



AIDS Activism, Stigma and Violence: A literature review

Dr. Jelke Boesten

ICPS WORKING PAPER 5

University of Bradford

Previous Titles in this Series

Working Paper 1 (2005)

Jenny Pearce and Heather Blakey

'Background of Distances' Participation and Community Cohesion in the North: Making the Connections

Working Paper 2 (2005)

Heather Blakey

Participation... Why Bother? The Views of Black and Minority Ethnic Mental Health Service Users on Participation in the NHS in Bradford

Working Paper 3 (2007)

Graeme Chesters and Ian Welsh

The Death of Collective Identity? Global Movement as a Parallelogram of Forces

Working Paper 4 (2007)

Jelke Boesten

Precarious Future: Community volunteers and HIV/AIDS in a Tanzanian roadside town

Series editor:

Maggie Bolton, Department of Peace Studies, University of Bradford

AIDS Activism, Stigma and Violence: A literature review

Dr. Jelke Boesten

ICPS WORKING PAPER 5

Abstract

This paper provides an overview of the literature on AIDS activism, stigma, and violence. The literature on AIDS activism, stigma and violence discussed suggests that the physical, emotional and social violence that AIDS as a disease, and stigma as a social construct tied to that disease, can be turned into an empowering experience that joins HIV positive people in productive and constructive networks, that this empowerment fundamentally changes one's identity, and that such disease-based identities are reshaping notions of citizenship around the globe. This hypothesis is built, however, on theory and on experiences in a) richer countries with a completely different epidemiology than that of sub-Saharan Africa, b) a highly politicised and activist country such as South Africa, and on c) initial ethnographic evidence from West African countries. Although this seems enough evidence to tentatively observe a trend, we need far more evidence from diverse contexts if this transformative potential is to be explored to the full. The paper concludes by drawing out a research agenda.

The Author

Jelke Boesten is a Research Fellow at the International Centre for Participation Studies, Department of Peace Studies, University of Bradford. She is finishing a book entitled *A Different Nation. Gender, Citizenship, and Social Policy in Peru*, based on her PhD thesis which she defended at the University of Amsterdam in 2004. Several related articles have been published in Journals. Currently, she works on a research project looking at meanings of sexual violence in war and peace-time Peru. In addition, she works on a research project examining AIDS activism, violence, and stigma in Sub-Saharan Africa. With Nana Poku, she is editing a book on Gender and AIDS, planned for spring 2008.

AIDS Activism, Stigma and Violence: A literature review

**Jelke Boesten
(University of Bradford)**

This paper provides an overview of the literature on AIDS activism, stigma, and violence. This is motivated by the idea that stigmatisation of HIV-positive people can result in ostracism, neglect, and even physical violence, but that this exclusion can also be turned into positive energy to participate in activism, to form new identities, and to contribute actively to the global response to AIDS.

The idea that HIV-positive people should be active partners in the global response to HIV/AIDS is widely accepted, but not necessarily widely implemented. Since the late 1980s, AIDS activists in the US and Canada have demanded active involvement in decision-making with regard to the AIDS response (Roy and Cain 2001). This demand was reflected in the Paris AIDS summit declaration of 1994, which acknowledged that the involvement of people living with HIV in the response to the AIDS epidemic should be central. The perspective and commitment that HIV-positive people can bring to care and prevention, to public health policy and community intervention, and to the fight against stigma and discrimination was recognized as valuable to interventions proposed by NGOs, governments, and international organizations. This idea became known as an intention to promote *greater involvement of people with AIDS*, or GIPA, and was adopted by all major players in the field, notably the UN and the World Bank. Nevertheless, as activists and observers claim, after the initial excitement about a constructive platform for action, GIPA was found to be tokenistic (Asia Pacific Network... 2004; Alliance 1999; Manchester 2004; Robins 2005; Global Movement of People... 2005). People living with AIDS were often called upon to provide an example, to put a face on the problem, and to tell personal stories. Rarely were they seriously asked for their opinion.

Despite the tokenism of GIPA as a concept and in practice, some organizations and networks of people living with HIV/AIDS have successfully engaged with the global response to AIDS. For example, US networks successfully pressured government and health institutions with regard to access to treatment and trials, and were central to organizing community based care and prevention campaigns. In South Africa, the Treatment Access Campaign (TAC) is increasingly successful in putting pressure on a reluctant South African government, and, in alliance with the government and *Medicins sans Frontières*, even managed to circumvent the power of US pharmaceutical companies (Robins 2004, De Waal 2006). The inclusion of people living with HIV/AIDS in national and international policymaking bodies may be tokenistic, but the activism that HIV-positive people have developed has generated dialogue and involvement.

This review explores how activism among people who are stigmatised and marginalised can be explained. The review is divided into four parts: first, I will examine the literature on AIDS activism and its potential for empowerment and

changing notions of citizenship. Second, I will examine the nature of stigma and its capacity to produce and reproduce inequalities, and its effects on identity. Third, I will briefly explore if stigma involves physical violence and if stigma should be conceptualised as violence. In a last section, I will draw the discussed themes together into a potential research agenda.

Activism, empowerment, citizenship

The majority of the literature on AIDS activism focuses on US and UK activism (Shilts 1987, Kramer 1989, Banzhaf and Act-Up 1990, Chambre 1991, Kayal 1993, Epstein 1996, Callan and Turner 1997, Hallet 1997, Smith and Siplon 2006). This literature – histories and analyses of organisations such as ACT UP, the associated networks, and the gay and lesbian community as major players in this activism – traces the uniqueness of the AIDS epidemic in itself, and the consequential changing social political positions of persons and communities affected. Although the specificity of the US context and the different structures in which AIDS thrives and groups that are affected does not make a comparison between the current African problematic straightforward, there are nevertheless lessons to be learned from the US experience. As Smith and Siplon (2006) show, the increasingly strong ties between US activist groups with ‘Southern’ organizations, their struggles in global activist networks, and the global influence of US policies also justifies a closer look at US activism.

Of the studies discussed below, Michael Hallet’s edited volume *Activism and Marginalisation in the AIDS Crisis* (1997) is the most pessimistic book with regard to activists’ capacity to influence institutional response. Looking at concrete institutional spaces (e.g. the media, prison administrations), the contributors to this volume suggest that institutions use and abuse discourses on AIDS, including activist interventions, to pursue their own interests. Hallet argues that institutions are far more powerful than the gay and lesbian activists (despite the high visibility of their actions), and that these institutions shape policy, neglect alternative discourses, and emphasise and reproduce stereotypical patterns of blame. While the book’s negative assessment is now, luckily, largely outdated by the relative success of US AIDS activism, the theme of Smith and Siplon’s 2006 book *Drugs into Bodies*, the volume’s emphasis on who, where, and how knowledge about AIDS is produced and reproduced, and how such hegemonic discourses on AIDS not only determine policy, but also exclude alternative voices, was and is a dominant theme in the literature on activism and the AIDS response.

Using her work on Zaire as a point of departure, Brooke Grundfest-Schoepf, argues that the management of knowledge, or the ‘struggles over meaning’, are central to the AIDS epidemic in the world. The strong link between power and knowledge can be observed in the effects that HIV has in Africa: as Grundfest-Schoepf further explains, knowledge is socially situated and meaning is constructed on a ‘terrain of unequal power’: ‘In the case of Africa, the defining power lay in the international biomedical arena, but these definitions met with

enduring disease representations and practices, especially with respect to contagion and 'disordered sexuality in afflicted societies. [...] AIDS brings forth representations that support and reproduce already constituted gender, colour, class and national hierarchies' (Grundfest-Schoepf 2004: 15-16). This analysis is of course supported by the work of Paul Farmer who also places the devastation that AIDS causes among certain groups and in certain regions within a geography of world inequality (Farmer 1992, 1999, 2003).¹ We need to take the centrality of inequality, and the role knowledge plays in the reproduction and maintenance of this inequality, seriously when addressing the position of people living with HIV/AIDS and the plight for a more effective response to the epidemic. In that sense, the idea of the *appropriation* of biomedical knowledge and its empowering effects on largely disenfranchised HIV-positive people is highly relevant for a discussion on the changing positions of people living with HIV/AIDS.

