TRANSCENDING GIPA

Towards an *Ubuntu* framework for mainstreaming participation of South African people living with HIV (PLHIV) in social change communication for HIV prevention

MUSARA LUBOMBO

Towards an *Ubuntu* framework for mainstreaming participation of South African people living with HIV (PLHIV) in social change communication for HIV prevention

MUSARA LUBOMBO
(210545995)

Research Protocol HSS/0338/012D

Supervisor: Dr Lauren Dyll-Myklebust

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DECLARATION

This doctoral thesis, *Transcending GIPA: Towards an Ubuntu framework for mainstreaming participation of South African people living with HIV (PLHIV) in social change communication for HIV prevention* was done at the Centre for Communication, Media and Society, University of KwaZulu-Natal from February 2012 to November 2014 under the supervision of Dr Lauren Dyll-Myklebust. I declare that the thesis is my own unaided work, and has not been submitted before, for any degree or examination at any other University. All figures, tables and panels, unless specifically acknowledged as being sourced from other persons, are mine. Where use has been made of the work of others, it is duly acknowledged.

Musara Lubombo

Signature ……………………………..   Date …………………….

Lauren Dyll-Myklebust

Signature ……………………………..   Date …………………….

To Sis Ma' B

For being fearless

For being an embodiment of Ubuntu

For soldiering on

Musara Lubombo

ABSTRACT

HIV/AIDS is a significant health, social, political and economic challenge whose devastating impact on development and subsequent threat to the human, national and global security is well documented. Early responses to the HIV epidemic are known to have dislocated people living with HIV (PLHIV) at the margins of society, crystallising them as patients who need treatment, care and support (Osborne, 2006). This thesis focuses on participation of PLHIV in social change communication for HIV prevention, an aspect that has only recently been acknowledged in the HIV response. It explores how South African PLHIV experience and perceive the framework guiding participation of PLHIV - the Greater involvement of people living with HIV/AIDS (GIPA) - which by virtue of it being a product of the Joint United Nations Programme on HIV/AIDS (UNAIDS) has become accepted as universal. The objective of the thesis derives from issues that arise from the dialogue between extant theory and local practice and thoughts about what constitute positive social change communication for HIV prevention and how such change can be achieved. To achieve this objective, thirteen AIDS Activists based in KwaZulu-Natal were interviewed to make sense not only of the ways in which they configure involvement of PLHIV in the HIV response but also to understand the philosophy that informs such configurations. The findings suggest that South African AIDS Activists predicate their involvement in the HIV response on visible participation, placing emphasis on serostatus disclosure as a signal for safer intentions meant to protect other people from HIV infection. They regard confidentiality of one's serostatus as negating feasible gains that could be realised from the HIV response involving PLHIV. However, this configuration of participation is contrary to GIPA guidelines which, based on individual rights, provide for the involvement of PLHIV without necessarily disclosing their serostatus (UNAIDS, 2007). The study concludes that GIPA's emphasis on individual rights atomises people and presents challenges for HIV prevention in local communities where cultural beliefs are such that individual health is inseparably bound to other people. It also considers the AIDS Activists' configuration of participation as bearing hallmarks of *Ubuntu,* an African worldview which perceives humans as relational beings who have weighty duties towards each other (Mbiti, 1969; Metz, 2007a/b). The study, therefore, proposes an *Ubuntu* model for future design and implementation of social change communication for HIV prevention with South African PLHIV in a manner that can not only account for their worldview and cultural frames through which they make behavioural choices but can also allow for the creation of a conducive environment for their visible participation in social

change communication for HIV prevention. That the model has been developed from the perspective of local people demonstrates the importance of regarding local realities and frameworks that members use to make sense of their lives as the basis upon which interventions must be formulated.

Key words: Ubuntu model, social change communication for HIV prevention, GIPA, configuration of participation, PLHIV

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ACRONYMS

ACT UP   AIDS Coalition to Unleash Power

AIDS   Acquired Immunodeficiency Syndrome

ART   Antiretroviral Therapy

ASO   AIDS Service Organisation

CCMS   Centre for Communication, Media and Society

CDC   Centres for Disease Control

CI   Categorical Imperative

DramAidE   Drama for AIDS Education

GIPA   Greater Involvement of People Living with HIV/AIDS

GNP+   Global Network of Persons Living with HIV/AIDS

HIV   Human Immunodeficiency Virus

HP   Health Promoter

HSRC   Human Sciences Research Council

MMC   Medical Male circumcision

NAPWA   National Association of People with HIV/AIDS

PLHIV   People Living with HIV/AIDS

SAFE   Serostatus Approach to Fighting the Epidemic

SANAC   South African National AIDS Council

SEMCHB   Social Ecology Model for Communication and Health Behaviour

STI   Sexually Transmitted Infection

TAC   Treatment Action Campaign

UN   United Nations

UNAIDS   Joint United Nations Programme on HIV/AIDS

US   United States of America

WHO   World Health Organisation

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Musara Lubombo

Durban, November 2014

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INTRODUCTION

This study was conducted under the auspices of The Centre for Communication, Media and Society (CCMS) at the University of KwaZulu-Natal (UKZN). The Centre embraces the field of cultural studies which emerged in the 1960s at the Centre for Contemporary Cultural Studies at the University of Birmingham. Consistent with the tradition of cultural studies which lacks a clearly defined subject area, principles, theories and methods (Saukko, 2002; Sardar and Van Loon, 1997; Hall, 1999), CCMS combines different theoretical and methodological positions in areas of culture, media, development and health communication.

My research interests at CCMS are development and health communication, with particular focus on how directed social change intersects with strategic communication. This study falls within the development and health communication research. Initially titled as "*Out from the margins: Mainstreaming participation of people living with HIV/AIDS in social change communication for HIV prevention*" the study focuses on participation of people living with HIV (PLHIV) in social change communication for HIV prevention, an aspect that has only recently been acknowledged in HIV prevention communication. The work explores how South African PLHIV participate within the framework guiding participation of PLHIV in the HIV response such as Greater involvement of people living with HIV/AIDS (GIPA) which, by virtue of it being a product of the Joint United Nations Programme on HIV/AIDS (UNAIDS) appears to be accepted as universal. The task that the thesis seeks to achieve derives from issues that emanate from the dialogue between a 'global' framework and thinking about social change visa viz local practices and thoughts by South African PLHIV about what constitute social change communication for HIV prevention and how such change can be achieved.

The disciplinary location of this study and my personal research interests mentioned above account not only for the humanistic commitment that I have, but also for the approach adopted for this study: to study the world not from the global theories but from the perspective, dreams, and desires of the concerned individual. A culture-centered approach (CCA) to social change as articulated by Mohan Dutta (2011) is thus employed as the conceptual framework for the study which elicits views of selected South African AIDS Activists involved in the HIV response to understand how they configure participation of PLHIV in the HIV response. Employing this approach is premised on the assumption that making sense of the underlying and tacit philosophy that informs their participation is important in developing communication programmatic interventions that seek to maximise participation of PLHIV in the HIV response. Accordingly, a framework or model for mainstreaming participation of PLHIV in social change communication for HIV prevention has been developed in this thesis from the point of view of South African PLHIV in a way that accounts for their life conditions, values and cultural circumstances.

Why this study?

Several reasons spurred this study. Among them is the need to contain HIV which remains a significant global security and social development challenge (McInnes, 2006; UNAIDS, 2001; Fourie and Schonteich, 2001) whose threat is felt strongly in sub-Saharan Africa which continues to bear the inordinate share of the epidemic (O'Reilly, 2006; UNAIDS, 2010). With only 12% of the global population, about 68% of global PLHIV resided in sub-Saharan Africa by 2012 (UNAIDS, 2013). During the same period, close to two million people became infected with HIV in the region, accounting for 70% of the global new HIV infections. Consequently, the region in the same period accounted for almost half of the global deaths from HIV/AIDS-related illnesses (UNAIDS, 2010). However, due to the expansion of access to antiretroviral (ARV) drugs, there has been a significant reduction of HIV/AIDS-related deaths but still; the

epidemic is far from contained. In South Africa, which hosts the highest number of PLHIV than any other country in the world (UNAIDS, 2013), by 2012 the estimated population of PLHIV stood at 6.4 million people (HSRC, 2014). These statistics suggest that, without a cure, people in critical sectors will continue to die, affecting the basic functioning of society with huge state security implications (Fourie and Schonteich, 2001; UNAIDS, 2001; UNSC, 2001).

Another reason for undertaking this study is the growing agreement among scholars that the problem of the unbaiting HIV epidemic in Africa is not because of the so called permissive sexuality of African people (Caldwell, *et al.,* 1989), neither is it solely because of poverty or patriarchy (Chasi, 2012); the problem may well be a result of the decentered approach that is being used for the HIV response. While years of what I have surmised as a Sisyphean engagement with the HIV epidemic have necessitated a shift from the dominant bio-medical and individual-centered approach to social change approach which, guided by the GIPA framework, places emphasis on active participation of people living with HIV (PLHIV) in the HIV response, limited success has been recorded in terms of prevention. 'Sisyphean' is an image drawn from King Sisyphus of Corinth, a figure in Greek mythology who, because of his trickery was condemned forever by the gods to roll a huge stone up a hill in Hades only to have it roll down again on nearing the top, forcing him to begin to roll it up again and again (*Oxford English Dictionary,* 2005). In spite of his stoicism throughout his life, he achieved nothing. The notion that participation of PLHIV is critical for an effective response to the HIV epidemic is now a common cause, having been utilised successfully in Western countries (Eisele*, et al.,* 2008; Wingood*, et al.,* 2004; Kalichman*, et al.,* 2001). However, its benefits for HIV prevention are yet to be fully realised in South Africa where participation of PLHIV largely remains focused on access to treatment care and support (Coates, *et al.*, 2008).

Globally, the perceived benefits of participation in social change have led to increased interest and recognition of the capacities of the previously marginalised communities to consciously and strategically participate in discursive spaces of processes of change, debating policies and finding solutions on issues that affect their wellbeing (Obregon and Tufte, 2013; Dutta, 2011; Figueroa, *et al.,* 2002). Participation has since enjoyed increasing influence on the global response to the HIV epidemic where previously marginalised PLHIV's voices are now privileged in finding solutions to the HIV epidemic (Paris Declaration, 1994; UNAIDS, 1999; 2000; Roy and Cain, 2001). Despite their involvement, a high proportion of PLHIV aware of their HIV status engage in HIV transmission risk behaviours (Eisele, *et al.,* 2008; Wingood, *et al.,* 2004; Kalichman, *et al.,* 2001; Kalichman, 2000). PLHIV risky behaviour is undoubtedly a motivation for the continued exploration, as this study does, of ways in which PLHIV can meaningfully participate in HIV prevention.

While GIPA has been embedded into national and international policies resulting in increased participation of PLHIV in the response to HIV, and indeed many benefits have been claimed for participation especially in developing support structures, policies and programs that have helped reduce HIV/AIDS-related stigma and discrimination (see HSRC, 2014); there is little evidence on its success in mainstreaming participation of PLHIV in HIV prevention. This is especially true in sub-Saharan Africa where the HIV epidemic continues unabated (Johnson, *et al.,* 2012). Also, there has been disillusionment among PLHIV who have felt that they are being used in the name of participation (Manchester, 2004). What this seems to suggest is a disconnect between frameworks guiding participation and the way in which PLHIV would want to be involved.

The above therefore warrants the third reason spurring this study; an interrogation of the relevance of GIPA in light of the broader concept of social change communication which is founded on the capacity of affected

communities to collectively enact their agency in addressing their social development challenges (Dutta, 2011; 2008). Studies on HIV prevention have concluded that it is arguably not more information about HIV prevention that the people need (Kelly, *et al.*, 2000, ii; Harrison, *et al.*, 2000) as evidence suggests that people do know the basics of HIV/AIDS and how to relate to it (Shisana and Simbayi 2002). Behaviours - including safe and HIV risky - are choices that rational beings make (Chasi and De Wet, 2007). However, these choices are not enacted solely out of one's free will as individuals are products of a complex social and psychological environment (Obregon and Tufte, 2013; Sallis, *et al.*, 2008). Of the multiple determinants or contexts that influence individual behaviours, culture is viewed as "the strongest framework for providing the context of life that shapes knowledge creation, perceptions, sharing of meanings, and behaviour changes" (Dutta, 2011, 11). Taking all this into account, it is intelligible that to be effective, responses to HIV must adopt a social change approach with the aim of seeking transformation in ways that are meaningful to the concerned people.

The above brings to bear the relevance of the culture-centered approach to social change (Airhihenbuwa, 1995, Dutta, 2008; 2011), a conceptual framework adopted for this study. At its heart, the culture-centered approach takes seriously the local contexts within which health meanings are constituted and negotiated (Airhihenbuwa, 1995; Dutta, 2008; 2011). Accordingly, this study elicits views of PLHIV in South Africa on what involvement in the HIV response means to them, and what they think about their current participation in HIV prevention. The aim is to make sense of the philosophy upon which involvement of South African PLHIV in social change communication for HIV prevention is and should be based. In order to achieve this objective, the study set out to answer the following key questions:

a) In what ways are South African PLHIV involved in the HIV response?

b) How (if ever) is their participation different from the global framework guiding involvement of PLHIV in HIV prevention?

c) What are their perceptions and feelings about the global framework guiding involvement of PLHIV in terms of HIV prevention?

d) How should PLHIV participate meaningfully in social change communication for HIV prevention?

Regardless of the ambivalent disciplinary status of cultural studies which Stuart Hall (1999) calls 'theoretical noise', the study is ontologically and epistemologically located within the cultural studies interpretive perspective (Denzin and Lincoln, 2005). Paula Saukko's (2005) integrative analytic framework that interlaces different epistemological positions within the qualitative research paradigm is employed in this study (see Chapter Six). Dialoguing with PLHIV around aspects raised in the above questions not only usher their voices into the discursive spaces but also provides insight into how theory and practice can be reconciled. The idea is to find ways in which participation, which is currently packaged within frameworks that have become to be accepted as universal, can be made meaningful among South African PLHIV involved in the HIV response.

