider some specific issues and review the literature about them.

### **Questions for southern African research on HIV/AIDS stigma**

#### **How can our theoretical models of stigma be improved?**

In the last few years a number of key theoretical issues have been debated in the published literature (for example, Link & Phelan 2001; Parker & Aggleton 2003). Using a critique of existing models as a starting point, we have suggested a new framework for understanding HIV/AIDS stigma. We need to extend this theoretical work through critical analysis and a close interface with new research and grassroots experiences (see Campbell 2001). For example, further work is required on the way in which the content of stigmatisation leads to differentiation and blaming, and what criteria can be used to identify stigmatising beliefs. We also need to continue the debate about the relationships between risk and resource concerns, moral judgements (stigma), ignorance, poverty and fear.

#### **What is the content of local beliefs around HIV/AIDS?**

Discourse analyses in the literary criticism mode generally focus on the nature of stigmatising attitudes expressed in the media or in literature (for example, Connelly & Macleod 2003; Sontag 1990; Treichler 1999), rather than on popular beliefs. Where popular beliefs are measured, most research focuses on identifying biomedically incorrect beliefs about HIV/AIDS as an index of 'AIDS ignorance' which is then sometimes correlated with increased stigma (for example, Herek & Capitanio 1994; Gughani & Ukeje 1993; Kalichman & Simbayi 2004; Li & Cole 1993).

Usually we work with a very broad understanding of the content of popular stigmatising beliefs. In countries with low incidence, HIV/AIDS is associated with homosexuality, immorality and drug use (Herek 2002); and in countries with high generalised incidence, it is associated with promiscuity, immorality and death (Patient & Orr 2003). As we suggested above, in order to effectively challenge these stigmatising beliefs, we need to understand them in the context of local circumstances and ideas, histories and politics.

Some detailed research has been done on local, popular understandings of and reactions to HIV/AIDS in South Africa (for example, Ashforth 2001; Campbell et al. 2005; Leclerc-Madala 1997, 2001, 2002; Malala 2001; POLICY Project et al. 2003a; Preston-Whyte 2003; Stadler 2003). Most of it focuses on the ways in which people view and speak about sex and sexuality. Presentations at the *AIDS in Context* conference at the University of the Witwatersrand in April 2001 on this topic included Delius & Glaser (2001), Mlungwana (2001), Hoosen & Collins (2001), Gear (2001), Hunter (2001), Ntlabati et al. (2001) and Epprecht (2001). There has been considerable work on the gendered nature of HIV/AIDS

## DEVELOPING A RESEARCH AGENDA

discourse (for example, Fox, Nkosi & Kistner 2003; Jewkes et al. 2003; Jobson & Wyckhoff-Wheeler n.d.; Walker & Gilbert 2002; Wojcicki & Malala 2001).

This research highlights the gendered, unequal and silenced or stigmatised nature of sexual transactions, which impact on HIV transmission modes, and the formulation of HIV/AIDS stigma. Posel, writing on the politicisation of sexuality post-1994, succinctly summarises the relationship between HIV/AIDS and sex in the public mind in South Africa:

Semiotically, the virus [HIV] is coupled with promiscuity – a sign of too much sex, a surfeit which becomes morally contaminating as much as physically life-threatening. The virus becomes a marker of rampant sexuality which spreads contagion as much through the family and the community as through the body ... The imagery of sex as freedom, sex as style, progress and upward mobility, jars when juxtaposed with the more alarmed, urgent calls for 'safety' and caution ... Discursively, the imagery of sex as freedom, as the symbol of a virile new lease on life, jostles with that of sex as menace, sex as death. (2004 draft: 16)

Posel points out that speaking about sex as a key vector of AIDS has been politicised within discourses of nation-building and transformation, and debate about it has led to a discussion of deeper uncertainties and cleavages in the country.

In spite of the dominance of sex in representations of HIV/AIDS, we also need to explore the content of HIV/AIDS stigma in relation to different forms of othering, such as beliefs around immigrant status (Mendès-Leite 2001) and race, and in relation to the fear of death (Carton 2003; see Mallinson 1999 on grief work). This is an important but somewhat neglected issue in our understanding of HIV/AIDS stigma (Patient & Orr 2003). In October 2004, a symposium was held on the issue at WISER in Johannesburg.

HIV/AIDS should also be conceptualised in relation to historical and current representations of other diseases such as TB (see Westaway & Wolmarans 1994). It would be informative to look at the process of othering (beliefs around 'carriers' and 'victims', popular narratives of aetiology and blame) in the history of HIV/AIDS and stigmatised diseases such as leprosy, and at how stigmatised individuals can be constructed as both heroes and villains.

There are other discursive frameworks for meanings attaching to HIV/AIDS. Ashforth has argued that:

To talk of a 'stigma' attached to AIDS in contemporary South Africa without understanding the witchcraft dimensions is ... to risk misunderstanding both the nature of community power relations and the impact of the epidemic. For even as they lie dying, most people do not know they or their loved ones have the disease. Nor would they want to know, or be wise in desiring to. This wilful ignorance arises not simply from fear of the name 'Acquired Immunodeficiency Syndrome,' nor from shame over the sexual licentiousness that presumably gave rise to the infection in the first place. After all, there is hardly a family in the country that does not have children giving birth to children, sons being sought to support their offspring, or fathers finding long lost progeny they secretly sired many years back. Sexual misdemeanors are shameful, sometimes, but commonplace nonetheless. The terrors, silences, and stigma associated with symptoms of the diseases decimating communities throughout the land in the wake of HIV/AIDS, however, make perfect sense if understood in terms of their

witchcraft dimensions. With cases of witchcraft, silence and discretion are the norm. No-one wants to publicize the fact that they have been cursed. Such publicity would not only be embarrassing, but is dangerous. (2001: 17)

He suggests that further research may show that, 'the HIV/AIDS epidemic in black townships and villages is likely to stimulate suspicions of sorcery, fear of witchcraft, and a general sense of spiritual insecurity as more and more people die at an early age of painful, debilitating, and incurable infections that resonate with indigenous categories of interpretation broadly subsumed under the rubric "witchcraft"' (Ashforth 2001: 18; see also Stadler 2003).

### **What are the histories and politics of stigmatising ideologies?**

Once we have fully understood the content of stigmatising beliefs around HIV/AIDS we can move towards understanding their histories and politics so that we can better understand how they may be changed or challenged.

Leclerc-Madala argues, for example, that there is a political (and gendered) dimension to popular understandings of and responses to the HIV/AIDS epidemic in South Africa, and that this will affect the tenacity with which people hold the belief:

The growing popularity of virginity testing [in KwaZulu-Natal must be understood] within a gendered meaning-making process consistent with commonly held beliefs that the epidemic is the result of women being sexually 'out of control' ... virginity testing is an attempt to manage the epidemic by exerting greater control over women and their sexuality. In addition, virginity testing of girls helps to draw attention away from the role of men in the maturing epidemic, consideration of which has been conspicuously absent in the popular discourse on AIDS at all levels of South African society. (2001: 533)

Campbell et al. (2005) make a similar point in regard to another study in KwaZulu-Natal: Stigmatisation of PLWA is part and parcel of a conservative reassertion of power relations of gender and generation and a public reinforcement of the social institutions whose moral authority rested on their ability to control the sexuality of women and young people (or at least be seen to control this sexuality at the level of rhetoric, if not at the level of reality, in the pre-AIDS days when it was easier for sexual 'transgressors' to be discreet about their activities).

Packard and Epstein (1992), Setel, Lewis and Lyons (1999), Phillips (2001), Fassin (2002), Hunter (2003) and Marks (2002) have begun to analyse the broad history of HIV/AIDS in terms of epidemiology and stigma in the African context. We need more detailed research on how patterns of stigmatisation have meshed with power dynamics in the society at different times. This includes, but goes beyond, the history of government responses to disease (for example, Jeeves 2001; Allen 2001; Nattrass 2004; and Goyer & Gow 2002 on prison HIV policies) to include a variety of lay representations of disease as well as epidemiological work. We also need to understand the relationship between epidemiological studies that show higher incidence of a disease in certain groups and stigmatising ideologies that blame these groups for disease.

The 'stigma follows power' approach works very well in helping us to understand the power dynamics behind the stigmatisation of already marginalised groups such as gay men, Haitians, Africans, sex workers and injecting drug-users. In places like South Africa,

where HIV/AIDS affects the general population, HIV/AIDS has been stigmatised through an association with promiscuity and poverty (see Goldin 1994 for a comparison of the different epidemics), and by many whites as an illness affecting black people. How do the power dynamics play out here?

There are many ways in which HIV/AIDS has been stigmatised – for example as an illness affecting rural black people or immigrants from other African countries and as an illness affecting gay white men by the urban black population (Joffe 1999). How do we understand the power dynamics involved when people stigmatise their own family members or neighbours? These complexities need to be placed in historical context and their power dynamics investigated.

### **What is the relationship between stigma and discrimination?**

Significant work has been done by the AIDS Law Project in identifying cases of discrimination (for example, Jennings et al. 2002; Richter 2001). More broadly, Lazzarini and Klitzman (2002) have suggested that we need to understand law as a pathway to, or shaper of, social determinants (such as inequality), as well as an index of how society responds to inequality. They suggest that we need to research the actual effects, intended and unintended, of the ways in which law and health policy are implemented, and how they are understood. This is a critical issue in South Africa, where a large gap exists between legislation, policy and implementation.

Most of the stigma research measures self-reported stigma and discrimination in surveys or interviews. Where respondents mention stigma as a cause of discrimination they have experienced, researchers do not usually explore what respondents mean by stigma, nor do they investigate the relationship between stigma and discrimination. Few studies directly investigate how discrimination occurs in specific contexts such as healthcare service points.

We need to find out under what circumstances stigmatising beliefs result in discrimination, to investigate the nature and extent of discrimination against PLHA, and understand the relationship between stigma and discrimination in specific contexts such as public healthcare delivery points or households containing a person living with HIV/AIDS. Some discrimination will have other causes than stigma, so we need to understand the entire range of factors causing or exacerbating discrimination against PLHA (such as the lack of money to attend clinics, or the lack of confidentiality in clinics). This is critical because each separate factor may require different remedies.

### **How do PLHA experience and respond to stigma and discrimination?**

Although stigma (ideas) and discrimination (actions) are analytically separable, they both affect PLHA (albeit in different ways) and are experienced as linked if PLHA believe that stigmatising attitudes are likely to be expressed in discriminatory actions. Stigmatisation has an effect on the self-image, mental health and self-esteem of PLHA if it is internalised, and both expected stigmatisation and discrimination and experiences of discrimination can affect the behaviour of PLHA (Berger et al. 2001; Fife & Wright 2000; Frable, Wortman & Joseph 1997; Santana & Dancy 2000). How HIV/AIDS stigma and related discrimination affects PLHA depends on the stage of the illness, the presence of other forms of social stigmatisation, and the resources available to them, as well as the social context in which a stigmatising interaction occurs.

Perhaps because of the highly stigmatised nature of the South African epidemic and its relatively later peak, as well as widespread reluctance to test, there has been less South African work on this issue than we found on the US. This finding may also be a consequence of low African publishing rates and the skewed nature of the online databases we searched. Exceptions include the work of Soskolne et al. (2003) and a number of projects currently in progress (for example, Freeman & Nkomo 2004 and Visser 2004) given the greater access to research participants through ARV treatment programmes and related services for PLHA.

Important work has however been done locally on the embodied and situational experience of stigma. Chapman (1998) and other memory work projects (Morgan 2004) have looked at how internalisation of HIV/AIDS stigma and the experience of the illness changes the perception of the body over the course of an illness (see also Malala 2001 on sex workers' perceptions of their bodies). Le Clezio is working on stigma maps that help participants to represent their stigmatising experiences in different social contexts. For many PLHA, financial and health concerns may override concerns about stigma.<sup>16</sup> HIV/AIDS research thus needs to focus on how living with HIV is integrated into a broader life experience rather than simply focusing on stigma and discrimination (Le Marcis 2004).

### **What are the barriers to testing and disclosure?**

It is important to examine the relationship between denial, stigma, absence of treatment options or a cure and financial issues in understanding people's failure to go for VCT. Decisions relating to HIV/AIDS care are integrated into everyday life (and death) – stigma is only one of the variables people take into account. The provision of wider VCT and treatment facilities in the ARV rollout means that urgent investigation is necessary to determine specific factors that create barriers to VCT and disclosure in the context of treatment provision, and to evaluate interventions addressing these barriers or creating incentives for testing and disclosure.

Stigmatisation of others, as we suggested above, allows people to deny their own risk by projecting risk onto outgroups. Denial, or 'optimistic bias', encapsulates the idea that others are more likely to experience negative events than oneself (Joffe 1999: 69). When an individual realises they may themselves be HIV-positive, acceptance of stigmatising ideas about the illness ('I am not a person like that') may prevent them from testing or going for treatment. However, denial can also operate outside of the ambit of stigmatisation of disease. Even if people challenge the social stigma associated with HIV/AIDS, they may not wish to spoil the experience of feeling well by finding out they are HIV-positive, especially in the absence of a cure. Larry Kramer, a well-informed AIDS activist in New York since the early 1980s, did not go for an HIV test until he became ill with hepatitis in 1988 (1994: 227, 291) – and he was not alone among HIV/AIDS activists in delaying his own testing before the development of symptoms. Fear of negative consequences of testing also played a large role in determining why American college students did not go timeously to STI clinics for VCT and treatment of STIs in general (Barth et al. 2002).

Fear of negative consequences and the absence of a cure may thus be powerful disincentives for HIV testing, quite independently of HIV/AIDS stigma (Day 2003 on South Africa). This may change with the introduction of ARVs, which have been

---

<sup>16</sup> Comments by J Stein on this study.

perceived in some quarters as a cure. Will the provision of free ARV treatment thus help to increase rates of VCT in southern Africa? Is the rollout too patchy to have any impact? We need more research on this.

Disclosure is also a complex problem. Non-disclosure of HIV-positive status has been ascribed to stigma (for example, Kilewo et al. 2001 in Tanzania; Black & Miles 2002 in the US; Chandra et al. 2003 in India) and encouraging disclosure has been seen as a means of challenging stigma (Paxton 2002). Disclosure has been related to improved psychological functioning and lower expected stigmatisation and discrimination (Clark et al. 2003). Disclosure of HIV-positive status, rather like 'coming out of the closet' as a homosexual or being open about one's alcoholism, is supposed to function both as therapy and as a form of social activism.

However, existing South African research on testing and disclosure suggests that people only test or disclose if they perceive stigma to be at acceptable levels (Etiebet, Fransman, Forsyth, Coetzee & Hussey 2004; Kalichman & Simbayi 2003). Or it may in fact mean that going through the process of VCT and disclosure reduces people's perceptions of community stigma. Levels of disclosure are currently very low. A survey of 726 HIV-positive patients at two sites in KwaZulu-Natal found that 65 per cent and 92 per cent, respectively, had not told anyone of their status (Pawinski & Laloo 2001). Other South African studies have also found relatively low rates of disclosure. This can be compared to 5 per cent who told no-one of their status in a UK study (Petрак, Doyle, Smith, Skinner & Hedge 2001 – this was a volunteer sample). In South Africa, where public sector ARV treatment is now available, disclosure is a condition of receiving treatment, so it will be very hard for researchers to establish real disclosure rates in the future.

