Chapter 8
HIV and Stigma in South Africa

Harriet Deacon, Leana Uys, and Rakgadi Mohlahlane

8.1 Introduction

Jonathan Mann (1996) was one of the first and most important lobbyists for HIV and AIDS-related stigma research on the international stage. He argued that stigma exacerbated the effects of the epidemic and reduced the efficacy of AIDS programming efforts. During the 1990s and 2000s there was thus an increase in the amount of research on HIV and AIDS-related stigma internationally. This research suggested that stigma and discrimination reduces the impact of prevention programmes, inhibits treatment take-up and adherence, exacerbates the psycho-social effects of HIV-infection and reduces the quality of life of people living with HIV and AIDS (for a review, see Deacon et al., 2005 and Deacon and Stephney, 2007). The United Nations agency for AIDS, UNAIDS, thus chose stigma as its campaign theme for World AIDS Day in 2003.

South Africans were jolted into sharp awareness of the effects of stigma and discrimination by the 1998 murder of a 36-year-old HIV-positive woman, Gugu Dlamini, 3 weeks after she had disclosed her HIV status on a local radio station. She was accused by the local community of shaming them by announcing her HIV status. Many similar cases have been recorded. One of the most important public figures to highlight the problem of stigma in relation to HIV and AIDS in South Africa has been HIV-positive judge Edwin Cameron (2005). Although South African researchers have made key contributions, there has until recently been relatively little research on HIV and AIDS-related stigma compared to other kinds of AIDS-related research in southern Africa. In social science research there has been more emphasis on understanding the behaviour that increases HIV risk, such as early sexual debut, transactional sex and gender violence, and on monitoring treatment access and human rights, than on stigma.

8.2 South African Contributions to Stigma Theory

South Africa is a society in transition coming from a troubled and divided past with high levels of social tension, gender-based violence and inequality. At the same time, the South African legal system has been hailed as one of the most progressive

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in the world since the development of a new human-rights-based Constitution in 1996. This combination of factors has made South African researchers particularly interested in understanding HIV and AIDS-related stigma within the broader context of theories about other kinds of prejudice and within the context of socio-economic and gender inequality.

8.2.1 Definitions of Stigma

Defining stigma sets the terms of the debate for how to measure it and how to address it. Defining stigma has proved to be rather difficult and a point of contention within the field (Link and Phelan, 2001). The definition of disease stigma today owes much to Goffman (1963), who suggested that people who possess a characteristic defined as socially undesirable (such as HIV infection) acquire a 'spoiled identity', which then leads to social devaluation and discrimination.

Various authors have challenged the tendency to see stigma as an individual attribute and have highlighted the importance of social power relationships in shaping stigma, through sociological analyses (Parker and Aggleton, 2003), and cognitive and psychoanalytic approaches from social psychology (Joffe, 1999; Link and Phelan, 2001). South African scholars have contributed to this debate by offering some new theoretical directions on stigma (Deacon et al., 2005; Jennings et al., 2002; Joffe, 1999; Stein, 2003), which were influenced by approaches to the study of social psychology and racism developed by Professor Donald Foster at the University of Cape Town during the 1980s (Foster, 1991). This work attempted to bridge the gaps between individualistic explanations for stigma (and racism) and broader socio-economic explanations. Along with collaborative research initiatives like ICRAAS (the International Consortium for Research and Action Against health-related Stigma), South African researchers have underlined the importance of understanding health-related stigma through comparative studies.

Joffe (1999), for example, suggests that stigma is a fundamental emotional response to danger that helps people feel safer by projecting controllable risk, and therefore blame, onto out-groups. Stigmatisation thus helps to create a sense of control and immunity from danger at an individual and a group level. HIV and AIDS-related stigma allows individuals to distance themselves from other ('promiscuous', 'gay', 'black', 'white', 'non-religious', 'young', 'urban') people who are presumed to be at greater risk of contracting HIV because of their behaviour. 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).