The ontological underpinnings of the task that this study endeavours to accomplish finds expression in the culture-centered approach to social change (Dutta, 2011) that places emphasis on listening to the previously marginalised voices that have been absent in the discursive spaces where policies and program implementation are debated, and solutions decided and carried out. According to this approach, by bringing the marginalised in these platforms through dialogue, not only can policies and programmes that account for their local contexts and also responsive to their unique situations be made, but meaningful frameworks and models based on their configurations can also be developed (see Dutta, 2011; 2008; Airhihenbuwa, 1995). Understanding the experiences of the interviewed AIDS Activists is useful in developing a

framework that accounts for their life conditions, values and cultural circumstances and could be used to understand and mainstream participation of South African PLHIV in social change communication for HIV prevention in ways that are meaningful to their system of thought and philosophy of life.

Research procedures and key findings

The study utilises experiential information from purposively selected South African AIDS Activists to deconstruct the so-called global frameworks for the involvement of PLHIV in the HIV response and bring to the fore what participation entails as understood by PLHIVs' interaction with their symbolic, social, natural and physical world. Within this episteme, the study adopts a qualitative research approach (Willig, 2001) utilising in-depth interviews (Rubin and Rubin, 2005) with a combination of two groups of PLHIV involved in the HIV response in KwaZulu-Natal, South Africa. The first group comprises AIDS Activists drawn from Drama in AIDS Education (DramAidE) Health Promotion (HP) project which involves young PLHIV in its HIV/AIDS interventions in institutions of higher learning across South Africa (see Myers, Kelly and Motuba, 2012). The other group comprises Activists who live openly with HIV and are individually involved in the HIV response around the country.

Analysis of findings takes into account realities arising not only from the interviews but also from the Activists' lived experiences as well as the context in which these experiences take place. Saukko's (2005) integrated analytic approach that combines (a) a hermeneutic/dialogic focus on Activists' lived realities; (b) a (post)structuralist/reflexive critical analysis of discourses that mediate both the Activists' experiences and my assumptions of reality; and also (c) a contextualist/realist investigation of historical, social and political structures of power is employed to understand the above realities so as to secure a deeper understanding of what meanings PLHIV give to their participation, and perhaps an insight into the underlying and tacit philosophy that shape these meanings.

Integrating the dialogic focus, the context and researcher self-reflexivity is consistent with cultural studies' preoccupation with "exploring the nexuses between the local and the global, the cultural and the real, and the personal and the political" (Sardar and Van Loon, 1997). It is also useful in providing an improved insight into the views of PLHIV in South Africa about their participation in social change communication for HIV prevention in the context of both the GIPA framework of participation (which is global) and the social reality of the South African epidemic. The integrated analytical framework is therefore deployed as a strategy to secure an in-depth understanding by adding rigour, breadth; richness and depth to the analysis.

The conclusion arrived at in this thesis is located at the intersection of the above analysed mosaic of realities. It suggests that the interviewed Activists conceive participation as representing a collective consciousness characterised by values such as brotherhood, caring, sharing and treating each other as human. The study confirms previous findings that PLHIV may be driven by a sense of duty to protect others from HIV infection (Serovich and Mosack, 2003; Kalichman, 2000). It concludes that the filters informing the Activists' configuration of participation in social change communication for HIV prevention can best be described as reflective of an *Ubuntu* ethic. *Ubuntu* is understood as the philosophy governing the worldview of most African people, binding each to have a stake in the other's wellbeing and, as such, ought to be aware of each other's problems including illness in order to be of assistance to each other (see Kasenene, 2000; Murove, 2005; Dube, 2009). The hallmarks of this worldview is visible in the Activists' configuration of meaningful involvement in HIV prevention, especially their privileging of visible participation as compared to keeping one's positive serostatus confidential to themselves both in sexual relationships as well as in programmes responding to the epidemic.

However, the above view appears contrary to the individualistic and liberal individual rights orientation GIPA which places emphasis on the right of PLHIV to be involved without necessarily disclosing serostatus (see Paiva, *et al.,* 2003). The study concludes, therefore, that the individualistic approach to HIV/AIDS cannot be meaningful in contexts whose cultural belief is that individuals are bound to the communal. In the African worldview, GIPA's privileging of confidentiality seems not only inadequate but may be misleading to guide meaningful participation of PLHIV in HIV prevention as it appears not to be able to account for the societal values that shape knowledge about health such as; that one's health is inseparably bound to the other (see Airhihenbuwa, 1995; Dube, 2009). Therefore, to change the course of the sub-Saharan HIV epidemic it is imperative to make sense of the Southern African worldview which privileges collectivity among community members. The collective contexts of people in this region constitute their way of thinking about health, interpretation of reality and define their configuration of participation in the HIV response (Airhihenbuwa, 2007).

What the above suggest for addressing the sub-Saharan epidemic is the need to bridge the gap between theory and practice by moving beyond individual-level focused polices and interventions informed by more individualistic Western moral philosophies such as Kantianism to address the collective contexts that influence African people's thinking and behaviour (see Obregon and Tufte, 2013; Thomas, 2014). A UNAIDS consultative workshop on HIV/AIDS communication in Africa held in Abidjan Cote d'Ivoire in 1997 recommended understanding of Africans' worldview as a pre-requisite to implement unique responses tailored to the needs of the African people (UNAIDS/PennState, 1999). Effective use of this approach can be seen in the way understanding Africans worldview was utilised after being recommended by Father Placide Tempels (1959) to help colonisers to understand the African philosophy in order for them to implement the colonial project "in a self-sustaining manner" (Eze, 1998: 216). He recommended that the European

"needed to understand the African worldviews and belief systems so that the missionary message and civilising projects could be implanted in the vital nodes of the structures of faith and the existential inferiority of the African" (Eze, 1998: 216).

Similarly, for HIV prevention interventions in sub-Saharan Africa to succeed in a self-sustaining manner, HIV prevention messages must be implanted in the vital nodes of cultural values of the communities. Compared to the civilising project noted above, the starting point in HIV prevention should similarly be an understanding of the African worldviews and belief systems. Any approach that fails to take the above into account is less likely to achieve any success. This study demonstrates this view by highlighting limitations of GIPA in guiding participation of PLHIV for HIV prevention in sub-Saharan Africa. It is in this context that the original thesis title mentioned earlier was altered to the current title: *"Transcending GIPA: Towards an Ubuntu framework for mainstreaming participation of South African people living with HIV (PLHIV) in social change communication for HIV prevention".* Observations made in the reviewed literature as well as participants' configuration of their involvement in the HIV response have led to the proposition of *Ubuntu* as an alternative framework through which participation of PLHIV in social change communication for HIV prevention in South Africa can be understood and mainstreamed.

It is important, however, to note here that the findings of this study must be interpreted as views of people who live openly with HIV and are involved in AIDS activism in KwaZulu-Natal, South Africa. The findings do not represent views of many PLHIV who have not disclosed their status (both in South Africa as well as in other parts of the world), or those who may have disclosed but were not included in this study, or are keeping their serostatus confidential at a certain level. Given that in South Africa alone, 6.4 million people were estimated to be living with HIV by 2012 (HSRC, 2014), it is unarguable that not

all of them have publicly disclosed. Views of those left out might therefore be different from the ones expressed in this study. Be that as it may, the relevance of the present views are dependent on the acceptability and effectiveness of this study's *Ubuntu* model for mainstreaming participation of PLHIV in social change communication for HIV prevention articulated in Chapter Nine.

The model derives from a systematic analysis of not only the findings of the study but also the available literature on participation of PLHIV in the HIV response. The thesis thus consists of a total of ten (10) chapters organised into three main parts that accommodate the interrogation of the notion of participation of PLHIV within its historical context, and the presentation of the discussion in a manner that conforms to the normative structure of an academic thesis.

Organisation of work

Part I *Unabating HIV epidemic and the continued search for effective responses* consists of two chapters the first of which provides an overview of the global HIV epidemic, interrogating the positions occupied by PLHIV in the dominant HIV/AIDS discourse. Overarching questions that the study addresses are outlined. Chapter Two outlines the conceptual framework which informs both ontological and epistemological positions adopted for the study. The concept of participation for social change is the principle that this study aims to advance in the context of HIV prevention. This concept whose main principle is dialogue allows voices of the most marginalised in society to be heard. The social change philosophy is thus placed within the African moral philosophy of *Ubuntu* which is juxtaposed with Kantian philosophy which is argued to be reflective of particular a Western ideology. The chapter is not necessarily an essentialist discussion of these in direct contradistinction with each other or where they are different to each other. Its focus is mainly on the importance of each in explicating the way(s) in which participation of PLHIV in the HIV response can be understood. This provides insight into possible ways through which

interventions seeking to mainstream participation of South African PLHIV in social change communication for HIV prevention can be maximised

Part II *An overview of the global responses to the HIV epidemic* is a literature review section consisting of three (3) chapters that takes the reader through discursive and pragmatic responses - including GIPA - that have been employed to contain the HIV epidemic. The first chapter in this section, Chapter Three grapples with the epidemiological history of HIV/AIDS, answering the question: in what ways did the dominant HIV/AIDS discourse contribute to the marginalisation of PLHIV? The discussion generated in addressing this question leads to Chapter Four that focuses on the pragmatic responses to the epidemic and their shortcomings. The concept of GIPA is interrogated in Chapter Five as a way of providing answers to the question: How and to what extent has the dominant HIV/AIDS discourse been countered by PLHIV? The chapter locates the resistance approach by PLHIV within a participatory communication for social change philosophy. The section notes that while PLHIV are now recognised, participatory approaches that involve them in the HIV response have no signs of success in containing the epidemic.

The final section; Part III *Configuration of participation by South African PLHIV* consists of five (5) chapters that present and discuss the findings. The first chapter in this section (Chapter Six) outlines the methodological procedures that were followed in the execution of the study. The ontological and epistemological insights of the study are further elaborated in this chapter. The penultimate chapter (Chapter Nine) outlines an *Ubuntu* model for mainstreaming participation of PLHIV in social change communication for HIV prevention based on the configuration of participation presented in Chapters Seven and Eight. The chapter also points to some limitations of the model. The final chapter concludes the thesis by summing up the task that has been undertaken, major conclusions that have been drawn and also pointing areas for further research.

Understanding the study in its proper context: A note on terminology

Overall, the study attempts to bridge the gap between theory and practice in as far as inclusion of South African PLHIV in social change communication in the HIV response is concerned. Participation of PLHIV has only recently been acknowledged in the preventive response HIV, an epidemic that has since been recognised not only as a health but a social development and global security challenge whose response by governments has often marginalised the PLHIV. Throughout this thesis, there are significant terms whose use ordinarily vary and therefore need clarification in order to put the reader in the proper context within which the concepts are here intended mean.

AIDS Activists: The term is used interchangeably with 'participants' referring to the thirteen (13) South African people living with HIV who participated in this study as interviewees. They preferred to be referred as such, and their names in this thesis (for example *White Female Activist 1shortened as WFA1*) are reflective of this. Four (4) are employed as Health Promoters (HPs) by DramAidE, an AIDS Service Organisation (ASO) in Durban which uses activism in its HIV/AIDS programs. The other nine (9) were individual Activists with no organisational affiliation, or who participated in the study in their individual capacities.

African culture: While the word 'African' refers to a polymorphous grouping of the indigenous peoples residing in more than 50 countries with different cultures and norms, African culture is used here referring to the values commonly associated with the largely black and Bantu-speaking indigenous peoples residing in the sub-Saharan part of Africa (Metz, 2007a). I use *Ubuntu* ethics as an embodiment of this 'African' culture.

Discourse: Discourse in this thesis is used from a culture-centered approach to social change perspective referring to discursive spaces of knowledge production (Foucault, 1972, Dutta, 2011). In Foucauldian sense, discourse is implicated with power which is believed to lie not only within the dominant

structures but also in the margins (Foucault, 1972). In the culture-centered approach to social change that informs this study, though marginalised, PLHIV are also believed to have power. However, enactment of their agency is only possible when they participate in discursive spaces, articulating their views in a manner that truly represents their experiences and aspirations. By so doing, they are able to challenge the structures that constrain their lives or limit their possibilities (Duta, 2011).

Marginalised: The term is used in the context of the historical exclusion of PLHIV from the discursive spaces or dominant structures where HIV/AIDS issues and policies are debated and solutions decided (Dutta, 2011). For long, voices of PLHIV have been erased from these spaces as they are shunned, stigmatised, discriminated and kept in the margins of society (Stephens, 2004). Listening to the voices of PLHIV creates openings for PLHIV to participate in these dominant discursive spaces from which their voices had been erased. By so doing, models for HIV prevention involving PLHIV can be built around PLHIV's configuration of participation in social change communication for HIV prevention.

Meaningful participation: Since the formalisation of (GIPA) "Greater Involvement of PLHIV" in 1994, policies have been made to support participation of PLHIV in the response to the HIV epidemic (UNAIDS 2007). However, some forms of participation have been accused for being tokenistic and not meaningful to PLHIV (Manchester, 2004). For this reason, "meaningful participation" is used to refer to the configuration of participation by research participants. The term refers to what the interviewed Activists consider as locally constituted scripts or frames through which PLHIV understand participation in HIV prevention. Participation is used synonymously with involvement.

People living with HIV/AIDS: UNAIDS uses this term to refer to people who are either affected on infected by HIV (UNAIDS, 2008). I find this definition

problematic especially when applied to an African perspective that societies are largely communal and made up of extended families (see Broodryk, 1997; Shutte, 2008). With the rate of HIV in sub-Saharan Africa, by extension this may as well mean that everyone in sub-Saharan Africa is a PLHIV as there is hardly a single family that has not been affected by HIV/AIDS. It is for this reason that in this thesis PLHIV is limited to refer only to people who are infected by HIV and are aware of their seropositive status. These may or may not be HIV/AIDS ill. There are different acronyms used to refer to HIV positive people. PLHIV are sometimes referred to as such as PLWHA (people living with HIV/AIDS), PWA (people with HIV/AIDS), and PLHA (people living with HIV/AIDS). In accordance with the UNAIDS (2008) terminology guidelines, in this thesis PLHIV is used.

Serostatus: This term refers to the state of either having or not having detectable antibodies against a specific antigen, as measured by a blood or serologic test. In this study the antigen is HIV. As such the terms 'positive serostatus' or 'seropositive' are used interchangeably in this thesis referring to an HIV positive person. Conversely, seronegative is used to refer to a person who does not have HIV. Another variant of this term also used in this thesis is serodiscordant which refers to a couple consisting of a seronegative and seropositive partner. Seroidentity is preferred in this thesis to clarify what I mean by people living with HIV who according to GIPA (shown above) include both the infected and the affected.