Testing and disclosure are key facilitators of prevention and treatment for HIV/AIDS in terms of healthcare and prevention, but can have serious negative consequences for individuals in a highly stigmatising environment. Negative consequences of disclosure are common in the South African context (Jennings et al. 2002; Skinner 2002: 5). Women who test first through antenatal services are often blamed for infecting the partner and because the mother is highlighted as the recipient of treatment in Prevention of Mother to Child Transmission programmes, mothers are also often blamed for infecting children (POLICY project et al. 2003a). Disclosure often takes place indirectly, through actions such as using formula milk for children, suggesting the use of a condom, going to an AIDS or TB clinic, or taking certain pills. Many of these kinds of activities are thus stigmatised by association, and thus avoided, in spite of their potentially positive impact on health, so as to avoid unintentional disclosure (Skinner 2002).

We need to understand more about the social contexts in which stigma around HIV/AIDS is perceived and articulated. Campbell (2002) showed that membership of community associations such as sports clubs was associated with lower HIV rates and safer sex practices, while membership of stokvels (communal savings associations) was associated with more frequent drinking, higher HIV rates for men, and more casual sex. What ideas about sex and HIV/AIDS are prevalent in these different kinds of social contexts? How do people talk about testing and disclosure in different contexts? How do these discussions differ in relation to gender, class, cultural or religious groupings?

### **What are the barriers to treatment and care?**

It is imperative to improve PLHA's access to treatment and care. Roeloffs, Sherbourne, Unutzer, Fink, Tang and Wells (2002: 311) have argued that the 'relationship between stigma and service use deserves further study in diverse settings and populations'. However, asking 'how does stigma create a barrier to treatment and care?' begs the question. We need to allow for a more complex relationship between stigma, discrimination and barriers to care. Thus, we turn the question the other way round, asking 'what are the barriers to treatment and care?' This is because our main concern, after all, is to reduce barriers to treatment and care, not just to reduce stigma itself.

International research suggests that, in general, barriers to treatment and care for a range of medical conditions include stigma, expected stigmatisation and discrimination, cost (poverty), denial, ignorance, cultural appropriateness of care, gender discrimination and physical availability and accessibility of healthcare (see for example Antai-Otong 2002 on mental illness; Bunting & Seaton 1999; Coughlan 2003; Heckman, Somlai, Peters, Walker, Otto-Salaj, Galdabini & Kelly 1998; Shaibu & Wallhagen 2002; Weiser, Wolfe, Bangsberg, Thior, Gilbert, Makhema, Kebaabetswe, Dickenson, Mompati, Essex & Marlink 2003). Such research generally resorts to drawing up a list of different barriers to care, rather than calculating their relative weightings. This is because it is often difficult to see to what extent inadequate care, for example, is related to stigma rather than other factors such as ignorance or the constraints of an overburdened healthcare system.

Researchers into barriers to HIV/AIDS treatment and care have only recently begun to collect data from PLHA themselves (see Heckman et al. 1998: 366); the ARV rollout in South Africa provides an opportunity to do this. This work should be integrated with research into the policy and organisational environment in which treatment is offered. More work on both public and private healthcare systems would thus be useful (for example, Dawes 2003), as well as histories of policy frameworks, as discussed above. It might also be useful to examine the development of HIV/AIDS policies in specific clinics and hospitals (such as Groote Schuur Hospital), since the beginning of the epidemic in order to track changes in how health professionals have regarded HIV/AIDS and integrated HIV/AIDS services into the healthcare system.

Another gap in our understanding of barriers to care in southern Africa is that we have little knowledge about how healthcare workers think about, and actually engage with, PLHA (see work by Siminoff, Erlen & Lidz 1991 and Bayer & Oppenheimer 2000, on the US; Bishop, Oh & Swee 2000, on Singapore; Surlis & Hyde 2001, on Ireland). Recent research on sub-Saharan Africa has shown that although caregivers and medical professionals might be better educated about HIV/AIDS than the general population, they continue to stigmatise and discriminate against PLHA, especially where there are limited resources for care (Bond et al. 2002: 353, on Zambia; Shisana, Hall, Maluleke, Stoker, Schwabe, Colvin, Chauveau, Botha, Gumede, Fomundam, Shaikh, Rehle, Udjo & Gisselquist 2003, on South Africa; Godfrey-Faussett & Ayles 2003: 70, on sub-Saharan Africa). The same pattern has been noted elsewhere (Paiva et al. 2003: 92). As Li and Cole note:

Frequently medical education about AIDS, like medical education in general, relies on a cognitive model with the implicit assumption that increased knowledge and skills will lead to improved care. Support for this assumption is especially weak in the case of AIDS, since anxiety and stigmatization play such a large part in the social response to this disease. ... most studies have shown that higher

levels of knowledge are not necessarily associated with more tolerant and less fearful attitudes towards people with AIDS (Stevens & Muskin 1987; Imperato et al. 1988; Crawford 1990; Currey et al. 1990; Feldman 1990; Gerbert et al. 1991). Increased knowledge may sometimes exacerbate fears and prejudice among health care providers (Feit et al. 1990), especially when the information provided seems vague or inconsistent with information from other sources (Surrey 1990). (1993: 305)

Sadow, Ryder and Webster (2002: 663) suggest that medical education can in fact increase the stigmatising attitudes of nursing students, as it often promotes the idea that there is a status differential between nurses and patients. We thus need a better understanding of the beliefs health professionals develop about HIV/AIDS through medical education and general socialisation, as well as how stigmatising beliefs and other factors (such as resources and healthcare environments) affect the interaction between PLHA and health professionals.

We also need to investigate how various factors might exacerbate stigma and form independent barriers to treatment and care. For example, it may be possible to reduce barriers to care by improving the confidentiality of healthcare contexts and by providing guidelines for professional interactions that reduce discrimination (for example, Kai & Crosland 2001 on mental illness). This issue will be touched on in Chapter 10.

### Conclusion

We should be careful not to conflate stigma (ideology) and discrimination (actions) in conducting our research, but we do need to examine both phenomena in some detail, and to understand the relationships between them. We do, however, need to remember that stigmatisation can affect PLHA's self-esteem and behaviour without necessarily resulting in discrimination, and that causes of discrimination other than stigma need to be identified to improve strategies for HIV/AIDS prevention, treatment and care.

We need to change the kinds of questions we ask in research about HIV/AIDS stigma, not only because some questions have already been answered, but also because our perspective needs to shift somewhat away from simply measuring *how much* people stigmatise, or how stigmatisation fits in with social patterns of inequality. We have discussed in the theoretical section the reasons why people stigmatise – in order to reduce the threat of HIV/AIDS we need to understand *how* people understand this threat – how stigma has local meanings, politics and histories. We need to know how stigma and discrimination *impact* on PLHA. We need to research the impact of stigma and related discrimination in specific contexts, and to identify other factors that might disadvantage PLHA or interfere with public health goals. In some cases, it may be possible to tackle causes of discrimination other than stigma; in other cases it may be possible to limit the expression or the impact of stigma and discrimination.



## 9. METHODOLOGIES FOR RESEARCHING STIGMA



In this chapter, we suggest some key interdisciplinary methodologies for researching stigma in the southern African context. Not only do we wish to find the best ways of investigating disease stigma, by looking at methods from a variety of disciplines and those used in other disease contexts, we also wish to ensure that these methods are appropriate and ethical for local investigations of HIV/AIDS stigma.

In conducting research into HIV/AIDS stigma the framework of disciplinary tools for investigating disease stigma need to be broadened beyond the ambit of psychology, sociology, law and literary criticism. Researchers agree that approaches to understanding and researching HIV/AIDS stigma need to become more interdisciplinary, both in practice and in theory (Link & Phelan 2001; Parker & Aggleton 2003). The same argument has been made with regard to HIV/AIDS prevention:

As the field of AIDS prevention looks for novel approaches and theoretic constructs, it should borrow ideas from other fields of study and foster interdisciplinary collaborations with professionals from complementary fields. In this manner, educational interventions can move beyond the individual context to begin to address the social influences on sexual behaviors. (Schonfeld 2000: 375)

Not only do we need to move towards an interdisciplinary theoretical approach, we need to implement research methodologies from different disciplines, such as language studies, anthropology, history, and economics.

In the international arena, much of the socio-medical research on HIV/AIDS stigma to date has been engaged in cataloguing and measuring stigmatising attitudes and knowledge about HIV/AIDS through public opinion polls and surveys (this is confirmed by Parker & Aggleton 2003). In our database, we identified a considerable number of papers using surveys and attitudinal measures to research HIV/AIDS stigma (for example, Green & Rademan 1997; Crandall & Glor 1997; Herek & Capitanio 1998; Kalichman & Simbayi 2003; Paiva et al. 2003). However, very few studies used in-depth interviews, focus groups or participant observation techniques *alongside* surveys (see Table 3).

The main qualitative methods used in HIV/AIDS stigma research are individual interviews and discourse analysis of the media. The database we developed contains numerous studies using interview methodologies, in particular to examine patient experiences (Hackl et al. 1997; Lewis 1999; Santiago 1998). Qualitative research on HIV/AIDS stigma draws mainly from psychological case study models, anthropological models (especially content analysis of interviews using grounded theory methods, for example, Powell-Cope & Brown 1992 – these results are sometimes quantified) and discourse analysis. Discourse analyses (for example, Connelly & Macleod 2003; Sontag 1990; Treichler 1999) generally focus on stigmatising attitudes expressed in the media.

The dominance of interviews and media analysis in qualitative studies is a consequence of the focus on asking people what they think and do, rather than observing what happens, using less direct techniques to access information from people, or investigating the social context in which stigma operates. This has deflected research attention from other qualitative methodologies such as participant observation, mapping techniques, diaries and historical analysis. Far too little stigma research attempts to combine different qualitative methods to compare different results and to augment the data available for analysis.

Table 3: A numerical analysis of methods used in recent research papers

Method	Number
Survey questionnaire, psychometric tests or psychological experiments only	73
<b>Total quantitative</b>	<b>73</b>
Detailed participant observation/ open-ended interviews only	62
Focus groups only	7
Psychological case studies	4
Focus groups and interviews	2
<b>Total qualitative</b>	<b>75</b>
Survey with focus groups and key informants	2
Survey/psychometric tests with interviews	10
<b>Total combined qualitative and quantitative</b>	<b>12</b>

*Note: The table should be read as an indication of the dearth of combined qualitative and quantitative studies rather than as an accurate measure of the absolute numbers of either. The numbers are gleaned from our database from papers researching or making findings related to HIV/AIDS stigma (including work on barriers to treatment and care, disclosure and testing, attitudinal studies and experiences of PLHA and carers) organised by methodologies used, based on details provided in abstracts. Most of the qualitative studies are based on interviews and participant observation methods. The amount of qualitative research is probably underestimated in the database. We have not included media reviews, policy reviews or historical analyses (the predominant remaining methods of research) in the numbers for qualitative research because in these fields our database was heavily skewed towards African material and thus may not be representative, and also much of it was not specifically about stigma although most articles were relevant to stigma research in its broadest sense.*

Qualitative methods have indeed been developed and used to research stigma; however, they are usually deployed separately from surveys. Where qualitative measures are used in conjunction with surveys, they are generally used as a means of checking the survey questions (exceptions are Bond et al. 2002; Varga 2001). We need far more integration of qualitative and quantitative measures in research, and more collaborative projects across regional, institutional and disciplinary boundaries. The South African AIDS Vaccine Initiative (SAAVI) is a good example of collaborative, multidisciplinary research on HIV/AIDS (Jewkes 2004).

**The survey: problems and possibilities**

Much attention has been focused on measuring the amount of stigma to gauge the relative severity of the problem in a specific country, in order to better prioritise funding and research work. The POLICY project team, for example, is attempting to develop standardised survey questions for this purpose, and a number of psychologists have created stigma indices. Given the situational and cultural variability of stigma even within countries, however, developing common indices of stereotyping or discrimination is very difficult.

Measuring the general amount of stigma in a country will not really help us to understand its specific local or situational forms, impacts and effects, which will blunt attempts to design local interventions. The impact of stigma depends not only on how widely or

strongly stigmatising beliefs are expressed, but also on reactions to stigma from the perspective of the stigmatised, and on whether and under what circumstances stigmatising beliefs are translated into discrimination.

We may wish to review the way in which we design our surveys. Most of the survey designs in South Africa seem to be cross-sectional studies conducted on a once-off basis (an exception being the planned review of the LoveLife campaign by Stadler and Hlongwa 2002, although this does not focus specifically on stigma). Some general surveys such as the Nelson Mandela/HSRC study, may be repeated in the future. Campbell argues that 'in cross-sectional research which examines any phenomenon at one moment in time – the complex mechanisms underlying human social behaviour and experience become "fossilised" and difficult to apprehend analytically' (2001: 6). Combining cross-sectional, sequential and longitudinal designs of surveys can separate age effects from historical or individual effects (Breakwell & Fife-Schaw 1994). Such surveys could detect changes in stigma perceptions and attitudes over a number of years, if the logistical problems involved in tracking people over time can be solved. This has in fact been achieved in other studies, such as the South African Birth to 20 study.

Unless we ask the right questions, however, longitudinal studies are not going to be more productive than cross-sectional studies. Continuous data collection (using computer software) in cellphone surveys can help in redesigning questions for local circumstances, as the findings are continually tracked and analysed (McQueen & Campostrini 1994). When combined with qualitative studies, such surveys could test new questions as the study progresses.<sup>17</sup> Telephone studies in the UK suggest that people are more willing to discuss sexual issues over the phone than face-to-face (McQueen & Campostrini 1994).

We also need to consider the kinds of questions that survey methodologies are best suited to answering. It is difficult to measure stigmatised or sexually-related behaviours accurately using questionnaires or brief surveys. In a study on reported sexual behaviour among gay men in the US, McKirnan, Doetsch, Vanable, Buchbinder, Douglas and Judson found that when brief screening reports 'were compared to subsequent in-depth, face-to-face interview data, 29% of the men who reported unprotected anal intercourse during the interview failed to disclose this behavior during screening' (1994: S285). Attitudinal surveys only measure what people say they believe when confronted by the surveyor (Stein 2003a), not what they might believe or say they believe in other social contexts, nor what they might or might not do in acting on those beliefs. Research methods other than surveys – including, for example, methods from history, anthropology and linguistics – are better at providing a historical or cultural context for beliefs and attitudes.

The best results can be gained by combining surveys with qualitative measures in such a way that the qualitative material both informs the survey design and helps to interpret the results. Weiser et al. (2003) used both qualitative and quantitative research methodologies in their Botswana study, including questionnaires and interviews with patients receiving ARV treatment and their healthcare providers, in order to identify principal barriers to adherence. Such combinations have been used in South Africa, where some HIV/AIDS research has already used focus groups and key informant interviews to inform survey

---

<sup>17</sup> Of course, it would be necessary first to investigate the local appropriateness of using cellphone surveys to answer questions about HIV/AIDS or sexual behaviour since privacy is not always possible. The question of informed consent has been addressed in other international telephone studies.

design (for example, Shisana & Simbayi 2002; Shannon Mitchell's stigma research project in the Eastern Cape). Kitzinger (1994) offers a useful discussion of focus groups in HIV/AIDS research.