The work of sociologist Steven Epstein is notable for this reason, as he has published on knowledge constructions, citizenship and AIDS in the US since the early 1990s (Epstein 1991, 1995, 1996, and 1997). Epstein's work is virtually ignored by the pessimistic contributors to Michael Hallet's volume when he argues that AIDS treatment activists have successfully engaged with the expert knowledge represented by bio-medical professionals. Out of a necessity for knowledge and lay participation in biomedical research, activists have constructed their credibility in the eyes of AIDS researchers and government officials, and have become serious partners in the construction of knowledge. Instead of 'pure' science – insulated from external pressures – AIDS research and knowledge construction became highly influenced by the daily lives and participation of HIV positive activists. A similar argument about the influence of lay knowledge upon the construction of scientific knowledge is made by Steven Robins, a South African social anthropologist. Writing almost a decade later, and in a different social, political and cultural setting, Robins (2004) argues that the South African AIDS epidemic has generated a 'democratization of science'. As a result of inadequate health care facilities, great inequality in access to existing services, and political neglect, people were forced into caring for themselves, creating an alternative community where knowledge and care was shared. Often poor and female, activists of the South African activist network the Treatment Action Campaign became self-educated experts about their own bodies and disease, appropriating biomedical discourse and practice along the way (while others opposed biomedical perceptions of AIDS and denied the relevance of such sciences). In Robins' view, knowledge was not only 'democratized' through this increased popular participation, but it empowered people and created a sense of community necessary to absorb the epidemic's impact and to sustain political pressure. Robins also reflects on the consequences such new forms of participation have on citizenship.

In his 1997 book *Replacing Citizenship: AIDS Activism and Radical Democracy*, Michael Brown examines the idea of changing forms of citizenship in the wake of AIDS activism and new forms of participation (and new groups who participate). In the radicalism of the collective action of ACT UP and less

obviously political activities such as local buddy programs, Brown argues that citizenship is not a static relationship between the individual and the state, but a dynamic practice in which the state, civil society, and the family overlap and interact. Using Canada as his case study, Brown's thesis is largely about broadening our existing understanding of citizenship as a liberal relationship between the state and the individual, to a more communitarian and fluid relationship.

The South African case studied by Robins is, of course, slightly different. Robins (2004) points at a historically marginalized group, comprised of individuals all too often dismissed from full participation as citizens – black, poor and ill men and women in a post-apartheid world. In the process of redefining citizenship through the democratization of biomedical science, people learn to know their bodies and their health, and their rights and entitlements, i.e., they become empowered through participation in AIDS activism and change their status as citizens as a result. Robins even argues that becoming a 'health citizen' is not enough; people also have responsibilities that should go hand in hand with their rights to health care. These responsibilities include active participation in their own treatment as ART otherwise does not work. People have to take control over their own health and seek a positive and collective form of acceptance of HIV, if they are to be expected to adhere to lifelong ARVs. Through participation, activism, and claiming rights to bodily autonomy, however, AIDS activists transform their position from a state of 'near death', physically but above all socially, to 'new life' as responsible and *positive* citizens (2005a, 2005b).ⁱⁱ

Jo Manchester, co-founder of the International Community of Women living with HIV/AIDS, analyses this movement in similar fashion (2004), but is slightly more cautious with regard to its positive impact. Manchester traces the activism of HIV-positive women to the lack of formal support and the prevalence of stigma, shame, and fear. ICW, set up in 1992 on the eve of the World AIDS Conference in Amsterdam (and with headquarters now in London) to fill this abyss of neglect, triggered the establishment of self-help groups and advocacy networks throughout the world, including Southern Africa. Manchester argues that women activists gained support among each other, created spaces for positive living, and were empowered on different levels (practical, knowledge-wise, collective, and personal empowerment). Manchester also looks at the question of participation in shaping the AIDS response. According to the author, the GIPA principle (Greater Involvement of People living with HIV/AIDS) was often empty rhetoric, an expectation for HIV positive people to set an example, but not to actually participate in global or national policy making or even in designing community-level strategies and campaigns. Apart from South African Treatment Action Campaign, discussed by Steven Robins, few national networks of people living with HIV/AIDS have been successful in advocating for further meaningful participation in the AIDS response – or, few governments and global institutions have successfully integrated the view of HIV-positive groups in their policies.

The discussion about citizenship and AIDS activism is pushed further by the medical anthropologist Vinh-Kim Nguyen (2005), who uses the concept of

'therapeutic citizenship' to refer to a similar form of bio-political citizenship as is observed by Robins and Manchester. Drawing on activist networks in Burkina Faso, Nguyen understands therapeutic citizenship as based on being HIV positive (biological) together with certain (political) claims to rights (i.e. access to treatment) and 'ethical projects' – ways of integrating being HIV positive into a (new) moral order. Nguyen argues that AIDS as a phenomenon, and AIDS activism as a practice, has brought together such wide-ranging issues as condom demonstrations, CD4 counts, sexual empowerment, and ethics of sexual responsibility and compliance with drug regimes. This has, in turn, transformed practices of both local and global participation, a reformulation of responsibility, and partially replaced the reliance on kinship or the state as safety nets. According to Nguyen, creating a global alliance in the struggle for antiretroviral therapy, local activists are drawn into discourse and practice that can provide them the minimum of social protection needed to survive in times of AIDS.

The discussion on changing forms of citizenship, i.e., changing forms of interaction between individuals and social groups on the one hand, and the state and its institutions on the other, focuses on the influence of science, biomedical notions and the 'medicalisation,' 'scientisation' and 'normalisation' of reproduction, sexuality, and sexual health (Adams and Pigg, 2005:26, Robins 2007, fn5). In the edited volume *Global Assemblages* (Ong and Collier 2005), Nikolas Rose and Carlos Novas argue that there is – and has been – something we could call biological citizenship, highlighting that the medicalisation of sexual health and reproduction is far from recent, but can be traced back to earlier ideas about race, eugenics, and demographics (2005). Vincenne Adams and Susan Pigg, in turn, observe that the biologisation of sex, and the drawing in of people in 'networks of science' has effects not only on health interventions, but also on 'political movements, identity formation, human rights and new forms of sociability' (Adams & Pigg 2005: 26). Indeed, these authors argue, the increased involvement of people in medicalised understandings and practices of sexual and reproductive health, are only successful if people behave responsibly and in an engaged manner (Rose and Novas 2005, Robins 2007 and 2005b). In response to such foucaultian notions of the all-encompassing reach and universal influence of biomedicine, Steven Robins shows how such notions are constantly, ferociously, and often successfully challenged by more conservative sectors in society, traditionalist views upon sexuality, health, and science. Robins reminds us that morality is indeed not neutral (Adams and Pigg 2005: 26), and that the space in which new forms of AIDS activism and sexual citizenship emerge is a contested one. In this contested space, the role of civil society and social movements in shaping progressive sexual and health rights is, at best, confined to a relatively 'small enclave of the educated middle classes' (Robins 2007).

Robins' conclusion unsettles somewhat the thesis of 'governance from below'. This concept, developed by Arjun Appadurai and others (Appadurai 2002), is often referred to in the case of AIDS activism and new forms of engaging with society and the state. Both Nguyen's study of local activists in Burkina Faso and Robin's studies of activists in South Africa refer to such concepts, although these authors also admit that these developments are in the

early stages and that contention in these processes is inevitable. These studies of the success of local activism also show the importance and even centrality of leadership. While AIDS activist movements often seem highly participatory and relatively democratic – something that is essential for creating the voluntary commitment from HIV-positive people to engage with the communal problematic of HIV/AIDS – they also seem to rely on charismatic, and often educated, leadership. This is certainly the case in South Africa, where Zackie Ahmat is largely responsible for the success of the Treatment Action Campaign, but also seems to fit the case of Burkina Faso studied by Nguyen. Although the centrality of leadership is perhaps not surprising in countries where relatively few people receive formal education and where kinship networks are profoundly shaken by the AIDS epidemic, it does place a question mark on the idea of the democratizing effect of ‘governance from below’.