Social change communication: This term refers to process of change that involves the concerned communities in a conscious and strategic process of change that is meaningful to them (Dutta, 2011). The objective of social change is to challenge the status quo; that is the existing processes, commitments and philosophies. Social change communication for HIV prevention is therefore used to mean communicative processes, strategies and tactics directed at preventing further transmission of HIV by PLHIV.

Ubuntu: The term does not have a single definition. It is used here to refer to a philosophy, way of life that seeks to promote and manifest itself and is best realised or made evident in harmonious relations within society (Metz, 2010). It is believed to be common among (sub-Saharan) African people. *Ubuntu* also means a socially acquired consciousness, an inner state, an orientation, a disposition towards good which motivates, challenges, and makes one perceive, feel and act in a humane way towards others (Munyaka and Motlhabi, 2009).

West/Western culture: Western is used to refer to social norms and ethical values that are broadly associated with Europe and countries whose history is strongly marked by European immigration, such as the countries of the Americas and Australasia. The idea of 'Western culture' refers not to a homogeneous but to a diverse range of practices and traditions, some no longer current. The term is used loosely to imply 'individualism' which as with the West is commonly associated with liberal ideology that privileges individualism over collectivism. Kantian moral philosophy (1724-1804) is used as an embodiment of the Western liberal culture. It is true, however, that not all Western democratic theory is liberal (see Enslin and Horsthemke, 2004).

PART I

CONTINUED SEARCH FOR EFFECTIVE RESPONSES TO THE UNABATING HIV EPIDEMIC

Behaviour cannot be permanent unless it is based upon a concatenation of ideas, a logical system of thought, and a complete positive philosophy of the universe, of man and of the things which surround him, of existence, life, death and of the life beyond.

Father Placid Temples, Bantu Philosophy, 1959.

CHAPTER ONE

LOCATING PEOPLE LIVING WITH HIV IN THE HIV/AIDS DISCOURSE

This chapter provides an overview of the HIV epidemic, interrogating the positions occupied by people living with HIV (PLHIV) in the dominant HIV/AIDS discourse. More than three decades into the epidemic, are the voices of PLHIV present in the discursive spaces where social response strategies to the HIV epidemic are debated? Are present frameworks meaningful enough to organise PLHIV to enact their agency in social change communication for HIV prevention? These are some of the questions this introductory chapter highlights as a way of providing a background to the task that this study grapples with. The objectives of study and overarching questions that the study seeks to unravel are also spelt out in the chapter.

Current situation regarding the HIV epidemic

The United Nations Educational, Scientific and Cultural Organisation (UNESCO) as well as the Joint United Nations Programme on HIV/AIDS (UNAIDS) acknowledge that Human Immunodeficiency Virus (HIV) is a significant global public health challenge. It causes AIDS (Acquired Immune Deficiency Syndrome) whose devastating impact include not only death but is felt in the social and economic spheres of human endeavour (UNESCO, 2001; UNAIDS, 2007). Globally, HIV/AIDS has thus emerged not only as a threat to human, but to national security so much so that it has also become a concern for the United Nations Security Council (McInnes, 2006; UNAIDS, 2001; Fourie and Schonteich, 2001). As such, HIV/AIDS is recognised not only as a health problem but as a social development challenge that overwhelms healthcare systems, weakens the productive and security capacities of countries, and entrenches poverty among other things (UNAIDS, 2010; Fourie and Schonteich,

2001). For those infected by HIV, "the likely ensuing illnesses and the possibility of a premature and distressing death have immediate and devastating consequences" (Kelly, Desmond and Cohen, n/d: 26).

According to the 2013 World AIDS Day Report, an estimated 35.3 million people are living with HIV worldwide (UNAIDS, 2013). This translates to about 17% increase from the last decade. Although the overall growth of the global HIV/AIDS epidemic appears to have stabilised, with the annual number of new HIV infections having declined since the late 1990s (UNAIDS, 2013), this is offset by high levels of new infections which increases the number of people living with HIV worldwide. The increase of PLHIV is also attributed to reductions in HIV/AIDS-related deaths as a result of the significant scaling up of antiretroviral therapy (ART) over the past few years (UNAIDS, 2010). For UNAIDS, HIV/AIDS-related deaths fell to an average of 1.8 million in 2010, down from an estimated peak of 2.2 million in the mid-2000s. An estimated 2.5 million deaths have been averted in low and middle-income countries particularly in sub-Saharan Africa since 1995 due to the introduction and uptake of ART (UNAIDS, 2013).

Globally, HIV/AIDS programmes focus on prevention of new infections, treatment of the infected, caring of the AIDS ill and providing socio-economic support to the ill. In spite of a massive global investments and efforts to address the epidemic (UNAIDS, 2013) no cure is currently available for HIV. Out of the 34 million global population of PLHIV, 60% is in sub-Saharan Africa. While South Africa, is among the countries where the epidemic is reported to have stabilised, it hosts the highest number of PLHIV in the world (HSRC, 2014; UNAIDS, 2011). In 2012, it is estimated that 6.4 million people were living with HIV in South Africa. There is consensus that in order to change the course of the sub-Saharan epidemic, preventing further transmission is important (UNAIDS, 2013). Prevention thus remains a priority concern on the global HIV/AIDS agenda.

This study sets out to explore possible ways in which PLHIV, particularly in sub-Saharan Africa, can meaningfully participate in social change communication for HIV prevention as a response to the epidemic. With no indicators of success by current frameworks guiding participation of PLHIV such as GIPA (greater involvement of PLHIV) especially when it comes to HIV prevention, the study seeks to develop an alternative framework based on the way PLHIV configure participation. From a cultural studies perspective (Saukko, 2005; 2002; Sardar and Van Loon, 1997; Hall, 1980) and a culture-centered approach to social change (Dutta, 2011) the study will utilise views of PLHIV in South Africa to understand how they configure participation and what they think about their current participation in the HIV response. Participants' perceptions, experiences and policy will be integrated to come up with an *Ubuntu* framework that could be used to mainstream participation of (South) African PLHIV for HIV prevention in meaningful ways.

HIV transmission risk behaviours of PLHIV

That every HIV transmission originates from an infected person in undisputable (see Koester*, et al.,* 2007). Be that as it may, research has shown that HIV positive people who are aware of their status continue practicing sexual behaviours that place their sex partners and themselves at risk for HIV and other sexually transmitted infections (STIs) (Olley*, et al.,* 2005). Gina M Winghood *et al.*, (2004) as well as Seth Kalichman (2000) among others found that an average of one in three PLHIV continue to practice unprotected intercourse after learning their HIV positive serostatus. Despite the fact that the sub-Saharan Africa hosts the worst HIV epidemic in the world, there is little effort to involve PLHIV in HIV prevention interventions as there are studies on finding ways through which this can be maximised to contain the epidemic. However, important work in this regard has been conducted in the United States of America (US) where researchers found out that HIV prevention

interventions with PLHIV are instrumental in reducing risky behaviour and new infections (see Janssen and Valdiserri, 2004, Janssen*, et al.,* 2001).

Extensive research on PLHIV risk behaviour has also been conducted in the US (see Kalichman, 2000). However, few such studies have been conducted in South Africa. These studies are summarised in Table 5.1 in Chapter Five. The findings also affirm previous studies which have shown that a high proportion of PLHIV aware of their HIV status practice sexual behaviours. As with the industrialised world, risk reduction interventions to help PLHIV reduce their risky behaviours in South Africa have also proved to be effective in changing these behaviours (see Cornman*, et al.,* 2008 and Eisele*, et al.,* 2009).

Indeed the approach depends on the levels of awareness of HIV status among PLHIV. While many infected people may not be aware of their status, recent statistics from the 2012 South African National HIV Survey shows that there is significantly higher rates of awareness of HIV status (HSRC, 2014). The same survey also reports low rates of stigma against PLHIV with a high percentage of people expressing a positive attitude towards caring for a family member with HIV/AIDS. On whether they would want to disclose the seropositive status of a family member, 50% of the respondents concurred. Overall, all the attitudes measured were mainly positive and had all changed for the better over the past three surveys (HSRC, 2014).

The above statistics indicate available opportunities of mobilising PLHIV for social change interventions for HIV prevention. However, there remains little interest to direct effort in coming up with deliberate interventions targeting and involving PLHIV. While there has been increased interest in responses involving PLHIV, these have been focused on challenging structures that hinder access to treatment as evidenced by the work of the Treatment Action Campaign (TAC) in South Africa, and less on prevention. Such focus is well aligned with the dominant discourse on HIV/AIDS that has crystallised PLHIV as patients who

need treatment care and support. Even in the struggle for recognition in terms of treatment care and support, it is PLHIV themselves that have been at the forefront of engaging and challenging the structures that limited their possibilities (see the Denver Principles, 1983).

Voices from below: PLHIV challenging marginalisation

In the first decade after the discovery of HIV, most responses viewed the epidemic as 'medical' requiring a bio-medical response from 'experts' (SafAIDS, n.d). It has been argued that this view consequently crystallised PLHIV as 'patients' who need treatment, care and support (ibid). However, the HIV epidemic has since been re-characterised as a developmental problem that goes beyond the realm of public health, but touches on all aspects of human life (UNESCO, 2001). The medical approach as a response to HIV skirted the complexities and structures whose alteration is vital in changing the course of the epidemic. Anton van Niekerk (2002) lists such complexities as: (a) poverty as niche or social context of the epidemic, (b) denial, lack of leadership and the politicization of the public discourse on HIV/AIDS, (c) problems related to accomplishing behaviour changes under conditions of deprivation and illiteracy, (d) women's vulnerability, and (e) the disenchantment of intimacy brought about by the epidemic.

The above social, economic and political complications make HIV prevention more challenging. For Sarah Cardey (2006, p.1) "a complex combination of socio-economic factors means that even a thorough individual understanding of the disease does not necessarily translate into less risky behaviour". While a consideration of the above complexities has been suggested as critical to a comprehensive response to HIV (van Niekerk, 2001; Cardey, 2006), the good intentions of the approach can be offset by the exclusion of PLHIV in HIV prevention interventions. This is the point where this study departs from, contending that the bio-medical approach to HIV and its simplistic and false assumptions about PLHIV as receivers of services from those living without HIV

(UNAIDS, 2007) perpetuate the othering and exclusion of PLHIV from participating in the global response to HIV/AIDS.

Yet, from both a social change perspective and a culture-centered approach to health communication (Airhihenbuwa, 1995; Dutta, 2011), active participation of PLHIV is critical for an effective response to HIV/AIDS. Years of what I have surmised (borrowing from Greek mythology already explained in the introduction) as a 'Sisyphean' engagement with the epidemic in trying to find solutions to curb its rapid spread points to the failure or ineffectiveness of the approaches used. This study argues that the dominant medical and scientific discourse on HIV/AIDS, compounded by stigmatisation and discrimination of PLHIV, has kept PLHIV in the margins of society. It is perhaps this conjunction that in turn made possible the emergence of counter discourses and resistance to this marginality as epitomised by the Denver Principles highlighted below. But how can PLHIV in South Africa mobilise each other or organise themselves to challenge and resist the dominant HIV/AIDS discourse that has limited their capacity to participate in discursive spaces where their views on how PLHIV can participate in HIV prevention are articulated?

The possibility of social change for the HIV response that is shaped by personal experiences was first voiced in 1983 by PLHIV at a national HIV/AIDS conference in Denver, Colorado in the United States of America. It was here that AIDS activism and the rewriting of the HIV/AIDS narrative began, suggesting an alternative response to HIV through announcement of the Denver Principles (1983). There is arguably no better way to cite the history of PLHIV's resistance to medical HIV/AIDS discourse by advocating self-empowerment than to quote the principles articulated by PLHIV in Denver:

> We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity,

helplessness, and dependence upon the care of others. We are "People with HIV/AIDS (Denver Principles, 1983).

This call marked the beginning of an alternative discourse originating from PLHIV, a discourse aimed at erasing the bio-medical discourse by advancing a pro-PLHIV agenda that recognised their agency in the HIV response; with emphasis on addressing HIV/AIDS-related stigma as well as participation of PLHIV in HIV prevention (see Denver Principles, 1983). PLHIV began to speak on their own behalf, slowly ushering themselves to the centre of the HIV/AIDS discourse. The ideas and language of PLHIV influenced not only later AIDS activism movements (for example the AIDS Coalition to Unleash Power (ACT UP) and the National Association of People With AIDS (NAPWA) in the US which were later emulated and replicated throughout the world including South Africa) but they also helped to illustrate the importance of considering an epidemic from the point of view of PLHIV (Wright, 2013). PLHIV considered their involvement in the HIV response as not only empowering but also significant in preventing further HIV infections (Denver Principles, 1983).

However, since 1983, PLHIV's call for self-determination and participation in the HIV response remained their own struggle for a decade, with little formal response from governments (Global Network of Persons Living with HIV/AIDS [GNP+], 2000). The status quo was eventually altered in 1994 when voices of PLHIV were recognised at the highest political level in the world, the United Nations (UN) through the announcement of the Paris Declaration (1994) that formalised GIPA.   Here the UN pronounced a declaration of support for a greater involvement of people living with HIV which was followed by various subsequent global, international and regional commitments on GIPA in 1999; 2001; 2006; 2007 (see AUC/UNAIDS, 2009).

Discussing the way discourses are linked to power structures in society, Michael Foucault (1982) posits that when a discourse is backed by

institutionalised force, the meaning and order it imposes on aspects of the world profoundly influence thought and social practice. This view begs questioning whether co-option of the agenda articulated through the Denver Principles into the established hegemonic political systems such as the UNAIDS did not result in a global institutional mandate that (mis)represent the voices of PLHIV. Does GIPA encompass all the aspects espoused in the Denver Principles? Is it reflective of local realities? These are some of the questions that this study interrogates from an HIV prevention standpoint of South African PLHIV.

The importance of active participation of PLHIV in HIV prevention is widely acknowledged (UNAIDS, 1994; 1999). For Kevin Osborne (2006) PLHIV are the nexus for future infections so much so that "to exclude them from dedicated prevention efforts is not conducive to successful global prevention" (Osborne, 2006: 9). The fact that PLHIV "have directly experienced the factors that make individuals and communities vulnerable to HIV infection - and once infected, the HIV-related illnesses and strategies for managing them" (UNAIDS, 2007: 1) implies that PLHIV are an integral element in the HIV/AIDS discourse and, therefore, a key actor whose agency, knowledge and experience must be recognised in any response to the epidemic.

