



# The Role of Social Research in the Fight Against HIV/AIDS in Brazil and South Africa, 1990s-2010s

## An Assessment of the Socio-Political Context of Knowledge Production and Use

José Katito

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The Role of Social Research in the Fight Against HIV/AIDS  
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An Assessment of the Socio-Political Context of Knowledge Production and Use

PhD Thesis in Sociology

José Katito

Supervisor: Peter Wagner

TRAMOD Project

University of Barcelona



TO THE TRAMOD PROJECT AND MEMBERS

*For the great opportunity that has enabled me  
to address such a central contemporary issue.*

*The AIDS epidemic is now considered not only a health  
problem, but also a development issue as well as a security  
threat.*

Javed Mohammad Iqbal (2009: 1)

*The urgent nature of the AIDS epidemic should push  
researchers towards new ways of thinking about and doing  
social science research.*

Naydene de Lange (2012: S9)

*Scientific research can only be conducted in a social system that is  
willing to take a critical look at itself. AIDS has forced us to  
examine certain previously ignored aspects of social life. Social  
as well as other scientists should be given opportunities to  
contribute to the development and evaluation of more effective  
methods for preventing the transmission of HIV.*

William W. Darrow (1991: 99)



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## ACRONYMS AND ABBREVIATIONS

ABIA	Associação Brasileira Intersdisciplinar de AIDS
ABRASCO	Associação Brasileira de Saúde Coletiva
ANC	African National Congress
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ARV	Antiretroviral
AZT	Azidothymidine (ARV drug)
CSO	Civil society organization
CSW	Commercial Sex Worker
Pharmas	Pharmaceutical companies
HAART	Highly Active Antiretroviral Treatment
HEAIDS	South Africa's Higher Education HIV and AIDS Programme
HEI	Higher Education Institution
HIV	Human Immunodeficiency Virus
HPV	Human Papillomavirus
HSRC	Human Sciences Research Council South Africa
IAS	International AIDS Society
IDU	Injecting/Intravenous Drug User
IMS	Instituto de Medicina Social
JIAS	Journal of the International AIDS Society
LGBT	Lesbian, Gay, Bisexual, Transgender/Transvestite
MSM	Men who have sex with men
NACOSA	National AIDS Convention of South Africa
NAP	National AIDS Program (Brazil)
NAPWA	National Association of People With AIDS
NEPAIDS	Núcleo de Estudos para a Prevenção da AIDS
NGO	Non-Government Organization
PEP	Post-exposure Prophylaxis
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission
PrEP	Pre-exposure Prophylaxis
SAUVCA	South African Universities Vice-Chancellors Association
SANAC	South African National AIDS Council
STI	Sexually Transmitted Infection
TAC	Treatment Action Campaign (South Africa)
TasP	Treatment as Prevention
UCT	University of Cape Town
UERJ	Universidade Estadual do Rio de Janeiro
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNGASS	United Nations General Assembly
VCT	Voluntary Counseling and Testing
WHO	World Health Organization
WTO	World Trade Organization



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## Introduction: HIV/AIDS and engaged social-science

*Social science is a bit like oxygen for modern democratic societies. It is of vital importance for any democracy that there is a free, dynamic, and critical discussion based on rational arguments, and hence also systematic, secular, and empirically validated knowledge about the basic features of the society we live in.*

Anna Larsson & Per Wisselgren (2013: 9)

### A. Objectives

The general objective of the present dissertation is to contribute to building a comparative analysis of social-science knowledge oriented to health-promotion. The discussion is concentrated on the 21<sup>st</sup> century pandemic denominated *Human Immunodeficiency Virus Infection/Acquired Immunodeficiency Syndrome (HIV/AIDS)*. The starting point of the discussion can be phrased as follows. Various fields and actors have been explored to understand the responses of nations to the HIV/AIDS epidemic, including state, civil society, public health systems, and the pharmaceutical industry. Multi and cross-disciplinary analyses have been prominent and the links between the aforementioned actors have been extensively documented to highlight the extent to which states and communities interact in order to advance HIV/AIDS prevention, treatment and care. Thus, approaches that look at institutional practices and cultural repertoires in an integrated manner have emerged in the field of HIV/AIDS, grasping the complexity of the epidemic and, consequently, suggesting holistic interventions in the sense of both politico-economic investment and cultural change. However, the role of social-science knowledge in states' capacity to tackle HIV/AIDS has been largely disregarded.

Scientists are often expected to play an active role in the realm of health promotion by having an informed understanding of the complexities of the illness-health process.

Social scientists are, therefore, expected to suggest sustainable measures which are conducive to healthier societies. Such expectation is grounded in the reasoning according to which intellectuals are always in a symbolic relationship with their time and have the task of representing collective suffering, for in the public consciousness they represent a force which can be mobilized on behalf of an ongoing struggle or embattled community, for example people living with HIV/AIDS (PLWHA) (Kippax 2012; Volks 2012: 8). In this sense, as Mary Crewe (2012: 51) explains, dealing with HIV/AIDS in the tertiary sector, both theoretically and practically, touches the heart of what the concept of university truly is, all about meaning its core functions of exploration, critique and creation of new knowledge.

In Brazil and South Africa, Higher Education Institutions (HEIs) and educators in general have historically been expected to be proactive in their nation's development. These expectations have been increasingly high since the devastating impact of HIV/AIDS became evident, showing a level of complexity that can only be understood through well informed social science. It is widely acknowledged that social scientists - generally viewed as well informed agents of HIV/AIDS prevention and health promotion - can and should provide an important link to saving lives and contribute to building a better future. In South Africa, particularly, this has revitalized the debate on engaged scholarship and use-inspired research. David Cooper (2011) conceptualizes engaged scholarship, particularly use-inspired research, in terms of a "third academic mission"; rooted in university social responsibility principles to directly and consciously contribute to national development, this third academic mission goes beyond the two traditional vocations of Higher Education, namely, teaching (first mission) and carrying out pure research (second mission).

I suggest that despite social scientists' awareness of contributing to curbing such an entrenched epidemic as HIV/AIDS, little is done to scrutinize the opportunities that social scientists have of making a difference in this struggle, as well as the challenges they face in the socio-political, economic and academic contexts in which they operate. More importantly, although the role of social-science is largely recognized as indispensable for the prevention of HIV/AIDS and health promotion generally, little is known about the impact of the academically produced social-science knowledge on HIV/AIDS policies. In other terms, social researchers have disproportionately focused on the most visible actors involved in health-promotion activities oriented towards HIV/AIDS, such as policy-makers (national and international), the pharmaceutical industry, and civil society

organizations. Ultimately, little is known about how social-science knowledge on the HIV/AIDS epidemic is produced, made available to and used by the aforementioned actors. In this regard, the socio-political contexts of HIV/AIDS scholarship, including use-inspired research and research-action, remain largely understudied.

The socio-political context is critical to understanding the role of social-science in HIV/AIDS prevention programs. It consists not only in conceptualizing HIV/AIDS as a pressing social problem, but above all in examining the complexity of the epidemic. In this sense, social-science is vital to demonstrating that: firstly, the HIV/AIDS epidemic is linked to a combination of biomedical, behavioral and structural factors or social drivers (Mannell et al. 2014; Parkhurst 2014); and secondly, effective prevention entails developing collective action and community capacity, and requires the public health system to address people not only as individuals but also as connected members of groups, networks and collectives in interaction (Kippax 2012: 1). This is especially true in the worst affected and at-risk countries like South Africa, where the epidemic is likely to affect every aspect of life, be it family, education, industry, livelihood, gender relations, governance or security.

The structural context of HIV/AIDS includes not only poverty and inequalities in access to health care (Rocha et al. 2011), but also cultural and political reluctance to respond significantly to the needs of vulnerable populations and communities (Parker & Aggleton 2013: 42). Structural factors shape the ways in which individuals, communities and institutions understand the HIV/AIDS pandemic. For example, social circumstances like poverty, violence, stigmatization, discrimination, denial, and fatalism often prevent people from coming forward for HIV testing or treatment uptake. These problems also partly explain why biomedical and public health systems often fail to respond effectively to the epidemic, especially in low and middle-income settings where HIV transmission remains unabated, despite some improvement in prevention campaigns and access to treatment. What is needed is “combination prevention” in the sense of interventions addressing the social drivers of vulnerability needed for effective and sustainable HIV/AIDS response, emphasizing the value of comprehensive interventions which combine biomedical models with social or structural programming (Mannell 2014: 1). Indeed, as Naidoo and Misra (2008) point out, HIV/AIDS is closely connected to the daily cultural, moral, economic and political panoramas, which means talking about HIV/AIDS in terms of causes, effects and prevention implies touching issues related to power, inequalities, as well as the context that defines who has or is entitled to having access to material and

symbolic resources. The authors (p. 1) specify that “such politics are played out not only in public arenas at macro-structural or institutional level - in law, policy, governance and media - but equally and importantly in moments and spaces that pertain to the most intimate and mundane aspects of the lives of ordinary people”. In short, as Watkins-Hayes (2014: 431) expresses it, HIV/AIDS is an epidemic of intersectional inequality that is fueled by class, racial, gender, and sexual inequities at the macro-structural, meso-institutional, and micro-interpersonal levels – which shape the likelihood of exposure to the virus; the realities of living with the infection; and medical, programmatic, political, and social-scientific responses.

In Brazil and South Africa, class, race and gender are largely documented as being the chief determinants of health generally, and this is especially true when the three variables are concatenated. With regard to HIV/AIDS, class-race-gender as a combined variable enables us to understand the complexity of the social construction of sexuality and health protection within concrete material and symbolic universes. This implies that scholarly reflections and interventional strategies directed towards alleviating the impact of HIV/AIDS require holistic approaches that look closely at the multidimensional or multilayered nature of the epidemic, disentangling the economic, political and socio-cultural dimensions of both vulnerability to the infection and the likelihood of success of intervention programs.

Having said this, the specific objective of the present work is to analyze comparatively the role of social-science knowledge in HIV/AIDS policy in Brazil and South Africa. The period considered extends from the 1990s to the present. It is in the 1990s when - a decade after the emergence of the epidemic - the major social studies were first conducted in the light of the epidemic’s trajectories and the related responses from various constituencies in the two countries, and globally. In the 1990s context, social scientists progressively recognized the impact of the HIV/AIDS crisis on societal spheres, including the social sciences, and started reasoning in terms of common threads between this new social problem and the social sciences (i.e. Ulack & Skinner 1991). The 2000s decade would witness impressive production of social-science knowledge on HIV/AIDS from various angles, which has consolidated inter/cross-disciplinary projects and academic institutions dealing with the epidemic (Mayer & Pizer 2004).

The discussion tries to step beyond pure analysis, holding a critical and normative stance: social justice. The core argument is that Brazil has been far superior to South Africa in terms of the timing and consistency of the inclusion of social-science knowledge in HIV/AIDS policies, thanks to an earlier and stronger collaboration among social scientists, politicians and AIDS movements. Therefore, the discussion tries to illustrate

the importance of social-science knowledge for health policy – HIV/AIDS policy in this case – through theoretical reflection, use-inspired research and research-action. To clarify, we here take the opportunity to define use-inspired research and research-action.

Use-inspired research is a type of scientific inquiry which seeks to produce an impact on society by delivering interventional or usable knowledge. Use-inspired research can either be commissioned by an interested non-academic entity or autonomously emerge from the scientists' will to make their work relevant beyond the academic world. Research-action (or action-research, as non-academic practitioners prefer calling it) is a specific type of use-inspired research that can be defined as a problem-solving cross-disciplinary and theoretical-practical approach that emphasizes participatory and democratic processes in pursuit of social change, that is relevant to people, especially to those socially disadvantaged (Reason & Bradbury 2001: 1). Combining reflection, theory and practice, research-action addresses issues of pressing concern to people and aims towards fostering social change through the empowerment of persons and their communities. Research-action is generally synthetically referred to as Community-Based Participatory Research (CBPR), and has been a central issue in development literature, as well as in health and social care studies (i.e. Winter & Munn-Giddings 2011; Horowitz et al. 2009).

The construction of emancipatory critical consciousness is particularly underlined in use-inspired research and research-action.

For academic researchers, participatory problem-solving represents a great opportunity for revitalizing theoretical and methodological approaches, since this scholarship helps to generate new data, ideas and concepts stemming from engagement with non-academic spheres.

I suggest that in the initial years of the HIV/AIDS epidemic, use-inspired scholarship and research-action found more fertile terrain in Brazil than in South Africa, which has contributed to radically divergent HIV/AIDS policies in the two countries. Combined with major national unity or sense of political community and openness to sex and sexuality discourses, the support and use of social-science insights by Brazil's politicians helped the country to forge aggressive HIV/AIDS policies. Often in symbioses with civil society organizations, social scientists in Brazil could infuse HIV/AIDS policies with concepts such as social vulnerability and structural factors, emphasizing both the economic dimensions (poverty and inequalities) and symbolic aspects (status, pride, self-esteem, shame and stigma, among others) of the health-illness process. This helped the

state to elaborate realistic political approaches on how to deal with the epidemic, seeking to support the empowerment of HIV-affected groups, including gays and injecting intravenous drugs users (IDUs) as agents of prevention.

In South Africa, by contrast, although some social research on the HIV/AIDS crisis in the country was already being undertaken, trying to contribute to building a modern democratic society in which inclusive science is given a central role, hostile political climate to HIV/AIDS science prevented social scientists from becoming key protagonists of HIV/AIDS prevention beyond the academic boundaries. HIV/AIDS social-science was isolated and often obstructed by the state, which made it difficult for social scientists to be vocal about the impact of the HIV/AIDS calamity in the country. Social scientists in South Africa could not make their voice heard to the post-apartheid government regarding, for example, the government's position on tackling the epidemic, in the end between 1990s and the beginning of 2000s when president Thabo Mbeki administration challenged, better yet, discredited the authority of HIV/AIDS biomedical science, and ultimately prohibited the use of ART in the public health system. Relatedly, social scientists could not speak out against the culture of silence that surrounded sex and sexuality, a behavior that still characterizes South Africa's society. Academics could engage more easily with civil society organizations which - besides and through prevention activities in communities - sought to advocate for public ART treatment, denouncing the state's lack of political will to protect its citizens in violation of the constitutionally enshrined right to health service. Consequently, it is only over the last decade or so that South Africa has started making efforts to truly include social scientists in anti-AIDS agendas.

Hence, use-inspired social-science is one of the forces responsible for the current HIV/AIDS scenarios in Brazil and South Africa. The prevalence rate in Brazil is estimated at less than 1% in the population aged 15-49, and the country is considered a world leader in terms of integrated plan of prevention, treatment and care. Conversely, effective actions against the pandemic in South Africa were late to emerge and, with 18% of HIV/AIDS infected in the 15-49 year old population, South Africa is at the top of the world's most affected countries. The 1993-2003 decade particularly, shows that Brazil acted far more aggressively and in consonance with mainstream HIV/AIDS social science, as well as orthodox biomedicine. 1993 is an important historical moment for both countries. Brazil started to receive loans from the World Bank, which helped the country improve not only its HIV/AIDS policies as such (Gauri & Lieberman 2004), but also scientific research in

every relevant field, including social-science research. In South Africa 1993 was the final year of the Apartheid regime. Following negotiations between the African National Congress (ANC) and the apartheid government, a comprehensive HIV/AIDS plan was developed in the transition period to democracy, and the plan was formally adopted by the ANC in 1994 (Nattrass 2003, 2007; Nunn et al. 2012). The year 2003 is particularly important in the history of HIV/AIDS policies in South Africa because it marks the final legal defeat of the ANC, under the presidency of Thabo Mbeki (1999-2008) on HIV/AIDS governance against the Treatment Action Campaign (TAC) - the leading South African AIDS movement, which would lead to the initiation of ART roll-out in the public sector (Coetzee et al. 2004; Nunn et al. 2012: 2).

ARTs had been in place since 1987 and the most effective ones, called Highly Active Antiretroviral Therapy (HAART), were first adopted in 1996. While Brazil adopted ARTs within its policies as soon as they became available, the post-Apartheid South African government first neglected and later refused their adoption. It was before 1999, under the Mandela administration, with Mbeki serving as Deputy President, that South Africa started embarking on controversial policies. But it was Mbeki who challenged the mainstream HIV/AIDS biomedicine and social-science, suggesting that there was no causal link between HIV and AIDS, that ART was harmful, for the state should not provide it. Denialism is the term used by activists and critical observers to describe such harmful policies. In this enterprise, Mbeki was supported by a handful of dissident scientists from the US, Europe and Australia. These are among the historical facts that show how Brazil's and South Africa's HIV/AIDS policies were for a long time in stark contrast. Such historical facts illustrate the overall contexts in which Brazil and South Africa forged their respective relations between politicians and social researchers regarding HIV/AIDS. Comparatively, Brazil's government was far more open than South Africa in supporting and using social-science knowledge oriented to HIV/AIDS policies.

All this despite the fact that Brazil and South Africa started from similar starting points in terms of epidemiological profile, general state capacity, and the level of democracy and civil society involvement. Concerning the epidemiological profile, the initial “risk-group” in both countries was constituted by white middle-class gays. As for democracy, among other aspects, the constitutions of the two countries define access to health as a right for all citizens and a duty of the state, guaranteed through social, economic and environmental policies that promote health protection and recovery on universal and equal grounds. Accordingly, the basic principles of the Brazilian and South African health

systems are universality, equity and integrality, which are in turn grounded in the human rights framework. Furthermore, both health systems are organized in a decentralized manner, involving articulation between the three administrative levels (Federation, States/Provinces and Municipalities/Regions and Districts), and are subject to social control for their effective implementation. For these reasons, we might expect similar HIV/AIDS policy records, as well as similar degrees of social-science involvement. But history proves the opposite.

## **B. Theoretical and historical backgrounds**

### *Theoretical backgrounds*

The theoretical framework that informs the present work is essentially constituted by sociological approaches that emphasize the role of social-science knowledge in problem-solving, state building, and social development. Prominent scholars in this line include Alain Touraine (1965, 2007), Michael Burawoy (2004, 2007), and John Goldthorpe (2000). Touraine and Burawoy believe in the transformative power of sociology and urge for public sociology (public in the sense of *res public*, rather than institutionally-based activities). On his part, Goldthorpe emphasizes and advocates for the centrality of sociological research in public policy-making (*cameral sociology*).

Public sociology is grounded in moral, critical and emancipatory thinking and is aimed at supporting social justice activities of common interest which are carried out by civil society organizations such as academic communities, often opposed to dominant structures of the state and market. Such support can be either theoretical or practical, external or organic. More importantly, as Joe R. Feagin (2004) describes, such way of viewing sociological knowledge is rooted in the assumption that many people in the world experience recurring economic exploitation, social oppression, immiseration, and looming environmental crises. These problems are often linked to the spread of capitalism or other dominant and exclusive systems such as patriarchy and gender inequality. Therefore, as Feagin phrases it, public sociologists intend to rediscover their roots within a sociology committed to social justice, to cultivating and extending the longstanding 'counter system' approach to research, to encouraging greater self-reflection in sociological analysis, and

re-emphasizing the importance of sociology in society. They attempt to do so by examining those big social questions, engaging with social movements that globally continue to raise the issues of social justice and democracy, thus committing themselves to sustainable social futures for more just and egalitarian societies. As for practical scholarship, public sociology tries to support civil society organizations and subaltern groups in order for them to emancipate and stand up for their rights in the face of powerful institutions, primarily the state and the market.

Additional normative perspectives concerning sociology's intervention in society see public institutions as the locus of engaged scholarship. In this sense, Goldthorpe is in favor of cameral sociology, which was previously conceptualized by Raymond Boudon (2002) as a set of sociological enterprises that are devoted to programing, supporting and evaluating public policies, thus being connected to politico-administrative power. Normatively and historically, public and cameral sociologies are grounded in both emancipatory critical thinking about society at large and robust scientific inquiry rooted in academia. Accordingly, they are concomitantly scientific and practical. They are scientific inasmuch as they seek to apply sociological tools to the analysis of social problems, and practical in the sense that they attempt to use social-science knowledge for the improvement of people's conditions. Similar to public sociology, the intervention of cameral sociology aims equally at fostering improvement of people's conditions in key fields such as education and social mobility, but it does so through government institutions rather than civil society. In the present work emphasis is placed on cameral social-science (HIV/AIDS social-science aimed towards supporting state policy), but public public social-science (linked to civil society) is discussed as well.

Analytical accounts of the role of social-science knowledge in relation to social problems, state building, modernity and development generally look at the wider national contexts that shape the development of social sciences. One concept that synthesizes this reasoning is the one that Peter Wagner (2008) denominates societal self-understanding. Applied to the analysis of knowledge production and use, self-understanding sheds light on the socio-political context in which social sciences operate. The socio-political context of Brazil and South Africa for the period considered here is primarily one of democratic transition and nation rebuilding, and has reciprocal links with the response to the

HIV/AIDS epidemic in the two countries. In this sense, the notion of self-understanding helps us understand, firstly, how social knowledge is produced, distributed across and used by different actors (academics, state, civil society), and secondly, how these actors interpret such knowledge according to their world vision and future prospectives. Experience and interpretation are, therefore, two key elements in Wagner's conceptualization of how social problems are approached, in this case, by social scientists, calling attention to the embeddedness of social actions such as the production and use of social-science knowledge oriented to health promotion. As Danell, Larsson and Wisselgren (2013: 11) put it, the self-understanding perspective “encourages a contextual and reflexive understanding of the changing roles and functions of the social sciences of the past in today’s globalized world”, shedding light on the institutionalization of social sciences, their links with politicians and communities, as well as disciplinary boundaries and interdisciplinarity. The authors emphasize the situated and contingent nature, thus the historical perspective of today’s knowledge configurations as the product of complex process of social change. They posit that the history of social sciences and their successful integration in modern society should be taken seriously in social research, as done by historical and theoretical works that show the centrality of the social sciences in the formation of modernity. Various issues are discussed in this light with regard to the connections between the social sciences and modernity-related issues in the twentieth century. These include the idea of policy-making guided by social-scientific advice (i.e. Wagner 1999, 2001; Wagner et al. 1991; Porter & Ross 2003), and diverse sociological traditions across the world (i.e. Patel 2010; Connell 2007).

This constitutes a theoretical framework that helps us understand the social sciences' engagement with HIV/AIDS, a very modern social problem, in Brazil and South Africa. In particular, contextualizing the relation between social-science knowledge and policy-making in modern societies like Brazil and South Africa helps us understand how the social sciences take health development as a proxy for social well-being, the most important element of modernity in the present work. Examples of social-science works pointing to health as a constitutive element of well-being include the following co-edited book-length publications: *Successful societies: how institutions and culture affect health*, by Peter Hall and Michele Lamont (2009); *Health and modernity: the role of theory in health promotion*, by

David V. McQueen et al. (2007); and *Emerging theories in health promotion practice and research: strategies for improving public health*, by Ralph J. DiClemente et al. (2002). While these works are equally important to understand the role of social-science knowledge in promoting health, it is only Hall and Lamont's book that will be consistently referred to throughout the present discussion due to its explicit use of the institutional-cultural approach, which facilitates the syntheses and the contextualization of HIV/AIDS as a multidimensional problem. As part of the contextualization process, the institutional-cultural perspective will be used, sometimes implicitly, in order to capture how political, economic and socio-cultural dimensions combine to advance or restrain collective health. Thus, the institutional-cultural approach is a useful analytical tool for the comprehension of both the determinants of health and the strategies that the state and other entities, including social scientists, adopt to tackle health problems. Disentangling such complexity is one of comprehensive social-science's approaches oriented towards health, particularly HIV/AIDS, to whose construction the present work aims to contribute. Let us discuss the matter of self-understanding further.

Societal self-understanding is a set of collective narratives whereby entities autonomously seek their own ways of solving and representing their economic, political and epistemic problematiques. It seems to me that this is connected to conditional meaning that the actors give to their own actions. But the notion of self-understanding goes beyond the descriptive nature of conditional meaning because it refers to the conscious, normative and (self-)critical part of a collective identity. Evidently, this is a multi-approach reasoning, which brings into the discussion aspects like social representations, Paulo Freire's reflective-critical consciousness and, ultimately, Amartya Sen's (2004) promotion of capabilities.

In reference to health-seeking attitudes, Catherine Campbell (2003: 50) has demonstrated through empirical research that the Freirian concept of reflective-critical consciousness involves the two interconnected dimensions of understanding and action. In turn, understanding involves the development of a group members' intellectual comprehension of the manner in which social conditions (i.e. unemployment and poverty, gender) foster their situations of disadvantage in ways that undermine their health (i.e. psychologically

and socially compensative sex). Intellectual understanding is an indispensable precondition for critical consciousness and collective action.

According to Paulo Freire (1972) critical consciousness is opposed to “adapted consciousness”, which is a situation in which an authoritarian and a-critical frame of mind whereby disadvantaged people accommodate to conditions imposed on them and develop attitudes prone to denial, fatalism, passivity, apathy, and unrealistic optimism. Critical consciousness requires perceived citizenship power in order to translate into action, such as the protection of sexual health. In this sense, Sen's economically-oriented capability approach is enriched by Wagner's notion of self-understanding because the latter enables the group to know itself and so develop emancipatory critical consciousness.

If a modern society autonomously solves its own vital problems, then this society should enhance the capabilities of people in order to pursue the goals important to their lives and thus be conducive to good health. Such capabilities involve people's access to material and symbolic resources so that they can face their health challenges. Income is a prime material resource, while symbolic resources include autonomy and ability to co-operate, social recognition and self-esteem. High levels of these resources generally correspond to higher levels of health and well-being. Such capabilities involve people's access to material and symbolic resources so that they can face their health challenges.

Having said this, let us clarify that in the present discussion modernity is primarily understood as a form of rights-based development that, looking beyond the increase of income, enhances people's capabilities to fulfill their needs, in this case, good health. Such an endeavor requires an institutional-cultural approach to capabilities: a positive correlation between institutional practices and deep-rooted cultures. In this sense, linking institutions and culture also leads to debates about cultural developmentalism, as opposed to merely institutional developmentalism. Cultural developmentalists emphasize the role of cultural values in human progress, inasmuch as they shape institutional structures (i.e. Manguel 1991; Huntington & Harrison 2000; Banfield 1958). In this perspective, it is argued that, in order to be effective for progress, social capital and collective action must translate into trust-reciprocity and social cohesion. Furthermore, these aspects have to be combined with hard work, the rule of law, control over the future (an idea of progress, as

opposed to merely day-to-day life preoccupations), and antagonism (as opposed to harmony aimed at maintaining the status quo).

These are some of the issues that scholars in Brazil and South Africa have tried to underline in their efforts against the HIV/AIDS epidemic, theoretically and through organic commitment with non-academic bodies.

### *Historical background*

Social scientists in Brazil and South Africa have a long tradition of commitment to pressing problems and national development. This is especially true with regard to sociology which, compared to other social sciences and humanities, emphasizes social problems more strongly, besides social action, social structure, and social construction – as discussed by Brian A. Pitt (2010) in continuation with a related debate initiated by Peter L. Berger (1963) in his book *Invitation to Sociology*. Since its institutionalization as an independent science in the 1930s, sociology in Brazil and South Africa has been characterized by an interventional slant in association with the construction of the state. Indeed, the history of sociology in Brazil and South Africa shows considerable involvement of sociologists in the elaboration and implementation of social engineering at different societal levels.

In Brazil, after the dismantlement of slavery, sociology sought to go beyond mere analysis and consider the social factors that could contribute to the formation of the Brazilian nation and identity, resulting in theories of modernization centered on the analysis of Brazil's transition towards modernization (Filho 2003a, 2005; Micelli & Massi 1995; Nogueira 1982). Various subjects were explored in the search for modernity factors, in association with racial and cultural contacts, conflicts and juxtapositions, industrialization, and the contrast between the changing society and the reminiscent folk cultures across the territory. These subjects included: racial and ethnic relations seen as problematic, for miscegenation was sometimes viewed as necessary to create a race-free national identity; the differentials between agrarian-rural and industrial-urban settings that divided the country into two main geographical and socio-economic realities (i.e. Lambert 1959; Azevedo 1962; later, Freire 2000); the factors of autonomous development in economic

and intellectual spheres (dependence theory), to be achieved through local production of goods, intellectual and theoretical tools (i.e. Cardoso 1980; Ianni 1971); and the relation between democracy and development (Cardoso & Faletto 2004). At civil society level scholars serving social medicine institutions, for example, have maintained close relations with Brazil's Sanitarian Movement through critical perspectives aimed at promoting rights to health care, as well as health-enhancing and supporting contexts. Use-inspired research generally and research-action in particular, which stems from Brazil's tradition of engaged sociology, have been prominent in the realm of social-science knowledge production.

In South Africa too, sociology has historically been preoccupied with problem-solving oriented to modernity and social change, say, development (Webster 2004; Uys 2004, 2005; Jubber 2007; Sitas 2006; Oloyede 2006). On the one hand, Afrikaner sociology first served the welfare state meant to improve white Afrikaners' life standards in response to white poverty caused by the Second Anglo-Boer war (1899–1902) and the Great Depression, and later racially-exclusive public policies in consonance with the Apartheid national program of “separate development”. Also, and especially in the 1970s-1980s decade, militant Marxist sociology, carried out in historically English-medium universities, sought to infuse Marxist concepts such as class struggle and class consciousness in black labor organizations – then banned by the state – in order for them to fight more effectively against the exploitative and oppressive regime (Bozzoli 2004; Buhlungu 2009). This resulted in research-action whereby Marxist-oriented sociologists provided black workers with knowledge about rights, emancipation and equality.

Such scholarship was triggered by a range of events linked to the struggle of black communities against apartheid policies, the most recent being the Durban uprising that led to waves of industrial workers strikes in early 1973. Other significant historical events include: the massacre of 69 black people at the hands of the state police during a demonstration against pass laws on 21 March 1960 in Sharpeville (Transvaal, today's Gauteng); the Soweto students' uprisings in mid-June 1976 in response to the introduction of Afrikaans as the teaching language in local schools; and the assassination of activist Steve Biko on 12 September 1977 by the state police (Pithouse 2006). These events led critical sociologists to recognize that industrial workers lacked theoretical tools, as well as material and symbolic support from more influential entities in order to further advance in their struggle for emancipation and social justice.

Thereafter, industry, work and labor studies were increasingly viewed by critical sociologists as necessary to, first, understand apartheid-based inequalities and the community's anti-apartheid struggles and, second, assist emerging black movements. It is in this climate that the *Institute for Industrial Education (IIE)* and the *South African Labour Bulletin (SALB)* were founded at Durban College (today University of KwaZulu-Natal) to lead such engaged scholarship in the field of industry, work and labor studies (Maree 2010; Çelik 2013). The cooperation with the *South African Allied Worker Union (SAAWU)* and the *Congress of South African Trade Unions (COSATU)* was one of the strengths of the IIE/SALB. By implication, in association with the diversification process within sociology and sociology departments (Jubber 2007: 531-8) research-action in the field of industry, work and labor studies led South African critical sociologists like Eddie Webster beyond academic boundaries in the name of social justice (Buhlungu 2009: 150-2). In addition to providing logistic support, scholars linked to the IIE/SALB would work on the ground and visit communities to impart education on better salary and working conditions, equality, and cooperation strategies (ibid). It is this history of organic engagement in South Africa that has most influenced Michael Burawoy's conceptualization of, and claim for, public sociology (see Burawoy 2007). My understanding is that this tradition of committed scholarship is still extant in Brazil and South Africa, and has shaped HIV/AIDS scholarship.

### **C. Snapshot of the chapters**

Chapter 1 presents key aspects concerning the HIV/AIDS disease and epidemic in order to provide the reader with basic information and a global contextualization of the cases of Brazil and South Africa. This includes discussion about the pathogen as such, its etiology, modes of transmission, the global epidemiological scenario of HIV/AIDS and the treatment measures that have been taken hitherto to manage the disease and mitigate the impact of the pandemic.

Chapter 2 presents an overview of Brazil's and South Africa's HIV/AIDS policies and the related outcomes. It lays the bases for the exploration of Brazil's success and South Africa's failure to tackle the epidemic by means of adopting appropriate biomedical science and engaging in collective action that is able to turn the tide against the HIV/AIDS epidemic. In this way, chapter 2 provides the background for: firstly, a theoretical assessment of the production and use of social-science knowledge for a comparative health-policy analysis, starting from the exploration of the way in which social scientists have been involved in HIV/AIDS policies in Brazil and South Africa (chapter 5); and secondly, the overall context that shaped Brazil's effective and South Africa's ineffective responses to the epidemic (Section 6).

Chapters 3 and 4 discuss the social-science knowledge that has been produced globally over the three decades or so of HIV/AIDS' existence. Chapter 3 focuses on the state of art, taking into account pioneer studies in the Americas and classic comparative studies in Africa, the latter being associated with the application of institutional-cultural approaches. The chapter also explores meta-analysis on HIV-related social-science. Chapter 4 focuses on the paradigm change in relation to the locus of behavioral and social change (from individual to communities) and the type of resource deemed necessary for such change (from information to material and symbolic power). The interlink between material conditions and symbolic dimensions in HIV/AIDS dynamics is particularly underlined. Brazil, South Africa and Africa generally are discussed, providing empirical examples of how this relationship operates.

Chapter 5 points towards the construction of something similar to social epistemology, whereby I suggest that the trajectories of HIV/AIDS scholarship in Brazil and South

Africa prompt us to reflect upon the kind of knowledge that is being produced regarding this problem in the two countries - and globally - and the social conditions for its spread across society, particularly from researchers to policy-makers and people affected by HIV/AIDS.

Chapter 6 strictly addresses engaged scholarship in Brazil and South Africa. Emphasis is placed on harm reduction in IDUs, HEIs' role in training teachers for school-based HIV/AIDS programs, as well as general scholarship on peer education.

Chapter 7, as alluded to earlier, explores the broader context that explains why Brazil and South Africa, initially two similar societies, have reached rather divergent records in HIV/AIDS policy. Large space is devoted to the historical, political, economic, and psychosocial factors of the South African government's denialism. This indirectly demonstrates how the lack of denialism in Brazil favored a shared vision of the epidemic among different social actors and conducted to aggressive and integrated policies at various levels. This is especially true with regard to the relationships between state and AIDS movements (7.3). Hence, those variables explain why South Africa's government was late to consider social scientists as key actors in the national response to HIV/AIDS.

The concluding chapter singles out some thematic issues emerging from the comparison between Brazil and South Africa. It starts out by looking at a few aspects that constitute a challenge today in both countries, including race as an important variable of HIV/AIDS vulnerability, the limits of policies focused on medical measures such as HIV treatment and adult male circumcision (A). Sub-chapter B reconsiders peer education, pointing towards the constraints and challenges that it faces in both countries and globally. Sub-chapter C looks at the impact of HIV/AIDS on social movements studies, related to the fact that, compared to the previous periods, AIDS movements and those alike have a greater capacity to articulate their activities in collaboration with, rather than opposition to, political forces in a context of democracy, neoliberalism and globalization. Sub-chapter D advocates for major cooperative scientific projects between Brazil and South. For such endeavor, it considers the existing international links between researchers globally, as well as Brazil's HIV/AIDS diplomacy in South Africa and Africa generally.

## **D. Methodological notes**

Comparing is always an arduous enterprise. There are at least two dilemmas to be sorted out when comparing big units of analysis such as Brazil and South Africa. The first dilemma concerns whether to focus on similarities or differences, and how far to go into detail. Another challenge concerns balance in the sense of giving proportionally equal space to each case study. Partly depending on the nature of literature on the two case studies, one always runs the risk of giving more space to this or that case. In the present text the reader might find some chapters unbalanced. This may be so, but this would leave space for further elaboration on the subject in possible future works. However, there are parts such as chapter 7, devoted to the explanation of controversial HIV/AIDS policies in South Africa, in which little space is devoted to Brazil precisely because Brazil did not experience any significant controversy in the period considered. Thus, in this case, the extensive discussion of the South African case also helps to illustrate how differently and better Brazil acted against the epidemic.

The thesis is informed primarily by literature from diverse sources, including academia, international organizations and social movements. UNAIDS is the major international source of most of the epidemiological data utilized. But it is important to clarify that UNAIDS national reports are provided by the Ministries of Health of each individual state, and Brazil's and South Africa's progress reports are also found on the respective ministries' websites. I mostly used the versions published on the UNAIDS pages for the sake of systematization. Also, in the case of Brazil this implies using the English version and avoiding translation, which could ultimately be unproductive.

The epidemiological scenarios of the two countries are not presented thoroughly throughout the text because, when available, the data-sets of the two countries do not match in terms of periods of time. It was only a decade ago that South Africa's government started producing epidemiological data on HIV/AIDS systematically. One alternative would have been to use the figures available without any modification, but this would have meant having one graph for each country on a certain HIV/AIDS phenomenon (i.e. incidence in different groups, mortality, people under ART). Nevertheless, since the few tables given are integrated with textual data, I believe they

provide sufficient historical and socio-political contextualization. What the reader will miss the most is the synthetic and photographic illustration of the data provided.

Face-to-face interviews with experts, health professionals, and activists were also conducted by myself in situ. However, interviews, indeed the entire field work, have been very useful to better comprehend the HIV/AIDS phenomenon and systematize literature, in the sense that they provided me with valuable insights into the role of social-science knowledge in HIV/AIDS policy. This is largely linked to the fact that HIV/AIDS social-science knowledge as an area of study is at an embryonic stage. It is only in the 2010s that, in line with the global context, scholars in Brazil and South Africa have started to ask themselves about the impact of social-science knowledge on HIV/AIDS policy and vice-versa, and about the new questions and insights stemming from such scholarship. For example, it was not before November 2013 that the Associação Brasileira de Saúde Coletiva (ABRASCO) devoted its annual congress to the exploration of health-related knowledge production and circulation in the social sciences and humanities.

Similarly, it was only in December 2013 that, under the coordination of the International AIDS Association (IAS), a major event on the scope of HIV/AIDS social science in Africa took place in South Africa. Therefore, instead of the production and use of social-science knowledge, my interviews had to be centred mostly on the HIV/AIDS epidemic in its “classic” forms, namely, social determinants and responses to it, and the complex web of challenges and constraints to such responses. In any case, this provided me with the opportunity to gain a better understanding of the multifaceted context in which the studies on HIV/AIDS and health promotion in Brazil and South Africa are embedded.



# 1 Understanding HIV/AIDS globally

## 1.1 HIV infection, transmission modes, and AIDS disease

We are now into the fourth decade of the HIV/AIDS epidemic, as the pandemic has existed since 1981 as both a clinical and social problem. The enormous impact of HIV/AIDS on societies indicates that it has been the most devastating pandemic in human history since the Black Death hit Europe in the mid-1300s (Whiteside 2008; Deacon et al. 2005). HIV/AIDS is the hardest hitting epidemic on human communities in terms of stigmatization and controversy in various societal spheres. Scientists are still racing to find a cure or vaccine for the pandemic. For these reasons, HIV/AIDS is now globally considered not only a health problem, but also a development issue, as well as a security threat (Iqbal 2009: 1; Ndinga-Muvumba & Pharoah 2008).

It is common to refer to HIV/AIDS simply as AIDS. Let us clarify the difference between HIV and AIDS. HIV is the infectious agent that causes AIDS. Broadly said, HIV is a retrovirus that infects cells of the host's immune system, destroying or hindering their function. AIDS is the most advanced stage of the HIV infection (Hutchinson 2001: 86; Sepkowitz 2001; Mayer & Pizer 2005: 13-35). At the AIDS stage the immune system is weaker and faces an increased risk of developing opportunistic infections such as Tuberculosis (TB) and tumors such as Kaposi's sarcoma, the latter being a form of skin cancer. In the absence of treatment, it may take circa a decade for an HIV-positive person to develop AIDS and die.

In the present discussion I will mostly use the term HIV/AIDS, rather than HIV and AIDS or just to one of the two, to emphasize the interconnection between the two phenomena. Because the epidemic is highly multilayered, it is not sociologically productive referring to HIV and AIDS separately. Hence, exploring HIV/AIDS as one problem is a way to look at the HIV/AIDS epidemic from multiple angles and - consequently - understand how, for example, poverty, marginalization and cultural opposition to safe sex place people in conditions of vulnerability to HIV/AIDS.<sup>1</sup>

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The multidimensional nature of HIV/AIDS entails at least two aspects. Firstly, people are more likely to act healthily if they possess sufficient economic resources, high self-esteem, positive social capital, and live in health-promoting and enhancing contexts that increase individual control over health. Secondly, and implicitly, HIV/AIDS prevention, treatment and care, very much depend on strategies that go beyond

However, for the sake of reading fluency, I simply refer to AIDS movements, rather than HIV/AIDS movements, which is also more common in the related literature when referring to social movements dealing with the HIV/AIDS epidemic.

The modes of HIV transmission have been well documented. It is now well known that HIV is highly concentrated in certain bodily fluids, namely blood, semen, pre-seminal fluid, rectal fluids, vaginal fluids, and breast milk (Hutchinson 2001: 87). Some bodily fluids like saliva and tears host HIV as well, but the viral load in these fluids is too low to be transmitted to another body. This implies that HIV is transmitted mainly via unprotected sexual intercourse, infected blood transfusion, hypodermic needles, and from mother to child during pregnancy, delivery or breastfeeding.<sup>2</sup> During the initial phase of the infection, the infected person may experience influenza-like symptoms, typically followed by a prolonged period of latent infection in which the seropositive status is unknown to the infected person and the members of their groups. Thus, the HIV infection remains symptomatically and socially silent for a long time.

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mere information-based campaigns about HIV risk and consequences. Effective measures must point towards the improvement of people's material conditions (poverty alleviation and facilitated access to health care), promotion of citizen rights and creation of cultures that increase people's propensity to HIV prevention (i.e. gender equality and consensual sex), as well as treatment seeking on the part of infected people (i.e. anti-stigmatization and measures against the belief in witchcraft, sorcery and diviners). Thus, the multidimensional perspective illustrates both the social factors that render people vulnerable to HIV-infection and those that promote or restrain access to treatment and care on the part of HIV-infected people. The multidimensional approach also helps to explore the ways in which, for example, poverty and inequality impact the social construction of sexuality and health, and the conception of biomedicine within a wider social and political context. This is essential to understanding the impact of the epidemic in the political, economic and social spheres, as well as state-society relations in the light of such impact. In turn, ultimately, handling HIV/AIDS as one social problem helps us to grasp the complexity of the current social- science knowledge about the HIV/AIDS epidemic.

2 Mother-to-child transmission (MTCT) of HIV is also called vertical transmission and the two expressions will be used interchangeably throughout the present discussion.

## 1.2 HIV-1 and HIV-2 types

There are two sub-types of HIV, namely HIV-1 and HIV-2 (Hutchinson 2001). Both subtypes are transmitted through fluid exchange via sexual, percutaneous, and perinatal routes, and seem to cause clinically identical AIDS. However, it seems that HIV-2 is less easily transmitted and its latent stage (the period between the initial infection and illness) is longer. HIV-2 seems to be predominant in West Africa and is uncommonly found in other regions of the world. By contrast, HIV-1 is predominant worldwide and it is to this sub-type that we generally refer to without specifying (Mayer & Pizer 2005: 16).

It is, indeed, HIV-1 type that was first clinically identified in 1981 in the United States, precisely in New York and San Francisco. The initial cases were found in injecting drug users (IDUs) and homosexual men with unknown cause of compromised immune systems who presented symptoms of rare opportunistic infections such as *Pneumocystis carinii* (PCP) and Kaposi's sarcoma (Pitchenik et al. 1983; Greene 2007; Sharp & Hahn 2011). It was subsequently discovered that the causative agent of such immunodeficiency was a retrovirus, now denominated HIV-1 (Barre-Sinoussi et al. 1983; Popovic et al. 1984). Before the terminology HIV/AIDS was coined, the US Center for Disease Control and Prevention (CDC) had no official name for the disease and often referred to it by way of the opportunistic diseases that were associated with it, including Kaposi's Sarcoma. At a certain point, the CDC also coined the "4H disease" term, since the syndrome seemed to affect mostly Haitians, homosexuals, hemophiliacs, and heroin users (ibid). "GRID", standing for "gay-related immune deficiency", was more common in the general press (i.e. Altman 1982). However, it was soon discovered that HIV/AIDS did not discriminate on any grounds and by mid-1982 the term AIDS started being used by health practitioners and the mass media (Sharp & Hahn 2011: 1).

## 1.3 The HIV pathogenesis

Several genetic and epidemiological studies have been conducted to trace the pathogenesis of HIV and literature is replete with insights (i.e. Grmek 1989; Shannon 1991; Pepin 2011). When HIV was discovered, the attainment of conclusive scientific evidence for locating its exact origin within a decade was expected, but this did not occur (Shannon 1991: 28). Neither is there consensus today, three decades after the pathogen

was discovered. Nevertheless, it is now largely thought that HIV originated in non-human primates in Central and Western Africa from a simian immunodeficiency virus (SIV) that infects chimpanzees, and was transmitted to humans in the early 20th century. How SIV was transmitted to humans is a more disputed issue.

One scientific line sustains that SIV probably first infected humans through bushmeat activities such as hunting and bushmeat vending (Gallo 2006; Max et al. 2001). It is believed that the genetic evolution of a SIV would become HIV through several and rapid successions of transferences of the virus across humans. An alternative view on HIV origins states that unsafe medical practices in Africa after World War II such as reusing unsterilized single-use syringes during mass vaccination, antibiotic and anti-malaria treatment campaigns, were the initial vector that permitted the virus to adapt to humans and spread across populations (Chitnis et al. 2000).<sup>3</sup> In his book *The River: a journey to the source of HIV and AIDS* of 1999, Edward Hooper documents that SIV was first transmitted from simians to humans in the Democratic Republic of Congo (Belgian Congo until 1966) in the 1950-60s through oral anti-poliomyelitis vaccines, which were developed by US scientists using chimpanzee's SIV-infected liver tissue. Chimpanzees were documented as being the first primates bearing SIV and scientists seem to have disregarded or not foreseen the danger that it presented for humans. The Democratic Republic of Congo is thus largely believed to be the most likely place from which HIV originated. The latest and arguably more accurate inquires situate the origins of HIV in the 1920s Kinshasa (called Léopoldville until 1966), where a “perfect storm” of a roaring sex trade, rapid demographic growth and internal migrations that followed the development of railways in Kinshasa, plus unsterilized needles used in health-care settings, allowed HIV to spread across the Democratic Republic of Congo (Faria et al. 2014).

Whatever the historical account, it seems clear that before the clinical diagnose of HIV as the cause of AIDS in 1981 in the US, one HIV case was found in 1959 and this is

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3 Various alternative theories have speculated about the hidden genesis of HIV, ranging from suggestions that HIV is an intentional or unintentional result of biological experiments in the development of drugs, to conspiracy-prone claims that HIV was deliberately created by scientists working for the US government for warfare or some other occult purposes like the demographic control of Third World populations (Carroll 2003).

considered to be the earliest well documented case of HIV (Hutchinson 2001: 98). It is now known that, by 1971, the virus had moved to many different regions of the world, but the exact time when it moved out of Africa is conjectural (Gallo 2006: 1). This has led scientists to suggest that HIV may have been present in the US as early as 1966, but most contagions occurring outside Sub-Saharan Africa can only be traced back to an unknown individual who became infected with HIV in Haiti (where there apparently were soldiers returning from the Democratic Republic of Congo) and then took the infection to the US (Gilbert et al. 1997). The epidemic then quickly spread among high-risk groups, namely sexually promiscuous men who had sex with men (MSM) and intravenous drug users throughout the 1960s-1970s. However, it has also been argued that more phylogenetic estimates, with appropriate confidence intervals, are needed to provide more reliable information about the date of origin of the US HIV epidemic (Gilbert et al. 1997: 18569). The authors argue that in the US “the virus may well have been spreading slowly for an extensive period, perhaps in the heterosexual population, before entering the highest-risk MSM sub-population, where it spread explosively enough to finally be noticed”.

#### **1.4 HIV/AIDS global epidemiology, preventive and treatment measures**

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2013: 8), as of 2012, an estimated 35.3 million people were living with HIV worldwide. Sub-Saharan Africa is home to circa two thirds (25 million) of the total. HIV/AIDS figures in Sub-Saharan Africa reflect the incessant large number of new HIV infections, despite the expansion of prevention campaigns and access to ART. It is estimated that in 2011, 92% of the world’s HIV-positive pregnant women lived in Sub-Saharan Africa (indeed, heterosexually transmitted HIV is the predominant pattern in the region), and only 59% of them received ART or prophylaxis during pregnancy and delivery.

An estimated 36 million people have died of AIDS worldwide since the disease was recognized in 1981. At the same time, according to UNAIDS, the progress in prevention education and biomedical treatment registered over the last decade has contributed to the decline in global figures of both new infections (from 3.4 million in 2001 to 2.3 in 2012) and AIDS deaths (from 2.3 million in 2005 to 1.6 in 2012). HIV is complex retrovirus

with a high mutation rate.<sup>4</sup> To date, cure or vaccine for HIV/AIDS are not available, but aggressive ART regimens suppress HIV viral replication and halt the progression of the HIV disease. The management of HIV/AIDS is normally carried out through the employ of life-saving, which has transformed the HIV disease into a chronic manageable condition in almost all high-income settings and to a lesser extent in middle and low-income contexts. In general terms, ART has been successful in both wealthy countries and resource-limited settings, and has had significant impact on morbidity and mortality. Furthermore, ART not only prolongs life but also dramatically reduces HIV transmission. ART is now available to 10 million people living with HIV in low- and middle-income countries. These achievements are a result of transformative science, advocacy, political commitment and effective partnerships with affected communities. However, substantial challenges still exist in regard to maintaining access to ART and finding the funding for lifelong ART for PLWH (Wainberg et al. 2014: 1).

Highly Active Antiretroviral Therapy (HAART) is the anti-AIDS medication regimen currently in use worldwide. HAART consists in a combined dose of three or more drugs with varying functions, making up what is commonly referred to as a “cocktail”. HAART is thus the latest generation of antiretroviral (ARV) medication and dates back to 1996, when it was officially approved at the 11th International Conference on AIDS in Vancouver, Canada (Zuniga et al. 2008). HAART has replaced previously less effective and highly toxic single-therapy ARVs, the earliest of which was Zidovudine (AZT), approved in 1987 by the US Food and Drug Administration (Sepkowitz 2001: 3). The next generation of ARV drugs is a “one-pill once-a-day” medicine (Stribild, formerly known as Quad), which is currently under trial studies in PLWH and is deemed to produce fewer and less severe side-effects, besides being more effective, more comfortable and less costly.