‘Grass roots globalisation’ or ‘deep democracy’, another term derived from the work of Appadurai, suggests that local networks such as those of the AIDS activists discussed, align themselves strategically with global networks and funding bodies on the one hand, and national institutions and policy makers on the other. Instead of seeking contention over issues that arguably deserve more confrontational politics (De Waal 2006), such grassroots groups seek to influence national and global politics by forging cooperation with the more powerful and the better connected. Of course, such an analysis also has its ‘buts’: as Nguyen observes, community based groups in Africa have often been accused of opportunism, or, in development workers-talk, of being ‘resource-capture driven’. The idea that funds for development projects are used by local elites for their own purposes – i.e., not necessarily for the general good – has also been called ‘elite capture’ (Platteau 2004, Toner 2005). Whereas such reservations with regard to the effectiveness of North-South relations forces us to look critically at the nature of local activism, a longer-term perspective may also show that democratic participation of local groups has slowly increased, and that the appropriation of Western discourses and practices might not turn out as expected, but they may be more effective.

The case studies of local activism show that public engagement with the highly stigmatized issue of HIV/AIDS is, albeit important, not without conflict and that local interpretations of disease, development, gender relations, and reproduction, play an important role in the re-fashioning and appropriation of discourses. In an article on AIDS in Ivory Coast, Nguyen explores ‘confessional techniques’ such as testimonials, role plays and discussion groups as part of the process of ‘coming out’ in public as HIV-positive, a technique championed by international donors (Nguyen 2005b). In this case study, Nguyen explores how ‘imposed’ techniques such as these were, as soon as they had taken root among small groups, appropriated by the participants and fashioned to meet a range of ‘material needs and desires’, including the consolidation and affirmation of sexual identity. Commenting on this study, Nguyen affirms: ‘It would be a mistake to take these early silences as evidence that these techniques were culturally inert and pragmatic failures. These confessional technologies, deployed by the AIDS industry, were taken up by individuals to fashion themselves. The evangelical

idiom within which 'living positively', 'taking responsibility' and 'caring for others' was phrased was not merely a form of religious mimicry but an ethical project, a way of integrating being HIV-positive into a moral order. The direction this ethical project took was determined by the inequalities inherent in the global therapeutic economy' (Nguyen 2005a: 131). The process of grassroots globalization, then, is not necessarily predictable within the paradigms of western benefactors, but is nevertheless a reality of some sorts.

Apart from the theoretical focus on grassroots mobilization, participation, democratization, and new forms of citizenship, AIDS activism can, of course, be analysed through the prism of social movement theory. This is what Smith does in the first part of *Drugs into Bodies* (2006), applying Doug McAdam's political process model (1982). Using broad socio-economic processes, resource mobilisation, mobilising structures, cognitive liberation, and political opportunity as conceptual guidelines, Smith successfully explains how US organisations such as ACT UP became highly visible and relatively successful. The second part of *Drugs into Bodies*, written by Patricia Siplon, is supported by transnational advocacy network theory as developed by Margaret Keck and Kathryn Sikkink (1998). As this model looks at global, dynamic, networks, this fits better with Siplon's analyses of how the US movement allied itself with global networks, and how networks elsewhere became part of this global treatment access movement. Although Siplon's focus is strongly focussed on the contribution of the US movement, and arguably gives too much credit to it as 'leaders' of something far more organic, using network theory may be relevant. Based on Keck and Sikkink, Siplon highlights that transnational advocacy networks, including the global treatment access movement, is characterised by 'voluntary reciprocal and horizontal patterns of communication and exchange and that network members share values and frequently exchange information and services' (Smith and Siplon 2006: 74). She further notes that these networks use four main types of tactics to pursue their goals: a) information politics, generating and sharing information among members also becomes a normative alternative for the media, the public and policy makers, b) symbolic politics, symbols and (personal) stories are strategically used to reach distant audiences, c) leverage politics, refers to the strategic use of more powerful members to convey messages or put pressure, and d) accountability politics, intends to hold powerful actors to their promises.

Although a wink to the social movement literature is useful, contemporary networks and organisations of AIDS activists are perhaps best understood through a transnational network perspective and the conceptualisation of 'global civil society' (Chesters 2005, Corry 2006). For example, Chesters examines how recent struggles against 'neoliberal axioms' are provoking a 're-articulation of a politics that privileges self-organization, direct action, and direct democracy'. Chesters suggests that these emerging networks and their practices attract and disturb existing civil society organizations, and thereby creates something that might be called 'global civil society' (Chesters 2005). Such an analysis could provide an overarching framework for looking at biological citizenship,

therapeutic citizenship, sexual citizenship, and health citizenship as discussed above.

AIDS as a phenomenon and, following from that, AIDS activism, is, if not a product of, then surely strongly influenced by, globalization. Manuel Castells, in his trilogy on the Information Age, observes that the contemporary world is characterized by two seemingly opposing trends, providing a breeding ground for tension and paradox: 'the globalization of economy, technology, and communication, and the parallel affirmation of identity as the source of meaning' (1998: 311). These tensions are visible in the global movement of AIDS activists: the resistance to exclusion and marginalization, caused by the stigma associated with HIV/AIDS, can lead to empowerment and to identities related to sexuality and health, and this process leads to a redefinition of citizenship for those who are consistently marginalized in their own communities and in the global world.

Activism around the world shows that people with HIV are capable of creative collective action which can empower them as citizens and provide for an identity that supersedes exclusion and depression. This 'positive living' – a slogan carrying a double meaning and increasingly used in sub-Saharan Africa and elsewhere to encourage people to take their fate into their own hands, to live responsibly and positively with HIV – has, in theory, the potential to provide the basis for community, inclusion, and even improved AIDS response where people living with HIV/AIDS get actively involved in prevention and care. The positive results of such activism have been observed in Europe and North America since the 1980s, in South Africa since the 1990s, and on a smaller scale in other African, Asian and Latin American countries. We know little about such smaller scale groups, organisations, and networks, but as the work of Vim Kim Nguyen in Burkina Faso and Côte d'Ivoire already discussed indicates, such local involvement might be as globally embedded and potentially transformative as are the Western and South African movements. The tokenism of GIPA might be overtaken by the actual (but for the time being far less visible) empowerment and involvement of people living with HIV/AIDS in alternative global networks. How such processes work in the largely poor and disempowered regions of the world is still subject for research.

Stigma, inequality, and identity

There are several bodies of literature looking at stigma and AIDS. First there is the literature based on social psychology which looks at stigma as a social phenomenon, second, there is a quite extensive body of literature on the US, and third, there is a growing empirical literature which deals specifically with AIDS and stigma in Africa. Of course, these literatures overlap and are in dialogue and cannot and will not be separated as such in this review. Rather, I will present the existing literature by first looking at the social-psychological explanations of the nature of stigma and its embeddedness in structures of inequality, then to

discuss the leading work on stigma in Southern Africa, to close with conceptualisations of stigma and identity.

The pioneer work on stigma is, of course, the work of Ervin Goffman (1990) who in 1963 defined stigma as the 'situation of the individual who is disqualified from full social acceptance'. The sociologist Goffman explains that 'stigma' originally referred to the bodily signifier of moral disgrace, imposed on those who did not conform to the social and moral rules of Greek society, and indicating the need to avoid the stigmatized. Today, Goffman adds, stigma is often more applied to the disgrace itself than to the bodily evidence although stigma is often strongly associated with othering based on physical difference and illness. The groups that are stigmatized, or, in Goffman's words, the 'kinds of disgrace that arouse concern' are susceptible to shifts, indicating the social nature of stigma. Just as in ancient Greece, stigma is a fabrication imposed on certain groups and people and serves a social purpose. It is therefore essential to understand how, why, and with which consequences stigma is attached to certain groups or individuals.