One of the debates raised by this work was the relationship between stigma and discrimination. Stigma can affect people negatively even where active discrimination does not occur, so only investigating it when it results in discrimination is problematic (Jennings et al., 2002). Drawing on some of this work, Deacon (2006) suggested that stigma can be defined as a social process in which illness is constructed as preventable or controllable; ‘immoral’ behaviours causing the illness are identified; these behaviours are associated with ‘carriers’ of the illness in socially stereotyped ‘other’ groups; some people are thus blamed for their own infection; and status loss is projected onto the ‘other’, which may (or may not) result in active discrimination.

The social context of stigma is thus a very important factor in defining the way in which it is expressed and experienced. Following the work of Ogden and Nyblade (2005), South African research has started to refine our understanding of the drivers of stigma (Campbell et al., 2007) such as

> fear, the availability and relevance of AIDS-related information, the lack of social spaces to engage in dialogue about HIV/AIDS, the link between HIV/AIDS, sexual moralities and the control of women and young people, the lack of adequate HIV/AIDS management services, and the way in which poverty shaped people’s reactions to HIV/AIDS (p. 403).

Holzemer et al. (2007a) also used Southern African data (from 43 focus groups in five African countries) to develop a conceptual model of HIV/AIDS stigma that seeks to understand both contextual factors (such as the health-care system) and the stigma process itself (such as the different types of stigma and stigma triggers).

8.2.2 Stigma Typologies

Various kinds of stigma have been differentiated in the international literature. Instrumental stigma (fear of infection from casual transmission) has been distinguished from symbolic stigma (moralistic shaming and blaming) and felt (internal) stigma from enacted or expressed (external) stigma (Herek, 2002). People who are stigmatised can internalise stigma (i.e. accept negative judgements) and make judgements about how much stigma they expect to experience, termed perceived stigma. Courtesy stigma is stigma directed at the families or friends of HIV-positive people. South African research (Siyam’kela Project, 2003) has used similar typologies.

The Southern African literature (Maughan-Brown, 2006a; Moon et al., 2002; Orr and Patient, 2003 cited in Stein, 2003) has contributed to this array of topologies by elaborating a category called resource-based stigma that describes stigma based on resource concerns due to judgements about the likely social contribution of a person living with HIV/AIDS. It is important to understand these ‘types’ of stigma not as separate entities, but as different dimensions of the same phenomenon. A growing understanding of the way in which stigma is shaped by its form and context will shape research and inform interventions.

8.3 South African Stigma Research

South African stigma research has documented the negative effects of stigma and discrimination and has provided qualitative and quantitative analyses of the nature and extent of stigma in the country. Broadly speaking, it has followed international methodological trends, although some new quantitative instruments and analytical insights have been developed.

8.3.1 Developing Stigma Instruments for South Africa

Quantitative measurement instruments for stigma were developed relatively early in the epidemic in the United States, measuring knowledge, attitudes and behaviours or some of these factors (Herek and Glunt, 1988). Most studies initially investigated knowledge and attitudes in the 'general population', without establishing their HIV status. Later it became evident that there was a need to research HIV-positive people's experiences of stigma (Berger et al., 2001) and the attitudes of health-care workers towards them. There was, however, initially no comprehensive stigma index designed to measure attitudes, knowledge, perceived stigma and the effects of stigma (Nyblade, 2006).

Stigma instruments have only recently been developed and validated for southern Africa. Nyblade et al.'s (2005) work for USAID on measuring stigma in Tanzania proposed comprehensive new indicators that were appropriate for the southern African context. A comprehensive set of internal and external stigma indicators were also developed by the Siyam'kela Project (2003). The study did not validate a new instrument but suggested how the indicators could be verified in different settings and listed conditions for use of the indicators.

Maughan-Brown (2004) published an instrument to measure HIV stigma in the community using 26 items on a five-point rating scale with reasonable statistical qualities. Kalichman et al. (2005) developed another validated instrument to measure HIV stigma in the general South African population: a nine-item AIDS-Related Stigma Scale with internal consistency, reasonable stability over time and some indications of construct validity, available in three languages. The University of KwaZulu Natal/University of California San Francisco (UKZN/UCSF) research project in five African countries produced two validated instruments. The first, the HIV/AIDS Stigma Instrument for persons living with HIV/AIDS (PLHA) (HASI-P) is aimed at measuring the stigma experienced by PLHA (Holzemer et al., 2007). It is a 33-item instrument, covering six factors (verbal abuse, negative self-perception, health-care neglect, social isolation, fear of contagion and workplace stigma), with acceptable internal consistency reliability, construct and content validity. The second, the HIV/AIDS Stigma Instrument for Nurses (HASI-N) is a 19-item instrument, comprised of two factors (nurses stigmatising patients and nurses being stigmatised) with a Cronbach alpha of 0.90 (Uys et al., 2009). It can also be adapted for use by other health professionals.