Other qualitative measures can also be used alongside surveys; these will be discussed further below. What we need at this stage is a re-evaluation of the way in which research projects are designed and a more integrated approach to conducting HIV/AIDS research across regional, institutional and disciplinary boundaries. We can, for example, use in-depth interviews, participant observation and attitudinal surveys to investigate the same questions with the same respondents. We could also use different methods to research different issues, and then bring the different data sets together for analysis. This approach could foster much-needed research collaboration, in which different research programmes come together to design a project, conduct the research separately where necessary, using different methodological approaches, and then share data for analysis.

### **Adapting survey tools to local contexts**

Most of the research on stigma has been done in the US. The social and political context of the US epidemic has been as important as disciplinary traditions in structuring theoretical and methodological approaches and setting the frameworks for debate around HIV/AIDS stigma. In the African survey work presented at the SAHARA conference in 2004, researchers tended to use focus groups and key informant interviews alongside surveys (for example, Shisana & Simbayi 2002), perhaps to a greater extent than in studies abroad. This may reflect the difficulties of adapting survey questions to African conditions where measures standardised for Western urban populations may not be appropriate to the circumstances, cultural or linguistic frameworks, or literacy levels of many African research subjects.<sup>18</sup>

A recent HSRC survey (Paterson & Le Roux 2004) showed that many South African psychologists have concerns about the cross-cultural validity of standard psychological tests, and the lack of translations of these instruments into African languages. Huang, Watters and Case pointed out that intravenous drug users differ by race, ethnicity, age, and drug use profiles and that 'their economic circumstances and social stigma make them a special case in terms of psychological assessment' (1988: 191). In using standard psychological tests on intravenous drug users, the authors were concerned about 'self-report biases, literacy, attentional focus, measurement constructs, and drug states confounding psychological states' and recommended 'further development of basic measurement tools' (1988: 191).

The same problem has been noted in researching Latino populations in the US: gender, immigration status, socio-economic status, and culture affect the capacity to reach and maintain a sample, interviewing procedures, and measurement (Land & Hudson 1997). Land and Hudson emphasise the need to establish culturally-appropriate rapport with research subjects, develop appropriate kinds of questions and use culturally-sensitive translations. Certain instruments, such as those with negative item stems, multiple choice answers, and mark-sense answer sheets, have been proven to be problematic for people of certain cultural backgrounds (Morishima & Mizokawa 1979 in Land & Hudson 1997).

---

<sup>18</sup> This finding may also be an artificial one shaped by our search methods, and the fact that in some cases, we were able to review only the abstracts of international papers, some of which did not contain detailed methodological information.

There are also marked cross-cultural differences in willingness to use Likert-type scales of intensity in questionnaires (Baranowski et al. 1990 in Land & Hudson 1997), or indeed self-administered written questionnaires at all (Land & Hudson 1997).

In adapting surveys and other instruments to local circumstances we should not assume that significant cultural or other differences (or similarities) do not exist within groups (black Africans, Muslims, white Africans) that we may have defined as culturally different from the 'standard' US white male or the 'standard' African urban dweller. Local calibration of instruments must be addressed by well-planned qualitative investigation of these issues in the field. This may significantly change what one decides to ask in a survey, and how one asks it. Focus groups are often used to achieve this end, but we need to supplement this work where possible with an analysis of language use, cultural and social dynamics, and the history of HIV/AIDS stigmatisation in that context. Culturally-sensitive translation procedures should be followed (see Land & Hudson 1997).

In concluding this section, we suggest that surveys measure reported attitudes and behaviour better than they can measure actual behaviour, hidden prejudice or aspects of belief systems not identified prior to the survey. This is why focus groups and key informant interviews have sometimes been used alongside surveys to improve the question design. Also, many issues are easily explored using qualitative methods, such as interviews. We need more research that uses other methods as well, including participant observation, historical studies of other forms of disease stigmatisation, analyses of the popular language used around HIV/AIDS and sexuality, mapping of stigmatising experiences and informant diaries.

### **Qualitative methods for researching stigma**

It is difficult to describe each qualitative methodology in detail in this overview: this will be done when we conduct further research. There is also insufficient time to assess the actual use of stated methods in each research study reviewed here. In their metasynthesis of 62 qualitative research papers on HIV-positive women in the US published between 1991 and 2001, Sandelowski and Barroso pointed out that it was difficult to classify the articles by stated methodology because close examination revealed that most of them did not actually use the methods they claimed to follow:

Twenty-four of the 62 journal article reports we read were presented as grounded theory, phenomenologic, ethnographic, narrative, and/or feminist works. However, despite these method claims, the findings in 12 of these 24 reports were produced from some form of relatively manifest content analysis. Thirty-eight of these reports had no explicit methodological orientation at all, had few or no citations to method literature, and/or assumed a generic or noncategorical research stance toward inquiry, their authors referring to their work as 'qualitative', 'descriptive/exploratory', and/or as 'focus group study'. (2003: 906)

While we may comment on how different methods have been used in research on HIV/AIDS stigma or indeed in other relevant fields, our main aim in this section is to open up the debate about extending consideration of methodologies for stigma research beyond what seems to be the dominant qualitative framework, that is, interviews and content analysis.

Detailed interviews have been extensively used to understand the nature of HIV/AIDS stigma and other disease stigmas (for example, Bunting & Seaton 1999; Lindsey, Hirschfeld & Tlou 2003; McGrath, Ankrah, Schumann, Nkumbi & Lubega 1993; Remien, Hirky, Johnson, Weinhardt, Whittier & Le 2003; also Cinnirella & Loewenthal 1999 on mental illness). A number of local studies have used thematic analysis of open-ended in-depth interview responses (for example, Ndinda 2004; see also Moneyham, Seals, Sowell, Hennessy, Demi & Brake 1996 and Black & Miles 2002 where field notes were analysed). Oral histories have been used to collect data from PLHA and their families. The advantage of a broad interview framework may be that it gives greater insight into people's subjective experience of stigma and how stigma interacts with other factors in producing discrimination (Denis & Makiwane 2001; Santiago 1998). A life-history interview can elicit interesting relationships between social factors, stigma and personal histories (Selwyn 1998). A more detailed analytical approach could employ hermeneutical techniques (Saunders 1994) and narrative analysis (Collins 2001) in small samples. Detailed analyses of counselling session transcripts (Silverman 1994), for example, have greatly increased our understanding of the counselling encounter and should be replicated in Africa.

Traditional ethnographic approaches are usually general and inclusive in their focus, which may be an advantage in understanding stigma as culturally, historically, socially and situationally contextual (Leclerc-Madala 1997, 2001, 2002; Preston-Whyte 2003; Stadler 2003). In an adaptation of traditional ethnographic approaches, 'grounded theory methodology' based on work by Glaser and Strauss (1967 cited in Timlin-Scalera, Ponterotto, Blumberg & Jackson 2003) and Strauss and Corbin (1990 cited in Timlin-Scalera et al. 2003) has been used in a number of HIV/AIDS stigma studies. Grounded theory methodology has combined participant observation with content analysis of interviews. For a discussion of how the methodology has been applied in the HIV/AIDS research field see the appendix in Lewis and Ross (1995). Grounded theory methods have been used to understand barriers to care (Timlin-Scalera et al. 2003), HIV-positive mothers' experiences (Ingram & Hutchinson 1999a, 1999b), disclosure by AIDS caregivers (Powell-Cope & Brown 1992) and anxiety associated with HIV-testing (Worthington & Myers 2003). All this research touches on the question of stigma.

Using participant observation and content analysis of interviews enables us to research the effects of stigma and discrimination on PLHA experiences of illness, and barriers to treatment and care, employment, education, social support networks and sexual fulfilment. We can use this approach, for example, to research both reported and observed barriers to treatment, and investigate the role stigma plays in creating such barriers. This would require a parallel understanding of the environment created for ARV provision in clinics and hospitals within the broader health system (see Dawes 2003) and how stigma and other factors affect PLHA responses to these contexts. We therefore need to couple these methods with other qualitative methods.

Document-based historical research has cast new light on the HIV/AIDS epidemic (Fee & Fox 1992; Fox & Fee 1988; Packard & Epstein 1992), and the development of government policy (Allen 2001; Goyer & Gow 2002; Jeeves 2001; Nattrass 2004; Posel 2004). However, discourse analysis of the media (Treichler 1999) or historical analysis of ideological frameworks around HIV/AIDS (Crewe & Aggleton 2003; Posel 2004; Sontag 1990) has probably had more impact on stigma research *per se*. Research on the historical relationship between HIV/AIDS and other stigmatised diseases or illnesses (for example,

Brandt 1988; Phillips 2001; Setel, Lewis & Lyons 1999; Volinn 1989) needs to be extended in the southern African context. Historical methods should also be used to explore the relationship between epidemiological work, public health programmes and stigma (for example, Oppenheimer 1988) in the southern African context.

Other research methods should also be used. Techniques such as PLHA diaries (Coxon 1994; De Visser & Smith 2000), body maps (for example, Chapman 1998), other memory work (including memory boxes, hero books and body maps, see Denis & Makiwane 2001 and Morgan 2004) and stigma mapping (Le Clezio, work in progress) can help us to contextualise stigma and discrimination and to understand PLHA paths to VCT, disclosure and treatment. These techniques can be combined with more traditional ones. Worthington & Myers (2003) identified situational and social factors underlying anxiety associated with HIV testing, by analysing transcripts in semi-structured interviews with HIV-test recipients in Ontario, Canada. These techniques, however, should be assessed for appropriateness in local contexts. The diary approach has been used in Africa (Pattman & Chege 2003) but may only be suitable in literate communities, unless one can use an audio or videotape diary system (which in turn may raise the problem of capital investment in equipment).

We need to be acutely aware of the effect of the nature and context of the research encounter on the research results. Pattman and Chege's (2003) study, for example, found that students talked about gender and sexuality differently in group situations and in their diaries; McKirnan et al. (1994) reported similar findings in relation to brief screening reports and in-depth interviews. Interview-related research with former political prisoners for Robben Island Museum by two of the authors of the present study found that the context in which interviews are conducted is critical to the content of an interview. Interviews held while looking at sites on the Island gave very different results from traditional life history interviews. In order to understand what factors influence the research results it may be fruitful to use several different methodologies in the same study, and to try and use different situational contexts for the research as well.

An understanding of popular use of language has been sadly lacking in much of the South African and even the international research on HIV/AIDS stigma (see Czechmeister 1994 on mental illness): content analysis of interviews does not usually investigate the actual terms used around HIV/AIDS, condoms and other related topics. Some literature has focused on media representations (for example, Connelly & MacLeod 2003; Treichler 1999) or ideological frameworks around HIV/AIDS, as mentioned above, but we need more linguistic analysis of local language use (for example, Dowling 2002). More research into the discursive field around HIV/AIDS at a popular level is critical in understanding the nature and content of stigma.

There is a growing literature on the quality of life experienced by people with a stigmatised disease (for example, Mast et al. 2004; Tostes, Chalub & Botega 2004; Manns & Chad 2001 on disability; Suurmeijer, Reuvekamp & Aldenkamp 2001 on epilepsy). Such studies provide a holistic self-reported patient assessment of the impact of specific medical conditions such as HIV/AIDS, and whether healthcare interventions have improved their situation. We have not specifically investigated this research, but note that more work should be done to pair such studies (and those on life chances [Link & Phelan 2001]) with prior research on expected stigmatisation and discrimination and the effects of stigma so that anti-stigma interventions can be more easily assessed.

Although metasynthesis of quantitative data is reasonably well established, the metasynthesis of qualitative data has only recently received significant attention (Sandelowski & Barroso 2003). Given the very large body of qualitative research on HIV/AIDS and the recent publication of methods for conducting metasynthesis of qualitative data, it seems sensible and urgent to begin applying those methods to the southern African literature. Care should be taken, however, in avoiding the assumption that combining qualitative research from different cultural, socio-economic and regional situations will necessarily give useful results. It may just reveal a lowest common denominator that is not helpful in designing effective interventions. Bearing this in mind, however, meta-analytical work should reveal some useful data.

### **Conducting ethical research**

Most of the debates about research ethics have to do with how people acquire informed consent from their survey respondents or interviewees, and whether respondents or interviewees get remunerated in some way for their contributions. We believe that this is an important arena of discussion for qualitative as well as quantitative research projects. It is particularly relevant at a time when there is a great need for social services and grinding poverty across the African continent, but money also needs to be spent on research. Good research is required to direct spending on interventions effectively, but it needs to be sensitive to the great gulf between most academic research projects and the communities within which they operate. In this section we address two related questions that arise specifically out of the work we have read for this literature review, and we note the need to address the question of informed consent in all research projects.

#### **Whom should we research?**

Almost all research on HIV/AIDS stigma so far has focused on the poorest and most marginalised communities (gay men, Latinos and Hispanics in the US, sex workers, poor black women and Africans in South Africa). In Africa, the majority of the population are poor, and most people living with HIV/AIDS are poor. HIV/AIDS is popularly perceived as an illness associated with poverty, with research suggesting that prevalence is higher in poor African communities (Shisana & Simbayi 2002:54), and that susceptibility is linked to poverty and malnutrition.

In both academic and popular discourses on stigma, the framing of HIV/AIDS as an illness associated with poverty (and like most other medical conditions, it disproportionately affects the poor) could reinforce the stereotype that the poor are ignorant. The 'culture of ignorance' debate could thus be accompanied (or even replaced) by theories of the 'culture of poverty' that are used to explain fatalism and thus continued risky behaviour without testing the validity of the theories on a variety of wealthier and culturally different populations (for a critique see Halperin & Allen 2001). If we conduct stigma research only among poor or otherwise marginalised communities, we will further stigmatise the already marginalised (Stein 2003a; see also Halperin & Allen 2001).

HIV/AIDS and related stigmatisation are problems that directly affect all sectors of society. Stigmatisation may have greater impact if it originates in powerful sectors of society that can influence public policy and the media, especially if it is shown that this has an effect on expected stigmatisation and discrimination (Green 1997). For example, Stein (2003b) suggests that government vacillation on HIV/AIDS could have discouraged the media

from taking an explicit advocacy role concerning the problem. Depending on our research questions, we will need to research stigma across different sectors of society, black and white, rich and poor (for example, Marcus 2001), and in both the private and the public health sectors, among PLHA and people who are currently HIV-negative. Public health messages and other interventions can then be focused appropriately and aimed at those areas where they will have greatest impact.

### **How can researchers provide a supportive function for communities?**

Most research focuses on getting results on the research questions and cannot provide support to the community being researched. In doing research in poor and under-resourced communities facing a serious threat from HIV/AIDS, this problem becomes particularly pressing. However good the intentions of researchers, we also need to recognise that engaging with research participants may not always have beneficial effects for the participants, and that any potentially negative effects of this engagement have to be identified, minimised and mitigated.