In a 2003 article, Richard Parker and Peter Aggleton observe that much research on stigma and HIV/AIDS uses a static interpretation of Goffman's analysis; stigma as an almost individual 'thing' that one can have. This is, as Parker and Aggleton rightly conclude, a mistaken and not very helpful use of the term, as stigma is particularly a social construct and highly relational (Parker and Aggleton 2003). Stigma related to HIV/AIDS refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have HIV/AIDS and the associated individuals, groups and communities (Herek 1999). In his work on AIDS stigma in the US, Herek recognizes, as others do, that AIDS related stigma is universal, but takes different forms and targets in different countries and communities. These differences are, amongst others, shaped by local epidemiology and preexisting prejudices in any given society (Herek 1999). Parker and Aggleton emphasise that stigmatization 'can only be understood in relation to power and domination [...] stigma plays a key role in producing and reproducing power and control'. Therefore, stigmatization is a tool that allows the reproducing and framing of social inequality (Parker and Aggleton 2003: 16). Thus, to understand particular forms of stigma involving particular groups in any given society requires an understanding of local inequalities and power struggles.

In their very useful conceptual framework to improve our understanding of HIV/AIDS related stigma, Parker and Aggleton link Foucaultian theory with Gramscian hegemony and Bourdieu's concept of symbolic violence (2003). Foucault examined how regimes of power are embedded in different knowledge systems (including, for example, biomedicine or psychiatry) and how such systems can exercise control over individual and social bodies. Foucault argued that physical violence to subject persons and groups was, in the course of late nineteenth and early twentieth century Europe, and later elsewhere, replaced by *subjectification*, or social control through, what Gramsci called hegemonic practice. By constructing 'normality' – by defining abnormality, or deviancy in Goffman's words – bodies were subjected to social control. As Parker and Aggleton highlight, Goffman's and Foucault's subject matter was very similar, but

they emphasise different things, and become complementary in the process: Foucault emphasised the link between the cultural production of difference in the service of power (*ibid*: 17), while Goffman focussed on the workings of this production itself by looking at stigma. Thus, stigma becomes a tool of differentiation and subordination, a mechanism with which to mark inequality and establish hierarchies. When stigma, subordination, and hierarchy become internalised by both 'normal' and 'different', by powerful and excluded, such systems are really effective and have become hegemonic. Of course, for stigma to be so effective, some kind of collective coercion and manipulation must be going on, which can be seen in light of Bourdieu's concept of 'symbolic violence'. Symbolic violence can be seen as a process of hegemony using symbolic systems (words, images, practices) that promote the interests of one group over another and create a credible ranking between social groups. Thus, using political, social, and cultural forces in a complex way that fits the existing norms and values of any society, structures of inequality are legitimised and reproduced (Parker and Aggleton 2003; p18)

Stigma and the processes associated with stigmatization benefit from an analysis which takes into account construction of power and inequality, and the mechanism with which hegemony is maintained and reproduced. However, relations are inherently dynamic and, as James Scott has shown, hegemony also invites resistance, albeit often invisible or seemingly confirming. In order to understand how stigma relates to changing identities – and to the possibility of resistance and empowerment – Parker and Aggleton look at Manuel Castells (1997). Castells examined how changing constructions of identity in the age of globalisation, or, in his own words, the 'information age', relate to stigmatization and oppression. He distinguishes three 'types' of identity: *legitimising identities* which are hegemonic identities that legitimise the dominance of particular groups and or institutions, *resistance identities* generated by those who are on the wrong side of the equation, i.e., these are the groups marginalised from the centre of domination, and *project identities*, which are formed when 'resistance identities' seek new identities that will reposition them in the social domain and will thus transform the existing social structures (Castells 1997, Parker and Aggleton 2003: 19). The observations discussed above of the timid emergence of new forms of citizenship that exceed national borders, that are based on a biological, sexual, health, or therapeutic relationship with the world's institutions, might just be what Castells meant by *project identities*. In time, research might confirm that, whereas resistance against AIDS stigma was very hard to conceptualise and practice, new identities were formed, and thereby, that the stigmatised feature was turned into an empowering and transforming characteristic one should not be ashamed to possess.

Parker and Aggleton also set out a broad research agenda with regard to AIDS-related stigma, differentiating between a) conceptual studies, i.e., studies that might use the above outlined framework to further develop explanatory models for understanding AIDS related stigma; and b) new investigative studies, case studies which disentangle the social processes at work in AIDS related stigma and 'the ways in which such processes contribute to HIV/AIDS

vulnerability, the possibilities for community action and positive participation in reducing stigma and discrimination'. These studies should be specific enough to provide empirical data, but broad enough to provide comparisons and lessons. They further identify that c), there is a need for policy oriented studies that use the conceptual and empirical work to design policies and interventions to reduce stigma, and improve care and prevention. Since Parker and Aggleton published their paper in 2003, much research on AIDS related stigma has been carried out to which I will now turn, with particular reference to Southern Africa.

Stigma research with regard to Southern Africa

Recent work on Africa and AIDS shows that poverty, the structure of institutions, and moral economies play a great role in the persistence and effect of stigma (Campbell et. al. 2005; 2007). Catherine Campbell, professor in socio-psychology at the London School for Economics, studied AIDS related stigma in South Africa working with local research groups. Campbell and her colleagues (2007) conceptualise stigma in a similar way as I explained above. Based on psychology literature (as opposed to the sociology literature of Goffmann and Parker and Aggleton), Campbell explains how general feelings of insecurity turn into fear, which can be projected upon out-groups. Drawing on Joffe (1999), Klein (1946), and Gilman (1988), Campbell et. al. argue that people have a psychological mechanism which makes them project general feelings of fear and insecurity, coupled with more concrete threats (such as HIV), onto identifiable groups that are other than the own. Out-groups are formed, stigmatized, excluded, and discriminated against. This othering provides feelings of comfort and security among the stigmatisers, as it not only excludes people, but seemingly also the object of fear. In the case of HIV, it gives people an unfounded feeling of invulnerability to infection, but also provides a barrier against emotional suffering. As Campbell further explains, these feelings are the key obstacle to HIV prevention efforts and create enormous suffering among those who are stigmatized.

Campbell et. al. identify six main factors that feed into the AIDS-related stigma in South Africa. Firstly, there is a fear embedded in general feelings of insecurity and fear of HIV itself. Secondly, many communities lack information, or make do with competing information which is difficult to verify for people with little access to independent sources of knowledge. Thirdly, there is a lack of social spaces in which HIV and related issues such as sexuality can be discussed. This is of course complementary: stigma feeds into this lack of space and the lack of discussion also feeds in to stigma. Fourth, the link between HIV, sex, morality and power relations is strong: sexual morality can be seen as a mechanism to reinforce inequality and control over certain groups (youth and women). This sexual morality places a taboo on sex itself, making it difficult to discuss and or manage autonomously. Formal structures such as the churches and traditional leadership support this system of control. AIDS makes women's and youths' resistance to such control (their secret sexual activity) visible, and thus stigma serves as a mechanism to reinforce that control: punishing the culprits for their transgression of power relations. A fifth factor that feeds into the

persistence and effectiveness of stigma is an actual lack of services and resources for care and prevention to which people can seek access. This is strongly related to the last factor, poverty. Household poverty as well as community-level lack of resources and financial means feed into the persistence of stigma and the effectiveness of excluding those who are perceived as useless – or even a burden – for the economic survival of such communities (Bond 2005, Smart 2005). Interestingly, Campbell et. al. also mention a socio-psychological factor which has to do with humans' necessity for recognition and external affirmation that most people seek in formal power structures and economic wealth. Standing largely outside of formal power structures and having little to no economic resources with which to affirm one's status in local hierarchies, poor South Africans might seek symbolic resources to distinguish themselves, for example through excluding certain groups and placing one's own group above others (Campbell et. al. 2007). The discussed factors that strongly influence the persistence of stigma can be summarized in three main clusters: i) fear of infection, ii) household and institutional poverty, and iii) the sexual nature of HIV.