8.3.2 Research Findings in South Africa

Although the Demographic and Health Surveys South Africa and HSRC/Nelson Mandela studies (Shisana et al., 2002, 2005) have included questions on knowledge and stigmatising attitudes, there have been few national surveys that use internationally or locally validated stigma instruments. More recently, the UKZN/UCSF study, one of the most comprehensive African stigma studies to date, has measured stigma experienced by a group of 1457 PLHA and 1384 nurses in five African countries, including South Africa, in three waves, 6 months apart (Greeff, et al., 2008b: Makoae et al., 2008a).

Most quantitative research in South Africa has used smaller localised samples and has focused on identifying stigma as one of a number of factors affecting access to testing, disclosure, treatment or support (Hutchinson and Mahlalela, 2006; Peltzer et al., 2007). A few stigma researchers have used local quantitative studies to explore the drivers of stigma in greater depth, for example, the relationship between stigmatising attitudes and behaviours and levels of biomedical knowledge, trust in biomedicine, traditional beliefs and other social and economic characteristics (Kalichman and Simbayi, 2003, 2004; Kalichman et al., 2006). Analysis of University of Cape Town's (UCT) Centre for Social Science Research (CSSR)'s Cape Area Panel Studies (CAPS) has explored relationships between different kinds of stigma and class, religion and other socio-cultural and economic factors (Maughan-Brown, 2006a, b).

Qualitative research on the nature and effects of HIV and AIDS-related stigma in South Africa includes a number of studies describing HIV-positive people's experiences of stigma (Campbell, et al., 2005a, b; 2006; 2007; Greeff and Phetlhu, 2007; Greeff et al., 2008b; Hosegood et al., 2007; Mills, 2006; Niehaus, 2007; Patient and Orr, 2003; Petros et al., 2006; Siyam'kela Project, 2003; Skinner and Mfecane, 2004). A limited number of studies have investigated courtesy stigma (Orner, 2006).

The nature and extent of stigma changes over time, as death rates from HIV in the community increase or decrease, as more people disclose their status and as testing and treatment becomes more widely available. Jewkes (2006) suggests that stigma could be decreasing as HIV becomes normalised, but recent research suggests that stigma is a significant problem in the country, that it has negative effects and that it may even be increasing. Opinions about the extent of stigma depend on how stigma is measured. Early surveys found relatively low levels of reported stigma in South Africa (Parker et al., 2002; Shisana et al., 2002; Whiteside et al., 2002). But Stein (2003) and Maughan-Brown (2004) argued that low levels of reported stigma could have been found in such studies because they focused on measuring intended stigmatising behaviour and not other aspects of stigma such as othering and blaming (symbolic stigma) and stigma based on fear of infection (instrumental stigma).

Access to ARV treatment seems to be associated with higher rather than lower rates of perceived stigma (Makoae et al., 2008b). Negative judgements (symbolic stigma) against PLHA and fear of HIV infection (instrumental stigma) were expressed by up to half of the respondents in the CAPS study in Cape Town, and measures of stigma are showing an increase over time (Maughan-Brown, 2006a, 2008). The UKZN/UCSF study showed that Quality of Life (QoL) measures for HIV-positive South Africans, which were associated with increased levels of perceived stigma, were among the lowest in the African countries studied (Greeff et al., 2008b). The AIDS Law Project identified numerous cases of discrimination against

HIV-positive people across the country (Jennings et al., 2002; Kohi et al., 2006; Richter, 2001), while Greeff and Phetlhu (2007) described incidents of neglect and abuse. Caregivers and medical professionals stigmatised and discriminated against PLHA, especially where there are limited resources for care (Shisana et al., 2003). Campbell et al. (2005a) described HIV-positive people being hidden in back rooms and kept from care in Kwazulu Natal. Cluver and Gardner (2007) identified stigma as a risk factor in the psycho-social adjustment of children affected by HIV and AIDS.