The contrast between employed, middle-class researchers who gain financial and career benefits out of research, and participants who give of their time without compensation or even receiving the results of the research in an understandable form, is stark. As a result, some projects cover the expenses of participants while others pay individuals for participation. However, paying people for participation may create a perverse incentive for participation, it may create jealousy or cause anger in some communities (Jewkes 2004), and it may cause funding problems with large sample sizes. These problems, and the prohibition of payment in many research ethics guidelines, have steered researchers away from direct payments, although the debate continues to simmer.

Some HIV/AIDS research projects employ previously unemployed HIV-positive people on their projects (for example, the CAPS study conducted by the Aids and Society Research Unit at UCT), training researchers from communities. Others apply for funding to deliver services to communities and then use community participation to refine the project and determine its efficacy (Campbell 2002). Research interventions sometimes provide people with services as part of the research, or improve public policy as a result. For example, one study hoped to strengthen the resilience of children who had lost a parent to HIV/AIDS through an interview process and the construction of memory boxes for the home (Denis & Makiwane 2001). Other memory work done by organisations like the Regional Psycho Support Initiative for the Ten Million Memory Project, such as body mapping and hero books, provide narrative counselling as part of the research (Morgan 2004).

Often, however, the immediate or even the broader needs of the research participants and associated communities are not met by the outcome of the research. A once-off payment may also not be the best way to help people. Enabling participants to gain access to social services from government and NGOs is a possible alternative; making donations to related local projects is another. Facilitating access to services is especially important in an environment where people need assistance, and it is available, but people have difficulty in gaining access to it. A successful Gauteng project on battered women networked with support structures in government and NGOs to provide housing and other support services to participants (Mohlahlane 2004). This kind of intervention could be coupled with a local advice office, where non-participants in the project could

also be assisted for the duration of the project or for as long as funds allowed. Partnerships with existing advice office facilities are thus desirable.

**Conclusion**

We need to review the kinds of findings we seek from survey methods and redesign the surveys accordingly. We also need to couple surveys with qualitative methods, not just to refine the questions but to inform the analysis of the problem at hand. In doing so, we need to expand our range of methodological tools beyond the standard interview and content analysis thereof. Innovative techniques such as PLHA diaries, body maps and stigma mapping can be valuable tools in furthering our understanding of stigma and discrimination. We need to look more widely for methodological tools, combine different methodologies where possible, and where possible, adapt them to local conditions.

To avoid further stigmatising poor communities as the main agents of stigma, we need to research stigma across different sectors of society, black and white, rich and poor. We should also carefully consider how research projects can be better designed to assist participants directly in the course of the research, as well as indirectly by suggesting more effective longer-term interventions.

We can apply these methods to the research agenda developed in the previous chapter as set out in Table 4:

*Table 4: 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 PLHA, and how do PLHA 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 healthcare systems, metasynthesis 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 healthcare systems, metasynthesis of qualitative and quantitative data
How can our theoretical models of stigma be improved?	Theoretical work in conjunction with grassroots observation and consultation

# 10. DEVELOPING MORE EFFECTIVE INTERVENTIONS: PRELIMINARY THOUGHTS



In this chapter we set out some preliminary thoughts about how our theoretical and methodological approaches could be translated into anti-stigma and anti-discrimination interventions. Because we have not yet conducted our research, because there is a relative dearth of literature on anti-stigma interventions, and because we have not fully investigated research on related interventions, the discussion in this chapter is intended to form the basis for future work and debate rather than being our final word on the topic.

Some stigma leads directly to discrimination, other forms of stigmatisation affect PLHA even where they do not necessarily result in discrimination (for example, through internalisation), and discrimination may not be caused only by stigma. Theorising stigma as ideology and separating it analytically from discrimination are both necessary to achieve some clarity on what we are actually measuring and what can be done about it; however, this does not mean that we cannot address stigma and discrimination together, where appropriate or strategic.

The focus on identifying incorrect beliefs has led to the prioritising of interventions that aim to educate the general population and increase their 'tolerance' of people with HIV/AIDS (Brown et al. 2001; Parker and Aggleton 2003: 15–16). We do need to reach the 'general public' but we also need to reach well-educated health workers and families of PLHA. Studies have shown that in many cases PLHA face the greatest discrimination not from the 'ignorant' and 'under-exposed' general public but from family members who have to care for them and from the relatively well-educated group of healthcare workers, especially in resource-poor situations (Bond et al. 2002: 353; Godfrey-Faussett & Ayles 2003: 70; Leasure, McKenney & Merrill 1995; Paiva et al. 2003: 92; Shisana et al. 2003).

Tackling stigma is likely to be a difficult, slow and long-term process, as it has been in relation to racism, sexism and other forms of prejudice. Stigma cannot be eliminated by providing educational materials. Improved access to knowledge about how HIV is transmitted does not prevent people from engaging in risky sexual behaviour (Campbell 2002: 7); neither have educational programmes been very successful in eliminating stigma. The experience of South Africa's Treatment Action Campaign (TAC), as well as AIDS activists in the US, have also demonstrated the important role that developing group identity, self-esteem, rights-based legal and policy frameworks and political activism can play in challenging stigma (Kramer 1994; Lazzarini & Klitzman 2002; Pinel 2002; Puhl & Brownell 2003).

Skinner (2002) sets out a number of possible interventions against stigma in South Africa and the theoretical models underlying them:

- Education (persuasive communication/social marketing);
- Demystification of threat (contact hypothesis/persuasive communication);
- Positive contact/exposure to PLHA (contact hypothesis, social cognitive theory);
- Empowerment of PLHA;
- Development of a spirit of resistance among PLHA; and
- Structural interventions (for example, law).

Because HIV/AIDS poses such an immense range of problems for relatively poor countries in southern Africa, interventions need to be carefully focused in critical areas. Parker and Aggleton (2003) contend that the first three kinds of interventions are somewhat resource-hungry and ineffective in tackling widespread epidemics in poor countries.

They argue that we should prioritise the latter three interventions: empowerment, resistance and structural interventions (2003: 22). However, the work of Patient and Orr (2003) suggests that it is also very important to challenge stigmatising beliefs in the southern African context. Link and Phelan (2001: 381) argue that we can focus interventions on changing stigmatising attitudes held by powerful groups and limiting the opportunities for making stigmatising attitudes dominant in society.

HIV/AIDS stigma is a social phenomenon that changes over time. New treatments and free treatment programmes may change people's attitudes towards HIV as a harbinger of death. At the same time, the increasing number of openly HIV-positive people and HIV/AIDS-related deaths in a mature and generalised epidemic may challenge the idea that HIV/AIDS is associated with the deviant behaviour of promiscuous people. As new benefits are made available for HIV-positive people, those with other illnesses may resent their special status in the public healthcare system.<sup>19</sup> Interventions should thus be paired with ongoing research to assess the impact of anti-stigma and discrimination interventions within a shifting social context, and to redesign them where necessary. This underlines the need for ongoing evaluation of anti-stigma interventions (for example, Visser 2004) in order to modify existing interventions and design future ones. Evaluating anti-stigma interventions falls outside the ambit of this paper, but we review some of the issues raised by the literature that could be useful when designing different interventions or evaluations thereof. In later work we hope to be able to make more concrete suggestions for future interventions.

We should also ensure that we are always focusing on the main barriers to prevention, treatment, care, and the implementation of vaccine trials, in a specific context. Stigmatisation and related discrimination are always only part of the problem, and as one factor becomes a less important barrier, another may take its place. Work in Zambia has indicated that factors affecting care-seeking behaviour for STIs include 'lay referral mechanisms, social cost, availability of care options, economics, beliefs, stigma and quality of care as perceived by the users' (Msisika, Nangawe, Mulenga, Sichone, Kamanga & Kwapa 1997: 248). Such factors may exacerbate the discrimination experienced by PLHA but they cannot be addressed purely by reducing stigma – they may also require changes to the way a clinic is set up, improved relationships between staff and patients, reduced transport problems, incentives for treatment, improved perceptions of the quality of care and so on. Msisika et al. suggest that 'understanding lay persons' perceptions of STI care is critical in the design and implementation of appropriate health services' (1997: 248). Broad interventions at a government level thus need to understand the impact of employment, benefits, housing, the way healthcare services are set up and how they function, support for healthcare workers and patients, as well as educational programmes, on the efficacy of public health programmes in dealing with HIV/AIDS. Interventions to improve access to prevention and treatment facilities need to be able to intervene within this broader context.

Because stigma and discrimination are such complex problems, interventions have to be 'multifaceted', addressing many different mechanisms that disadvantage PLHA, and 'multilevel', dealing with both individual and structural discrimination (Link & Phelan 2001: 381). Interventions must be made by a variety of actors at different levels of society

---

<sup>19</sup> Comments by J Stein on this study.

## DEVELOPING MORE EFFECTIVE INTERVENTIONS

and over different time frames (Sayce 2003 on disability; Campbell 2002: 185; see also Pronyk, Hargreaves, Kim & Makhubele 2001 on the Expanded Microcredit Initiative to reduce vulnerability to HIV infection in the Northern Cape).

We will now provide a brief discussion of some of the main issues relating to anti-stigma interventions covered in the HIV/AIDS stigma literature.

### **Removing barriers to treatment and care**

Klein, Karchner & O'Connell (2002) emphasise the importance of multiple interventions against stigma and the integration of these into the public health system. Insufficient literature currently exists on interventions to remove barriers to treatment and care, a key area of research and intervention proposed by this paper. Once we understand more about the role of stigma and other factors as barriers to treatment and care we can take effective steps to remove or ameliorate their effects. This must include interventions to address stigma and discrimination experienced by PLHA in the public health system, because medical professionals make moral assumptions concerning how they contracted HIV. Before treatment was available, the notion that 'they're going to die anyway', coupled with resource constraints, sometimes led to PLHA being refused admission into, or being offered adequate care in, public health facilities. Now that ARVs have become part of free public health treatment programmes in some southern African countries, this may change, but health professionals may still discriminate against PLHA who are not defined as 'deserving' of treatment: for example, those who continue to have children.<sup>20</sup>

The design of the healthcare system and its treatment programmes affects the impact of stigma on access to treatment. Providing separate clinics for HIV/AIDS treatment forces PLHA to publicly disclose their status by attending the clinic. This may function to reduce stigma, as people realise how widespread the problem is, but it may have less positive effects as well. Some people may not feel comfortable about coming to HIV/AIDS clinics for VCT and ARVs in the current stigmatising climate; while others may resent the special status of PLHA.<sup>21</sup>

### **Promoting disclosure and protecting confidentiality**

Testing and disclosure have been at the centre of de-stigmatising campaigns in South Africa, and have been seen as markers of the degree of stigma around HIV/AIDS. Public healthcare services, especially overburdened in Africa, generally fail to provide confidential treatment. Patients are therefore effectively forced to disclose their status when using public healthcare services. This human rights problem is not receiving sufficient attention because of the emphasis on disclosure as being 'good for everybody' anyway. In South Africa, the public health treatment programme requires PLHA receiving treatment to disclose to a 'treatment buddy' and to come to a special clinic.<sup>22</sup> We need to find ways of assuring confidentiality while promoting and supporting disclosure in both public and private health contexts.

---

20 Comments by J Stein on this study.

21 Comments by J Stein on this study.

22 Comments by J Stein on this study.

### **Developing and enforcing a rights-based approach**

Parker and Aggleton emphasise the need for a rights-based approach to reducing HIV/AIDS-related stigmatisation and discrimination (2003: 21). The public nature of legislation, policy and legal challenges against discrimination can play a very important role in teaching the general population about the nature and consequences of discrimination. Activist groups can play a large role in asserting the rights of PLHA, but they will be more effective if they include government and both HIV-positive and HIV-negative people.

A rights-based approach to managing discrimination includes:

- Developing a human rights-based legal framework defining and protecting the rights of HIV-positive people;
- Ensuring that other public policies and programmes also protect the rights of HIV-positive people;
- Ensuring that discrimination is monitored and challenged at the local level (Bond et al. 2002); and
- Providing education, monitoring and support systems that reach the people who are being discriminated against.

A rights-based approach can help to prevent and challenge discrimination on a large scale (for example, the provision or lack of government benefits, or access to pharmaceuticals) and on an individual scale (for example, doctors refusing care). To be sustainable, however, appropriate education, monitoring and support systems have to reach PLHA who are likely to suffer discrimination, and these systems have to help them challenge the discriminators, while protecting them from harm. After all, uneven power relations are critical to the development of stigmatisation in the first place. Many PLHA may not wish to challenge discrimination since this involves disclosure of HIV-positive status.

The medical system creates a particularly marked status differential between patient and health worker, especially where patients are poor and are being cared for within the public health system. Historically, public healthcare developed out of support systems provided for the 'deserving poor', with little focus on respect for the rights of patients. A rights-based approach to patient care (based on charters of patient rights) or different care provision environments can help to address the problem, but it needs to be monitored and linked to patient mobilisation.

One of the problems with implementing rights-based approaches is that we cannot ensure adherence to the law simply by passing laws. In southern Africa, we generally have an excellent legal framework with which to protect PLHA against discrimination, but implementation lags far behind.

### **Interventions reducing the impact of stigma on PLHA**

In general, public health programmes have neglected interventions directed at HIV-positive people. Most interventions in HIV-prevention have focused on helping HIV-negative people to stay that way. This needs to be rectified, as interventions with HIV-positive people could encourage safe sex behaviour (Patterson & Semple 2003), thereby preventing the spread of HIV. Similar interventions could improve the quality of

## DEVELOPING MORE EFFECTIVE INTERVENTIONS

life of PLHA by reducing the effects of stigma and discrimination on access to testing, treatment and care, as well as other basic rights. Because perceptions of stigma significantly influence PLHA's responses to HIV/AIDS, we also need to reduce expected stigmatisation and discrimination, at the very least by targeting those forms of stigma and discrimination that are of greatest concern to PLHA.

Parker and Aggleton suggest that interventions to reduce the impact of stigma should include 'localized intervention strategies aimed at community mobilization and social change' (2003: 21). What they seem to be suggesting is that PLHA become social activists and lobby for improvements (as the TAC has done on the HIV treatment issue in South Africa), rather than some external authority (government or a project) setting up a collaborative campaign for change, which is the basis for most projects (for example, Campbell 2002). The two models come together in the idea of peer education, as activists could set up projects within communities as well as lobbying government. Of course, the intervention would be most effective if HIV-negative people joined PLHA as activists against stigma.

The difference between mobilisation and education is that mobilisation empowers people to fight for their rights, however these may be defined, while education tells people what they are doing wrong but does not necessarily give a framework for action beyond the individual level (see Freire 1970). Ultimately, change is required at both individual and social levels, but what Parker and Aggleton seem to be suggesting is that fostering an activist identity, based on an assertion that PLHA deserve certain rights but are being denied them, can help to reduce the range and effects of HIV/AIDS stigmatisation.