Thus, ART leads to near-normal life quality and expectancy for PLWH. This is linked to the fact that, with timely administration, treatment is immunologically and psychologically empowering. Immunologically, ART not only prolongs life by diminishing the chance to develop AIDS-related opportunistic infections (TB, primarily), but also dramatically reduces HIV transmission because people who are successfully treated with ARVs have vastly diminished viral loads in their bodies and are, consequently, far less able to transmit

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4 In general terms, because viruses have inhabited the Earth longer than humans, having resisted all natural changes occurred hitherto, they are able to adapt to any organism type: should the human species disappear from planet Earth, viruses would survive (Bastos 2006).

HIV than untreated individuals (Wainberg et al. 2014: 1-2). This is because ART raises the CD4 cell counts or T-cells, that is, the type of white blood cell that activates the body's immune response to germs such as viruses and bacteria. CD4 cell counts are an important measure of immune status and ART effectiveness. HIV-negative adults usually have between 500 and 1500 CD4 cells/ml, while HIV-positive adults generally have less than 500 (Acton et al. 2012). An HIV patient under ART is expected to rise 50 to 100 cells per ml in the first year of therapy (ibid). The timing of when to initiate ART has historically been a central controversy within the international medical community (Darbyshire 1995), but there is now large consensus for starting medication when the patient has a CD4 cell count of less than 350 (Harrington & Carpenter 2000). There is also consensus around the necessity of rising the CD4 cell count threshold and start ART as early as possible in order to maximize the effectiveness of the medication (Kelley et al. 2009; Kitahata et al. 2009). At any rate, an international policy on HAART initiation seems hard to establish, as each country makes autonomous political decisions on the issue.

Medical male circumcision is also being used as a method of HIV prevention for men in generalized epidemic settings like South Africa. Male circumcision is deemed able to reduce by 60% the chance of acquisition of HIV or other sexually transmitted infections (STIs) (Justman et al. 2013). There are several biological arguments that sustain that the removal of the gland foreskin reduces the risk of HIV acquisition among men because “the foreskin has a tendency to develop epithelial disruptions, or tears, during intercourse, which may provide HIV a portal of entry, and compared with the tissue of the outer foreskin, the foreskin’s HIV target cells (Langerhans cells with CD4 receptors) are closer to the epithelial surface” (Justman et al. 2013: 140). Male circumcision is the most controversial HIV medical measure globally, not only due to its uncertain or low efficacy-efficiency, but also for the fact that it is difficult to implement in communities that lack cultural familiarity with male circumcision. Genital mutilation as an offense to the human body’s integrity is a further argument used by detractors of anti-HIV male circumcision.

Efforts are also underway for the progress of Pre-exposure prophylaxis (PrEP) in order to protect people at high risk of acquiring HIV, such as prostitutes. Investment in this sense is directed to the development of microbicides – vaginal, primarily – that contain an ARV drug. However, despite encouraging results, more research is needed to evaluate the efficacy of microbicides (Wainberg et al. 2014: 1-2).

ARVs, both in the form of treatment and PrEP, have given birth to a research field denominated “treatment as prevention” (TasP).<sup>5</sup> It argues that the successful mass use of ARVs will lead to diminished viral loads within populations and the consequent decline, perhaps elimination, in the transmission of new HIV infections (Cairns et al. 2014). However, concerns have been raised that the development of HIV drug resistance and the transmission of drug-resistant HIV might frustrate such efforts. Nevertheless, this hope is also grounded in the recent development of the “one-pill once-a-day” program, which may not be as susceptible to drug resistance as earlier AIDS medicines (Hall et al. 2011).

One implication of the situation described above is that there is now a widespread consensus that, for the time being, ART is the sole truly effective way to manage this chronic disease over the long-term. However, it is also recognized that, even for high-income countries, ART may become economically unsustainable over the next 20 years, and that it is hard for patients to have to take drugs daily for the rest of their lives, as it is not easy for them to adhere to ART regimes, which decreases the effectiveness of medication. Hence, since attempts to develop effective HIV vaccines have been largely unsuccessful despite the heroic efforts of the research community (Wainberg et al. 2014: 2), strengthened HIV prevention efforts are needed and advocated as a political priority of nations. Such reinvigorated efforts include measures prone to reducing mother-to-child transmission of HIV, social change for increased condom use and reduced sexual multi-partnership, as well as incremented provision of sterile needles and syringes to IDUs. It is now well documented that while ARTs can be efficacious at individual level and reducing HIV acquisition, condom use and non-promiscuity play a greater role in limiting the spread of the virus across populations. Indeed, instead of the expected decreases, there have been increases in HIV incidence in gay communities in various mid-

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5 Treatment as a form of prevention is sometimes referred to as secondary or tertiary prevention, as opposed to primary prevention in terms of avoiding contagion. Public health literature (*i.e.* Last 1988, cited in Schneiderman et al. 2001: 9) distinguishes between primary, secondary and tertiary prevention. Primary prevention concerns measures taken to reduce the incidence of disease, whereby individuals may be encouraged to, for example, quit smoking, decrease intake of dietary fat, and increase physical activity. In the case of HIV, primary prevention regards condom use (and abstinence). Secondary prevention involves reducing the prevalence of disease by shortening its duration and limiting adverse physiological and psychological effects: *i.e.* screening programs for early detection of the disease. Tertiary prevention involves reducing the complications associated with the disease process and minimizing disability and suffering. In patients with chronic AIDS, medication adherence training is an example of tertiary prevention. However, sometimes the boundaries of prevention strategies are indistinct, and also intervention itself may address a combination of primary, secondary, and tertiary preventions. In the present work I simply refer to prevention (without a qualifier) and treatment, which ultimately is the most common and intuitive terminology.

and high-income countries where HIV testing rates and uptake of ARVs are high, which suggests that risk compensation and related decrease in condom use by gays plays a major role in HIV transmission.

This situation poses various challenges for social-science knowledge with regard to structural factors underpinning the HIV/AIDS epidemic and the health-illness process generally. Such structural factors include the efficiency of public policy, the combat against stigmatization and discrimination, and the demonization of homosexuality, among others. These are some of the issues discussed throughout the present work, in relation to the capability of social scientists to explore the complexity of these issues and suggest the most appropriate measures against HIV/AIDS and for health promotion generally.



## 2 HIV/AIDS policy in Brazil and South Africa: an overview

### 2.1 The epidemiological scenario

Brazil and South Africa are similar for being HIV/AIDS-affected societies and for currently providing HAART through the public sector. However, Brazil and South Africa are far different countries with regard to their HIV/AIDS prevalence rates. As of 2012, the HIV prevalence rate in Brazil's population aged 15-49 had been stable at approximately 0.5%,<sup>6</sup> since 2004, being 0.4% in females and 0.8% in males.<sup>7</sup> On the contrary, considering the same period of time and age, South Africa has a severe HIV/AIDS epidemic: it has a prevalence rate of HIV as high as approximately 18%<sup>8</sup>. The absolute number of HIV sufferers in Brazil is far lower than in South Africa: 600,000 vs 6,000,000 approximately. Furthermore, HIV infection in Brazil is concentrated in certain vulnerable population groups, (namely, MSM and CSWs).<sup>9</sup> Conversely, South Africa has a generalized HIV epidemic, which has been stable since 2008, and a national antenatal prevalence of around 30%.<sup>10</sup>

Brazil has had a special trajectory in terms of HIV sex or man-woman ratio, shifting from 40-1 in 1983 to 1.7-1 in 2010.<sup>11</sup> Although this change is of an enormous proportion, it occurred at a slower pace than in South Africa and, above all, MSM is still the most affected group in Brazil. On the contrary, in South Africa the epidemiological profile change from white gays being the chief risk group to a generalized epidemic, with higher

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6 See UNAIDS 2014. Available from: <http://www.unaids.org/en/regionscountries/countries/brazil/> (Accessed on 18 July 2014).

7 See Brazil's *AIDS Progress Report 2012*, p. 14. Available from: [http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/UNGASS\\_2012\\_ingles\\_rev\\_08jun.pdf](http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/UNGASS_2012_ingles_rev_08jun.pdf) (Accessed on 18.07.2014).

8 See UNAIDS 2014. Available from: <http://www.unaids.org/en/regionscountries/countries/southafrica/> (Accessed on 18.07.2014).

9 See South Africa's *AIDS Progress Report 2012*, p.12. Available from: <http://www.unaids.org/en/regionscountries/countries/southafrica/> (Accessed on 18.07.2014).

10 See South Africa's *AIDS Progress Report 2012*, p.32.

11 See Brazil's *AIDS Progress Report 2012*, p.17.

incidence in the black population, occurred very quickly and in a radical way. Such dramatic change in sex ratio in both case studies is attributable to, concomitantly, decrease of male and increase of female cases of infection. For this reason, despite differences, feminization and heterosexualization are, together with pauperization, among the main characteristics of HIV/AIDS in both countries. This concatenation draws attention to the investment in people's economic conditions and gender equality. Young women in South Africa are the most vulnerable sub-population. This is largely a result of intergenerational sex (young women having sex with older men) and sexual multi-partnership, which includes "intimate economy", that is, women's surviving strategies through multi-partnership transactional sex and prostitution. Brazil and South Africa follow an HIV sexually-transmitted mode, as the majority of world's countries. The two countries differ, however, in the fact that in Brazil most cases of contagion occur through man-man intercourse – as indirectly observed above. On the other hand, HIV in South Africa is transmitted predominantly heterosexually between couples, with mother-to-child transmission being another main infection route (see note 7). As for age, the highest HIV incidence rate in Brazil was found in the 35-39 age group (38.1 cases/100,000 inhab.) in 2010, while between 1998 and 2010 an increase in AIDS cases was observed in the 05-12, 50-59 and 60 and age groups.<sup>12</sup> In South Africa, by contrast, the highest prevalence was found in the 15-24 year old group, making up 21.8% in 2010.<sup>13</sup>

Both Brazil and South Africa have heterogeneous populations and race/color is a critical factor of socio-economic status, and low socio-economic status is a major factor of vulnerability to HIV today. In both countries wealth continues to be stratified along racial lines and, overall, the white group (a minority in the case of South Africa) dominates the upper-income strata. However, despite rapid change in the epidemiological profile, as of 2010, Brazil's black population<sup>14</sup> accounted for only about 10% of HIV infections, whilst

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12 See Brazil's *AIDS Progress Report 2012*, p. 19.

13 See South Africa's *AIDS Progress Report 2012*, p. 30.

14 It is necessary to make two notes on the terms "race" and "black". Firstly, while race is a common and undisputed term in South Africa, it is a more complex issue in Brazil, often being referred to as color or ethnicity. In Brazil color is considered a more superficial and flexible concept, for it matches with the high level of Brazilian population miscegenation, while race is viewed as a more profound and demarcating anthropological concept. More importantly, secondly, "black" in South Africa is generally used to indicate non mixed-race individuals with solely African descent, whilst in the case of Brazil the

the highest proportion was found in the white population (45.6%), followed by the yellow population, that is, Brazilians of Asian descent (35.5%).<sup>15</sup> Nevertheless, now that the epidemic has pauperized, caution is increasing among Brazilian researchers and activists regarding a likely major epidemic in the black group in Brazil. In South Africa the race variable does not explicitly appear in recent reports, but the black/African population is undoubtedly overwhelmingly the most affected. According to UNAIDS (2014), the annual AIDS-related mortality is much lower in Brazil (11000 – 19000) than in South Africa (220.000-270.000). Due to the expansion of the ART program since the mid-1990s in the case of Brazil and since the early 2000s in the case of South Africa, there has been a substantial downturn in AIDS-related mortality in both countries. In particular, since the adoption of public ART in 2004, South Africa saw its national AIDS-related mortality dropping from about 257,000 in 2005 to about 194,000 in 2010.<sup>16</sup>

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term (negro/a) indicates individuals with at least half African ancestry, so to speak. Indeed, *Negro* in Brazil can be divided into *Preto* (African/Negroid type) and *Mestiço* (mixed-race). *Mestiço* is also often referred to as *Pardo*, but this may generically indicate people with varied racial ancestries. Afro-descendent is a more comprehensive term.

15 See Brazil's *AIDS Progress Report 2012*, p. 22.

16 See South Africa's *AIDS Progress Report 2012*, p. 52.

*Table 1: Brazil and South Africa HIV/AIDS estimates (2012)*

	<b>Brazil</b>	<b>South Africa</b>
Population in 2013 (millions)	196.5	53.0
Number of people with HIV	530,000 – 660,000	6,100,000 [5,800,000 – 6,400,000]
Prevalence rate in adults aged 15-49	0.4% - 0.5%	17.9% [17.3% - 18.4%]
Adults aged 15 and up with HIV	520,000 – 650,000	5,700,000 [5,500,000 – 6,000,000]
Women aged 15 and up with HIV	160,000 – 190,000	3,400,000 [3,200,000 – 3,600,000]
Children aged 0-14 with HIV	N/A	410,000 [370,000 – 450,000]
Death due to AIDS	11,000 – 19,000	240,000 [220,000 – 270,000]
Orphans due to AIDS aged 0-17	N/A	2,500,000 [2,300,000 – 2,700,000]

Source: UNAIDS 2014. Available from

<http://www.unaids.org/en/regionscountries/countries/brazil/>;

<http://www.unaids.org/en/regionscountries/countries/southafrica/> Accessed on 18 July 2014.

The HIV/AIDS scenario described above in both countries is self-explanatory. It illustrates that Brazil acted far more aggressively and timely against the HIV/AIDS crisis by implementing a comprehensive program of prevention, treatment and care. As we will see, this involved various actors, often in concerted action, namely politico-administrative entities at various levels, civil society organizations, the health sector and pharmaceutical industry. I suggest that the inclusion of social scientists in the construction of Brazil's effective response also played a crucial role. In South Africa, by contrast, similar efforts only began to be made over the last decade. South Africa's response to HIV/AIDS in its initial two decades was characterized by negligence and denial.

All this occurred in a context of democratization processes in both states – after decades of military dictatorship in the case of Brazil, and apartheid, in the case of South Africa (respectively until 1986 and 1994). Brazil's effective anti-AIDS policy has earned the country the reputation of world's model for changing the course of the HIV/AIDS pandemic in the eyes of international health policy-makers (Nauta 2011). On the contrary,

South Africa is one of the countries most cited as a negative example, so to speak. As we will see, the politics of the fight against HIV/AIDS is an important part of the overall context that has shaped the social-science of HIV/AIDS prevention in Brazil and South Africa.

## **2.2 Brazil and South Africa: similar starting-points, highly different outcomes**

This sub-chapter provides an account of the rationale behind the comparison between Brazil and South Africa. First of all, Brazil and South Africa are both middle-income countries with universal rights-based constitutional laws, yet unequal societies, race being one critical factor of socio-economic status. Brazil and South Africa are also similar for being young democracies, with inclusive constitutions promulgated in 1988 and 1996, respectively. The democratic setting allowed the two countries to recover from decades of authoritarian and exclusive regimes: from military dictatorship since 1985, in the case of Brazil, and from Apartheid since 1994, in the case of South Africa.

From a more historical angle, it is worthy stressing that at the onset of HIV in the early 1980s, Brazil and South Africa were in the same line of development. In other words, Brazil and South Africa were similar in terms of state capacity (effective, although exclusive bureaucracies), political participation and freedom of expression (limited, but with notable signs of civil society emergence), as well as health systems (socially exclusive, but scientifically advanced).<sup>17</sup> Solid institutionalization and engagement of the social sciences at the onset of the HIV pandemic is a further common feature between Brazil and South Africa.

Development indicators in the two countries were similar at the beginning of the 1980s and remained so until the early 2000s, before South Africa became torn by the HIV/AIDS epidemic, which has contributed to the deterioration of the country's human development – contrary to Brazil where, in the same period of time, human development has improved (UNDP 2013: 1-12). In the 1980s, Brazil and South Africa had a similar

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<sup>17</sup> I mostly draw from and elaborate on the works by Gauri and Lieberman (2006), Mauchline (2008), and Halbert (2012) for the comparison between the Brazilian and South African trajectories regarding the HIV/AIDS epidemic and their related policies, in which the production and use of social research has played a pivotal role.

average life expectancy, reaching 66 in the former and 63 in the latter in 1992 (World Bank 2005). Per capita income in 2002, in international dollars adjusted for purchasing power parity, was slightly higher in South Africa (\$9,810) than in Brazil (\$7,450). Concerning income inequality, as of the 1994-1998 period, the GINI index was of approximately 60 in Brazil, and 57 in South Africa.<sup>18</sup>

However, despite these similarities, the two countries have performed rather differently in the fight against the HIV/AIDS epidemic. By the end of the 1980s Brazil had already managed to establish an aggressive HIV/AIDS program through a holistic approach that combined prevention, treatment and care (Gauri & Lieberman 2006: 55-56), which involved different levels of administration and social actors, including social scientists. In combination with large scale realistic prevention campaigns, Brazil adopted HAART as soon as it became available in 1996, which also meant major and more effective PMTCT.

In contrast, particularly in the period between the late 1990s and 2003, South Africa developed controversial HIV/AIDS policies that turned out to be unproductive, better yet, disastrous. Such controversies concerned primarily the questioning of orthodox HIV/AIDS biomedicine and social science, which were instead embraced and fomented by the Brazilian state. This was the result of number of political actions, including the fact that in the same period Brazil was fighting for the improvement of ART and more articulated social knowledge on HIV/AIDS. On the other hand, South Africa did not provide public ART<sup>19</sup>, nor supported biomedical measures and appropriate use-inspired social-research. As for Human Development indicators, over the last twenty years or so, massive control of the epidemic has contributed to the rise of life expectancy from 66 to 74 years in Brazil, whilst in the case of South Africa, largely due to AIDS-related mortality and morbidity, life expectancy has declined from 62 to 53 years.<sup>20</sup>

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18 See 2012 World Bank estimates. Available from: <http://data.worldbank.org/indicator/SI.POV.GINI/countries?page=3&display=default> (Accessed on 26.05.2014).

19 In 2003 the government was finally obligated by the Constitutional Court to provide ART in the public sector, following a long judicial process, promoted by South Africa's own AIDS social movement called Treatment Action Campaign (TAC) (Mauchlin 2008; Mbali 2013).

20 See the UNDP interactive map. Available from: <https://data.undp.org/dataset/Life-expectancy-at-birtheyears-/7q3h-ym65> (Accessed on 26 May 2014).

### 2.3 HIV/AIDS bureaucracies and policy steps

As Gauri and Lieberman (2004: 9) state “neither Brazil’s nor South Africa’s trajectory of state capability building has been entirely consistent or linear, but it is clear that in Brazil the state made a commitment to establish policy space for the AIDS response sooner, and that the bureaucracy was endowed with broader and stronger authority than in South Africa”. Indeed, Brazil has been superior to South Africa in terms of the timing of the institutionalization of HIV/AIDS policy, including universal access to ARTs. Brazil established an HIV/AIDS bureaucratic body as early as 1985, creating a National AIDS Program (NAP) within the Ministry of Health (Parker 1994a, 1994b). Furthermore, there was substantial continuity in the NAP structure, even concerning its personnel, as well as adhering to scientific expertise. In 1988 the AIDS inter-ministerial National Commission was established. The Commission reported to the Ministry of Health, but included representatives from the Ministries of Education, Labor, and Justice, the main association of lawyers in Brazil, HEIs, and four NGOs (Gauri & Lieberman 2004: 9). This task force developed a national policy to respond appropriately and sustainably to HIV/AIDS with particular attention to most-at-risk-groups (MARGs) such as MSM, CSWs, IDUs and youngsters, but also targeting the entire population. By the end of the 1980s, information about HIV/AIDS was accompanied by concrete actions like supplying free condoms and clean needles to IDUs. Also, and focusing on human rights and social justice approaches, by the early 1990s the tolerance of politicians, administrators and health professionals towards prostitutes and IDUs increased significantly nationwide. There was by now an increased shared public and governmental consensus that prostitution should be addressed as a profession deserving rights, and that drug use was a public health issue rather than simply a criminal justice problem (Berkman et al. 2005: 1169).

The national AIDS program in Brazil was shaped by local initiatives at municipal and state level (see ch. 6 for details). In general, big cities in Brazil were at the forefront of the struggle against HIV/AIDS and their experience, mainly that which was acquired via NGOs and social movements, became an integrated model for the National AIDS Program.<sup>21</sup> The São Paulo region was the leading constituency. In South Africa, by

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21 Social movements devoted to health promotion will be broadly discussed throughout the present work for two interrelated reasons. Firstly, they have played a crucial role in fostering HIV/AIDS policies in Brazil and South Africa. Secondly, social movements are of vital sociological interest because they are key civil society organizations which are predisposed to changing society through mass mobilization in defense of rights, generally perceived as a matter of collective interest and social

contrast, politics massively centralized HIV/AIDS interventions, thus limiting the expansion of good experiences of prevention and treatment activity from both activists and the most advanced provinces, such as the Western Cape and KwaZulu-Natal. There were rebukes and refusals from the national government to go forward with similar policies and share responsibilities (Gauri & Lieberman 2006: 60). As for the role of civil society, after the advent of democracy in Brazil in 1986, many actors from the Sanitarian Reform Movement, including those dealing with HIV/AIDS, entered political-administrative institutions and played a key role in designing the ordinary Universal Health System (*Sistema Único de Saúde: SUS*). The SUS is indeed one of the novelties of the 1988 Constitutional Law, whose principals are universality, equality and integrality. More recently, with the arrival in power of Lula's Workers' Party, the shift of health experts from CSOs has been more pronounced. Concluding the argument about the influence of former civil society health militants in fostering public policies in the Brazilian democratic era, it is reasonable to affirm that their international links also assisted the Brazilian government's capacity to negotiate the first in a series of three loans from the World Bank in 1993 (see ch. 6). As Gauri and Lieberman (2004: 9) point out, "that targeted funding for AIDS gave the NAP substantial autonomy within the Ministry, including the ability to hire its own staff on a contractual basis with more flexibility than civil service rules generally allowed". A decade after 1993, around 480 staff and consultants worked under contract for the NAP and were responsible for the formulation of AIDS policies regarding prevention and treatment on behalf of the government.

The first National AIDS Plan had already been created in 1992, following a process called National AIDS Convention of South Africa (NACOSA). Analogous to Brazil's NAP, NACOSA became a platform aimed at bringing together central government, local administrations, scientists, civil society and business for the implementation of a comprehensive and progressive AIDS Plan. In 1996 Deputy President Thabo Mbeki was given responsibility for coordinating the AIDS Plan. Such progressive attitude occurred partly thanks to the role of progressive health workers (including white workers) who had opposed the Apartheid government by advocating inclusive health policies, and who were then integrated into the ANC government structure (Mbali 2013: 108-120). This resonated with the *Reconstruction and Development Programme (RDP)*, upheld by the 1996 constitution, which reflected the principles of a non-racial, rights-respecting, and

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justice, in the face of political institutions (Castells 2000; Touraine 1978; Escobar 1992; Morris & Mueller 1992).

development-oriented state. Among other aspects, this meant that, at first glance South Africa's post-apartheid government maintained warm relationships with the national scientific community and AIDS civil society organizations, particularly health professionals concerned about the pandemic.

In 1993, the AIDS Law Project was set up to use legal processes to protect the rights of PLWHA. As a result, a number of organizations, ranging from those involved in advocacy to those focused on direct care and support, were created at national and provincial levels (Mbali 2013: ch. 1). The premises of these initiatives raised hope, if not certainty, that strong collaboration between government and civil society would become the norm, and that an integrated and progressive policy of HIV/AIDS prevention, treatment and care would be truly implemented. However, as the liberal democratic state was consolidated, the post-apartheid context subsequently allowed for critical thinking regarding biomedical paradigms, with an active participation of the international HIV/AIDS dissident community in national policy. AIDS dissidents contributed to South Africa going through regressive HIV/AIDS policies – in the same period that Brazil consolidated its national HIV/AIDS policies by means of employing biomedical expertise, among other factors. It was in this climate that the relationship between South Africa's politics and scientific authorities in HIV/AIDS biomedicine began radically changing, souring the relations between the state and AIDS activists, as well as the progressive local administrations who supported HIV/AIDS science. More specifically, this occurred due to four national controversies (Marais 2000: 33-43): Sarafina II (a lavish but ineffective AIDS education musical), Virodene (a scientifically untested AIDS drug), notification (compulsory reporting of HIV/AIDS cases), and AIDS denialism (maintaining that HIV did not cause AIDS and ARVs were just harmful). I will come back to the explanation of the social contexts and impacts of these controversies later on.

By 1994 Brazil had already consolidated its national AIDS program (Nunn 2009: chs. 3, 4, 5). On the other hand, in South Africa NACOSA was negatively affected by the aforementioned controversies, as well as by the lack of both autonomy and supportive political will from the government. It was not until 1998 that the first truly autonomous and authoritative national AIDS program was set up, when an inter-ministerial National HIV/AIDS Directorate was established within the Ministry of Health (Schneider 1998). Schneider and other scholars point out that by 1998 the epidemic had already reached alarming proportions in South Africa. Yet, South Africa's National Directorate was

staffed with only 18 permanent members and 7 short-term consultants. Therefore, the policies carried out across the country had limited and unsuccessful prevention policies, since NACOSA was also very poor in terms of funds, decentralization, proper government infrastructures, and use of biomedical and social-science knowledge (Gevisser 2009).

In 2000 the South African National AIDS Council (SANAC) was created (UNAIDS 2012a). Chaired by the Deputy President, SANAC is the multi-sectorial coordinating and advisory institution for government HIV/AIDS policies with representatives from all government departments and 19 CSOs. Three representatives of PLWHA are also members of SANAC: TAC, National Association of People with AIDS (NAPWA), and Positive Conventions. However, various non-state actors and experts observe that until 2007 SANAC had quite a poor reputation as the authoritative source of decision-making on AIDS policy. As a consequence, in practice, there was no clear decision-making centre for addressing the epidemic in South Africa until recently. Furthermore, ten years after the advent of democracy and four years after the creation of SANAC (2004), although the infection rate was six times higher than in Brazil, the South African national government employed only around 100 people who were directly responsible for HIV/AIDS (much fewer per capita than the Brazilian government). For these reasons, in that period there was a considerable divide between policy planning and the implementation of government anti-AIDS measures (Wouters et al. 2010). The only major initiative carried out at this time was *Sarafina II*, an AIDS education musical based on the film *Sarafina* and designed to tour the country from 1996 onwards. As we shall see, *Sarafina II* was criticized and abandoned by civil society for providing a confusing and ineffective message, despite the astronomical funds of over 14 million ZAR spent (Martin-Tuite 2011: 12, Gauri & Lieberman 2004: 15, Mackintosh 2009).

We might argue that in those years, compared to Brazil, the later arrival of democracy in South Africa counted for the government's late adequate action against HIV/AIDS. This is an important research question, that is, whether South Africa's HIV/AIDS policy would have been stronger if the country's democratic transition had taken place earlier. I suggest that this is not the case. It seems that South Africa's elites have historically invested in public health for state building and as a proxy of modernity in the same manner as Brazil. South Africa lacked other relevant social factors with which to conjugate such tradition. These include a lack of openness towards sex, sexuality and

sexual diversity, which is a precondition for conceiving gay citizens and sex workers' organizations as key actors in the handling of the HIV/AIDS crisis. Even the confusing and ineffective message delivered through the *Sarafina II* musical can be associated to South Africa's difficulty to talk openly about sex and sexuality. Indeed, comparatively, Brazil's openness to sexual discourses (despite the predominance of Catholicism) enabled policy-makers to combine their traditional attention to public health with the inclusion of gay movements' activities in HIV/AIDS programs (Gómez 2006), as well as demonstrating tolerance towards commercial sex, whereby CSWs could act as agents of prevention.

Under the Mandela administration (1994-1999), HIV/AIDS was not viewed as an urgent matter. Reconciliation and the restructuring of the state's bureaucratic apparatus were the highest priorities. The inability to construct an effective response to HIV/AIDS and share a vision regarding the epidemic meant scientists and political leaders of the apartheid and Mandela eras did not challenge the authority based on orthodox scientific knowledge (Martin-Tuite 2011: 12). The conformity of apartheid politics had merely privileged Western scientific knowledge and excluded the indigenous majority from proper biomedical services. It was after Mandela, under the presidency of Thabo Mbeki (1999-2008) that South Africa's government questioned the biomedical model over the causal link between HIV and AIDS, as well as the effectiveness of ARTs. With the consolidation of the liberal democratic state by 1994, the post-apartheid context subsequently allowed for critical thinking on the biomedical paradigm, also thanks to the irruption of international AIDS dissidents into the national debate. Later, Mbeki went through more harmful policies, even compared to the latter stages of the apartheid government, which had simply neglected the HIV problem by viewing it as an exclusive plague of groups that generally did not deserve political attention, namely, blacks, the poor, prostitutes and gays. Brazil consolidated its national HIV/AIDS policy by the early 1990s, partly thanks to international loans and the participation of orthodox biomedical experts. In the same period South Africa went through regressive HIV/AIDS policies. Such policies would lead to a situation of tragic confluence: that of the remarkable victory of the ANC over apartheid rule with the rising mortality of the AIDS epidemic (Susser 2009: ch. 3).

### *HIV/AIDS expenditure*

The differing HIV/AIDS policies also meant there were discrepancies between Brazil and South Africa in their states' expenditure on prevention and treatment. Brazil was far superior to South Africa concerning HIV/AIDS expenditure in the period 1987-2003. Some crucial years are worth analyzing. HAART was by now largely available and affordable, and various countries improved their HIV/AIDS programs, Brazil's per capita expenditure in US dollars was 0.68 in 1996 and 1.59 in 1997. In the same years South Africa only spent 0.41 and 0.37 US dollars per capita. This was significant. Cumulatively, in the period 2000-2003 Brazil spent slightly more than South Africa: 6.55 vs 5.33 US dollars per capita. When it comes to treatment and other services provided to every single HIV-positive person, Brazil spent as much as 184.28 US dollars in 2003, whilst South Africa only spent 13.20 in 2002 and 4.44 in the previous two years. Additionally, in early 2002, South African government refused to allow the KwaZulu-Natal provincial administration to accept a US\$72 million five-year grant allocated by the Global Fund as a supplemental budget to the US\$93 million awarded to the country (Mbali 2013: 212). The battle would be resolved only in 2003 when the government was forced to provide public ARTs. KwaZulu-Natal was awarded that additional grant because the province needed to enhance its health care system, including the provision of combination ARTs at pilot AIDS clinics, since KwaZulu-Natal was and still is the AIDS-most affected province in South Africa. The grant was a product of the representation of South African civil society, medical academics and corporate sectors' in the Global Fund board, and these actors then expressed fury and resentment for the debacle.

### *The struggle for ARVs*

Brazil and South Africa have reasonably sized ARV manufacturing industries. However, Brazil outweighs South Africa in this field, since Brazil is the third major ARV drugs producer in the world, behind India and Thailand, produced for both domestic use and for export purposes (40% of ARVs by 2012). Domestically, this has been vital for the provision of affordable AIDS treatment in developing countries. Internationally, Brazil's capacity to manufacture ARV drugs has resulted in competition between producers, which has contributed to reducing the price of various ARVs from as high as 15000 US dollars a year per person for a course of combination treatment in 2001, to as little as 150 US dollars today. The Brazilian and South African markets are notably large for ARVs, and for this reason pharmaceutical companies usually exclude the two countries from differential pricing deals offered to lower income countries, and press them to increase patent protection for ARVs. Nonetheless, the two countries have resisted such pressures rather well, partly by invoking legal frameworks of the latest WTO Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreement of 2001 (held in Doha, Qatar), which provides developing countries with some flexibility in regard to the issuing of compulsory licenses for ARVs and basic medicines in general. Indeed, not only has the 2001 Doha TRIPS statement led to dramatic lowering of the prices of ARV drugs, but it has also extended the possibility for developing countries to domestically manufacture and import generic drugs in the name of access to medication as a human right instead of a property right. But the most crucial point here for the present comparative work is that, strengthened by its Sanitary Movement, Brazil played a pivotal role in these agreements (Fonseca & Bastos 2014), whilst on the part of South Africa, it was only AIDS activists who battled for cheap and available ARVs (Wogart et al. 2008) - because the South African state was going through regressive HIV/AIDS policies that denied the provision of public ART (see 6.2.1 for details).

#### **2.4 South Africa's controversial policies vs Brazil's adherence to science**

It is largely due to the impact of controversial policies that South Africa's central government remained for a long time disconnected from, and opposed to, anti-AIDS progressive actors such as the Western Cape Province, scientific communities, health professionals, and social movements. In this sense, controversies created a

contemporaneous South African world of “conflicting multiple presents” (Fassin 2007, after Michael Herzfeld), whereby different social actors belonging to the same world – AIDS affected South Africa – experienced the epidemic differently for the lack of a shared understanding or representation of the same problem. These dynamics partly explain the lack of significant controversies regarding HIV/AIDS policy in Brazil and the prominence thereof in South Africa until a decade ago. Let us broaden the discussion about South Africa's controversial HIV/AIDS policies.

Comparatively, such controversies occurred in South Africa when Brazil had already consolidated its multi-sectorial anti-AIDS program, which demonstrates that the Brazilian government considered HIV/AIDS with a major sense of urgency than its South African counterpart. In particular, by the mid-1990s, Brazil had already made progress in AIDS communicative tools (including artistic products), medical and pharmaceutical resources (including measures for affordable ARV and extension of ART). At an institutional level this was part of the progressive activities aimed towards calling the attention of Brazilians towards safe sex and the availability of treatment and care services. This contributed to forging much deeper cooperative relationships between the state and NGOs/social movements, despite conflicts between them.

#### **2.4.1 The *Sarafina II* controversy**

As alluded to earlier, *Sarafina II*, an anti-AIDS musical launched in 1996, was the only major anti-AIDS initiative carried out in the very early years of the democratic era in South Africa (Mbali, 2013: 110-112). Based on the film *Sarafina* and played by prominent playwright Mbongeni Ngema, the musical's aim was to change the general youth's sexual behavior by creating AIDS awareness across the country. However, as soon as the play was released, the media and opposition parties raised concerns on various issues regarding the musical, namely the amount of money spent on it (14.27 million Rand) and its management, the tendering procedure that awarded the contract to Mbongeni Ngema, and the clarity on the source of funding (European Union or the Department of Health). In addition, AIDS activists highlighted the lack of consultation around the project and raised concerns regarding the appropriateness of the play's content and message to change the youth's sexual behavior. Following NACOSA's calls, the Parliamentary Health Portfolio Committee held a hearing on the issue (28 February

1996). Many questions surrounding the controversy remained unanswered. Ultimately, the Public Protector reported that the AIDS message conveyed by *Sarafina II* was inadequate in terms of reversing the epidemic and suggested that the play had to be revised and improved if it were to continue. Negative views on procedural matters surrounding the play were also expressed by the Public Protector. It was claimed that there had been a disregard for the law in the tendering process that awarded the contract to Mr Ngema. For example, while it was clear that the budget came from a European Union donation, it was not clear if the decision had been taken by Chief Directors of the National Program Dr. Mtsali and Mrs Abdool Karim or the Health Minister Mrs Nkosazana Zuma. As for the 14.27 million Rand spent on the production of the play, the Public Protector declared that it had not been officially authorized and that it exceeded the Health Department's expenditure for provincial AIDS education.

Inevitably, the *Sarafina II* scandal was an embarrassment for the government. Tom Lodge (1998: 176-177) states that “though the Public Protector's investigation of the *Sarafina II* affair did not indicate that officials sought personal gain through neglecting regular tendering procedures, it did feature the kind of heavy handed efforts to prevent disclosures which engender corruption”. Convincingly, Lodge also argues that the misuse of money to fund the *Sarafina II* AIDS musical was partly a consequence of ministerial impatience with established bureaucratic procedures. In this sense, the *Sarafina II* case is partly a consequence of the government's incapacity to, first, clearly define institutional bodies and persons in charge for HIV/AIDS policies and, second, strategies for bringing together different social actors in the response to the HIV/AIDS crisis. Also, the musical illustrated the challenges which activists-turned-bureaucrats faced in familiarizing themselves with the state mechanisms (Mbali 2013: 9). The government's hostility towards AIDS activists created a storming crisis at NACOSA because it was no longer possible for this organization to fulfill its coordinating mission, that is, bringing together different social actors in response to the HIV/AIDS crisis. In 2000 NACOSA ceased to exist as a national organization and carried on as a mere NGO in the Western Cape province (Mbali 2013: 10).

#### **2.4.2 The controversy over Virodene**

A year after the *Sarafina II* scandal broke out (1997) allegations emerged reporting that the Mandela government was supporting an inappropriate AIDS drug, Virodene, which

was produced by the University of Pretoria scientists Olga and Zigi Visser (Myburgh 2009). The Vissers' research team met and informed Deputy President Thabo Mbeki and Health Minister Nkosazana Dlamini-Zuma that they were locally developing an AIDS drug and said that the "AIDS Establishment" was blocking their research. We need to bear in mind that in this period the international scientific community had already approved the Highly Active AIDS Retroviral Therapy (HAART). HAART was presented at the 11th International Conference on AIDS in Vancouver in July 1996 and most countries adopted it immediately, with Brazil becoming a leading country in the field. In this climate, Virodene would become part of what has been characterized as heresies with regard to the scientific and medical discourse, as part of the new South Africa national project represented, in this case, by its autonomy and self-reliance in face of the international pharmaceutical industry. Meanwhile, Brazil, in tandem with India, was preparing its leadership in the negotiations within the WTO that since 2001 have resulted in the reduction of the previously prohibitive prices of ARVs, break from pharmaceutical companies' patents and relatively significant national production of ARVs. Notwithstanding, in South Africa Virodene was presented by the Vissers as a valid and a positive alternative to prohibitively expensive ARVs by asserting that unofficial clinical trials of Virodene had already taken place in PLWH and the results were encouraging. After giving the Vissers a standing ovation, the Cabinet resolved to help them with the approval of a scientific drug trial (Nattrass 2008: 160). But Virodene would be short-lived. South Africa's Medicines Control Council, the national drug regulatory authority, had to halt the Vissers' trials because Virodene resulted to be a mere mixture of industrial solvent (Dimethylformamide: DMF). In this period South Africa's Medical Research Council was led by internationally acclaimed scientists, such as immunologist Malegapuru Makgoba and pharmacologist Peter Folb. Sensitive to public health dynamics, and at odds with the government's attitude, these key figures sought contacts with prominent AIDS activists and academics such as Mark Heywood and Mary Crewe from the AIDS Consortium over the Virodene issue. The University of Pretoria and the national Medical Research Council joined Medicines Control Council and launched an urgent investigation into the Vissers research team's deviation from established scientific and ethical standards (Mbali 2013: 113-115; Nattrass 2008). Apparently, DMF had previously been tested in cancer therapy but had been abandoned as ineffective and toxic, and Olga Visser was investigating something similar before she found out that the substance could inhibit AIDS. Embarrassment ensued within the ANC government for its support of pseudo-science. But health Minister Manto Tshabalala-

Msimang continued making statements in support of Virodene and she publicly urged the Medicine Control Council (MMC) to work in the same direction in order to resolve the status of Virodene (Mbali 2013: 114). MMC scientists refused to comply and Folb and his prominent colleagues were forced to leave office, which is why the MMC ceased to function for a short period before Helen Rees, a former anti-apartheid activist, took Forb's place with the same vigor that had characterized Folb.

Thus, Virodene matters for the history of South Africa's AIDS policy for a number of reasons. Firstly, the two key producers of Virodene played a pivotal role in introducing President Mbeki to the AIDS dissidence from the HIV/AIDS “Western” biomedical model and, by implication, the Health Minister’s decision not to introduce AZT for pregnant women to prevent mother-to-child transmission of HIV in primary care settings, alleging that AZT was toxic (which is partially true) – “a medicine from hell, akin to napalm-bombing a school to kill some roofrats” (Myburg 2009); secondly, Virodene set a harmful precedent due to the government’s meddling with the independence of the Medicines Control Council and Medical Research Council, which included the capacity to regulate key spheres of public health within the Health Department and exercise control over medical charlatans and self-styled traditional healers, who boomed as a result of the HIV/AIDS epidemic (Nattrass 2008: 167); thirdly, the Virodene story contributed to fomenting conspiracy theories, which included the black South Africans’ suspicion and distrust towards “white” anti-AIDS measures (Kalichman 2009); fourthly, together with other controversies, the Virodene case contributed to dividing the central state from progressive AIDS fighters such as the scientific community, social movements, the Western Cape province and even some individual figures within the Department of Health; finally, fifthly, as a consequence of the government's failure to capitalize on new advances in HIV treatment, AIDS activism became more radical, a change that would lead to the emergence of the TAC, which would become the embodiment of South Africa's AIDS movement and one of the world's most successful movements.

### **2.4.3 The controversy over notification**

The controversy over notification started when, in 1997, health Minister Nkosazana Dlamini-Zuma announced the compulsory reporting of HIV cases by medical practitioners to the public health authorities, and added HIV/AIDS to the list of “notifiable diseases” (Schneider 2001). She announced the project in parliament and in a

speech at a national meeting meant to review South Africa's HIV/AIDS policy. The Minister justified compulsory notification as being aimed towards implementing an efficient reporting system for the appropriate provision of health services to persons diagnosed with HIV. Deputy President Thabo Mbeki and other government senior officials supported the initiative, alleging that the measure was for the good of the country. This was understandable, but the government's list of measures included elements that undermined the project, such as the deportation of HIV-positive migrant workers (Ngwena 1998).

Concerns were raised by gay movements and epidemiologists, tensions followed (Mbali 2013: 115). Gay groups claimed that compulsory notification involved breacking doctor-patient confidentiality and non-discrimination principles for which they had fought since the early 1990s. They also argued that the measure could increase attacks on AIDS-sick citizens, as well as slippery discrimination of HIV transmission. On their part, epidemiologists denounced that compulsory reporting was an ineffective method of collecting scientific data because it led to under-reporting dynamics, pushing the infection underground and increasing spiraling infection rates. Epidemiologists also argued that, partly due to high infection rates in South Africa, compulsory reporting would provide only a snapshot of those who had been infected a decade before. Instead, they suggested that a better method to track the epidemic should concentrate on data from sentinel sites and more detailed enumeration of HIV-related diseases at health facilities.

Compulsory notification of HIV cases has never been implemented and the project seems to have been abandoned after the June 1999 elections. Mandisa Mbali (2013: 117) suggests that the project was dropped probably due to: firstly, the government's recognition of the bureaucratic problems implied by the implementation of the measure; secondly, the changes within the national government following the 1999 elections, namely the appointment of a new Minister of Health Manto Tshabalala-Msimang; and thirdly, the utter conflict over the appropriateness of AZT from October 1999, a controversy which would take the government into the heart of AIDS biomedical dissidence. Although never implemented, compulsory notification demonstrated the coercive nature of the South African government's initial response to the HIV/AIDS crisis, rather than its engagement in rights-based strategies. To my best knowledge, compulsory HIV reporting has never been proposed by Brazilian authorities. On the contrary, the involvement of scientific communities has prevailed throughout the history of the epidemic in Brazil.

#### **2.4.4 Mbeki's HIV/AIDS denialism: the public face of controversy**

HIV/AIDS denialism was the most important controversial policy in South Africa for most of Thabo Mbeki's presidency. Mbeki embraced the ideas of a handful of International dissident scientist groups and freelance journalists, with some of whom he maintained personal communications, being able to instruct himself on HIV/AIDS using dissident material available on the Internet (Nattrass 2007; Posel 2008). HIV/AIDS denialists are united by their unshakable belief that the existing canon on HIV/AIDS science is wrong and that AIDS deaths are caused by malnutrition, narcotics and even ARV medications. They differ in that they either follow the views of a few Australian pseudoscientists ("The Perth Group") who disseminate the belief that HIV does not exist at all, or those of the University of California at Berkeley biologist Peter Duesberg, who claims that HIV does exist but it is a harmless passenger virus (Nattrass & Kalichman 2009). This HIV/AIDS international denialist network promotes its agenda predominantly through the internet, the "independent" press and occasionally through public meetings. They promote untested treatments for AIDS, ranging from vitamins to ozone therapy, over which they sometimes build personal businesses, as in the case of Mathias Rath (a German doctor and businessman), Gary Null and Roberto Giraldo (Nattrass & Kalichman 2009: 125). However, AIDS denialists downplay their links with the purveyors of alternative therapies, preferring instead to portray themselves as brave "dissidents" and lone persecuted standard-bearers of the truth, who attempt to engage in a genuine debate with the hostile medical-industrial establishment. They complain that their attempts to raise questions and pose alternative hypotheses have been unjustly rejected or ignored at the cost of scientific progress. Nattrass and Kalichman posit that this is disingenuous because AIDS denialists continue to champion views that have long been discredited, and ignore evidence that does not confirm their belief paradigms.

Biologist Peter Duesberg is the most noteworthy HIV/AIDS denialist. He is a (former) member of the National Academy of Sciences and the first person to isolate cancer genes. But Duesberg has no research experience on HIV/AIDS, which is why he has no evidence to support his erroneous claim that AIDS is caused by malnutrition or narcotics rather than HIV (Kalichman 2009: 25-54; Nattrass & Kalichman 2009: 124). Duesberg became a member of the South African Presidential AIDS Advisory Panel (PAAPR), when it was established in 2000 (PAAPR 2001). Duesberg and other prominent

HIV/AIDS denialist scientists would shape the rhetoric and actions of Mbeki's administration on HIV/AIDS policies, especially with regard to the use of ARVs in anti-AIDS treatments. One crucial historical moment is represented by the 2000 Durban biannual AIDS Conference. Mbeki summoned a group of HIV/AIDS denialists for the conference. Besides Duesberg, this group included Anthony Brink (a South African lawyer), David Rasnick, Elani Papadopoulus-Eleopulos (head of the "Perth Group"), Roberto Giraldo (a "natural health counselor and businessman"), Etienne de Harven (former head of a network called "Rethinking AIDS", who later became an adviser to South Africa's Health Minister), and Sam Mhlongo, who, in conjunction with Rasnick and Brink became involved in spreading disinformation on AIDS, while Rath was running illegal clinical trials in South African townships in which HIV patients were asked to go off ARVs and onto vitamins instead (Nattrass & Kalichman 2009: 126).

Mbeki made several public statements to express his way of re-politicizing HIV/AIDS science in South Africa's post-apartheid context (Mbali 2013: 120-135). Scholars point out that as scandals surrounding HIV/AIDS policy multiplied and thousands of HIV-infected South Africans fell ill and died, Mbeki denied knowing anyone with AIDS. When the cabinet recognized the crude reality of HIV, the health Minister's office went as far as distributing texts based on conspiracy theories to key officials, which claimed that HIV had been concocted by Westerners to reduce the global population. In such a context, progressive health professionals became enemies of the state:

Witch hunts were mounted against health officials who tried to perform their duties and provide AIDS drugs to patients and rape survivors. Scientific evidence was rubbished the one day, cherry-picked the next for snippets to prop up bankrupt arguments. (Marais 2011: 279).

Public anger grew. Opposition parties and AIDS activists held massive protests. At times reason seemed to prevail in governmental decisions, but too often bewilderment ruled AIDS policies, because "in the ANC denialism was not simply dominant, it was hegemonic" (Marais 2011: 360-381). To some extent and due to various complex factors, denialism could also be found at societal level, so there seems to have been a sort of cultural match between institutional and societal levels. Indeed, locally, Mbeki's questioning of Western scientific knowledge found support of various individuals and organizations with the same vision. According to Cullinan (2009), in 2005 figures like South African lawyer Anthony Brink and Dr. Matthias Rath launched the Treatment Information Group, an advocacy coalition for science-critical organization, which included the Traditional Healers Organization (THO), the South African National

Civic Organization (SANCO), and NAPWA. By 2005, Dr. Rath had gone as far as establishing his own “alternative medicine” operations in the Khayelitsha township in Cape Town, apparently framing his critique of Western science within the relative community’s sentiments. On the other hand, mass media reporting was neglectful of important details and contexts. This was in line with the ANC general thinking on HIV/AIDS. In short, as Lawson (2008: 172) proclaims:

There were many shades and shapes of denial of the AIDS crisis in late 20th century South Africa: from the politicians who played down the seriousness of the crisis to the ordinary people who denied their own risk and vulnerability; from the mass media, which dodged difficult and meaningful debate, to the teachers who refused to talk about safer sex. It is not surprising then, that this national state of benign denial created the space for a more malignant version to emerge.

The legacy of denialism is certain to endure far beyond Mbeki’s days as President. Mbeki’s bluster about sovereignty and ‘African solutions’ has resulted in much lower ART coverage and in thousands of avoidable deaths. The amount of AIDS-related deaths attributed to the Mbeki administration's obstructionism and large-scale political inaction in South Africa is estimated at 500,000 (Venter 2014), of which 340,000 occurred in the period 1997-2003 (Chigwedere 2008). As for treatment, to date only a third of those needing antiretrovirals actually receive them across South Africa. Furthermore, from the Cabinet, denialism spread over various South African society spheres, reinforcing not only pre-existing misconceptions and misinformation about HIV/AIDS causes and treatment, but also cultural difficulties to discuss sex and sexuality. Messages according to which it is not HIV but rather poverty that causes AIDS and that ARVs are toxic poison have misinformed an entire country (Nattrass & Kalichman 2009: 127). Denialism has reinforced stigmatization and undermined the fight against HIV/AIDS by diverting political, economic and social resources away from the epidemic. By undermining people’s trust in science, medicine and public health facilities, denialism dissuaded those affected by HIV/AIDS from testing and seeking appropriate information about the availability and effectiveness of life-long treatments. More importantly, HIV/AIDS denialism fomented people's unsafe sex behavior, as it states that HIV either does not exist or, if it does, it is harmless.

### *The end of denialism*

HIV/AIDS policy in South Africa began to improve in 2003-2004 when ART was finally introduced into the public health system, at least two years after the

Constitutional Court ruled against the government, instructing it to provide Nevirapine to all HIV-positive pregnant women (Friedman & Mottiar 2005). HIV/AIDS and tuberculosis were declared a national emergency. By 2004, the PMTCT and ART program were being rolled out nationally and most of the HIV drugs dispensed in the state program were generic versions manufactured by a local company. By mid-2001 the government's arguments for not introducing a full-scale program to prevent vertical transmission of HIV were already threadbare: ARVs prices had lowered, clinical trials had confirmed the safety and effectiveness of the ARV Nevirapine and South Africa's Medicines Control Council had licensed it (Marais 2011: 280; Mauchline 2008).