Expressing stigmatising views against PLHA was associated with delayed testing and treatment in a Cape Town study (Kalichman and Simbayi, 2003). Many other studies reported that stigma seems to inhibit or delay access to HIV treatment and testing services and affects adherence (Cameron, 2007; Doherty et al., 2006; Hutchinson and Mahlalela, 2006; MacPhail et al., 2008; Maughan-Brown, 2007; Mills, 2006; Nachega et al., 2005). In a study of PLHA in a Cape Town township, Maughan-Brown (2007) found that both experienced stigma and perceived stigma were related to inconsistent condom use, fear of disclosure, depression or anxiety and lack of self-efficacy or confidence. South Africa seems to be characterised by low levels of disclosure (Kouyoumdjian et al., 2005; Pawinski and Lalloo, 2001), and relatively late disclosure, which may be linked to stigma (Almeleh, 2006). Low rates of disclosure are correlated with lower access to services (Norman et al., 2007). Levels of perceived HIV stigma were the strongest predictor for job satisfaction in nurses (Greeff et al., 2008b).

HIV and AIDS-related stigma is generated and expressed in different symbolic, economic, political and institutional contexts (Campbell et al., 2005b). People may stigmatise friends and family differently (Maughan-Brown, 2006b). Women may be less stigmatising than men towards PLHA, perhaps because of their gender role as caregivers in families (Visser et al., 2006). The South African work has confirmed that stigma shares many common features across contexts (Ogden and Nyblade, 2005). For example, in the context of a generalised heterosexual epidemic, HIV infection is commonly associated in shaming and blaming discourse with sex and specifically with promiscuity (Harrison, 2008; Petros et al., 2006; Preston-Whyte, 2003). In a Kwazulu Natal study, Campbell et al. (2005a) reported that 'Virtually every informant reported that stigma originated in the association between HIV/AIDS and sex' (p. 810). In this kind of blaming discourse, some people are commonly characterised as 'innocent victims' and others are seen as more blameworthy, often depending on their age, gender, class or the mode of infection. Women who test HIV-positive through antenatal services are often blamed for infecting their partner, 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 (Siyam'kela Project, 2003). In a survey of 843 women at 26 primary health-care clinics in South Africa, Myer et al. (2006) found that less than half of these women thought that PLHA should remain sexually active and only 13% said that PLHA should be allowed to have children if they so wished.

Patient and Orr (2003) and Niehaus (2007) have highlighted the importance of the ways in which HIV and AIDS has been associated with death. Late disclosure and treatment seeking heightens this association in the Southern African context (Almeleh, 2006). Niehaus (2007) sees the construction of persons with AIDS as 'dead before dying' (p. 845) as more important than promiscuity in defining stigma locally. He conceives of the association between AIDS and death as 'an outcome of the manner in which biomedical discourses have articulated with religious and popular ones' rather than as an outcome of folk beliefs. These beliefs may develop specific features because of the association between 'witchcraft' and AIDS (Ashforth, 2001). Thus, there are specific ways in which HIV and AIDS-related stigma is expressed in South Africa. Some research points to the highly gendered and culturally specific nature of HIV and AIDS-related stigma (Clark, 2006; Petros et al., 2006). Derogatory terms such as 'winning the Lotto' (Uys et al., 2005) or stigmatising gestures using three fingers to denote the three letters of HIV (Mills, 2006) are sometimes local and sometimes more widely used and understood.

Stigma is of course only one of the problems facing PLHA and their families. Other problems include ill health, increased poverty, gender-based violence, inheritance issues and lack of control over areas such as reproductive and sexual decision making. Focusing on stigma and discrimination in isolation from these other factors in decision making, and on investigating failures in caring for PLHA rather than successes, might be problematic in itself. Jewkes (2006) argues that stigma researchers need to explore the diversity of social responses to AIDS, including contexts where 'HIV/AIDS has become part of the repertoire of normal misfortune' (p. 431). HIV and AIDS-related stigma also has to be understood in the context of other forms of stigma and prejudice (Link and Phelan, 2006). New research on TB-related stigma in South Africa and Zambia has shown that it has a close relationship to HIV and AIDS-related stigma (Bond and Nyblade, 2006; Moller and Erstad, 2007).