The literature suggests that both the development of HIV-positive group identities, and group work with PLHA, can play a positive role in addressing HIV/AIDS stigma, both at the level of HIV-positive individuals and at a broader social level. Group work can help PLHA to challenge stigmatising attitudes and avoid self-stigmatisation. People with socially stigmatised conditions, like obesity or HIV/AIDS, that are perceived as resulting from a lack of self-control are more likely to suffer self-blame and low self-esteem, especially if they accept this explanation of their own condition (Crocker & Major 1989 and Crocker 1999 in Puhl & Brownell 2003: 59–60). Self-protective methods may only be useful if a stigmatised person feels that his or her stigma is linked to a meaningful group identity (Puhl & Brownell 2003: 59 on overweight people). Groups of similarly stigmatised individuals can increase self-esteem by reducing stigmatising encounters, exposing individuals to different ideologies about AIDS, providing social support, and establishing a positive collective identity (Siegal et al. 1998 in Puhl & Brownell 2003: 59).

However, work on cancer self-help groups suggests that their impact on reducing stigma was less important and substantial than their information procurement and distribution function. Although the groups were able to substitute for some missing or disturbed interpersonal relationships, isolation from families was harder to address through group work (Schaeffer & Garms-Homolova 1986). Also, as Tunnell (1991) pointed out, the highly variable course of illness, and stigma related to the illness can seriously interfere with establishing and maintaining group cohesion in HIV/AIDS support groups.

Berbrier (2002) shows that groups of people who share a stigmatised status can change this into a valued status by portraying their group as resembling other, more established,

minorities. In the US case, most such groups assert similarity to African Americans and incorporate civil rights themes. For example, homosexual men in the US claimed minority status alongside racial and religious minorities as early as 1963, resisting the medicalisation and pathologisation of homosexual behaviour (Berbrier 2002: 567). Berbrier (2002: 573) thus concludes that when stigmatised groups restyle themselves as minorities they become non-deviant, and can be accepted within the multicultural model of society, without having to change their identity.

There has been a relatively long history of gay activism in the US (Kramer 1994). In spite of a long and august history of human rights activism around race, HIV-positive gay men seem to have had greater success in addressing AIDS issues than minorities such as African Americans, or, less surprisingly, than intravenous drug-users or commercial sex workers. South Africa does have a strong historical tradition of community mobilisation on political issues, but government vacillation on addressing the epidemic as a priority, and the lack of a single understanding of the problem within government, may create divided loyalties among activists. Can HIV-positive people in South Africa represent themselves as a group and use this self-categorisation to fight for normalisation of status and for access to care? In this regard, what are the implications of the reality that HIV-positive people in South Africa constitute a significantly large group, not a minority?

### **Educational interventions**

Interventions to reduce stigma have tended to focus on educating people by providing medically correct information about HIV/AIDS. We do need to challenge stigmatising beliefs and correct misconceptions about HIV/AIDS, but education does not address stigma very effectively. Stigma is not primarily a problem of ignorance and cannot be shifted by telling people that what they believe is wrong. In earlier chapters, we defined stigma as an emotional response to danger that helps to make people feel safer – it is not a rational or even conscious process, which explains why it is not easily modified through education (Joffe 1999).

Educational programmes may have a role to play in challenging stigmatising beliefs, and informing PLHA about rights and services. Education also seems to have some effect on whether people express stigmatising views or not in surveys (Brown et al. 2001; Visser et al. 2004). However, because of the way most research has defined stigma, these studies may be measuring changing perceptions about the acceptability of expressing stigmatising attitudes or reduced levels of intended discrimination based on fear of infection, rather than stigma as we have defined it. In Chapter 6 we suggested that intended discrimination based on an inflated fear of contracting HIV is not always due to stigma. Such fears may indeed be mediated by education as Herek (2002) suggests, however, thus possibly reducing discrimination against PLHA, if not stigma as such.

The most effective educational interventions take local contexts and meanings associated with HIV/AIDS into account, are community-based, and are linked to skills-building, counselling and social interaction programmes (Brown et al. 2001). Brown et al. (2001) examined 22 studies that documented strategies for the reduction of HIV/AIDS stigma. They found that the following methods were most often used:

- An information/education/communications-based approach – the most common approach – provided information about HIV/AIDS in a didactic manner, with an emphasis on the idea that PLHA should not be blamed for their condition;

## DEVELOPING MORE EFFECTIVE INTERVENTIONS

- A skills-building approach, which entailed teaching individuals how to resolve conflict at individual or group levels, as well as coping skills for hypothetical contact with PLHA;
- Counselling, which involved providing information and emotional support to PLHA through support groups; and
- Contact between the general population and PLHA in the form of a media message or real interaction.

Brown et al. (2001) noted that it was difficult to generalise from the studies in terms of effectiveness when small samples were used and long-term impacts could not be observed. They also found that, in the majority of studies, impacts were limited or superficial. They concluded that multiple interventions in combination were advisable, given that no single approach to reduce stigma was clearly more effective than others.

Where educational programmes are offered, they should be part of a broader community programme (including peer education, VCT, counselling, STI clinics). People may be more likely to express stigmatising views, and discriminate based on these views, if they believe these views are widely shared and openly or tacitly accepted in society. In terms of content, such programmes need to go beyond correcting misconceptions about HIV/AIDS and fostering self-esteem, although these are important issues to address. Educational interventions need to teach people that stigma is a social problem, not a problem of individual ignorance. The links between social prejudice, socio-economic power relations and disease should be explicitly discussed. Using historical examples of discrimination against people with other diseases, such as leprosy, that are not currently a threat in this country, may provide some insight into the social nature of stigmatisation.

### Community projects

Community-level projects are often seen as the most manageable and effective level of intervention against a pandemic such as HIV/AIDS (see Ramirez-Valles 2002). They are local enough to allow the implementation of medium-term interventions with reasonable budgets. Campbell (2002) points out that, even though they are an essential corrective to the largely individualistic approaches of the past, it is very difficult to develop effective community-based interventions. They require the full support of different sectors of society, who often have competing interests and priorities, are unwilling to view the problem in a new light, and have a vested interest in maintaining the status quo (Campbell 2002: 188). To succeed, such projects need broad-ranging commitment, a shared holistic and innovative conceptual framework, sufficient infrastructure, capacity, and accountability (Campbell 2002: 189–191). For community-based interventions to work on a large scale, they also need to address both middle-class communities that perceive themselves to be at low risk, and marginalised or disempowered communities that express fatalism and denial about their level of risk.

Communities need to be mobilised in different ways to fight HIV/AIDS for the good of the whole community. Discussions about the consequences of contracting HIV/AIDS should be frankly dealt with in educational programmes, but both overly positive and overly negative representations of the consequences of HIV infection should be avoided (Soskolne et al. 2003). Peer-to-peer discussion and observations about the negative consequences of HIV infection might be more successful in drawing in the wider

community than discussions that only focus on sexual behaviour (Low-Beer & Stoneburner 2003). Programmes have to include discussions of positive ways to deal with the problems associated with HIV infection, and counter an overly negative view of the future by representing HIV/AIDS as a chronic, rather than as a terminal, condition.

### **Adapting public health messages**

One of the most worrying findings of the literature was that public health messages, such as the ABC campaigns and the association of AIDS with death, sometimes deepen stigmatisation of HIV/AIDS (Skinner 2002; Stein 2003a). Likewise, public health messages that suggest that HIV/AIDS prevention is a personal responsibility can encourage blaming of PLHA (Herek et al. 1996).

The close relationship between AIDS and sex is a major source of stigmatisation, and it is being reinforced by the almost exclusive focus of researchers on sexual transmission and sexual mores. Although sex is a key mode of transmission, it is not the only one. In spite of suggestions by Packard and Epstein (1992) that re-use of infected needles in Africa (for example, in healthcare settings and of course in drug-injecting populations) may be a major vector, insufficient attention is currently being paid to exploring whether vectors other than sexual transmission may be critical in spreading HIV/AIDS, and what to do about it (Brody et al. 2003; Gisselquist et al. 2003). If sterilisation is only available in 65 per cent of hospitals in South Africa over 75 per cent of the time (Shisana et al. 2003: 102), and if sufficient and consistent supplies of sterilised needles are not available, people in hospital may be at risk of contracting HIV through unsterilised needles.

Discussing more 'neutral' vectors may open up debate on HIV/AIDS in communities where talking about sex is traditionally considered a private matter. On the other hand, public health officials could rightly fear that talking about transmission via dirty needles may link public health services with the transmission of HIV, and thus create barriers to general medical treatment. Nevertheless, public health campaigns need to educate the general public (not just intravenous drug-users) about the need to ensure that sterilised or new needles are being used in clinics and hospitals for their relatives and themselves.

The growing trade in, and use of, 'street' drugs in developing countries such as South Africa will increase the probability of HIV-transmission among intravenous drug-users. Alcohol use is also a co-factor in HIV-transmission (Jooste 2004). However, the association of vulnerability to HIV infection with the use of drugs and alcohol may open up new modes of stigmatisation if public health messages concerning these issues are not handled correctly (Brown et al. 2001: 2). It may increase the stigma associated with HIV/AIDS because people conflate the cause of HIV (unprotected sex or unsafe needles) and factors that make people more likely to engage in these practices (misuse of drugs or alcohol).<sup>23</sup>

We need to find ways to challenge existing norms and stereotypes relating to HIV/AIDS and sexual transmission, using our research about the content of stereotyping and stigmatisation, their histories and politics and the social contexts in which they occur. In doing this we need to focus on men as well as women, the wealthy as well as the poor. Although initially most HIV-prevention research and public health interventions focused

---

<sup>23</sup> Comments by J Stein on this study.

on getting women to negotiate condom use with men, more recent research has begun to focus on norms of masculinity and how to shift male attitudes towards safer sex practices (for example, MacPhail 2003).

### Conclusion

Sayce concludes about interventions to reduce stigma and related discrimination against disabled people that we need to:

use a combination of law, particularly systemic powers like investigations, and interventions in public debate. Influence the beliefs of people who have the power to discriminate and support those prepared to promote positive change. Do not bother to downplay differences between disabled and non-disabled people, but do value the difference positively. Stimulate open debate about different experiences of discrimination. Make inclusion happen because inclusion changes attitudes and behaviours. Most importantly, address power. Do not get seduced by the naïve view that 'informing' or 'educating' people will change their attitudes, let alone their behaviour: why should it, unless you have carefully analysed their motivations? Do not make the opposite error – that law alone will bring the depth of change sought. Why should it when it is framed and interpreted in the context of a discriminatory culture? Where research is lacking there is a need to identify levers for change, test approaches and share learning, so the work is continually refined. Good intentions are not enough. (2003: 640)

The same kinds of points apply equally to interventions to reduce HIV/AIDS stigma. 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 limit its impact while chipping away at the fears that support it, and taking advantage of broader trends that may shift some of the power relationships and beliefs that entrench it. As with racism or sexism, there is no magic bullet that can eliminate 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 – as recommended by Sayce – is a crucial step in developing more effective interventions. We must not assume that PLHA alone should carry the burden of activism against stigma. We need to focus on the main problems facing us in relation to HIV/AIDS: barriers to prevention, treatment and care, discrimination against PLHA, and the difficulties and 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 concentrate 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 PLHA responses to stigmatisation (and other challenges posed by the social and medical context of HIV/AIDS), the focus will be on removing as many barriers to prevention, treatment and care as we can (such as confidentiality), rather than blaming lack of access on maladaptive responses to stigmatisation. We can focus on reducing opportunities for discrimination against PLHA, and on reducing the impact of discrimination when it occurs, whatever its cause.



# GLOSSARY

ABC	An HIV/AIDS prevention campaign: Abstain, Be faithful, Condomise.
ARV	Antiretroviral drugs, such as AZT and Nevirapine, can be used to treat people who have been infected with HIV. Nevirapine can be taken by HIV-positive pregnant women to prevent the transmission of the virus to their unborn children.
Functionalist arguments	Arguments in which the effects of something are also defined as its cause, or an essential part of its nature. Functionalist arguments are limiting because, as circular arguments, they are teleological and non-disprovable.
HAART	Highly Active Antiretroviral Therapy, a treatment programme using ARVs, that prolongs survival in people with HIV/AIDS. It has been available in the USA since 1996.
HIV/AIDS	The Human Immunodeficiency Virus, identified in 1983, that causes Acquired Immune Deficiency Syndrome, first identified in Los Angeles in the US in 1981. The virus is transmitted in blood, semen, and other body fluids. It is mainly transmitted by unprotected sexual activity.
Instrumental stigma	Stigma that arises from utilitarian self-interest, for example fear of infection with a fatal disease or a fear that people living with HIV/AIDS will consume too many resources (Herek 2002). In this paper we redefine instrumental stigma as intended discrimination based on inflated risk of infection or on resource concerns, and suggest that combining these two issues in the same category is not very useful.
Internalisation	Also called self-stigmatisation, this involves accepting some of the stigmatising judgements of one's identity.
Perceived stigma	The stigma people expect from others should they be known to be HIV-positive. In this paper we prefer the term 'expected stigmatisation and discrimination', as people living with HIV/AIDS experience stigma and discrimination as intertwined, and we do not wish to suggest that people living with HIV/AIDS necessarily perceive something that is not there.
Social control theory	A theory dominant in the fields of criminology and sociology, that understands human behaviour as being regulated by social controls (such as institutions, practices, beliefs) to perform activities fulfilling social needs, sometimes at the expense of individual needs. As sociologists have become more critical of society, they have understood social control as operating to the advantage of dominant members of society (for example, by perpetuating social inequalities).

## GLOSSARY

---

Stigma	Disease stigma can be defined 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. Disease stigma is negative social 'baggage' associated with a disease that is: (a) generated by the stigmatisation process; and (b) not justified by the medical effects of the disease on the human body (e.g. higher morbidity).
Stigmatisation	Disease stigmatisation can be defined as a social process by which people use shared social representations to distance themselves and their ingroup from the risk of contracting a disease by: (a) constructing it as preventable or controllable; (b) identifying 'immoral' behaviours causing the disease; (c) associating these behaviours with 'carriers' of the disease in other groups; and (d) thus blaming certain people for their own infection and justifying punitive action against them.
Symbolic stigma	Stigma that arises from value-based ideology that imposes moral judgements on others to affirm the ingroup's safe and moral identity (Herek 2002). For example, symbolic stigma involves blaming people for getting infected with HIV because they are homosexual or use drugs. In this paper we suggest that symbolic stigma be simply defined as stigma.
TAC	The Treatment Action Campaign is an AIDS activist group that was launched in 1998. Its main objective is to campaign for greater access to HIV treatment for all South Africans, by raising public awareness and understanding about issues surrounding the availability, affordability and use of HIV treatments.