From a social change communication perspective, success is more likely when the affected communities are actively involved in discursive spaces where their issues are debated and solutions are suggested (Dutta, 2011, Bessette, 2004; Figueroa, *et al.*, 2002; Tufte and Mefalopulos, 2009; Melkote and Steeves, 2001). As such, success of HIV/AIDS interventions is most likely when PLHIV are involved in response to the epidemic. Involvement of PLHIV at all levels of programme development and implementation improves the relevance, acceptability and effectiveness of programmes (UNAIDS, 2007).

While GIPA has enjoyed increasing influence of current programmes responding to HIV, it appears that participation of PLHIV is being applied in a utilitarian fashion where participation of PLHIV is applied as a means to an end (see Manchester, 2004). Such a form of participation cannot be meaningful as it denies the political character of participation that places emphasis on the duties of PLHIV as espoused at Denver. The implementation and application of participation of PLHIV as a response to HIV/AIDS has thus not only been perceived by PLHIV as 'manipulation' or oppression' (Manchester, 2004), but it has ostensibly failed to address prevention of new HIV infections as envisaged by the Denver Principles.

Almost two decades after the 1994 UN declaration on GIPA, participation of PLHIV in the HIV response still remains a concern for many. In 2010, the Indian Network for People Living with HIV/AIDS (INP+) together with the International Planned Parenthood Federation (IPPF) and Fulfilling People's Aspirations India (FPA India) expressed concern that prevention programmes are not meaningful to them as they have mostly targeted those people who are HIV negative eschewing both the needs and important role of PLHIV in HIV prevention (INP+, IPPF and FPA India 2010; Kalichman, 2005). A recent review of literature by Patricia Gilliam and Diane Straub (2009) also suggests that HIV prevention education has historically been directed towards those individuals considered at risk for exposure to HIV and assumed to be uninfected (also see Marks, 2005). Similar sentiments were echoed by the AIDS Activists in this study who then suggest ways that they think PLHIV can meaningfully participate in social change communication for HIV prevention (see Chapters Seven and Eight).

Participation of PLHIV in HIV prevention is viewed here as resonating with the constructivist idea that meanings are made by individuals based on the past and present experiences. This conjures what Paolo Freire (1970) calls praxis which grants primacy to the lived experiences in the world as a way to resist

marginalisation and internalized oppression. From this perspective, keys to development are presumed to reside within the minds of social actors (Dervin and Huesca, 1999), in this case PLHIV.

The study explores implications of the inclusion of PLHIV in HIV prevention since they are the nexus for future infections (Osborne, 2006). How can PLHIV, as a nexus to new infections, be deliberately and meaningfully involved in preventing the transmission of HIV? PLHIV are an integral population in the HIV/AIDS discourse and a 'factor' whose consideration is germane to participatory communication for HIV prevention. Because of their experiences, PLHIV should be at the centre of HIV prevention discourse (see Kalichman, 2005). But how can PLHIV actively participate in this discourse? Which discursive location (Willig, 20010) should PLHIV occupy in terms of rights and responsibilities?

As a point of departure, the study questions not only the (current) nature and purpose of PLHIV's participation but the philosophy upon which this participation is based. This is considered from the perspective of selected PLHIV who are already involved in the HIV response in light of the letter and spirit of the Denver Principles. The aim is to understand why participation is important in the context of HIV, and how PLHIV can effectively participate in HIV prevention.

It is in this context that the relevance of interrogating the extent to which GIPA – the cardinal policy which directs the current form of participation of key populations in the HIV responses – is found: has GIPA enhanced or defeated the letter and spirit of the Denver Principle? Since, in a constructivism sense, meanings are rooted in individual responses to events (Delia, 1977), a consideration of perspectives of PLHIV who are involved in the HIV response is necessary if we are to find ways in which PLHIV can meaningfully enact their agency in social change communication for prevention of HIV transmission.

The study thus explores PLHIV's perceptions to resist the 'marginalising' HIV/AIDS discourses and whether or not their perceptions of participation are different from GIPA. The primary objective is to develop a social change communication for HIV prevention model that meaningfully integrates PLHIV's perceptions and experiences, policy, as well as lessons learnt from a South African project which actively involves PLHIV in the HIV response. In light of the culture-centered approach to social change (Dutta, 2011) the model has to account for the life conditions, values and cultural circumstances of (South) African people. As will be shown in the following chapters, *Ubuntu* accounts for the values of people living in sub-Saharan Africa and differs in some way from for instance some liberal philosophies that are influential in contemporary Western ethics (Metz, 2007a/b). The study attempts to capture and elucidate forms of moral wisdom and behaviour grounded in the web of the South African peoples.

As the Denver Principles (1983: 1) clearly states, PLHIV "have an ethical responsibility to inform their potential sexual partners of their health status" so as to substitute ... sexual behaviours ... which could endanger themselves or their partners". In the South African context, the Denver Principles could possibly be interpreted within the spirit of *Ubuntu*. The convergence between *Ubuntu* and the Denver Principles becomes clear in Chapturs Two, Seven, Eight and Nine. However, it is perhaps fitting here to view the Denver principles through Western ideological lenses as they were founded in a Western context - in the United States of America (US) - and therefore can hardly be divorced from the influence of Western moral theories.

For Matthew C Altman (2011) Western moral reasoning is impossible without the background of Immanuel Kant's (1724-1804) practical philosophy as Kantian philosophy is ingrained in the Western moral discourse. I did not have an intention to involve Kant in this study for two reasons. First because this study is African centered, it is located within an African context which is

unique to Africa and not the Western worldview. Secondly because of criticism levelled against Kantian philosophy. Kant's ethical theory is so often accused of being too abstract to be relevant for real life decisions (Altman, 2011). However, considering the centrality of Kant in Western moral reasoning noted above, Kant's relevance for this study became so apparent. For this reason, while locating participation of South African PLHIV largely within the doctrine of *Ubuntu*, the study also appeals to the Kantian philosophy to for the interpretation of the Denver Principles.

In this chapter, the significant questions that the study attempts to explore in order to achieve its objectives have been highlighted. Many questions have been posed that help to locate the study in a meaningful context. One of the important aspects highlighted is the fact that the HIV epidemic has been recognised not only as a health, but a development issue whose solution requires active participation by PLHIV in discursive spaces where the issue is debated. This view finds expression in the culture-centered approach to social change (Dutta, 2011), a conceptual framework within which this study is located. This framework is described in the next chapter.

CHAPTER TWO

THEORISING SOCIAL CHANGE COMMUNICATION FOR HIV PREVENTION

A CULTURE-CENTERED APPROACH

It has been noted in the previous chapter that formalisation of the Greater involvement of people living with HIV/AIDS (GIPA), a framework that recognises agency of people living with HIV (PLHIV) in responding to the HIV epidemic occurred after PLHIV themselves (who had been marginalised by the dominant HIV/AIDS discourse) challenged the status quo that kept them in the margins of society. This study set out to explore the experiences and perceptions of South African people living with HIV (PLHIV) about their participation in the HIV response as they continue seeking spaces to enact their agency in altering the face of the HIV epidemic. The notion of marginalisation and resistance to it has been the focus of cultural studies; a discipline within which this study is located and a field of inquiry which draws from different fields such as postcolonial and subaltern studies among others (see Dutta, 2011).

Conceptually, both the phenomenon examined in this study and the methodological approach adopted for its execution (see Chapter Six) find expression in the culture-centered approach to social change which recognises the agency of the marginalised in negotiating structures and in seeking spaces for change (Dutta, 2011). In health communication the culture-centered approach revolves around concepts of structure, culture, and agency (Airhihenbuwa, 1995). The key proponent of this approach, Collins Airhihenbuwa (1995) and his 'disciples' in this aspect such as Mohan Dutta (2008) define structure as the distributary mechanisms for health resources in societies which simultaneously limit and create cultural participants' opportunities for enacting agency to engage in practices that influence their

health and well-being. These structures include policies, medical infrastructures, food resources, and transportation systems. They define agency as the capacity of individuals, groups, and communities to participate actively in determining the health agendas at the local level and creating solutions for community health problems. The culture- centered approach posits that culture and health are mutually constitutive it provides the communicative context for health meanings in communities. It is also through the expression, interpretation and reinterpretation of culturally circulated meanings that individuals enact their agency (Dutta, 2011).

Premised on the view that in the (South) African context culture and beliefs exercise a great influence on the thought and actions of people (Ovens, 2003) including those that may predispose people to HIV, this study seeks to gain a deeper understanding of the philosophy upon which the participants' configuration of involvement of PLHIV in social change communication for HIV prevention is, and its mainstreaming should be based. From a cultural studies perspective as well as the culture-centered approach to social change, listening to PLHIV is critical as it allows cultural members opportunities to participate in processes aimed at identifying their own social development problems so much so that they can develop solutions to these problems (Dutta, 2011). A key argument in this thesis is that in order to change the course of the South African HIV epidemic, effective ways in which PLHIV can meaningfully participate in social change communication for HIV prevention are required. This is only possible when PLHIV are, and indeed feel recognised and part of the community from which they have been decentered. PLHIV as with everyone are bound to the community in which each has an equal moral worth and agency as human beings.

The view advanced in this thesis is that the notion of agency and humanity are mutually constitutive. The cultural-centered approach to social change is indeed a response to the structural violence that perpetuates subalternity

through discursive erasures that render the marginalised inhuman. This violence is enacted in the form of inability to the basic capabilities of life (Farmer, 1999), a process which - by limiting agency of human possibility - effectively dehumanises. It means, therefore, that central to the politics of agency is the question: what is being human/what is humanness? Indeed this question and an answer to it arise from the way one person views the other. Clearly an understanding of what it means to be human can only happen when one views themselves in relation to the other. As such, this fundamentally locates participation of PLHIV in social change communication for HIV prevention in a philosophy that addresses human relations.

Participation, as shall be shown ahead is a key concept underlying mutual human relations. The argument presented in this chapter is that participation of/dialoguing with PLHIV - a cardinal principle for social change communication - is axiological. The axiology here is twofold. Firstly, for HIV prevention to occur, it is normative for PLHIV to participate. Secondly, allowing participation of PLHIV in dialogue on HIV prevention enjoins everyone to respect, not only each other's right to be heard but also each other's views. In my estimation, this view about participation provides a useful starting point for theorizing HIV prevention whereby respect for the dignity of the other might serve as a mechanism for developing meaningful HIV prevention interventions involving PLHIV.

A brief highlight of the policy guidelines on participation of PLHIV here are useful in laying the context and a broader theoretical insight to the framework presented in this chapter. The two main principles: the Denver Principles of 1983 and the GIPA Principle of 1994 discussed at length in Chapter Five are the instruments guiding involvement of PLHIV. Both instruments can also be said to be axiological as they enjoin people to respect each other as humans regardless of serostatus. However, the former has an ethical and human

responsibility emphasis and the latter adopts an individual rights approach to the HIV response.

Implied in the respective approaches of the two instruments mentioned above are two different conceptions of a human being. Consistent with its emphasis mentioned above, the Denver Principles arguably characterise humans as beings who have a responsibility to do what is ethical and to respect others. The GIPA Principles on the other hand conceive a human being as an agent with individual rights that always need to be respected. It advocates policies to be made that do not hinder PLHIV from exercising their individual rights. This distinction will be much clearer further in this chapter when I discuss Kantian philosophy and *Ubuntu* as the two philosophies underlying the notion of participation. The significance of the distinction of emphasis between the Denver Principles and GIPA is fundamental in the understanding of the configuration of participation by South African PLHIV. This will provide a foundation on ways to mainstream participation of PLHIV - as human beings - in social change communication for HIV prevention in meaningful ways.

This chapter conceptualises social change communication for HIV prevention. Dutta (2011) argues that conceptualisation of social change is integral to the ways in which we practice social change initiatives and the ways in which these initiatives are measured. In the section below, the concept of social change communication for HIV prevention is conceptualised from Dutta's (2011) culture-centered approach to social change. It is in the culture-centered approach that both the ontological and epistemological positions of the study are rooted. The philosophy underlying two central elements underlying the social change process: dialogue and collective action are examined from the perspective of the cultural participants. Two principles guiding involvement of PLHIV, The Denver Principles, and GIPA are also viewed from the same perspective.

Social change communication for HIV prevention

Communication for social change is generally understood as transition or change in people's lives that occurs when the affected people take part in decision making of the change processes. Neil Ford *et al.,* (2003) define social change communication as a process of dialogue "through which people define who they are, what they want and how they can get it" (Ford, Odallo and Chorlton, 2003: 607; also see Gray-Felder and Deane, 1999). From a culture-centered approach perspective, social change is premised on the capacity of local communities to come together as a collective and engage, through dialogue, in what Paulo Freire (1970) calls communal reflection or social praxis. According to Dutta (2011), in social change, the affected community is the locus and their collective agency to seek out spaces for transformation draws upon the cultural resources. There may be no better way of conceiving participation of PLHIV in their struggle for recognition; against social death created by HIV/AIDS-related stigma, and their contribution to HIV prevention and self-determination than through communication for social change philosophy.

What is clear in the above understanding of social change is that transformation results from communal reflection. According to Freire (1970) people converge to reflect and act upon their situation in order to transform it. In other words people converge to discuss the problem in order to act collectively upon it. In Freirian terminology, this is called social praxis. He defines praxis as "reflection and action upon the world in order to transform it (Freire, 1970: 33). For Freire, praxis is a central defining feature of human life and a necessary condition of social change. This, Freire holds, enhances people's capacity to be self-defining subjects by providing necessary conditions for each person to be conscious of their situation. It is only after one is conscious of their situation that they can act to transform it. The lifeblood for action/transformation here is participation in open dialogue or critical inquiry

and analysis that seeks to reconstruct the undesired situation and transform it.

For some scholars, communitarianism has been argued to be a metatheoretical assumption underlying social change communication described above (see Dervin and Huesca, 1999). However, for the purposes of this study, communitarianism has to be construed not as Western collectivism but as African socialism or communalism espoused by African communal thinkers such as Leopold Senghor (1964). It may also be viewed in light of Kenneth Kaunda's humanism, Julius Nyerere's (1967) Ujamaa and Kwame Nkrumah's (1964) Consciencism. These ideologies by African thinkers enjoin people not to be merely a collection but to depend on each other in order to safeguard and respect humanity or dignity of the other. Because of dialogue and reciprocity, the group has priority over an individual without crushing him but allowing him to blossom as a person (Senghor, 1966). This can only occur through respectful and empowering dialogue in which each other's views are valued. Locating 'respect for the other' in social change communication thus conjures elements of communalism which stipulates dialogue, reciprocity, tolerance of diversity/harmonious relationships and interdependence as normative requirements for what Leopold Senghor (1963: 4) calls "a community based society" where people conspire together, united to the very centre of their being".