Like Parker and Aggleton, Campbell places the reproduction of inequality at the centre of her analysis of stigma. Stigma is not only a social phenomenon that protects against founded or unfounded fears, but it actually excludes certain groups of people in favour of other, more powerful groups. In several other articles, Campbell explores this relationship further and links it to patriarchal power, supported by the church (Campbell, Foulis, Maimane and Sibiya, 2005, Campbell and Maimane 2006 Campbell, Nair, Maimane and Nicholson, 2007a). Being HIV positive makes sexual activity outside the 'allowed' structures visible; it is the evidence of sexual activity outside marriage. As sexual morality is chiefly a mechanism with which women and girls' bodily autonomy is controlled, women and girls are more punished for having HIV than men are (Baileys and Bujra 2000: 4; Scorgie 2002). This means that stigma is gendered: it is not only targeted more at women, blaming women of being the vectors of disease, but it functions as a mechanism, or tool, for further oppression. Campbell and her colleagues call this the 'social psychological policing' of youth and women by punishing those who presumably breach established power relations based on gender, age, and ethnicity. Stigma serves to protect patriarchy, church authority, and generational (adults over young) authority (Campbell, Foulis, Maimane and Sibiya. 2005, Campbell and Maimane 2006).

Both gender and ethnicity play a role in the effectiveness of stigma. Campbell sustains that the patriarchal causes and effects of stigmatizing women is a result of the combination of traditional African culture, a colonial heritage, and religious/missionary patriarchal ideals. In addition, she links this assertion of patriarchy to the lack of other means to assert (male) power and self-esteem. In the meantime, young people's sexuality is often denied, there is little to no communication between generations, little formal education, no leadership for positive change, and no resources for health care and prevention. While stigma plays a controlling and marginalizing role here, it also further constraints communication and leadership to prevent further infections. A range of historical and socio-political factors have led to the disempowerment of community

leadership – a vicious circle that increases the marginalization of HIV-positive people and obstructs positive action. AIDS unsettles existing social relations and makes visible the possible shifts in power. Steven Robins, also referring to South Africa, likewise sees stigma as a conservative reassertion of power relations based on gender and generation, and adds that ethnicity – being black or African – plays a part in self-stigmatization (Robins 2007).

Impact of stigma

The so-called 'grey' literature on stigma is more directed at naming actual expressions of stigma and its effects on prevention and care. Documents published by the USAID organisation for reproductive health policy, Policy Project (nd), by the International Centre for Research on Women (Banteyerga et. al. 2003, Ogden and Nyblade 2005, Smart 2005), and by the Panos Institute (Aggleton and Chase 2001) recognise the centrality that the fight against stigma should take in HIV policy. These documents use case studies from a variety of countries to highlight that stigma not only deters individuals from seeking help and support, from accessing health care and from 'living a life worth living'ⁱⁱⁱ, but also impedes prevention and care. As Ogden and Nyblade observe, a key determinant of effective HIV prevention and AIDS care is the existence of a humane and supportive environment for people living with AIDS. This is, as discussed above, often not the case.

According to the Tanzanian National AIDS Control Programme (NACP), the existing stigma, and in particular, the fear and shame associated with disclosing one's HIV status, prevents many Tanzanians from seeking ARVs (www.PlusNews.org, 25 Oct 2006). This observation is supported by empirical research (Kilewo et al 2001, ICRW 2003). Stigma also increases the incidence of mother-to-child transmission as it might prevent mothers from bottle feeding babies (Whiteside 2006: 1-15, 13; Aggleton and Chase 2001, Bond, Aggleton and Chase 2002). As Aggleton and Chase emphasise: 'women throughout the research were subjected to stigma as women, as HIV-positive women and as HIV-positive women who are pregnant and/or have children. Stigma was reported everywhere to be more extensively directed against women than against men. Stigma surrounding mother-to-child transmission prevents women coming forward for testing, reduces their choices in terms of health care and family life once they are known to be HIV-positive, and negatively impacts on their quality of life' (Aggleton and Chase 2001).

Stigma also affects care regimes. Caregivers often 'hide' ill family members in back rooms, while also hiding their own role as care givers. In doing so, both patient and carer are isolated from their kinship networks and community, and are prevented from using available resources optimally (Small 1996, Radstake 2000, Mill and Mwinituo 2006, Thomas 2006). While there are many examples of the efforts and energy people invest in caring for their loved ones, most go hand in hand with accounts of isolation and deprivation (*ibid.*).

Grey literature also makes an effort to identify expressions of stigma. Such identification may facilitate recognition of stigmatising behaviour in intervention

areas. The table 'expressions and forms of stigma' designed by Ogden and Nyblade (2005) distinguishes between physical, social, verbal, and institutional expressions of stigmatising behaviour. Fifty-two expressions are grouped under these four categories, including beatings, kicks, stone throwing, and arrests (p26). While these are explicitly violent, other actions meant to isolate, blame and shame, exclude or otherwise humiliate people living with HIV, also appear to be rather violent (see below).

Fighting stigma

The literature on the fight against stigma can be divided in two streams: an individual and a social, transformative focus. While these two dimensions are obviously strongly intertwined, for analytical purposes their separation seems helpful. The literature on social transformation is largely meant to feed into policy. Catherine Campbell and her colleagues focus on three different actions: 1) education and information, 2) legislation against health and gender discrimination, and 3) participation and involvement of community members in these efforts to create dialogue and a space for critical learning. While education is widely recognized as central to fighting HIV and related stigma, it is also a tested method (Vavrus 2003, Campbell 2003). According to Campbell and MacPhail (2002), education and information campaigns should be actively directed at democratising local social relationships and should be an empowering process with the aim to change social identities towards more equal gender relations. If not, as the research of the authors shows (see also, Campbell 2003, Vavrus 2003), peer education cannot and will not change sexual behaviour necessary to halt the AIDS epidemic in Africa. This empowering process should be guided by what Freire called the development of 'critical consciousness', i.e., the ability to evaluate and understand the circumstances in which one lives. A sociological understanding of the context of one's own behaviour, especially as shaped by the peer group, might help people to take responsibility to change such behaviour. Through discussion, argument, and reflection, peers might critically change social identities and the norms that determine their sexual behaviour (Campbell and MacPhail, 2002; Campbell 2003: 109, and also 2004 and Campbell et. al. 2007).

Legislative reform is central to fighting stigma and discrimination, and can form a basis for promoting gender equality (Chase and Aggleton 2001, Rwebangira and Tungareza 2000, Smith and Siplon 2006)). A volume edited by Joanna Bond (2004) shows the necessity for legal reform from a feminist point of view, and suggests that such campaigns are being set up throughout sub-Saharan Africa. Not irrelevant to the current debate is the issue of penalization of HIV transmittance and the protection of human rights in general (Global Movement of People Living with HIV/AIDS 2005).

Individual management of stigma is often directly linked to changing identity. Peter K Manning suggests that an HIV-positive person had a 'career line' or went through different 'stages' from ignorance and denial to questioning and worry, and finally of knowledge of being tested positive (Manning in Hallet 1996: xxi). This idea of stages of identity change was further developed by the

sociologists Angelo Alonzo and Nancy Reynolds (1995). Alonzo and Reynolds mapped out what they call a 'stigma trajectory': a) *at risk*, pre-stigma and 'worried well', b) *diagnosis*, confronting and altered identity, c) *latent*, living between illness and health, and d) *manifest*, passage to social and physical death. Such a conceptualisation may be useful in order to increase our understanding of HIV-related altered identity, or, in Goffman's words, 'spoiled' identity. Of course, the question posed by the more recent literature discussed in this review is when, where, and how such a 'spoiled' identity, or manifest road to social and physical death, can be turned around into positive living.