# REFERENCES

- Allen DM (2001) Beyond the HIV/AIDS/STD Strategic Plan for South Africa, 'AIDS in Context' Conference, University of the Witwatersrand, 4–7.
- Alonzo AA & Reynolds NR (1995) Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory, *Social Science & Medicine* 41(3): 303–315.
- Angermeyer MC & Matschinger H (2003) The stigma of mental illness: Effects of labelling on public attitudes towards people with mental disorder, *Acta Psychiatrica Scandinavica* 108(4): 304–309.
- Antai-Otong D (2002) Culturally sensitive treatment of African Americans with substance-related disorders, *Journal of Psychosocial Nursing and Mental Health Services* 40(7): 14–21.
- Arboleda-Florez J (2003) Considerations on the stigma of mental illness, *Canadian Journal of Psychiatry* 48(10): 645–650.
- Arnold D (1986) Cholera and colonialism in British India, *Past and Present* (113): 118–151.
- Ashforth A (2001) AIDS, witchcraft, and the problem of public power in post-apartheid South Africa, Paper delivered at the 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April 2001.
- Barth KR, Cook RL, Downs JS, Switzer GE & Fischhoff B (2002) Social stigma and negative consequences: Factors that influence college students' decisions to seek testing for sexually transmitted infections, *Journal of American College Health* 50(4): 153–159.
- Bayer R & Oppenheimer GM (2000) *AIDS doctors: Voices from the epidemic*. Oxford: Oxford University Press.
- Berbrier M (2002) Making minorities: Cultural space, stigma transformation frames and the categorical status claims of deaf, gay and white supremacist activists in late twentieth-century America, *Sociological Forum* 17(4): 553–591.
- Berger BE, Ferrans CE & Lashley FR (2001) Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale, *Research in Nursing & Health* 24(6): 518–529.
- Bishop GD, Oh HM & Swee HY (2000) Attitudes and beliefs of Singapore health care professionals concerning HIV/AIDS, *Singapore Medical Journal* 41(2): 55–63.
- Black BP & Miles MS (2002) Calculating the risks and benefits of disclosure in African American women who have HIV, *Journal of Obstetric, Gynaecologic, and Neonatal Nursing* 31(6): 688–697.
- Bollinger L (2002) Stigma: Literature review of general and HIV-related stigma, Draft POLICY project report, Washington.

## REFERENCES

- Bond V, Chase E & Aggleton P (2002) Stigma, HIV/AIDS and prevention of mother-to-child transmission in Zambia, *Evaluation and Program Planning* 25: 347–356.
- Bos AE, Kok G & Dijker AJ (2001) Public reactions to people with HIV/AIDS in the Netherlands, *AIDS Education Preview* 13(3): 219–228.
- Botnick MR (2000) Part 1: HIV as ‘the line in the sand’, *Journal of Homosexuality* 38(4): 39–76.
- Boulton M (1994) *Challenge and innovation: Methodological advances in social research on HIV/AIDS*. London: Taylor and Francis.
- Brandt AM (1988) The syphilis epidemic and its relation to AIDS, *Science* 239 (4838): 375–380.
- Brashers DE, Neidig JL, Reynolds NR & Haas SM (1998) Uncertainty in illness across the HIV/AIDS trajectory, *Journal of the Association of Nurses in AIDS Care* 9(1): 66–77.
- Breakwell G & Fife-Schaw C (1994) Using longitudinal cohort-sequential designs to study changes in sexual behaviour, in M Boulton (ed.) *Challenge and innovation: Methodological advances in social research on HIV/AIDS*. London: Taylor and Francis.
- Brody S, Gisselquist D, Potterat JJ & Drucker E (2003) Evidence of iatrogenic HIV transmission in children in South Africa, *Bjog-An International Journal of Obstetrics and Gynaecology* 110(5): 450–452.
- Brown L, Trujillo L & Macintyre K (2001) *Interventions to reduce HIV/AIDS stigma: What have we learned?* New Orleans: Horizons Program/Tulane School of Public Health and Tropical Medicine.
- Bunting SM & Seaton R (1999) Health care participation of perinatal women with HIV: What helps and what gets in the way? *Health Care Women International* 20(6): 563–578.
- Campbell C (2001) HIV/AIDS research in South Africa: Developing theory through action and for action, Plenary address at the ‘AIDS in Context’ Conference, University of the Witwatersrand, 4–7 April 2001.
- Campbell C (2002) *Letting them die: How HIV/AIDS prevention programmes often fail*. Oxford: James Currey.
- Campbell C, Foulis CA, Maimane S & Sibiya Z (2005) ‘I have an evil child at my house’: Stigma and HIV/AIDS management in a South African community, forthcoming in *American Journal of Public Health* 1–31.
- Carton B (2003) The forgotten compass of death: Apocalypse then and now in the social history of South Africa, *Journal of Social History* 37(1): 199–218.

## UNDERSTANDING HIV/AIDS STIGMA

- Chandra P, Deepthivarma S & Manjula V (2003) Disclosure of HIV infection in South India: Patterns, reasons and reactions, *AIDS Care – Psychological and Socio-Medical Aspects of AIDS/HIV* 15(2): 207–215.
- Chapman L (1998) Body image and HIV: Implications for support and care, *AIDS Care* 10(2): S179–S187.
- Charalambous S, Grant AD, Day JH, Rothwell E, Chaisson RE, Hayes RJ & Churchyard GJ (2004) Feasibility and acceptability of a specialist clinical service for HIV-infected mineworkers in South Africa, *AIDS Care* 16(1): 47–56.
- Cinnirella M & Loewenthal KM (1999) Religious and ethnic group influences on beliefs about mental illness: A qualitative interview study, *British Journal of Medical Psychology* 72(4): 505–524.
- Clark HJ, Lindner G, Armistead L & Austin BJ (2003) Stigma, disclosure and psychological functioning among HIV-infected and non-infected African-American women, *Women and Health* 38(4): 57–71.
- Collins T (2001) Sense and sensibility: Towards a conceptual framework for bridging the ‘gap’ between knowledge and sexual practice, Paper delivered at the ‘AIDS in Context’ Conference, University of the Witwatersrand, 4–7 April 2001.
- Connelly M & MacLeod C (2003) Waging war: Discourses of HIV/AIDS in South African media, *African Journal of AIDS Research* 2(1): 63–73.
- Corrigan PW & Penn DL (1999) Lessons from social psychology on discrediting psychiatric stigma, *American Psychologist* 54(9): 765–776.
- Coughlan M (2003) Pain and palliative care for people living with HIV/AIDS in Asia, *Journal of Pain and Palliative Care Pharmacotherapy* 17(3–4): 91–104.
- Coxon APM (1994) Diaries and sexual behaviour: The use of sexual diaries as method and substance in researching gay men’s response to HIV/AIDS. In M Boulton (ed.) *Challenge and innovation: Methodological advances in social research on HIV/AIDS*. London: Taylor and Francis.
- Crandall CS & Glor J (1997) AIDS-related stigmatization: Instrumental and symbolic attitudes, *Journal of Applied Social Psychology* 27(2): 95–123.
- Crawford AM (1996) Stigma associated with AIDS: A meta-analysis, *Journal of Applied Social Psychology* 26(5): 398–416.
- Crawford R (1994) The boundaries of the self and the unhealthy other: Reflections on health, culture and AIDS, *Social Science & Medicine* 38(10): 1347–1365.
- Crewe M (1992) *AIDS in South Africa*. Harmsworth: Penguin.

## REFERENCES

- Crewe M & Aggleton P (2003) Racism, HIV/AIDS and Africa: Some issues revisited, *South African Journal of International Affairs* 10(1): 139–149.
- Czechmeister CA (1994) Metaphor in illness and nursing: A two-edged sword. A discussion of the social use of metaphor in everyday language, and implications of nursing and nursing education, *Journal of Advanced Nursing* 19(6): 1226–1233.
- Davenport-Hines R (1990) *Sex, death and punishment: Attitudes to sex and sexuality in Britain since the Renaissance*. London: Collins.
- Davies P (1994) Acts, sessions and individuals: A model for analysing sexual behaviour, in M Boulton (ed.) *Challenge and innovation: Methodological advances in social research on HIV/AIDS*. London: Taylor and Francis.
- Dawes RC (2003) Investigating the interface between health system reform and HIV/AIDS in sub-Saharan Africa, *African Journal of AIDS Research* 2(1): 23–31.
- Day JH (2003) Attitudes to HIV voluntary counselling and testing among mineworkers in South Africa: Will availability of antiretroviral therapy encourage testing? *AIDS Care* 15(5): 665–672.
- De Visser RO & Smith MA (2000) When always isn't enough: Implications of the late application of condoms for the validity and reliability of self-reported condom use, *AIDS Care* 12(2): 221–4.
- Deacon HJ (1994) A history of the medical institutions on Robben Island, 1846–1910, PhD thesis, University of Cambridge.
- Delius P & Glaser C (2001) Sexual socialisation in historical perspective, 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April.
- Denis P & Makiwane N (2001) Oral history in the context of Aids: Memory boxes as a way of building up resilience in orphans and traumatised children in KwaZulu-Natal, Paper delivered at the 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April 2001.
- Douglas M (1970) *Purity and danger: An analysis of concepts of pollution and taboo*. Harmondsworth: Penguin.
- Dowling T (2002) *UQedisizwe* – The finisher of the nation: Naming and talking about HIV/AIDS in African languages, unpublished article, African Voices.
- Eastwood SV & Hill PC (2004) A gender-focused qualitative study of barriers to accessing tuberculosis treatment in the Gambia, West Africa, *International Journal of Tuberculosis and Lung Disease* 8(1): 70–75.
- Eliason MJ (1993) AIDS-related stigma and homophobia: Implications for nursing education, *Nurse Educator* 18: 27–30.

- Epprecht M (2001) *Umteto ka sokisi*: 'The rules of mine marriage' and the sexual content of male-male sexual relationships in early 20th century southern Africa, 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April.
- Epstein S (1996) *Impure science: AIDS, activism and the politics of knowledge*. Berkeley: University of California Press.
- Etiebet MA, Fransman D, Forsyth B, Coetzee N & Hussey G (2004) Integrating prevention of mother-to-child HIV transmission into antenatal care: Learning from the experiences of women in South Africa', *AIDS Care* 16(1): 37–46.
- Fanon F (1986) *Black skin, white masks*. London: Pluto Press.
- Fassin D (2002) 'Embodied history. Uniqueness and exemplarity of South African AIDS', *African Journal of Aids Research* (1): 63–68.
- Fee E & Fox D (eds.) (1992) *AIDS: The making of a chronic disease*. Berkeley: University of California Press.
- Fife BL & Wright ER (2000) The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer, *Journal of Health & Social Behavior* 41(1): 50–67.
- Figueira M (2000) Development of notification policy in Namibia, *Sexual Health Exchange* (1): 15–16.
- Foege WH (1988) Plagues: Perceptions of risk and social responses, *Social Research* 55(3): 331–42.
- Foote-Ardah CE (2003) The meaning of complementary and alternative medicine practices among people with HIV in the United States: Strategies for managing everyday life, *Sociology of Health & Illness* 25(5): 481–500.
- Fox DM & Fee E (1988) *AIDS: The burdens of history*. Berkeley: University of California Press.
- Fox S, Nkosi Z & Kistner U (2003) *Gender-based violence and HIV/AIDS in South Africa: A bibliography*. South Africa: Department of Health.
- Frale DE, Wortman C & Joseph J (1997) Predicting self-esteem, well-being, and distress in a cohort of gay men: The importance of cultural stigma, personal visibility, community networks, and positive identity, *Journal of Personality* 65(3): 599–624.
- France N (2001) Stigma and HIV/AIDS in Africa. Review issues and responses based on literature review, focus group discussions and Stigma-AIDS email discussion forum.
- Freeman M & Nkomo N (2004) Coping psychologically with HIV/AIDS – supportive and aggravating factors, HSRC Research Conference, Birchwood, South Africa, 27–28 July.

## REFERENCES

- Freire P (1970) *Pedagogy of the oppressed*. New York: The Seabury Press.
- Gear S (2001) Sex, sexual violence and coercion in men's prisons, 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April.
- Gee JP (1988) Discourse systems and aspirin bottles: On literacy, *Journal of Education* 170(1): 27–40.
- Gee JP (1989) The legacies of literacy: From Plato to Freire through Harvey Graff, *Journal of Education* 171(1): 147–165.
- Gilbert L & Walker L (2002) Treading the path of least resistance: HIV/AIDS and social inequalities – a South African case study, *Social Science & Medicine* 54(7): 1093–1110.
- Gilman S (1985) *Difference and pathology: Stereotypes of sexuality, race and madness*. Ithaca: Cornell University Press.
- Gisselquist D, Potterat JJ, Brody S & Vachon F (2003) Let it be sexual: How health care transmission of AIDS in Africa was ignored, *International Journal of STD and Aids* 14(3): 148–161.
- Godfrey-Faussett P & Ayles H (2003) Can we control tuberculosis in high HIV prevalence settings? *Tuberculosis* 83: 68–76.
- Goffman E (1963) *Stigma: Notes on the management of spoiled identity*. New Jersey: Prentice Hall.
- Goldin CS (1994) Stigmatization and AIDS: Critical issues in public health, *Social Science & Medicine* 39(9): 1359–1366.
- Good B (1994) *Medicine, rationality, and experience: An anthropological perspective*. Cambridge: Cambridge University Press.
- Goyer KC & Gow J (2002) HIV/AIDS policies, practices and conditions in South African prisons: Criticisms and alternatives. Towards a research agenda, *African Journal of AIDS Research* 1(1): 69–74.
- Green G (1995) Attitudes towards people with HIV: Are they as stigmatizing as people with HIV perceive them to be? *Social Science & Medicine* 41(4): 557–568.
- Green G & Rademan P (1997) Evangelical leaders and people with HIV, *AIDS Care* 9(6): 715–726.
- Grossman AH (1991) Gay men and HIV/AIDS: Understanding the double stigma, *Journal of the Association of Nurses in AIDS Care* 2(4): 28–32.
- Grundlingh L (1999) HIV/AIDS in South Africa: A case of failed responses because of stigmatization, discrimination and morality, 1983–1994, *New Contree* 46: 55–81.

## UNDERSTANDING HIV/AIDS STIGMA

- Gugani A & Ukeje MA (1993) A study on existing knowledge about AIDS among undergraduates of a Nigerian university, *Journal of Communicable Diseases* 25(2): 52–56.
- Gussow Z (1989) *Leprosy, racism and public health: Social policy in chronic disease control*. Boulder: Westview Press.
- Hackl KL, Somlai AM, Kelly JA & Kalichman SC (1997) Women living with HIV/AIDS: The dual challenge of being a patient and caregiver, *Health and Social Work* 22(1): 53–62.
- Halperin D & Allen A (2001) Is poverty the root cause of (Southern) African AIDS? 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April.
- Hayes RA, Vaughan C, Medeiros T & Dubuque E (2002) Stigma directed toward chronic illness is resistant to change through education and exposure, *Psychological Reports* 90(3 Pt 2): 1161–1173.
- Heald S (2002) It's never as easy as ABC: Understandings of AIDS in Botswana, *African Journal of AIDS Research* 1(1): 1–10.
- HDN (Health & Development Networks) & UNAIDS (2001) Stigma and HIV/AIDS in Africa: Setting the operational research agenda, Retrieved from <http://www.hdnet.org/library/Operational%20Research%20Agenda%20for%20HIVAIDS%20in%20Africa.pdf>.
- Heckman TG, Somlai AM, Peters J, Walker J, Otto-Salaj L, Galdabini CA & Kelly JA (1998) Barriers to care among persons living with HIV/AIDS in urban and rural areas, *AIDS Care* 10(3): 365–375.
- Herek GM (1986) The instrumentality of attitudes: Towards a neofunctional theory', *Journal of Social Issues* 42: 99–114.
- Herek GM (2002) Thinking about AIDS and stigma: A psychologist's perspective, *Journal of Law, Medicine and Ethics* 30: 594–607.
- Herek GM & Capitanio JP (1994) Conspiracies, contagion, and compassion: Trust and public reactions to AIDS, *AIDS Education and Prevention: Official publication of the International Society for AIDS Education* 6(4): 365–375.
- Herek GM & Capitanio JP (1998) Symbolic prejudice or fear of infection? A functional analysis of AIDS-related stigma among heterosexual adults, *Basic and Applied Social Psychology* 20(3): 230–241.
- Herek GM, Capitanio JP & Widaman KF (2002) HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991–1999, *American Journal of Public Health* 92: 371–377.