While stigma research is often tagged on to studies focusing on other aspects of the pandemic, it has now developed into a research area in its own right in South Africa. While confirming the negative effects of instrumental, symbolic and enacted stigma, South African research has highlighted the ways in which internalised and perceived stigma also affect the quality of life and health-related behaviour of PLHA. Further research is needed to understand the contexts where stigma is low and HIV has been normalised. The development of instruments and the extensive descriptive studies that has been done now allows the research agenda to move to intervention studies and the evaluation of such interventions.

8.4 Stigma Interventions in SA: Politics and Pragmatics

Interventions to address stigma are particularly important in countries like South Africa with high levels of HIV/AIDS and a long history of discrimination and prejudice. A number of interventions have been developed, and a few have been implemented in Southern and Eastern Africa, but most have not been formally evaluated. The relative lack of interest in anti-stigma interventions is part of a broader emphasis on providing biomedical treatment and changing the behaviour to reduce HIV risk in South African AIDS programming. But it is also a consequence of dissatisfaction with, and disputes about, the value of various kinds of anti-stigma interventions.

Initially, anti-stigma interventions in South Africa focused on mass media campaigns to increase knowledge about HIV and AIDS, such as Soul City and LoveLife. Anti-stigma messages are often simply added to existing information campaigns. However, in a review of stigma interventions, Brown et al. (2003) showed that mass media education campaigns are not particularly effective by themselves. Anti-stigma interventions should combine educational programmes, for example, with counselling, coping skills acquisition and contact with PLHA, coupling education and awareness programmes with the empowerment of PLHA. Campbell et al. (2007) have proposed that facilitated community-led group discussions about stigma in safe spaces should not impose views of stigma from outside but should build on community experiences and understandings of the problem and link solutions into broader social activism around poverty and human rights.

Workshop tools have been developed to create platforms for addressing problems of knowledge and attitudes towards PLHA, but there have been a limited number of interventions using them and no formal studies evaluating their impact in South Africa. Although not exclusively developed for Africa, one of the first anti-stigma interventions to be used in South Africa was the information-based Engender Health manual (2004). In 2003, Uys developed a similar information-based workshop manual, aimed at nurses, and with the UKZN/UCSF collaboration developed and tested another workshop intervention for nurses. Francis (2006) developed two visual arts-based anti-stigma interventions for university students called ‘Diversity and Education’ (Francis and Francis, 2006a) and ‘Hope and Healing’ (Francis and Francis, 2006b). The International Council of Nurses (ICN) has also developed an information and action toolkit for nurses entitled, *TB and Stigma: A Double Burden, Nursing Interventions for a TB Stigma-free Health Care Facility* (ICN, 2003). In 2003, the CHANGE project published a toolkit for NGOs, community groups and HIV educators based on research in Ethiopia, Tanzania and Zambia called ‘Understanding and Challenging HIV Stigma’, revised and republished in 2007 (Kidd et al., 2007). (The CHANGE Project, a USAID cooperative agreement with the Academy for Educational Development, in collaboration with the Manoff Group between 1998 and 2005, aimed to make health and nutrition programmes more effective by developing and applying practical solutions to behaviour change problems.) The CHANGE and ICN toolkits have not, to our knowledge, been tested in South Africa.

Some stakeholders see stigma as part of the ‘second generation’ agenda – something that will be dealt with, if it still exists, after structural inequalities, service delivery and human rights issues have been tackled (Parker and Aggleton, 2003). Reducing poverty, gender inequality, integrating anti-stigma interventions into the health-care system (Klein et al., 2002) and providing better human rights protection can help to minimise opportunities for stigma and discrimination. But these aims are very broad and long term, and the impact of legislation on improving access to human rights has been limited. A collaborative study conducted by the Centre for the Study of AIDS (CSA) and the Norwegian Centre for Human Rights (NCHR) thus recommended a focus on HIV and human rights training for AIDS service organisations and the creation of para-legal human rights champions within communities (Viljoen, 2005). South Africa's Treatment Action Campaign (TAC) has focused on human rights and treatment provision as its central agenda, tackling ignorance, internalised stigma and discrimination as by-products of these campaigns. PLHA support groups have been shown to be effective in reducing stigma (Dageid and Duckert, 2007) and have been widely implemented in South Africa by TAC and other organisations. The signature 'HIV-positive' TAC T-shirts have come to symbolise the role of disclosure in challenging stigma (although some of their activists have been targeted for attacks because of this openness).