Nkrumah's Consciencism, Senghor's Communalism and Nyerere's Ujamaa are all similar in that they seek to rally African colonies in their pursuit for social change; that is independence from Western hegemony. As with Freire's (1970) dialogue for critical consciousness that takes into account the experiences of colonisation and exploitation, these philosophies were emancipatory movements with a strong orientation to affirming the dignity of the formerly colonised/oppressed by empowering people to achieve a level of critical consciousness so that they are able to recognize their situation as well as their

own roles to transform (see Vervliet, 2009). This conjures a Marxist view of social change which, as with the structure aspect of the culture-centered approach to social change, engages with revolutionary possibilities of structural transformation in order to address material inequalities in society (Dutta, 2011). In this sense, social change is constituted in challenging the relationships that maintain the status quo. Here dialogue still plays a central role in organising the social change process.

The African thinkers' philosophies highlighted above have often been regarded as key elements of African moral philosophy whose key principle is respect for the dignity of the other which is often achieved through dialogue and consensus. Detailed analyses of these ideologies are offered by Emmanuel Chukwudi Eze (1998), Chris Vervliet (2009), Parker English and Kibujjo Kalumba (1996) among others. In light of the foregoing, social change communication thus foregrounds the role of communication/dialogue in organising the social change process. Unlike the dominant paradigm of development which used one-way communication channels (Lerner, 1964; Schramm, 1964) to create changes in knowledge, attitude and behaviour at an individual level (See Chapter Four), here communication is seen as an active process of meaning making through which affected communities come to understand their context and act upon them (Dutta, 2011).

Dialogue as shared space for meaning making

At the core of the culture-centered approach to social change is the idea of listening to communities at the margins, those whose voices have been erased and silenced from dominant platforms. The politics of the dialogic approach top social change lies in articulation of subaltern standpoint, hence listening to their voices offers possibilities of change as it ensures presence of their narratives in the discursive spaces where policies and decisions for the social change process are made (Dutta, 2011). This view had earlier been expressed by Brenda Dervin and Robert Huesca (1999: 170) who contend that if social

change has to occur, ordinary human subjects, the grassroots, the oppressed "are the most solid vessels of wisdom and knowledge concerning their situations and must be involved in planning as well as implementation process of social change". The act of collective problem identification, decision-making, planning as well as implementation is thus a fundamental communication for social change principle (Figueroa, *et al.*, 2002; Bessette 19996). For Freire's (1970) liberation theology, dialogue is a catalyst for critical consciousness that is a prerequisite for one's transformation. It brings people together and ensures widespread participation in all aspects in the public sphere in order to resolve conflict.

Dialogue is thus a cardinal principle for social change (Bessette, 1996; 2004; Melkote and Steeves, 2001 and Servaes, 1991; Dervin and Huesca 1999) and is fundamental to the journey that humans collectively travel towards finding solutions to their problems. As Maria Elena Figueroa, *et al.,* (2002: 17) postulate, a key characteristic of social change is "participation of those who are most affected by the problem". Through dialogue, concerns, ideas and opinions of all the people are able to occupy space in any public discussion. For Freire, dialogue for critical consciousness is not some kind of conversation but a social praxis that allows the oppressed to "speak a true word" and overcome their silencing (Freire, 1970). In this dialogue, the everyday language, understanding, and way of life of the concerned people must be respected so that they can more deeply express their own hopes and intentions. Here dialogue is axiological. Tolerance of diversity and respect of each other's views is normative.

Ngaire Blankenberg (1999: 46) posits that dialogue creates relationships, and valuing of these relationships as well as each other's opinion ensures freedom of expression which is the foundation of effective participation. While individual freedom may be interpreted in a Western liberal democracy perspective that premiums individual or freedom of the sacred self from intrusion by others, in

most African communities a person's freedom as depends on personal relationships with others in the community (Christians, 2004). Freedom of expression therefore means that "a community is able to freely articulate its questions and concerns" (Blankenberg, 1999:47). From an African perspective, humans are relational; they depend completely on one another for their development and one's desire for freedom is realised to the full the more one is fully involved in community with others (Shutte, 1994). This conjures a moral value approach to communication which stipulates that communication "begins with dialogue between people who respect each other", a dialogue without which sustainable development becomes difficult to achieve (Ford, *et al.,* 2003: 611).

Collective participation is, therefore, essential for human development, "for what your neighbour has to offer in terms of experiences, knowledge and ideas is essential to your own growth" (Blankenberg, 1999: 46). Here participatory communication for social change, as Blankenberg (1999) observes, resonates with African traditional open air sessions known as *pungwe* where all people can air their grievances, propose ideas and solutions in response to the question of 'what shall we do' that is common to African communities.

As shall be shown in this chapter, in the African thought the personal pronoun 'I' is always replaced by plural 'We' signalling an *Ubuntu* principle that an individual is inextricably bound to their community and is enjoined to always think of themselves as part of a group (Metz, 2007a). In the *pungwe* practice leadership function is shared as much as is the facilitative function in Freire's dialogue for critical consciousness. As with Freire's (1970) dialogical process, this becomes a process of learning for both 'facilitator' and 'participant' (Blankenberg, 1999). The Freirian pedagogy contends that mere transfer of knowledge by experts or authorities to passive recipients cannot transform the latter to become a human being with an independent and critical conscience capable of influencing and changing society (Bessette 1996).

Social change communication thus moves from a focus of informing and persuading people to change their attitudes, to focus on facilitating self-determination through dialogical and respectful communication between the concerned people to address a common problem or achieve a common goal (Dutta, 2011; Bessette 2004; Figueroa, *et al.,* 2002). In *Ubuntu* normative theory for African ethics discussed later, respect, shared identity are cardinal principles that are emphasised in order to achieve harmonious relations.

Social development problems such as HIV/AIDS have demonstrated how health is linked to social, political and economic environments where issues of sex and sexuality are difficult to debate in public (Gray-Felder and Deane 1999). This has triggered the need for a wider social and political change, a change of which to be sustainable has to emerge from all affected people within societies, acting as a collective with shared objectives. Ideally, this is what has been construed above as self-determination. Communication for social change in the context of HIV/AIDS thus entails placing emphasis on self-determination of PLHIV through peer exchanges as well as integrating expert knowledge with experiential knowledge of PLHIV among other things (Medley, *et al.*, 2009; Ford, Odallo and Chorlton 2003). From what has been pointed out in the foregoing, for self-determination to occur, cooperation between the infected and experts demands respect for each other. For Immanuel Kant (1724-1804), a German moral philosopher, self-determinism entails respect for the other person. Kant believed that self-determination is a "basic goal that ought to be preserved out of respect for the person" (Altman, 2011: 2).

It should be noted that the underlying objective of participation is empowerment of marginalised communities who in this study are PLHIV. As discussed in the next chapter (Chapter Three), PLHIV have been dislocated in the margins of society, their voices having been erased from the dominant HIV/AIDS discourse where responses to the epidemic are planned and implemented. This violent dislocation of PLHIV through the dominant

HIV/AIDS discourse crystallised them as passive and without agency or say in issues defining their existence. Participation thus seeks to address power inequities between those who have power and those without it. For Gary Craig and Marjorie Mayo (1995) the concept of empowerment connects to the aspects of self-help, participation, networking and equity. It is the taking of power at both the individual and social levels. Participation is thus a vital component in the empowerment process as people must be involved in the decisions that affect their lives.

Theorising empowerment, Douglas Perkins and Marc Zimmerman (1995: 570) postulate that empowerment concerns a consciously directed "process centered in the local community, involving mutual respect, critical reflection, caring, and group participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources". Here we see again all the four elements constituting the framework espoused in this chapter: (a) social change, (b) dialogue, and (c) respect for the dignity of the other seen through both the African and Western conception of (d) humanity.

This study appeals to Kant (1724-804) to provide the Western view (Altman, 2011) and to *Ubuntu* to appreciate the same from an African perspective. As the context for defining personhood in the African worldview is community, I argue that "the isolated and static self of mainstream Eurocentric philosophy" (Christians, 2004: 237) such as Kantian ethics may be insufficient to explain what constitute humaneness in the African context. While Kant, at least within Western moral reasoning remains useful to explain the current forms of global participation of PLHIV as articulated in the Denver Principles, it is the above inadequacy of the Eurocentric philosophy to explicate local issues that I appeal to *Ubuntu*. In this regard, the key argument in this study illustrated in Chapters Seven, Eight and Nine is that an understanding of *Ubuntu* moral ethos may provide valuable insights on mainstreaming meaningful participation of PLHIV in HIV prevention in the (South) African context in much

the same way the concept (*Ubuntu*) was successfully utilised to sustain colonialism in Africa. According to Father Placide Tempels' (1959) book *Bantu Philosophy* whose aim is stated as "to serve as the European colonialist handbook on indigenous African philosophy" colonisers needed to appropriate colonial discourse through the African worldview in order for colonisation to "succeed in a self-sustaining manner (Eze, 1998: 216). As such, "the European needed to understand the African worldviews and belief systems so that the missionary message and "civilizationary" projects could be implanted in the vital nodes of the structures of faith and the existential inferiority of the African" (Eze, 1998: 216).

There is consensus in African philosophy that *Ubuntu* moral ethos is engraved in African people's hearts as part of their socialisation, and it has influence on the daily ethical, political and economic existence of the African (see Murove, 2009; Ramose, 2009; Shutte, 1994; Mbiti, 1969). For meaningful participation of PLHIV in social change communication for HIV prevention to succeed in a self-sustaining manner; to borrow Tempels' (1959) phrase, "one must work through this ontological system which grounds the subjectivity of the Bantu" (Eze, 1998: 216). It is, however, pertinent to note here that not all Africans always exemplify *Ubuntu* values. This can be better illustrated by the way *Ubuntu* has been used/or abused. For example, the value of 'sharing burdens' embodied in *Ubuntu* has at one point been reversed from its original meaning by a youth culture in KwaZulu-Natal that 'in the spirit of *Ubuntu*' sought to spread HIV as a way of sharing the community burden (see Leclerc-Madlala, 1997). Even in this day some PLHIV continue practicing risky sexual behaviours that expose others to the risk of HIV infection long after they have learnt of their seropositive status (see Chapters Five and Seven). A further critique of *Ubuntu* is offered at the end of this chapter.

Misuse of *Ubuntu,* however, should not be construed to mean that African values are discredited or of no significance. Because nobody is born with

Ubuntu - as the values are socially transmitted and acquired throughout one's life (Letseka, 2000 Odora-Hoppers, 2004) socialisation or information education campaigns can arguably play an important role in sustaining the idea of finding insights from *Ubuntu* that can be beneficial in mainstreaming meaningful participation of PLHIV in HIV prevention in (South) Africa.

The section below conceptualises social change from a both Western and an African philosophical standpoint. As indicated in the introduction, Kantian ethics are used in this thesis to epitomise Western philosophy, and *Ubuntu* values are used in the same manner to epitomise the sub-Saharan African worldview. These are the two philosophical legs upon which participation of PLHIV in social change communication for HIV prevention is viewed.

Due to the argument that Kantian ethics are individualistic and therefore more applicable in the Western moral thought than in the moral conscience of most (South) African societies; I did not have an intention to appeal to Kant in this study because the objective is to find meaningful ways of participation that reflect the moral conscience of (South) African PLHIV. However, two reasons compelled me to do so. Firstly, Kant's relevance to the broader understanding of the background of participation of PLHIV in the HIV response, and therefore in the achievement of this study's objectives, cannot be totally ignored. Here, it suffices to say that globally, current participation of PLHIV in the HIV response is guided by the ethics oriented Denver Principles which are Western. For Augustine Shutte (2008) Kant had a great influence on European ethics which lives today in all forms deontological or duty ethics and moral rights. As Altman (2011) argues, understanding Western moral reasoning is impossible without the background of Kant's moral philosophy.

The second reason relates to the acknowledged influence that Kantian philosophy is believed to have on other philosophies including African philosophy (see Wood, 2002, Tomaselli, 2009). Indeed as a result of

colonialism, modernisation and the continued contact between African and Western cultures, contemporary African cultures cannot be completely divorced from the implicit influence of Kant through Western cultures. As such, it has been argued that for many years African cultures have been adapting to the influences of Western cultures (Louw, 2001; Ovens, 2003). It is in this context that, because of its valuable insights to the argument in this thesis, the inclusion of Kantian philosophy explained below is inescapable.

Western moral reasoning: Kantian respect for the other

Kantian philosophy is a moral law formulated by Kant in his (1785) foundational text *Grundlegung zur Metaphysik der Sitten [Groundwork of the Metaphysic of Morals].* Commonly referred to as The *Groundwork,* this small book is commonly acclaimed to be the most significant in the history of Western ethics, as with the *Republic* of Plato and *Ethics* of Aristotle (Paton, 2005, Wood, 2002). The book "has exercised on human thought an influence almost ludicrously disproportionate to its size…Its main topic – the supreme principle of morality – is of the utmost importance to all who are not indifferent to the struggle of good against evil" (Paton, 2005: vii). It has since been a standard of reference for moral philosophers of all persuasions (Wood, 2002). The English translation referred to in this study is the second (G 2) and the fourth (G 4) editions of the *Groundwork* by Herbert James Paton (2005) and Allen Wood (2002) respectively. I use 'G [edition: page number]' for citations from the *Groundwork.*

The moral law formulated by Kant has as its cardinal principle 'good will' which motivates and defines a morally good human action. Good will is for Kant the only thing in the whole universe and outside it that is good without qualification or limitation (G 4: 393). Kantian moral law does not focus on the consequence of an action but considers good will to be good "not through what it effects or accomplishes, not through its efficacy for attaining any intended end, but only through its willing" (G 4: 394). The moral law thus considers the

action as the right one. This principle makes Kantian philosophy deontological and distinguishes it from utilitarianism and other teleological or consequential theories which hold that the sole standard of morality is determined by its usefulness. For this reason, the utilitarian calculus propounded for example by Jeremy Bentham (1781) and John Stuart Mill (1861) gives primacy to actions that result in happiness of the greatest possible number.