South Africa's government approval or support of science-critical enterprises remained in place until very recently (Martin-Tuit 2011). Even after being instructed by the Constitutional Court to provide ARVs, Health Minister Manto Tshabalala-Msimang continued stressing the benefits of alternative untested treatments and describing ARVs as toxic, while Mbeki's government balked and turned its guns on those who tried to fight for HIV/AIDS treatment, especially the TAC. In particular, Mrs Tshabalala-Msimang continued to jump from one controversy to the next, persecuting healthcare professionals who tried to fulfill their duty, thus ignoring scientific evidence-based effective HIV interventions. She continued promoting untested and unlicensed alternatives to the medical treatment of AIDS. Even when Mbeki quit making public commentaries on AIDS treatment, Tshabalala-Msimang appeared at the XVI International AIDS Conference in Toronto, Canada, with a display of her infamous anti-AIDS prescription: vegetables and vegetable products, including garlic, beetroot, and olive oil (Cullinan & Thom 2009). "Whose science?" was her rhetorical response to a United Nations officer's critical comments of the ANC government's lack of scientific support.

Embarrassment engulfed the ANC government and this eventually led to some changes. By the end of 2006 a new progressive strategic plan for HIV/AIDS was adopted to revitalize the South African National AIDS Council (SANAC), which now included health workers, AIDS activists, and scientists from various disciplinary areas. By then, social consequences of ineffective AIDS policies, largely avoidable, were evident to everyone. But President Thabo Mbeki and Health Minister Manto Tshabalala-Msimang remained in office for a decade.

By 2008 tumultuous changes in the South African political structure would tear down political HIV/AIDS denialism at an unprecedented speed. It became clear that Mbeki's AIDS policies were shaped by some degree of authoritarianism, and that the ANC is a controversial-non monolithic organization. Denialism had collapsed on itself and most government officials had by now felt the burden of the Mbeki-headed ANC understanding of HIV/AIDS and African Renaissance. On September 22<sup>nd</sup> 2008 Thabo Mbeki resigned from the presidency of South Africa after being voted out from the presidency of the ANC. In one of his first acts on his first day as interim President of South Africa, Kgalema Motlanthe removed Manto Tshabalala-Msimang from her post as Health Minister. In less than 48 hours, the politics of HIV/AIDS in South Africa turned away from denialism. The new government immediately set new policies into motion and the country seemed optimistic that a concerted effort from the top of the government would forge a new way forward. Mbeki almost completely disappeared from public life. Tshabalala-Msimang died in mid-December 2009 after a prolonged illness. Besides public ARTs, now made legal, significant changes in the struggle against HIV/AIDS in South Africa began to emerge. In the following years, partly thanks to civil society pressure, the South African National AIDS Council was completely restructured. A new and positive attitude of the political leadership towards the epidemic in South Africa's Health Ministry is now in place. Civil society organizations<sup>22</sup> and orthodox scientific communities are now important actors in national HIV/AIDS policy (UNAIDS 2012b: 36). The implementation time-frame of the *2007-2011 South African National Strategic Plan of HIV/AIDS and STIs* shows a substantial increase in several prevention and treatment fields. National HIV counseling and testing campaigns increased and reached 13-15 million people. As for treatment, progress was made by providing universal access to free ART, including the PMTCT, which also entailed an increase in public health expenditure. As for prevention, early diagnosis of the virus and co-infection testing (of HIV, TB, Syphilis, Hepatitis) constituted a major improvement. Additionally, across South Africa, male medical circumcision is being massively rolled out as an HIV prevention method, as it

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<sup>22</sup> Concomitantly, the TAC restructured itself, with former General Secretary Zackie Achmat leaving his position to Vuyiseka Dubula, a young HIV positive lady, thus allowing the emergence of a new generation of TAC activists and, consequently, forging new alliances with the government and other partners.

is recognized as being able of potentially reducing the risk of men catching STIs by 60-70%.

In such a restructuring atmosphere, indigenous medical practices and beliefs – historically marginalized by white domination, a problem that Mbeki tried to solve in a particular manner – are portrayed as peripheral to science. According to Martin-Tuite (2011: 21), “the consequence may be pushing indigenous populations even further to the edge of national politics”. But, it could as well be an opportunity for the South African government and civil society to demonstrate their abilities to extend or enhance their activities – including prevention and treatment – in the rural homelands of indigenous populations (Robins 2008: 126).

By 2003, when South African HIV/AIDS policy began to improve substantially, the provision of public ARTs in Brazil was already a well established policy. Indeed, in Brazil the battle against HIV/AIDS has adopted biomedical science since the onset and has assured universal and free access to AIDS treatment as a basic human right. The state has politically and economically invested in modern technologies by encouraging the use and production of condoms, but also in ARV drugs (Nunn 2009: ch. 4). A pivotal role has been played by the *Fundação Oswaldo Cruz (FIOCRUZ)*, the leading Brazilian institution in medical research oriented towards health-policy development (ibid). This, together with other interventions, has resulted in Brazil having one of the lowest HIV infection rates and being considered as the world leader in global response to the HIV/AIDS epidemic.

#### *Interim concluding remarks*

To my best knowledge, denialist Roberto Giraldo has never shaped any AIDS policy in Brazil, neither has he been invited by political or scientific authorities to publicly expose his “alternative ideas” on the HIV/AIDS disease and epidemic. As for other actors, evangelic churches have generally maintained discourses which are detrimental to HIV prevention and treatment in Brazil. But it is only after 2010 that evangelic rhetoric started having an impact at institutional level with regard to HIV/AIDS policy. The evangelical wing is a parliamentary ally of the ruling Workers Party (*Partido dos Trabalhadores: PT*). In addition to their influence in Congress, some evangelic figures now hold high positions in the departments of health and human rights. They have recently capitalized on their political strength to propose regressive measures

including a “gay cure”, dropping HIV/AIDS from the top of national priorities, and the exclusion of sex workers carrying out HIV prevention peer education. These are certainly relevant threats to the future of the politics of HIV/STIs prevention, treatment and care in Brazil. It is also true that, due to a dearth of financial support and mobility in terms of dynamics at a senior level, the AIDS civil society in Brazil has recently lost ground in favor of the government, which makes the evangelical stance more threatening. However, the country's solid tradition of comprehensive AIDS programs in various social spheres makes it hard to hypothesize about a highly regressive scenario. Brazilian critics suggest that much needs to be done in order to reduce the hegemony of multinational pharmaceutical companies and vigorously re-politicize AIDS at a macro level (Veriano Terto Jr, interview 19 Nov 2012; Vera Paiva, ABRASCO Congress speech 18.11.2012; Richard Parker, SMI-RJ Conference, IMS/UERJ 11.10.2012). But undoubtedly, Brazil remains a key global leader in integrated, multi-level and multi-sectorial AIDS policy, while South Africa has only recently started taking significant steps towards a truly aggressive response to the HIV/AIDS epidemic.

In such environments, it is not surprising that social-science knowledge on HIV/AIDS was far more encouraged and used by the state in Brazil than in South Africa. Indeed, most implemented prevention activities until recently in South Africa were not sufficiently informed by social or political theory and there was no real comprehension of the outcomes that could accordingly inform future interventions (Uys & Alexander 2002). South Africa did carry out some necessary policies in the field of HIV/AIDS epidemic. For example, with regard to prevention, South Africa preceded and has been more aggressive than Brazil in blood safety since 1985, passing a law that prohibited blood commerce and subordinated its control to health authorities, while it was not until 1988, when the post-dictatorship constitution was promulgated, that Brazil took such a measure (Gauri & Lieberman 2004: 15). But, overall, South Africa did not carry out solid policies that involved engagement with society, in order to produce significant social change leading to healthier behaviors and prompt availability of AIDS treatment.

On the other hand, Brazil's AIDS policy is not exempt from flaws. For example, the very early reaction to HIV cases on the part of government and health institutions was rather negative. Politicians and health workers considered the infection as a disease of the high-income homosexual minority, and they argued that the magnitude

and spread of the virus would remain substantially limited, and that if handled by the public sector, HIV care would divert attention from more important issues like other infectious diseases, primarily TB (Galvão 1997). Also, in the beginning of the pandemic, the media in Brazil held a stigmatizing and discriminatory stance towards HIV positive persons, gays being the most targeted group (Citeli 2003). The initial phase for HIV-infected people in Brazil was indeed strongly characterized by a mixture of panic, stigma and discrimination. However, in stark contrast to South Africa, Brazil's society at large, including the government and health professionals took a short time to view HIV as a pressing national problem that needed to be addressed through modern science and collective action. This was certainly due to the pressure exercised by middle-class HIV-affected homosexual groups that from the beginning of the 1980s stood up against HIV (i.e. *Somos*, *Grupo Gay da Bahia*, *GAPA*). But what mattered the most was the articulation of the debate regarding the epidemic among administrative authorities, the health sector, social movements, and the academic world. By contrast, the South African government, operating in a profoundly divided society, restrained the role of gay groups, health workers and social researchers who tried to tackle HIV in the same manner as their Brazilian counterparts, that is, through community education and alliance building, nationally and internationally.

#### *Denialism and HIV/AIDS social-science*

In relation to engaged scholarship in Brazil and South Africa, the analysis of controversies over HIV/AIDS in South Africa matters for the exploration of HIV/AIDS social-science due to two fundamental reasons. Firstly, the government's antipathy towards HIV/AIDS scientific authority obstructed the social scientists' role to join the government in the fight against the HIV/AIDS calamity. This is especially true with regard to denialism, the public face of controversies, in Christopher Colvin and Steven Robins' words (2009). In this debate, the role of social scientists in nation building through the struggle against the epidemic has been emphasized. Indeed, a recurrent question is whether social scientists could have been more vocal against denialism in its heyday and made a difference in a society whose future and security was compromised by HIV/AIDS. Unlike in Brazil, where the response to HIV/AIDS was to a great extent a shared national project and where social-science knowledge played a crucial role-, in South Africa controversial responses resulted in the isolation of social researchers by the government.

The facts described in this chapter – epidemiological profile of HIV/AIDS in Brazil and South Africa, causes of the pandemic and the obstacles to reversing it – demonstrate the complexity of the epidemic and call for a comprehensive social-science approach to the epidemic. It is the latter that is crucial for understanding both health-policy success and the context that shapes the way in which social-science knowledge is produced, circulated across societal spheres and used for HIV/AIDS prevention, treatment and care. The institutional-cultural perspective is a comprehensive approach to health policy. A few words will be said about this later on (1.4). Overall, one example of comprehensive social-science was given by the explanation of HIV/AIDS controversial policies in South Africa, particularly denialism, in contrast with the absence of them in Brazil (see ch. 5). We here summarize the main issues concerning the timing and scope of state response to HIV/AIDS in Brazil and South Africa.

*Table 2: Timing and scope of state response to HIV/AIDS*

<b>Bureaucracy</b>	<b>Brazil</b>	<b>South Africa</b>
National HIV/AIDS program established	1985: AIDS declared a public health problem to be addressed by state health secretariats	1988: process initiation of National AIDS Convention of South Africa (NACOSA) in 1992
Inter-ministerial HIV/AIDS Council established	1988	1998 NACOSA restructured
Appearance of HIV/AIDS as a budget line item	1988	2000
Number of HIV/AIDS program staff	476 (2002)	100 (2004)
Partnerships with CSOs	Collaborative direct budgetary supported to CSOs since 1993	Mixed/Conflictual: CSOs challenge and sue government

Monitoring and evaluation	Ad hoc monitoring among MARGs since 1989; Systematic population based monitoring since 1998	Systematic antenatal clinic surveillance since 1990; little surveillance among risk groups
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**Prevention**

Bureaucracy	Brazil	South Africa
Education and outreach	TV adverts and workplace programs by 1988; Targeted outreach-based programs: MSM (1985)	1996: Controversial “Sarafina II” musical; Epidemiology already generalized before significant campaigns initiated
Condom distribution	Extensive, high visibility of government programs; Government announces distribution of 3 billion in 2004 (17 units per capita)	More modest programs with less outreach; Government distributes 540 million in 2004 (12 units per capita)
Prevention of Mother to Child Transmission (PMTCT)	1994: Launch of Zidovudine (AZT) 076 protocol	(2001) 2003: Nevirapine provided only following a legal battle
Safety of blood supply	Mostly safe in 1988, clandestine blood market eliminated in 1998	Deemed safe in 1985
Commercial sex workers (CSW) outreach/involvement	1998-2002: 547 prevention projects reached/involved about 900.000 CSW	
Distribution of clean needles for harm reduction Harm Reduction Programs for IDUs: supply of clean needles and syringes, counseling	1996: 267 harm reduction local initiatives, reaching 145,000 IDUs by 2003 By 2005: over 100 large Harm Reduction Programs	

## Treatment

Bureaucracy	Brazil	South Africa
Monotherapy	1991: Universal and free AZT; 1993: ARVs local production initiated (World Bank loans)	AZT deemed toxic and ineffective; 1997: government supports untested Virodene
Combination Highly Active Antiretroviral Therapy (HAART) introduced in public health sector	1996: 175,000 on ART or monitored	2004: 21,000 on HART in 2003, of which 1,500 funded by Govt.

## Struggle vs Pharmas

Bureaucracy	Brazil	South Africa
Patent amendment: flexibility on compulsory licenses for essential medicines (following negotiations in WTO on TRIPS & with Pharmas)	2001: Government enhances local production and import or generic ARVs	

## Human Rights

Bureaucracy	Brazil	South Africa
Workplace/school non-discrimination (legal protection)	1988: law extends disability protection to PLWHA; 1992: in schools, compulsory testing of students before admission and dismissal of HIV-positive staff made illegal	1995: employment equity law; 1997: compulsory testing and expulsion of HIV-positive migrants announced – never implemented

Table 3: Central Government Expenditure on HIV/AIDS (1987-2003)

	ARVs expenditure (\$US million)		Non-ARVs expenditure (\$US million)		Total (\$US per capita)		Total (\$US per HIV+)	
	Brazil	South Africa	Brazil	South Africa	Brazil	South Africa	Brazil	South Africa
1987				0.5		0.01		
1988								
1989								
1990			0.3	2.1	0	0.06		
1991			14.2		0.09			
1992			7.8		0.05			
1993			26.9		0.17			
1994			36.9		0.23			
1995			49.7	10.7	0.31	0.27		
1996	34	0	75.2	16.3	0.68	0.41		
1997	224	0	36.2	15.2	1.59	0.37		
1998	305	0	55.9		2.18			
1999	336	0	85.9		2.51			
2000	303	0	73.5	10.8	2.21	0.25		
2001	232	0	54.5	40	1.66	0.89		4.44
2002	179	0	30	61.4	1.2	1.35	184.28	
2003	181	12	80	116.6	1.48	2.84		13.2
<b>T. 2000–2003</b>	895	12	238	228,8	6,55	5,33		

Note: empty cells indicate lack of available data; Sources: Gauri & Lieberman 2006: 53, after World Bank (2005).

### 3 Comparative analysis on HIV/AIDS policy: the state of knowledge

#### 3.1 Pioneer studies in the Americas: the case of Haiti

Haiti is one of the first countries to have reported HIV cases in the early 1980s. HIV progressed quickly from initial infection to AIDS and death, with people dying twice as fast as in developed countries (Gaillard et al. 2006: 1). By the early 1990s, at least 6% of pregnant women attending antenatal clinics in Haiti were reported to be HIV positive (ibid). Haiti has now the highest HIV prevalence rate in the Americas (circa 3% in people aged 15-49) and the largest number of PLWHA in the Caribbean (approx. 150,000),<sup>23</sup> disadvantaged rural communities being the most affected by HIV/AIDS. However, Haiti has made enormous progress in HIV/AIDS prevention and treatment regimens since the mid-1990s, when these measures started reaching high levels of complexity and efficiency. Intervention efforts were made since then in securing blood supply, increasing condom use among commercial sex workers and in the general population, as well as providing effective ART regimens for the PMTCT (Gaillard et al. 2006). This has occurred despite the fact that the age of sexual debut has decreased and the proportion of sexually active people has increased over the last two-three decades, especially among the youth (ibid). The regional context appears to have been critical to such success in Haiti, despite the country's endemic political, economic and environmental crisis. Much should be said about the trajectories of HIV/AIDS infection and policies in Haiti, but this is beyond the scope of the present discussion. Suffice it to say that effective prevention and treatment measures in the Americas seem to have produced a positive impact on Haiti. Haitians' appreciation for flexibility seems to have played a crucial role in welcoming prevention and treatment insights and strategies from other American countries.

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23 Glance through *UNAIDS Report on the Global AIDS Epidemic 2013*. Available from: [http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS\\_Global\\_Report\\_2013\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_2013_en.pdf); See also *ONUSIDA/Programme Nationale de Lutte Contre le SIDA: Rapport de la Situation Nationale Haiti 2014*. Available from: [http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2014countries/HT\\_narrative\\_report\\_2014.pdf](http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2014countries/HT_narrative_report_2014.pdf) (Accessed on 28 August 2014).

The trajectory of the HIV/AIDS epidemic in Haiti is certainly an attractive element for international research on the country. But Haiti has historically attracted social scientists' attention primarily for being the first colony to become an independent republic of free people in 1804, and for its subsequent neocolonial subjugation by the USA since the mid-1800s, as well as for its endemic underdevelopment. When HIV/AIDS started becoming a pressing global issue, researchers felt attracted by the Haiti case due to its eloquent nature. With Haiti's extreme poverty "a sex industry catering to North American gays flourished in the '70s and early '80s, particularly in the Port-Au-Prince suburb of Carrefour" (Yamada 1999a: 312). This was probably a major pathway for the introduction of HIV into Haiti, by North Americans or Haitians returning from North America. Indeed, according to Yamada, inquiries demonstrated that in 1984, 17% of HIV positive Haitians reported sexual contacts with North American tourists. Stigma and discrimination against Haitians resulted from this in the USA. The negative perception of Haitians as being the vectors of HIV in the USA was somehow reinforced by literature that signaled the existence of religiously-motivated homosexual sex among Haitian Voodoo practitioners. The Haitian HIV scenario, and the representation of Haitians as the vectors of HIV in the USA encouraged the emergence of studies that marked the initial phase of HIV/AIDS international literature.

Comparative studies with other Caribbean countries were conducted (i.e. Farmer 1992), revealing that Cuba, for instance, had very low prevalence rates of HIV because, besides its draconian AIDS policies, the country was by now free from the USA sphere of influence. Comparative investigations also found that while HIV transmission in the Caribbean basin had predominantly followed (it still does) the heterosexual pattern since the beginning, Haiti was initially an exception. Indeed, half of Haiti's HIV positive male population had had a history of homosexual contacts, and the trend would only change recently. As for women and economic determinants jointly, it was showed that by the late 1990s there was a close association between HIV-risk in Haitian women and poverty. This is especially true with regard to poor women from the countryside, most of whom, having a variety of *liaisons*, entertained sexual relations with urban soldiers and truck drivers who were more affluent and, consequently, more likely to provide women with economic resources in exchange for sexual relations.

It is important to devote a few words to some USA pioneering studies on the epidemic for at least two reasons. Firstly, the USA is the country where the first HIV infection cases were diagnosed and where the related inquiries initiated. Secondly, for good and for bad,

the USA remains the most important player in the international game in terms of plurality of, including health policy and related social-science. Together with homosexual transmission of HIV in big metropolises like San Francisco and New York, the Haitian case encouraged studies that sought to better understand HIV dynamics in the USA (i.e. Katz & Morens 1995). Besides focusing on homosexual contexts, particularly those considered as promiscuous, in the USA initial HIV/AIDS research works sought to identify the sex industry as one key sphere for priority interventions. Typically ethnographically and epidemiologically oriented, these investigations suggested that while it was important not to portray prostitutes as simple vectors of HIV/STIs, the Haitian scenario of HIV transmission via the commercial sex industry could also be repeated in the US (i.e. Shoepf 1992; Yamada 1999b). In broad terms, the heterosexual transmission of HIV was now seriously considered. These inquiries resonated in the reports of the World Health Organization (WHO). Among other aspects, the WHO suggested that although world literature showed that the majority of women who were at risk of contracting HIV were not engaged in commercial sex, including wives, future investigations should examine the complexity of prostitution, focusing on marginalization, migration and social disintegration, and networks in relation to the capitalist economic system that shapes individual and social processes of appropriation (Wallace & Wallace 1995). This certainly includes recognizing that it is a complex combination of large scale political, economic, and cultural forces that determines who will contextually be at increased risk of contracting HIV. It was in this atmosphere that male prostitution (i.e. Aggleton 1999) and HIV-risk related to injecting drugs use started attracting investigators' attention in the USA and in the world (Farmer et al. 1996). In general terms, one preoccupation on the part of researchers was the absence of a clear vision of sexual network structures that influence patterns of HIV transmission, as well as behavioral indicators such as age of sexual debut and number of lifetime sexual partners (Ellison et al. 2003: 106).

By the mid-1990s, epidemiology, medical psychology and medical anthropology were predominant in HIV/AIDS literature in the Americas and worldwide, but inter/cross-disciplinary or inter/cross-sectorial works were by now gaining space. These approaches made an effort to recognize that more usable interdisciplinary investigations were necessary to understand: why HIV/AIDS was becoming a disease of marginalized people; how societal responses to the epidemic, including those of the media, reflected deep cultural values; and how first-hand individual and communities' experiences with

HIV/AIDS could contribute to data collection, as well as planning, implementation and evaluation of HIV/AIDS interventions.

### **3.2 Recent international reports on the state of HIV-related social-research**

In December 2009 the International AIDS Society (IAS) published a document whose vital importance is expressed in its eloquent title: *The State of Social and Political Science Research Related to HIV*.<sup>24</sup> The document was prepared by Susan Kippax and Martin Holt, who work at the National Centre for HIV Social Research in The University of New South Wales, Australia. The authors reviewed a sample of literature on the social and political science research on HIV/AIDS prevention, treatment, care and impact mitigation in the period 2005-2009 (p. 9).

A range of the most commonly published types of social and political science research on HIV/AIDS was carefully reviewed and analyzed. They mapped out and scrutinized some of the major HIV/AIDS and social and political science journals: *AIDS*; *AIDS & Behavior*; *AIDS Care*; *AIDS Education and Prevention*; *American Journal of Public Health*; *Culture, Health & Sexuality*; *Health Affairs*; *International Affairs*; *International Journal of Drug Policy*; *Journal of the International AIDS Society*; *Journal of International Development*; *Journal of Sex Research*; *Lancet*; *Medical Anthropology*; *Sex Education*; *Sexualities*; and *Social Science & Medicine*.

Fifty experts, nearly all of them from North America, Europe and Australasia made up the sample and offered their insights into how to strengthen and disseminate their HIV/AIDS research outputs. A reasonable response rate was obtained from those approached in Africa and South America, while there was a low response rate from HIV experts in Asia (p. 23). Arguably, Kippax and Holt restricted their research to academic journals on the assumption that “while social and political scientists are more likely to turn to publishing books in order to have their say, it is unlikely that these books will be read by their biomedical colleagues” (p. 15). Related to this is the fact that Kippax and Holt targeted social research and excluded biomedical research in their work.<sup>25</sup>

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24 See Jenevieve Mannell et al. (2014: 3-10) for a critical evaluation of the indicators which are internationally used in research and interventions.

25 See Celeste Watkins-Hayes' article *Intersectionality and the sociology of HIV/AIDS: past, present, and future research directions*, of 2014, for a review of the main topics that have dominated the sociological literature on HIV/AIDS in the United States: the demographics of the epidemic and the dynamics of structural, and individual-level risk; and the collective response to HIV/AIDS through community-based services, political activism and social movements, and public policy. This is an important

An eight by four table categorized the most researched subjects and the journals where they were predominantly published (p. 17). Briefly, in my own reconstruction, the subjects are the following: “drivers” (interpersonal, socio-cultural, political), “response to HIV threat and response to intervention” (socio-behavioral, biomedical intervention), “impact” (social, political, economic), and “reflexion-theory”. These subjects appeared in medical, behavioral and social science journals.

Overall, the largest proportion of publications fell into the “response/intervention” category (circa 50%), including descriptions of programs designed to mitigate HIV-risk practices and vulnerability, and to ensure uptake of treatment in terms of access to ART and adherence to medication regimens (p. 16-21). There were far more works concerning social and behavioral interventions (30% ca) than biomedical ones (16% ca). Equally, socio-cultural drivers of HIV were far more studied than political, and interpersonal drivers (17% vs 5-6% ca). There was a comparatively smaller proportion of reflective-theoretical works (10%), most of which consisted of editorial pieces, thus rather short, which point to the complexity of HIV causes and responses, including the socio-cultural conditions in which the uptake of particular health-promotion messages leads to changes in HIV social understanding/representation and norms. While this seems a laudable effort, the authors suggest, very few papers categorized under “response to intervention” concentrated on long-term responses by nations or communities in promoting and enhancing the sustained change of social and cultural norms that create HIV risk. Rather, the papers tended to describe either short-term social-behavioral interventions (i.e. voluntary counseling aimed at encouraging condom use and HIV testing) or efficacy trials of biomedical technologies. The low rate of reflective-critical publications is somewhat visible in the equally low rate of works under the category “social, political and economic impact” (9% ca).

Besides being a rare case study seeking to assess social knowledge production on HIV/AIDS, to my best knowledge, this report is important for at least three reasons. Firstly, it surveyed an array of disciplines in various international publishing arenas; secondly, it shows that social scientists are strongly concerned about the limitations and, in many cases, the persistence of rationalistic-individual approaches, as well as the limitations of “solely” biomedical interventions on the part of governments (p. 25);

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publication because it shows how sociologists in the USA, among other aspects, have advanced the use of approaches that reveal the HIV/AIDS' embedded power relations.

Thirdly, as the title suggests, the report is somehow an assessment of what social and political sciences have hitherto achieved in terms of responding to the HIV/AIDS epidemic. Ultimately, as Kippax and Holt explicitly state, the aim of this research was to take stock of the mainstream social and political research on the epidemic, considering challenges and opportunities within the field, so that the IAS can better encourage and support researchers through its activities and, primarily, its international conferences.

Hence, on the one hand social and political scientists recognized the crucial role of their research in understanding HIV/AIDS causes, prevention, treatment and care (p. 3). This is obviously a result of an understanding of HIV as a profoundly social disease, in the sense that its causes and consequences are deeply rooted in the social, cultural and political structures and processes that shape national development, social institutions and civil society, as well as daily interpersonal relations. But, on the other hand, the report asserts, that socio-political research has declined and has been marginalized over the last decade, as the focus on treatment and biomedical prevention technologies has grown stronger. This criticism has been expressed by various observers, suggesting that HIV/AIDS policies around the world have not seriously considered social research insights regarding the structural dimensions of the epidemic<sup>26</sup>. For instance, social scientists have criticized governments' "clinicization" of HIV/AIDS policies, that is, overemphasis on biomedical measures to the detriment of primary prevention. The argument is that "overemphasis on biomedical solutions may create a narrowing of focus from person to patient, and it may encourage a shift in education and advocacy activities from communities into clinics" (Overs & Bebe 2013: 4). This means that the otherwise delightful and necessary push for universal access to ART has to some extent weakened the focus on HIV vulnerability and prevention, exacerbating competition for limited resources among researchers (p. 26). By implication, social science's effective responses have been weakened. Various factors were considered as undermining this social and political research status in the field of HIV/AIDS (p. 4). The exiguous political and financial support is identified as one constraint, not least in association with the failure of social scientists in making their findings accessible to non-academic environments. Further constraints are related to the lack of social science representation in institutional bodies and editorial boards, and the difficulty to maintain a critical perspective on

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<sup>26</sup> The cultural politics of HIV/AIDS and their effects have been largely investigated as well. A recent comprehensive account is given in the three volume work *Global HIV/AIDS politics, policy, and activism: Persistent challenges and emerging issues*, edited by Raymond A. Smith (2013).

development programs within the HIV realm, dominated by biomedical, clinical and public health research.

The document states that the aforementioned constraints undermine the role of social-science knowledge in curbing HIV/AIDS, which is why they need to be challenged for the sake of bigger and better informed socio-political research on HIV causes and prevention, and necessary for complementing and strengthening biomedical research, and identifying holistic progress factors in terms of the global pandemic. The report suggests that in order to reconquer major space in HIV/AIDS research and policy, and contribute more substantially in mitigating the epidemic, social scientists need to make a greater effort in demonstrating the vital importance of their works to, powerful national and international political, financial, and public health systems.

Briefly, for these researchers, the priority is to build bridges between socio-political science and biomedicine in order to strengthen public health systems. This requires concerted work whereby both biomedical researchers and social scientists can gain a better understanding of each other's *modus operandi*. In this sense, interdisciplinary and collaborative work would, for instance, help to clarify the conceptual confusion surrounding the efficacy and effectiveness in HIV interventions. The distinction between efficacy and efficiency is crucial. For example: biomedical prevention technologies (ARV, PrEP, PEP, microbicides, medical male circumcision) may prove to be efficacious (they would technically work), but they would not effectively work when used by people under real-world conditions (p. 5-14). On the conceptual distinction between efficacy and efficiency the authors draw upon Jeremy Kagan's 2009 book *The three cultures: Natural Sciences, Social Sciences, and the Humanities in the 21st Century*, which is in turn inspired by CP Snow's 1959 book *The two cultures*. According to Snow, Western society's intellectual life was split into "sciences" and "humanities", and this was the major obstacle to solving problems. The emphasis here is that natural sciences, the mother of HIV biomedical technology, rely predominantly on the efficacy of technologies in a generalizing way, as they follow up test controls under experimental conditions. By contrast, social sciences are more inclined to understanding the efficiency of such technologies under concrete socio-cultural and historical conditions. Therefore, social scientists warn that we must not excessively rely on biological processes, because these are only one of the main drivers

and determinants of human behavior variation, the other major determinants being historically given socio-cultural conditions.<sup>27</sup>

Thus, the authors stress the fact that social sciences play a unique role in explaining: first, how and why practices like the sustained use of condoms or male circumcision vary across concrete socio-cultural and historical conditions; second, how to explore the way in which patterns of practices will generate indicators of socio-cultural variables that influence the uptake and use of prevention technologies. These include interpersonal and individual factors or social vulnerability within wider collective responses to the threat of the HIV/AIDS epidemic, as well as to biomedical and social interventions.

Furthermore, in relation to inter/trans-disciplinarity, Kippax and Holt compared the disciplinary training of 50 respondents with the fields in which they were working and found out that there were nearly twice as many psychologists and behavioral scientists as political scientists (p. 4). It appears that for many people, notably anthropologists and sociologists, there has been a shift away from a location within single academic disciplines towards interdisciplinary contexts of HIV/AIDS research, especially in NGOs and public health departments. Conversely, for psychologists and political scientists the fields where they were trained and currently work in appear to be the same. This might suggest two aspects. Firstly, anthropologists and sociologists are more engaged with extra-academic entities than psychologists and political scientists. Secondly, anthropology and sociology departments and research programs are institutionally more transversal and heterogeneous than psychology and political science ones.

As for journals, curiously, the report found that socio-political research on HIV/AIDS is poorly represented in specialist journals which concentrate on behavioral HIV research like *AIDS & Behavior* and *AIDS Care*. Conversely, HIV/AIDS research is best

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<sup>27</sup> Hence (p.13), effective prevention is not only dependent on efficacious HIV prevention tools and/or technologies, but also on their successful uptake and their large-scale adoption and use as strategies in everyday life. The efficacy test of condoms or male circumcision meets the criteria of the natural sciences: under controlled trial conditions, researchers can establish that male circumcision or proper and consistent condom use reduces the likelihood of HIV transmission. The relationship between such ideal use of technologies (male circumcision or condoms) and HIV transmission rates is potentially generalizable. The test for effectiveness on the other hand – or the strength of the relationship in the real world – is unlikely to meet these same criteria. Given that male circumcision and condom use are socio-cultural practices, as are all sexual practices, it is extremely unlikely that there is any one mechanism or process that accounts for the observed relationship between the adoption of male circumcision and sustained use of condoms, on the one hand, and a reduction in HIV transmission rates, on the other. Such relationships are likely to vary and the processes underlying them differ from one set of socio-cultural conditions to another. Social transformation and the embedding of preventive practices in everyday life are necessary to translate efficacious technologies into effective ones.

represented in non-specialist social-science journals like *Social Science & Medicine*, followed by medical and public health journals, including the *American Journal of Public Health and AIDS*. Moreover, apparently, many papers published in specialist HIV journals were primarily concerned with HIV interventions, rather than social and political drivers of HIV. Kippax and Holt argue that this suggests that “the readership of specialist HIV journals is unlikely to be well-informed about current developments in social and political research, particularly those concerned with the contexts and drivers of HIV epidemics or the critical scholarship on HIV interventions and policies” (p. 3). Thus, the authors advocate for the revision of editorial policies and editorial board memberships in order to improve social and political science research within specialist HIV/AIDS journals. In general terms, the report urges the creation of an HIV/AIDS journal devoted to HIV/AIDS meta-analysis, whose main focus should be the impact of social-science research on HIV/AIDS policies. In addition, the report claims that (p. 21) more effort is needed to ensure that social-science research, especially impact research, is published in the medical and behaviorally-oriented or public health-focused HIV/AIDS journals. And this is most likely to occur if those journals have both social-science editors and biomedical or behavioral science editors. Among other aspects, this calls for capability building in the social and political science fields related to HIV/AIDS (in symbiosis with biomedical disciplines, nevertheless), including literacy and training in HIV/AIDS social-science techniques (p. 57). International links strengthening, sponsorship of training in interdisciplinary social and biomedical research, as well as targeting fellowships and scholarship for HIV-focused researchers in developing countries are advocated by Kippax and Holt as being among the pathways to such capacity building.

### **3.3 Further reflections on the HIV/AIDS international scholarly arenas**

Still on the knowledge production in the international arena and North-South relationships, I suggest that there are a few additional HIV/AIDS international organizations to those discussed above whose work calls for greater attention. This is the case of the Association for the Social Sciences and Humanities in HIV (ASSHH), the French National Agency for Research on AIDS and Viral Hepatitis (Agence Nationale de

Recherche sur le SIDA-vih et Hépatites: ANRS), the World Social Science Report (WSSR) and the International Social Science Journal (ISSJ) – the two latest entities being part of the UNESCO system.

The ASSHH runs a number of single-disciplinary and multi-disciplinary journals on a range of HIV-related aspects, including “Culture, Health & Sexuality”, “Sex Education”, and “Psychology & Sexuality”. Among other strengths, the ASSHH gathers world leading senior and junior critical scholars. The ASSHH first two biannual conferences took place in Durban (South Africa) in 2011, and Paris (France) in 2013. In both conferences scholars sought to reflect, first and foremost, on the state of HIV/AIDS knowledge production, its local contextualization, as well as its circulation across the world and social spheres.

The ANRS works predominantly with southern countries, particularly those in Francophone Africa and Latin America. The ANRS’ primary mandate is to encourage and support collaborative research projects in a fashion that they themselves would define as “innovative research-action”, guided by “committed reflection”. This is evident in the ANRS’ most recent works carried out in multi-partnership teams comprising researchers and community-based organizations (CBOs), and guided by the needs of communities. Thus, they have focused on methodological, theoretical and ethical issues associated with community-based<sup>28</sup> and collaborative research<sup>29</sup> in different national contexts (i.e. Demange et al. 2012; Chabrol & Girard 2010), as well as economic challenges in the access to HIV/AIDS treatment and care in developing countries (i.e. Moatti et al. 2003). In the field of HIV prevention, treatment and care, issues related to methodological, theoretical and ethical approaches are strictly interlinked. The authors compellingly argue that those aspects raise research questions which are difficult to answer without the proper involvement of communities. This is the case for the disclosure of seropositive

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28 Community-based research-action is said to be recent and still tentative in francophone contexts. But the related debates stretch back to Alain Touraine's calls in the 1960s-70s for an engaged scholarship (i.e. permanent sociology) with the social movements of the time (of students, women, workers, environment). Today as then, more use-inspired research is advocated for finding an efficient, shared and sustainable response to the HIV/AIDS epidemic.

29 These reflections are partly rooted in historical links between researchers and activists. The thrust here is that despite or perhaps precisely thanks to their problematic nature, such relations have helped to understand not simply the role of activists in the initial answer to the HIV/AIDS epidemic, but also the structural factors of the epidemic. In other terms, research-action has also contributed to increasing social knowledge by opening the way to community studies and increased legitimacy for civil society organizations to take part in the debates on research projects, whereby they could question the definition of academic knowledge goals and epistemological.

status, rapid HIV testing, treatment as prevention, harm reduction associated with drugs use, PrEP, focus on MARGs, hard-to-reach groups, and serodiscordant couples. As for the WSSR, this publication devoted its 2010 issue to “Knowledge Divides”, and a major debate issue throughout the volume concerned precisely the challenges and opportunities posed by the HIV/AIDS epidemic to social sciences in relation to policy, development and global interconnections (ch. 9).

Meanwhile, in 2005 the ISSJ dedicated a special issue to the *Social Sciences Perspectives on HIV/AIDS*. Similar to the ANRS works mentioned above, this issue is clearly scholarly engaged in its intent: the contributors reiterate that HIV social sciences have the tools and the obligation to positively influence decision-making, especially by helping them to better understand that HIV/AIDS is an epidemiologically puzzling social phenomenon. Thereafter, this publication explores a set of interlinked aspects. One set of issues concerns beliefs, attitudes and behaviors that impact on and shape the HIV/AIDS epidemic. A second set of issues regards political, economic and ethical aspects of prevention and treatment, with a strong emphasis on human rights for PLWHA. The contradictions between policy discourses or planning and practice, particularly in Sub-Saharan Africa, constituted another central subject in the ISSJ’s 2005 issue. The latter point opens up space for the analysis of discrepancies between manifest and latent functions, in the words of Robert Merton, whose evaluation requires institutional-cultural approaches (see 2.3 on this issue).

#### *International scientific collaboration in HIV/AIDS*

International cooperation between researchers is one specific terrain in which the role of social-science knowledge in the fight against HIV/AIDS can be analyzed. The HIV/AIDS studies carried out by the international research bodies discussed above – ASSHH, ANRS, WSSR, ISSJ – call for further comparative meta-analysis that includes research questions about knowledge divides, hierarchies, and symbioses in the world of HIV/AIDS social sciences, as well as representations of that knowledge production. This is ultimately essential for revitalizing the debate about engaged scholarship across the world, in the light of the success, failures and challenges of research-action programs.

In this regard, one exemplary research work was conducted by Tazio Vanni et al. (2014), an international team focused on international scientific collaboration in HIV and HPV epidemiology. The results have been discussed in *International scientific collaboration in HIV and*

*HPV: A network analysis.* This study considered the international networks of epidemiology researchers in high, middle and low-income countries who work on HPV in PLWHA. Let us focus on some of its outcomes. When it comes to North-South relations, the USA stands out as the country with the highest degree centrality of international cooperation, particularly with South Africa, Uganda and Brazil. Researchers from high-income countries seem to have higher degree centrality and tend to cluster together in densely connected communities (p. 1), whilst most low and middle-income countries do not even produce significant HIV and HPV epidemiological studies, let alone international collaboration in the fields. However, surprisingly, despite the geographical proximity, cooperation between the US and Canada in HIV and HPV research was found to be rather infrequent. Conversely, there was significant intra-continental collaboration between European countries, the Northern region being at the forefront and low-income countries like Uganda. A corollary of this is that there is a high collaboration degree between France and the UK, and the two countries collaborate with several other countries in Africa. Among middle-income countries in the global south, Brazil and South Africa are reported as standing out as the most collaborative countries. The same is true with Uganda and Kenya, among low-income countries. Independent HIV and HPV epidemiological studies were also found in some countries like the Democratic Republic of Congo, Central African Republic, Mexico and Chile. The report itself suggests that this kind of independent research should lead us to hypothesize that, at least in the case of middle-income countries, there is a great proportion of countries which are autonomous concerning knowledge production in HIV epidemiology and social science. Indeed, the study considered predominantly researchers who were involved in international networks, which took to a higher underlining of central nodes, that is, densely linked networks, thus overshadowing the work of independent researchers who typically operate in low and middle-income countries.

Although the study only considered internationalized researchers who work on HPV in PLWHA from an epidemiological angle, this study is a milestone in terms of the comparative analysis of social-science knowledge production on HIV/AIDS across countries. The IAS' report forces us to reflect on the role of social-science international arenas where the production of HIV/AIDS knowledge takes place. The same applies to UNAIDS biannual AIDS Progress Reports which are elaborated by, or together in conjunction with, individual health ministries. The relations between Brazil and South Africa are a good example of scientific cooperation in the field of HIV/AIDS social-science. The

largely unique histories of the two countries with respect to policies and social-science knowledge oriented to the HIV/AIDS epidemic serve as records that the Brazilian and South African scientific communities can utilize for vigorous use-inspired scholarship aimed at contrasting information. Due to its success, Brazil is a significant other in South Africa's HIV/AIDS governance (Nauta 2011: 133), as well as with in the fields of HIV/AIDS use-inspired and research- action, but South Africa too has a lot offer to Brazil. For instance, as we have seen, compared to South Africa, the involvement of social scientists in HIV/AIDS policy has deeper roots and vaster ramifications in Brazil. And vice-versa, South African scholars dealing with the difficulties posed by controversial policies, racial and ethnic relations, the culture of silence around sex and sexuality, among others, may help Brazilian scholars to refresh their self-understanding. I suggest that these are among the resources that should be considered for the achievement of vigorous cooperation projects in the field of HIV/AIDS social-science, especially with regard to engaged scholarship.

### **3.4 Institutional-cultural approaches**

Peter Hall and Michèle Lamont (2009) have recently revitalized the debate about how institutional practices and cultural repertoires combine to promote or hinder public health, the latter being taken as a proxy of well-being. *The authors reasonably assert that health is a relatively uncontroversial* indicator of well-being because longer life expectancies and lower rates of mortality can be linked to successful societies. In this sense, societies are defined as patterns of social relations structured by institutional practices and cultural repertoires. Thus, Hall draws on questions posed by classic theorists of social change like Comte, Tocqueville, Durkheim, Weber, and Marx regarding the nature and quality of social change determinants, namely collective identity and collective action, symbolic boundaries, social networks and social capital. In brief, the question relates to how these aspects combine in order to advance or limit social change, in this case, health-promotion. Here social capital is conceived in its positive sense, that is, as a necessary condition for social justice-prone collective action mediated by trust and common identity, thus common fate and interest in carrying out a particular project. In the present discussion, this project represents the reduction of unequal power relations and the creation of health-enabling and supportive contexts. Indeed, Bourdieu (1986) reasonably argues that unequal power relations are maintained through a set of social processes that sustain

inequalities in the interlocking field of economic capital, human-cultural capital and social capital. Let us concentrate on social capital, taking for granted the potentialities of the other forms of capital in social change theory. Social capital has been extensively explored in relation to health promotion (i.e. Hyypä 2010; Kawachi 2008). Following Bourdieu, emphasis has been placed on the unequal distribution of social capital as one key mechanism, whereby poverty and ill-health are perpetuated and poor people are hindered in the improvement of their life circumstances. Thereafter, scholars have been concerned with building social capital in order to improve the life circumstances that place people at particular risk of HIV/AIDS (i.e. Campbell & Foulis 2002: 326; Steyn, interview, 21 May 2013).

According to Catherine Campbell (2003: 54), for health-promoting programs, social capital is conceptualized in terms of people's participation in mutually beneficial goals, in this case, the goal of reducing HIV-transmission. Literature shows that people are more likely to engage in healthy actions in communities which are characterized by high levels of social capital because they are more likely to provide their residents with high levels of psychosocial empowerment (i.e. self-esteem, assertiveness, status and dignity, and emotional support) and, by implication, high levels of perceived control over their everyday lives (individual autonomy). High social capital also provides people with supportive contexts within which people can collectively negotiate social identities in ways that promote the increased likelihood of health-enhancing behaviors (Campbell 2003: 52).

In relation to community-based HIV-prevention activities, social capital refers to civic engagement in local community networks, with particular emphasis on local people participation. Such commitment is associated with high levels of trust, generalized reciprocal help and support, and local identities. These are the ingredients which jointly encourage community solidarity and social cohesion, the latter being also understood in terms of state-society relations. Although not sufficient, social cohesion is a necessary precondition of health policy success because it helps to promote collective action, in this case, in the field of health promotion.

It is essential to mention the distinction that Robert Putnam (2000: 19-24) makes between bonding social capital and bridging social capital. Bonding social capital concerns exclusive, inward-looking social capital located within homogenous groups, whilst bridging social capital refers to links that occur between diverse social groups with divergent degrees of access to material and symbolic power. Catherine Campbell has authoritatively highlighted the importance of social capital for the success of HIV/AIDS

programs. In particular, she has shown that bridging social capital is particularly essential to multi-sectorial and multi-level HIV-interventions aimed at maximizing their effectiveness. This is especially true when the constituencies involved in the action share HIV-prevention as an overlapping mutual interest, despite possessing varying levels of power and world views. For instance, this occurs when marginalized groups like prostitutes, transvestites, IDUs or rural communities act as partners in government-led HIV programs.

According to Catherine Campbell (2003: 57), the importance of bridging social capital in relation to HIV-prevention is based on three interlinked assumptions that we have indirectly seen above. Firstly, epidemics arise when existing methods of managing diseases are inadequate and demand creative establishment of new strategies and new symbiotic relations at various levels, being built specifically for the new demands presented by the epidemic in question; secondly, HIV/AIDS is too multi-layered to be dealt with through traditional biomedical or behavioral disease prevention or any single constituency alone; finally, thirdly, the notion of bridging social capital draws attention on the importance of ensuring that historically marginalized and disadvantaged groups are put in contact with vertical networks of influence and expertise (i.e. policymakers), whose support may be crucial if they are to maximize their health-enabling efforts. Thus, Campbell concludes, HIV-prevention programs need to maximize the development of bridging social capital at three levels. The first level concerns links between small local communities (i.e. sex workers, youth peer groups) and more powerful local groups (i.e. local associations of some sort) who can support them in developing more health-promoting community contexts. The second type of bridging social capital refers to links between small local groups and networks of influence beyond their geographical location so that they become involved in initiatives which aim towards social change beyond their immediate community contexts. Finally, the third genre of bridging social capital relates to links between small local groups and more powerful extra-community groups or agencies in the political, economic, medical and donor spheres, whose support might be pivotal to the effectiveness of their initiatives. In this sense, bridging social capital is an essential part of the discourse on institutional-cultural approaches, inasmuch as institutional actions and deep-rooted cultures promote or discourage collective action against the HIV/AIDS epidemic. Collective action in this case is understood as a concerted work between the state and civil society. This leads to debates about inter-sectorial HIV/AIDS interventions, which are deemed to be vastly more productive than mono-sector

approaches. This highlights the importance of the concept of social capital, particularly bridging social capital in health-policy analysis, especially with regard to how it operates within the institutional-cultural approach.<sup>30</sup>

### **3.4.1 Exemplifying cultural repertoires: openness to sexuality and Ubuntu values**

Now the question is what cultural repertoires should be considered for the promotion of health and wellbeing. This is a difficult question to answer. Positive social capital is certainly one vital resource. Let us briefly consider some cultural repertoires that have been advocated and to some extent used, in the construction of social capital for an effective response to the HIV/AIDS epidemic in Brazil and South Africa. Especially in the initial phase of the epidemic, openness to sex/sexuality talks and sexual diversity in Brazil helped the state to map out the complexity of HIV transmission, and enhance or encourage new initiatives against the epidemic among various groups. In this perspective, homosexuals, prostitutes and PLWH are defined as citizens with not only sexual rights, but also legal protection. It is important to remember that, since Brazil is a profoundly unequal society, the situation of low-class gays, prostitutes and PLWH remains precarious. However, it is undoubtable that openness towards sexual diversity allowed the Brazilian state to have access to the insights provided by HIV/AIDS gay movements and prostitute groups, among others, including the reasoning according to which sexuality in Brazil is highly multi-layered, which is why investment in combating HIV vulnerability had to be realistic, multi-dimensional and holistic. This implies that, first, rather than focusing exclusively on “risk groups”, HIV prevention education had to target the whole population and, secondly, rather than relying on KAB/ABC and moralizing strategies, policies had to foster condom use, guarantee sexual rights, and improve the socio-economic circumstances of people. Solidarity with PLWHA, stemming from the culture of reciprocity, combined with openness towards sexual diversity, helped to mitigate stigma, which in turn helped PLWH to undertake HIV prevention activities, whereby they could influence people through first-hand experience and so that they perceive themselves as valued agents of social change. This agency and sense of community have been extensively documented as enhancing assertiveness in

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<sup>30</sup> Institutional-cultural approaches to prevention, treatment and care are increasingly recognized as urgent, particularly in Africa, in the light of Uganda’s success story, denialism in South Africa and Kenya, plus the relentlessness of HIV/AIDS in the continent.

PLWH, collaborative attitudes and advocacy capacities, among others. This helped Brazil's National HIV/AIDS program to emerge early and vigorously, since it resulted from the adoption and development of activities which had previously been elaborated at local, state and municipality levels, mainly in the São Paulo region, with a significant role played by civil society entities.

On their part, Ubuntu values have been taken as an essential cultural repertoire that can be utilized to foster health promotion in South Africa. Ubuntu traditional values include a sense of community and caring, cooperation and reciprocity, gratuity, hospitality and mutual respect. For instance, Ubuntu values have been explored through action-research programs in order to understand and combat women's susceptibility to HIV in schools, in the sense of understanding gender inequalities and creating gender-sensitive school climates which are conducive to a reflective-critical consciousness among teachers (i.e. Wood 2012). Lesley Wood reports extensively on this research in her article '*Every teacher is a researcher!': creating indigenous epistemologies and practices for HIV prevention through values-based action research*'. She uses empirical data from a one year action-research project of HIV-education purposely named *Masilingane*, Xhosa for "Let us be equal", to remind participants of both gender equality and the "polyvocal" nature of the research. Focus was placed on the Xhosa patriarchy culture that shapes gender inequalities. The *Masilingane* project involved 17 Xhosa speaking volunteer teachers (13 females and 4 males). The teachers are said to have been key role-players in the design, implementation and evaluation of the *Masilingane* project. Hence, they seem to have gained opportunities for generating indigenous epistemologies and practices that effectively create sustainable and empowering learning contexts for HIV education. These include "insider" community-based reflections on, and challenges to, current local problems like the abandonment of women, rape, bullying and aggressive behavior perpetrated by boys against girls, as well as the violation of children's rights. Apparently, the focus on Ubuntu values helped the *Masilingane* project give a voice to all participants, which in turn fostered reflections about both the causal factors of women's vulnerability, such as women's limited authority in sexual decision-making and other spheres, as well as solidarity among teachers in the implementation of school HIV/AIDS programs. In particular, Ubuntu values like individual commitment to the community seem to have raised teachers' consciousness about not being judgmental of PLWHA or uselessly blame externals, but rather look at the community's culture to find internal responsibilities in relation to

HIV/AIDS vulnerability, as well as potentialities in relation to how to handle the epidemic.