3. Violence

In 1998 Gugu Dlamini, a young woman in Kwazulu Natal decided to 'come out of the closet' about her HIV-positive status and started to campaign on her own and other sufferers' behalf. She was stoned to death in her neighbourhood. (Cited in Van Niekerk 2005: 63).

After telling her children and her mother about her HIV-positive status, Leatitia Hambahlane felt ostracised from her home, and looked upon as a monster. One day local youth barged into her room, cursed her as a witch and a whore and beat her. When she told the police, the youths returned, threatening to burn down the house. (*Ibid.*)

'In 2003, TAC activist Lorna Mlofana aged 21, was gang-raped at a Khayelitsha shebeen toilet in Cape Town, and beaten to death when she told her attackers that she was HIV positive, (cited in Robins 2004: 666)

In Jamaica prominent AIDS activist Steve Harvey was abducted and shot dead. Steve was a brave and committed activist, representing the interests of all people living with HIV/AIDS. In Honduras gay AIDS activist Amed Baraona was brutally stabbed to death. Amed was 25 years young.' (www.gnpplus.net, 20 Dec 2005).

Other anecdotal evidence shows that HIV-positive people are often physically ostracised from their homes and social networks, they lose their jobs, are publicly scolded, beaten up, or their houses are burned down. These extremities of stigma are what people living with HIV/AIDS, scholars and activists tend to call 'social death': before you actually physically die of AIDS or opportunistic infections, you will be declared socially dead by 'society', all too often also by family members. A 1992 survey in the US showed that of 1800 participants, 21.4 per cent had experienced violence because of their status (Herek 1999a). In December 2005, people living with HIV/AIDS associated with the Global network of PLHA pledged to set up a database to register violent incidents committed against them, a project to date not completed. Nevertheless, the above

discussed characteristics of the persistence of stigma plus anecdotal evidence with regard to stigma related violence suggest that this may be a far greater problem than is acknowledged in mainstream policy networks.

The relation between HIV and violence is far more profound and intrinsic than the physical violence committed against HIV-positive people. Ample evidence suggests that women in particular are victims of sexual violence both in war and peace and that this increases their vulnerability to contracting the HIV virus considerably (e.g. Bop 2001, Jewkes et. al. 2003, Bond 2004, Jejeebhoy, Shah, and Thapa 2005). However, it is not only gendered violence that contributes to the persistence of the AIDS epidemic. As scholars such as Brooke Grundfest-Schoepf (2004a/b) and Paul Farmer (1992, 1999, 2003) indicate, the persistent structural and social violence that permeates many developing countries, and the unequal political, economic, and social relationship with the rest of the world that feeds into this structural violence, has contributed profoundly to the dissemination of HIV. Arguably, this structural and social violence continues to determine the effectiveness of interventions and the efforts to halt further infections.

In addition, there is the question of symbolic violence. As discussed above, Bourdieu's idea of symbolic violence as a common tool for reproducing inequalities and consolidating power regimes has conceptual relevance for thinking about HIV-related stigmatisation (Parker and Aggleton 2003, Bourdieu 1977, 2004). Without distinguishing too narrowly between 'physical', 'social' and 'emotional' violence, symbolic violence indicates an effective and tolerated form of small, daily-life oppressive mechanisms that cause the 'victims' of such violence to accommodate themselves in the marginal place in which they are put. Symbolic violence is 'the violence which is exercised upon a social agent with his or her complicity' (Bourdieu and Wacquant 2004). Thus, in the case of AIDS related stigma, such acts result in fear and self-stigmatisation. Self-stigmatisation can lead to acts of hiding away, denial, and fear for exposure. As a result, the dual stigmatisation-self-stigmatisation does not only affect the quality of life of HIV-positive people, but likewise the effectiveness of prevention. If people do not come out about their sero status, or fear testing, then HIV has a fertile ground for further transmission.

Symbolic violence and the self confirmation of marginalisation often also generate resistance in the margins. These moments of resistance against stigmatisation, discrimination, exclusion, marginalisation, and violence can be as hidden and everyday as the symbolic violence which reinforces it: talking to a neighbour about one's suffering, seeking pain killers or medical care by-passing those who stigmatise. When such actions are taken in public or even collectively, everyday resistance becomes something else, perhaps something transformative. Public resistance against stigma might be one of the most important developments in the fight against AIDS. The collective fight against stigma certainly helped contain the spread of HIV in the US and Europe. Today, networks of PLHA in sub-Saharan Africa might have set in motion the most transformative process in the global fight against AIDS. In any case, their efforts are worth further support, study, and resources.

Research Agenda

The literature on AIDS activism, stigma and violence discussed suggests that the physical, emotional and social violence that AIDS as a disease, and stigma as a social construct tied to that disease, can be turned into an empowering experience that joins HIV-positive people in productive and constructive networks, that this empowerment fundamentally changes one's identity, and that such disease-based identities may be reshaping notions of citizenship around the globe. This hypothesis is built, however, on theory and on experiences in a) richer countries with a completely different epidemiology than that of sub-Saharan Africa, b) a highly politicised and activist country such as South Africa, and on c) initial ethnographic evidence from West African countries. Although this seems enough evidence to tentatively observe a trend, we need far more evidence from diverse contexts if this transformative potential is to be explored to the full.

Of course, the empowering potential of networks of AIDS activists is not only, or perhaps I should say, not at all, a result of stigma; rather, it is a resistance against death, a search for physical and social survival in very difficult circumstances. As such, this 'movement' has two components: a biomedical component of physical survival, and a socio-psychological component of social and emotional survival.

Evidence suggests that the use of physical and symbolic violence against people affected by HIV/AIDS is widespread. Nevertheless, there is little analytical understanding of the role of such violence within communities, and in people's personal lives. The literature discussed suggests that introducing an analysis of violence as a mechanism used to stigmatise and thereby, for reproducing inequality in families, communities, and larger social entities such as (inter)national institutions, may be helpful if we want to further understand the effectiveness of stigma, fear, and self-stigma. If we can document and understand the use of violence better, perhaps it also becomes easier to develop mechanisms to counter such violence.

Based on these thoughts, there are four main themes that can be identified as in need of further research. I propose the following research priorities: i) *Stigma and violence*; how to conceptualise the violent expressions of AIDS stigma, and examine the latter as a serious element of the relationship between violence, sex, and stigma? ii) *Gendering stigma*; if stigma is a mechanism to reproduce gendered and generational inequality, how is this gendering reflected in daily stigmatisation and daily activism? iii) *Illness, identity, citizenship*; what is the relation between stigma- (social) and illness- (biological) induced identity formation, citizenship, empowerment, and activism in a poor country such as Tanzania? iv) *AIDS Activism: possibilities and constraints*, how does personal misery lead to local activism, and how does local activism link up to global trends? Is AIDS activism perhaps more powerful (transformative) than formal structures such as GIPA?

Notes

ⁱ The relationship between knowledge and power is often associated with Foucault. His work is of relevance here and seems to confirm the validity of his theories beyond his own case studies. However, as Brooke Grundfest-Schoepf suggests (2004: 121), the awareness of the power of knowledge long predates Foucault. In addition, in the case of AIDS the link between power and knowledge is strongly linked to a complex global system of inequality and structural violence.

ⁱⁱ The concept of 'near death' may also be explored in relation to Butler's 'livable life', i.e., what is needed to live a life worth living?

ⁱⁱⁱ This phrase, taken from Judith Butler (2004), indicates the dilemmas of living with HIV in general, but particularly in Africa where poverty, stigma and structural violence make living openly with HIV a very difficult task. In future writings, the notion of a 'life worth living', the search for a 'precarious future' (Boesten 2007) and the collective project of 'living with hope' will be further explored.