Unlike Utilitarianism that condones insensitivity to the needs of some other human beings such as the marginalised or permanent minorities in favour of the greatest numbers (see Bentham, 1781; Mill, 1985). Kantian moral law focuses on human action regardless of its consequences. Below is an outline of the principle of good will which for Kant motivates and defines a morally good human action. Within good will are three propositions - motive of duty, principle of duty and reverence of the law - that constitute a morally good action and underlie the central principle in Kantian law, the Categorical Imperative which is explained further below.

Morally good action: Good will

Kantian philosophy proposes that "an action done from duty has its moral worth, not from the results it attains or seeks to attain, but from a formal maxim of doing one's duty whatever that may be" (Paton, 2005: 12). It is thus based on three propositions that define a morally good action. These are (a) motive of duty, (b) principle of duty, and (c) reverence of the law (G 2: 8 – 17). Below is Paton's (2005) explication of these principles.

(a) The motive of duty - which includes the concept of good will - is the first proposition which defines a moral worthy action. It states that *"A human action is morally good, not because it is done from immediate inclination … but because it is done for the sake of duty"* (Paton, 2005: 10). This proposition is strict to an extent that even if an action is in a sense right, it is not regarded as morally good if it is done out of self-interest or other motives other than duty. While the motive of duty may be present with

other motives, an action can only be morally good if the motive of duty is sufficient enough to determine the action (Paton, 2005: 11).

(b) The principle of duty is Kant's second proposition of a moral worthy action. This proposition holds that *"An action done from duty has its moral worth, not in the purpose to be attained by it, but in the maxim according with which it is decided upon; it depends therefore, … solely on the principle of volition in accordance with which … the action has been performed"* (G 2: 14). This propositions means that human actions are accorded a moral worth by a maxim or principle of doing one's duty "irrespective of all objects of the faculty of desire" (G 2: 14). This worth "can be found nowhere but in the principle of *the will* irrespective of the ends which can be brought about by such an action" (G 2: 14).

While the notion of duty here is to oneself (individual centered) the same principle, as shall be discussed ahead, also features in *Ubuntu*. However, in *Ubuntu* the individual has duty to service another being or the community.

(c) Reverence of the law is Kant's third proposition which is an inference from the two propositions above. It states that "Duty is the necessity to act out of reverence for the law" (G 2: 15). This proposition suggests that only actions conjoined with one's will - as a ground not effect – "and therefore only bare law for its own sake, can be an act of reverence" (G 2: 15). The proposition further state that an action done from duty has to set aside other influences so that "there is nothing left able to determine the will except objectively the law and subjectively pure reverence for this practical law" (G 2: 15). Here reverence is a self-produced feeling that emanates not from mediation of external influences on their senses but a consciousness that one's will is subordinated to a universal law.

The critique against this third proposition is that it is egoistic because its universality includes the person who both gives and obeys the command (Firestone and Jacobs, 2008). This injunction to act out of reverence of the self-produced law is known as the Categorical Imperative (CI). As already noted, action or participation in accordance with *Ubuntu* values is argued to be done not out of reverence of self but out of reverence of the other in order to maintain harmonious relations (Metz, 2007a, 2010). This is illustrated in the

section on *Ubuntu* further below. Meanwhile it is important to examine the cardinal principle of Kantian philosophy; the Categorical Imperative.

The Categorical Imperative (CI)
The CI is the central principle in Kantian moral law. It states that as human beings we have certain moral rights and duties. We should treat all people as free and equal to ourselves, and our actions are morally right only if we can apply them universally. It is a deontological maxim which holds that right is right and must always be done, regardless of the circumstances. This principle has drawn criticism that it is cold and dead because it is to be followed without love, feeling, or inclination, but merely out of a sense of duty as a universal law that a good man seeks to revere and obey. The CI consists of three statements that function as formulae of (d) universal law (FUL) (whose variant is formula of the law of nature); (d)(i) humanity as an end in itself (FH); and (d) (ii) autonomy (FA) (whose variant is formula of the realm of ends) (Wood 2002: xviii). The statements are as follows:

(d) FUL: The Formula of Universal Law: *"Act only in accordance with that maxim through which you can at the same time will that it become a universal law"* (G 2: 52).

The above is the first statement and formulation of the CI which according to Kant is the supreme principle of morality (Paton, 2005). From this principle, further practical imperatives can be derived. Kant recognises that the CI constitutes nature, as in things determined by universal laws, the CI also has the Formula of the Law of Nature (FLN) as its variant The statement of the FLN runs as follows: *"Act as if the maxim of your action were to become through your will a universal law of nature"* (G 2: 52).

Good will - which is conceived in Kantian philosophy as the power determining action in reverence of the law/CI as shown in (c) above – can be found only in rational beings. "What serves the will as a subjective ground of its self-

determination is an end; and this if given by reason alone, must be ... valid for all rational beings" (G 2: 63). As such, Kant holds that every rational being exists as an end not as a means for arbitrary use by whatever motive. This premise leads to a practical imperative known as the formula of humanity as an end. Its statement reads as follows:

i. FH: The Formula of Humanity as End in Itself: *"Act so that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end "* (G 2: 67)

The above principle is grounded on the basis that rational nature exists as an end in itself. It is a universal supreme limiting condition of every man's freedom of action. The principle postulates that "man must in all his actions, whether directed to himself or to other rational beings, always be viewed at the same time as an end" (G 2: 64). This leads to the last but equally important practical imperative which is a principle of autonomy of the good will.

Good will of every rational being is considered in Kantian philosophy as a will that makes universal law (G 2: 70). This means that all maxims which are not in line with the good will's enactment of universal law are repudiated. Good will is thus not merely subject to law, but is so that it can regard itself as the author of the law – making the law for itself. In this way it can be considered as autonomous. This leads to the principle of autonomy formulated as follows.

ii. FA: The Formula of Autonomy: *"So act that your will can regard itself at the same time as making universal law through its maxim"* Its variant is the Formula of the Realm of Ends (FRE):

Derived from combining the FUL and FH above, this formulation enjoins man not merely to follow universal law but to follow that which he makes as a rational moral agent and one which he can particularise through his maxims (Paton, 2005: 29). This conjures the idea of man's freedom as a rational being. The principle suggests that if a rational being is truly an end, he must be the

author of the laws which he is bound to obey. This makes him autonomous. Here we will see a sharp contrast with the *Ubuntu* injunction that an individual is inextricably bound in community with the other.

Thus the variation of the FA is thus *"So act as if you were through your maxims a law-making member of a kingdom of ends"* (G 2: 75). This is based on the fact that rational beings are all subject to universal laws which they themselves make. As such, they constitute a kingdom. Since the laws enjoin them to treat each other as ends in themselves, they constitute the realm of ends (Wood, 2002). As legislative members of the realm of ends, rational agents have dignity which is "an intrinsic, unconditioned, incomparable worthiness" (Paton, 2005: 31). Thus Kantian moral law considers a human being as rational, autonomous and morally valuable entitled to respect and dignified treatment by others.

Good will manifests itself in struggling against obstacles placed in its way by sensual desires which rational human beings experience (G 2: 8). Here good will acts as a 'categorical imperative' that enjoins one to act in the way they wish to be treated as stipulated in Formula of Universal Law above. The *Ubuntu* model for participation of PLHIV in social change communication for HIV prevention which is illustrated in Chapter Nine presents *Ubuntu* not only as a principle enjoining one to serve humanity but also as a the source or basis of feelings of responsibility, care and compassion among other traits that are responsible for producing harmonious relations by influencing people to become sensitive to the well-being of others. As with good will, the model argues that *Ubuntu* can function as a law of autonomous will or self-governing reason whose presence in each person offers decisive grounds for viewing each as possessed of equal worth and deserving of equal respect (see Altman, 2011; Wood, 2002

Guided by good will, human actions should therefore reflect a regard for other people as having dignity, rights and morals. This is a command without

exceptions, a CI formulated around a principle that enjoins human beings to treat one another in such a way that respects the intrinsic human dignity of each other as in the Formula of Humanity.

In the foregoing a rational human being is regarded as an end-in-him/herself who is able to form his/her own opinions, plans and goals in life (Formula of Autonomy with its variant Formula of the kingdom of Ends). Treating anyone as a means to an end can be interpreted as reducing human beings to tools, a position which clearly contradicts all the above formulations. Thus, imposing risks and harm on another person without their knowledge is impermissible as it violates the respect they deserve as self-determining agents (Altman, 2011). As such a human being must never treat anyone as a mere tool to bring about goals or objectives she or he has not and could not possible accept or consent to. By doing so, against their consent, you are treating the person against his or her dignity. The CI thus enjoins human beings to have moral duties to all people by virtue of the fact that they are rational moral agents. As Altman (2011: 2) puts it, for Kant "self-determination is the basic goal that ought to be preserved out of respect for the person". This principle also features in *Ubuntu* that enjoins individuals to have moral duties to other people not because they are rational moral agents but because they are human whose wellbeing is inseparably bound to the other's wellbeing. It is important to reiterate here that while these moral duties are not always presents among community members, the culture-centered approach to social change reminds us as change agents to engage with the affected communities listening to their voices as they articulate meanings of their lives within local contexts. Here linear HIV prevention communication interventions aimed at influencing the behaviour of a 'rational' person become limited as a human actions and behaviour, - regardless of their rationality or motivations – are influenced by the broader context within which an individual is found (see Obregon and Tufte, 2013). Configurations of participation by the AIDS Activists interviewed in this study is such that

agency is determined and enacted in a unique socio-cultural context (see Chapters Seven, Eight).

We have seen from the above that when a person acts morally they give the moral law to themselves, with the CI propelling their actions. Every person is thus an autonomous moral agent who can practise ethics. Be that as it may, Kant warns that this premise can only stand if it can be proven that rational beings can act only under the presupposition of rationality and not any external impulsions (G 2: 100). The philosophy here presents an individual as rational.

The rational nature of being: I think therefore I am
Kantian philosophy holds that exercising the CI depends on the way we perceive a human being to be. As a rational agent, human beings must think of themselves from two standpoints which, though contradictory are both plausible (G 2: 110 – 112). On one hand, a human being can be considered as a member of an intelligible world; that is as rational with an ability to freely choose to do the right thing when he or she also knows that they could choose to do something that is wrong. On the other hand, a human being can be thought of as being natural, determined by natural laws, biology and his environment. Here, a human being becomes a member of the sensible world (G 2: 110). As solely members of the intelligible world, all human actions would necessarily accord with the principle of autonomy, and as solely members of the sensible world, human actions would entirely be subject to the law of nature (G 2: 110).

The above contradictory conceptions of a human being are problematic when it comes to practicing ethics. As solely members of a sensible world, a human being is not free as his actions are subject to the laws of nature or natural necessity (G 2: 97). What this means is that he is not a moral agent and cannot therefore do ethics. For Kant, ethics presupposes free will and only

rational/free/autonomous human beings are able to do ethics (G 2: 97). Under Kantian philosophy, autonomy is the principle of morality. A free will can act causally under self-imposed laws; that is, laws that could not be imposed on it by something other than itself (Paton, 2005: 37). In the contrary, non-rational beings can act causally through the influence of something other than themselves.

Kant's formulation of an individual contrasts *Ubuntu* principles that consider a person to be a relational being whose existence depends on other beings. While *Ubuntu's* conception may be closer to Kant's sensible world, for *Ubuntu* participation in relationships is not a sensual impulse but is a normative principle prescribed by societal norms and values which for Kant would be as good as the CI.

If the CI which propels our action solely depends on autonomous human beings then the above contradictory conceptions of a human being indeed limit its possibility. In order to escape from this limitation, Kantian philosophy places supreme value on the moral excellence (good will) for its own sake, not to any other motive or influence. Good will ought to govern human action regardless of the fact that they belong to the intelligible and sensible world (G 2: 110). Even under overwhelming impulses, man appeals to the ordinary moral consciousness "I ought to". While man "does not consider himself responsible for his desires and inclinations, he considers himself responsible for indulging them to the detriment of the moral law" (Paton, 2005: 45). Morality thus resides with the *action* rather than the actor. Whether it is rational (has been exercised freely) or has been influenced by the environment, for Kant one should act in the way they wish to be treated.

The conceptualisation of a human being in Kantian moral law is largely based on a person's ability to reason, and in part to sensual impulses from different outside influences. Although it acknowledges the other, it is only through one's

individual reasoning that they apply this rule. This conceptualisation depicts the theory as more liberal, cognitive and individualistic; typical but not exclusive to most Western societies. In HIV prevention, such a conceptualisation of being would imply development of linear prevention communication interventions assuming that the rational individual will be easily influenced to change behaviour by well-planned and clear communication messages (Obregon and Tufte, 2013). Such a conceptualisation of being is contrary to the notion of social change communication for HIV prevention which considers a person as a product of their environment, and therefore takes seriously the context through which human behaviour and actions take place (Dutta, 2011). Moreover, application of such models in community based societies like those commonly found in sub-Saharan Africa maybe problematic (see Dube, 2009). Here communities conceptualise a person as "being through other people". This is discussed further below under *Ubuntu.* An empirical analysis follows in Chapters Seven and Eight with aid of illustrations on how PLHIV view themselves in relation to other people.

My intention is to highlight possible ways in which Kant and *Ubuntu* can provide a useful starting point for theorising meaningful participation of PLHIV in social change communication for HIV prevention in a way that is close to the people's hearts or moral conscience while at the same time addressing structural and behavioural issues perpetuating HIV transmission. Suzanne Leclerc-Madlala, a prominent HIV/AIDS scholar decried the paucity of research in this regard. She once observed that "no research as to how the African ethos of *Ubuntu* may influence a people's disease response has ever been undertaken" adding that this "may be an area which needs further exploration" (Leclerc-Madlala, 1997: 372).

However, few studies known to me have since appealed to the wisdom and ethos of *Ubuntu* as a conceptual framework within which HIV prevention interventions with PLHIV can be modelled. Musa W. Dube (2009) proposes

from a religious perspective that values of *Ubuntu* through divination and healing can be applied for HIV prevention while Ezra Chitando (2008) who, also from a religious perspective, advocates use of African traditional religion's concept of solidarity to transform masculinities as a way of addressing HIV/AIDS in Africa. Colin Chasi (2014; 2007) also appeals to *Ubuntu* advancing a humanist agenda for recognition of the existential experiences of Africans affected by HIV/AIDS granting them recognition and dignity as *Ubuntu* demands. Other scholars, Martha Chinouya and Eileen O'Keefe (2008; 2006) have observed that *Ubuntu* influences ways in which Africans access or make sense of health promotion interventions. They employ the concept of *Ubuntu* to develop the delivery of services among African communities in United Kingdom.