### **3.4.2 Botswana vs Uganda: exemplifying the institutional-cultural approach**

Generally speaking, before the mid-1990s, even when cultural determinants of HIV had been identified – typically by anthropologists, socio-psychologists and micro-sociologists the analysis of states' responses to the epidemic tended to assume that democratic and effective governments alone could promote healthy behavior<sup>31</sup> and that policies could rely on information-based programs carried out by health experts, which would lead individuals to act rationally in their own personal interest, that is, to protect their health. However, these assumptions have been disproved since the 1990s as the epidemic progressed and the results of the related policies started to become clear, showing that rational-individual approach to health promotion could change the behavior of only an insignificant number of people, typically the most affluent individuals.

Owing to the disproportionate impact of the epidemic on the sub-continent, Sub-Saharan Africa has become the major research target in the world and some countries have particularly attracted researchers' attention. Comparative studies have particularly focused on Botswana and Uganda due to the huge divergence between the two countries in their HIV/AIDS policy records, which has highlighted the importance of looking at institution-culture connections, rather than assuming that effective bureaucracies alone are able to solve problems. Botswana is wealthy and well administered, with a good system of public health, whilst Uganda is poor, historically undemocratic and politically unstable. Yet, Uganda has a good HIV/AIDS governance, while Botswana's prevention efforts have largely failed and ART was late to be adopted.

According to the UNAIDS (2006), in just a decade, Botswana's HIV prevalence rate in ante-natal clinic attendees rised from around 18% in 1992 to approx. 36% in 2001. The overall HIV prevalence rate among adults aged 15-49 in Botswana has been as high as 23% since 2004. On the contrary, although much poorer and less well administered, Uganda is depicted as one of the most successful African countries in responding to the

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<sup>31</sup> The assumption according to which democratic regimes alone could provide better responses to HIV/AIDS is also disproved by the case of Cuba, which has historically implemented a reasonably effective, though draconian, HIV/AIDS program.

HIV/AIDS epidemic, having mobilized an early all-out battle against the epidemic, thus lowering HIV prevalence from around 29% of ante-natal clinic attendees in 1992 to approx. 11% in 2001. Uganda has managed to maintain the HIV adult infection rate stable at an estimated 7% prevalence since 2005.<sup>32</sup> These comparative studies have compellingly suggested that what made substantial difference is Botswana's non-collective understanding versus Uganda's collective understanding of the HIV/AIDS crisis – the former having resulted unproductive and the latter productive. In other terms, what most mattered in such divergence is the quality of mobilization of the local actors (combined with use of cultural resources – to be expanded on later):

Uganda's AIDS efforts differed in a critical respect from those of Botswana because Uganda's national efforts included a considerable degree of mobilization of local communities, while Botswana pursued AIDS prevention through a top-down program of information and education... The [Ugandan] government instigated a broad social mobilization that linked the campaign against AIDS to a nation-building rhetoric and a sense of collective empowerment that galvanized political party officials, churches, international NGOs, and community-based organizations in what was seen as a struggle for collective survival. (Swidler 2009: 132-3).

Importantly, Uganda's President Yoweri Museveni included the AIDS issue in every speech he gave, insisting that all the officials of the National Resistance Movement (NRM), down to the local level, discussed AIDS in every speech and every public meeting (Swidler 2009: 146). Museveni's position on AIDS was greatly shaped by Fidel Castro's warning about a looming AIDS epidemic in Uganda. This was a result of HIV testing on Ugandan guerrilla officials in Cuba who were sent by Museveni himself to the island for training in 1986, when he took power after fifteen years of dictatorships of Idi Amin and Milton Obote. Drawing on Cuba's AIDS-control policies<sup>33</sup> Museveni used his peasant-

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32 See HIV And AIDS Uganda Country Progress Report 2013. Available from: [http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2014countries/UGA\\_narrative\\_report\\_2014.pdf](http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2014countries/UGA_narrative_report_2014.pdf) (Accessed on 11 August 2014).

33 In addition to health education in the press, radio, television, workplace, and schools, Cuba's HIV/AIDS program includes blood donor screening, a ban on imported blood and blood products, widespread semi-compulsory screening of defined and general populations, research and clinical trials on treatment and diagnostic method (Santana et al. 1991: 511; Stable 1992). The most controversial of the program's measures has been the treatment of HIV antibody-positive persons through a "sanatorial regimen" consisting of compulsory admission into an institutional setting where both preventive and curative treatment is offered, and where residents have limited contact with their families, neighborhoods, friends, and the rest of society (ibid). The Cuban HIV control program merits attention because it helps us understand the history of the disease in the world. The Cuban case is a good example of an effective anti-AIDS program in a non-democratic and, above all, poor country. Cuba's experience – of screening large populations and early identification and follow-up of HIV antibody-positive individuals, with an apparent societal consensus on the controversial issue of

based NRM as a vehicle for spreading HIV/AIDS awareness and the collective struggle against the epidemic.

Regarding leadership, Botswana's presidents have also been far more active than most other African leaders in the openness and commitment to the AIDS struggle, and vigorous condom promotion programs have been rolled out. However, until the mid-2000s, Botswana lacked a set of truly vigorous and committed policies that could construct community-based collective action and accountability for HIV/AIDS management, and instill a sense of shared fate in the nation. It appears that, despite the AIDS-related growing number of deaths and orphans in many families, the general culture in Botswana is one of little sense of outrage or urgency, as well as privacy, the latter being often confused with fear of stigma and social death resulting from the disclosure of one's HIV-seropositive status. Also, the political culture until the mid-2000s was one of pride, as well as reliance upon the Botswana effective, capable, stable and bureaucratically efficient modern state. This is said to have been partly reinforced by the lack of real action against AIDS on the part of Botswana traditional leaders (*dikgotla*, sing. *kgotla*).

Based on local courts and customary law, the *dikgotla* have retained some power at all levels after Botswana's independence from the British in 1966, including the constitutionally enshrined House of Chiefs, an advisory body of the contemporary national legislature. This is a result of historical compromises between the British Empire and the Botswana chiefdoms in the independence transition. The *dikgotla*'s position in modern Botswana's democracy provides them with possibilities and capabilities to simultaneously dialogue with, and gain resources from, rural-traditional communities and urban-based state institutions (Allen & Heald 2004). However, the *dikgotla*'s hierarchical chiefdom tradition, combined with the general tendency of Botswana people to rely on the government to handle their problems, hindered the emergence of a truly aggressive response to HIV/AIDS. This is all understandable, as the authors themselves suggest.

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institutional semi-confinement – helps us reflect upon the cultural, political, and socio-economic conditions that give rise to different epidemiological profiles of the disease. One important aspect in this sense is the fact that, on the one hand, the institutional semi-confinement of Cuba's HIV/AIDS program has triggered controversy and disdain since the 1990s, but on the other hand, its effectiveness has been valued and referred to as a model strategy. One implication involves debates about the compatibility between aggressive approaches to HIV/AIDS management, rights and ethical issues in relation to the level of democracy (Hoffman 2004; Anderson 2009a, 2009b). However, in the 1990s, this debate did not seem to produce a strong impact on the assumptions according to which democratic regimes are more effective than non-democratic systems in promoting health and in combating the HIV/AIDS epidemic.

Nevertheless, from a critical perspective, the devastating story of HIV/AIDS in Botswana raises important questions about the effectiveness of such societal configuration, since it further undermined the effectiveness of the government's HIV/AIDS initiatives. Indeed, *dikgotla's* individual interests and hierarchical system are detrimental to social cohesion and have greatly contributed to the fragmentation, weakness and delay of HIV/AIDS policies.

By contrast, according to Mikael Karlström (1996), Museveni government strategies against AIDS included the construction of a “cultural match”, described by Swidler (2009: 132) as a sort of element of compatibility between deep-rooted cultural patterns and contemporary governing structures. Despite having a limited spectrum and despite being based on the leadership of few individuals, Buganda polities would contribute to aggressive HIV/AIDS policies because of their integration in, and articulation with, the national plan. There was a sort of close cultural connection between Uganda's contemporary one-party democracy and traditional Buganda political forms. In the absence of a competitive democracy and direct representation, Museveni's NRM introduced a complex system of unprecedented local elections on a non-party individual basis, which eventually fits the Buganda leadership tradition. According to Karlström (1996: 498–9), this provided Ugandans with their first meaningful experience of democratic governance at a local level, since previous governments ran local affairs through centrally appointed civil servant officers. In such a climate, at least in the Buganda region, even clans and less well-educated local people had a feeling of participation in the democratic process and in a unified socio-political order (*okwegatta*). This unity suits the Ganda model of legitimate authority, built from the bottom-up and founded on nested solidarities. Local elections motivated traditional officials to encourage, rather than boycott or exploit NGO's goods and activities, whose flourishing was also due to the appropriate political climate that promoted public goods through the “cultural match”. As for economic compensation, traditional officials were originally not remunerated by the state, but could make informal charges for their services (Allen & Heald 2004: 1150), which also somehow matches with the elementary economic dynamics of Buganda's local traditional communities. Furthermore, with the objective of promoting HIV/ AIDS awareness and enforcing behavioral change, often in connection with NGOs, Uganda's local officials practiced advocacy for their people at different levels of administration, and were charged of the collaboration with aid agencies and monitoring security. It is reported that scientifically proven information

would not simply flow from the top to the Local Council leadership who would disseminate it to a receptive population, but local authorities and communities would take active part in the design and implementation of local initiatives in symbiosis with the national program (Swidler 2009: 141). In addition to or in combination with the role of NGOs like TASO (the Ugandan prime AIDS Support Organization) in providing information and training, the flowing of scientific evidence was facilitated by free debate in the media and the wider public space, which helped to demystify the disease. In such a context, HIV voluntary test uptaking, disclosure and search of biomedical treatment and counseling were encouraged.

In contrast, until the mid-2000s, although Botswana's political culture is one of effective government institutions, it was unable to combine such capacity with cultural repertoires to mobilize local communities against the HIV/AIDS epidemic.

### **3.5 The production and use of social-science knowledge**

We conclude this chapter by asserting that a comprehensive social-science approach is needed to understand the conditions of success in health policy oriented towards HIV/AIDS, particularly with respect to institutional-cultural approaches mediated by bridging social capital. In other terms, social research has predominantly focused on either institutional and community activities around HIV/AIDS or socio-cultural factors of HIV vulnerability. An integral social-science approach that seriously addresses the interlink between institutional practices and cultural repertoires that shape health protection of individuals and communities is needed, and this is especially critical to use-inspired research aimed at helping holistic interventions.

The implication of this point is the following: many insights have been gained from the above studies, particularly from those engaged in comparative enterprises. But hardly any of them focuses on the kind of knowledge on HIV/AIDS, and the social conditions that shape its diffusion and use. If we look closer, however, what is crucial is precisely the shifts in knowledge, the use of different kinds of knowledge by different groups, and the social channels for spreading knowledge across society, in particular from social groups to policy-makers as well as from policy-makers to health-policy actors and people affected by HIV/AIDS. This gives a sense of social-science knowledge being intrinsically social, for it should not be taken as neutral or exempted from socio-political influence. For example,

overall, in Brazil and South Africa HIV/AIDS studies have been relevant to confronting the epidemic. But, as we will see, because Brazil's government made a greater effort to support AIDS-related social research, AIDS large-scale studies and related scholarly bodies (i.e. social medicine institutes, research groups) emerged earlier in Brazil and their positive impact on the national AIDS program has been more consistent. So did researchers' engagement with policy-makers in conjunction with Brazil's major will to respond effectively to HIV/AIDS as a new threat to the nation's development and security.

### *The role of epistemic communities*

Scientific knowledge has historically played a central role in policy-making. Scientists generally engage policy through epistemic communities. In short, epistemic communities are professional networks with authoritative and policy-relevant expertise (Cross 2013). More broadly, according to Peter Haas (1992: 3), who first popularized the concept, an epistemic community consists in:

A network of professionals with recognized expertise and competence in a particular domain and an authoritative claim to policy-relevant knowledge within that domain or issue-area. Although an epistemic community may consist of professionals from a variety of disciplines and backgrounds, they have (1) a shared set or normative and principled beliefs, which provide a value-based rationale for A network of professionals with recognized expertise and competence in a particular domain and an authoritative claim to policy-relevant knowledge within that domain or issue-area. Although an epistemic community may consist of professionals from a variety of disciplines and backgrounds, they have (1) a shared set or normative and principled beliefs, which provide a value-based rationale for the social actions of community members; (2) shared causal beliefs, which are derived from their analysis of practices leading or contributing to a central set of problems in their domain and which then serve as the basis for elucidating the multiple linkages between possible policy actions and desired outcomes; (3) shared notions of validity – that is, intersubjective, internally defined criteria for weighing and validating knowledge in the domain of their expertise; and (4) a common policy enterprise – that is, a set of common practices associated with a set of problems to which their professional competence is directed, presumably out of the conviction that human welfare will be enhanced as a consequence

The concept of epistemic communities is generally applied beyond scientific communities and can refer to any group that produces knowledge, provided that it presents the characteristics described above. The central thrust is how knowledge translates into power. HIV/AIDS policies have contributed to illustrating this process, that is, how

knowledge circulates from its producers to policymakers and other partners (Youde 2007). In this sense, HIV/AIDS is also “an ideal issue for promoting the emergence of an epistemic community because it is a new scientific problem requiring action by policy makers who themselves are not versed in the scientific complexities of the disease” (Youde 2007: 15). In this sense, the role of epistemic communities in the public arena helps us understand the over all context in which knowledge is produced and made available to relevant groups, particularly policy-makers.

The history of scientific governance with respect to HIV/AIDS policy in Brazil and South Africa provides a good example of the role of epistemic communities in health programs and in state building projects generally. It exemplifies how orthodox epistemic communities helped Brazil to respond effectively to the epidemic and, on the other hand, it partly explains the paradox of the Mbeki administration’s challenge to the international AIDS control regime from which, South Africa would otherwise have benefited.

Compared to South Africa, Brazil has a far longer and less conflictual history in terms of integration of social scholarship in HIV/AIDS activities. Differences in historical, social and political conditions in both countries provided the conditions for the kind of social-science knowledge produced and, above all, its use for much of the history of the HIV/AIDS epidemic. Historical and current race relations played a crucial role in shaping the politics of social knowledge production and use, since they influenced both governments’ attitude to HIV/AIDS science, that of Brazil being far more sympathetic. Overall, the Brazilian elite has historically been predominantly composed by white people and there has been a substantial continuity from colonial times to the present day. This, combined with a bigger sense of political community among Brazilians, compared to South Africa, provided the grounds for the state to support white dominated social research for the improvement of policies oriented to HIV/AIDS.

The history of biomedicine and its impact on post-apartheid policies in South Africa with reference to the HIV/AIDS epidemic illustrates the historical and socio-political context of South African social science and HIV/AIDS epistemic communities (see ch. 5 for further discussion). When South Africa inaugurated its democratic regime in 1994, the white political elite was replaced by a black one – the previously oppressed and revolutionary movement African National Congress (ANC) - while the academic/intellectual elite has remained overwhelmingly white. “Racial discontinuity” in the South African political establishment contributed to the President’s late support of the HIV/AIDS social-science on behalf of the government. In particular, although President Mbeki rightly pointed to

structural factors like poverty being key determinants of HIV vulnerability, he substantially considered white-led social-science as part of a neocolonial system, in a similar manner to biomedicine – and this had to be replaced by more indigenous solutions (African Renaissance). When he seemed to recognize that HIV was sexually transmitted – sometime after claiming that AIDS was caused by malnutrition and not sexually transmitted HIV – Mbeki suggested that the HIV/AIDS social science constructed in HIV homosexually-transmitted contexts like the US, which had an impact on South African scholarship, was not appropriate to capture African predominantly heterosexually-transmitted epidemics. To some extent Mbeki was right on this point. But he pushed his argument so far that he was not humble enough to establish a productive dialogue with South African social scientists and epistemic communities in order to understand that their research on the epidemic was much richer than he assumed. In particular, Mbeki's position on HIV/AIDS prevented him from listening to social scientists and activists who warned against social and cultural values underpinning (black) South Africans' vulnerability to HIV/AIDS, including witchcraft thinking, patriarchy, misogyny, and the culture of silence surrounding sex and sexual discourses, the latter being exacerbated by AIDS-related stigma and discrimination. As a result, social-science scholarship in the field of HIV/AIDS remained long confined in the academic and, to a much lesser extent, civil society worlds. White scholars were hardly vocal partly due to the fear of being labeled racist, ethnocentric or neocolonialist. This situation has only started changing substantially in the last decade.



## 4 Approaches to HIV/AIDS globally: a shifting debate on the locus of social change

### *Overview*

This chapter explores knowledge production in the international social sciences around HIV/AIDS. It tries to clarify the steps of the debate, showing the main paradigm shifts regarding the locus of behavioral or social change: individuals and “risk-groups” (first step), peer groups (second step), and community (third step). Such paradigmatic evolution calls attention to the need for a comprehensive social-science approach to HIV/AIDS, and to the fact that the kind of knowledge one develops and applies is crucial for understanding health-policy success. This is very evident in the third phase – focused at community level – which addresses the importance of looking at the interaction between institutional, economic and socio-cultural dimensions of the epidemic. The study of such interfaces is essential to understanding the mechanisms of multi-level interventions, which are by now widely recognized as being the most successful strategies in contrasting the HIV/AIDS epidemic and promoting health generally. There is here a big drift from early HIV-prevention programs based on mere cognitive models of rational-choice and individual responsibility, generally associated with members of “risk-groups”, to the more nuanced notion of social/structural vulnerability. In other terms, the first generation approaches focused concomitantly on information as a strategy for behavior change to be imparted by health experts to supposedly rational-individuals (the locus of change), who pertain to risk-groups (the target unit of interventions). It was assumed that information infused in individuals was sufficient to enforce healthy behavior. Indeed, early HIV-prevention education was based on the so called KAB/ABC model, that is, *Knowledge-Attitudes-Behaviors* (KAB) and *Abstain-BeFaithful-Condormize* (ABC). KAB/ABC approaches were grounded in the assumption that once individuals were knowledgeable about the HIV transmission process and its consequences, they would act in their personal interest. It is now widely known that the direct link between knowledge and behaviors under threatening conditions is a weak strategy to promote health behaviors. It is weak because it is based on the misleading assumption according to which individuals have full control over their actions and can accordingly modify their cognitive processes. The new paradigms break with such a simplistic vision of human agency. They are more realistic and emancipatory, as they view HIV risk and prevention within broader social contexts and promote social justice-prone structural change in terms of socio-economic

improvement. Community mobilization is viewed as a key element of this strategy. This implies, among other aspects, taking into account sexual (and drug injecting) behaviors against people's existential conditions, both material and symbolic, which jointly construct their logic of sexuality and health protection. Thus, behavioral change strategies must contextually consider the collectivities' world views and life experiences within their socio-economic and cultural specificities. In this respect, symbolic aspects like status, trust and the sense of protection are more palpable and scientifically operationalizable, particularly with regard to the social construction of gender and sexuality, the way in which these are shaped by socio-cultural, political and economic factors. This means that HIV/AIDS requires an integrated social-science approach that takes seriously the structural factors of vulnerability and intervention success.

#### **4.1 From individual-information focus to structural vulnerability and community mobilization**

Scholars delineate three major generations of approaches to HIV/AIDS research and management (i.e. Campbell & Cornish 2010; Parker & Aggleton 1999, 2013; Parker 1996, 2000). These generations are referred to in a quasi-historical way and can be sketched as follows: “individual and risk-group focus for HIV awareness” (mid 1980s - late 1980s); “group-focus and peer education” (late 1980s – early 1990s); and “structural vulnerability and community mobilization” (early 1990s – 2000s). As Campbell and Cornish (2010: 3) clarify, the quasi-historical and schematic nature of these generations of HIV/AIDS research and management underlines that elements of all three approaches have characterized responses to HIV/AIDS in a more complex and contradictory way than the simple periodization reported here would acknowledge. However, the authors believe, this rough evolutionary account has analytical value, since it enables us to map out how dominant understandings of HIV/AIDS vulnerability and behavior change have increasingly focused on the social determinants of the epidemic and the possibility of intervention success. It is also worth clarifying that in the passage from first to second and third phase, behavior change remains to a large extent the all important end, but emphasis is placed on the need for more complex approaches that consider the broader context of HIV/AIDS and, in doing so, steps beyond mere individual and information-based strategies.

#### **4.1.1 The first generation: individual-information focus for HIV/AIDS awareness**

The initial phase of world HIV/AIDS studies refers to the period between the mid and late 1980s. This is when the initial attempts to understanding behavioral and micro-social patterns of the HIV risk were made, with the ultimate goal of producing intervention strategies able to contain the spread of the virus across populations. As Campbell and Cornish put it (2010: 3, after Aggleton et al. 1992; Rosenstock, et al. 1994; Terry et al. 1993), by targeting individuals and being informed by traditional health psychology, first generation approaches to behavior change took the form of traditional didactic health education, seeking to provide individuals with information about HIV/AIDS, how to avoid HIV contagion, and how to respond once infected. The authors refer to two versions of individual-focused strategies in HIV prevention:

The crudest versions assumed that people engaged in health-damaging behaviours due to ignorance, and would make rational choices to change such behaviour once in possession of accurate factual information. More sophisticated approaches drew on social cognition models. These gave a more complex and elaborated account of how health-related behaviors were driven by people's individual perceptions of the risks, costs and benefits of those behaviors.

A range of factors contributed to social scientists focusing on individuals as the locus of behavior change. These factors were closely linked to the novelty of the HIV infection and epidemic. At the onset of HIV the world's social sciences lacked theoretical tools to handle it and define effective responses to an epidemic that would rapidly become simultaneously a health problem, development issue and security threat. This was associated with the fact that in this period, sexuality in connection to HIV was not even considered as sufficiently noble to deserve academic attention, although there had been notable studies about sexual and reproductive health since the 1970s, when feminists claims for gender equality and anti-conceptual methods increased (Pimenta et al. 2002). Before the advent of HIV, STIs were certainly one visible issue in the social sciences and humanities but, unlike HIV/AIDS today, they did not constitute a major research field. Sex and sexuality studies focused primarily on sexual orientation, contraceptive methods, pregnancy, maternal mortality and women morbidity, often in relation to demographic growth and economic development. It is therefore not surprising that considerable time passed before HIV/AIDS literature started to address sexuality in a nuanced manner, emphasizing the factors of HIV vulnerability and the conditions that determine the likelihood of success of HIV/AIDS interventions.

The necessity to collect data on human sexual behavior and related HIV-transmission resulted in the emergence of research work and intervention initiatives with limited theoretical and methodological concerns (Oppenheimer 1992). This implies that inquiries were not oriented by a theory of human sexuality, but dictated by the epidemiological and political urgent need to gather descriptive data on the pandemic. This is one reason why these studies massively focused on individual behaviors and the epidemiological profiles of “risk groups”, namely, gays, IDUs, prostitutes, and hemophiliacs. Prevention discourses devoted scarce attention to the complex dynamics of the epidemic, in the sense that historical, socio-cultural, political, and economic factors were largely disregarded. Alarmist approaches gained ground in the initial years of HIV and they distinguished infected people between the “guilty ones”, for disseminating the virus (i.e. gays, deviants, prostitutes) and “defenseless victims” (i.e. children, hemophiliacs). Public opinion tended to blame HIV infected people for their “inappropriate” sexual behavior, typically associated with promiscuity, male homosexuality and female prostitution. Infected prostitutes and youth were considered irrational in their risk-taking. Biomedical policymakers and professionals generally held the same moralizing stance. The tabloid press particularly contributed to alarmist and simplistic approaches, portraying HIV as a gay cancer or plague. But religious groups were more conservative, portraying HIV-infection as a divine punishment for immoral behaviors. All over the world, homosexual men, prostitutes, Africans, Haitians, just to mention a few, were labeled by the “pure” as dirty and promiscuous. At best, they were assigned the status of “dangerous others”, who are morally contagious and sexually polluting. This value laden process of otherness easily leads to scapegoating dynamics, hence the social or corporeal death of PLWHA, to not mention discrimination in housing and jobs. As Edwin Cameron expresses it:

No corner of our social effort or investment – from health care to social security, education to the economy, correctional services or judiciary – escapes AIDS. Hence, no single approach can begin to secure the proper prevention, containment, treatment and care we need. The words “holistic” and “multi-sectorial”, though grievously over-used, have practical meaning: that imagination, cohesion and commitment are what we have to start with. Edwin Cameron (in HIV/AIDS in South Africa 25 Years On: Psychosocial Perspectives, by Rohleder et al. 2009:3).

Focusing on “rational-autonomous individuals” and “KAB/ABC models”, first generation approaches to HIV/AIDS prevention and management elaborated on the concept of “risk group”. By implication, sexual identities in relation to HIV constituted a central research subject and people’s accounts would appear later on in

often co-edited book-length works. Not unexpectedly, sexual minorities gained particular academic attention in this period, focusing on male homosexual and bisexual groups (i.e. Parker et al. 1995; Aggleton 1996). Male prostitution in association with HIV risk is also a central issue in this period. It raised new questions for social research, including those related to gender identities and self-understanding beyond classic categories of heterosexual, homosexual, bisexual (i.e. Aggleton 1999: chs. 2, 4, 9).

This phase was short lived in theoretical terms in most countries. It was also short lived in practical terms in developed countries, as well as in developing countries which established prompt and aggressive HIV/AIDS programs like Brazil. Theoretically, individual-focused approaches came under attack from scholars who drew attention to the broader social drivers of HIV-risky behaviors, including the role of peer norms of specific groups, as well as the difficulties faced by people in impoverished contexts in accessing effective HIV education, care and treatment (i.e. Waldo & Coates 2000). These critiques led to a second generation of approaches to HIV/AIDS studies, which paved the way for multi-dimensional analysis and intervention in HIV-prevention social-science.

#### **4.1.2 The second generation: group-focus and peer education**

By the early 1990s, knowledge production in the world's social sciences on HIV/AIDS had increased comprehensively and critical thinking about prevention approaches started to emerge. This was associated with three interlinked social processes in many societies. The first factor concerned the accelerated progress of HIV beyond “risk groups” and the consequent HIV heterosexualization and femininization, as well as pauperization in many cases. The second factor concerns the strengthening of symbiotic relations between social researchers and prevention practitioners, especially civil society organizations. Finally, progress in HIV/AIDS policies, especially in high-income countries and in some middle-income countries, with Brazil at the forefront, caused serious reflection about theoretical assumptions on HIV-prevention.

These social processes led social scientists to criticize first generation approaches to HIV/AIDS, illustrating the lacunae of “rational individual-information” and “risk-group” (i.e. Farmer 1992; Glick-Schiller et al. 1994). Eileen Stillwaggon (2006) characterized the

first generation approach as the “derailment of HIV/AIDS research” (ch. 7), based on “individual bias in methodology” (ch. 8). It was also emphasized that “the currently dominant biomedical model incorporates capitalist economic assumptions about health resulting from individually chosen lifestyles, leaving little scope for understanding how behaviors are related to social conditions, or how communities shape the lives of their members” (Schoepf 2001: 339).

As for the notion of “risk group”, in early the 1990s researchers started suggesting that while “risk group” is a useful concept for identifying the groups for which intervention is most urgent, it may obscure differences among people assigned to this simplistic category because it implies that everyone who is beyond those boundaries is not at risk. Furthermore, “risk group” is a stigmatizing, degrading and dehumanizing category because individuals placed into it are separated from other sources of identity. Such narrow vision is at odds with the critical tradition in epidemiology and public health, which has historically emphasized a wider range of social determinants of health. This literature suggested that “sexual promiscuity”, for instance, attributed to “risk groups”, is a scientifically imprecise notion and is not a sufficient condition for HIV risk. Researchers suggested that it is more appropriate talking about risk behaviors such as unprotected sex or injecting drugs intravenously, which can be associated with a range of factors that cannot necessarily or easily be attached to specific groups. Therefore, scholars started focusing on social vulnerability in terms of economic, social and psychological powerlessness – besides cultural factors. In this regard, calling attention to power relations and social inequalities, scholars have since then pursued inquiry that suggest that, when confined to specific groups and used in a stigmatizing manner in the public health discourse, the concept of sexual promiscuity helped dominant groups to maintain, reinforce and reshape their hegemonic position, and obscure the social process leading to inequalities. As for information-based focus, researchers pointed out that information alone is a weak determinant of behavior change, because individuals can find themselves under circumstances that force them to cling on to behaviors that place their lives in danger, even when they possess sufficient information about the perils of such actions.

The pauperization of the HIV infection illustrated that economic factors are critical to HIV vulnerability. This was largely recognized by researchers, but in this phase priority was given to social aspects like peer norms and the way they contribute to social vulnerability related to HIV/AIDS. Focus on peer norms would foster a form of scholarship oriented to peer education programs for HIV/AIDS prevention, which in

many contexts took the form of research-action. This scholarship pointed out that rather than cognitive properties, peer norms – including those that underpin peers' pressure for early sexual debut, macho man attitudes, sexual multi-partnership, and unprotected sex – influence sexual and health behaviors. In this sense, peer education programs were a response to the perceived shortcomings of individual-focused approaches. By targeting peer groups as the locus of social change, peer education programs emphasized the impact of small-group interactions on behavior (Kelly et al. 1992). Rather than information, focus was now placed on stronger strategies for empowering people with negotiating capacities on sex, and the procurement and use of condoms. Conversational skills and assertiveness were among the prime aims of peer education and it was argued that understanding peer norms was crucial to such capability approaches. The youth was and is particularly viewed as the most privileged group of peer education programs.

Peer education can be defined as a psychosocial emancipation approach that uses some criterion of affinity existing among the members of a given group. In this sense, the group is regarded as a space of identities, that is, a space where the members of the group share cultural values and norms, whereby individuals are recognized as peers and their actions legitimized. According to this perspective, AIDS peer education among youth is based on the assumption that peers are the most influential agents of young people's sexual behaviors, which is why young people are more likely to change their behavior if their peers whom they trust and love, do the same or at least inform them.

Peer education has surely been advocated for its characteristic low cost. But it has been mostly advocated due to other practical aspects and advantages that portray peers as credible sources of information and positive models for healthy behavior. This concerns the framework in which peer education is rooted, namely, the threefold motto: include, involve, inspire – a trilogy which is generally emphasized by education and communication psychology. Broadly speaking, peer education programs rest on three premises (Campbell & Cornish 2010: 1572; Grisewood 2008: 144; Kerrigan 1999). Firstly, people, especially young people, are more likely to listen to and respond to information when it comes from their peers, rather than from adults and/or experts. Furthermore, people are more likely to change their behavior if they see that loved and trusted peers are changing theirs. Secondly, given their “insider” status within hard-to-reach groups, peers are best placed to reach socially marginalized HIV/AIDS vulnerable groups which might be inaccessible to mainstream health professionals, or unwilling to heed their advice. Thirdly, peer education assumes that the mere provision of information is unlikely to

change behavior in the absence of the empowerment of “at risk” group members, thus converting information into action through the acquisition of skills, including sexual negotiation, assertiveness, knowing where to find condoms and how to use them.

Peer education is now a popular approach worldwide in the field of health promotion, particularly among adolescents. It began to gain popularity in the 1960s in education programs on drugs, sexuality and reproductive health among adolescents (Calazans 2012: 137-140). Although it is generally regarded as a method in search of a theory (i.e. Shiner 1999; Turner & Shepherd 1999), peer education has grown in popularity since the 1990s in the field of health promotion. The advent of HIV has boosted peer education and it is now globally one of the most widely used approaches to tackle HIV/AIDS. In this method, education on risk perception and negotiation capacities are associated with awareness of raising adolescents' self-esteem, sense of citizenship and self-organization (collective autonomy). Peer education programs were first grounded in cognitive-behavioral psychology and focused on “appropriate behaviors” that were viewed as a model, as well as in the provision of rational, and motivational arguments that young people could use in response to peer pressure. In principle, peer education as a method emphasizes interactive and participative didactic approaches – as opposed to top-down approaches whereby adult teachers seek to fuel young people with information. Peer education typically involves training and supporting members of a given collectivity to effect social change that is relevant to them by raising awareness of a pressing problem. This ideally occurs through critical consciousness about the group's own knowledge, attitudes, beliefs, and behaviors surrounding the problem at stake. Thus, peer education aims towards modifying norms and stimulating collective action in order to bring about change in the group. It may involve academic support or advocacy, enhancing communication and interpersonal skills, or counseling.

In the field of health promotion, peer education aims at mobilizing and involving communities, and is understood within social capital discourses, which entails strategies of participation and partnerships able to promote contexts that favor healthy behaviors. Thus, health-promoting peer education requires contexts where people can collectively negotiate their identities, on the assumption that sexuality and individual decisions are mediated by peer norms. Ideally, peer education should enable people to elevate not simply their self-esteem, and negotiation ability, but also the perception of possessing sanitary intervention skills, which are often erroneously considered exclusive territory of medicine experts.

By considering peers as the best communicators of knowledge and skills, peer education programs trained members of various groups, including “high-risk groups”, in HIV/AIDS information and skills, sending them back to their communities to disseminate it (Campbell & Cornish 2010: 1572). The success of peer education is difficult to grasp. Nevertheless, there is vast literature to draw upon (i.e. Kim & Free 2008; Campbell 2003). Campbell and Cornish suggest that peer approaches have had some successes, especially in more affluent countries and contexts, where target groups already had a high level of freedom over their behavior (agency), and were already linked through pre-existing solidaristic networks and a common identity, as well as being able to mobilize the support of powerful social groups. This is the case of gay men in the USA at the early stages of the epidemic. However, peer education has been less successful in materially and symbolically poor contexts (Medley 2009). Catherine Campbell's research-action (2003: 165-196) in a South African community of sex workers is illuminating in this sense. She argues that in poor contexts peer education success is undermined by low levels of perceived agency on the part of the members of peer education groups and communities, scarce solidarity, and occupational precariousness, among others. These constraints offer few opportunities for individuals to exercise control over their health, since they tend to have little faith in their ability to avoid diseases and therefore develop fatalist attitudes. In the sex workers group analyzed by Campbell this became worse in light of a lack of solidarity amongst sex workers competing for clients who paid more for unprotected sex, which lowered dramatically their propensity to use condoms. A further constraint to HIV peer education was the lack of support from both more influential constituencies in the community and regional health and welfare agencies. The limits of peer approaches to HIV/AIDS opened up the way for a third generation approach, which focuses on structural factors and community mobilization.

#### **4.1.3 The third generation: structural vulnerability and community mobilization**

Finally, the third stage of international HIV/AIDS studies stretches from early the 1990s to the 2000s decade, indeed till today. By the early 1990s HIV/AIDS was a big concern worldwide. The ferocity of the epidemic on individuals, families, communities and nations was by now evident. It became clear that most of the wealthier and some developing countries, including Brazil, had managed to limit the propagation of the virus, while less developed countries, particularly those in Sub-Saharan Africa, were facing a

dreaded epidemic. By 1996, biomedical treatment had made impressive progress with the development of HAART, which replaced the less effective and toxic early drugs such as AZT. The most advanced states in HIV/AIDS policies began to extend access to life-saving drugs for PLWH, following advances not only in the medical and pharmaceutical spheres, but also in terms of legal and political commitments. Awareness had risen worldwide at different societal and political levels. It was clear by now that community mobilization and involvement, including AIDS movements, played a vital role in national AIDS control programs. Connected to this reasoning is the fact that the cases of the USA and Brazil, among others, demonstrated that state-society synergies were essential for communities and movements in order to: advance HIV education at local level, empower individuals (economically, cognitively and socially), lobby national and global policy-makers for massive investment to alleviate the impact of the epidemic in the name of citizenship rights. Consequently, communities' capacities to create health-enhancing and supporting contexts were increasingly emphasized in association with social justice-prone national development. For this reason, scholars advocated the improvement of communities' material conditions and social capital for the sake of relational social spaces for critical dialogue (see Campbell & Cornish 2010: 1572-6 for a recent debate).

The focus on structural factors and community mobilization was also associated with the international debates that recognized the multifaceted and global nature of the epidemic. It was increasingly recognized that it is a complex interlink of factors (politico-economic and socio-cultural), locally and globally, that determine HIV vulnerability, as well as the success of prevention and treatment programs. This phase was considerably shaped by researchers and militants acting as part of the Global AIDS Policy Coalition, as well as international institutions such as UNAIDS/WHO and the World Bank (Paiva et al. 2013: 25-43). UNAIDS/WHO (2005) has sought since then to urge national governments to intensify HIV/AIDS prevention and treatment and, more importantly, to do so through holistic approaches that emphasize contextual and structural factors that place people into vulnerable circumstances (i.e. poverty and lack of access to health facilities, gender inequalities, high value placed on procreation in detriment of HIV prevention, etc.), as well as community involvement.

So, a sharper shift from “individual-focus” and “groups and peer education” to approaches focused on “communities and structural vulnerability” - in short, a multidimensional model - is the novelty of the third generation approaches to

HIV/AIDS inquiries and interventions. Hegemonic prevention policies that focused on “risk groups” and rational-individual approaches came under more serious attack than during the second phase because it was now clear that they wrongly relied on explanatory potentialities of individual risk behaviors, as well as on surveys (Monteiro 2002: 26). Moving beyond “peer group models”, unprotected sex has been increasingly analyzed in its broader structural context, taking into account large communities and nations that cannot be reduced to peer groups. Empirical data and theoretical analysis concerning HIV/AIDS interventions and the related social change now focus on large-scale poverty, social inequalities, symbolic power, and broader social change (i.e. Paiva 1994, 1996, 1999; Parker & Aggleton 2013).

Hence, larger communities and nations are now the main units of analysis. Research-intervention is now particularly interested in broad political, economic and cultural factors underpinning the likelihood of success of prevention and treatment measures adopted by national governments, local communities, and international agencies (i.e. Aggleton et al., 1991; Farmer 1999a, 1999b; Parker 2000; Campbell 2003). Thanks to the focus on structural vulnerability, treatment availability, and policies effectiveness, international HIV/AIDS research (i.e. Keenan & McDonagh 2009) has emphasized three central concepts: “treatment as prevention (TasP – alluded to in the introduction)”, “positive prevention”, and “structural violence” (Scambler 2001, 2002).

The concept of “treatment as prevention (TasP)” is associated with the increasing recognition of the falseness of the prevention-treatment dichotomy and has become a sort of mantra in international social-science on HIV/AIDS prevention (i.e. Ambrosioni et al. 2011), as well as in global policy-making (i.e. WHO 2014).<sup>34</sup> This literature posits that the availability of treatment has opened up new possibilities for preventive interventions. Firstly, as argued above, ARVs diminish viral load in persons who are under proper treatment, thus the chance for them to transmit the virus. Secondly, the availability of treatment motivates people to uptake voluntary HIV/STIs test and counseling, and most people who are knowledgeable of their seropositive status tend to protect the others by using condoms or abstaining from sex. Finally, thirdly, from a psycho-sociological viewpoint, access to treatment and health facilities increases patients' sense of citizenship and agency, which militate against fatalism, defeatism and denialism, stigma and social

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34 See also the material from the latest *International HIV Treatment as Prevention Workshop held in April 1-4, 2014 in Vancouver*. Available from: <http://www.treatmentaspreventionworkshop.org/conference/2014-treatment-as-prevention-workshop/> (Accessed on 8 September 2014)

death, which generally affect marginalized patients. This means that the availability of life-saving drugs does not simply encourage HIV-infected people to know and disclose their seropositive status, but also aids the construction of social capital. This implies collective capabilities to cope with the disease and to build participatory prevention strategies in groups or communities. This is especially true in more vulnerable and hard-to-reach groups like prostitutes, IDUs and homeless people. Thus, treatment availability creates the necessity to rethink responses to HIV/AIDS, nationally and internationally, pointing to both prevention *tout court* (primary prevention) and treatment (secondary/tertiary prevention).

“Positive prevention” refers to a comprehensive set of clinical, physical, psychological, social and legal assistance that allow PLWH to conduct a better life, including the avoidance of re-infection when they are already undergoing treatment, and the exercise of sexual, reproductive, and labor activities (Barcellos 2009; Paiva 2009). Since ART diminishes the chance to transmit HIV, including from mother to child, and empower PLWH (psychologically and socially), positive prevention is strictly connected to TasP.

The notion of “structural violence” is generally employed in the systematic investigation of the interface between poverty, exploitation and oppression in historically given contexts. The expression “structural violence” was first coined by the pioneering scholar of peace and conflict research Johan Galtung (1969) in his article *Violence, Peace, and Peace Research* to refer to a form of violence where certain social structures or social institutions may hurt people by preventing them from meeting their basic needs. According to Galtung, structural violence is strictly linked to social injustice, for it is a cause of suffering, disability and premature death of those on the bottom rungs of society. Examples of structural violence include elitism, sexism, racism, ethnocentrism and classism. For disadvantaged groups in unequal societies, these behaviors constitute not only sources of discrimination, denigration and exclusion, but they are also a cause for shame and low assertiveness – which are essential elements of symbolic power, associated with status. This way of looking at the social vulnerability of HIV and health, helps us to enlighten how social condemnation and marginalization place disadvantaged people into HIV risk circumstances. In association with advances in popular and professional interventions to the epidemic at national and local levels, these studies have revitalized the debate about HIV susceptibility and perception among gay men, bisexuals and prostitutes, especially in Northern countries (i.e. Aggleton et al. 1991). Equally, gender inequalities

have increasingly been underlined in relation to institutionally or culturally based violence, especially with regard to women's reduced power in the sexual sphere (Remme et al. 2014; Richardson et al. 2014) and, not rarely, in the access to treatment (Geary & Bukusi 2014; Mastro et al. 2014). This means that the notion of structural violence has boosted debates about gender issues. Gender analysis and claims for women emancipation is social science's main contribution to understanding and contrasting the HIV/AIDS epidemic, especially with regard to how gender and sexuality articulate with one another and throughout HIV/AIDS (Connell 2013: 253). Among other things, in third generation approaches to HIV/AIDS epidemiologists and psychologists no longer enjoy hegemony over empirical data. Rather, inter and cross-disciplinary works have been in place in HIV/AIDS scholarship since the 1990s. The same applies to theorization and research-action meant to inform interventions.

The paradigmatic shift discussed above reminds us that HIV/AIDS is a social disease, for it cannot be understood or tackled through individualistic and merely information-based approaches, neither is it fruitful to focus exclusively on "risk groups" or peer groups. Rather, it requires macro perspectives that explore the structural factors (political, economic and cultural) of vulnerability and interventions success, including communities' capacities to mobilize and articulate their activities within public policies. The reduction of structural violence and the adoption of inclusive policies are part of the enterprise. Social-science knowledge has an indispensable role to play here, especially through use-inspired research guided by robust theoretical and methodological tools.

#### **4.2 The interlink between poverty and symbolic dimensions**

Poverty contributes to both social and immunological vulnerability. As for poverty and HIV/AIDS vulnerability, it has been underlined that impoverished people are less likely to be effectively impacted by prevention education and to have access to medication. Based on this well documented argument, both in Brazil and South Africa, scholars hold pedagogical stances and urge particular attention not only to poverty as a key social determinant of vulnerability, but also on how poverty interlinks with symbolic dimensions like status, desire, manhood and womanhood, consumption, and social representations, just to mention a few. The research conducted by Naidoo and Misra (2008) on *Child Grant* in relation to HIV-risk among poor people in South Africa is

insightful in this regard. *Child Grant* is a state policy consisting in the allocation of an amount of money to every South African child up to early adolescence age. Naidoo and Misra posit that in combination with reproductive behaviors, including the ones related to procreation as an economic and symbolic investment, *Child Grant* policy is often a critical factor of HIV vulnerability for men and women. Despite the fact that the *Child Grant* amount is derisory, it increases poor people's propensity to procreate, even in conditions of well known high prevalence of HIV. Hence, economic constraints and the high value placed on procreation and children, together, increase men's and women's susceptibility to catching or transmitting HIV.

Since the beginning of the third phase of HIV/AIDS scholarship worldwide, a growing number of studies have documented the ways in which people, especially sufferers and their families and communities, experience and respond to the disease in contexts of poverty and social exclusion. It is renowned that material conditions influence our worldview, which in turn impacts our construction of health protection and access to health facilities. Building on these premises, the present sub-chapter addresses the indissoluble link between poverty and symbolic dimensions. Special focus is placed on social representations as a particular symbolic dimension to be discussed in association with poverty. To some extent, this is part of the debate on institutional-cultural approaches to health (see 2.4). For the sake of clarity, the two dimensions will be discussed separately, while trying to infuse in each one of them elements of the other.

#### 4.2.1 On poverty

*For the poor HIV is simply one new link in the chain of life-threatening phenomena.*

Campbell (2003: 110)

The correlation between poverty and HIV/AIDS vulnerability has been well documented. The most evident link concerns the fact that the economic and social cost caused by HIV/AIDS implies impoverishment for families and communities. But much more needs to be said about how poverty contributes to HIV susceptibility, which is why researchers suggest that HIV/AIDS is exceptional when compared to other social

problems (i.e. Whiteside & Smith 2009).<sup>35</sup> It is true that in many countries the most visible “risk group” in the first stage of HIV in the early 1980s was formed by middle-class gays, rather than the poor. But this was in the early stage of the pandemic, when scientifically informed knowledge about the virus was unavailable. Additionally, among other aspects, being middle-class gay often implied major sexual freedom and involvement in cosmopolitan groups that could result in pockets of infection - since HIV is a good cosmopolitan traveler - which was exacerbated by unprotected sex with multiple partners. Once middle-class gays attained information, socio-political mobilization and, later on, treatment, they could use these resources to protect themselves from HIV infection. The poor generally have much more limited access to those resources. Indeed, it was before the turn of the second decade of the pandemic that HIV began to be characterized by pauperization. This is the spirit of Catherine Campbell's remark reported above: For the poor HIV is simply one new link in the chain of life-threatening phenomena. A viral that began with invisible symptoms – and that would take years to manifest in full-blown AIDS– does not seem as a pressing problem as a day-to-day struggle against poverty and violence.

This is especially true in the case of poor urban contexts where, to speak like Robert Merton, there are greater incompatibilities between goals (of attaining and consuming modern material and symbolic resources) and appropriate means to accomplish such goals. Let us disentangle social vulnerability of HIV for the poor, following Aggleton and Parker (2013: 30). Firstly, the poor may be unable to seek treatment for STIs, and the presence of untreated STIs increases the risk of contracting HIV. Secondly, the poor tend to achieve poor educational levels because of exclusion and early drop-out, which reduces their life and career opportunities. Thirdly, poor women (and young people) are more likely to engage in unprotected transactional sex to support themselves and their families, which increases the chance of them becoming infected with HIV/STIs. Finally, the poor are more likely to dismiss disease symptoms as “nothing serious” and postpone the seeking of health care. As for risky sex, for instance, prostitutes who are lowly

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35 HIV/AIDS pandemic is exceptional because it involves every aspect of life – ranging from the biological to the cultural, economic and political spheres – which makes the reality of the epidemic hard to grasp, especially in its early stages and above all in already burdened contexts like Sub-Saharan Africa. The biological dimension of HIV is important inasmuch as the pathogen is predominantly transmitted via body fluids, sex and reproduction. Additionally, this is the epidemic that most affects young people, many of whom die “at the height of their productive and reproductive years – stretching the medical, educational and welfare capacity of states beyond their limits, undermining development efforts and casting a shadow over the future of the continent” (Crewe 2004: 3).

empowered due to their low socio-economic background are more likely to succumb to clients' willingness to engage in unprotected sex in exchange for extra money. Low assertiveness, trust and unrealistic optimism regarding the client's state of health, imply reduced power to negotiate protected sex in the case of poor prostitutes. It is evident that, even in stable relationships, women who are economically dependent on their male partners are more likely to be compliant with, or succumb to, their partner's polygynous behaviors, which may expose them to HIV-risk. This is so because extra affairs do not necessarily imply safe sex, which may constitute a risky scenario for a man first and then for his female partner. Among IDUs, the poor are more likely to share needles and syringes, as they may not be able to afford personal ones or access health facilities, which increases their susceptibility to HIV infection. In every group, poverty also undermines people's engagement in collective action, especially in those of long-term collaborative initiatives, not only because they lack resources to devote to such activities, but also because of high levels of jealousy and suspicion among members of poor groups, which stems from the struggle for the scarce resources available. These are indeed among the factors that have produced the disproportionate impact of the HIV/AIDS epidemic on disadvantaged populations. In the case of Sub-Saharan Africa, it has rightly been observed (i.e. Heimer 2007) that, among the social aspects of the disease, it is especially poverty that make HIV/AIDS in the sub-continent different - and worse - than HIV/AIDS in the United States or Europe, as poverty makes Africans more vulnerable to economic and sexual exploitation, which decreases their social and psychological power and increases their likelihood to be infected. Furthermore, by making Africans unattractive customers for pharmaceutical companies, poverty makes therapies unaffordable for most Africans who need them.

The debate about poverty as an important variable of HIV/AIDS vulnerability increased enormously in international institutions at the end of the 1990s. The World Bank (1997) and the United Nations Development Programme (UNDP, 1997) have increased their attention on the vicious circle of poverty, HIV propagation, and social disintegration. Academically, more and more, anthropologists conducted processual ethnographies that linked micro worlds with global structures and processes, highlighting how these aspects are involved in the spreading of HIV. In particular, efforts were made to show how macro-level factors create conditions for responses to the epidemic at local, national and international levels.

It is worth remembering that the 1990s were also characterized by Structural Adjustment Programs (SAPs) in the global south, imposed by international finance institutions (IFIs: World Bank, FMI, USAID) as a condition for further borrowing. Macro-economic measures were imposed as key factors that would enable economic development, debt reimbursement and autonomy. But they would lead to disasters because they exacerbated economic and social crises in many poor and developing countries. Indeed, SAP measures included currency devaluation, liberalization of markets and privatization, and compression of government budgets – which became unsustainable for poor countries. Schoepf (2001: 343) describes the SAPs tragedy lyrically:

Agricultural and health services, education and social programs, which the poor depended on governments to provide, were sacrificed. Urban unemployment grew, crops remained uncollected, and migration in search of work increased. The informal economic sector ceased to absorb new micro-enterprises. Many poor people lost their land to transnational firms that pay very low wages. Deepening poverty brought mass social dislocations, hunger, disease, and untold suffering.