Bibliography

Adams, V. and S. L.Pigg. 2005. *Sex in Development: Science, Sexuality, and Morality in Global Perspective*. Durham, Duke University Press.

Aggleton, P., and E. Chase. 2001. 'Stigma, HIV/AIDS and Prevention of Mother-to-Child Transmission: A Pilot Study in Zambia, India, Ukraine and Burkina Faso.' from http://www.unicef.org/AIDS/AIDS_panosreportBS.pdf (Accessed Jan. 2007).

Alonzo, A. A. and N. R. Reynolds. 1995. 'Stigma, HIV and AIDS: An Exploration and Elaboration of a Stigma Trajectory', *Social Science and Medicine* 41 (3): 303-315.

Appadurai, A. 2000. 'Grassroots Globalization and the Research Imagination', *Public Culture* 12(1): 1-9.

Appadurai, A. 2002. 'Deep Democracy: Urban Governmentality and the Horizon of Politics', *Public Culture* 14(1): 21-47.

Asia Pacific Network of People Living with HIV/AIDS APN+. 2004. 'Position Paper 2 GIPA'

International Center for Research on Women (ICRW).2003. *Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia*, Washington DC, International Center for Research on Women (ICRW).

Banzhaf, M. with New York ACT UP. 1990. *Women, AIDS, and Activism*. Boston, MA, South End Press.

Baylies, C. L. and J. M. Bujra. 2000. *AIDS, Sexuality and Gender in Africa: Collective Strategies and Struggles in Tanzania and Zambia*. London and New York, Routledge.

Boesten, J. 2007. 'Precarious Future: Health Care Provision, Community Volunteers and HIV/AIDS in a Roadside Town, Tanzania.' ICPS Working Paper 4, International Centre for Participation Studies, University of Bradford.

Bond, V., E. Chase, and P. Aggleton, 2002. 'Stigma, Hiv/Aids and Prevention of Mother-to-Child Transmission in Zambia.' *Evaluation and Programme Planning* 25: 347-356.

Bond, J. 2004. *Voices of African Women: Women's Rights in Ghana, Uganda, and Tanzania*. Durham, N.C., Carolina Academic Press.

Bond, V. 2005. *Stigma When There Is No Other Option*. Paper presented at the International Conference HIV/AIDS and Food and Nutrition Security, 14-16April,

Durban <http://www.ifpri.org/events/conferences/2005/durban/ppt/bondPP.ppt>
[retrieved, January 2007]

Bond, V., E. Chase, and P. Aggleton, 2002. 'Stigma, Hiv/Aids and Prevention of Mother-to-Child Transmission in Zambia.' *Evaluation and Programme Planning* 25: 347-356.

Bop, C. 2001. 'Women in Conflicts, Their Gains and Their Losses', in *The Aftermath: Women in Post-War Transformation*. S. Meintjes, A. Pillay and M. Turshen (eds.), London and New York, Zed Books: 19-34.

Bourdieu, P. 1977. 'Sur le pouvoir symbolique.' *Annales* 3: 405-11.

Bourdieu, P. 2004. 'Gender and Symbolic Violence', in *Violence in War and Peace*. N. Scheper-Hughes, and Phillippe Bourgois (eds.), Oxford and New York, Blackwell: 339-342.

Brown, M. P. 1997. *Replacing Citizenship: AIDS Activism and Radical Democracy*. New York, Guilford Press.

Butler, J. 2004. *Undoing Gender*. New York and London, Routledge.

Callan, M, and D. Turner (1997). 'A History of the People Living with AIDS Self-Empowerment Movement.' *Body Positive Magazine* 10(12): 12-25.

Campbell, C., and C. MacPhail. 2002. 'Peer Education, Gender and the Development of Critical Consciousness: Participatory HIV Prevention by South African Youth.' *Social Science and Medicine* 55(2): 331-345.

Campbell, C. 2003. *Letting Them Die: Why HIV/AIDS Intervention Programmes Fail*, Oxford, International African Institute.

Campbell, C. 2004. 'Creating Environments That Support Peer Education: Experiences from HIV/AIDS-Prevention in South Africa', *Health education* 104(4): 197-200.

Campbell, C., C. A. Foulis, S. Maimane and Z. Sibiyi. 2005. "'I Have an Evil Child in My House": Stigma and HIV/AIDS Management in a South African Community', *Public Health Matters* 95(5): 808-815.

Campbell, C., Y. Nair, S. Maimane and J. Nicholson. Forthcoming 2007a. "'Dying Twice": A Multi-Level Model of the Roots of AIDS Stigma in Two South African Communities', *Journal of Health Psychology* 12(3).

Campbell, C., Y. Nair, S Maimane, and Zweni Sibiyi, Forthcoming 2007b. 'Building Contexts That Support Effective Community Responses to HIV/AIDS: A South African Case Study', *American Journal of Community Psychology*.

Campbell C, Y. Nair, and S Maimane. 2006. 'AIDS Stigma, Sexual Moralities and the Policing of Women and Youth in South Africa', *Feminist Review* 83 (Special Edition on Sexual Moralities).

Castells, M. 1997. *The Power of Identity*. Malden, Mass., Blackwell.

Castells, M. 1998. *End of Millennium*. Malden, MA, Blackwell Publishers.

Chambre, S. 1991. 'The Volunteer Response to the AIDS Epidemic in New York City: Implications for Research on Voluntarism', *Nonprofit and Voluntary Sector Quarterly* 20(3): 279-280.

Chesters, G. 2005. 'Global Complexity and Global Civil Society', *Voluntas: International Journal of Voluntary and Nonprofit Organizations* 15(4): 323-342.

Corry, O. T. 2006. 'Global Civil Society and Its Discontents', *Voluntas: International Journal of Voluntary and Nonprofit Organizations* 17(4): 302-323.

De Waal, A. 2006. *AIDS and Power: Disease and Democracy in Africa*. New York, Zed Books in association with the International African Institute.

Epstein, D., R. Morrell, R. Moletsane, and E. Unterhalter. 2004. 'Gender and HIV/AIDS in Africa South of the Sahara: Interventions, Activism, Identities', *Transformation: Critical Perspectives on Southern Africa* 54: 1-16.

Epstein, S. 1991. 'Democratic Science? AIDS Activism and the Contested Construction of Knowledge', *Socialist Review* 21(April-June): 35-64.

Epstein, S. 1995. 'The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials', *Science, Technology & Human Values*, 20(4): 408-437.

Epstein, S. 1996. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley, University of California Press.

Epstein, S. 1997. 'AIDS Activism and the Retreat from the 'Genocide' Frame', *Social Identities* 3(3): 415-438.

Farmer, P. 1992. *AIDS and Accusation: Haiti and the Geography of Blame*. Berkeley, University of California Press.

Farmer, P. 1999. *Infections and Inequalities: The Modern Plagues*. Berkeley, University of California Press.

Farmer, P. 2003. *Pathologies of Power: Health, Human Rights, and the New War on the Poor*. Berkeley, University of California Press.

Gilman, S. L. 1988. *Disease and Representation: Images of Illness from Madness to AIDS*. Ithaca, Cornell University Press.

Global Movement of People Living with HIV/AIDS 2005. 'Revitalising the Global Movement of People Living with HIV/AIDS, a Think Tank Meeting'. Nairobi, Kenya.
http://www.gnpplus.net/cms-downloads/files/Nairobi_meeting_report.pdf.
[retrieved April 2006]

Goffman, E. 1990 [1963]. *Stigma: Notes on the Management of Spoiled Identity*. New York and London, Penguin.

Grundfest-Schoepf, B. 2004a. 'AIDS in Africa: Structure, Agency and Risk', in *HIV & AIDS in Africa. Beyond Epidemiology*. E. Kalipeni, S. Craddock, J. Oppong, and J. Gosh (eds.), Oxford, Blackwell Publishing: 121-132.