## REFERENCES

- Herek GM, Mitnick L, Burris S, Chesney M, Devine P, Fullilove MT, Fullilove R, Gunther HC, Levi J, Michaels S, Novick A, Pryor J, Snyder M & Sweeney T (1996) Workshop report: AIDS and stigma: A conceptual framework and research agenda. Later published in 1998 in *AIDS Public Policy Journal* 13(1): 36–47.
- Hergovich A, Ratky E & Stollreiter M (2003) Attitudes toward HIV-positives in dependence on their sexual orientation, *Swiss Journal of Psychology* 62(1): 37–44.
- Heywood M (2002) 'Chaffed and waxed sufficient': Drug access, patents and global health, *Third World Quarterly, Journal of Emerging Areas*: 1–19.
- Hoosen S & Collins A (2001) Women, culture and AIDS: How discourses of gender and sexuality affect safe sex behaviour, 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April.
- Huang KH, Watters JK & Case P (1988) Psychological assessment and AIDS research with intravenous drug users: Challenges in measurement, *Journal of Psychoactive Drugs* 20(2): 191–195.
- Hunter M (2001) The ambiguity of AIDS 'awareness' and the power behind forgetting: Historicizing and spatializing inequality in Mandeni, KwaZulu-Natal, Paper delivered at the 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April.
- Hunter SS (2003) *Who cares? AIDS in Africa*. New York: Palgrave MacMillan.
- ICRW (2002) *Understanding HIV-related stigma and resulting discrimination in sub-Saharan Africa. Emerging themes from early data collection in Ethiopia, Tanzania and Zambia*, Research Update.
- Ignatieff M (1983) State, civil society and total institutions: A critique of recent social histories of punishment, in S Cohen & AT Scull (eds.) *Social control and the state: Historical and comparative essays*. Oxford England: M. Robertson.
- Ingram D & Hutchinson SA (1999a) Defensive mothering in HIV-positive mothers, *Qualitative Health Research* 9(2): 243–258.
- Ingram D & Hutchinson SA (1999b) HIV-positive mothers and stigma, *Health Care Women International* 20(1): 93–103.
- Janowitz M (1975) Sociological theory and social control, *American Journal of Sociology* 81(1): 82–108.
- Jeeves A (2001) Public health and epidemiology in the era of South Africa's VD pandemic of the 1930s and 1940s, 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April.
- Jennings R, Mulaudzi J, Everatt D, Heywood M & Richter M (2002) Discrimination and HIV/AIDS, Paper for the Department of Health written by Strategy & Tactics and the AIDS Law Project. See [http://www.alp.org.za/resctr/rpapr/pdf/200210\\_Reserch.pdf](http://www.alp.org.za/resctr/rpapr/pdf/200210_Reserch.pdf).

- Jewkes R (2004) What is innovative research? Presentation to the 'Conceptualising the AIDS Museum' Conference, University of the Witwatersrand, 1–2 November 2004.
- Jewkes RK, Levin JB & Penn-Kekana LA (2003) Gender inequalities, intimate partner violence and HIV preventive practices: Findings of a South African cross-sectional study, *Social Science & Medicine* 56: 125–134.
- Jobson MD & Wyckhoff-Wheeler DL (n.d.) Intersections and constructions of gender and HIV/AIDS, Institute for Women's and Gender Studies, University of Pretoria. <http://iweb.hsrc.ac.za/GenderNetwork/OCC1.doc>.
- Joffe H (1999) *Risk and 'the other'*. Cambridge: Cambridge University Press.
- Jones EE, Farina A, Hastorf AH, Markus H, Miller DT & Scott RA (1984) *Social stigma: The psychology of marked relationships*. New York: WH Freeman.
- Jooste S (2004) Alcohol use and sexual risks for HIV infection among men and women receiving sexually transmitted infection services in Cape Town, South Africa, HSRC Research Conference 2004, Birchwood, South Africa, 27–28 July.
- Kai J & Crosland A (2001) Perspectives of people with enduring mental ill health from a community-based qualitative study, *British Journal of General Practice* 51(470): 730–736.
- Kalichman SC & Simbayi LC (2003) HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa, *Sexually Transmitted Infections* 79(6): 442–447.
- Kalichman SC & Simbayi L (2004) Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa, *AIDS Care* 16(5): 572–580.
- Katz A (2002) AIDS, individual behaviour and the unexplained remaining variation, *African Journal of AIDS Research* 1(2): 125–142.
- Kelly B, Raphael B, Statham D, Ross M, Eastwood H, McLean S, O'Loughlin B & Brittain K (1996) A comparison of the psychosocial aspects of AIDS and cancer-related bereavement, *International Journal of Psychiatry in Medicine* 26: 35–49.
- Kelly JA, St Lawrence JS, Smith S Jr, Hood HV & Cook DJ (1987) Stigmatization of AIDS patients by physicians, *American Journal of Public Health* 77(7): 789–791.
- Keogh P, Beardsell S & Sigma Research (1997) Sexual negotiation strategies of HIV-positive gay men: A qualitative approach, in P Aggleton, P Davies & G Hart (eds.) *AIDS: Activism and alliances*. London: Taylor & Francis.
- Kilewo C, Massawe A, Lyamuya E, Semali I, Kalokola F, Urassa E, Giattas M, Temu F, Karlsson K, Mhalu F & Biberfeld G (2001) HIV counseling and testing of pregnant women in sub-Saharan Africa: Experiences from a study on prevention of mother-to-child HIV-1 transmission in Dar es Salaam, Tanzania, *Journal of Acquired Immune Deficiency Syndromes* 28(5): 458–462.

## REFERENCES

- Kitzinger J (1994) Focus groups: Method or madness? In M Boulton (ed.) *Challenge and innovation: Methodological advances in social research on HIV/AIDS*. London: Taylor and Francis.
- Klaaren J (2004) The right to life in a time of AIDS: Does the South African Constitution really contain a right to life? Paper presented at the WISER 'Life and Death in a Time of AIDS' Symposium, Johannesburg, 14–16 October.
- Klein SJ, Karchner WJ & O'Connell DA (2002) Interventions to prevent HIV-related stigma and discrimination, *Journal of Public Health Management and Practice* 8(6): 44–53.
- Klingemann HK (1999) Addiction careers and careers in addiction, *Substance Use and Misuse* 34(11): 1505–1526.
- Kramer L (1994) *Reports from the holocaust: The making of an AIDS activist*. New York: St Martin's Press.
- Land H & Hudson S (1997) Methodological considerations in surveying Latina AIDS caregivers: Issues in sampling and measurement, *Social Work Research* 21(4): 233–247.
- Lazzarini Z & Klitzman R (2002) HIV and the law: Integrating law, policy, and social epidemiology, *Journal of Law, Medicine and Ethics* 30(4): 533–547.
- Le Marcis F (2004) Death as a competition over meanings and resources: Alexandra and Diepkloof, Paper presented at the WISER 'Life and Death in a Time of AIDS' Symposium, Johannesburg, 14–16 October.
- Leasure R, McKenney LA & Merrill A (1995) Factors influencing baccalaureate nursing students' attitudes towards persons living with AIDS, *Journal of Professional Nursing* 11(5): 299–305.
- Leclerc-Madlala S (1997) Infect one, infect all: Zulu youth response to the AIDS epidemic in South Africa, *Medical Anthropology* 17(4): 363–380.
- Leclerc-Madlala S (2001) Virginity testing: Managing sexuality in a maturing HIV/AIDS epidemic, *Medical Anthropology Quarterly* 15(4): 533–552.
- Leclerc-Madlala S (2002) On the virgin cleansing myth: Gendered bodies, AIDS and ethnomedicine, *African Journal of AIDS Research* 1(2): 87–95.
- Lewis J (1999) Status passages: The experience of HIV-positive gay men, *Journal of Homosexuality* 37(3): 87–115.
- Lewis L & Ross MW (1995) *A select body: The gay dance party subculture and the HIV/AIDS pandemic*. London: Cassell.
- Li VC & Cole BL (1993) HIV-related knowledge and attitudes among medical students in China, *AIDS Care* 5(3): 305–308.

## UNDERSTANDING HIV/AIDS STIGMA

- Lichtenstein B (2003) Stigma as a barrier to treatment of sexually transmitted infection in the American deep south: Issues of race, gender and poverty, *Social Science & Medicine* 57(12): 2435–2445.
- Lindsey E, Hirschfeld M & Tlou S (2003) Home-based care in Botswana: Experiences of older women and young girls, *Health Care Women International* 24(6): 486–501.
- Link BG & Phelan JC (2001) On stigma and its public health implications, *Annual Review of Sociology* 27: 363–85.
- Lorentzen K & Morris S (2003) The enigma of HIV/AIDS-related stigma: A theoretical exploration of HIV/AIDS-related stigma in sub-Saharan Africa, Psychology thesis, Universitas Bergensis.
- Low-Beer D & Stoneburner R (2003) Behaviour and communication change in reducing HIV: Is Uganda unique? *African Journal of AIDS Research* 2(1): 9–21.
- MacPhail C (2003) Challenging dominant norms of masculinity for HIV prevention, *African Journal of AIDS Research* 2(2): 141–149.
- Malala J (2001) The perceptions of the body, illness and disease amongst sex workers in Hillbrow, Paper delivered at the 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April.
- Malcolm A, Aggleton P, Bronfman M, Galvao J, Mane P & Verall J (1998) HIV-related stigmatization and discrimination: Its forms and contexts, *Critical Public Health* 8(4): 347–370.
- Mallinson RK (1999) Grief work of HIV positive persons and their survivors, *Nursing Clinics of North America* 34(1): 163–177.
- Mann J (1996) *The impact of homophobia and other social biases on AIDS*. United States of America: Public Media Center.
- Manns PJ & Chad KE (2001) Components of quality of life for persons with a quadriplegic and paraplegic spinal cord injury, *Qualitative Health Research* 11(6): 795–811.
- Mantler J, Schellenberg EG & Page JS (2003) Attributions for serious illness: Are controllability, responsibility, and blame different constructs? *Canadian Journal of Behavioural Science Revue Canadienne des Sciences du Comportement* 35(2): 142–152.
- Marcus T (2001) Kissing the cobra: Sexuality and high risk in a generalised epidemic – a case study, 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April.
- Marks S (2002) An epidemic waiting to happen?: The spread of HIV/AIDS in South Africa in social and historical perspective, *African Studies* 61(1): 13–26.

## REFERENCES

- Mast TC, Kigozi G, Wabwire-Mangen F, Black R, Sewankambo N, Serwadda D, Gray R, Wawer M & Wu AW (2004) Measuring quality of life among HIV-infected women using a culturally adapted questionnaire in Rakai district, Uganda, *AIDS Care* 16(1): 81–94.
- McGrath JW (1992) The biological impact of social responses to the AIDS epidemic, *Medical Anthropology* 15(1): 63–79.
- McGrath JW, Ankrah EM, Schumann DA, Nkumbi S & Lubega M (1993) AIDS and the urban family: Its impact in Kampala, Uganda, *AIDS Care* 5(1): 55–70.
- McKirnan DJ, Doetsch J, Vanable P, Buchbinder S, Douglas JM & Judson F (1994) Preparations for AIDS vaccine trials. Developing brief valid screening instruments for HIV-related sexual risk behavior among gay and bisexual men, *AIDS Research and Human Retroviruses* 10(2): S285–S288.
- McQueen D & Camprostrini S (1994) Monitoring behavioural change in the population: A continuous data collection approach. In M Boulton (ed.) *Challenge and innovation: Methodological advances in social research on HIV/AIDS*. London: Taylor and Francis.
- Meier RF (1982) Perspectives on the concept of social control, *Annual Review of Sociology* (8): 35–55.
- Mendès-Leite R (2001) The meaning of otherness: Representations on immigration, xenophobia and Aids epidemic in Johannesburg, 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April.
- Miles R (1989) *Racism*. London: Routledge.
- Miller CT & Kaiser CR (2001) A theoretical perspective on coping with stigma, *Journal of Social Issues* 57(1): 73–92.
- Miller N & Rockwell RC (1988) *AIDS in Africa: The social and policy impact*. Lewiston, New York: Edwin Mellen Press.
- Mlungwana J (2001) Cultural dilemmas in lifeskills education in KZN: Umbonambi Primary School Project, 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April.
- Mohlalane R (2004) The HIV/AIDS and trauma among abused women in South Africa: Prevention intervention, Paper presented at the SAHARA 'Social Aspects to Care and Treatment' Conference, Cape Town, 9–12 May.
- Moneyham L, Seals B, Demi A, Sowell R, Cohen L & Guillory J (1996) Perceptions of stigma in women infected with HIV, *AIDS Patient Care STDS* 10(3): 162–167.
- Moneyham L, Seals B, Sowell R, Hennessy M, Demi A & Brake S (1997) The impact of HIV on emotional distress of infected women: Cognitive appraisal and coping as mediators, *Scholarly Inquiry for Nursing Practice: An International Journal* 11(2): 125–145.

- Morgan J (2004) Body maps, Poster presentation at SAHARA 'Social Aspects to Care and Treatment' Conference, Cape Town, 9–12 May.
- Msiska R, Nangawe E, Mulenga D, Sichone M, Kamanga J & Kwapa P (1997) Understanding lay perspectives: Care options for STD treatment in Lusaka, Zambia, *Health Policy Plan* 12(3): 248–252.
- Muehrer P (2002) Research on co-morbidity, contextual barriers, and stigma: An introduction to the special issue, *Journal of Psychosomatic Research* 53(4): 843–845.
- Mundell J, Gcabo R & Visser M (2004) A review of interventions to reduce stigma in South Africa: What have we learnt? Paper presented at the SAHARA 'Social Aspects to Care and Treatment' Conference, Cape Town, 9–12 May.
- Muyinda H, Seeley J, Pickering H & Barton T (1997) Social aspects of AIDS-related stigma in rural Uganda, *Health Place* 3(3): 143–147.
- Nattrass N (2004) *The moral economy of AIDS in South Africa*. Cape Town: Cambridge University Press.
- Ndinda C (2004) Gender relations in the context of HIV/AIDS in rural SA, Paper presented at the SAHARA 'Social Aspects to Care and Treatment' Conference, Cape Town, 9–12 May.
- Nelkin D & Gilman S (1988) Placing blame for devastating disease, *Social Research* 55(3): 361–378.
- Ntlabati P, Kelly K & Mankayi A (2001) The first time: An oral history of sexual debut in a deep rural area, 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April.
- Oppenheimer GM (1988) In the eye of the storm: The epidemiological construction of AIDS, in DM Fox & E Fee (eds.) *AIDS: The burdens of history*. Berkeley: University of California Press.
- Packard RM & Epstein P (1992) Medical research on AIDS in Africa: A historical perspective, in E Fee & D Fox (eds.) *AIDS: The making of a chronic disease*. Berkeley: University of California Press.
- Paiva V, Filipe EV, Santos N, Lima TN & Segurado A (2003) The right to love: The desire for parenthood among men living with HIV, *Reproductive Health Matters* 11(22): 91–100.
- Parker R & Aggleton P (2003) HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action, *Social Science & Medicine* 57: 13–24.
- Paterson H & le Roux N (2004) The role of the HSRC in psychological test development in South Africa, HSRC Research Conference 2004, Birchwood, South Africa, 27–28 July.
- Patient DR & Orr NM (2003) Stigma: Beliefs determine behaviour, Unpublished paper. Nelspruit, South Africa: Empowerment Research.