Thus, according to this literature, the capitalist SAPs are among the macro economic processes that contributed to the flourishing of HIV/AIDS and related structural violence in many southern countries in the 1990s, particularly in Africa. This scenario prompted a growing number of social scientists to explore the way in which poverty and social disintegration exacerbated major drivers of HIV/STIs dissemination, namely prostitution, transactional sex, hopelessness, multiple concurrent sex partnership, gender violence, and illegal trafficking (i.e. Porter 1993; Heise 1994; Schoepf et al. 2000). It was reported that in Sub-Saharan Africa, particularly, large demographic segments were pushed out of the economic system, both in terms of production and consumption. The HIV/AIDS epidemic became a new mirror of these global processes and the associated configurations of societies, shedding light on, for example, the increasing feminization of poverty, shame, fear, stigma and discrimination. One implication is that the interface between poverty-based vulnerability and variables such as gender becomes more visible in their historical contexts. Following this path, efforts were also made for the establishment of historically-oriented comparative studies between the spreading of HIV and the spreading of other infectious diseases in the colonial period, suggesting that trade migration routes constitute a commonality among them (i.e. Setel 1999). Moreover, the macro order of international political and economic relations might have fueled civil wars in Central and West Africa, Uganda being one example. In this regard, while investigating the political-economic contexts of violence, some scholars have documented the

correlation between recent wars and HIV propagation in West Africa, focusing on, for example, the common use of rape as a weapon of war (Baldo & Cabral 1990). In these disempowering dynamics, women are further disabled – economically, socially, and psychologically. It is not surprising that gender studies concerning HIV/AIDS representations and vulnerability are among the most developed in international literature – building on feminist literature (stemming from the 1960s-70s transformations in gender relations, including anti-conceptual biomedical progress) and subaltern studies from Africa, India and other areas of the global South (see Susser 2009: 1-46 for a recent debate). In addition, HIV/AIDS gender studies have recently explored the stigmatization and discrimination of prostitutes and migrants, for example, as well as the male elite's denial of their risk and responsibility while subjecting youth and women to conservative and moralizing discourses.

In general terms, materially and socially impoverished contexts are fertile terrain not only for diviners, but also proselytic charismatic churches – which also happen to be one important socializing agent and one able to offer psychosocial support to sufferers. The role of charismatic churches concerning the epidemic has been generally negative: their conservatism regarding sexual morality, leads them to unrealistically believe in the consistency of their faith followers' chastity and sexual mono-partnership. However, studies have focused on general responses of religious groups to HIV/AIDS, disentangling both their negative impact, typically through anti-condom attitudes, and faith-based activities of prevention (i.e. Bongmba 2007; Haddad 2011; Weinreb & Trinitapoli 2012).

#### **4.2.2 On symbolic dimensions**

The emergence of third generation approaches to HIV/AIDS in international literature was somehow associated with the impact of social representation theory, which has been prominent within social psychology in countries since the early 1990s. Sociopsychologist Serge Moscovici (1976) defined social representations as a set of concepts, values, metaphors, propositions and explanations that drive and justify our actions in everyday interpersonal interactions, and ultimately give birth to common sense.<sup>36</sup> In relation to

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<sup>36</sup> Sociologically, social representation theory is generally associated with micro-perspectives like phenomenology and ethnomethodology. More broadly, social representation perspectives are associated with micro-macro reasonings, which stress the way in which micro behaviors, values, beliefs, attitudes, perceptions and self-attributed significances generate macro phenomena. However,

HIV/AIDS, social representations refer to a culturally established common sense regarding the epidemic. In this sense, HIV/AIDS is an epidemic of signification and brings forth representations that support and reproduce already constituted gender, race, and class hierarchies (Schoepf 2001: 338).

The study of social representations since the 1990s in the field of HIV/AIDS has been predominantly associated with anthropologically-oriented paradigms centered on what Schoepf (2001: 337) called “historically-grounded political, economy-and-cultur strategy”. In this sense social representations are essential to the social-science of HIV prevention, particularly use-inspired research, inasmuch as they facilitate the exploration of cultural values that common people - to whom researchers are committed - express from their own point of view.

In the study of the significance that people attribute to HIV/AIDS in their daily life, social representation theory gives micro accounts of the spatial-temporal variations of the epidemic, especially regarding people's perception of HIV transmission and the actions taken to reverse it. For example, research works related to social representation have contributed to understanding that: first, as in most countries, AIDS in Brazil is indeed the most stigmatizing disease; second, the perception of AIDS as a social, biomedical and intimate problem is high even among adolescents, although people tend to project their negative emotions and risk perception regarding HIV to their in-group members (Paulilo

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methodologically, in the exploration of attitudes towards HIV/AIDS, social representation research is probably unique in asking the double face question “what do you think of AIDS?” and “what do you think people (peers, generally) think of AIDS?”. This probably helps to explore more deeply men and women's coital debut and initiation processes, for example, as well as the subsequent development of sexual practices, taking into account cultural and historical influences in the definition and differentiation of gender patterns of sexual experiences. Symbolic aspects that shape condom disuse acquire grand importance in this perspective. Pointing towards that direction, we find the following works: *Qual prevenção? AIDS, sexualidade e gênero em uma favela carioca* by Simone Monteiro (2002); *Early coital debut and associated HIV risk factors among young women and men in South Africa* by Pittfor et al. (2009); and *The relationship between age of coital debut and HIV seroprevalence among women in Durban, South Africa: a cohort study* by Wand & Ramjee (2012). Although implicitly, and despite being predominantly quantitatively oriented, these works used social representations to disentangle HIV risk factors among Brazilian and South African adolescents in poor contexts. Social representation theory helped to understand that the age of first sex in Brazil and South Africa is averagely 16 years old, with no significant differences between boys and girls. Despite the availability of HIV information, poor adolescents' susceptibility to the infection is worrying. For female adolescents, major factors accounting for this situation include, coerced and forced sex at the first or subsequent intercours, plus the older age of the male partner. Coerced and forced sex is correlated with hegemonic masculinities. Poor education and scarce prospective for the future, besides and as a result of economic factors are clearly involved in such dynamics and concern both women and men. This is particularly true in South Africa, where the prevalence of HIV infection in the general population is high and sexual behaviors that might be deemed low risk in low-prevalence settings convey a much greater risk therein (Pittfor et al 2009: 88).

1999); third, a stable relationship often justifies condom disuse, while the consumption of alcohol and other drugs makes people, especially young boys, more likely to engage in unprotected sex; and fourth, the supposed selectivity of the disease, portraying homosexual men, prostitutes, transvestites and IDUs as “risk groups” is still present in the population's common sense, which means that, despite enormous progress, that old representation has left a lasting mark in the construction of AIDS, partly due to the fact that a considerable amount of information is acquired from friends who may be themselves ill-informed (ibid).

In the West, particularly in the USA, social representation approaches revealed prevailing public opinion and attitudes regarding the HIV/AIDS epidemic. For instance, they helped to understand that the terribly disproportionate impact of AIDS among gay communities often obscured the fact that for a long time most new cases of HIV infection had been among heterosexuals (Watney 1991: 2). Also, inquiries into social representations contributed to debates about HIV heterosexual transmission and the future course of the epidemic in the USA and the West generally. Regarding the perception of the contribution of various constituencies to the AIDS struggle, “gay men were casually portrayed as selfish and insensitive, ‘only’ concerned with the fate of other gay men”. Watney adds that, by the mid-1990s, it was almost fashionable to depict gay men negatively, perpetuating their uneven effects of marginalization - on account of being among the communities most affected by HIV/AIDS – and to overlook the crucial fact that throughout the entire course of the epidemic it has been gay men who have most fought to alert other social groups about the potential risks of HIV infection (ibid). In this sense, the exploration of social representations helped to illustrate the big picture of the HIV/AIDS epidemic and to indicate nuanced intervention strategies in the US and the Western world generally. Positive changes in Western public opinion and common sense in the 1990s were also associated with the WHO's new studies that reported both an HIV expanding crisis in Sub-Saharan Africa and marked increases of new HIV cases throughout Asia and Latin America. These trends led to a dramatic upward revision of previous estimates about the epidemic in the world. The WHO's reports also illustrated the indissoluble linkage between the history of HIV propagation and global migrations, focusing on new forms of social exclusion, increased poverty and inequalities – as discussed earlier.

Internationally, the major contributions came from anthropologists working in Sub-Saharan Africa. Indeed, Sub-Saharan Africa has been the most studied region in relation

to the HIV/AIDS epidemic, not only because it is the world's most affected area, but also because it has presented the major controversy in the policy sphere, popular media and scientific arenas. Within social representations thought, controversy means contradictions between situational need and response, to speak like Schoepf, which involves a struggle over meaning. Sub-Saharan African cultures are reported as the context where AIDS has freighted with the highest levels of symbolic and emotional power, including psychical, social and spiritual “pollution”. By implication, for instance, research on the role of witchcraft and traditional healers in the construction of, and response to, the epidemic in Sub-Saharan Africa has been prominent (i.e. Niehaus 2012; Hagenbucher-Sacripanti 1994).

#### **4.2.2a Social representation approaches: the case of Sub-Saharan Africa**

In the witchcraft and traditional healing cosmologies in Sub-Saharan Africa, jealousy is one constitutive element. Jealousy is generally conceived as the chief force driving illness and misfortune. Interlinking cultural and economic variables, studies on these aspects have enlightened the fact that among lay people, culturally-rooted sentiments of jealousy are exacerbated by poverty, exclusion and the battle for the scarce resources available. In contexts of deprivation characterized by a lack or insufficiency of access to modern medical services, the jealousy-prone thinking of those cosmologies leads to suspicion according to which one's disease is a consequence of being bewitched by someone who is jealous for some reason. The implications of such dynamics include at least two aspects. Firstly, in impoverished contexts there is an increased likelihood of sufferers who seek cure in traditional healers (diviners, herbalists and faith healers) rather than in biomedical services (hospitals, clinics, pharmacies). Secondly, the development of an emancipatory critical consciousness and positive social capital is undermined, because collective action aimed at social change is hard to establish.

However, this social representation of health dispensation systems is more complex in pluralistic contexts. It is true that the social construction of the disease in deprived contexts in Africa can read the Western HIV/AIDS message as an aspect of political and ideological domination rather than a neutral scientific fact (Heald 2003: 211). But the coexistence of different belief systems in the sphere of health dispensation, as well as their interrelations and the social contexts in which the response to Western messages is delivered, are often complementary. As Campbell (2003: ch. 1) demonstrates in her study

of South African mineworkers in Summertown, in impoverished contexts where biomedicine knowledge coexists with witchcraft and sorcery cosmologies, people do not necessarily cling exclusively to the traditional healing system. Rather, they often move between biomedical and traditional healing without any tension or sense of contradiction. In other terms, according to Campbell (p. 26), people oscillate between representations of biomedicine and traditional healers. This has resulted in an academic focus on Sub-Saharan Africa, demonstrating that for those people located in a plurality of healing systems, biomedicine only provides physical cure, while “traditional healers play a key role in diagnosing and restoring the social disharmony that had led to the development of the disease” (Campbell 2003: 28). Aware of the public health system’s inability to assist most of the people with HIV and biomedicine's therapeutic “impotence”, many traditional healers represent AIDS as an "old African disease", which they claim to cure. Furthermore, besides being more affordable for the desperately poor, traditional healers claim to provide psychosocial support that “biomedicine practitioners cannot”, including answers to the question "why me?". The answer is generally found in occult forces, representing AIDS as a “sent sickness” by a sorcerer who is jealous or non-mundane forces. This seems satisfactory to many people. Yet, literature shows that many patients find little satisfaction in either systems of health dispensation, and desperately go back and forth – which often results in further anguish for patients, as well as social and physical death.

One implication of this discussion for a comprehensive social-science on HIV/AIDS policy is that institutional interventions must be explored in connection with the cultural contexts in which they are embedded (and which shape symbolic dimensions, particularly social representations) in order to find out the concatenation of factors that impact upon the likelihood of policy success at local and national levels. This is part of the discourse related to institutional-cultural approaches. Poor African contexts which are heavily hit by HIV/AIDS offer illustrating examples of social representations of the epidemic.

Apparently, it was not until the mid-1990s that cultural determinants of HIV started gaining scientific attention in the international arena. But from this period onward, anthropological literature on the epidemic in the international arena shows researchers' increasing attention to connections between local socio-cultural processes that create HIV susceptibility and the life-worlds of affected people to the global political economy (Schoepf 2001). Several scholars have pointed out that, not unexpectedly, focus on Sub-Saharan Africa triggered defensive reactions in many countries. Defensive reactions were

not only exacerbated by colonial scars, budget shortage, scarce democracy and centralization, the role of witchcraft and sorcery cosmologies competing with modern biomedicine in the field of health dispensation (Schoepf 2001: 341-2).<sup>37</sup> When the harsh reality of HIV/AIDS was recognized, it was declared to have come from the West, supposedly through American militaries, businessmen, and sex tourists. In many African countries, unfamiliarity with the pathogen, low education, plus the scars caused by colonial biomedical misdeeds led early grassroots-based education to oversimplify biological explanations, portraying the epidemic as an imaginary disease invented by Westerners to discourage Africans from sex and procreation. This was partly linked to the worldwide spread argument that HIV had possibly been deliberately created in US laboratories for biological warfare purposes during the Cold War. Although the history of anti-poliomyelitis vaccine campaigns with supposedly SIV-infected drugs in the 1950-60's Belgian Congo was not well known, echoes of Western scientists' responsibility for the spread of HIV had resonated in the continent. Sexual citizenship was also a concern, since women and youth suspected that government and church officials tried to control their sexuality through HIV prevention education.

Researchers raised concerns about the negative effects of stigma beyond the retardation of HIV/AIDS policy and research in many African countries. For example, they explored how stigma fostered the social isolation of sick people and their families. In particular, they gave accounts of suspected women or "free women" ("living without male protection") being scapegoated, rounded up, and sometimes evicted from their homes, thus being deprived of livelihoods and families through deportation to inhospitable rural areas or even imprisonment (i.e. Fassin & Dozon 1989). As we saw earlier, when stigma is combined with traditional representations of "sent sickness," many Africans attributed HIV infection to sorcery and some of those accused as witches were even killed (Lawuyi

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37 Cosmologies that compete with biomedicine contributed to HIV/AIDS policies emerging belatedly in most of Sub-Saharan Africa. When adopted, policies were heavily dependent on international donors through the WHO and centralized in health ministries. Governments sought to closely control the programs through top-down and vertical approaches. Centralization is indeed a politico-administrative culture in Sub-Saharan Africa. With health ministries perennially underfunded, policy implementation seldom went beyond the capital city to powerless risk groups. Also, authoritarian states, Uganda being one laudable exception, hampered the mobilization of local organizations and peer education. Popular culture was seldom considered in educational responses. As for research, in some countries like Kenya, policy makers' economic personal interests exacerbated the difficulty in conducting social research on HIV/AIDS: they made private fortunes with AIDS funds, while at the same time being reluctant to publicly acknowledge the devastating full-scale of the epidemic on the pretext that such publicity could damage central sectors of the economy like tourism. Inevitably, governance and corruption have also found space in HIV/AIDS inquiries, especially in those which have held a pronounced critical stance.

1998a, 1998b). Not unexpectedly, in such contexts many African healers claimed to cure AIDS – they still do. Researchers, particularly anthropologists, were caught between “pure” science and the advocacy for human rights and cultural change. Critique and scientific detachment increasingly became a major concern (i.e. Farmer 1997, Fassin 1997). This debate resulted in events and publications.<sup>38</sup>

### *Gender and men's seeking of HIV facilities in South Africa*

Gender is the field that most concentrates scientific discourses related to vulnerability, emancipation and social development in general. The social science of HIV/AIDS has extensively documented how gendered relations and inequalities impact men's and women's construction of sexuality, and health protection, the latter consisting also in the propensity to seek health facilities.

Now, gender studies are generally associated with feminist approaches. However, in South Africa this vision would result rather narrow if we refer to HIV/AIDS scholarship. Indeed, masculinities constitute a central theme in South Africa's gender studies, both in terms of theoretical analysis and, to some extent, research-action. One illustrative example in this respect is a research conducted by Mia Faull (2010) on a men-only HIV facility called *Site C Men's Clinic* in Khayelitsha, Cape Town. *Khayelitsha Site C Men's Clinic* is located in a Xhosa speaking context and it is aimed at motivating men to seek public HIV facilities. Physically, the Clinic is situated in a location separate from the community health centre clinic, as a result of claims according to which the factual low propensity of men to seek HIV facility was to a large extent dependent on gender relations (p. 6). Faull's analysis is centered on the question if male-friendly health facilities improve the uptake of voluntary counseling and testing (VCT) services by men. She concludes that this is indeed the case: in this specific case, Xhosa men are reluctant to seek public HIV services.

In South Africa, HIV testing rates and health care seeking are particularly low among men (they actually generally use public health facilities to a much lower degree than women). This strongly undermines efforts to mitigate the impact of the epidemic. Men's scarce willing to seek HIV facilities is linked to gender-related norms and practices that shape

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38 A crucial and recent publication on HIV/AIDS and anthropology is the french book *Sida, un défi anthropologique*, which is a collection of anthropologist Françoise Héritier's texts by herself and Salvatore D'Onofrio, published in 2013.

manliness and sexual discourses. Manly health attitudes include men's need to portray an image of general well-being and dismiss illness as a minor issue, regardless of its severity, which often leads men to think that it is “too early” (p. 3). Literature and my own field work in university-based HIV centers in South Africa suggest that for men, testing would imply being seen as vulnerable, an aspect that is perceived as a sign of being “less manly”. The assumption underlying this social representation is that men are stronger than women, that they can cope with pain, and are more physically able to fight the infection than women: men who succumb to pain and go to the clinic are like women (p. 8-10). It is more likely to be socially acceptable for men to seek help when the seriousness of the disease is evident to everyone and the patient himself. In such a context, according to Faull, in the Khayelitsha community, probably in South Africa generally, AIDS is to some extent perceived as a women's disease and health facilities are seen as female places. Additionally, in South Africa's health facilities staff members of primary health care institutions are overwhelmingly female. Men who attend the Khayelitsha *Men's Clinic* assert that, besides insinuating that men are inconsiderate and violent towards their partners, female health workers blame men for allegedly putting themselves in HIV-risky circumstances through promiscuity and alcoholism (p. 4, after Levack 2005). Even worse, men report that female health workers shout at them in public, which is a contravention of Xhosa traditional gender norms whereby women are expected to be submissive to men (p. 9). Furthermore, men view female health workers as unable to keep a secret (they gossip). This makes men feel judged when seeking sexual and reproductive health services. They feel defeated, maltreated and powerless. HIV positive men experience conflict between displaying signs of illness and societal pressures to deny pain. Also, poor quality service, implying long waiting periods, may prevent men from waiting or returning for HIV test results. In connection to this, men have the perception that “women talk at unnecessary length and go off on tangents instead of going to the point” (p. 20).

Thus, male-friendly clinics are regarded by men as able to increase the uptake of VCT because men feel free and safe, being able to reaffirm their masculinity, male dignity and autonomy (p. 18). Even if some staff members at men-friendly HIV clinics are women, Xhosa men hold more positive attitudes when compared to mixed clinics. Indeed, in Xhosa society, it is unacceptable to talk about sex openly and publicly, let alone a man telling his sexual matters to a woman. Additionally, waiting with other man in a men-only clinic, uptaking the HIV test in their own time, without pressure, even mitigates the

psychological impact caused by the fear of testing positive. In relation to this, opening hours at the Khayelitsha *Men's Clinic* are reported as being adjusted to suit men.

*Interim concluding remarks*

Sub-Saharan Africa's HIV/AIDS epidemics are undoubtedly the most studied in the world, in general terms, and in relation to the impact of culture on vulnerability, in particular. Thus, anthropological observation has returned to the work that stretches back to the colonial era, and the region has become once again the main target of anthropological inquiries. But, contrary to the previous historical periods, the HIV/AIDS epidemic has since the 1990s forced cultural anthropologists to move beyond their classic epistemological and methodological approaches – focused on “unique” cases – and engage in the search of regularities regarding the social production of sexuality and HIV drivers (class differentials and poverty, gender, ethnicity, powerlessness, and stigma). Therefore, approaches that consider culture as the main determinant of more or less predictable actions have been seriously questioned and, by implication, attention to broader political and economic contexts has increased. For example, more than in the previous decades, youth violence, including rape, has been analyzed in association with unemployment and powerlessness. Furthermore, anthropologists have gone beyond “descriptive” and “neutral” accounts, embarking on engaged scholarship. Furthermore, the urgent nature of HIV/AIDS prevention has led to questioning theoretical scholarship per se, thus legitimizing applied research prone to social change among anthropologists, who would otherwise define themselves as “pure” scientists. Advocacy for a more engaged anthropology and greater public visibility has grown among anthropologists (Fassin 1998; Nyamwaya 1993; Ramin 2007; Susser 2010). Dialogue with civil society and policy makers has been inevitable and anthropologists have sought to bring the voices of sufferers and grass-roots entities into the public debate, presenting them as crucial for policy planning, implementation and evaluation. This has inevitably caused creative tensions and sufferance among anthropologists:

Much like physicians who suffer from therapeutic impotence in their inability to cure, anthropologists who believe they know how to effectively engage people in protecting themselves suffer from a kind of social and political impotence. Some suffer in silence; others write, use gallows humor, or scream; still others disengage. Schoepf (2001: 346).

Overall, these studies apparently encouraged UNAIDS (1999, 2004) to engage in the exploration of the links between HIV dissemination and sensitive issues like rape,

violence against women, female genital mutilations, and widow or single women abandonment. These issues are indeed difficult to be researched, especially when they are interlinked with deep-rooted cultures.

#### **4.2.3 Urban youth, poverty and symbolic dimensions in Brazil and South Africa**

*Young people remain the great hope for the ending of the epidemic, for the care and support of those who are infected as well as for being secure adults in the future.*

Mary Crewe (2012: 56)

The interlink between poverty and symbolic dimensions with regard to HIV susceptibility has been well documented. Particular attention has been devoted to the youth in poor urban contexts like Brazil's shanty towns and South Africa's townships. Masculinities and femininities that underpin young people's susceptibility to HIV behaviors are the central subject for this particular scholarship. In the present sub-chapter, two exemplary works in this respect are discussed: *Qual prevenção? AIDS, sexualidade e gênero em uma favela carioca*, by Simone Monteiro (2002), focused on the Vigário Geral shanty town, Rio de Janeiro, and *The ingagara, the regte and the cherry: HIV/AIDS and youth culture in contemporary urban townships* by Selikow et al. (2002), whose empirical data was predominantly collected in the Alexandra township, Johannesburg.

Both works are crucial also on account of laying connecting bridges between the prevention research done in the initial two decades of the epidemic and that which was conducted in the last decade in Brazil and South Africa, respectively. Methodologically, the two works are ethnographically oriented, providing explanations about youth HIV-risky conditions, which can reasonably be generalized to youth urban contexts because they are rich in contextualized reflections on macro factors. As for economic factors, for example, Monteiro and Selikow consider the effects of a capitalist economy on the construction of sexuality and health among poor urban youngsters. In this regard, drug dealing in Vigário Geral and the associated stigma and marginality constitute an essential point in Monteiro's discussion. On her part, Selikow examines the impact of labor market restructuring on masculinities and femininities that affect youth in Alexandra.

*Monteiro's study on Vigário Geral, Rio de Janeiro*

Monteiro disentangles masculinity and femininity trajectories of young groups, including sexual debut, to examine youth behaviors and world visions that interfere with HIV prevention. Boys' trajectory in Vigário Geral is associated with internalized social expectations of traditional masculinity: they are supposed to become the breadwinner and resources provider. This means, among other aspects, males' propensity to occupy public spaces (as opposed to house/home), early investment in remunerated labor and vocational work to the detriment of formal schooling. Although schooling has a high symbolic value as a major tool against social exclusion, harsh circumstances and the necessity to help the family economy and acquire consumer goods increase the school drop-out rate. As a result, compared to girls, boys in Vigário Geral have lower levels of formal education. On the other hand, girls are expected to play the role of mother, wife or daughter, which implies occupying the housing space.

The distinction between family household and the extra-home world is essential in Vigário Geral. There is a high perception of opposition between a safe and ordered world ("home") and an unsafe and disordered one ("the street" - public spaces), the latter being typically characterized by illegal and informal market labor with a predominance of narcotrafficking.<sup>39</sup> "Home" space is identified as "protective/familiar" (relatives, neighbors, friends, drug dealers, divine forces), whilst the "street" is associated with "strangers" (police violence, dancing clubs, and legal power). In general terms, young men and women enter public spaces to seek remunerated activities or because of domestic violence. However, due to a combination of material conditions and social norms, girls tend to return home, whilst boys continue dominating public spaces, partly due to the provider attribute that they are expected to fulfill. Monteiro (p. 122) notes that even young women who left home early because of family conflicts or seeking financial independence and "respect" via involvement in drug dealing tend to abandon this dangerous "street" environment and set up a family. In any case, protected and non-penetrative sex increases in the case of encounters with strangers, that is, when sex is perceived as a potential threat to health. The perception of "the familiar" as a "safe/protective" world and the significance of protection in Vigário Geral is shaped by harsh socio-economic conditions, police violence, as well as by the alternative offered by drug trafficking. In this sense, poverty and symbolic conditions in Vigário Geral combine to maintain traditional gender values that make masculinities and femininities sharply

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39 The boundaries separating the two worlds are however sometimes blurred: the police is simultaneously perceived as protection and threat agents.

demarcated. Within this gender demarcation, despite women's improvement over the last decades, primarily through increased autonomous control over reproductive health, men's domination over women persists in the sexual sphere and beyond.

This has important implications for the interrelation between gender and sexuality, also by virtue of sex in Vigário Geral being predominantly heterosexual and penetrative. According to Monteiro, men in Vigário Geral associated sexuality with virility, the latter being substantiated in taking initiative, seduction capacities, domination, as well as a strict distinction between affective relations and sexual apprenticeship; on the other hand, women demonstrated more sexual conduct control mechanisms, valuing virginity, as well as the connection between sex and affective ties. This poses serious questions about the success of HIV campaigns focused on perceptions of individual rights and the equality and negotiation between partners regarding safe sex, condom use or non-penetrative sex. Hence, HIV/AIDS education based on the modern conception of individual rights, rational choice and mere negotiation capacities is undermined. Indeed, the author reveals that even in the first case of unprotected intercourse, rather than an agreement, it was symbolic aspects of a different nature such as trust, affective ties or curiosity that prevailed. This is also correlated with the high symbolic value given to maternity, which contributes to high teenage pregnancy rates, plus the criticism of self-eroticism as a form of individual satisfaction.

Besides economic improvement, Monteiro (p. 127) urges the intensification of dialogue between community-based organizations, and education and health institutions, to be placed within macro projects of structural change in resource-deprived settings like Vigário Geral. Such projects need to recognize that poor young people are caught in a contradiction between the strong appeal of the consumer industry and the weakening of the micro economic system in Brazil's shanty towns, which largely explains the flourishing of the illegal drug trade among poor urban populations. Social exclusion forces young people in poor conditions to seek protection in drug trafficking power, which is the closest agency to them.

*Selikow et al.'s study on the township of Alexandra, Johannesburg*

This work is similar to Monteiro's with regard to the exploration of young gendered relations. But it is more nuanced when it comes to the exploration of the types of masculinities and femininities that affect sexual and health behaviors. According to the

authors, masculinity in Alexandra is perceived along a continuum between a hegemonic macho type, *ingagara*, and a subordinate one, *isithipa* (sissy man or dumb). The *ingagara* type is associated with a playboy status, control over his numerous girls, as well as the possession of expensive material resources, primarily a car and clothing. Conversely, lacking these fundamental resources in the township, the *isithipa* seems to be an undesirable alternative. However, the authors demonstrate that the *ingagara* and *isithipa* conditions are more complex. Peter Alexander and Tina Uys (2002) discuss such complexity in three points.

First of all, *ingagaras* are reported as behaving differently according to the kind of partner. They distinguish between *regte* (Afrikaans for “the right one” or stable partner), and *cherries* (unsteady, occasional partners), the latter condition also being referred to as *makhwapheni* (from a Nguni term for deodorant, implying something to be hidden under the arm). The *ingagara* status requires investing considerable amount of material resources, time and attention to satisfy partners and the expectations derived from such playboy status. On the contrary, *isithipas* seem more educationally ambitious, they are not involved in crime and enjoy a more stable psychological condition, whilst *ingagaras* generally experience conflict between their playboy identity and the desire or expectation to become a good father and husband.

Alexander and Uys report a similar study which was conducted in Hlabisa, a rural settlement in North KwaZulu-Natal. According to the study, in Hlabisa women contrast *regte* to *ATM* or *Minister*. They seem to prefer older and more educated men as stable partners and taxi drivers or soldier, that is, more affluent men, for occasional relationships. The authors point out that although the implications of the distinction between stable and occasional relationships for safe sex are not clear, some conclusions can be drawn: several women in economically disadvantaged conditions declare not to insist on condom use when engaging in sexual intercourse with their *ATM/Minister*, since this would be regarded as a lack of trust (the constitutive element of a stable relationship) and so undermine the possibility to elevate themselves to the status of *regte*; in this respect, men declare to have protected sex with the *cherries* and not with the *regtes*. Thus, trust, associated with status, is a main social determinant of protected sex, not only among adolescents, but also among spouses.

The second aspect revealed by Selikow's research team concerns “transactional relationships”, associated with occasional sexual partners. When the results were published, the “*Three Cs*” (*clothes, cash, cellular*) were among the resources that women

expected from their occasional partners. However, it is worth noting that, generally, occasional partners are not considered prostitutes by playboys or society generally, but as “girlfriends”: a cherrie is a kind of lover and the relationship can last long and is not necessarily devoid of love, while a prostitute exchanges sexual services for money or other resources. Morrell et al. (2002: 12) point out that in this example women are not only represented as victims, but also as agencies having the capacity to decide what to do with their body. Indeed, the authors argue, that women generally view multi-boyfriends as a way to gain control over their lives, rather than being mere acts of desperation (although the two aspects may coincide).

The third aspect of Selikow's research on gender-class and HIV in South Africa's townships concerns globalization in association with formal economic assets and its repercussions on gender relations. The industrial-capitalist labor market has implied disastrous consequences for “male identity” such as insecurity, isolation and various types of vulnerability, and a relatively positive impact on women's lives (especially in rural and sub-urban contexts), reducing gender-based economic inequalities. For many South African young men, poverty means a difficulty to gather resources for *lobolo* (dowry) and marry. This sometimes encourages “*gift-based transactional sex*”. Contrary to *lobolo*, where material resources are allocated by the young man or his family to his fiancée's family, typically older members, gifts directly benefit young women. In this case class, gender, generational and cultural dimensions are strictly interlinked and somewhat shaped by capitalist economy. As for class, while financially gifted men can have numerous girlfriends or wives and provide them with precious gifts, poor men are unable to do so, but can sometimes invest more sustainably on their future through education. What is important here, as Alexander and Uys suggest, is the fact that in these dynamics class consciousness is constructed upon sexual production and not merely upon economic production. In the township, contexts of economic deprivation, multi-partnership and sexual activity are among the few sources of status and self-esteem, which, in the South African case of high HIV prevalence means increased chance to contract or transmit the infection.



## 5 Social-science knowledge production on HIV/AIDS in Brazil and South Africa

*At any given point in history, certain forms of knowledge privilege certain sectors of society. But then the state needs to regularly redistribute the advantage that these forms of knowledge have accumulated over time.*

Steve Fuller (2002: xviii)

This chapter tries to show that the analysis of the mechanisms of knowledge – what is produced, by whom, how it circulates, where the “epistemic boundaries” are - underpins the analysis of policy choices. Concretely, the chapter compares Brazil and South Africa with regard to social-science oriented to HIV/AIDS. It particularly considers use-inspired research, both in terms of production and impact on national policies in both countries. The period most considered stretches from the 1990s till the mid-2000s. The core argument is that the impact of social research on HIV/AIDS policy was stronger in Brazil. It is argued that this is largely due to major political will on the part of Brazil's government to support and use mainstream HIV/AIDS science, in this case, social science. Conversely, particularly in the period between the end of the 1990s and the early 2000s, the South African government made a much smaller effort to support HIV/AIDS conventional social-science, to say the least. Rather, embarking upon dissidence from the HIV/AIDS biomedical authorities, indifference and hostility to mainstream social-science knowledge prevailed. Consequently, while Brazil's government made social-science knowledge a constitutive element of its HIV/AIDS national program, HIV/AIDS social-science in South Africa found it difficult to travel beyond the academic world (and civil society, to some extent) and so make a difference in the national policy against the epidemic.

It is important to reiterate that most of the scientific works discussed here fall into the category of engaged scholarship in the sense of critical and use-inspired research. Here theoretical and methodological issues are often addressed in conjunction with research-action stemming from the intellectuals' commitment to anti-AIDS programs. We could talk about critical, public and cameral scholarship, following Boudon's and Burawoy's categories of sociologies, but I opt for the generic expression “engaged scholarship” because it comprises all the forms of committed scholarly works, namely critical analysis, use-inspired research, and research-action.

The discussion is divided into two parts. The first part (4.1) assesses research (and teaching) bodies which were established in Brazil and South Africa in response to HIV/AIDS, whilst the second part (4.2) analyzes actual scholarship regarding an array of HIV/AIDS-related issues like sexuality, risk perceptions, and state policies. The latter includes a brief discussion about meta-analysis in both countries. Meta-analysis is one central field in the debate about social-science oriented to HIV/AIDS. Moreover, I consider the discussion about meta-analysis important here because this is still an emerging field, and I hope to contribute to its construction.

## 5.1 Research bodies in Brazil and South Africa

### *Brazil's prompt scholarly response to HIV/AIDS*

A unique feature of Brazilian HIV/AIDS scholarship consists in its researchers' symbiotic relationship with state health institutions and civil society organizations. Brazil's government played a crucial role by establishing a number of HIV/AIDS research spaces in different cities and by including a specific area within the STIs/AIDS health department in 1992 (Pimenta et al. 2002: 50). Consequently, health academic and para-academic institutions emerged or were strengthened in order to achieve a high publication regime and advances in theoretical and methodological fields.

*Bem-Estar Familiar* (BEMFAM) – a national NGO devoted to social development through research-action on sexual and reproductive rights, and family planning – has carried out HIV/AIDS large-scale inquiries since the mid-1990s. Part of this particular scholarship explored masculinities and femininities of young groups in relation to sexual and reproductive health, as well as HIV/STI vulnerability (BEMFAM 1997a, 1997b, 1999a, 1999b). On the other hand, from the end of the 1990s, the *Centro Brasileiro de Análise e Planejamento* (CEBRAP) – an interdisciplinary institution, based in São Paulo, and devoted to public health, sexual and reproductive rights – conducted longitudinal studies that attempted to explore the factors and barriers to female condom use in six urban areas, namely São Vicente in São Paulo, Rio de Janeiro, Belo Horizonte in Minas Gerais, Santo Agostinho in Pernambuco, and Porto Alegre in Rio Grande do Sul (see Pimenta et al. 1999a). It was observed that the larger majority of women who took part in the sample (70-80%) was strongly in favor of female condoms, because of its potential to provide women with greater power and control over protected sex, since it is generally women

themselves who carry and manage this technological item (Peters et al. 2013). Despite the limited time and space spectrum that these studies analyzed, they provided insights that have constituted the grounds for justifying the increase in number of female condoms in the Brazilian public health system.

In the same period, existing research entities were strengthened and new academic health institutions were created in response to the challenges posed by the HIV/AIDS epidemic.<sup>40</sup> Renewed institutions include the *Fundação Carlos Chaga (FCC)* at the *Universidade de Campinas (INICAMP)* in São Paulo State and examples of new entities include the *Instituto de Medicina Social (IMS)*, a teaching and research institution at the *Universidade Estadual do Rio de Janeiro (UERJ)*; the *Associação Brasileira Interdisciplinar de AIDS (ABIA)*, an NGO based in Rio de Janeiro; and the *Núcleo de Estudos e Prevenção da AIDS (NEPAIDS)*, at the University of São Paulo. Now we shall concentrate on ABIA and NEPAIDS.

Initially led by sociologist Helbert de Souza (Betinho), who was HIV positive himself, ABIA was established as early as 1986 with the intent of further mobilizing politically organized groups, committed to sanitary reform, who sought to use HIV/AIDS as a battle horse: health professionals, gays, women, churches, and other entities linked to the struggle for democracy and social justice. ABIA has since then probably been the most active think-tank and HIV/AIDS knowledge producer, as well as the *trait-d'union* of all Brazilian (and international) AIDS organizations: public health departments, academic institutions of collective health, and LGBT movements (LGBT standing for Lesbians, Gays, Bisexuals, and Transvestites/Transexuals). ABIA has published numerous books and articles on a vast range of issues related to HIV/AIDS scenarios, policies and, studies, among others. Let us just mention that over the last decade ABIA has predominantly discussed HIV/AIDS social determinants and epidemiological profiles with a strong emphasis on (socially) sustainable development – advocated as the aim of public policy (i.e. Corrêa 2003). Nuanced debates in such scholarship address issues related to: poverty mitigation (i.e. Barber-Madden 2003; Rocha 2003; Brito 2003; Edmundo 2003), intellectual property on ARVs and the related industrial technological advances and access to AIDS treatment (i.e. Lotrowska 2003; Gontijo 2003), financing of anti-AIDS actions (i.e. De Mattos et. al. 2001; Grangeiro 2003; Vianna Júnior 2003),

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40 For further information on these institutions see <http://www.fcc.org.br/institucional/>; <http://www.ims.uerj.br/>; <http://abiadays.org.br/>; <http://www.ip.usp.br/portal/index.php?option=comcontent&view=article&id=3545:nepaids-apresentacao2&catid=422:nepaids&Itemid=298> (Accessed on 20.08.2014).

HIV/AIDS policy decentralization (i.e. Ferla et al. 2006), and sexuality as a key issue in the social development discourse (i.e. Corrêa et al. 2011).<sup>41</sup>

NEPAIDS was established in 1991 and has particularly focused on school-based HIV/AIDS education, especially with regard to research-action. NEPAIDS's recent works include a four-volume book-length publication entitled *Vulnerabilidade e Direitos Humanos* of 2012 and 2013, edited by psychologist Vera Paiva, NEPAIDS director, with other leading Brazilian and international scholars. This publication is a good example of both NEPAIDS and Brazil's committed scholarship oriented to HIV/AIDS: emphasis on human rights, theory and practice links, trans-disciplinarity, and multi-level analysis, among others.

The IMS, ABIA and NEPAIDS have historically articulated their studies and activism in concert with *FIOCRUZ*, the Brazilian leading institution in medical research and public health policy. This is one indicator of symbiosis between academics, politics and civil society in the field of HIV/AIDS in Brazil. Such relation has not always been harmonic, since AIDS is a field of conflict, reflecting different groups' interests and approaches. However, these actors have historically converged on the urgent necessity to turn the tide on the epidemic. In such a climate, social sciences found fertile terrain to forge usable knowledge for changing the course of HIV/AIDS, often in the name of academic social responsibility.

#### *South Africa's AIDS scholarship and the government's unsupportive stance*

The South African government's negligence and questioning of the authority of HIV/AIDS science until the mid-2000s implied rather cold and, at best, conflictual relations between academics and the state. By the mid-2000s realistic academic works on HIV/AIDS were not welcomed within the government's policies. This meant limited financial and political investment in HIV/AIDS social research. Consequently, articulations between academically-rooted AIDS institutions and the government, as well as large-scale inquiries, were late to emerge.

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<sup>41</sup> Other publications indirectly address macro development issues, including *Saúde, desenvolvimento e política: respostas frente a AIDS no Brasil*, edited by Richard Parker, Jane Galvão and Marcelo S. Bessa (1999), which explores the complexity of responses to the epidemic given by different actors over the previous fifteen years, including those by social-science and humanities; *A construção da solidariedade* (1994c), and *Na contramão da AIDS* (2000), both by Richard Parker; and *AIDS no Brasil: a agenda de construção de uma epidemia* by Jane Galvão (2000); *Ciência, poder, ação: as respostas à SIDA* (2002), by Cristina Bastos.

It was not until the late 1990s that significant academic AIDS institutions were established across the country, to ensure that Universities responded appropriately to the pandemic in a coordinated and collaborative way in the areas of HIV/AIDS management, teaching, research and social responsiveness.

In any case, these entities have since their foundation handled the epidemic vigorously. Moreover, the initially unfavorable political environment forced scholars to become critical towards the state and society at large. Let us refer to a few, some which will be further discussed later on in relation to their actions.

*Social Aspects of HIV/AIDS and Health (SAHA)* is a well established research unit within the *Human Sciences Social Research Council (HSRC)*. *SAHA's* prime mandate is to conduct and disseminate policy-relevant research to inform about HIV/AIDS prevention, treatment, care and impact mitigation.

*Health Economics and HIV/AIDS Research Division (HEARD)*, coordinated by economist Alan Whiteside until a few months ago, was established in 1998 at the University of KwaZulu-Natal in Durban and conducts applied research to support development HIV/AIDS interventions in South Africa, the Southern African Development Community (SADC) and Eastern Africa.

*Higher Education HIV/AIDS Programme (HEAIDS)*, established in 2000/2001, is the coordinating unit for university-based AIDS activities in partnership with the Department of Education, and the South African Universities Vice-Chancellors Association (SAUVCA), among others.

The University of Pretoria's *Centre for the Study of AIDS (CSA)*, established in 1999 and coordinated by sociologist Mary Crewe, is among the most active bodies in critical scholarship and engagement in civil society.

The Rhodes University *Centre for AIDS Development, Research and Evaluation (CADRE)*, started between the late 1990s and early 2000s, is particularly attentive to peer education programs.

The University of Cape Town's *HIV/AIDS Institutional Co-ordination Unity (HAICU)*, formed in 1994, and *AIDS and Society Research Unit (ASRU)*, which came into existence in 2001, conduct applied research and are particularly focused on stigma.

Finally, *Africa Centre for HIV/AIDS Management at Stellenbosch University*, created in 2003, is particularly devoted to peer educators training educators who in turn principally

work at university campuses. Similar noteworthy institutions are found at the universities of Western Cape, Witwatersrand, and Johannesburg.

These institutions have been among the key research drivers of HIV/AIDS scholarship. HEAIDS, HEARD and CADRE have become university leaders in the support of the government's HIV/AIDS policies, since these started improving in 2004, while other institutions like the Pretoria's *Center for the Study of HIV/AIDS* have maintained a more critical and analytical stance, while engaging with civil society. (We could talk about a division of labor – sometimes antagonistic – between cameral and critical-public scholarship).<sup>42</sup>

The research outputs of all these institutions are extensively published in an infinite number of Open Access Journals, as well as books in South Africa and internationally. National and, to some extent, continental publishing arenas include *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, the *South African Review of Sociology (SARS)*, and *Agenda*, the latter being a women media platform comprising academics and activists.

As noted above, compared to Brazil, direct and consistent inclusion of HEIs in the HIV/AIDS policies in South Africa is far more recent. Improvement in this sense is largely a result of the appropriate new attitude towards the epidemic within the National Integrated Plan (NIP) framework that has been in place in the post-Mbeki era (2009 onwards). Importantly, the NIP comprises various entities and a major role is played by the Departments of Health, Education, and Development and Welfare (Campbell & Foulis 2002). In the education system in general, there is increasing concern caused by the impact of the epidemic on education quality, which is due to the AIDS-related mortality of students and teachers, as well as financial cutbacks.

According to Mary Crewe (2002), the historical starting point in the HEIs engagement on HIV/AIDS is a 1999 report on the national epidemic, containing indications for future actions, which was elaborated by the Association of Commonwealth Universities (ACU) and supported by SAUVCA. Later, according to Crewe, the inclusion of the British Department for International Development in the project enabled placing AIDS within

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<sup>42</sup> The CSA has been critically reflecting on a number of AIDS-related issues since 2000: among others, stigma (i.e. Eba 2007); the social terrain and impacts of South Africa's controversial policies, here referred to as a scandalous lack of political will to tackle the epidemic through a rights-based approach on the part of the South African government, African nations and the international community (i.e. Jones 2001; Kisoon et al. 2002; Marais 2000; Rickard 2008: 37-56); the devastating impact on gender, generational relations, and family (i.e. Barolsky 2003; Kometsi 2004); and Higher Education's response to the epidemic through intellectual debate and activity, the latter being usually conducted in the form of peer education programs (i.e. Volks 2012).

the development discourse. Among other aspects, this facilitated the establishment of individual coordinators in order to attribute clear responsibilities. Role coordinators are particularly vital to channeling and systematizing the contribution of different actors involved in the project. This is the case of administrations, health institutions, NGOs and social scientists. HEAIDS is the major institution encharged of coordinating AIDS initiatives at HEIs.

Alongside the differences described above – timing of specialized academic bodies foundation, large scale studies, and links with the government – Brazil and South Africa are similar with regard to the leading states/provinces in social-science knowledge production regarding HIV/AIDS and health in general: most studies are conducted in the São Paulo and Rio de Janeiro states, in the case of Brazil, and in Gauteng, Western Cape and KwaZulu-Natal, in the case of South Africa.

## **5.2 Scholarship**

One implication of the nature of state-academics relationships described above concerns the fact that government-backed use-inspired research arose earlier in Brazil than in South Africa. It was in a collaborative atmosphere that studies on sensitive issues – sex, primarily – in Brazil emerged and ultimately informed HIV/AIDS policy. These studies first sought to explore prevention factors like attitudes towards condom use in specific groups – MSM, working class, truck drivers, IDUs, sex workers, the army, and university students – and later, more complex issues like ART adherence and the impact of interventions. Researchers' contact with international epistemic communities also played a great role in the development of those institutions and studies because they allowed the exchange for insights and expertise, primarily. This is the case of relationships with CAPS/University of California, promoted by Brazil's AIDS Prevention and Control Project (AIDSCAP). In South Africa, similar efforts only became prominent and, above all, valued by the state when the political view on how to counter HIV/AIDS epidemic began to incorporate appropriate HIV/AIDS science. As for publications, in Brazil and South Africa the decade of 1980s was mostly characterized by production of articles in different social sciences (and humanities). It was in the early 1990s that pioneering books were extensively published by specialists, nationally and internationally, taking stock of the research and interventions existing until then, thus laying the basis for broader analysis.

### 5.2.1 Brazil

In 1993, when Brazil started benefiting from a series of World Bank loans, about half of HIV cases in Brazil were found in MSM, but epidemiological data already showed the increasing feminization of the pandemic. To grasp these dynamics, longitudinal and methodologically mixed studies were conducted in the period between 1989 and 1995 in São Paulo, Rio de Janeiro, Fortaleza and Porto Alegre. The outcomes were reported in two volumes, corresponding to the first and second phases of the research: *A AIDS no Brasil*, by Richard Parker (1994a) and *Entre homens: homsexualidade e AIDS no Brasil*, edited by Richard Parker and Veriano Terto Jr. (1998). We shall concentrate on the second volume. It builds upon the first one and shows changes in sexual self-understanding, knowledge, attitudes, and practices. As for sexual identities, it was reported that the group that self-identified as gay increased considerably, while the bisexual group decreased. Besides basic information about HIV transmission, the percentage of those declaring that they would never engage in unprotected penetrative sex increased significantly (from 62% to 80%). More importantly, the proportion of those who had used condoms in penetrative sex in the last month increased from 35% in 1990 to 69% in 1995. This improvement is attributable to education campaigns in which the academic world played a significant role in helping the government and civil society to implement scientifically informed prevention activities.

Sexual identities, meaning self-understanding were increasingly problematized, pointing out that the connections between sexual self-identification and sexual practices in Brazil were not clear-cut. It was underlined that self-definitions do not always correspond to sexual behaviors: there are those who self-identify as bisexuals, despite having sex with men only; and, vice-versa, at least in that period, many respondents who self-identified as gays declared to have sex with both men and women. In this scenario, bisexuality becomes more complex. Sometimes bisexuality represents neither a “sharply defined identity”, nor a mere refusal of self-definition as a homosexual. Rather, it often represents a temporary status whose sentiments and experiences escape from hegemonic sexual categories (heterosexual, homosexual, bisexual). In connection to the bisexual status complexity is the fact that, as Regina F. Lago (1999) posits, contrary to the idea diffused by the media according to which bisexual people were the chief vectors of HIV from men to women, bisexuals do not seem to be more prone than heterosexuals or

homosexuals to neglect prevention methods; neither does a bisexual individual correspond to the male profile that is generally thought of as maintaining stable relationships with women and occasional ones with men. These debates were revealed as crucial in that historical period in Brazil, when HIV/AIDS policies primarily targeted “risk groups” because they helped to conceive the epidemic as a threat to the entire population. Research works on Brazilians' perception of HIV/AIDS risk has been relentless since the 1990s in Brazil (i.e. Ferreira 2008).

Drawing on those considerations, research conducted in AIDS NGOs such as PELA VIDA (based in Rio de Janeiro) sought to explore the processes of sexual identity formation in relation to HIV susceptibility, in order to address the challenges posed by such link to epidemiology, prevention and care programs. Most of these and successive works are based on a mixed methodology comprising bibliographic documentation, ethnographic inquiry, and interviews (i.e. Valle 2002; Terto Jr 2002). Focus on youth and school settings also increased in that period. For example, Vera Paiva (1992) conducted psychosociologically-oriented applied research on youth's sexual attitudes, condom use and HIV, which would become a model for school-based HIV/AIDS education programs in Brazil and Latin America.

The mid-1990s period also witnessed the increase of co-edited and co-published books in Brazil. One exemplary publication in this sense is *A AIDS no Brasil: 1982-1992*, edited by Richard Parker, Cristina Bastos, Jane Galvão, and José Stalin Pedrosa (1994), and co-published by ABIA and IMS/UERJ. This book summarizes the main issues that had framed the debate on HIV/AIDS dynamics since the early 1990s and sheds light on the categories related to sexuality and prevention of venereal infections. The development of this discussion would appear in three publications that set the basis for nuanced large-scale inquiries: *AIDS no Brasil: an agenda de construção de uma epidemia*, by Jane Galvão (2000); *Quebrando o silêncio: mulheres e AIDS no Brasil*, by Richard Parker and Jane Galvão (1996); and *Sexualidades brasileiras*, by Richard Parker and Regina M. Barbosa (1996). *Quebrando o silêncio: mulheres e AIDS no Brasil* is particularly important because of its focus on structural factors of HIV feminization (including poverty and decreased power in sexual relations with men), sexual social representations of female sexuality and, the necessity for prevention agendas to pay particular attention to the case of women. Of a different kind is *Ciência, poder, ação: as respostas à SIDA*, of 2002, in which Cristiana Bastos and her colleagues explored the correlation between the role of science, politics and civil society activism in anti-AIDS activities across the country. In the

same line, works reflecting on the role of science include the 17th volume of the thematic journal *Horizontes Antropológicos*, edited by Daniela R. Knauth and Ceres G. V'ictora (2002), and *AIDS e sexualidade: o ponto de vista das ciências humanas*, by Maria Andrea Loyola (1994). In these works, Brazilian scholars demonstrated their awareness of the potentiality and duty that social-science knowledge had in handling HIV/AIDS and thus contributing to a better future. As a result of this, scholars conceived the epidemic as an opportunity for the renewal of social sciences, theoretically and methodologically. Inter-sectorial and cross-disciplinary approaches were increasingly perceived as an inevitable path.