Integration of anti-stigma interventions into the health-care system has not happened very effectively in South Africa. PLHA experience of stigma is affected by the structure of health-care services. Cameron (2007) suggests that the exceptionalisation of HIV, especially in testing procedures within the health-care services, reinforces internalised stigma. Receiving special services may result in involuntary disclosure (Doherty et al., 2006) and more stigma and discrimination from community members (Kelly, 2005). Alongside the development of the National Strategic Plan (NSP) for HIV/AIDS and STIs (South Africa, 2007), the Department of Heath developed a National Stigma Framework and Plan of Action to mitigate stigma, but the two processes were not well integrated. The National Stigma Framework focused more broadly on a range of anti-stigma initiatives across a number of sectors besides health. Within the NSP, stigma was covered in a separate section called 'Key Priority Area 4: Human Rights and Access to Justice' that focused mainly on legal rights and protections and did not highlight the importance of developing anti-stigma programmes integrated into testing, treatment, care and support services.

Jewkes (2006) argues that since educational and legislative interventions have not been very effective in changing behaviour, we should focus on research and interventions into positive role modelling in care and support instead of dwelling on the negative aspects of stigma. Both research and interventions to address stigma need to focus more on successes than failures of social support for PLHA, but, as with racism, combating stigma requires not only positive role modelling but also the development of critical tools to 'expose, confront, and resist the webs of signification and practice that sustain stigma' (Campbell et al., 2005a, p. 814).

Stigma is hard to define and research, it is easy for health-care services to deploy as an excuse for non-delivery, and the efficacy of existing interventions has not been fully investigated. Although stigma is often mentioned as a problem, interventions to reduce stigma are thus in their infancy in the South African context and too little work is being done to evaluate them. Because of the complex and multi-layered array of factors feeding into HIV/AIDS stigma, it needs to be tackled at a number of levels in addition to the level of health education (Campbell et al., 2007). The best kinds of interventions will probably combine social activism like that of the TAC that models positive images and supportive care with targeted programmes to develop social support for supportive communities that is based on a critique of stigmatising ideology. These will be combined with integrated initiatives to ensure that stigma does not limit access to health-care services and social support for HIV-positive people and their associates.

8.5 Funding and International Collaborations in Stigma Research

Stigma research in South Africa has been characterised by a number of international collaborations. This chapter will focus on the Siyam'kela collaboration between the POLICY Project (now the Health Policy Initiative), the National Department of Health and the Centre for the Study of AIDS (CSA) at the University of Pretoria; and the UKZN/UCSF collaboration between the University of Kwazulu-Natal (UKZN), various other African universities and the University of California at San Francisco (UCSF). Other significant collaborations include those between researchers at the HSRC and the University of Connecticut (Kalichman et al., 2006); and the collaboration between researchers at the London School of Economics and the Centre for HIV/AIDS Networking (HIVAN) (Campbell et al., 2007).

An analysis of funding priorities for AIDS programmes showed that comparatively few public sector resources were made available in education and social development – public sector funding has focused on the Department of Health (Ndlovu, 2005). Donor-funded and international collaborative projects have thus been particularly important in gaining financial support for 'soft' issues like stigma research. For stigma research as much as for other AIDS research, external funding provides an opportunity to conduct larger studies than would otherwise be possible. Given the scientific brain drain in South Africa, it can also help to support projects with additional skills where capacity gaps exist.