Grundfest-Schoepf, B. 2004b. 'AIDS, History and Struggles over Meaning', in *HIV & AIDS in Africa. Beyond Epidemiology*. E. Kalipeni, S. Craddock, J. Oppong, and J. Gosh (eds.), Oxford, Blackwell Publishing: 15-28.

Hallett, M. A. 1997. *Activism and Marginalization in the AIDS Crisis*. New York, Haworth Press.

Herek, G. M. 1999. 'AIDS and Stigma.' *Am Behav Scientist*. 42(7): 1106-16.

Jejeebhoy, S. J., I. H. Shah, et al. 2005. *Sex without Consent: Young People in Developing Countries*. London and New York, Zed Books.

Jewkes, R. K., J. B. Levin, and L. A. Penn-Kekana, 2003. 'Gender Inequalities, Intimate Partner Violence and HIV Preventive Practices: Findings of a South African Cross-Sectional Study.' *Social Science and Medicine* 56: 125-134.

Joffe, H. 1999. *Risk and 'the Other'*. Cambridge; New York, Cambridge University Press.

Kayal, P. M. 1993. *Bearing Witness: Gay Men's Health Crisis and the Politics of AIDS*. Boulder, Westview Press.

Keck, M. E. and K. Sikkink. 1998. *Activists Beyond Borders: Advocacy Networks in International Politics*. Ithaca, N.Y., Cornell University Press.

Kilewo C, M. A., E. Lyamuya, I. Semali, F. Kalokola, E. Urassa, M. Giattas, F. Temu, K. Karlsson, F. Mhalu, and G. Biberfeld. 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.' *J Acquir Immune Defic Syndr.* 28(5): 458-62.

Klein, M. 1946. 'Notes on Some Schizoid Mechanisms.' *International Journal of Psychoanalysis* 27: 99-110.

Kramer, L. 1989. *Reports from the Holocaust: The Making of an AIDS Activist.* New York, St. Martin's Press.

Manchester, J. 2004. 'Hope, Involvement and Vision: Reflections on Positive Women's Activism around HIV', *Transformation: Critical Perspectives on Southern Africa* 54: 85-103.

McAdam, D., 1982. *Political Process and the Development of Black Insurgency, 1930-1970.* Chicago, Illinois: University of Chicago Press.

Mill, J. E., and P. Mwinituo. 2006. 'Stigma Associated with Ghanaian Caregivers of AIDS Patients.' *Western Journal of Nursing Research* 28(4): 369-382.

Nguyen, V.-K. 2005a. 'Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship'. In Aihwa Ong and Stephen J. Collier (eds.), *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems.* Oxford, Blackwell Publishing.

Nguyen, V.-K. 2005b. Uses and Pleasures: Sexual Modernity, HIV/AIDS, and Confessional Technologies in a West African Metropolis. In V. Adams and S.L. Pigg (eds.), *Sex in Development. Science, Sexuality, and Morality in Global Perspective,* Durham and London, Duke University Press: 245-268.

Ogden, J., and L. Nyblade. 2005. *Common at Its Core: HIV and AIDS Stigma across Contexts.* Washington DC, ICRW.

Ong, A. and S. J. Collier (2005). *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems.* Oxford, Blackwell Publishing.

Parker, R., and P. Aggleton, 2003. 'HIV and AIDS-Related Stigma and Discrimination: A Conceptual Framework and Implications for Action', *Social Science and Medicine* 57(1): 13-24.

Platteau, J.-P. 2004. 'Monitoring Elite Capture in Community-Driven Development', *Development and Change* 35(2): 223-246.

Policy Project n.d. *Siyam'kela. Measuring HIV/AIDS Related Stigma. A Literature Review*. Pretoria, Policy Project, USAID.

Program on International Health and Human rights. 2006. *HIV/AIDS: A Gender-Based Violence Literature Review*, Harvard School of Public Health.

Program on International Health and Human rights. 2006. 'Meeting Report'. Paper presented at: Action on Gender-based Violence and HIV/AIDS, Toronto, Harvard School of Public Health.

Radstake, M. 2000. *Secrecy and Ambiguity: Home Care for People Living with HIV/AIDS in Ghana*. Leiden, African studies Centre.

Robins, S. 2004. "'Long Live Zackie, Long Live": AIDS Activism, Science and Citizenship after Apartheid.' *Journal of Southern African Studies* 30(3): 651-672.

Robins, S. 2005a. 'Rights Passages from "near Death" to "New Life": AIDS Activism and Treatment Testimonies in South Africa', IDS Working Paper 251, Institute of Development Studies, University of Sussex.

Robins, S. 2005b. 'Rethinking Rights and Responsibilities in a Time of AIDS.' From: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC20709> Retrieved, January 2007

Robins, S. Forthcoming 2007. "'Brothers Are Doing It for Themselves". AIDS Activism, Sexual Politics and "New Masculinities" after Apartheid.' *Journal of Southern African Studies*.

Rose, N., and Carlos Novas, 2005. 'Biological Citizenship', in Aihwa Ong and Stephen J. Collier (eds.), *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, Oxford, Blackwell: 439-463.

Roy, C. M., and R. Cain, 2001. 'The Involvement of People Living with HIV/AIDS in Community-Based Organizations: Contributions and Constraints.' *AIDS Care* 13(4): 421-432.

Rwebangira, M., and M. Tungaraza, 2000. 'Review and Assessment of Laws Affecting HIV/AIDS in Tanzania'. Tanzania Women Lawyers Association, Dar Es Salaam.

Scorgie, F. 2002. 'Virginity Testing and the Politics of Sexual Responsibility: Implications for AIDS Intervention.' *African Studies* 61 (1): 55-75.

Shilts, R. 1987. *And the Band Played On: Politics, People, and the AIDS Epidemic*. New York, St. Martin's Press.

Small, N. 1996. 'Intimacy, Altruism and the Loneliness of Moral Choice: The Case of HIV Positive Health Workers', in J. Weeks and J. Holland (eds.), *Sexual Cultures: Communities, Values, and Intimacy*. New York, St. Martin's Press: 201-219.

Smart, T. 2005. HIV Stigma, Treatment and Prevention. *IV InSite*, University of California San Francisco, <http://hivinsite.ucsf.edu/InSite?page=pa-hatip-56> [Retrieved November 2006]

Smith, R. A. and P. D. Siplon 2006. *Drugs into Bodies: Global AIDS Treatment Activism*. Westport, Conn., Praeger.

Thomas, F. 2006. 'Stigma, Fatigue and Social Breakdown: Exploring the Impacts of HIV/AIDS on Patient and Carer Well-Being in the Caprivi Region, Namibia.' *Social Science and Medicine* 63(12): 3174-3187.

Toner, A. 2005. 'The Illusion of Community Ownership: Community-Based Water Management in Uchira, Tanzania'. Paper presented at: East African River Basin Conference 7th-9th March 2005, Sokoine University of Agriculture (SUA), Morogoro, Tanzania, SUA.

Van Niekerk, A. A. 2005. Moral and Social Complexities of AIDS in Africa. In A.A. Van Niekerk and L. M. Kopelman (eds.), *Ethics & AIDS in Africa : The Challenge to Our Thinking*, Walnut Creek CA, Left Coast Press: 53-70.

Van Niekerk, A. A. and L. M. Kopelman (2005). *Ethics & AIDS in Africa: The Challenge to Our Thinking*. Walnut Creek CA, Left Coast Press.

Vavrus, F. K. 2003. *Desire and Decline: Schooling amid Crisis in Tanzania*. New York, P. Lang.

Whiteside, A. 2006. 'HIV/AIDS and Development: Failures of Vision and Imagination' *International Affairs* 82(2): 327-343.

Websites:

www.PlusNews.org, 25 Oct 2006

www.gnpplus.net,

International Centre for Participation Studies
Department of Peace Studies
University of Bradford
BD1 1DP

Working Paper No. 5, 2007