It is important to stress that these debates were largely based on vigorous research projects which emerged in public health and social medicine university institutions across the country. One crucial example is the project called *Os impactos sociais da AIDS no Brasil*, carried out by the IMS/UERJ in the period 1989-1992. This project sought to explore the incidence and purpose of masculine condom use in the large cohort of the sexually active population aged 17-50 in the state of Rio de Janeiro. The sample included over 160 people (at least 90 being women) from three professional groups, namely, metallurgical, banking, and university sectors – the majority of whom self-identified as heterosexual. It became clear to researchers that, as for prevention methods, the population was knowledgeable about male condoms and the vast majority had used them a few times, thanks predominantly to the role of mass media in disseminating knowledge about HIV, moral discourses that caused panic and insecurity. Nevertheless, condoms were used prevalently as a contraceptive method and less consistently for the prevention of HIV/STIs. A similar scenario was highlighted by studies conducted in 1990 in Campinas by Berquó and Souza (1991, 1994) on young men aged 18-30 in university student, banking, and working class groups.

*AIDS e sexualidade: o ponto de vista das ciências humanas*, by Maria Andrea Loyola, mentioned above, deserves special attention due to the methodological innovation that it represented and the substantial insights that it provided to the panorama of HIV/AIDS research. Methodologically, since it combined quantitative and qualitative approaches, this investigation revealed that surveys on fertility and contraception tended to sub-estimate pro-condom use attitudes, since the related samples typically consider women in their reproductive age in stable relationships (i.e. Guimarães 1996a, 1996b). This, combined with other factors, excluded most women from anti-HIV campaigns. The scenario was corroborated by ethnographic works conducted on low-income demographic segments in

Porto Alegre (i.e. Knauth 1995, 1997) and in Rio de Janeiro shanty towns (i.e. Heilborn & Gouveia 1999). Trust was identified as one important element for condom disuse in stable relationships. For women, especially, insisting on condom use would imply not only a lack of trust, but also a conjugal crisis, and thus abandonment and loss of other social ties. In this sense, the perception of social risk exacerbates passive and victimizing attitudes. This suggests that maintaining affective ties is the most important aspect in the social risk hierarchy. There are strong correlations between reproductive attitudes, perception of health, and family relations. Knauth found out that among low-income populations in Porto Alegre HIV, positive women tended not to blame their partners from whom they contracted the virus, asserting that “the contagion had occurred in a normal relationship and not deliberately”. Silence or even “legitimacy” of the contagion often prevailed. Furthermore, the author argues that even when women knew that their partner had been infected in extra-affair intercourse, they viewed men’s occasional sexual multi-partnership as part of male nature. Apart from macho men cultures, this was somehow a strategy that women used to maintain their status of wife and mother. Hence, women in this situation did not self-identify as part of a “risk group”. This was one factor contributing to the feminization and pauperization of HIV in the 1990s. The authors conclude that in resource-constrained settings HIV/STIs prevention and health promotion generally are extremely difficult, largely because material and symbolic poverty, as well as the presence of other deadly diseases, led people to minimize the AIDS threat, since AIDS related mortality is just one among many others. Simone Monteiro (1999a, 2002) and Regina Barbosa (1999) compellingly suggest that this is especially true in Brazil's shanty towns, which are affected by the narcotrafficking armed conflict between the police and drug dealers, which represents the prime major risk for young people, especially men. In general terms, armed conflict in shanty towns contributes to low life expectancy, which undermines individual agency and social capital.

The biggest publication in Brazil's late 1990s is undoubtedly *Comportamento sexual da população brasileira: percepções sobre o HIV/AIDS* (1999), whose research was conducted by CEBRAP and backed by the ministry of health. Coordinated by Elza Berqué, this inquiry interviewed a large sample of urban people aged 16-65 from about 170 micro-regions, including the capital cities of 25 states. Besides sociodemographic data, this inquiry utilized a rich set of independent variables, including age at first sex, use of psychoactive drugs, sexual orientation, and HIV/AIDS knowledge. The outcome is a comprehensive picture of Brazilians’ sexual behaviors in relation to the epidemic. More importantly,

researchers constructed a new index of knowledge on exposition to HIV infection (0-9). As for the perception of the forms of HIV transmission and risky behaviors, overall, half the population was sufficiently informed and declared having to use a condom in their first intercourse (Pimenta et al: 53; Citeli 2003: 63-82). However, a significant proportion (over 40%) was ill-informed about the risk of needle and syringe sharing – this incidence certainly decreases in the IDUs group. Comparing data diachronically, the inquiry showed that, despite HIV presence and related knowledge, adolescents' sexual debut was increasingly early, at about 15 years of age. The report also confirmed previous works results which pointed out that a large majority of population (76%) did not use condoms (male or female) in stable relations. This research laid the basis for the analysis of a number of issues, including the limits of the medicalization of health, and culpabilization and discrimination of certain groups. It also fueled gay groups with more complex notions of solidarity with PLWHA. In this sense, AIDS might have contributed to overthrowing the hegemonic role of medical discourse in the “normalization of sexual behaviors”, bringing into the broader public debate issues related to individual sexual behaviors (with whom, how, how often, and for what purpose one engages in a sexual relation). The contribution of social scientists operating in federal state institutions like CEBRAP was crucial for this achievement of progress.

In order to understand social intervention historically, Sérgio Carrara (1994a, 1994b) compared anti-AIDS actors' programs with those carried out in the early 1900s on old venereal infections like syphilis by medical doctors, lawyers, legislators, and conservative religious entities. Carrara argues that on the one hand there is continuity between the past and the early years of HIV, in the sense that in the same way as syphilis was relegated to prostitutes, HIV was relegated to male homosexuals in a stereotyped manner. However, on the other hand, whilst in the case of syphilis the focus was placed on the rights of healthy people and patients were blamed, in AIDS times newly emerged pressure groups brought legal claims of patient's rights into the institutional arena. Carrara sees this novelty as a new conception of health and disease, namely the notion of collective threat.

A set of texts were published in the early 2000s, and addressed an array of research subjects, including clinical, epidemiological, economic, and political aspects (i.e. Bastos 2002; Bastos & Malta 2002, and Raxach et al. 1998). Throughout the 1980s and in the early 1990s various Brazilian academic bodies were financially supported chiefly by international agencies like UNAIDS and the Ford Foundation (Pimenta et al. 2002: 48).

### *Interim concluding remarks*

Generally speaking, comparative works, both diachronic and synchronic, have been prominent in Brazil. However, according to Maria Teresa Citeli (2003: 82), until 2002, HIV/AIDS scholarship in Brazil lacked ethnographic works on “the symbolic practices and constellations of Brazilian middle and high-class women and men”.

As for cohorts, a comparison between adolescent and over 50 years old populations regarding sexuality and representations of HIV is necessary today. Recent studies point out that although awareness of HIV/STIs is far higher today than two decades ago, safe sex in Brazil still has to reach the expected level. Besides poverty – despite its reduction in recent years, AIDS banalization counts for the persistence of unprotected sex. AIDS banalization is somehow associated with the availability and efficacy of ART, which contributes to people taking a stance that sounds like “I could afford free treatment and stay healthy” (Maria Helena C. Couto, interview 15 Dec 2012). Unprotected sex seems to be predominant in adolescents and over 60 years old cohorts. The sexual activism of these cohorts' seems to have increased over the last decades in Brazil. In the case of old people, the increase of life expectancy and quality, including outdoors socialization forms, also contributes to their more active sexual life when compared to three decades back. At the same time, adolescents belong to the generations which have not strongly experienced the heyday of the HIV/AIDS alarm. Researchers-activists argue that the language that they themselves have hitherto used in order to promote ART procurement and combat stigma - “living with HIV is possible” - has contributed to the banalization of AIDS. Thus, their self-criticism points to the development of a new approach whose motto should be “living with HIV is possible, but not good”. This suggests a greater focus on ART side effects – physical, psychological, social – besides AIDS related stigma and discrimination. Taking into account the complexity of sexuality in Brazil, Richard Parker (1994a, 1994b) uses his own previous ethnographic works to call attention on the necessity for developing more sophisticated educational technologies of information in prevention campaigns, ones that are able to capture and explicitly address sex nuances and cultural specificities. In his view, these communicative strategies should include messages encouraging non-penetrative sex such like masturbation, oral erotism, for their potentiality to reduce HIV/STI risks.

## 5.2.2 South Africa

After a phase of relative hibernation, social science oriented to HIV/AIDS has been vibrant in South Africa since the late 1990s. Critique, as well as a commitment to non-academic actors, are among the main features of this scholarship, largely due to the high prevalence of the pandemic and the failure of the state to act promptly and effectively against it. The 2000 HIV/AIDS World Conference in Durban also played a role in encouraging this engaged approach. It was indeed on that occasion that the South African government strengthened its support for dissident science on HIV/AIDS, which triggered impressive knowledge production. The subjects of the debates are generally categorized within demography and mortality; prevention and treatment; public policies and civil society activities; social, economic, and juridical aspects; the media; and migration labor and mines. Many specific subjects in this regard were discussed in the early 2000s in several journals: i.e. *Agenda* 44 (2000), *Agenda* 53 (2002), *Social Dynamics* 28(1) (2002), *African Studies* 61(1) (2002), *Human Sciences Research Council (HSRC)* (2002), *Society in Transition* 32(1) (2001), and *Society in Transition* 33(3) (2002). Among the most studied issues from the late 1990s onwards, I here particularly consider general works, prevention studies, and public policy studies.

Pioneering and prominent general works include publications by Mary Crewe, which can be defined as critical-public sociology. They broadly address the failures of politics, the university system and society at large to tackle the epidemic: i.e. *AIDS in South Africa: The myth and the reality* (1992); *South Africa: touched by the vengeance of AIDS: responses to the South African epidemic* (2000); *HIV/AIDS in South Africa: a crisis both of will and of leadership* (2000); *Commentary: reflections on the South Africa HIV/AIDS epidemic* (2002).

### *Prevention studies*

Most prevention studies focus on sexuality and the related construction of health protection, with particular reference to the socio-cultural, economic and political factors underpinning such relation. Some works in this area include *Traditional healers and AIDS prevention*, by Abdool-Karim S.S. (1993); *Letting them die: Why HIV prevention programs fail*, by Catherine Campbell (2003); *Institutionalizing the Response to HIV/AIDS in the South African University Sector: A SAUVCA Analysis*, by Piyushi Kotecha (2000); and *The jagged tear:*

*Human capital, education and AIDS in South Africa, 2002-2010*, by Charles Simkins (2002). Let us briefly consider Abdool-Karim's and Campbell's books.

Abdool-Karim's book addresses the role of traditional healers in hindering HIV/AIDS prevention. By discussing the ways in which traditional healers infuse or reinforce the representation of the disease as being a “sent” illness that they claim to cure, in this work Abdool-Karim provides insights into the cosmological world of common people in relation to the AIDS crisis, which would later gain greater space in South Africa's AIDS literature (i.e. McNeill & Niehaus 2009; Wreford, 2008). It concerns a discussion about magical visions, specifically witchcraft discourses, a phenomenon that makes South Africa rather different from Brazil. Let's examine a few points. In South Africa there are currently two major paradigms of health dispensation, namely biomedicine and the spirit-inspired tradition of healers (*izangoma*: diviners who combine spiritual power with herboristic techniques). This is mostly the case where there is a lack or deficiency of modern health services and appropriate information about ART, and an openness towards discussions about sex and sexuality. Indeed, in most of Africa, as well as with the westerner, witchcraft-sorcery constitutes a target for the scapegoating mechanism related to HIV, in the precise sense of people's externalizing responsibility for their sickness. Efforts have been made to explore the interface between the two blaming systems in African cultural and political panoramas, especially in relation to the catastrophic growth of the pandemic in the continent (i.e. Rödlach 2011). Due to its severe epidemic and marked history of controversies over the epidemic these studies have been prominent in South Africa. As for holistic approaches to HIV/AIDS interventions, Catherine Campbell's works deserve special attention because they represent a good example of the epistemological drift from behavioral, individual, top-down or localized perspectives to one that stresses psycho-social and community-level determinants of sexuality and HIV, as well as collective action and multi-level interventions. In other terms, Campbell's works break with the traditional dominance of medical psychology in HIV/AIDS studies, which was often characterized by behaviorist, and cognitivist reductionism. Campbell draws on her own empirical research to reflect on the micro-macro link and the meso-level of analysis (communities) in relation to HIV-risk and the likelihood of intervention success. This angle enlightens the interface between the economic and symbolic factors involved in the social construction of sexuality and HIV vulnerability at various levels: i.e. poverty, gender and generation. This implies a shift of attention from a prevention approach that focuses on individual properties like knowledge on HIV awareness, and rational behavior,

to one that emphasizes the urgent need for the improvement of economic and social circumstances of individuals and communities, under the assumption that the improvement of communities' circumstances provides individuals with stronger healthy behavioral skills. In this sense, Campbell's works constitute an excellent example of third generation approaches to the HIV/AIDS scholarship that we have discussed above. In her book *Letting them die: why HIV/AIDS prevention programs fail*, Campbell examines the ineffectiveness of the Summertown Project, alluded to earlier, a South African grassroots AIDS intervention initiative that was carried out in the mid-1990s in the 200,000 inhabitant (sub)urban area of Summertown, Johannesburg. She considered a range of micro and macro factors that generally promote or hinder HIV/AIDS prevention. As for the economic sphere, the major remunerated activity in Summertown was working in the mining industry, which is why a notable proportion of the population was composed of young males with no partner or family who came along from South African rural areas and foreign African countries. The unemployment rate was high and female prostitution was a main source of income for young women. At the same time, problems related to the dangerous conditions of mining work, male loneliness and poverty, militated in favor of young men heavily relying on sex and sexuality for psychological relief, emotional support and to gain manhood-related self-esteem. These were among the chief drivers of HIV in Summertown. In the mid-1990s in Summertown, HIV/AIDS was likely to kill one in two young people (six out of ten young women and four out of ten young men). HIV information was available, but community members had no ownership of it, partly because it came from far away (Johannesburg city), rather than being constructed within and by the community itself, ideally through binding and bridging social capital. To contain the problem, the project sought to mobilize local miners, sex workers, school learners and youth in general for HIV-prevention programs. Building on the already widely available information about HIV-risks, the Summertown Project sought first and foremost to build health-enhancing and supportive contexts through community-led peer education programs, development of critical consciousness, and multi-stakeholder partnerships. It is worth reiterating that this involves the construction of social capital, whereby autonomy and capacities of negotiation do become key properties of individuals, inasmuch as they result from collective understanding. Strategic elements of peer education include the valuing of counter-normative sexual behaviors and gender relations for the construction of health-enabling and supportive contexts. In particular, international literature considers young people who

cling on to these counter-normative behaviors as being the major agents of peer education programs.

Campbell examines the Summertown Project longitudinally through surveys, in-depth interviews and focus groups in order to find out the factors that create conditions for the likelihood of success of HIV/AIDS programs. She points out that the Summertown Project was well-intentioned, well-financed, richly equipped, built from the bottom-up, and run by exceptionally dedicated staff. The staff comprised administrative figures, local civil society organizations, and well-trained South African researchers. Therefore, the initiative was expected to be highly successful in terms of changing the contexts of the social construction of sexuality and health protection where the HIV epidemic flourishes. However, various obstacles and challenges undermined the success of the program and, in its initial five years, rather than a decrease, there was an increase in HIV/STIs in the community. To highlight such barriers and constraints, the author asks a set of fundamental questions that can be summarized in two: first, why do people knowingly risk a slow and painful premature death by clinging on to attitudes and norms that lead them to high levels of HIV risk?; second, consequent to the former, why do even well-intentioned and equipped HIV programs fail to build health-enhancing contexts? Campbell (2003: 165-196) finds explanations for the Summertown Project's failure by interlinking the stories of the four groups of people involved in the initiative: miners, sex workers, young people and partners. First of all, the coordination between the aforementioned groups, the local administration, and the national government was weak, which was in a way linked with a gap between the rhetoric of the program and reality. One implication of such a scenario was the over-emphasis on the quantity of activities to the detriment of quality. A second set of flaws has to do with the unequal distribution of resources – economic capital, symbolic capital, cultural capital and social capital – between powerful Johannesburg-based entities (researchers, NGOs, administrators) and powerless local groups (sex workers, miners), plus conservative teachers' leadership in school-based peer education programs. A third problem relates to a lack of political will at national government and local levels (lack of: commitment, trust and capability building, conceptualization, infrastructure and accountability).

These problems greatly contributed to a situation characterized by the lack of a sense of common fate and ownership of the project on the part of local groups and individuals, a problem which was also exacerbated by denial and the taboo nature of HIV/AIDS. But

the most visible hindering factor was poverty, which, among other aspects, led landladies who strongly depended on prostitution economy to encourage sex workers to drink heavily to create a convivial atmosphere that attracted clients, undermining the use of condoms. In a climate of this kind climate, attempts to implement peer education strategies are bound to fail. Social capital, critical consciousness and successful forms of collective action in the Summertown community could not arise.

### *Government policy studies*

The debates about HIV/AIDS public policy in South Africa have primarily focused on the government's HIV/AIDS denialism in the post-apartheid period and the consequent controversial measures, like refusing to roll out public ART. Scholars have made efforts to understand the complex spectrum of factors that explain denialism, including colonial and apartheid history and the associated uneasy racial relations. Between 2002 and 2012, economist Nicoli Nattrass published extensively on these issue from a very critical standpoint, addressing the social and symbolic aspects of denialism, such as conspiracy theories and the scientific governance of biomedicine. Her major early work is *The moral economy of AIDS in South Africa* (2004), whose discussion she would extend in later works. This and similar publications would contribute to the current debate on South Africa's HIV/AIDS policy, domestically and internationally. This is evident in works that, among other aspects, concentrate on the history of medicine and the public health system in South Africa, as well as traditional cultures. This is the case of *The political management of HIV and AIDS in South Africa: one burden too many?*, by Pieter Fourie (2006), and *HIV/AIDS in South Africa*, by S. S. Abdool-Karim and Q. Abdool-Karim (2005).

Literature on denialism is extensive and multi-disciplinary. Besides, and in association with, South Africa's severe epidemic, denialism is the issue that has most kept researchers busy. In the period of denialism, some scholars like Hein Marais (2000) and Zia Jeffrey (2003) implicitly or explicitly referred to the HIV/AIDS epidemic as being a new form of apartheid, in the sense that the government considered AIDS-affected people as not worthy of political attention. Other scholars called attention on the specificities of the South African (and African) AIDS epidemic, emphasizing the need for alleviating poverty and improving human development: LS Togni (1997), Lor Bollinger and John Stover (1999), Alan Whiteside (2000).

The enormous amount of literature on HIV/AIDS in South Africa seems to make it difficult to publish comprehensive bibliographic works. In any case, Peter Limb's select bibliography of 2002 is noteworthy, especially because it came out in a watershed period, that is, when denialism started to wane and social-science knowledge began to gain space in HIV/AIDS policy.

### **5.2.3 Meta-analysis, with focus on South Africa**

As referred to earlier, meta-analysis in the field of HIV/AIDS social-science is in its infancy in Brazil and South Africa (and globally). However, there is some material in the two countries on which scholars are trying to build upon. In Brazil, ABRASCO devoted its latest annual congress, held in November 2013, to “social sciences and humanities in Health”, and one large session was devoted to HIV/AIDS scholarship.<sup>43</sup> The congress was preceded by smaller and more localized events addressing more specific issues, all pointing to the construction of meta-analysis as a research field. In South Africa, the Centre for Research in HIV & AIDS at Western Cape University has been holding interdisciplinary conferences on HIV/AIDS studies since the early 2000s.<sup>44</sup>

One rare and central meta-analytical work is the article by Peter Alexander and Tina Uys entitled *AIDS and sociology: current South African research*, from 2002. In this article, Alexander and Uys reflected upon HIV/AIDS sociological research, raising fundamental theoretical and methodological issues about the state of the social-science of HIV/AIDS. It is worth reporting some of them, although many of the knowledge gaps that Alexander and Uys found have by now been filled.

Firstly, the authors pointed out that there was a scarcity of broad sociological knowledge about the national situation of HIV/AIDS, including the correlation between sexual practices and HIV. The authors argued that this problem was partly associated with the dearth of large-scale quantitative studies. In turn, I suggest, that at some extent this was linked to low coverage of epidemiological registration of HIV/AIDS cases in the health

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43 See <http://www.cienciassociaisesaude2013.com.br/> for further information (accessed on 16 August 2014).

44 See <http://www.hivaids-uwu.org.za/index.php/hiv-aids-symposia1>, for example (accessed on 16 August 2014).

system during the period of the government's inaction and denialism. This critique is grounded in the observation according to which HIV/AIDS social inquiries were historically based on small-scale ethnographies, which made it difficult to generalize research outputs and inform macro interventions. A corollary of this discussion is that little effort was made to carry out the micro-macro connection until the early 2000s. On the one hand, micro-level studies attempted to explain sexual behaviors and predict related change in terms of individual properties, such as knowledge and attitudes. Conversely, at macro-level the existing investigations sought to explain the high prevalence of the infection, especially in youth, in terms of global social environments like socio-sanitary conditions. But scarce attention was paid to how micro factors translate into a macro phenomenon at a national level. This means that the meso-level of communities was not seen as important.<sup>45</sup> As for quantitative approaches, the authors seem to advocate that, as John Goldthorpe (2000) points out, historically and contextually informed quantitative inquiries enable more effective comparisons and, discernment on major tendencies, and offer tools for hypothesis testing, which can in any case derive from qualitative perspectives.

A second observation refers to the fact that most HIV/AIDS investigations focused on young-black-poor people. Consequently, scarce attention was devoted to other important variables as religiosity, age (excessive focus on youth), ethnicity, geotype (urban formal, urban informal, rural formal, rural informal or tribal), among others. In that context of high AIDS-related mortality and, above all, an accelerated trend of new infections, this shift of attention encouraged important methodological reflections. According to Alexander and Uys, the classic research and intervention approaches focused on the most vulnerable groups (young-black-poor), who are asked the question “what renders people vulnerable to HIV?”, which led to unsuccessful interventions because they are based on notions of causality – which do not adequately address the most important drivers of the epidemic like poverty, gender inequalities and peer norms. Therefore, according to the authors, the question must be posed in the opposite way, that is, “who is not vulnerable to HIV?”, in order to find out, for instance what led to increased condom use across time, and why some men do not use coercion in their sexual relations with women in contexts

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45 Here communities are defined as groups of people who live or work in the same geographical place. These are places which for pragmatic reason are typically targeted by health development programs. From a theoretical standpoint, communities are of primary importance for public health debates because they are the entities that both shape individual behaviors and enhance or restrain the possibilities of success of prevention initiatives.

in which coercion generally represents a prevalent strategy. This implies taking into account the positive experiences of minorities, like the ones that Robert E. Park would put into the “rebel” category, *in relation to* hegemonic cultures that incentive conformism. These reflections are associated with the increasing popularity of social vulnerability and structural factors of HIV/AIDS – the core of third generation approaches to HIV/AIDS studies and intervention.

A third observation that Alexander and Uys made about HIV/AIDS research carried out until the early 2000s, tries to respond the question “how far does research cover the phases of the epidemic?”. To do so, they retrieve a conceptualization of the HIV/AIDS life circle with four overlapped stages (proposed by Charles Crothers): pre-condition, infection, dependence, and consequences. The pre-condition stage refers to factors and levels of vulnerability; the infection phase concerns the current and latent situation of HIV contagion, in which the individuals and their associates are not knowledgeable about their seropositive status; in the dependence phase the individual is seriously ill and has to be looked after by others; finally, the consequences regard all the social, psychological and economic burdens that the patient's inability or death imply for their family and the community. Alexander and Uys suggested that much of HIV/AIDS research limited itself to the first and second stages, which means that the various insights that could have been gained from the exploration of the third and fourth stages, were left out, so to speak.

Now, it is worth noting that the scarcity of HIV/AIDS quantitative inquiries other than epidemiological by the early 2000s in South Africa was correlated with at least two aspects. The first aspect is associated with the dominant epistemological paradigm at a global level, namely KAB/ABC, the theoretical framework that shaped the HIV/AIDS scholarly and intervention approaches in the initial years of the epidemic. The second aspect concerns the unfavorable political context, discussed above. Let us concentrate on the latter. Mary Crewe (2002: 450) observed that, analogous to politicians, academics in South Africa were late to critically analyze HIV/AIDS, in the sense that, until recently, the discussion around the epidemic lacked the intellectual rigor that had characterized academic anti-apartheid scholarship. Adopting simplistic categories like apartheid legacy and poverty as the explanation and justification – in the same manner as politics – social scientists made little effort to understand how individuals and groups interpret power relations and HIV/AIDS education in order to change the course of the epidemic. At macro level, it is suggested, intellectuals largely failed to place the discussion on the

epidemic within a conceptual framework of socio-economic development, rights and Renaissance discourse that could truly challenge the one proposed by President Mbeki. It seems that in post-apartheid South Africa intellectuals in general have regressed from drivers of change, which they emphasized in the apartheid era, and appear to fear critical engagement, almost paralyzed by fear of angering the political establishment. This is the idea expressed in the book *The poverty of ideas: South African democracy and the retreat of the intellectuals* from 2009, edited by Leslie Dikeni and William Gumede. Together with the discussions that followed Michael Burawoy's appeal for more public scholarship, this book has contributed to revitalizing the debate about the intellectuals' engagement on social problems. In this line we find scholars who militate in the *AIDS Review*, the critical HIV/AIDS annual journal discussed above. In the 2012 issue, Cal Volks discusses the academics' failure to stem the HIV/AIDS epidemic and provides some indicators of such failure:

HIV and AIDS are in many ways a reflection of our society: a reflection not just of sexual patterns of behaviour but a reflection of our failure, intellectually, to understand the societies in which we live because we tend to cling to and defend what we know. We fear the challenge of opening debates on race, gender, class and culture. We acquiesce in the face of authority. We defend lies and corruption. We refuse to confront difficult issues. We blame others and we are cautious about stepping 'outside' and being the voices that challenge the status quo, orthodoxy and state policy (p. 9-10).

More incisively (p. 9):

We have oversimplified very complex issues and formulated responses that are too simple for the complexity of the problem. We have often been caught up in an uncritical populism – in attempts to serve 'the people' we have failed because we have not applied academic rigour and knowledge to the problems and so we have often failed in our role as thinkers, social commentators and problem solvers. We have also treated the communities and 'the people' in simplistic and patronising ways by thinking that they cannot engage in these kinds of debates. At times we have essentialised their ways, traditions, cultures and beliefs, afraid or unwilling to challenge them or to engage with aspects which are problematic.

However, I suggest that, to a great extent, the situation that Volks describes does not apply to the last decade or so, which has indeed witnessed vibrant critical and well-informed knowledge production, plus the commitment of academics to the state and civil society. In this line, I suggest that HIV/AIDS scholarship has greatly improved in terms of units of research over the last decade. Criticism of society and the government is considerable, as the debate about the consequences of denialism demonstrate. Large-scale quantitative inquiries are now in place and the impact of the epidemic on various spheres (i.e. family, economy, politics, housing, employment) have been extensively documented (i.e. Thomas 2003; Kyle 2004). This can be said despite problems related to the main

target of HIV/AIDS scholarship in South Africa, namely the fact that emphasis on the young black-poor (indeed the most vulnerable group) and heterosexuals (due to the predominance of heterosexual transmission of HIV populations) diverts research attention from other groups. For instance, white, as well as homosexual and MSM groups are understudied (Leo Wilton, interview 17 May 2013). Be that as it may, as recently discussed by Ifeoma N. Onyeka (2014), the most urgent issue is to increase and better the communication of HIV/AIDS research findings to relevant stakeholders, primarily the state and civil society organizations, in order to improve interventions.



## 6 Engaged scholarship and innovative educational approaches

This chapter discusses academics' social responsibility, understood as the commitment to social justice, in concrete fields of health promotion, namely, harm reduction in IDU groups, peer education in educational settings and other innovative approaches to HIV/AIDS education. To some extent, this is part of the discourse related to the role of HEIs in activities aimed at strengthening civil society, which is a resource deemed as critical to socially sustainable development. As Cooper (2011) has stated, this is the third academic mission (that is, commitment to development and social justice), supposed to transcend the first and second ones (teaching and doing pure research). This way, university-based applied scholarship on HIV/AIDS helps to foment civil society's participation in the public sphere and in health promotion. In short, as for the three academic missions, the curriculum modules dealing with the epidemic provide knowledge and skills on how HEIs can provide intellectual leadership in HIV/AIDS education, prevention, care and research at HEIs and to society at large:

Tertiary and higher institutions must be aware of how HIV and AIDS are affecting their functioning and operation, especially in countries where the virus is endemic. HIV and AIDS can reduce student enrollments through deaths, illness, financial constraints, and demand for home care of sick relatives and friends. HIV and AIDS also increase the cost of training academic and support staff due to attrition, premature deaths, and employee benefits given in case of illness or after death. Moreover, these impacts can adversely affect the quality of education within the institution because sick, depressed, unmotivated or demoralized staff cannot be expected to teach effectively, nor can infected and affected students be expected to fully comprehend educational instructions or assume all the course workloads. It is possible that HIV-related absenteeism, the loss of skills, and the overall costs and impacts due to HIV and AIDS are seriously undermining the capacities of tertiary institutions to achieve their defined educational and research goals. (Mary Crewe & Charles Nzioka) <sup>46</sup>.

In this light, more concretely, the present chapter addresses more explicitly and consistently the ways in which social scientists contrast HIV/AIDS social vulnerability in concrete fields, including harm reduction in IDU groups, teachers training for anti-AIDS initiatives in school settings and communities, and peer education.

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46 [http://www.iiep.unesco.org/fileadmin/user\\_upload/Cap\\_Dev\\_Training/pdf/4\\_6.pdf](http://www.iiep.unesco.org/fileadmin/user_upload/Cap_Dev_Training/pdf/4_6.pdf), pp.210-211. (Accessed on 12.05.2014)

## 6.1 IDUs and harm reduction in Brazil, and teachers training at South Africa's HEIs

### *IDUs and harm reduction in Brazil*

Harm reduction policies oriented to IDUs concern primarily the supply of kits of clean needles and syringes to IDUs (in “exchange” of used ones), and condoms. These policies emphasize the rights dimension, both in terms of health protection of marginalized and vulnerable people, and in terms of their participation in health promoting initiatives. This way, harm reduction policies for IDUs operate against inequalities and exclusion, violence, stigma, and decriminalization that underpin vulnerability to the HIV/AIDS epidemic. Harm reduction studies and action-research follow this reasoning.

In Brazil, the studies on the association between injecting drugs use and HIV transmission emerged in the late 1980s within UNAIDS centers located in Rio de Janeiro and Santos. These studies seek to explore IDUs behaviors with regard to needle exchange, the psychosocial effects of drug consumption, sex, and IDUs condition of marginality. Strategies to achieve such endeavor include revealing serological markers of HIV in IDUs' and an assessment of their demographic profiles. This scholarship has historically been associated with researchers' claims for the provision of comprehensive care to drug-addicts who are HIV-infected. By the mid-1990s various IDU-HIV research and teaching programs were established at numerous Brazilian HEIs. These triggered massive studies (including research-action programs) on various issues related to harm reduction (i.e. Delbon 2006; Elias 2011; Fonseca 2007; Piccolo 2002; Queiroz 2001; Siqueira et al. 2008). There are currently over one hundred harm reduction programs for IDUs in Brazil, a significant number of which are carried out by HEIs (Acselrad 2005: 304).

The rise of harm reduction studies in Brazil was also associated with the state's willingness to set up harm reduction policies to prevent undue use of drugs and mitigate the transmission of HIV, Hepatitis B and C (caused by needle sharing, drug abuse-related sex and IDUs reluctance to seek health services, given their marginal conditions), as well as physical, psychological and social harm caused by drug abuse.<sup>47</sup> Financed by the WHO,

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<sup>47</sup> Internationally, harm reduction policies have largely been adopted by various European societies (i.e. the UK, Germany, Sweden, Australia, the Netherlands, France, Spain, and Portugal), whose blueprint Brazil tends to follow, in accordance with its own realistic vision of the local situation. Today the debate about harm reduction policies is more alive and multifaceted than ever in Brazil, in association with a vibrant political debate regarding the idea of compulsory admission in anti-drug clinics of

the UERJ-based *Núcleo de Estudos e Pesquisas em Atenção ao Uso de Drogas* played a crucial role in the establishment of these studies in the early 1990s. So did the works conducted in Santos, which were jointly financed by the WHO and the local Municipality Health Secretariat. In turn, the political will to mitigate the impact of drug use on health was a response to the rapid spread of the HIV infection among excluded and criminalized demographic segments, women, children and the elderly (Siqueira et al. 2008: 45-48). In particular, IDU-HIV studies in Brazil revealed that the nation was experiencing an AIDS epidemic among IDUs and the correlation between injecting drugs and susceptibility to HIV infection had not yet been understood (Mesquita & Sibel 2000). Therefore, researchers urged massive inquiries and policies in the states that had the country's highest incidence rates of HIV: São Paulo, Santa Catarina, Mato Grosso do Sul, Bahia, and Rio Grande do Sul. Soon, with the participation of university institutions, a nationwide initiative called *Projeto Brasil* was run in the 1990-1997 period, in order to raise awareness about the interface between drug use and HIV transmission (Siqueira 2008: 46). Commissioned by the Ministry of Health and carried out by a multidisciplinary team of social scientists, the study revealed that, indeed, 10% of HIV positive cases were related to injecting drug use and, that most IDUs had unprotected sex with non IDU partners. Among other consequences for PLWH, injecting drug use is associated with a more rapid CD4 cell decline.

Importantly, harm reduction initiatives constitute an essential strategy for motivating drug consumers' to seek health services and, by implication, ameliorate their “hard to reach” condition. As Siqueira, Colombo and Conte (2008: 45) explain, the basic idea is that the harm reduction movement is articulated in three interrelated arguments. The first argument suggests that drug consumption has a long history in human communities and cannot be eliminated. Furthermore, the argument continues, drug consumption is a manifestation of this contemporary society, characterized by pronounced individualism, anxiety and depression, which some people try to combat by consuming drugs. The implication is that it is necessary to open up a debate about drug decriminalization and legalization in order to protect consumers from various forms of associated risk. One pragmatic solution suggested by the harm reduction movement relates to selling drugs in pharmacies. The second argument underpinning harm reduction thinking is that drug consumption is a rather heterogenous world that reflects varying economic and social

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homeless crack users. This kind of measure has been advocated by some policy-makers as part of the “hygienic” modernizing project of urban areas with a view to the 2014 Soccer World Cup and the 2016 Olympic Games to be hosted by Brazil.

dynamics, for the context in which drug consumption and associated risks occur needs to be emphasized in order to understand the causes, values and languages of drug consumption and respond to the problem with social justice-prone policies. In particular, it is suggested that the endemic drugs economy ruling various Brazilian shanty towns – the chief source of violence and unprotected sex attitudes – is very much connected to social injustice and a lack of alternatives, for which reason government repression policies are unlikely to bring about positive change if structural poverty and inequalities are not effectively addressed. Finally, in relation to HIV/AIDS, the third basic idea motivating the harm reduction movement is that treating HIV is economically much more costly than distributing kits of needles and syringes. In this sense, harm reduction arguments and initiatives are based on social medicine principles and advocacy for social justice (say, full exercise of individuals' citizenship), which are in turn infused with realistic, pragmatic and non-moralistic discourses that, among other aspects, consider that there are people who cannot or do not want to conduct their existence without consuming drugs. In this sense, harm reduction programs render the materialization of universal health principles possible, that is, the protection and defense of all citizens' health. Also, pulling back used – potentially infected – needles and syringes from communities provides a symbolic dimension to health, which reinforces the citizens' perception of preoccupation with the health status of marginalized people on the part of public power. Accordingly, harm reduction strategies lead to drug addicts' willingness to openly express their thoughts, which in turn encourages them to actively commit themselves to responsible life projects and, consequently, avoid risky situations. Briefly, scholars committed to harm reduction posit that drug consumption must be addressed as a public health problem, rather than a solely criminal justice matter. Hence, disciplinary and abstinence discourses, which to a large extent dominate Brazil's security and health systems, are weak prevention measures.

The situation becomes more complex when we go beyond IDUs in the strict sense, and include in the category groups such as users of anabolic substances, transvestites, and crack users within the category of IDUs, as harm reduction policies in Brazil do (Mello & Andrade 2001). Anabolic substance users are those who self-inject substances (some of them being veterinary solvents) in order to increase body mass. They are covered by harm reduction programs because they often share needles and syringes when injecting substances. Transvestites are covered by harm reduction policies due to both needle and syringe sharing when they self-inject silicon and to the infections caused by harmful substances contained in silicon itself, whose origin is sometimes unreliable. For its part,

until very recently, crack did not constitute a national emergency in Brazil, but it increasingly became so, partly due to its association with high incidence rates of HIV/STIs and TB in crack-addicted populations. In general terms, injecting drug use in Brazil has declined over the last decade and HIV transmission through infected material is almost insignificant (i.e. Bastos & Malta 2012: 190). However, although scientific evidence is still confined to the Rio de Janeiro, São Paulo, and Rio Grande do Sul states, the association between crack use and HIV risks seems to have increased (i.e. Duali, Ribeiro & Laranjeira 2008). In a 2003 book that he edited by Fernando Bastos et al., *Drogas, dignidade e inclusão social: a lei e a prática de redução dos danos*, Bastos warns against the crack emergency in Brazil, especially among young people, most of whom seem to have come from disadvantaged backgrounds.<sup>48</sup> In order to mitigate TB contagion among crack users – and thus slow down the speed of AIDS in HIV-infected individuals – some initiatives have sought to provide crack users with filters to be applied to pipes in order to reduce the quantity of smut and other vaporized impurities. However, a crack piece can be vaporized in a variety of manners and there are not yet filters which are adaptable to the different items used to smoke crack. The high level of contagion of HIV among crack users is facilitated by needle sharing, inconsistent use of condoms and commercial sex, the latter often being essential for them to self-finance crack consumption. On the other hand, TB, the chief AIDS-related opportunistic infection, is facilitated by the constant coughing that accompanies smoking, especially in promiscuous and non-ventilated closed environments.

Hence, harm reduction scholars pose the question of what kind of social-science knowledge on human beings should be addressed in order to nourish the hope of effectively contributing to the formulation of new paradigms of anti-AIDS policy, with particular attention to harm reduction. The response resides in the centrality of humanity as the focus of use-inspired knowledge production in the field of public health. In order to grasp the complexity of the drug-HIV problem and suggest integrated intervention approaches, scholars have increasingly viewed the interface between injecting drug use and HIV as a “double human tragedy”, encompassing pleasure and harm, life and death, repressors and pseudo-humanists, intolerance, misinformation and discrimination (i.e. Acselrad et al. 2005; Andrade 2001; Bastos 1998, 2002; Caiaffa et al. 2003; Karam 2003; Mello & Siqueira et al. 2001; Mesquita et al. 2001). It is important to note that most of these scholars operated in institutions devoted to studies or policy planning in the drugs-

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48 For subsequent debates see, for example, *Profile of cocaine and crack users in Brazil* by Dualibi et al. (2008).

health fields. This is the case of the *Núcleo de Estudos Drogas/AIDS e Direitos Humanos* (within the *Laboratório de Políticas Públicas* at UERJ), *Secretaria Nacional de Políticas sobre Drogas (SENAD)*, and *FIOCRUZ*. The titles of published outcomes of such scholarship reflect the high level of attention paid to human rights on the part of these scholars. This is the case of Acselrad et al.'s book of 2005 *Acessos do prazer: drogas, AIDS e direitos humanos*.

Scholars (i.e. Siqueira et al. 2008: 48-58) argue that by adopting the harm reduction program, Brazil has made progress in limiting the consequences of HIV transmission related to intravenous drug use and given visibility to IDUs in the health system (Clair et al. 2009). They have also contributed to the revision of drug-related laws, and boosted reflections on mental health, as well as improving the legal and social protection of sufferers, including longtime PLWHA, transvestites and other groups which are subject to violence, discrimination and marginalization. However, the authors suggest, that much remains to be done in terms of adopting democratic alternatives. With this critique, scholars denounce the oppressive – thus inefficient and unjust – nature of most of Brazil's public policies regarding drug commercialization and consumption. More broadly, they denounce the problems against which alternative democratic strategies should operate: the prohibitionist, repressive and often violent strategies enforced by the police and the judiciary against drug consumers (in the case of illicit drugs); the negligence of the harmfulness of licit drugs (alcohol, tobacco, psychopharmacological drugs); and the inappropriate societal generalization of drug consumption, as if this conduct were not dependent on socio-economic status, among other aspects.

The illegal narcotics market is particularly emphasized in these debates. The role of poverty and inequality in the flourishing of narcotrafficking has been stressed, suggesting that recent the history of drug dealing is strictly linked to the history of capitalist economy, whereby drug consumption and addiction are largely a result of the contradictions of the current social relations of production (Acselrad et al. 2005: 240). The thrust of the argument is that if we take the addiction issue seriously, for instance, it becomes clear that most people become addicted to drugs because of habitual consumption in order to mitigate feelings of anxiety, angst or depression. According to this view, by demanding extremely high personal performances, either mental or physical, the current capitalist economic system forces people to consume drugs in order to increase their ability to accomplish arduous tasks demanded by, the labor market. Furthermore, as for recreational drug consumption, contemporary

messages which foment the exasperated search for excitement and pleasure is also a way in which people can get addicted to narcotics.

As for knowledge production and symbiosis between disciplinary areas, the analysis of the interface between drugs and HIV-risks and the associated harm reduction research programs in Brazil constitute a good example of interdisciplinary and inter-sectorial studies: they transcend psychology, sociology, law and jurisprudence, ethnography, ethics and religious studies, as well as popular knowledge. Nevertheless, as Siqueira et al. observe, the disputes between disciplines claiming to possess a “better” comprehension of, and solutions to, the phenomenon, in the name of a certain truth, pose a big challenge for applied social-science oriented to drug-HIV policy. Brazil's experience with drugs harm reduction is now a blueprint for other Latin American countries, to which Brazil offers university-based internship programs and support for the reform of their drug related law systems.

#### *Teacher training at South Africa's HEIs*

Various anti-AIDS activities are conducted at South Africa's HEIs by specialized entities, including HEAIDS, as noted above. HEAIDS activities include teaching, applied research, peer educators training, and commitment to non-academic communities. The Teacher Education Pilot Project is an important initiative undertaken by HEAIDS to enable teacher educators to take an informed and stronger leading role in the fight against HIV/AIDS. The initiative includes investigative and reflective activities in school settings to ensure that principals and teachers can be highly motivated to provide proactive leadership in the struggle against the HIV/AIDS crisis, with the aim to provide care and support to HIV affected students and teachers (Holderness 2012). The Teacher Education Pilot Project has included the development of learning materials to address HIV/AIDS in pre-service and in-service teacher education courses (Holderness 2012: S52). The development of these materials involved various organizations, including the South African Institute for Distance Education and SAUVCA. A full version of the course material, *Being a teacher in the context of the HIV/AIDS pandemic*, was produced in 2006 and published in 2008 (ibid). By 2010 over 6000 pre-service and in-service teachers benefited from the project. HEAIDS (2010) has seen a relative success of the project over the last decade and posits that at South Africa's HEIs several student-teachers (peer educators) are reported to have been enlightened and influenced by the project, providing

them with knowledge, skills, support and material resources to carry out prevention programs in school settings and student communities. Within the academic realm, dissertations addressing HIV/AIDS issues have increased at postgraduate level, and doctoral students have increasingly undertaken research-action programs aimed at enhancing self-esteem in and assertiveness among graduate students in their marginalized communities (Didloft 2010; Geduld 2010). This scholarship seems to validate the argument according to which the enhancement of self-esteem can produce long-term benefits in students' personal lives in terms of quality of relationships, educational performances and future careers. High self-esteem provides a positive self-image for self-actualization, which, in the sphere of health "can also aid learners to resist peer pressure and to be more assertive and goal-directed when urged to participate in sexual activities that could put them at risk of contracting HIV" (Holderness 2012: S53).

Overall, HEAIDS projects seem to have contributed to opening debate about the epidemic, not only at HEIs but also in school contexts. In particular, the context-specific nature of the projects is reported as having helped to acknowledge the existence of the severe HIV epidemic in schools and communities, on the part of school principals. These school officials tended to deny the existence of the problem but, thanks to HEAIDS projects, they are now increasingly eager to proactively address HIV/AIDS challenges. In brief, through engagement with HIV/AIDS at HEIs and at school level:

HEAIDS has brought to light what teacher-educators are doing in both undergraduate and post-graduate programmes, to address the challenges of the pandemic and provide support to educators to deal with HIV and AIDS at both professional and personal levels. This initiative has also put the spotlight on what teacher-educators could be doing. (Naydene de Lange et al. 2012: S1).

However, "despite the success of the [Teacher Education Pilot] project, the challenge remains for education to sustain prominence and importance alongside the equally important biomedical aspects of prevention and intervention" (ibid). De Lange et al. refer to a series of constraining factors that seriously limit HEIs providing support in HIV/AIDS education in South Africa. One constraint concerns the need to reach satisfying numbers of motivated and appropriately trained teacher-educators and student-teachers, since there are usually few incentives and very few opportunities for HEI academics to further their studies in the field of HIV/AIDS. The difficulty of gaining time and status for HIV/AIDS education in South African educational settings is another constraint: long-established, high-status subjects that are supported by examinations tend to take precedence in the curriculum and timetable, for HIV/AIDS education is frequently not given the recognition it requires and the respect it deserves (Holderness

2012: S5). A further obstacle to implementing HIV/AIDS education programs and research-action relates to the confidential nature and ethical problems surrounding most HIV related issues, including the rights of individuals not to disclose their HIV status.

## 6.2 Peer education in educational contexts

*For many students university life provides their first taste of freedom and independence and they cannot always cope with this new-found liberation... Students often display a sense of invulnerability and omnipotence, focusing more on future dreams than on present risks.*

Pierre Brouard (2012: 38-39)

As discussed above, peer education is globally recognized as a key strategy in health promotion. In Brazil and, to a larger extent, South Africa, there are now several HIV/AIDS peer education programs at HEIs aimed to reverse the course of the HIV/AIDS epidemic among students, primarily. One starting point is precisely the aforementioned students' difficulties to manage their relative sense of freedom and independence in an HIV-affected milieu, associated, to some extent, with the often overwhelming physical, emotional, cognitive and spiritual changes that may accompany students' shift from late adolescence to early adulthood (Brouard 2012: 38). One further challenge for peer education at HEIs, especially in the case of South Africa, concerns students' conservative beliefs – acquired from their parents and communities – which prevent them from finding out information about sex and sexuality, leaving them vulnerable when they are in sexual contexts (ibid).

It is crucial to stress that differences in the history of peer education in the field of HIV/AIDS between Brazil and South Africa abound. Partly due to diverging epidemiological scenarios of and responses to HIV/AIDS, peer education has a longer history in Brazil. In South Africa, by contrast, despite the high prevalence of HIV, peer education only became a national priority in the mid-2000s when the political climate surrounding HIV/AIDS started to improve. However, it seems that peer education is now far more diffused and academically discussed in South Africa. Nevertheless, literature on peer education in Brazil is rather scarce and it is only now that efforts are being taken to fill up this knowledge gap. In any case, as in the case of South Africa, Brazil's practical experience with peer education offers useful points for rethinking engaged social-science for health promotion. In general terms, the guidelines of HIV/AIDS peer education, which

are more pragmatic than theoretical in orientation – the pragmatic part including the potential of peer education to create major credibility, facilitate communication about health-enhancing practices among individuals of small groups - were initially predominantly based on experience and hypotheses, rather than on social theory. In any case, empirically-oriented peer education programs for HIV/AIDS prevention and treatment literacy have constituted the milestones both for fully intervention initiatives and research programs on the issue. This is especially true in the case of Brazil, where the government supported this kind of initiatives.

In Brazil HIV/AIDS peer education dates back to the 1980s and gained prominence in the 1990s, mainly in LGBT communities, organized sex workers, IDUs, inmates and adolescents. School settings have also been targeted. But most initiatives have taken place in informal contexts: entertainment and convivial places such as bars, dancing clubs, porn cinemas, drive-ins, informal soccer fields and stadiums, and women’s meetings (Oliveira & Silva 2012: 271). Initially, the cities of Santos and Salvador led peer education policy and their initiatives had an impact on the federal AIDS/STIs teaching documents called *Manual do Multiplicador: Prevenção às DST e AIDS*, whose first publication dates back to 1996. The *multiplicador* is a professional – either in health, education or other field encharged of recruiting, training and evaluating *monitores* (peer educators) in specific groups (Calazans 2012: 145). Today, the terms *multiplicador* and *monitor* are generally used interchangeably in Brazil, the former being more common. However, in the present discussion I have opted for the more common ‘peer educator’ expression.

There are now several curricula module that examine how HEIs can develop effective policies and strategies for mitigating the impact of HIV/AIDS in South Africa. The modules are concerned with how members of HEIs can be equipped with the knowledge and skills to address HIV/AIDS in the process of the three academic missions (teaching, doing pure research and engagement), as well as in staff recruitment and retention. *CADRE*, a Rhodes University's AIDS institution discussed above, refers to a number of issues related to peer education at HEIs:

Universities are able to promote healthy attitudes and risk reduction behaviours, given that young people often explore serious relationships for the first time and form lasting sexual behaviour patterns at university. HEIs are also milieus in which the nation's future leaders can develop positive attitudes about how to manage HIV and AIDS; attitudes that they can carry with them throughout life. Institutions are further uniquely able to share information and expertise with

surrounding communities and the influence of campus-based programmes may therefore spill over informal knowledge-sharing.<sup>49</sup>

Furthermore:

On many campuses there is an established culture of risk-taking that includes casual sex with different partners, transactional sex and the abuse of alcohol and drugs. First year students face an increased risk as they enter a new environment with sex and alcohol. Female students entering universities for the first time are especially vulnerable and are often preyed on by older male students and sometimes even lecturers.<sup>50</sup>

It is against this background that HEIs in Brazil and South Africa feel ethical and intellectual responsibilities to finding effective and sustained responses to HIV/AIDS at HEI and community levels. The prime goal of this response is to make the campuses safe for students and staff, especially women, in terms of reducing the likelihood of HIV transmission. Practical peer education in campus contexts generally consists in promoting VCT, the negotiated use of condoms, and the provision of knowledge on the social and biological aspects of HIV.