Given the vast literature on HIV/AIDS and the paucity of effort in appealing to the moral ethos of the African people particularly values native to sub-Saharan Africa - paradoxically a region that is most and continues to be affected by the epidemic presumably due to futility of current response that is arguably far removed from the indigenous people's existential realities - the need for a culture-centered approach to social change embracing the moral ethos of *Ubuntu* as a conceptual framework for social change communication for HIV prevention needs no emphasis. The futility of current responses to the epidemic is dealt with extensively in Chapter Four.

African moral philosophy: *Ubuntu*

The aim of this section is to discuss *Ubuntu* as a moral philosophy ingrained in the African moral thought just as much as Kantian philosophy, discussed above, is ingrained in the Western moral thought. In African cosmology, the universe is built upon the principles of coexistence characterised by harmony, peace, interdependence, love and justice (Munyaka and Motlhabi, 2009; Metz, 2007b; Shutte, 1994). While opinion is divided on whether *Ubuntu* philosophy is uniquely African or not, there is unanimity among scholars that *Ubuntu* characterises norms and values of co-existence that are inherent in many

traditional African societies (Bhengu, 2006; Shutte, 1994, Samkange and Samkange, 1980). Socio-linguistically, the term *Ubuntu* which means humaneness or being human is commonly found in the Nguni languages of Southern Africa, with almost all South African indigenous languages. Its phonological variants exist in many other languages throughout sub-Saharan Africa for example *hunhu* - Shona spoken in Zimbabwe; *botho* - Sotho spoken in Lesotho and Botswana; *bumuntu* - kiSukuma and *Kihayi* spoken in Tanzania; *bomoto* - Bobangi spoken in Congo; *gimuntu* - kiKongo and giKwese spoken in Angola; *umundu* - Kikuyu spoken in Kenya; *umunthu* – chiChewa spoken in Malawi; *vumuntu* - shiTsonga and shiTswa spoken in Mozambique (see Kamwangamalu, 1999; Ovens, 2003).

Even though there is no universally agreed definition of *Ubuntu*, different authors writing from different perspectives and traditions depict *Ubuntu* philosophy as representative of African worldview on the relational nature of persons (coexistence): persons exist only in relation to other persons (Shutte, 2009). As Nkonko M Kamwangamalu (1999) observes, one finds evidence of this *Ubuntu* cardinal virtue throughout all corners of Africa from Dakar in Senegal to Addis-Ababa in Ethiopia, and from Cairo in Egypt to Pretoria in South Africa. This idea of persons calls for the respect for another human being, for human dignity and for human life and encompasses values, attitudes, feelings of collective shared-ness, solidarity, caring, hospitality, and interdependence among other values (Shutte, 2009, Mkhize, 2008 Kamwangamalu, 1999). *Ubuntu* is thus the essence of humanity – of what it really means to be a 'human being. It is recognised as the African philosophy of humanism that links the individual to the collective through 'brotherhood' or 'sisterhood' (Swanson, 2007).

For Mfuniselwa John Bhengu (1996) *Ubuntu* is "the humanistic experience of treating all people with respect, granting them their human dignity. Being human encompasses values like universal brotherhood for Africans, sharing,

treating and respecting other people as human beings (Bhengu, 1996:5). Erasmus Prinsloo (1996: 113-114) concurs with Bhengu and best expresses this notion of being by adding that "*Ubuntu* is the collective consciousness of the people of Africa". For Prinsloo, "*Ubuntu* involves alms-giving, being sympathetic, caring, and sensitive to the needs of others, being respectful, considerate, patient and kind (Prinsloo, 1996:113- 114). While Prinsloo's definition is more utilitarian, its depiction of *Ubuntu* as consciousness (also see Nassbaum 2003, 2009) is significant in that it highlights that *Ubuntu* is acquired. For Ncedile Saule (1996) *Ubuntu* consciousness is not innate but is rather acquired from or inculcated in an individual by society through socialisation (also see Munyaka and Motlhabi 2009; Kamwangulu, 1999). According to Johann Broodryk (1997), *Ubuntu* norms have been orally transferred from generation to generation over time.

Ubuntu places emphasis on the interpersonal quality of humanity which according to Mvumelwano Dandala (1994) is intrinsic among cultures in Southern Africa. This harmonic connectedness among African people is embodied in the expression '*umuntu ngumuntu ngabantu*' (a person is a person through other people) an African thought that a person is defined by harmonic relationships between them and others (Shutte, 1994). The aspect of harmonious relationships is articulated by Archbishop Desmond Tutu (1999: 35) like this: "Harmony, friendliness, community are great goods. Social harmony is for us the summum bonum - the greatest good. Anything that subverts or undermines this sought-after good is to be avoided like the plague". This thought expresses a value system against which Africans in their individual communities measure their 'humanness', that is conceiving of the self as in common with others (Blankenberg, 1999; Christians, 2004, Metz, 2010, 2009, 2007a/b; Swanson, 2007). As Thaddeus Metz (2009: 340) puts it, the ultimate goal of a self should be to become fully human, however, "a person entirely alone might fail to act to maximise his own wellbeing". This

propagation suggests interdependence which in the African thought is part of the essence of traditional African life. For Desmond Tutu (1999) a person who values the humanity of the other has *Ubuntu*, a unifying force that "leads to social harmony and cohesion starting at the family and cultural community, circling out to the global community" (Venter, 2004).

Harmony as a good that a moral agent ought to promote is also captured in the expression *'umuntu ngumuntu ngabantu'*. This expression captures the African conception of a human being differently from the Kantian philosophy that conceives a person as a self-realising or autonomous rational being whose moral actions are merely a result of having assented to rational principles, and in the context of health communication, to linear communication models (Obregon and Tufte, 2013). *Ubuntu* rejects this Cartesian cogito ergo sum argument (I think therefore I am) which is a fundamental Western philosophical proposition that conceives a person as an atomised and unfettered self (Bujo, 2001; Hintika, 1962). For *Ubuntu* to be human always means sharing life with others. A person is therefore relational; s/he can only say "I am because we are" (Mbiti, 1969). According to *Ubuntu* philosophy which; without dissolving the ethical identity of the individual is relational (Bujo, 2001), achieving the state of humanness is constituted by positively or harmoniously relating to others (Metz, 2009, Vervliet, 2009). By stressing the centrality of the other person in one's existence, *Ubuntu* philosophy can be said to be allergic to any form of discrimination (Museka and Madondo, 2012). Individuality in Africa is emphasised by among other things the fact that each person has his own name different from others (Bujo, 2001).

A person (*umuntu*) and the concept of being human (*Ubuntu*) are of great importance in the African worldview. The African conceptualisation of personhood acknowledges that a person possessing *Ubuntu* has a spirit of caring for each other's well-being and can harmoniously relate with others, preserving "a bond with one another, an intimate ontological

relationship…interaction of being with being" (Tempel, 1959: 58). A number of questions immediately arise from this conceptualisation of 'being'. Many have argued that the communal philosophy shares some features with other ideologies such as communitarianism and Buddhist ideas of the human community (Venter, 2004). I shall outline shortly the propositions and core values of the *Ubuntu* as a as a normative theory for African ethics. But before doing so, it is pertinent here to acknowledge the controversy and criticism confronting *Ubuntu* as a philosophy of life for African people so as to avoid confusion regarding what I mean by *Ubuntu* moral philosophy in this thesis. Due to limitations of space, I am unable to explore all problems confronting *Ubuntu* but the most critical issues that have bearing to the functional meaning intended in this study are highlighted.

Unlike Kantian philosophy that is attributed to Kant no one has claimed singular authority over *Ubuntu* moral philosophy. Even though the word *Ubuntu* appeared in written sources since 1846 (Gade, 2011), *Ubuntu* has remained a philosophy associated with no particular authoritative text (Blankenberg, 1999). While generally regarded as 'African' philosophy whose cardinal principle is reverence of human dignity, opinion is divided on the correctness of referring to *Ubuntu* as uniquely 'African'. Some philosophers have argued that *Ubuntu* characteristics can be identified in some norms and philosophical expressions such as communitarianism, feminism and Christianity among others (see Tomaselli, 2003, 2009; Broodryk, 1996; Prinsloo, 1996; Shutte, 1994).

Owing to these and some recognisable similarities between values of people - for example compassion, respect, hospitality, solidarity, togetherness among others – common in Africa and other continents, *Ubuntu* is thus "conceptually and practically associated with a long and profound tradition of humanist concern, caring and compassion, also prominent in Western thought" (Enslin and Horsthemke, 2004: 548). Since human dignity is argued to figure strongly

in the Western thinking (Prinsloo, 1996), the *Ubuntu* values cannot therefore be considered uniquely African as "the refusal to acknowledge the similarity between *Ubuntu* and other humanistic philosophical approaches is in part a reflection of ...parochialism...and a refusal to learn from others" (Ramphele, 1995: 15). This nevertheless, does not disqualify *Ubuntu* from being African. In my view, denying that *Ubuntu* is African is as good as denying that Kantian philosophy is Western. It is important to reiterate here that this study is informed by a culture-centered approach. what this means is that the problem of cultural location takes precedence over the content under consideration.

Contending the view that human dignity figures strongly in Europe; Nkonko Kamwangamalu (1999) questions some Western inhuman practices such as slavery, colonialism, Nazism, holocaust and Apartheid which are sharply opposed to respecting human dignity. However, Penny Enslin and Kai Horsthemke (2004); Kamwangamalu (1999) argue that *Ubuntu* as philosophy of life for Africans is faltered by some equally dehumanising African events and practices such as *muti* killings (sacrificing one another to improve the status of an individual) dictatorships, sexism, genocide, corruption, and xenophobia. Related to these and most importantly to this study is the adoption of human insensitive policies such as such as former President Thabo Mbeki government's widely condemned views on HIV/AIDS discussed in the next chapter. While such practices indeed happen in Africa, one can still argue that such practices may still be linked to the influence of the violent nature of capitalism (Western) which seeks to displace other for profit motives.

However, proponents of *Ubuntu* as African humanism such as Augustine Shutte (2008) contend that *Ubuntu* holds a view of humanity or human dignity that is sharply opposed to all kinds on individualism and equally opposed to collectivism of a Western kind (Shutte, 2008). This argument presents some problems. First, is the argument posited by Enslin and Horsthemke, (2004) that like 'Africa', the idea of the West refers not to a single homogeneous

system but to a diverse range of practices and traditions, some no longer current. While individualism is commonly associated with Western liberalism, equating liberalism with the West "is to ignore the fact that not all Western democratic theory is liberal, but that some are strongly critical of liberalism" (Enslin and Horsthemke, 2004: 549)

Lastly, African communalism is also problematic as discourses broadly associated with it are seen to negate individuality. However, asserting African communalism "is not in any way to imply the denial of the recognition of individual human beings qua individuals" (Kaphagawani, 2004: 338). In fact, 'we are' presupposes recognition of the individuality of those making up the 'we' (op. cit.). Rather, what is discouraged is the view that the individual should take precedence over the community (Teffo, 1996). Even though not underscored, the ontological uniqueness of each individual is recognised.

It is neither this study's aim to debate the uniqueness of *Ubuntu* from other philosophies, nor to advance it as uniquely African suffice to say that given the history of colonisation of Africa, one cannot deny the irrevocable influence of Western norms on indigenous cultures, for example Christianity (see Swanson 2007). I acknowledge the ills that are broadly associated with both the mechanical use and misuse of *Ubuntu*. Not everything that happens in Africa is good, even as a result of values broadly associated with *Ubuntu*. Also, not every single individual in Africa embraces *Ubuntu*: its values are not innate but are products of socialisation. The violent nature of capitalism and its dislocation of Africans to the margins of society may have decentered their philosophies. The example I gave earlier on how some youth in KwaZulu-Natal willfully infected others with HIV in the spirit of sharing that is propagated through *Ubuntu* shows how adulterated their conceptualisation of *Ubuntu* is.

Juxtaposing Kantian and *Ubuntu* philosophies in this study is a deliberate attempt to call on both Western and indigenous philosophies respectively to

supplement each other with ideals that can help formulate a culture-centered approach to HIV prevention that privileges local culture and values in modern African communities' endeavors to address their social development challenges. Indeed as Mzamo Mangaliso (2001: 31) posits, "in the contemporary African milieu the conventional wisdom is that customs will only be endorsed to the extent that they serve the common good. Otherwise, they will be challenged and changed". It is also accepted that culture is not static but continuously changes due to many things including changing people's behaviors and contact with other cultures (see Louw, 2001; Ovens, 2003). This, for example, has resulted in a (behaviour) generational gap and different cultural practices between inter alia the younger and old, the college-educated and the semiliterate, the urban and the rural (Mangaliso, 2001). This also has inevitably resulted not only in the adaptation but also adulteration of the principles of *Ubuntu.*

The relational nature of being: I am because we are
As with Kantian philosophy, the understanding of a person in *Ubuntu* is that persons are ends in themselves. However, unlike the former that sees personhood as autonomous/self-determining moral agents who have duty not only to others but themselves, *Ubuntu* sees community as an essential aspect of personhood. It "focuses on human relations, attending to the moral and spiritual consciousnesses (sic) of what it means to be human and to be in relationship with an-Other" (Swanson, 2007: 53) *Ubuntu.* Persons are recognized, valued and respected not because they are rational but in respect of their relations to others regardless of social status, gender, race, known or not known. All people have dignity which makes them worthy to be respected and valued. Respect for a person thus signifies recognition of another person's humanity. Each individual values being treated as an equal with respect and dignity. People are conscious of their common humanity in which no one is superior or inferior. Thus one person's worth as a human being is always

considered as great as another's. *Ubuntu* thus flourishes in respect and honour for others and is averse to anything that is harmful to a human person (Munyaka and Motlhabi 2009).

According to *Ubuntu* philosophy, a human being is therefore inseparable and incomplete without others. One's value is best realised in relationships with others, or as Chris Vervliet (2009: 21) puts it "human beings achieve their fullness in community". With community as the context for defining the meaning of personhood, the isolated and static self of Kantian philosophy is contradicted (Christians, 2004). The African view of a being is clearly articulated by John Mbiti, an African theologian who says,

> Only in terms of other people does the individual become conscious of his being, his own duties, his privileges and responsibilities towards himself and towards other people…What happens to the individual happens to the whole group, and whatever happens to the whole group happens to the individual. The individual can only say "I am because we are; and since we are, therefore I am." (Mbiti, 1969: 108-109)

Mbiti sums up the importance of the community in the *Ubuntu* conceptualisation of personhood. He clearly captures that it is with reference to the community that a person is defined giving meaning to the saying '*umuntu ngumuntu ngabantu'*. For Nhlanhla Mkhize (1998) the *Ubuntu* view of personhood thus "denies that a person can be described solely in terms of the physical and psychological properties" (cited in Nussbaum, 2003: 3). *Ubuntu* as Barbra Nussbaum (2003) concurs with Mbiti above "is consciousness of our natural desire to affirm our fellow human beings and to work and act towards each other". In essence, *Ubuntu* speaks to our interconnectedness, our common humanity and the responsibility to each other that flows from our deeply felt connection.