## REFERENCES

- Patterson TL & Semple SJ (2003) Sexual risk reduction among HIV-positive drug-using men who have sex with men, *Journal of Urban Health – Bulletin of the New York Academy of Medicine* 80(4): 77–87.
- Pattman R & Chege F (2003) 'Dear diary I saw an angel, she looked like heaven on earth': Sex talk and sex education, *African Journal of AIDS Research* 2(2): 103–112.
- Pawinski R & Lalloo U (2001) Community attitudes to HIV/AIDS, *South African Medical Journal* 91: 448.
- Paxton S (2002) The paradox of public HIV disclosure, *AIDS Care* 14(4): 559–567.
- Petrak JA, Doyle AM, Smith A, Skinner C & Hedge B (2001) Factors associated with self-disclosure of HIV serostatus to significant others, *British Journal of Health Psychology* 6(1): 69–79.
- Phillips H (2001) AIDS in the context of South Africa's epidemic history: Preliminary historical thoughts, *South African Historical Journal* 45: 11–26.
- Pinel EC (2002) Stigma consciousness in intergroup contexts: The power of conviction, *Journal of Experimental Social Psychology* 38: 178–185.
- POLICY project, Centre for the Study of AIDS, USAID & Department of Health (2003a) *Siyam'kela: Measuring HIV/AIDS related stigma: A report on the fieldwork.*
- POLICY project, Centre for the Study of AIDS, USAID & Department of Health (2003b) *Siyam'kela: Measuring HIV/AIDS related stigma: Literature review.*
- Posel D (1983) Rethinking the race-class debate in South African historiography, *Social Dynamics* 9(1): 50–66.
- Posel D (2004) Sex, death and embodiment: Reflections on the stigma of AIDS in Agincourt, South Africa, Paper presented at the WISER 'Life and Death in a Time of AIDS' Symposium, Johannesburg, 14–16 October.
- Powell-Cope GM & Brown MA (1992) Going public as an AIDS family caregiver, *Social Science & Medicine* 34(5): 571–580.
- Preston-Whyte EM (2003) Contexts of vulnerability: Sex, secrecy and HIV/AIDS, *African Journal of AIDS Research* 2(2): 89–94.
- Prior L, Wood F, Lewis G & Pill R (2003) Stigma revisited, disclosure of emotional problems in primary care consultations in Wales, *Social Science and Medicine* 56: 2191–2200.
- Pronyk PM, Hargreaves JR, Kim JC & Makhubele MB (2001) Generating social capital through microfinance: The design of a multi-level HIV prevention and control strategy, Paper delivered at the 'AIDS in Context' Conference, University of the Witwatersrand, 4–7 April.

- Puhl R & Brownell KD (2003) Ways of coping with obesity stigma: Review and conceptual analysis, *Eating Behaviors* 4: 53–78.
- Rakotonanahary A, Rafransoa Z & Bensaid K (2002) Qualitative evaluation of HIV/AIDS IEC activities in Madagascar, *Evaluation and Program Planning* 25: 341–345.
- Ramirez-Valles J (2002) The protective effects of community involvement for HIV risk behavior: A conceptual framework, *Health Education Research* 17: 389–403.
- Ranger T & Slack P (eds.) (1992) *Epidemics and ideas: Essays on the historical perception of pestilence*. Cambridge: Cambridge University Press.
- Remien RH, Hirky AE, Johnson MO, Weinhardt LS, Whittier D & Le GM (2003) Adherence to medication treatment: A qualitative study of facilitators and barriers among a diverse sample of HIV+ men and women in four US cities, *Aids and Behavior* 7(1): 61–72.
- Richter M (2001) *Nature and extent of discrimination against PLWAs in South Africa: Interviews and a study of AIDS Law Project client files 1993–2001*, University of the Witwatersrand: AIDS Law Project, Centre for Applied Legal Studies: 1–46.
- Ritsher J, Otilingam PG & Grajales M (2003) Internalized stigma of mental illness: Psychometric properties of a new measure, *Psychiatry Research* 121(1): 31.
- Roeloffs C, Sherbourne C, Unutzer J, Fink A, Tang L & Wells KB (2003) Stigma and depression among primary care patients, *General Hospital Psychiatry* 25: 311–315.
- Rosenberg CE (1992) *Explaining epidemics and other studies in the history of medicine*. New York: Cambridge University Press.
- Sabatier R & Tinker J (1988) *Blaming others: Prejudice, race, and worldwide AIDS*. Washington: Panos Institute.
- Sadow D, Ryder M & Webster D (2002) Is education of health professionals encouraging stigma towards the mentally ill? *Journal of Mental Health* 11(6): 657–665.
- Sandelowski M & Barroso J (2003) Toward a metasynthesis of qualitative findings on motherhood in HIV-positive women, *Research in Nursing and Health* 26: 153–170.
- Sankar A & Luborsky M (2003) Developing a community-based definition of needs for persons living with chronic HIV, *Human Organization* 62: 153–165.
- Santana MA & Dancy BL (2000) The stigma of being named ‘AIDS carriers’ on Haitian-American women, *Health Care for Women International* 21(3): 161–171.
- Santiago LE (1998) Oral testimonies: The other face of the HIV story, *Puerto Rico Health Sciences Journal* 17(4): 375–380.
- Saunders JM (1994) Self-caring in a family unit of an HIV-positive individual: A hermeneutical inquiry, *Clinical Nursing Research* 3(4): 334–352.

## REFERENCES

- Sayce L (2003) Beyond good intentions: Making anti-discrimination strategies work, *Disability & Society* 18: 625–642.
- Schaeffer D & Garms-Homolova V (1986) Significance of self-help groups for psychosocial rehabilitation in cancer, *Rehabilitation (Stuttg)* 25: 128–133.
- Schonfeld DJ (2000) Teaching young children about HIV and AIDS, *Child and Adolescent Psychiatric Clinics of North America* 9(2): 375–387.
- Schrimshaw EW & Siegel K (2003) Perceived barriers to social support from family and friends among older adults with HIV/AIDS, *Journal of Health Psychology* 8: 738–752.
- Schulze B & Angermeyer MC (2003) Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals, *Social Science & Medicine* 56: 299–312.
- Schumacher M, Corrigan PW & Dejong T (2003) Examining cues that signal mental illness stigma, *Journal of Social and Clinical Psychology* 22(5): 467–476.
- Selwyn P (1998) *Surviving the fall: The personal journey of an AIDS doctor*. New Haven: Yale University Press.
- Setel P, Lewis MJ & Lyons M (eds.) (1999) *Histories of sexually transmitted diseases and HIV/AIDS in sub-Saharan Africa*. Westport, Connecticut: Greenwood Press.
- Shaibu S & Wallhagen MI (2002) Family caregiving of the elderly in Botswana: Boundaries of culturally acceptable options and resources, *Journal of Cross-Cultural Gerontology* 17(2): 139–154.
- Shelton JN (2003) Interpersonal concerns in social encounters between majority and minority group members, *Group Processes & Intergroup Relations* 6: 171–185.
- Shih M (2004) Positive stigma: Examining resilience and empowerment in overcoming stigma, *Annals of the American Academy of Political and Social Science* 59: 1175–1185.
- Shisana O, Simbayi L et al. (2002) *Nelson Mandela/HSRC study of HIV/AIDS: South African national HIV prevalence, behavioral risks and mass media, household survey 2002*. Cape Town: HSRC Press.
- Shisana O, Hall E, Maluleke KR, Stoker DJ, Schwabe C, Colvin M, Chauveau J, Botha C, Gumede T, Fomundam H, Shaikh N, Rehle T, Udjo E & Gisselquist D (2003) *The impact of HIV/AIDS on the health sector: National survey of health personnel, ambulatory and hospitalised patients and health facilities 2002*. Cape Town: HSRC Press.
- Silverman D (1994) Analysing naturally occurring data on AIDS counselling, in M Boulton (ed.) *Challenge and innovation: Methodological advances in social research on HIV/AIDS*. London: Taylor and Francis.

- Siminoff LA, Erlen JA & Lidz CW (1991) Stigma, AIDS and quality of nursing care: State of the science, *Journal of Advanced Nursing* 16: 262–269.
- Skinner D (2002) Stigma and the ABCD: A consideration in South Africa, Unpublished paper, HSRC.
- Skinsnes OK (1964) Leprosy in society III: The relationship of the social to the medical pathology of leprosy, *Leprosy Review* 35(4): 175–81.
- Sliep Y, Poggenpoel M & Gmeiner A (2001) The experience of HIV reactive patients in rural Malawi – Part I, *Curationis* 24: 56–65.
- Smart L & Wegner DM (1999) Covering up what can't be seen: Concealable stigma and mental control, *Journal of Personality and Social Psychology* 77: 474–486.
- Songwathana P & Manderson L (2001) Stigma and rejection: Living with AIDS in villages in southern Thailand, *Medical Anthropology* 20: 1–23.
- Sontag S (1990) *AIDS and its metaphors*. New York: Doubleday.
- Soskolne T, Stein J & Gibson K (2003) *Working with ambivalence: Finding a positive identity for HIV/AIDS in South Africa*, Centre for Social Science Research Working Paper No. 53, University of Cape Town.
- Sowell RL, Seals BF, Moneyham L, Demi A, Cohen L & Brake S (1997) Quality of life in HIV-infected women in the South-Eastern United States, *AIDS Care* 9(5): 501–512.
- Stadler J & Hlongwa L (2002) Monitoring and evaluation of Love Life's AIDS prevention and advocacy activities in South Africa, 1999–2001, *Evaluation and Program Planning* 25(4): 365–376.
- Stadler JJ (2003) The young, the rich, and the beautiful: Secrecy, suspicion and discourses of AIDS in the South African lowveld, *African Journal of AIDS Research* 2(2): 127–139.
- Stallybrass P & White A (1986) *The politics and poetics of transgression*. London: Methuen.
- Stein J (1996) Coping with HIV infection: The theory and the practice, *African Anthropology III* (2).
- Stein J (2003a) *HIV/AIDS stigma: The latest dirty secret*, Centre for Social Science Research Working Paper no. 46, University of Cape Town.
- Stein J (2003b) What's news: Perspectives on HIV/AIDS advocacy in the South African print media, *African Journal of AIDS Research* 2(1): 75–83.
- Surlis S & Hyde A (2001) HIV-positive patients' experiences of stigma during hospitalization, *Journal of the Association of Nurses in AIDS Care* 12: 68–77.

## REFERENCES

- Suurmeijer TP, Reuvekamp MF & Aldenkamp BP (2001) Social functioning, psychological functioning, and quality of life in epilepsy, *Epilepsia* 42(9): 1160–1168.
- Taub DE, Mclorg PA & Fanflik PL (2004) Stigma management strategies among women with physical disabilities: Contrasting approaches of downplaying or claiming a disability status, *Deviant Behavior* 25(2): 169–190.
- Taylor B (2001) HIV, stigma and health: Integration of theoretical concepts and the lived experiences of individuals, *Journal of Advanced Nursing* 35(5): 792–798.
- Timlin-Scalera RM, Ponterotto JG, Blumberg FC & Jackson MA (2003) A grounded theory study of help-seeking behaviors among white male high school students, *Journal of Counseling Psychology* 50(3): 339–350.
- Tostes MA, Chalub M & Botega NJ (2004) The quality of life of HIV-infected women is associated with psychiatric morbidity, *AIDS Care* 16(2): 177–186.
- Treichler P (1999) *How to have theory in an epidemic: Cultural chronicles of AIDS*. Durham: Duke University Press.
- Tunnell G (1991) Complications in group psychotherapy with AIDS patients, *International Journal of Group Psychotherapy* 41(4): 481–498.
- Turner BS (1992) *Regulating bodies: Essays in medical sociology*. London: Routledge.
- Uys LR (2003) Aspects of the care of people with HIV/AIDS in South Africa, *Public Health Nursing* 20(4): 271–280.
- Van Krieken R (1991) The poverty of social control: Explaining power in the historical sociology of the welfare state, *Sociological Review* 39(1): 1–25.
- Varga CA (2001) Coping with HIV/AIDS in Durban's commercial sex industry, *AIDS Care* 13(3): 351–65.
- Visser M (2004) HIV+ women's experiences of stigma and social support, Paper presented at the SAHARA 'Social Aspects to Treatment and Care' Conference, Cape Town, 9–12 May.
- Volinn IJ (1989) Issues of definitions and their implications: AIDS and leprosy, *Social Science & Medicine* 29(10): 1157–1162.
- Wailoo K (2001) Stigma, race, and disease in twentieth century America, Paper presented at the 'Stigma and Global Health' Conference, 5–7 September 2001, Bethesda, Maryland, USA.
- Walker L & Gilbert L (2002) HIV/AIDS: South African women at risk, *African Journal of AIDS Research* 1(1): 75–85.
- Weiner B, Perry RP & Magnusson J (1988) An attributional analysis of reactions to stigmas, *Journal of Personality and Social Psychology* 55(5): 738–748.

- Weiser S, Wolfe W, Bangsberg D, Thior I, Gilbert P, Makhema J, Kebaabetswe P, Dickenson D, Mompoti K, Essex M & Marlink R (2003) Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana, *Journal of Acquired Immune Deficiency Syndromes* 34(3): 281–288.
- Weiss MG & Ramakrishna J (2001) Stigma interventions and research for international health, Paper presented at the 'Stigma and Global Health' Conference, 5–7 September 2001, Bethesda, Maryland, USA.
- Westaway MS & Wolmarans L (1994) Cognitive and affective reactions of black urban South Africans towards tuberculosis, *International Journal of Tuberculosis and Lung Disease*, 75(6): 447–453.
- Whiteside A, Mattes R, Willan S & Manning R (2002) *Examining HIV/AIDS in South Africa through the eyes of ordinary South Africans*, Centre for Social Science Research Working Paper No. 11, University of Cape Town.
- Wojcicki JM & Malala J (2001) Condom use, power and HIV/AIDS risk: Sex-workers bargain for survival in Hillbrow/Joubert Park/Berea, Johannesburg, *Social Science & Medicine* 53(1): 99–121.
- Worthington C & Myers T (2003) Factors underlying anxiety in HIV testing: Risk perceptions, stigma, and the patient-provider power dynamic, *Qualitative Health Research*, 13(5): 636–655.