Students constitute the chief group involved in peer education programs at HEIs, which ideally seek first and foremost to provide students with critical consciousness with regard to the status quo, dealing with ideas, visions and reflections that fuel a hope for the possibility of social change:

Tertiary institutions need to develop in their students critical minds that constantly challenge the taken-for-granted. We need 'intellectual activists' who will utilise intellectual curiosity, looking for hidden agendas, intriguing patterns and inter-related forces, and constantly asking difficult questions. We need vision, optimism and honesty. The HIV and AIDS epidemics have highlighted how many people inhabit areas of dishonesty, unable to discuss their sexual experiences, unable to understand the sexuality of young people and in denial about sexual lives and identities which do not fit into neat pre-determined formulas. (Cal Volks 2012: 9).

To achieve this:

[Students] are trained in factual knowledge about HIV/AIDS and participatory education techniques (e.g. dramas and role playing). They are also given free supplies of condoms to distribute. Ideally, they are given full control of setting up and running peer educational meetings in formal and informal settings. (Campbell & Foulis 2002: 319).<sup>51</sup>

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49 <http://www.cadre.org.za/files/CADRE%20Health%20Promoters%20project%20poster.pdf>, accessed on 12.5.2014.

50 Students' sexual relations with lecturers often involve cases of offering in return for favors such as promotions or good grades, a dynamic that in South Africa is euphemistically called 'sexually transmitted degrees and diplomas'.

51 The authors actually refer to young people in general, not to students specifically. But the context in which they do so does allow to circumscribe the reasoning to students.

The involvement of arts celebrities generally constitutes a central communicative strategy of peer education. Celebrities play a critical role in diffusing messages in a quick and attractive manner. But more important is the active involvement of PLWH, which helps to fight the stigma and discrimination associated with the infection. Furthermore, as the history of HIV/AIDS programs shows, when involved and valued as agents of positive social change, PLWHA's assertiveness arises, which helps them to build or improve the social capital they need in order to cope with psychological and social difficulties.

In South Africa the proliferation of peer education in HIV/AIDS programs has resulted in notable debates about the contexts in which peer education typically takes place, namely, education settings, local communities, sex industry (i.e. Campbell 2002, 2003; Satande 2008). The potential of peer education to both employ and generate concepts such as human/social capital and critical consciousness has been part of this debate (i.e. Campbell & MacPhail 2002; Dickinson 2009; Simkins 2002).

When it comes to transferring peer education from HEIs to students' communities, South African scholars argue that the task consists in articulating such initiatives ably and through a vision that considers the way in which gender problems are interlocked with economic problems, among others (the link between economic and symbolic dimensions). As Catherine Campbell (2003: 50) phrases it, peer education programs might provide a group of men with the opportunity to discuss the way in which the construction of masculinities increases their risk of poor sexual health. They might further discuss the way in which the achievement of conventional male identities is limited by poverty and unemployment. In South Africa, unemployed men aiming to take on the male breadwinner role and set up their own families are constrained when they lack the money to buy houses or pay a lobola (dowry). They may over-compensate by adopting an overly macho and controlling attitude towards women in sexual relationships. From a Freirian perspective, such understanding would form the starting point from which men could collectively work towards redefining their masculinity in ways that are less dangerous for their sexual health, and acting on this newly developed understanding.

### **6.2.1 Playful and other innovative approaches to HIV/AIDS peer education**

In addition to the improvement of economic circumstances, engaged researchers have made the effort to explore the potential of innovative educational strategies in the

primary school system, including collaborative learning, which address sex, sexuality and HIV prevention before adolescents start having sex. Drawing on a vast range of research-action experiences, these scholars posit that such innovative didactic methods should provide children with capacities to negotiate significances and deeply internalize the most useful skills for mastering individual sexual life responsibly and respectfully. These skills include the ability to negotiate the “no”, persistence, optimism in cases of failure, as well as ability to seek alternatives or help and manage solitude (Schall 1996). The combination between self-learning and cooperative learning is particularly emphasized. The former is deemed to provide individual autonomy, whilst the latter is encouraged by virtue of its potentiality to provide a sense of belonging, a critical-freedom slant in education (conscientization), and articulation between individual and collective responsibility in social interactions.<sup>52</sup>

It is believed that, in the field of HIV/AIDS peer education, playful-affective approaches are the most appropriate innovative methods to infuse individual and social responsibilities in school learners.<sup>53</sup> It is assumed that games and sports may facilitate access to HIV&AIDS messages because they do not simply constitute a well-loved pastime, but are also considered to be a good way of promoting sound moral principles like respect for diversity, tolerance, non-discrimination, solidarity, cooperation and negotiation (Esau 2012: S9). In other terms, playful-affective approaches are based on pedagogical insights that emphasize the potential of groups to enhance the construction and negotiation of learning methods, collective identity and collective action – say, social capital. This implies the empowering process that creates supportive networks through commonality of needs, objectives and mutual aid. In HIV/AIDS, prevention programs using groups as forums for education and empowerment are particularly essential to

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52 These reflections are based on didactic theories, which date back to Sigmund Freud, Jean Piaget, Lev Vygotsky, Jerome Bruner, and Paulo Freire, whose psychosocial explanations are topical in the field of education. These include children's psychical development, especially in relation to sexual urge and super-ego construction (Freud); “egoism paradox”, consisting in a lack of real mutual comprehension between partners, which leads them to a mutual respect based on more or less tacit rules, whereby each partner plays the game that in a way pleases them, paying scarce attention to the other (Piaget); processes of language development, including the formation of concepts and individual learning mechanisms, which is largely a result of interaction between imagination and emotion (Vygotsky), and the combination between individual and cooperative learning methods that provide individuals with both individual and social skills (Freire). Advocates of playful-affective methods also draw on Allan G. Brown (1992) and Lily Becker (2005) who have more recently reformulated these arguments.

53 The authors discussed in this piece do not refer to their innovative methods in HIV education as part of peer education programs. But I suggest that this is actually the case since peer education is an alternative didactic method to teacher-learner approaches.

erode the 'culture of silence' around sexual discourses and HIV/AIDS, oppression and apathy. Silence around HIV/AIDS is associated with stigma and discrimination, fear, and denial, which inevitably lead to ignorance, and misinformation. These social processes create fertile grounds for the epidemic to flourish, since they prevent counseling and appropriate treatment from being accessed by those who are affected by HIV (Holderness 2012: S48). It is not by chance that 'how to break the silence' was the major subject that challenged the 13th International AIDS Conference delegates in 2000 in Durban.

In Brazil and South Africa, HIV/AIDS education policy guidelines indicate opportunities for integration across teaching curricula. This is a major concern and focus among academics and teachers, especially in South Africa, where stand-alone academic modules have thus far constituted the major vehicle of HIV/AIDS education in educational institutions. There are plenty of differences of interpretations concerning how to integrate innovative initiatives in individual teaching programs and in the mainstream HIV/AIDS educational policies. But educational systems in Brazil and South Africa seem to concur on the fact that integration increases students' opportunities to attain and expand knowledge, skills, attitudes and values. In South Africa, particularly, information overload and repetitiveness have led to what experts denominate "HIV/AIDS fatigue": "young people are sick and tired of HIV/AIDS messages and do not care anymore about them, because we have given them repeatedly the same kind of message and in the same way" (David Dickinson, interview 23 May 2013). Well, alternative-integrative didactic methods grounded in games and sport codes projects are regarded as able to combat "HIV/AIDS fatigue" (Interviews: Furrar Simbeku, 23 May 2013; Kammila Naidoo, 16 May 2013; Niger, 17 May 2013).

In the debate about the commitment of intellectuals to social development, integrative playful projects portray the role of the teacher as a researcher and critical change agent in an HIV/AIDS-challenged society (Esau 2012: S27). These initiatives bring new insights into the debate about trans-disciplinarity in the sense that they constitute an illustrative example of how social aspects of HIV/AIDS can be taught in educational programs which are otherwise generally regarded as purely technical (i.e. mathematics) or a purely creative pastime (i.e. chess). This is the guiding idea of innovative didactic methods and games to be discussed in the next pages.

### *“Zig-Zaids” and “Jogo da Onda” in Brazil*

*Zig-Zaids* and *Jogo da Onda* – the latter standing for “Wave Game”, alluding to drug's disorienting effects – are among the most popular HIV/AIDS playful-affective methods in Brazil. *Zig-Zaids* and *Jogo da Onda* were designed to raise, respectively, HIV and drugs awareness in school children. They have been developed and tested since the early 1980s by the FIOCRUZ research team operating in the *Laboratório de Ambiente e Saúde (LEAS)* in Rio de Janeiro, and then supported since 1998 by another scientific community based in the *Laboratório de Educação em Saúde (LABES)* in Belo Horizonte (Acselrad 2005: 224). *Zig-Zaids* and *Jogo da Onda* are played with card decks that creatively ask questions and give answers and explanations about sex and HIV (in the case of the *Zig-Zaids*) and drugs (in the case of *Jogo da Onda*). The two issues are merged at a certain point into the sex-HIV-drugs education process. The two games are said to have become popular in the late-1990s in Brazil, not only by virtue of their entertaining interpersonal interaction nature, but also because they did promote knowledge about HIV transmission, prevention and treatment, reproductive health, and gender relations (Schall et al. 1999). Furthermore, *Zig-Zaids* and *Jogo da Onda* represented an opportunity for involving health professionals and local administrations in school projects, enabling them to reach out to street girls. In doing so, *Zig-Zaids* and *Jogo da Onda* created a public debate that resulted in the formulation of further complementary pedagogical languages in schools, including peer education programs focused on illnesses other than HIV/AIDS (ibid). For these and other reasons, *Zig-Zaids*, particularly, was later exported to other Latin American countries (Acselrad 2005: 270-274).

### *HIV statistics in maths and the ‘Checkmating HIV & AIDS’ project in South Africa*

In South Africa too, playful methods are now seriously considered in HIV/AIDS teaching programs. Recent reflections on the issue include the six articles in Issue 9 of the *SAHARA-J*, Supplement 1, published in December 2012 (I will only discuss two of the six articles). Drawing on empirical research based on both quantitative and qualitative approaches, as well as participatory paradigms, the articles bring forth debates about the creative ways in which teachers and educators are responding to the epidemic. In this sense, the articles re-assert the voice of teachers and educators in tackling HIV/AIDS in South Africa.

In her article *Using HIV and AIDS statistics in pre-service mathematics education to integrate HIV and AIDS education* (S11-S18), which draws on her own research-action, Linda van Laren focuses on the higher education system and recognizes a lack of clear understanding of HIV/AIDS on the part of most student peer educators. The author suggests that integrating HIV/AIDS into mathematics education, through cross curricula integration, could help to better comprehend the epidemic. She argues that this requires developing a unit with pre-service teachers which utilizes HIV statistics, whereby teachers could also increase their reflective and active pastoral role, and university could improve its teaching contexts. Some individual initiatives in this sense seem to be emerging.

Omar Esau's article (S28-S36), *'Checkmating HIV&AIDS': Using chess to break the silence in the classroom'* is based on the author's PhD dissertation presented in 2008 under the title *Breaking the Culture of Silence in Checkmating HIV/AIDS as a Teacher Researcher*. The article gives an account of the author's *'Checkmating HIV&AIDS' action research project*, which was an attempt to erode the culture of silence concerning HIV/AIDS and sex and sexuality in his own school classroom (S28). The project took place over a period of 6 weeks in three Grade 7 classes of a Cape Town primary school and involved nearly 90 learners.

Chess is generally considered to be the gymnasium of the mind. Studies demonstrate that playing chess improves players' creative and logical skills (calculation, abstract thinking, inductive and deductive reasoning), concentration, visual imagery and memory pattern recognition, as well as self-esteem. When it comes to problem-solving, chess also develops patience and perseverance, endurance and determination, and impulse control – because one has to think three moves ahead before taking a decision, the right decision. One implication is that chess enhances responsible action. Therefore, Omar Esau believes that promoting the game of chess in linkage with sex and sexuality issues could be a creative and strategic way of taking up the HIV/AIDS challenge. Drawing on theorists of HIV prevention (i.e. Barnett & Whiteside 2006) and emancipatory action research strategy (i.e. Carr & Kemmis 1986), the author argues that, together with other sport code projects with similar aims and objectives, *'Checkmating HIV&AIDS'* can help not only to develop openness and willingness to talk about sex, sexuality and HIV/AIDS, but also to challenge the defeatism, powerlessness, and helplessness that accompany the epidemic.

Esau also sought to respond to three questions that Michael Fullan (1991: 63, cited in Esau 2012: S31) noted as key factors that determine the success of the initiation phase of any didactic innovation: the relevance of the innovation for teachers; the resources available to support change; and the readiness of the school to initiate, develop or adopt

the innovation. Esau inquired about the school environment and found out that the school community as a whole was enthusiastic about the '*Checkmating HIV&AIDS*' project. Personally, Esau says, "as a teacher, I viewed chess as fulfilling a need to equip the youth in my charge, and felt the change required was reasonable, that I was sufficiently equipped to teach them chess and to teach them about HIV, sex and sexuality, and as a class teacher I had enough time..." (ibid). The author states that this enthusiasm would not be crashed down by the results of the project: not only has the 'culture of silence' surrounding HIV/AIDS been broken, but the '*Checkmating HIV&AIDS*' processes would also provide a suitable space in which to make the learners' voices heard.

Methodologically, Omar Esau changed his classroom approach to integrate chess into Life Orientation (LO) learning lessons, which he sought to integrate into the school's already existing HIV/AIDS policy. Linking chess play to LO lessons is an interesting aspect because the author asserts, like life, chess is a continuous interaction between the mind and the other, and there are numerous choices or moves that one can make. Thereafter, Esau decided to use the following five complementary data-collecting techniques (S30-31): (1) on-going record keeping and *aide-memoire* in the form of field notes, which are useful to capture activity processes; (2) learner diaries and journaling, which provided the teacher-researcher with feedback from the learners' perspectives, revealing contrasts with his own field notes about the lessons and activities in which learners were engaged; (3) individual interviews of learners held by the teacher and one of his three observers- assistants (the *triangulators*) and of the teacher being held by learners, which served to build up a close relationship between all participants; (4) focus group video that recorded discussions with eight different LO educators from a neighboring school in order to gather their responses to the project, gain motivation to continue, and see that the project was making progress in terms of curriculum integration and partnerships, disclosure and confidentiality, awareness and safety, counseling, and monitoring and evaluation; finally, (5) handing out of an anonymous questionnaire at the beginning and at the end of the project and school year, which removed the need for face-to-face contact, and enabled participants' to give direct responses.

To start, Omar Esau and an invited coach laid down some ground rules of chess play, provided each learner with a set of pieces and a chessboard with the logo 'Checkmating HIV&AIDS!' printed on it, and explained the basic rationale behind the initiative. More importantly, as far as peer education is strictly concerned, each learner was encouraged to teach another how to play chess, and also engage in simultaneous game sessions,

which were also meant to allow two or more players to play against one player (S32-34). The author reports that the liberating phrase ‘each one will teach one’ was the highlight for all participants involved in the project and “most of the learners from the new class were completely enthralled by what their young peer coaches had to teach them” (S33). This chess peer teaching included exchanges between learners from different classes. As simultaneous sessions and inter-class meetings progressed, the two coaches coupled and played against 20 players at a time to test what they had learned and promote further interactions. Learners were also given some incentives: “they were informed that as soon as they could move the pieces correctly, they would receive their own free set of chess pieces and chessboard to take home with them (S31). Among other purposes, these incentives had to ensure that learners increased the discussion of issues related to HIV/AIDS with their families and peers in the community in which they lived. Indeed, chess play was taught in conjunction with LO and HIV&AIDS, a program that has to be taken beyond school settings and infused into families and communities. A few learners' parents-observers declared to have noticed progress in such direction. They were also reported as asserting that chess play was indeed useful to sharpen thinking skills, boost self-confidence and keep people positive. This was attributed to the interactive nature of the game and its slogans-principles, which were deemed as being helpful values in everyday life: ‘make the right move and do it safely’, ‘be alert, concentrate and think before you move’, ‘think three moves ahead’, and ‘anticipate your opponent’s moves before deciding on your own move’. Esau and his team referred to peer pressure as a key everyday life sphere where those decision-making skills are needed. Managing peer pressure – for early sexual debut, unprotected sex, and sexual multi-partnership, among others – is one type of skill that Esau sought to teach. Some degree of discipline appeared to have been instilled in learners: before leaving the class, they were asked to repack their boards, as well as double-check that all the pieces were there for the next game. Completing and returning questionnaires to the teacher at learners' earliest convenience was another practice that seems to have helped infusing discipline.

Also, Esau ‘*Checkmating HIV & AIDS*’ project seems to have helped learners, teachers and learners' parents to understand the school’s HIV/AIDS policy better, since the chess project covered much of the information reflected in it, including the need for discussing sex and HIV/AIDS among peers and relatives. Esau felt that the information gathered revealed that the ‘*Checkmating HIV & AIDS*’ project had contributed to trustworthiness among learners. For teachers, particularly, the project constituted a good opportunity for

reflecting on their work and on the potential of action-research. They broadened their role as teachers. Esau believes that the '*Checkmating HIV & AIDS*' project took a small but significant step towards “checking” the HIV&AIDS pandemic in the big game aimed at “checkmating” it. The school community became “aware of the threats on the board and in life” to an increasing extent, and their “defense mechanisms are in place for taking control of the game” (S35). In this sense, seeds for productive peer education, as well as social capital and community mobilization seem to have been scattered. One proof of the '*Checkmating HIV & AIDS*' project's success as an emancipatory action is the fact that, following its implementation, teacher Omar Esau was invited to replicate the initiative in other sectors, including prisons and sport fields.

## 7 Understanding HIV/AIDS policy in Brazil and South Africa

### *Overview*

This chapter explores divergences between Brazil's and South Africa's responses to the HIV/AIDS epidemic, in continuation with the discussion initiated in chapter 2. Particular focus is placed on the period between the 1990s and mid-2000s. This period is crucial to understanding the general history of HIV/AIDS policies in the two countries. In this period, the impact of the epidemic on families, communities and national development started to become clear. Consequently, the success and failures of anti-AIDS measures taken by the state and civil society could now be evaluated and inform new strategies for handling the epidemic. Worldwide, as discussed above, it became clear in this period that prevention had to focus on groups and communities, rather than individuals, and be placed within broader development agendas at regional and national levels. Life-saving drugs were by now highly effective and people with HIV could live longer and better, thanks to both advances in pharmaceutical technology, and legal reforms at national and international levels that made ARV drugs more available and affordable.

The core argument here is that in that period Brazil acted far more timely and aggressively than South Africa against the spreading of the virus across its population by implementing a nationwide integrated and transversal program of prevention, treatment, and care, whilst similar efforts were late to emerge in South Africa. The task is now to grasp the factors that most explain Brazil's success and South Africa's failure in the management of the HIV/AIDS crisis in that period. The importance of multi-territoriality at institutional and societal levels is emphasized. As for the main issue in the present work, the history of institutional responses to HIV/AIDS in Brazil and South Africa enlightens the socio-political context that shaped the social-science responses to the epidemic in terms of use-inspired research and research-action in the two countries. Now, several factors have been explored in order to explain such divergent policies. The initial works were not consistently and explicitly comparative in nature (i.e. Parker 1994, 1996, 2000), but did suggest that Brazil was superior to many other middle-income countries by virtue of having had a stronger civil society. Connected to this is the argument that compared to South Africa, specifically, Brazil's effective response to the epidemic was facilitated by its relatively early democratic transition. This scenario is generally regarded as having helped AIDS gay movements to influence Brazil's AIDS

plan, together with their high socio-economic status and political organization prior to the advent of the epidemic. World Bank loans since 1993 and major international links were also generally regarded by these initial inquiries as a strong variable explaining Brazil's better record of HIV/AIDS policy, in comparison with South Africa.

More consistent and explicit comparative works (i.e. Gauri & Lieberman 2004, 2006; Lieberman 2009) consider that, to complicate the picture, by the onset of the epidemic the two countries were at the same stage of development in terms of general state capacity and civil society involvement, as well as medicine advancement. Brazil and South Africa also had similar epidemiological profiles by the end of 1980s in the sense that the initial “risk group” in the two countries was constituted by middle-class white gays. Furthermore, according to the authors, HIV-affected middle-class white gays were not less politically organized in South Africa. As for the role of the World Bank, Brazil's AIDS plan was already well established by 1993 when the loans were first assured. For these scholars, therefore, the critical variable explaining Brazil's better HIV/AIDS policy is the state's political will to tackle the epidemic concertedly – say, collectively – problematizing it as a threat for the entire nation. The collaboration between politics and civil society, central government and local administrations, and politics and the pharmaceutical industry in Brazil was far better. Importantly, this implied the active participation of scientific communities, which made it easier for the government to embrace orthodox medical science in the construction, implementation and evaluation of HIV/AIDS policy. Brazil's easiness to bring different actors together to procure a strong response to HIV/AIDS is largely related to the history of race relations and biomedicine in the country, which is less problematic than in South Africa. This contributes to Brazil's stronger sense of political community, which helped its government to make conventional HIV/AIDS biomedicine a central tool in the struggle against the HIV/AIDS epidemic.

My analysis of the two states' responses to HIV/AIDS confirms the Gauri and Lieberman argument of there being a stronger sense of political community, and political will, as well as biomedicine having a more important role in Brazil. But it attempts to go beyond by adding two factors that in my view counted for Brazil's more effective response to HIV/AIDS. Both factors are linked to the type of knowledge available and used for health promotion at different levels. The first factor concerns the use of social-science knowledge, the very core of my thesis. Thanks to its support and use of the HIV/AIDS biomedical model, the Brazilian state recognized the crucial role of social-

science knowledge in the fight against the epidemic and, consequently, encouraged use-inspired social-science and social-research for interventions to be scientifically well informed (chapter 5). In other words, social-science knowledge in Brazil was better integrated into the anti-AIDS political agenda than in South Africa. Social-research in Brazil helped to better understand the broader structural factors of HIV/AIDS vulnerability (i.e. poverty, cultural resistance to condom use, among others), which resulted in a more realistic understanding of, and strategies against the epidemic. In South Africa the government did recognize the structural factors shaping the HIV/AIDS epidemic, in line with social scientists' view, but they did so in a superficial and rather controversial way that led to ineffective policies. The second argument of this thesis is that at societal level Brazil had it and has it easier than South Africa when it comes to adherence to biomedical science for the prevention and treatment of HIV: while biomedicine is a hegemonic health system in Brazil, South Africa is characterized by a plurality of competing health systems, the extremes being biomedicine and traditional healing of diviners and herbalists. In the case of South Africa, health dispensation is more complex and traditional healers are at a time a result of the limited coverage of the biomedical health system and an obstacle for people to seek biomedical HIV/AIDS facilities. In any case, the latter issue is not given much space in the present discussion, since my thesis focus is the role of social-science knowledge in handling HIV/AIDS.

### **7.1 Explaining the divergence between Brazil's and South Africa's HIV/AIDS-policy records**

We shall now go into detail about Brazil's effective and South Africa's ineffective anti-AIDS measures, or better said, we will now see why Brazil acted far more timely and holistically, for most of the epidemic's history. In Gauri and Lieberman's reasoning, the divergent boundaries in the Brazilian and South African societal and political systems constitute the factor that most explains the timing and quality of HIV/AIDS governance in both countries. Compared to South Africa, Brazil's good and timely governance of the HIV/AIDS epidemic depended on lower boundary levels in various spheres. A first sphere concerns the general national identity or sense of political community, which is

largely given by racial and cultural miscegenation, plus de facto monolingualism.<sup>54</sup> A second sphere relates to administrative decentralization, which enabled autonomous development of AIDS intervention strategies at municipal and state level, becoming later a model for the integrated national AIDS program. In this sense, more than decentralization per se, what has to be stressed is the symbiotic relations between various administrative levels, as opposed to centralized policies that are detached from communities' realities. A third sphere refers to Brazil's cultural openness with regard to sex, sexuality and sexual diversity discourses, which revealed to be crucial when it was uncovered and utilized as a national value for HIV/AIDS prevention education, and solidarity with HIV-affected people. These people could often feel identified with "risk groups". Their participation in HIV/AIDS activities earned them some power and rights to act as agents of social change by carrying out prevention programs at community levels, especially through peer education initiatives. This was part of the collective action reasoning in Brazil's handling of the epidemic, whereby policy-makers considered HIV/AIDS-affected groups as active agents of prevention and social change. But this was also associated with the fact that a few years after HIV surfaced – thanks also to the role of researchers and activists – the concept of social vulnerability, by now in vogue globally, was largely welcomed by policy-makers in Brazil. Even the expression "commercial sex workers" was coined in that climate in Brazil (and intentionally) to characterize prostitutes as persons entitled to rights, legal protection and participation in HIV prevention initiatives.

In short, compared to South Africa, the lower degree of boundaries at socio-cultural and political-administrative levels played a crucial role in Brazil's timely and more effective response to the HIV/AIDS tragedy. This sort of social cohesion surely provided fertile terrain for higher degrees of trust. Trust is not debated explicitly by the HIV/AIDS scholarship considered here. But it is clear that, especially in the early stage of HIV, Brazil's lower degree of boundaries resulted in higher levels of trust that led to stronger collaborations among different actors dealing with the HIV/AIDS crisis.<sup>55</sup> This meant

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54 I suggest that together with multiculturalism and racial divisions, linguistic boundaries in South Africa have also contributed to limiting the effectiveness of anti-HIV/AIDS messages, since most campaigns are delivered in English, which is hardly the language of the majority of the population.

55 Trust is in fact a major driver of progress, as extensively discussed in *Culture matters: how human values shape human progress* by Lawrence Harrison and Samuel Huntington with other scholars ([1997]2000).

trust in conventional scientific communities, including social scientists; trust between local and federal administrative levels; and trust between administrative power and civil society organizations.

South Africa's HIV/AIDS measures were until very recently characterized by negligence and denialism, largely due to the problematic history of race relations given by decades of colonialism and apartheid regimes. The problematic history of race relations in South Africa has resulted in a low sense of political community and mutual distrust, especially between white and black populations. This contributed to late apartheid government's neglecting the danger posed by HIV, and to the second post-apartheid President Thabo Mbeki questioning the "white" biomedical authority on HIV/AIDS, as well as him presenting his alternative Renaissance project that even led to refusing the implementation of ART in the public sector. Furthermore, the lack of support for social-science knowledge on the part of the South African government, stemming from its questioning of biomedical science in HIV/AIDS policies, which also implied limited debate about the values underpinning sex, sexuality and reproductive behaviors that place men and women in HIV vulnerable conditions. Researchers did conduct notable research in this field, underlining the negative role of polygamy and sex multi-partnership, for example. But their works were not considered by high level institutions, partly due to the fact that researchers were and still are overwhelmingly white in such a massively black-ruled and populated country.

### *The history of race relations*

Race relations have played a crucial role in dealing with HIV/AIDS factors, bureaucracies, and science in Brazil and South Africa. Here most words are devoted to the case of South Africa, where the race issue impacted more strongly on HIV/AIDS governance, contributing to the initial response to the epidemic being negligent, coercive and stigmatizing, rather than being characterized by a sense of emergency and collective destiny (Wouters et al. 2010: 74).

Even after the first case of HIV was reported in South Africa in 1982, the spread of the virus was barely registered by the National Health System and the apartheid state took very limited actions to protect its citizens through prevention of HIV contagion and treatment measures (Nattrass 2007). Instead, even when the epidemic was generalized in the country, the apartheid state labeled it as a plague of demographic groups that

generally did not deserve political attention, namely, gays, the poor, prostitutes, blacks and IDUs (Crewe 2002: 448-452). As the incidence of HIV grew throughout the non-white South African demographic segments, Afrikaner rulers started publicly celebrating HIV as a method to control the growth of the black population (Butler 2005). This attitude would later contribute to post-apartheid governments using conspiracy theories claiming that HIV was a white man invention intended to control the growth of black population (Gauri & Lieberman 2006: 65).

Furthermore, not only did political rhetoric and social discourses on HIV begin to be more stigmatizing, but also highly racialized, taking the black population as the main group in danger on account of its poverty, asymmetric gender relations and, presumably, hyper-sexualization and promiscuity. As a result, in contrast to Brazil – where HIV/AIDS prevention measures targeted the whole population, often on the basis of human rights, although with a special focus on the MARGs – HIV/AIDS, statistics and public policies in South Africa were (still are, to some extent) strongly racialized, taking the black population as the main risk group. As a reaction, black people have spent more energy in fighting against that simplified and stereotyped vision than in searching for the real factors underlying vulnerability to HIV in order to develop social change.

### *Science and traditional healing in HIV/AIDS*

Brazil and South Africa are also set apart by the varying role of cosmologies concerning traditional healing systems, typically mediated by magical visions, herb-based traditional medicine, sorcery and witchcraft. Biomedicine in Brazil enjoys primacy over other forms of health systems, namely the ones which are generally defined as popular forms of medical knowledge, like herb-based and/or spiritual-based therapies, many of which are associated with AfroBrazilian religious practices such as candomblé. Conversely, as discussed above, in South Africa there are currently two major paradigms of health systems, namely biomedicine and the spirit-inspired tradition of healers (*izangoma*). The *izangoma* system forms a complex body of concurrent health paradigms competing with the biomedical model (Ashforth 2005; Paul Germond, interview 22 Dec 2009; Solange Rocha, interview 10 May 2013). The negative role of traditional healing systems in South Africa's HIV/AIDS epidemic constitutes one more factor explaining the country's difficulty to deal with the epidemic. In such a socio-cultural context, social-science knowledge oriented to HIV/AIDS policy found it more difficult to make difference.

It is true that Brazil is rich in popular forms of medicine that portray themselves as alternative or complementary to the biomedical model in the field of health dispensation. But there is no significant antagonism between the two paradigms with regard to HIV prevention and treatment in Brazil. Rather, in my field research I observed AfroBrazilian religious entities and leaders encouraging biomedical treatment while providing, at the same time, complementary spiritual and sociopsychological support to their HIV-patient followers. Despite racialized forms of inequality at different levels, popular forms of health provision like the ones which are provided by AfroBrazilian religious systems are only complementary to biomedical models when needs be. Accounting for such harmony is Brazil's considerable degree of racial and cultural hybridity, plus biomedicine's more inclusive history in Brazil – compared to South Africa. By implication, unlike in South Africa, biomedical treatment would not be dismissed by non-white people as a harmful “white or western tool”. In the case of South Africa, the difficult race relations exacerbate the negative impact of beliefs in sorcery/witchcraft and *izangoma* seeking, scarce access to modern health services, and silence around sex issues and HIV/AIDS. This is particularly easily observable in rural areas where sorcery/witchcraft thinking, combined with endemic poverty, even leads villagers living within walking distance of reasonably well-resourced AIDS clinics to seek *izangoma's* intervention rather than ART (Steinberg 2009).<sup>56</sup>

## 7.2 A Multidisciplinary explanation for South Africa's denialism

The present sub-chapter attempts to explore the main factors that propelled South Africa's government to embark on HIV/AIDS denialism. References to Brazil are almost absent here because the country's history of HIV/AIDS governance has registered no form of denialism. In other terms, the absence of denialism in Brazil is largely indirectly explained by the South African case. Similarly, among South Africa's controversial policies, it is only denialism that is being considered here because denialism was indeed both responsible for the biggest impact as well as the public face of controversies.

The history of HIV/AIDS denialism in South Africa has been well documented (i.e. Fourie & Meyer 2010; Gumede 2007: ch. 7). Various factors have been explored to understand this infamous issue. To give a comprehensive account of the phenomenon, I

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<sup>56</sup> This also occurs in pluralistic urban settings like townships, characterized by a plurality of health care systems and where alternative explanations for HIV/AIDS continue to flourish. David Dickinson's book *A Different Kind of AIDS: Alternative Explanations of HIV/AIDS in South African Townships*, from 2014, is one recent work addressing this issue.

shall try to bring together historical, politico-economic, and psychosocial explanations that have sought to unravel the issue. Altogether, these explanations give an account of why President Thabo Mbeki and his Health Minister rejected all scientific evidence on HIV/AIDS pathogens and treatment, despite rising social anger, losing political standing both domestically and abroad, and causing thousands of unnecessary deaths. One recurrent factor which somehow transcends historical, politico-economic and psychosocial explanations is Mbeki's African Renaissance, alluded to earlier, which he understood as an attempt to achieve the complete emancipation of the continent from the social, cultural, political, and economic legacy of colonialism and apartheid. Accordingly, in former President Mbeki's view, AIDS was a global threat to the future of Africa that had to be tackled by a uniquely African solution (Posel 2008).

### **7.2.1 Historical explanation: the burden of the past and African Renaissance**

Historical explanations for HIV/AIDS denialism in South Africa generally refer to Mbeki's attempt to correct the legacy of colonial and apartheid deeds in the direction of empowerment of African nations and black people in various domains. Such attempt has been referred to as the Renaissance project, defined as an anti-colonial Africanist ideology committed to autonomy and the correction of historical subordination to, and racism of, the West. Scholars argue that Mbeki's Renaissance project was well intentioned and, by all measures, could well be endorsed. However, the way in which he conducted it in relation to handling HIV/AIDS undermined the foundational principles of the project itself. This is particularly visible in the field of HIV/AIDS science: Mbeki's Renaissance thinking predisposed a fertile terrain for the international HIV/AIDS counter-epistemic or dissident community to irrupt into South African politics and shed doubt on the benevolence and coherence of biomedical explanations of the HIV/AIDS pandemic.

This has been documented as being linked to the exclusive history of biomedicine and public health system in South Africa and Africa. This, as well as Mbeki's attempt to correct such historical injustice, illustrates how scientific knowledge translates into power and, by implication, how epistemic communities influence the policy arena. Scholars argue that the history of biomedicine in relation to race and the consequent unequal health system is particularly important in South Africa because black South Africans' negative experiences with public interventions during colonial and Apartheid periods contributed to predisposing the ground for the emergence of HIV/AIDS denialism and irruption of

the counter-epistemic community. Patrick Martin-Tuite (2011: 9-15) points out that the argument made by prominent historian of colonial medicine David Arnold (1993) about the central role of modern medicine in colonizing processes is clearly undeniable when applied to South Africa's history. Indeed, more than in Brazil, in South Africa, under both colonialism and apartheid, biomedicine provided not only self-worth and pride to European colonizers and apartheid rulers, but also justification for the segregation and domination of indigenous populations, thus producing a dominant set of racialized biomedical practices as well as an increasing the separation between medical experts and common people. Serving as a unifying force for white rule, heavy faith and investment in Western scientific practice granted further legitimacy to European scientists, whose classification systems contributed to differences between themselves and their ruled indigenous. For instance, as Didier Fassin (2007: XVIII-XIX) asserts, under colonialism and apartheid in South Africa, tuberculosis and syphilis provided a foundation on which to construct theories of black inferiority and African sexual promiscuity. By consequence, Fassin argues, racist disease-control policies underpinning white supremacy exacerbated Africans' suspicions on AIDS and its "Western" science: they created "an economy of resentment, whereby the past constitutes an inexhaustible reservoir of painful memory, and an economy of suspicion, whereby the present is interpreted through the lens of an intense mistrust of anyone making any claim to authority" (p. XIX). All this becomes very clear through the lens of the HIV/AIDS crisis. At societal level, race, gender, class, and generational relations – the four most determinant factors of people's health status and their degree of well-being – are caught up in, and shaped by, diversified experiences of time (ibid). Indeed, race, class, gender, and generational relations "influence the experiences of PLWHA, community and political reactions, the nature of institutional practice, and the dynamics of social change. In conjunction, they would affect perceptions of health and illness, kinds and availability of care, modes of delivery, anticipated illness, and discourse and interaction patterns of doctor-patient relationships" (Schneider 1991: 135). These relations are often expressed by denouncing the Western world in subaltern, nationalist and fundamentalist discourses. At institutional level, it has been suggested, this history inevitably shaped Mbeki's attempt to make South Africa's responses to the HIV/AIDS epidemic reflective of an anti-colonial Africanist ideology.

In this regard, the generational issue matters because AIDS mostly kills young people, upon whom Renaissance ought to rely. This makes Mbeki's African Renaissance thinking more complex. As investigative South African journalist Jonny Steinberg (2009: 7) wrote:

An epidemic that kills young adults in droves spawns difficult politics. How does a society absorb the death of its young? Whom does it blame? When the dying is transmitted by sex, the politics get more difficult still. And when the dead were voters in brand-new democracy, sons and daughters of people just liberated from a white dictatorship, the spectacle appears cynical in extreme, as if guided by an evil hand...

In such a context, albeit in *bona fide*, Mbeki's administration found it difficult not to overemphasize whites/westerners' responsibilities in his structural theory of Africans' vulnerability to HIV/AIDS. The devastating impact of HIV/AIDS on Africans in South Africa testifies the limits of such reasoning and will keep historians busy for decades to come.

### **7.2.2 Politico-economic explanation**

At the heart of Mbeki's African Renaissance views is, of course, anti-imperialism and economic autonomy. Economic self-determination also passes through parsimonious expenditure. Before Mbeki's coming to power, one central issue was the South African Medicines and Related Substances Control Act Amendments, passed in 1997, which aimed at the restructuring of the procurement, distribution, selection and pricing of medicines (Halbert 2006, 2012). The act primarily intended to provide AIDS medicines to the millions of South African citizens. During the discussion of the draft, a healthy disgust at the practices and ethics of giant pharmaceutical companies circulated in the ANC and among health activists. Using the Medicines Bill, health Minister Nkosazana Dlamini-Zuma attempted to improve national drug policy. One measure consisted in endorsing a smaller range of more affordable generic drugs. Preoccupied with their drugs patents, the bill seriously alarmed international pharmaceutical companies, who tried to block the bill's passage using legal tools and informal contacts. When the act was passed, pharmaceutical companies responded by filing a lawsuit against South Africa's government. They would not desist from the case before 2003, when South Africa began taking its initial steps in the provision of public ARTs. The battle sparked worldwide debate. United Nations Secretary General Kofi Annan was on the side of access to medication and called attention to the role that pharmaceutical companies needed to play in providing cheaper medicines to HIV-infected people. In contrast, unsurprisingly, in line with its endorsement of pharmaceutical corporations, the US government aligned alongside the pharmaceutical companies and tried to halt South Africa's attempt to provide AIDS treatment to its citizens.

The newly established South African government viewed this as a challenge to its sovereignty and to its right to improve public health. AIDS increasingly became a field of battle between patent rights and human rights-based public health, opposing international pharmaceutical companies and the South African government. While all parts acknowledged the scope of the AIDS crisis, how to go about solving the problem became the subject of significant moral and legal debate (Halbert 2012: 258). In the following years, international consensus on the necessity of access to medicines at affordable prices as a basic human right and public interest would follow. But South Africa's government was resolute to going through a more “radical” reform of its public health system. This included breaking with international pharmaceutical companies and WTO-based intellectual property rights on drugs. It was in this political climate that South Africa's government viewed Virodene (discussed above) as a “cheap cure developed in Africa for Africans”, that is, a sustainable and autonomous politico-economic solution to the epidemic. This self-gratifying sense of resisting ‘imperialist bullying’ would render HIV/AIDS the preferred arena for anti-imperialist posturing (Marais 2011: 278). As Marais puts it, Mbeki's Africanist ideology resulted in the post-apartheid HIV/AIDS response becoming entangled in a nationalist morality tale in which neither equivocation nor criticism would be tolerated.

To make things worse, the idea of cheap products fitted the government's fiscal stringency program. Fiscal austerity policies might also have contributed to Mbeki invoking out-of-date WHO data to claim that AIDS was a minor cause of death in South Africa and to health Minister Nkosazana Dlamini-Zuma declaring, in 1998, that AZT was not cost-effective because sufficient public funds for its implementation were unavailable. Now, the costs of ARVs were indeed prohibitively high for developing countries and were absorbing enormous proportions of national health budgets. However, observers suggest that budget constraints are a weak explanation by the government and what mattered the most was the South African government's lack of political will to place AIDS at the highest level of national priorities. As activists had done, health professionals and social scientists warned that providing public ARVs could be cost effective because it helped reduce the number of HIV/AIDS-sick cases at public hospitals, including children born HIV positive. In this context, the South African government failed to adopt a realistic view of, and more articulated measures against, the pandemic. In her book *AIDS and the ecology of poverty*, Eileen Stillwaggon (2006: 173) observes:

HIV/AIDS policy is constrained by a simplistic cost-effectiveness approach that would do nothing to keep a 14-year-old off the streets, but would validate

an internationally funded program to provide peer educators to warn her of HIV when she engages in survival sex with a tourist. Everyone understands that health and development are complex webs, but the interventions that are implemented are only those that pass the simplest test of single-input, single-output cost-effectiveness analysis, and such interventions are last-minute, curative, individual, and dead-end .

### **7.2.3 Psychosocial explanation**

Mbeki's denialism was much more complex than historical, institutional and economic approaches would acknowledge. As for economic explanations, particularly, analysts (i.e. Kalichman 2009: 129-132; Mauchline 2008: 3) concur on the fact that the decision to provide ARVs through the public sector requires a balance of various fiscal, political and humanitarian considerations. However, economic accounts fail to consider at least three essential points. The first point concerns the fact that, in the same manner as Brazil, the Mbeki administration could well have taken action to lower the costs of HIV treatment by means of negotiation with pharmaceutical corporations for massive discounts, getting international donations and assistance, issuing compulsory licenses to produce or import inexpensive generics. Secondly, in the heyday of denialism, it was already globally known that ARVs for the prevention of vertical transmission of HIV, for instance, would save the government money by limiting the number of HIV-infected children needing treatment. Finally, thirdly, President Mbeki was not himself the sole public face of a deeply cynical government agenda to mislead the public on AIDS in order to protect the government's budget, as demonstrated by the resistance that Mbeki experienced towards inter-government critics (including that from the Minister of Finance) and from provincial leaders (particularly Western Cape's authorities). Hence, psychosocial conspiracy explanations are needed because they provide a further key element in the puzzle.

Throughout the ANC's struggles against apartheid, Mbeki served as a public intellectual, which afforded him higher positions of power in the highest periods of the battles (Gevisser 2009: ch. 33). He had acquired those capacities through his early involvement in ANC activities, education attained in England and Russia, and his work for the ANC in exile as both a high-level operator and speechwriter. As Deputy President during the Mandela administration, Mbeki revealed himself as a triumphant and visionary leader for African Renaissance, whose conception, in combination with other factors, would result in HIV/AIDS denialism.

It is worth clarifying that denialists are suspicious thinkers prone to conspiracy theories and other eccentric beliefs (Kalichman 2009: X, forward by Nicoli Nattrass). Suspicious thinkers are predisposed to biased perceptions that sustain their generally erroneous belief systems. Indeed, suspicion, plus a sense of grandiosity and paranoia are among the foundational elements of conspiracy theories. In this sense, HIV/AIDS denialism grows out of a general suspicion that – by stating that HIV causes AIDS and ARVs are effective to treat the disease – government, industry, and science are motivated by intertwined sinister agendas. The sense of assertiveness that follows suspicion takes to challenging those established forces with heterodox measures.

HIV/AIDS denialists actively propagate myths, misconceptions, and misinformation to distort and refute reality. One of their beliefs is that the pharmaceutical industry has somehow conspired with the world's doctors and scientists to invent HIV in order to sell harmful drugs (Kalichman 2009: ch. 4). HIV/AIDS denialists treat everyone who is not a fellow as idiots and dupes. This is a psychosocial mechanism useful for them to discredit the mountains of scientific evidence on AIDS causes and treatment, and discourage any possible internal dissidence. Indeed, as Kalichman (2009: 2) states, denial is a passive coping response or avoidance. In psychological terms, denial is a nearly universal emotional defense mechanism. It is generally an immediate reaction to trauma and involves a subconscious refusal to believe the unbelievable. In this sense, denial occurs when we confront something too painful or frightening to face, providing a protective buffer zone, a time and space to assimilate a stress or trauma into one's sense of reality.

Denial involves a paradox of simultaneously knowing and not knowing (a sort of twilight), keeping us from consciously knowing and shielding our emotions from a harsh reality. However, the author warns, although denial can, for a time, serve very well as a way of adjusting to the truth, it may become maladaptive or malignant when it goes on for too long, keeping us from moving on to active coping strategies. Thus, people diagnosed with HIV/AIDS can experience denial in the process of coping with the traumatic experience of testing positive for HIV. The same can be true for those simply affected by HIV, that is, a friend, a lover, or a relative. But to be positive, denial must last a short time, maybe a few months, otherwise it may reach its most extreme case: maladaptive or malignant denial of HIV.

In South Africa, former President Mbeki's denial is an illustrating example of malignant denial: it set back prevention and care and encouraged people to delay or avoid protected sex and opportunities for medical treatment. Psychosocial explanations posit that

President Mbeki's denialism was inspired by a conspiracy-thinking-prone personality, which made him intellectually arrogant and stubborn, despite the consequent political problems he could well have predicted (Nattrass & Kalichman 2009: 126). Mbeki's mistrust in medicines and medical authorities that followed the Virodene failure has to be interpreted through the lens of conspiracy theories. Rather than relying on conventional scientific and medical expertise – which rejected Virodene – Mbeki is said to have been autodidactic on HIV/AIDS through the Internet. He went as far as trying to convince his cabinet that there was a conspiracy between pharmaceutical companies, the US CIA and AIDS treatment activists to introduce harmful medicines into developing countries. That is how he came across HIV/AIDS denialist websites, which led to mistaking credentials for credibility, placing equal value on the views of denialists like Peter Duesberg and a top South African scientist. By giving access to the world's greatest HIV/AIDS denialists in his Presidential AIDS Advisory Panel, Mbeki revealed that he was psychologically vulnerable to the rhetoric and pseudo-science of HIV/AIDS denialism. The multidisciplinary explanation of Mbeki's denialism discussed here is a good example of a comprehensive social-science of health policy to whose construction the present work aims to contribute.

### *Was Mbeki totally wrong?*

South African analysts concur on the fact that Mbeki had it right on some aspects, but he pushed his arguments too far and failed to propose a valid alternative to the problems that he sought to address, such as autonomy in biomedical interventions. Precisely, analysts agree on the fact that Mbeki did have a reasonable political and structural explanation of the epidemic, which focused on poverty as a prime determinant of vulnerability, on the lucrative spirit of the pharmaceutical industry at the expense of sick Africans, as well as on the hidden racism of the Western scientific community against Africans. But Mbeki overemphasized the belief according to which the orthodox HIV/AIDS scientific community had been corrupted by pharmaceutical companies or in any case wrong with respect to the dynamics of the pathogen and the epidemic. This explains Mbeki's option for US, European and Australian HIV/AIDS denialists as advisers to the detriment of globally acclaimed senior African scientists, notably Malegapuru Makgoba (head of the South African Medical Research Council), and Zolile Mlisana and Kgosi Letlape (successive chairmen of the South African Medical Association). This means that despite his Africanist ideology, Mbeki would rather trust

non-African scientists and pseudo-scientists whose opinions on HIV/AIDS fitted his own, rather than African scientists whose position was in conformity with the orthodox scientific canon. Let us disentangle the puzzle.

At a certain point Mbeki finally recognized that HIV caused AIDS. Subsequently, with his Africanist ideology for emancipation and autonomy, Mbeki rightly sought to combat the hidden racism against Africans that apparently played a role in US scientists developing a SIV-infected anti-polio vaccine in the Belgian Congo from which HIV might have originated. However, Mbeki failed to provide a comprehensive approach that considered, among others, deep-rooted cultural factors of vulnerability. Examples in this sense include masculinities and femininities that underpin sexual multi-partnership and shape the construction of sexuality and health protection. Neither did Mbeki adequately address the role of witch doctors, who claim to cure AIDS, in hampering people's propensity for HIV prevention.

As for the association between poverty and susceptibility to HIV, Mbeki had it right when he suggested that poverty implied malnutrition, but he was wrong in thinking that malnutrition alone could cause AIDS. Indeed, it is true that malnutrition debilitates our organism, rendering it highly vulnerable to illnesses. But malnutrition alone does not cause the AIDS disease. Therefore, Mbeki's association between poverty and vulnerability to AIDS was haplessly misinformed, since it only considered the direct link between material dispossession that leads to malnutrition and consequently to AIDS. Intimate economy in association with poverty, for example, do not seem to have been central in Mbeki's reasoning.

Mbeki was also partially right on the toxicity of AZT, the first generation ARV drug used primarily for the PMTCT. However, AZT was toxic mostly in patients with advanced HIV disease, so the main task was early detection and treatment of the virus, which was not possible under Mbeki's ideology. More importantly, in the period of denialism, ARV drugs underwent substantial technical improvement, so South Africa could well have invested in the development of more effective and less toxic ARVs, like Brazil and other middle-income countries did. Connected to increasing efficacy of ART are the politics of multinational pharmaceutical corporations. Mbeki rightly claimed that multinational pharmaceutical companies were only interested in profits and therefore broke the basic rules of scientific research and medical ethics. Consequently, he convincingly saw Africa's autonomy in the field of medicine manufacturing as a remedy to this problem.

However, as the case of the Virodene scandal illustrates, Mbeki's Renaissance project was too radical, ending up scandalously and breaking scientific rules and ethics as well. In addition, Mbeki's timing was spectacularly ill-judged because in this period, whilst South Africa's national adult HIV prevalence had already reached almost 20%, various advancements had already been accomplished in the field of HIV/AIDS combat globally. As discussed earlier, middle-income countries were embarking on international negotiations in order to make medicines cheaper and more available; Durban was hosting the biennial International AIDS Conference, which put the spotlight on the devastating African AIDS epidemic and on the need for African governments to capitalize on HIV/AIDS scientific evidence. Importantly, the Durban Conference gave international notoriety to South Africa's ineffective AIDS policies. But unfortunately, Mbeki's denialism would prevail because not only was he the head of South Africa's government, but also because he invited all the major international AIDS denialists onto his Presidential Panel on AIDS to "debate" with credible South African AIDS scientists on the causal relation between HIV/AIDS and its treatment (Kalichman & Nattrass 2009: 126). Giving equal representation to AIDS denialists and AIDS orthodox scientists, Mbeki's Presidential AIDS Panel gave the illusion of a genuine scientific contestation and the impression of credibility to fringe AIDS pseudoscientists and academics, giving denialists the space to resist the introduction of ARVs in South Africa (*ibid*). It seems that Mbeki never articulated a clear position on the causal link between HIV and AIDS, although he did say that a single virus could not cause a syndrome, which would not make him a denialist. But Mbeki questioned instead of confirming the link between HIV and AIDS (Heywood 2004).