At the same time, external funding priorities and the needs of collaborating organisations do affect the way in which research is done and services are provided (Birdsall and Kelly, 2007). Tucker and Makgoba (2008) have suggested that there continues to be a 'neo-colonial' relationship between regions like Africa and these global public–private partnership organisations that contract out the majority of clinical trials to address AIDS, TB and malaria in the developing world. They have called for more significant African involvement in these partnerships and the relocation of some of them to developing countries to reduce the brain drain. The real dangers that these critics identify, which could apply to locally driven projects as much as to international collaborations, is that the agenda for research is sometimes not locally relevant, that beneficial outcomes do not filter down to the country where the data is collected and that local skills are not recognised where they exist, and developed where they need further capacity. These issues have to be addressed both within specific projects and in the broader research planning process for AIDS research within the South African National AIDS Council (SANAC) Research Sector.

The way in which collaborations are organised can ensure that developing country agendas and strengths become a priority. On the UKZN/UCSF collaboration, Uys (pers. comm., 2008) commended the leadership of Bill Holzemer from the School of Nursing at UCSF in creating a collaborative working arrangement in which country coordinators from the five African countries could contribute ideas and insights in managing the project. This level of collaboration was possible because of a generous budget for communication and face-to-face meetings between the collaborators. The partners used the meetings to review and finalise the analysis of data and review articles prepared by members in the latter stage of the project. The structure of the UKZN/UCSF project aided collaboration. Country PIs (senior academics in the African university nursing schools) were responsible for all the work in their own countries, the general African PI (Uys, pers. comm., 2008) was responsible for giving support and collating all country work, managing the finances and meetings and assisting with data entry, analysis and article writing and submission. The UCSF PI (Holzemer) managed the relationship with the funding agencies (NIH, Fogarty, etc.), gave major input into the planning of each phase, the analysis of data and the submission of articles for publication.

One of the ways in which collaborative projects often seek to ensure implementation of research findings is to involve local service providers, often government departments. The Siyam'kela collaboration (meaning we accept or together we stand) aimed to develop tools to better understand and mitigate HIV/AIDS stigma. The project conducted a national research process to understand the shape and form of stigma in three main areas: the faith sector, government workplaces and the relationship between the media and PLHA. These sectors were chosen because they were seen as influential in shaping attitudes. The project developed indicators for measuring stigma as well as a stigma-mitigation capacity-building intervention in each of these settings that included a resource document for trainers, opinion leaders, PLHAs, community members and anyone interested in finding out more about HIV/AIDS stigma and how to challenge and address it. The Project also helped develop and evaluate the National Stigma Framework with the National Department of Health. Because of the challenges faced by the Department, however, these initiatives have not been implemented as fast as would have been desired. The UKZN/UCSF collaboration also worked with local government departments, developing a stigma intervention based on their research, implementing it in one setting in each of the five countries and describing the results. This has led to real engagement with the issue of HIV and AIDS stigma in countries and policy change in countries like Lesotho and Malawi.

The better collaborations also include capacity-building initiatives. The Social Aspects of HIV/AIDS Research Alliance (SAHARA) ran a capacity-building project, sponsored by the Ford Foundation to mentor local researchers doing work on HIV and AIDS stigma in a number of Southern African countries. To date, the UKZN/UCSF collaboration has produced 11 published articles, 2 more are in press and 6 more are in review. A total of 27 presentations and posters have been presented at conferences, and two more have been accepted for 2008. Local scholars have been the first authors on a majority (8 of 11) of published papers generated by the collaboration (Dlamini et al., 2007; Greeff and Phetlhu, 2007; Greeff et al., 2008a, b; Kohi et al., 2006; Makoae et al., 2008a, b; Naidoo et al., 2007; Uys et al., 2005).

8.6 Conclusion

Research in South Africa has highlighted the importance of understanding both the socio-economic contexts of stigma and its local manifestations. It has improved our theoretical understanding of the problem and shown how different dimensions of stigma affect the health-related behaviour of PLHA and their associates. It suggests that stigma will not recede as HAART becomes widely available, and indeed it may be that certain forms of stigma are on the increase. The effects of stigma in the South African context seem to be very broad and deep: stigma is more than just an injury to an individual, but an indicator of the health of the social environment. Researchers should now focus on developing and evaluating targeted anti-stigma interventions that can be owned by communities and integrated into the provision of health and social services. Donor funding and international collaborations should help develop local capacity building and agency in this process.

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