Mbeki also rightly suggested that HIV/AIDS social theory forged in predominantly homosexually-transmitted HIV contexts and, therefore, could not be fully applied to the South African and African cases, where the infection is mostly heterosexually transmitted. But Mbeki failed to see that, by the year 2000, HIV/AIDS social-science in South Africa and globally had improved in quantity and quality. In relation to this, social scientists, including epidemiologists, had warned against the propagation of the virus across the country.

By forging ineffective HIV/AIDS policies in such a crucial period, Mbeki's denialism seriously compromised South African Renaissance. It is now clear that the uneven distribution of HIV infection across South African racial groups has compromised reconciliation, as the epidemic has contributed to the hardening of racial relations. Also,

the devastating impact of the epidemic in the country – social, political, economic and demographic – poses serious questions about South Africa's state capacity to cope with, for example, AIDS-related orphaned children and family disintegration, as well as occupations for PLWH, not to mention stigma and discrimination.

### **7.3 The significance of state-civil society relations**

Civil society is of prime significance in democratic societies.<sup>57</sup> It fosters social development from below, by pressing institutions to act in the collective interest. The relationship between state and civil society in Brazil and South Africa is one important aspect that greatly shaped and impacted upon the respective HIV/AIDS policies. In particular, the quality of Brazil's and South Africa's relations with the respective social movements dealing with the epidemic played a pivotal role in the two countries' capacities to roll out HIV prevention and treatment activities. In this regard, it is here argued that Brazil's prompt and effective response to the epidemic was facilitated by the symbiotic dialogue between the state and the Sanitarian Movement, whilst cold and conflictual relations between politics and the Treatment Action Campaign (TAC) contributed to South Africa's failure to handle the epidemic with appropriate measures. HIV/AIDS biomedical science was particularly affected by such relations (by implication, the same applies to the production of social-science knowledge and its circulation across policy-makers and stakeholders). Brazil was far superior to South Africa in managing the battle over HIV/AIDS scientific knowledge in the sense that there was significant convergence

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<sup>57</sup> In the present discussion, civil society is understood in its most large and historical sense, that is, as a set of associations, initiatives, movements and networks that act in the collective interest in a given social space, being simultaneously connected to and separated from the three main social sectors, namely, the state, business and the private sphere (Wagner 2006: 2-27). Conceived in this way, civil society refers to actions that take place in the public sphere and which are characterized by non-violence, debate, self-organization and recognition of diversities. Civil society formulates criticism about an array of social problems in contemporary society, starting from those related to political participation in its fight against the state's patriarchal attitude or injustice. Indeed, according to Wagner, the concept of civil society has historically been used to explore the possibilities and the limits of collective self-determination at the onset of democratic revolutions. It gradually declined during the institutional consolidation and normative acceptance of democratic systems, and re-emerged recently for the renewal of democratic impetus, deemed as threatened or emptied by the domination of bureaucratic agencies and market interests. For example, over the last three decades or so, the renewal of civil society has been observed in central and eastern Europe in the wake of claims for civil rights against communist-style authoritarian governments, as well as in South East Asia and Latin American countries, where the backstage and the consequences of political participation are discussed with particular focus on democratic institutions and economic development.

between Brazil's politics and the Sanitarian Movement on how to deal with HIV/AIDS biomedical measures, and more precisely, on the fact that ART was the sole way to treat HIV. By contrast, the battle over ART provision was rather pronounced in South Africa, opposing the denialist government against the pro-ART TAC.

### **7.3.1 Brazil's Sanitarian Movement and South Africa's Treatment Action Campaign**

Although social movements in both Brazil and South Africa collaborated with policy makers in the early responses to the HIV/AIDS epidemic, their relationships with the state were increasingly divergent. In Brazil politics opened up a public space that enabled civil society to become a central actor in the construction of an integrated response to HIV/AIDS, in which the Sanitarian Movement played a great role. Conversely, in South Africa the TAC had to confront the government's hostility to public ART roll-out, and saw its efforts to provide prevention education and treatment literacy in communities unbacked by the state. In particular, Brazilian AIDS activists in the Sanitarian Movement played a pivotal role in the development of health-policy oriented to HIV/AIDS and have worked closely with the National AIDS Program since the early 1990s. We shall here look at the Brazilian case in detail.

Long before the federal government took action against the epidemic, AIDS movements (and NGOs) had already reached out to extremely marginalized populations, providing them with HIV/AIDS knowledge, treatment and care (Berkman et col. 2005: 1169). In this way, by establishing the National AIDS Program (NAP) in 1985, among other aspects, movements' solidarity with PLWHA had already made history throughout the country and it could be observed beyond care activities carried out by religious entities.

Brazil's social movements emerged in the 1970s during authoritarian regimes from progressive middle-class experiences in dialogue with left-wing political parties, as well as academia and the scientific world generally (Corrêa & Cassier 2010: 30-32). Brazil's Sanitarian Movement emerged during the democratization process in the 1980s from progressive health professionals, before AIDS grassroots NGOs joined the movement.<sup>58</sup> The Sanitarian Movement would influence the formulation of public

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<sup>58</sup> Grassroot AIDS NGOs in Brazil emerged specifically for the advocacy and psycho-social support of PLWHA. Their projects were based on principles of solidarity, human rights and anti-discrimination. Important examples are represented by the *Grupo pela Valorização, Integração e Dignidade do Doente de Aids (Pela Vidda*, Rio de Janeiro), *Grupo de Apoio à Pessoas com Aids (GAPA*, São Paulo). These were

health programs, including those aimed at reducing the power of pharmaceutical multinational companies, for national interest in terms of the expansion of health care (ibid). Concerned primarily with the expansion of public care covered by the public sector, the Brazilian Sanitarian Movement sought to foster debate about, and take action for, government's transparency in the field of health management, which implied communities' social control of, and participation in, *Conselhos de Saúde* (Health Councils) - the latter being a set of bodies at national, state and local level, aimed at society's intervention in health policy, particularly through the enforcement of the SUS foundational principles (universality, equity, integrity). With the advent of democracy in 1986, many actors from the Sanitarian Movement entered political institutions and played a key role in designing the SUS.<sup>59</sup>

When the HIV/AIDS crisis grew during the 1980s, civil society organizations in São Paulo and Rio de Janeiro rallied around the issue, formed NGOs and began pressing the government to develop HIV/AIDS prevention and treatment programs (Galvão 1997, 2000). Favored by the political will to tackle the epidemic with appropriate measures and long-term partnerships between the state and civil society, HIV/AIDS became a new battle ground for civil society organizations committed to health development. This was the most appropriate moment for the Sanitarian Movement to fight for increased public health coverage. *Sanitaristas* began education and anti-stigma campaigns, and established informal partnerships with policy-makers, which were legally formalized in the early 1990s when AIDS activists were asked by the ministry of health to help draft World Bank loan proposals for HIV/AIDS assistance in order to improve the National AIDS Program (NAP) (Nunn et al. 2012: 5). Thanks to the World Bank loans, Brazil's NGOs were

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historically connected to organizations that in the first decade of HIV/AIDS were already politically organised, namely homosexual, feminist, black and haemophilic groups. In particular, according to Edward MacRae (1990), by the end of the 1980s, the battle for equal rights for homosexuals had been successful in: firstly, constructing durable networks and “sharp sexual identities” that promoted homosexuals’ positive attitudes, which militated against sentiments of guilt and illness-abnormality; secondly, pushing the printed press to less discriminatory attitudes and the inclusion of sexual orientation in the journalistic non-discrimination ethics code; and, thirdly, pushing public policies in order to exclude homosexuality as a form of disorder from the National Institute Social Security’s Code. As Veriano Terto Jr (1996, 1999, 2002) pointed out, the existence and activism of homosexual organizations would be crucial in the struggle against HIV/AIDS, when the epidemic expanded in the country, as they provided expertise and political resources to AIDS organizations.

59 With the coming of Lula's Workers' Party to power, the shift of sanitarians to the center of power has revitalized the debate about state-society relations in Brazil, which includes discussions about the cooptation of leading activists with the government in relation to the capacity of local administrations and communities to cope with the ongoing decentralization of HIV/AIDS services (Interviews: Ivo Brito, 7 Nov 2012; Veriano Terto Jr. 19 Nov 2012).

granted financial resources to support their HIV/AIDS education campaigns and advocacy, which also incentivized civil society organizations in general to form (World Bank 2004). Within the ministry of health, since the mid-1990s, every director of the NAP has been either a *sanitarista* or part of a specific AIDS movement (Galvão 2002; Nunn 2009). In the field of treatment, for instance, access to ART had been sporadic until 1996, when HAART was approved. As soon as they assumed the leadership at the NAP, *sanitaristas* prioritized development of health infrastructure to promote widespread provision of HAART and to lower ARV prices (Nunn et al. 2012: 6). On the wave of mounting social pressure to respond to the AIDS crisis, NAP-based *sanitaristas* played a great role in lobbying Brazil's Congress to pass a law (the *Sarney law*) guaranteeing free and universal access to HAART. The implementation of the 1996 law helped the government to make extraordinary efforts to manufacture generic ARV drugs and reduce prices for patented medicines. This was associated with the fact that Brazil's Health Minister José Serra challenged multinational pharmaceutical companies on drug policy, forcing them to lower medicines prices, also through Brazil's power in the international negotiations, culminating in the 2001 TRIPS agreements, which facilitated such advances in developing countries. As a result, HAART became available in public clinics on a massive scale, even in remote areas. The number of PLWHA receiving HAART increased from 35.000 in 1997 to over 200,000 in 2009 (UNAIDS 2010). Ultimately, AIDS-related mortality and morbidity have declined dramatically as a result of early introduction and massive nationwide implementation of HAART (Dourado et al. 2006). The availability of treatment is also reported to have contributed to de-stigmatizing HIV/AIDS and prompting people to get tested for HIV, particularly vulnerable groups like sex workers, IDUs and pregnant women (Galvão 2005). The role of Brazil's civil society organizations was crucial in fostering science upon which these advancements relied. In 2001, in Rio de Janeiro, the Sanitarian Movement even created a scientific group devoted to the analysis of intellectual property laws related to medicines (*Grupo de Trabalho Propriedade Intelectual: GTPI*), a work that helped to scrutinize the state's duty to guarantee ARV drugs to all persons in need as a fundamental basic human right, in opposition to pharmaceutical companies' interests (Villela 2010; Reis et al. 2011a, 2011b). In doing so, civil society also demonstrated that, in the neoliberal context, politics has the duty and the capacity to put pharmacological science and industry at the service of public health by producing generic

drugs and lowering the price of patented drugs for a more equitable access to ARVs (Corrêa & Cassier 2010: 141-176).<sup>60</sup> We shall now turn to South Africa.

Before the TAC was founded, civil society sectors had warned against an imminent AIDS epidemic in South Africa, but did not find a sufficiently positive response from the government in South Africa's democratic transition. As Mandisa Mbali (2013: 27-48) and Hein Marais (2011: 277) have documented, much before the TAC emerged, progressive public health workers were alarmed enough to attempt to model the likely course of the epidemic. As early as 1990, surveys had found that 0.76% of pregnant women attending antenatal clinics in South Africa were infected with HIV. Health professionals urged for a proper national AIDS plan to be ready at the advent of democracy in 1994. A team of specialists composed by Jonathan Broomberg, Malcolm Steinberg and Patrick Masobe predicted that by 2000, 5.2 million South Africans would have become infected with HIV and by 2005 there would be 2.9 million cumulative AIDS related deaths. In fact, NACOSA was largely a response to those health professionals' worries and was adopted by the Mandela government. Nevertheless, AIDS and its co-passenger TB did not truly become national priorities and NACOSA did not match up with the complexity of the epidemic in South Africa. Consequently, the health professionals' forecasts turned out to even underestimations of the level that the epidemic would reach in the country. Marais quotes journalist and historian R. W. Johnson as saying that it felt 'a bit like sitting in an oceanographic laboratory waiting for a tidal wave to hit'.

Equally, exiled anti-apartheid leaders soon warned about the spread of HIV in South Africa. This is the case of Chris Hani, a leader of the South African Communist Party, who urged the ANC to learn how to tackle the epidemic head-on, when he partook in the Maputo 1990 and Lusaka 1991 AIDS conferences (Marais 2011: 116). But Chris Hani's call could not find prompt response in such a "unique" African country. Indeed, largely due to South Africa's comparative higher level of development in the region and relative closedness given by apartheid, South Africans have developed a self-understanding that could be described as exceptionalism in face of the rest of (Southern) Africa. By the early 1990s, this sentiment of exceptionalism, rather than giving birth to developed country-like strategies of prevention and treatment of HIV, made South African society at large assume that the devastation of the epidemic in Mozambique, Zambia, Malawi or Uganda – "such different African societies" - could not reach South Africa at all. At a political

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<sup>60</sup> For a general discussion on ARV differential pricing and the related international negotiations see Patrizia Danzon (2003), Prashant Yadav (2010), and *Medicins Sans Frontières* (July 2013).

level, exceptionalism-prone self-understanding contributed to post-apartheid South Africa failing to learn from positive experiences of AIDS interventions across the (sub)continent, like those of Uganda and Senegal, the most successful African anti-AIDS examples. This was in stark contrast to Brazil: looking at Latin America's experiences, particularly the disastrous case of Haiti, one interesting slogan in Brazil was *O Haiti não é aqui* (Bastos 2006: 65-83), which we can loosely translate as "We are not Haitians/Brazil is not Haiti", suggesting that Brazil could and wanted to deal with the HIV/AIDS epidemic much better than Haiti. It is against the South African government's failure to address the HIV/AIDS crisis that the TAC (has) worked.

In stark contrast to Brazil, where the AIDS-oriented Sanitarian Movement partnered closely with the federal AIDS program, in South Africa the TAC functioned largely independently of, and in opposition to, the public sector because the ANC government failed to prioritize AIDS. Despite opposing Mbeki and Tshabalala-Misimang's AIDS policies, the TAC has reportedly maintained its loyalty to the ANC. This has facilitated the improvement of the relationship between the TAC and the state since 2009, when the newly elected Jacob Zuma appointed a new Health Minister, Aaron Motsoaledi, and started to prioritize HIV/AIDS. After thousands of AIDS-related deaths, the history of the TAC's struggle for universal access to ART has contributed to improving HIV/AIDS policies, including the provision of HAART to approximately one million people. Also, in 2010 the so called "Know Your Status" campaign (a UNAIDS-promoted policy to reduce HIV incidence by 50%) was launched in South Africa. However, the adversarial relationship between the South African state and civil society, here represented by the TAC, has contributed to South Africa's poor outcomes in HIV treatment: as of 2010, approximately 1.9 million people were still in need of HAART and other AIDS-related services (UNAIDS 2010). We will now concentrate on the TAC's actions.

In contemporary South Africa the TAC spearheads civil society leadership in the field of HIV/AIDS and is one of the most visible social movements to emerge after the end of apartheid (Colvin & Robins 2009: 157; Geffen 2010; Mbali 2013: ch. 6). The movement strongly opposed the government's reluctance to provide ART. The TAC was established in December 1998 by a group of activists from within and outside NAPWA following tensions that emerged in the organization over strategic direction. This occurred when around fifteen people demonstrated on the steps of St George's Cathedral in Cape Town in order to demand ART for PLWH. The initiative was successful: in a few days the protestors collected over a thousand signatures calling on the government to develop a

treatment plan for all PLWH. From then on, the TAC's membership base has grown notably, attracting mainly young urban Africans, mostly female<sup>61</sup>, unemployed, and with secondary schooling. However, the TAC has also managed to attract middle-class health professionals, journalists, academics, and university students. The TAC's international visible face, Zackie Achmat, a former anti-apartheid and seropositive activist, played a great role in politicizing the movement's fight for universal access to ARVs globally. Achmat went as far as refusing to undergo life-extending treatment, until then available in the private sector, almost until 2003 when the government was finally instructed by the supreme court to provide ART publicly. This strongly contributed to the TAC becoming the most transformative HIV/AIDS social movement in South Africa and a global icon of AIDS activism:

The TAC has not only recast the political and legal environment in South Africa through its lengthy, vigorous and creative campaign to ensure access to anti-retroviral treatment (ART) in the public sector; it has also changed the social landscape of many communities and improved the personal lives of its many members and supporters. Christopher Colvin (2009: 157).

The TAC was the main protagonist of the process that mobilized communities and took Mbeki's government to court over the provision of ART, evidencing the necessity for the government to follow the steps of HIV/AIDS scientific authorities (Mbali 2013: 120-200). Indeed, as Nunn et al. (2012: 5-6) summarize, the TAC developed a national network which built grassroots support for AIDS policy reform, promoted treatment literacy and HIV prevention, and worked to de-stigmatize HIV/AIDS. Backed by the Congress of South African Trade Unions (COSATU), church organizations, and US AIDS activists, the TAC challenged the government, pharmaceutical corporations, and health service providers to bring AIDS treatment to South African public health facilities. The TAC also pressured the government with widespread social mobilization, public protests, media campaigns and legal action to promote and enforce policy change. It was through these efforts that in 2002, the TAC, in partnership with the AIDS Law Project, brought and won a case against the government to force the implementation of a national PMTCT program. The following year, the TAC commenced a civil disobedience campaign which, amongst other positive changes, resulted in President Mbeki's cabinet overruling his opposition to providing ART in the public sector, culminating in the

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61 The PMTCT of HIV was prioritized in the initial phase of TAC's activism. This, together with the feminization of the epidemic in the country, plus the fact that community education and lower sectors of public health systems are generally carried out overwhelmingly by women, might explain the large amount of female membership in TAC.

country's first commitment to providing HAART. Even after 2003, the TAC's victories were hampered by Mbeki administration's ongoing opposition to HAART roll-out and PMTCT program. Health Minister Manto Tshabalala-Msimang went on promoting unproven medical therapies for AIDS treatment such as vegetables-based diets. But the TAC's legal victory would radically change the panorama of HIV/AIDS policy in South Africa. In particular, pharmaceutical companies were defeated and shamed by the TAC and eventually dropped their legal challenges against the Medicines Bill that they opposed. The impact of the TAC's work on the social introduction presentation of HIV medication in South Africa merits a few more words. Against the state's reluctance, better yet, antipathy towards ARV drugs and the HIV/AIDS scientific canon (Geffen 2010: ch. 4; Natrass 2008: 163), the TAC's capacity to mobilize different segments of society, as Martin-Tuite (2011: 17) describes, "signaled a gradual reframing of scientific authority to pockets of South Africa, whereby the public no longer viewed scientific knowledge as exclusively for elite, educated professionals but also for broader public understanding". In doing so, unlike the ANC AIDS policies until 2003, in a way the TAC's activism reconstructed the South African nation by forging social cohesion around the epidemic. Combining law and social mobilization to enforce the right to health was one of the TAC's winning strategies (Heywood 2009).

In its heyday, Mbeki's controversial AIDS policy also pushed the TAC to more radical positions against the ANC government's arrogance and centralized power, which increased the movement's activism, domestically and internationally. Domestically, the TAC also established alliances with *Médecins Sans Frontières* to set up and run two pilot AIDS clinics in the Khayelitsha township, Cape Town, and Lusikisiki town, in the Eastern Cape province, the two being resource-poor settings. Importantly, the TAC capitalized the success of these clinics to demonstrate to the government and to reluctant international donors that it was fruitful, cost-effective and sustainable to provide ART in resource-poor settings. Internationally, the TAC's established links with US and Brazilian AIDS activists, as well as global-health policy-makers whose support encouraged the TAC to pursue its objectives domestically and globally. Examples include the TAC's advocacy for extended ART to all HIV-positive persons in the biennial AIDS International Conferences (2000 in Durban, and 2002 in Barcelona), plus the Doha WTO/TRIPS Agreement in 2001, which liberalized the production and importation of generic drugs so that developing countries could afford basic medicines for their citizens (i.e. Mbali 2013: ch. 7).

### *Interim concluding remarks*

There are various institutional aspects to consider in national and international contexts when analyzing the success of Brazil's Sanitarian Movement and South Africa's Treatment Action Campaign in their demands for extended access to HIV medication and adherence to the related science. The democratic nature of the two countries' constitutions, as well as the autonomy of the judiciaries, overseen by the rule of the law, are among the noteworthy institutional resources that benefited the two movements. Nationally, Brazil's judiciary supported breaking with medicines patents. In the case of South Africa, the TAC's invoking of the South African constitution contributed to the court instructing the government to introduce public ART regimes in 2003 (Robbins 2008).<sup>62</sup> Internationally, the human rights framework played a crucial role as well. Both movements used these legal tools to lobby the respective governments and global health-policy makers for extended life-saving treatment in the name of "health for all". In the case of Brazil, this strategy helped health Minister José Serra to break pharmaceutical companies in 2001, following the TRIPS agreement, which would contribute to Brazil enhancing its treatment policy and becoming a world leader both in ART provision and in generic ARV manufacturing (Berkman 2005 et al.: 1171).

The two movements use the courts system to bring cases against the government to promote wider and equitable access to health and HIV medication. It was largely thanks to the courts being notably independent and autonomous institutions from the government that they could freely give legal standing to the claims of AIDS movements and define the legal obligation of the state to provide ARV drugs (Nattrass 2003; Scheffer et al. 2005; Nunn et al. 2012: 11). This is more clearly observable in the case of South Africa, where the TAC brought a court case against the government for publicly denying the efficacy of ART and opposing HAART provision for the PMTCT, despite new evidence that PMTCT could dramatically reduce vertical transmission of HIV and so diminish the burden of the public health system caused by the large number of HIV/AIDS patients. It was due to its freedom and autonomy that South Africa's high court and constitutional court ruled the government should implement a national ART program with particular attention to the PMTCT.

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62 See also 'Legal and Human Rights Responses to the HIV/AIDS Epidemic in South Africa' by Edwin Cameron, available from <http://www.escri-net.org/docs/i/403060> (Accessed on 28 August 2014), and *Judging the epidemic: A judicial handbook on HIV, human rights and the law* by UNAIDS, available from [http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2013/201305\\_Judging-epidemic\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2013/201305_Judging-epidemic_en.pdf) (Accessed on 28.08.2014).



## Concluding reflections: key thematic issues emerging from the comparison

*Social problems have always been of prime significance in stimulating the sociological imagination [...].*

Chachage Seth Chachage (2004: 60)

### A. Looking sparsely at some issues

The trajectories of HIV/AIDS social-science in Brazil and South Africa teach us that a comprehensive and engaged scholarship is crucial for understanding health policy, and for social scientists' capacity to make the difference in health promotion. We also learn that for social scientists to play a significant and positive role in the national problem-solving agenda political will and openness on the part of the state is needed.

Engaged scholarship also constitutes a good opportunity for scientific innovation. Overall, from the discussion presented so far, we can firmly conclude that social sciences in Brazil and South Africa (indeed globally) have been profoundly affected and renewed by HIV/AIDS engaged scholarship since the early 1990s. Social sciences now look more closely at sex, sexuality and reproductive health, as well as human rights and gender relations. Theoretical and methodological diversification of the social-science oriented to health are also among the epistemological implications of the HIV/AIDS scholarship. In Brazil and South Africa, engagement with HIV/AIDS has boosted the consolidation of working groups and thematic areas related to sexuality and health (chapter 4), facilitating dissemination of research works across academic entities, the state and civil society. In social medicine institutes issues that are somehow related to the HIV/AIDS epidemic have increasingly been addressed in dissertations which, among other aspects, imply increased research and training in the field. Canesqui (2007) characterizes this change as a sign of vitality of social sciences, given not only by increased attention to social problems and problem-solving approaches, but also by a shift from disciplinary boundaries to disciplinary flexibility and non-totalizing theories (I will come back later to this point). Reflections about the combination of quantitative and qualitative approaches, as well as the systematization thereof, have been inevitable. Moreover, the challenges posed by the complexity and the urgency of HIV/AIDS have led social sciences to build closer connections with epidemiology, public policies, the pharmaceutical industry, and civil society organizations dealing with the pandemic. By implication, extensive literature on

HIV/AIDS is now available, which means that a large and varied amount of HIV/AIDS dimensions are being studied, including the impact of ART on social life, in the form of hope, longevity and attention to human dignity and citizenship rights.

South Africa is now making efforts to make up for its delay in reversing the epidemic. This includes increasing domestic production of ARVs – an old challenge, in fact – and coping with changes characterizing many countries. Such challenges include: the involvement of communities, PLWH, CSW, IDUs in prevention initiatives, and positive prevention.

Brazil's successful and South Africa's controversial and unsuccessful responses to the epidemic have particularly served as opposite examples on which to build scientific discourses about rights-based health-coverage. In this sense, social scientists operating in global health management have underlined the need for looking at the international dimension of the pandemic, especially in terms of the struggle for rights to health. As Ann Swidler (2009: 130-131) points out:

AIDS has in some ways been the poster child for a global commitment to health. AIDS is worthy of special attention in part because it appeared during an era in which an emergent “transnational citizenship” has made the welfare of all people everywhere seem to demand global care and concern... the emerging rules of the global order – from international tribunals to transnational political campaigns – have increasingly created a global cultural understanding in which all individuals have human rights that transcend their nation-bound citizenship rights and every collectivity has claims on the world’s conscience.

The global vision on the epidemic has clarified that in the absence of a vaccine or cure, tackling HIV/AIDS will continue to rely on prevention through holistic approaches that combine medical, economic and relational resources at local and national level. This means a focused analysis of structural determinants of the epidemic that transcends information approaches. Particular emphasis is placed on the combination between economic power and symbolic power (i.e. status). This involves improving both individuals' power to negotiate and control their sexual life and health, and communities' power for collective action in terms of local HIV prevention initiatives.

This is of utmost importance for clarifying that the emphasis on structural factors does not mean complete abandonment of behavioral approaches. It means that behaviors have to be addressed in face of the economic, socio-cultural and political contexts in which they are embedded. For example, *ceteris paribus*, high economic status may help delay sexual debut – which is a behavioral strategy deemed to reduce HIV/STIs susceptibility

among adolescents (i.e. Pittfor et al, 2009: 88; Wand & Ramjee 2012: 7) – because not only can high economic status imply better educational records, including sexual and health education, but it also motivates people to have better life projects that inhibit them from, for example, engage in potentially risky compensatory sex.

Interdisciplinary approaches are needed to understand the relationships between the different levels at which HIV/AIDS operates, and to support the development of effective, multi-level, and multi-sectorial interventions. In their introduction to *Learning from HIV and AIDS*, Ellison, Parker and Campbell (2003) discuss the importance of moving from multi-disciplinary syntheses to dedicated inter-disciplinary work – a change in research culture they arguably see as crucial to understanding the biological, social and political complexity of HIV/AIDS. Indeed, HIV/AIDS has forced scholars to go beyond their traditional boundaries and revise their identities in terms of the scopes of their objects, methods, theoretical assumptions, and relation with extra-academic worlds – as we have seen in the case of harm reduction and peer education (5.2). The sociology of controversy and ethnography and critical writing are among such enterprises that now go beyond the classic conception of science neutrality. As we have seen, Brazil's and South Africa's epidemics have particularly encouraged the combination of various approaches, including historical, economic, social and psychosocial, to explain the divergence in their responses to the epidemic.

Today, Brazil's HIV/AIDS policy is domestically criticized by a coalition of health professionals, civil society organizations, and social scientists. These actors argue that rather than a “model”, it is today more appropriate to talk about “Brazil’s good experience”, because in recent years political and financial investment in HIV/AIDS activities have decreased, especially with regard to the involvement of civil society (i.e. Veriano Terto Jr, Interview 20 Nov 2012). By consequence, they argue, not only are the government’s HIV investments insufficient in historically “risk groups” (MSM, CSWs, IDUs), but they are also unable to understand the new cases of contagion in age groups that had remained largely untouched by the epidemic: 12-18 year-olds, 50-60 and over. Civil society organizations like ABIA also criticize the government for “co-optation” of their leaders in the centres of power, thus impoverishing AIDS civil society at large. The government responds to these critics affirming that, regarding the co-optation argument, with the coming of Brazil's Workers Party to power, the entering of AIDS movement leaders into politics and institutions is part of a normal process in state-society relations in a dynamic country. On their part, AIDS activists rebut this by pointing out that they do

indorse the project of a strong state, but such strength should primarily imply appropriate involvement of civil society and its autonomy. As for financial support, the government declares that AIDS movements have not been able to adapt to the neoliberal context, being excessively dependent on both government' funds (since the international loans ceased in the late 1990s) and AIDS-only projects. Therefore, the government is urging civil society organizations to find new sources of financial support, such as philanthropic entities, or submit to the government projects which address AIDS in tandem with other social problems like land restitution. The debate on the boundaries of citizenship is therefore very much alive in Brazil. However, it is correct to point out that whatever the case, as in various contexts, in Brazil the relation between the government and civil society on development projects is less problematic when civil society is not sharply critical of the government. The controversy is generally more easily observable at local level, where the current decentralization of public health services reveals important contradictions between good policy planning and its effective implementation, and poor settings and groups being the most disadvantaged. The call for a secular state in Brazil, is also mentioned by researchers and health practitioners, as a major challenge in today's struggle against the HIV/AIDS epidemic. Indeed, the Brazilian government has recently appointed figures from evangelical groups the Congress for key positions in health and human rights departments – dismissing historical progressive figures – who go as far as attempting to ban HIV/AIDS peer education among prostitutes, and proposing a “gay cure” (Malta & Beyrer 2013). The role of conservative evangelic churches are indeed detrimental to HIV prevention in South Africa as well, since they focus unrealistically on abstinence and sexual mono-partnership as the main very prevention method (Furrah Simbeku, interview 23 May 2013).

Adult medical male circumcision as a prevention method is now being largely rolled out in South Africa, especially among communities who traditionally practice male circumcision as a passage rite to adulthood and/or for religious purposes (i.e. Xhosa, Muslims, Jews). Advocates (i.e. Alan Whiteside, interview 29 May 2013) suggest medical male circumcision be routinely rolled out at maternal hospital settings for newborns, provided that parents freely decide to get their male babies circumcised. Brazilian society and authorities exclude male circumcision as an HIV prevention method on the grounds that: the efficiency of such a measure has not been sufficiently demonstrated, the practice does not match with the Brazilian mainstream culture since it implies genital mutilation, offending human integrity because of it. Furthermore, even in South Africa, medical male

circumcision is a central subject for debate and disagreement. One related debate concerns disinhibition mechanisms whereby circumcised men could feel exempted from protected sex and reduced sexual multi-partnership. Critical scholars such as Mary Crewe, Ray Lazarus and Pierre Boulard (focus group interview, 4 June 2013) go further by observing that medical male circumcision is part of the HIV/AIDS clinicization process in South Africa (I will come back to this later on), which reflects the predominance of the biomedical model in the national approach to the epidemic. They posit that male circumcision is unethical and has tremendous gender consequences, since a circumcised penis is viewed (by supporters who value male circumcision as an adulthood passage rite) as esthetically more appealing, hygienically better, and circumcised men are considered “more men”. According to these scholars, medical male circumcision is also loaded with implicit racism because it targets blacks and their communities (i.e. townships). In this way, it even foments traditional cultures which are detrimental to modernity, since traditional leaders who are supportive of ritual circumcision play a great role in promoting this practice. Furthermore, the authors suggest, male circumcision is problematic in relation to sexual citizenship: “you lose the right to your sexuality and become a subject of the people who roll out medical male circumcision”.

Race is a crucial issue in health matters. In South Africa, race has historically been a central issue in public health debates. Today one tough issue concerning race and HIV interventions regards the question whether to target (poor) black people – the MARG – or follow the UNAIDS framework that points to the entire population in accordance with the Zero HIV/AIDS Model. The full scale up model is based on the assumptions according to which people are interrelated, for the virus can travel across populations, plus the fact that even the lowest HIV incidence in a given group must be eradicated as soon as possible. Well, generally speaking, my interviews with experts and practitioners reveal that, taking extreme positions, black people are in favor of the full scale-up model as a way to de-racialize HIV/AIDS policies, whilst white people advocate for what I would term as “positive racialization” of interventions, as opposed to full scale up, under the assumption that racial groups in South Africa live in rather “separate worlds” that do not allow for significant interracial sexual relations. In addition, white South Africans generally possess sufficient economic and social resources, as well as awareness, which protects them from pockets of infection, so to speak.

As we have seen, Brazil's history does not show such a level of explicit debate on race. However, in recent years the subject has been increasingly problematized in association with both affirmative action policies and massive use of the race variable in health statistics, the latter being useful for enlightening race-based socio-economic disparities that affect health. These debates can be observed within the Brazilian Sanitarian Reform Movement: historically Marxist-oriented in its social analysis, for which class is the very key explanatory concept and race the least important one, the movement's new generation now challenges that way of understanding in relation to unequal access to health. One question stemming from these debates is whether, considering the progressive pauperization of HIV/AIDS in the country and considering that non-white populations are generally economically disadvantaged, Brazil's (white) political will to tackle the epidemic will be there in the foreseeable future (Deividson Faustino, interview 5 Nov 2012). This worrying question has recently triggered academic debates focused on Afrodescendants' access to HIV/AIDS and health services generally. This is the case of the First *Simpósio Nacional de Saúde da População Negra e HIV/AIDS* which took place at the UNICAMP in May 2010, and whose findings were published in 2011 in *Saúde da população negra HIV/AIDS: Pesquisas e práticas*, by Campos et al. The event and the publication congregated researchers, health professionals, and social movements activists who underlined that Afrodescendants' disadvantages in income, social and educational fields, as well as in access to health services, makes them delay HIV diagnoses and treatment. The sustainability of HIV/AIDS policy and the protection of minorities' in the name of social justice are part of the background of such debates in accordance with the foundational principles of the Brazilian health system, namely, equity and equality. Accordingly, racism at societal and institutional level is increasingly being problematized. Poor black women are unexpectedly identified as particularly vulnerable to the infection, which simultaneously confirms the increasing pauperization and femininization trend of the HIV/AIDS epidemic in Brazil. In general terms, more research on the racial dimension of HIV/AIDS in Brazil and South Africa is needed (Interviews: Deividson Faustino, 5 Nov 2012; Alan Whiteside, 29 May 2013). So is the comparative analysis between Brazil's novel policies which now emphasize the race issue and South Africa's commitment to de-racialization.

## **B. Reflecting on the challenges to peer education**

Peer education is undoubtedly one of the most popular educational approaches to HIV/AIDS and health promotion in general, especially among young people. It has already been made clear that peer education faces enormous difficulties in poor settings (3.1.2), where people are often unable to build durable forms of solidarity for facing pressing issues that require strong collective action. In school contexts, HIV/AIDS peer education has surely helped to increase critical thinking, improving the situations that undermine human and youth development in terms of assertiveness and the sense of agency: rigid control of the programs on the part of teachers at the expense of students' interaction approaches; excessive stress on biological aspects of HIV/AIDS and scarce attention to social dimensions such as sexuality and gendered relations; limited opportunities of discussion between young people and adults or boys and girls.

In South Africa, particularly, the improvement of HIV/AIDS policy since 2003 has led to the increase or strengthening of university-based centers devoted to peer education, which involves condoms distribution and education, HIV testing, and counseling. HIV/AIDS-related curricula modules and research works, including student dissertations addressing HIV/AIDS have also increased since the mid-2000s. (All this has encouraged social-science engaged scholarship: critical, public, cameral).

However, a lot remains to be done and this has been extensively documented since the 1990s (i.e. Milbrun 1995; UNESCO 1999). Peer education has been strongly criticized for various reasons and from different angles. Schematically, critics of peer education fall into two groups, which together provide a picture of peer education lacunas in the representation of peer education, as well as in its design, implementation and evaluation (Cornish & Campbell 2009; Calazans 2012). The first focuses on the methods used by peer educators, arguing that whilst peers may be best placed to reach marginalized groups, most programs use outdated teaching methods, involving the linear transmission of technical information, rather than the construction of truly equal relations. Peer educators generally portray themselves as “little teachers”, that is, the main prevention agents in front of their peers (Calazans 2012: 140-152 after Ayres et al. 2003; Oliveira & Silva 2012: 279). In this way, peer educators play the role of active experts in front of a passive audience to whom information is offered. In this sense, peer education has not made significant steps forward when it comes to interaction and negotiation in the process of information elaboration and transmission. In other terms, peer education programs often lack dialogical educational approaches, which are more likely to lead to the development

of critical views and the building of collective action, whereby young people can challenge the status quo and engage policy-makers.

One corollary of this criticism refers to substantive issues, maintaining that peer education tends to focus on the distribution of condoms, how to wear them, how to negotiate their use in a sexual relationship, etc. The social dynamics that create HIV vulnerability such as poverty, early sex and values related to patriarchy, misogyny, for example, are largely disregarded by peer education practices (Mary Crewe, interview 4 June 2013). In connection with values, we find a rights and human dignity framework, which is said to be overlooked in peer education actions. One related issue is the fact that, as Catherine Campbell et al. (2002) observed with reference to the South African case, investigations about peer education tend to be fragmented and descriptive, rather than comprehensive and analytical, and are consequently unable to systematize the results of these studies and inform peer education-based interventions.

The second group of criticisms focuses on the contexts of peer education, arguing that programs need to be supported by health-enabling social contexts. In this sense, the improvement of material and symbolic conditions as well as community mobilization have been advocated. Furthermore, peer educators are wrongly romanticized and viewed as a sort of super-heroes, both in terms of duties attributed to them and in terms of expectations as agents of social change (Tomaz 2002, cited in Oliveira & Silva 2012: 280). Indeed, prevention through peers should only aim at maximizing efforts already being made by institutions and other social actors, in whose framework peer educators are expected to contribute in revising the social representations of HIV/AIDS, as well as the construction of social capital. In this sense, peer educators should not be seen as information owners, but rather as catalysts of doubts, questions and challenges regarding prevention, as well as life projects that can be mobilized for a creative construction of solutions, partly due to the artificial nature of the social process inherent in peer education environments (i.e. Milburn 1995). This is particularly true in poor contexts where peer educators may even feel impotent in the face of the magnitude of the existing social problems. In this regard, economic problems are among the most practical challenges surrounding peer education because peer education is generally based on voluntary or semi-voluntary work, which makes it difficult to recruit, train and keep a sufficient number of peer educators for efficient and sustainable initiatives. Economically and symbolically, rich communities which are influential in dialogue and political terms with HEIs are necessary for the sustainability of HIV/AIDS peer education.

### **C. The impact of HIV/AIDS on social movements studies**

Globally, civil society organizations, especially HIV-affected gay movements were the first actors to address the epidemic in a more nuanced manner than policy-makers did, often pointing to stigma and social exclusion as critical factors to HIV/AIDS vulnerability, which AIDS movements sought to fight through human rights discourses, solidarity, alliances and advocacy. This is important for the study of HIV/AIDS social-science because the activities carried out by HIV-affected groups have produced notable impact on social research, especially in terms of major critique and research-action. This is particularly true in high-income countries, as well as in middle-income countries with advanced AIDS programs like Brazil, where considerable links were forged between activists and researchers, giving birth to well-equipped research-action entities within the realm of social medicine (the medical area interested in social determinants of health and prevention, as opposed to merely curative medicine).

Given their historical role in fighting the epidemic, AIDS movements have been broadly studied since the 1990s, and the relative literature has increased restlessly in volume, empirical research and conceptualization. It is hard to overlook the impact of HIV/AIDS on social movements studies, since HIV/AIDS movements have provided insights into various issues related to health promotion, including mobilization, organizational capacities, and the formulation of a collective understanding of, and action against the epidemic. Applied research, particularly research-action, is one the main impacts of HIV/AIDS movements' on social-science scholarship due to bringing civil society instances into political agendas and academic works. In this sense, as suggested by Richard Parker and Peter Aggleton (2013: 38-42), drawing on their commitments with affected groups and communities, AIDS movements have helped social-science to focus on the interface between prevention and treatment policies – in combination with an emphasis on the structural factors of social vulnerability, communities mobilization, and collective action.

By articulating their activities locally and globally in an interdependent way, AIDS movements have gained the capacity to operate in today's democratic, global and neoliberal context. For social scientists, this is said to imply new ways of looking at social movements in general. The core argument is the following: the social movements that emerged in the 1970s and 1980s were concentrated on class and state questions, whereby

they boosted the process of politicization of everyday life, reconstruction of civil society and, ultimately, democratization. Accordingly, the 1970s-80s social movements struggled for social justice in terms of expanding economic prosperity and citizenship rights, whose attainment involves political autonomy, representation, and responsibility. Consequently, social scientists emphasized social movements' emancipatory and radical potentials, developing new theories on how these potentials could be translated into political mobilization and social change in various contexts (i.e. Laclau & Mouffe 1985; Touraine 1985). Now, the ultimate goal of social justice has been maintained by the social movements that emerged in the 1990s like the ones dealing with HIV/AIDS, but social research has focused mostly on movements' capabilities to dialectically engage with political and economic structures in the new context of democratization, globalization, and neoliberalism (i.e. Brown & Zavestoski, 2004; Castells 2000; Touraine 1998; Escobar & Alvarez 1992). Alliances, a key strategy for AIDS activism constitute a key field of social research today, worldwide (i.e. Aggleton et al. 1991).

Ethnographic approaches to social movements seem to have been predominant in these inquiries (Parker & Aggleton 2013: 40). HIV/AIDS ethnographies have particularly looked at the roles of individual and collective figures within AIDS movements – who often have some first-hand experience with the disease – both in the struggle for the availability of prevention and treatment measures generally, and in movements' relations with the state, mass media, and science (i.e. Robbins 2004; Parker 2003; Epstein 1996; Smith & Siplon 2006). As for the research focused on AIDS movements' battles for access to life-saving AIDS drugs, efforts have been particularly implemented to understand the cultural, political and legal norms that, until the early 2000s, in some contexts (like South Africa), portrayed AIDS life-saving drugs as malevolent “foreign poisons” within sovereign nations (i.e. Schneider 2002). Another field regards the studies about AIDS movements' struggles against the restriction of intellectual property rights on ARVs and other basic drugs within the WTO/World Bank and the UN (i.e. Petchesky 2003) - as argued above (6.2.1).

#### **D. International relations and scientific cooperation**

In this globalized world, social-science knowledge needs to be articulated through connections between national and international scientific arenas. Specifically, social-science knowledge oriented towards such a global issue like HIV/AIDS requires networks of experts from different backgrounds for the construction of comprehensive approaches to HIV/AIDS policy.

There seem to be some micro cooperative projects between Brazil and South Africa at university level. But they seem very insignificant so far. Hence, I suggest that co-operation between the Brazilian and South African HIV/AIDS scientific communities can be built on the already existing international relations between the two countries. Some of these relations fall into Brazil's international diplomacy aimed at technological assistance, capacity building, and financial donation to African countries for a more aggressive response to the HIV/AIDS epidemic in Africa – a diplomacy that was initiated during Lula's presidency (Gómez 2009, 2010). By being a member of the BRICS group and due to its epidemic severity, South Africa is one privileged country benefiting from the Brazilian new international diplomacy in the field of HIV/AIDS. In turn, this new international policy marks the continuity of historical relationships between the two countries since 2000 or so. This historical background consists in the co-operation between Brazil and South Africa's TAC, which had its highest moment in 2001, when the two collaborated in order to influence the TRIPS talks which paved the way for Brazil and South Africa's cooperation in the area of intellectual property on AIDS medicines (see Follér 2010 for a recent debate). The second historical relationship is linked to Brazil's and South Africa's commitment to the UN's "Zero HIV/AIDS model". Indeed, Brazil and South Africa are both signatories to the 2001 Declaration of the UN General Assembly (UNGASS) on HIV/AIDS, through which 189 member states commit themselves to intensifying efforts to eliminate HIV and AIDS, within the Millennium Development Goals framework to be achieved by 2015 [initially by 2010] (UNAIDS 2001). The UNGASS strategic plan for an effective response to the epidemic consists in scaling up towards universal

access to comprehensive prevention programs, treatment, care and support. This commitment is reaffirmed every five years in a UNGASS High Level Meeting. Calling for grander political and financial investment in the struggle against HIV/AIDS, the 2011 UNGASS Political Declaration defined new targets: to halve sexual and injecting drug transmission of HIV, to eliminate vertical transmission, and to halve TB deaths among PLWH. Thus, the UNGASS 2011 Political Declaration draws attention to increasing prevention and ART programs for all infected persons, which also implies reducing AIDS-related maternal deaths, ensuring that no children are born with HIV. This is the sense of the “Zero HIV/AIDS model”. The whole strategy involves enhancing access to health services for vulnerable populations such as PLWHA, CSWs, IDUs, MSM, as well as civil society organizations. Advocacy for CSWs rights reminds us of women's conditions, principally, and the mitigation of gender based inequities and abuse through measures aimed at women's economic and psycho-social empowerment.

Social-science knowledge has a pivotal role to play in contemporary international relations between Brazil and South Africa for the fight against HIV/AIDS, by circulating the insights gained from the HIV/AIDS studies of the two countries (and the world) to policy-makers and stakeholders. This requires interchangeability between scientists from the two countries. It is not possible to imagine the accomplishment of the “Zero HIV/AIDS model” without the serious inclusion of social-science knowledge for, firstly, the explanation of the complexity and the global dimension of the HIV/AIDS epidemic and, secondly, the design and implementation of appropriate measures that consider the inextricable interlink between economic, political, a cultural factors underpinning HIV/AIDS vulnerability. Additionally, since UNGASS' objectives resonate with those announced in the two countries' respective constitutions (Cl. 27/1988, in the case of Brazil; Cl. 196/1996, in the case of South Africa), social scientists could cooperate in understanding and constructing the social contexts that promote universality, equity and integrality of health policies oriented to the HIV/AIDS epidemic. The inclusive and egalitarian democratic regimes currently in place in Brazil and South Africa should serve this purpose.



### *Concluding remarks*

The present work will have been successful if it enlightens the way in which, historically and normatively, social-science knowledge can contribute to fighting HIV/AIDS and promoting health in general through use-inspired research and engagement with policy, as a form of academics' social responsibility to contribute to social justice-prone development. In this sense, this work will have reached its objective if it helps to understand the complexity of HIV/AIDS policy in Brazil and South Africa, and sheds light on the socio-political contexts that – in the period between the early 1990s and early 2000s – enabled social science knowledge to play a significant role in the formulation and implementation of HIV/AIDS policy in Brazil and, vice-versa, prevented South African social scientists from engaging with policy-makers. It is also hoped that the dissertation has made clear that South Africa is now trying to make up for its delay in responding effectively to the HIV/AIDS crisis through interventional strategies that include the participation of social scientists. Ultimately, it is hoped that the present work has contributed to making social sciences visible, as Anna Larsson and Per Wisselgren (2013) have advocated.

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## Interviewees

Abueng Mkhonza	THEMBA (arts-based AIDS initiative) University of the Witwatersrand	04.05.13
Alan Whiteside	HEAIDS, University of KwaZulu-Natal	29.05.13
Alexandre Grangeiro	Universidade de São Paulo (USP)	29.10.12
Ana Lúcia Spiassi	Universidade ABC, São Paulo	05.11.12
Angela Necadonini	ABIA	09.10.12
Anthony Maniov	Gay and Lesbian Memory in Action (GALA) University of the Witwatersrand	03.06.13
Carmen Lucia Oliveira	ASSOBECATY (Telecentro de Terreiros), Guaíba	18.11.12
Celso R. Monteiro	Secretaria da Saúde de São Paulo	14.11.12
Cleci Gomes	Secretaria da Saúde do Rio Grande do Sul	01.10.12
David Dickinson	University of the Witwatersrand	23.11.13
Deividson Faustino	Universidade ABC, São Paulo	05.11.12
Denise Serafim	Departamento DST/AIDS, Ministério da Saúde	07.11.12
Eliana Barboza	Centro de Referência e Treinamento DST/AIDS São Paulo	26.10.12
Eliana C. Xavier	Secretaria da Saúde do Rio Grande do Sul	01.10.12
Ezio T. Santos Filho	PELA VIDDA, Rio de Janeiro	16.10.12
Fabiola Ottati	Universidade ABC, São Paulo	05.11.12
Fernando Seffner	Universidade Federal do Rio Grande do Sul (UFRGS)	27.09.12
Furrah Simbeku	The Institutional Office for HIV and AIDS (IOHA) University of Johannesburg	23.05.13
Grey Magayeza	University of the Free State	31.05.13
Ivo Brito	Departamento AIDS/STs, Min. da Saúde Brasília	07.11.12
Jair Andrade	Secretaria da Saúde do Rio Grande do Sul	01.10.12
Joaquim	Centro de Referência e Treinamento DST/AIDS São Paulo	25.10.12
Jan Du Toit	African Center HIV/AIDS (ACHA), University of Stellenbosch	07.05.13
Judith Head	University of Cape Town	10.05.13
Kammila Naidoo	University of Johannesburg	16.05.13

Laura Cecilia Lopez	Universidade do Vale do Rio dos Sinos (UNISINOS)	25.09.12
Leo Wilton	University of Johannesburg	17.05.13
Mandisa Mbali	University of KwwZulu-Natal	29.05.13
Maria H. C. Couto	IMS/UERJ	15.12.12
Marcelo Muscari	Universidade Federal do Rio Grande do Sul (UFRGS)	18.11.12
Mary Crewe	Center for AIDS Study, University of Pretoria	04.06.13
Meire A. Ishibashi	Centro de Referência e Treinamento DST/AIDS São Paulo	26.10.12
Melissa Steyn	University of the Witwatersrand	21.05.13
Monica Du Toit	Office for Institutional HIV Co-ordination (OIHC) University of Stellenbosch	09.05.13
Naila J. S. Santos	Centro de Referência e Treinamento em DST/AIDS São Paulo	26.10.12
Nicoli Natrass	University of Cape Town	10.05.13
Niger	The Institutional Office for HIV and AIDS (IOHA) University of Johannesburg	17.05.13
Pierre Brouard	Center for AIDS Study, University of Pretoria	04.06.13
Ray Lazarus	Center for AIDS Study, University of Pretoria	04.06.13
Regina	Centro de Referência e Treinamento DST/AIDS São Paulo	25.10.12
Solange Rocha	University of Cape Town	10.05.13
Tamara Gordon	Drama for Life, University of the Witwatersrand	04.05.13
Veriano Jr. Terto	ABIA	19.11.12



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