Such values are common in African culture as shown in proverbs and the way people greet. For example, IsiZulu greeting in South Africa is:

'Sa- wubona' (hi).

It means 'we see/recognise you'. Clearly this way of greeting encapsulates recognition of the other, one of the key values of *Ubuntu* highlighted above. In the same way, a Shona greeting in Zimbabwe is:

'Ma- kadini' (how are you).

The response is:

'Ti- ripo kana mu- ripowo' (we are there if you are there).

This shows interdependence and is evident of the principle that a human being is inseparable and incomplete without others.

The prefixes in all the greetings above - (Sa-) in *Sawubona*, (Ma-) in *Makadini*, and (Ti-) in *Tiripo* – are plural forms of the self 'I'. For Metz (2009; 2007a) this signifies a shared identity characterizing the relational nature of African people enjoined by *Ubuntu*. The self always conceives themselves as bound to community, as in common with others. The relational nature of being is discussed in detail further below.

Kamwangamalu (1999) discusses and illustrates *Ubuntu* values of communalism and interdependence with proverbs from *Ciluba*, a Bantu language spoken in the Democratic Republic of Congo. Key in these and many other proverbs common in all Bantu languages in sub-Saharan Africa articulate *Ubuntu* values of interdependence that are concerned about the development and maintenance of mutually affirming and enhancing relationships. After all, *Ubuntu* holds that people are born into a human society to which individuals are bound. For Senghor (1966) African societies are based on the community and on the person and are found on dialogue and reciprocity. Dialogue and conversation here are seen as an activity and ultimate purpose of a community (Shutte, 2008). Directly linked to this is the idea of participating in the community.

Ubuntu as a call for participation

From the preceding discussion, *Ubuntu* basically refers to the complementarity of the individual and the community (see Vervliet, 2009). For Shutte (2008) the best model of community in the African thought is family which serves as a means for personal growth of its members through the interaction, conversation and companionship among members. Personal growth, as expressed by the expression *umuntu ngumuntu ngabantu* presupposes dependence of human being on other people. Thus for Mkhize (2008) *Ubuntu* defines self in relation to the quality of his or her participation in a community. Gabriel Setiloane (1986) also observes the same. He argues that *Ubuntu* conception of personhood explains the kind of participation which takes place when people live together. For Setiloane (1986: 14),

> The essence of being is 'participation', in which humans are always interlocked with one another. The human being is not 'vital force' but more: 'vital force in participation' which forms the very soul of the community body and accounts for the miasma which attaches to the group...'Participation with its concomitant element of belonging is made possible by '*seriti*'... [emphasis original].

Seriti denotes that value of dignity - expressed by the expression *umuntu ngumuntu ngabantu* – an invisible human force that manifests itself in the relations between persons and the external world (Setiloane, 1986; Shutte, 2008).

Relations between persons as an *Ubuntu* injunction demands practical service to humanity. One is connected to their community through positive acts that's alleviates human suffering or furthers self and the other's wellbeing (Munyaka and Motlhabi, 2009; Metz, 2007a). Here the utilitarian definition of *Ubuntu* as "the quality of being human...the quality, or behavior of '*ntu*' or society that is sharing, charitableness, cooperation...a spirit of participatory humanism" (Nussbaum, 2003: 2) find relevance as the principle is for one - motivated by

feelings of compassion, caring and kindness - to provide assistance to the other with the stronger helping the weaker or those in an advantaged position helping the disadvantaged. Such acts "bring sense not only to one's own life but also to the life of others" (Broodryk, 1997: 74).

From a social change communication perspective, it is important to reiterate here that dialogue creates relationships which are important for the change process to occur (see Kincaid and Figueroa, 2009). These relationships are possible through respectful dialogue which presents *Ubuntu* as an ethos that equalises everyone's potential contributions to knowledge by allowing community members to assert themselves as active citizens rather than as passive subjects (see Letseka, 2013b; Tomaselli, 2003; Blankenberg, 1999). Here emphasis is placed on dialogue. According to Blankenberg, dialogue is necessary to fulfil one's humanity. As such, opinions of the other must be valued as much as one's own. A relationship with others and a respect for that relationship is the foundation of all information and knowledge. Participation is essential for human development, for what your neighbour has to offer in terms of experiences, knowledge and ideas is essential to your own growth (Blankenberg, 1999: 46). Communication begins with dialogue between people who respect each other, a dialogue without which sustainable development becomes difficult to achieve. Dialogue is thus indispensable in communal societies as they engage with social development challenges such as HIV/AIDS. It is the objective of this study to find ways in which *Ubuntu* moral philosophy can be applied to inform and guide meaningful participation of PLHIV in HIV prevention.

According to Louis Pojman (2006) moral philosophy "seeks to establish principles of right behaviour that may serve as action guides for individuals and groups... investigat[ing] which values and virtues are paramount to a worthwhile life or society" (Pojman, 2006: 2). The Kantian philosophy discussed earlier in this chapter is testament to these philosophical principles and

normative action guides for persons at least in the Western context. While there is no single definition to *Ubuntu* - having been defined as a quality of humanity (Bhengu, 1996; Shutte 1994), as a consciousness (Prinsloo, 1996), as a concept or idea of solidarity (Mkhize, 2008; Laden, 1997), as a process of becoming an ethical being (Karenga, 2004) and indeed as a philosophy (Temples, 1959; Blankenberg, 1999; Nussbaum, 2009) - it is also apparent from the foregoing that it is a moral philosophy which similarly confers human beings with a code of conduct with other human beings (Louw, 2001). For an individual to be labeled virtuous, *Ubuntu* enjoins one to demonstrate utter respect for practices that govern harmonious relationships with other human beings. It both describes being human as being-with-others and prescribes what being-with-others should be all about. It also reminds human beings about their obligations to other people and other life forms, obligations which one ought to respect. This *Ubuntu* normative framework is not different from Shutte's (1994: 38) understanding of the double aim of philosophy that its aim is to come to a "true insight into knowledge" and to develop "an understanding of ourselves as subjects and agents"

This study regards as plausible the argument that *Ubuntu* moral philosophy aptly explains salient beliefs and practices of many people in sub-Saharan Africa (Letseka, 2013a). The objective is to explore possible ways in which the *Ubuntu* values, principles and injunctions may serve as a philosophical grounding and theoretical framework for mainstreaming participation of South African PLHIV in social change communication HIV prevention, also addressing ills such as HIV/AIDS-related stigma and willful transmission of HIV. While I acknowledge that *Ubuntu* values are not alien to African people particularly those in South of the Sahara, I do not intend to limit *Ubuntu* potential (if any) in HIV prevention with PLHIV to this region, or to the Africa alone. HIV epidemic remains in my estimation a global social development challenge that I believe requires concerted effort to engage with.

Indeed this chapter has outlined and included both Kantian and *Ubuntu* principles in a possible framework through which participation of PLHIV in social change communication for HIV prevention can be viewed. It is, however, important to end by noting that these philosophies have not been immune to criticisms. It is not the study's purpose to compare the two and chose a better one. Rather, the use of these philosophies is complementary. The critique is therefore not against these philosophies' own sake but as it relates to the perceived usefulness in informing participation of PLHIV in HIV prevention. The study is therefore neither advocating a wholesale adoption of Kant or *Ubuntu* in viewing participation; neither does it advocate outright rejection of one for the other.

Critique of Ubuntu

Even though the 'African' thought expressed through *Ubuntu*; that which sees personhood as subsisting in relationships with the other cosmic and social forces can be contrasted to Kantian philosophy's conception of self as something inside a person, others have brandished as "essentialistic thinking" any presentation of *Ubuntu* as "African values" owing to a "myriad array of cultures, religions and languages" in the polymorphous grouping of the indigenous peoples in all African countries (Tomaselli, 2003: 428). *Ubuntu* is seen by Keyan Tomaselli (2009) as not unique from the moral injunctions in Kantian and Aristotelian moral philosophy. He argues that the Western ethical discourse is not unique from African contemporary communitarianism or even Christianity as their "principles link the individual to the community via practice and social action" (Tomaselli, 2009: 585). For this debate on whether there is anything as African Ethics, see Ronald Nicolson (2008); Shutte (2008, 2005); Broodryk (1996); Prinsloo (1996) among others.

This study acknowledges the influence of Western theories on most cultures in the world. Present African cultures are arguably a product of centuries of colonialism whose Western philosophies have to some extent been successfully

imposed as universal (see Louw, 2001; Ovens, 2003). For this study a simple structural and discourse analysis of Metz's formulation of *Ubuntu* as a normative theory for African ethics (see Chapter Nine) bears testimony to the inescapable influence of Kant's *The Groundwork* as "a standard of reference for moral philosophers of all persuasions" (Wood, 2002). The use by Metz (2007a) of terms such as "good will", "formula of", "variation…" and even the structure of the formulation gives Metz's formulation a pure Kantian perspective shown in earlier. The same can be said of this study. Involving Kant in this study may similarly be viewed as acknowledgement of his influence on the rationale of this thesis. This, however, must not in any way be construed to mean that there are no other philosophies of knowledge production.

The cultural-centered approach adopted for this study privileges participation or agency of cultural actors, deconstructing their absences from the narratives of the knowledge production imposed by dominant structures that present themselves as universal, dislocating other cultures in the margins. As shall be clear in Part III of this thesis, the configuration of participation by interviewed PLHIV, and their motivation is comparable to the values described here as *Ubuntu*. Also notable is the difference between this configuration with the individual rights oriented GIPA. While the configuration resembles the Denver Principles which are Western, motivations for the Activists in this study speak to the values described here as *Ubuntu*. What this suggests is a different center of culture or knowledge from Kant, GIPA and other frameworks that bear hallmarks of Western liberalism.

It is, however, important to note that a wholesale acceptance of all African customs and practices broadly associated with *Ubuntu* is not always helpful. Mangaliso (2001) cautions against this arguing that several customs and practices carried out in the name of *Ubuntu* are based on superstitions and can end up being oppressive and sexist. Denying individual behaviours and feelings which do not fit the cultural norm of a community by shaming such people

often stifle individual aspirations and progress. "Where the individual has to give up personal needs to fit the role expected of them in any group, then the unwanted behaviours and feelings are pushed into a metaphorical bag which is carried around as unresolved issues (baggage)" (Mangaliso, 2001: 31). Because being human is to relate, the need to belong on which *Ubuntu* places emphasis makes one sacrifice individual needs for the good of the community. The sacrificed individual need results in an internal conflict that causes an individual to adapt their behaviour or manipulate so as to become acceptable and to get the needs met (Mangaliso, 2001). This inevitably inhibits an individual's potential and causes dysfunctional interactions.

In light of the above caution which for this study appears plausible, only attractive principles from both philosophies which are deemed capable to mainstream participation of PLHIV in social change communication for HIV prevention particularly in the contemporary sub-Saharan Africa are emphasised. As will be clear in Chapters Seven and Eight, such principle - Kantian or *Ubuntu* - are used not in contrast but complementarily. This is arguably because weaknesses of one strengthen the other.

In the next section of this thesis – Chapters Three to Five – literature surveying current response to the HIV epidemic is reviewed. Focus is paid on how the response has contributed to the exclusion of PLHIV from participating in discursive spaces of the global HIV response and how successful this HIV response has been. The section ends by acknowledging attempts made to involve PLHIV in response to the epidemic and examines the policy framework regulating such involvement. It is this policy framework that this study seeks to ground in a philosophy that can be used to mainstream participation of South African PLHIV in social change communication for HIV prevention in a way that accounts for their life conditions, values and cultural circumstances.

PART II

OVERVIEW OF THE GLOBAL RESPONSES TO THE HIV EPIDEMIC

Although it is unlikely that the world's first HIV epidemic ... could have been prevented from causing terrible suffering, it is also true that the measures taken by national and international authorities during the 1980s and 1990s were generally considered inadequate

John Iliffe, The African AIDS Epidemic, 2006.

CHAPTER THREE

DISCURSIVE RESPONSES TO THE HIV EPIDEMIC AND THE DISLOCATION OF PEOPLE LIVING WITH HIV

Since its first clinical symptoms were initially described in 1981 in the United States of America, HIV/AIDS has been presented in a wide variety of ways. As Merrill Singer (1998: 23) has pointed out, "[t]he politics of HIV/AIDS-from the beginning-have not been one sided. The HIV/AIDS text is multi-vocal and includes not only the voice of authority but also the counterhegemonic voice of resistance". The picture of HIV/AIDS and the image of people living with HIV (PLHIV) have always been quite complex, being linked to a wider set of political, economic and cultural patterns and associations. In Europe and North America, HIV/AIDS was initially reported a problem of deviant and minority groups in society such as the gay community (homosexuals), but was later linked to intravenous drug addicts, haemophiliacs and restricted groups of heterosexuals particularly Haitians and black populations (Caraël 2006; McGough, 2005; Rossow, 2003).

As Singer (1998) observed, these minority groups were 'vectors of disadvantage' along which HIV was shown to be spreading. Associating HIV with these groups has resulted in the placement of PLHIV at certain levels of social systems of hierarchy and domination (Singer, 1998). While this may be argued to have, over the years, shaped the dominant HIV/AIDS discourse(s), more recently HIV/AIDS has been redefined and represented as a as a global concern for human development as it affects all human populations regardless of race, sexuality, class and gender.

This chapter explores the dominant and alternative discourse(s) around HIV/AIDS in light of Gill Seidel (1993) and Cindy Patton's (1997)

categorisations of HIV infection. They categorise HIV in terms of patterns of transmission. The first pattern has been associated with Europe and North America where most infections occur through drug injection and homosexual contacts; whereas the other pattern is linked to Africa where heterosexual intercourse is the dominant method of HIV transmission. Exploring the discourses around HIV/AIDS is useful in understanding not only how the epidemic has been represented but the position of PLHIV in these discourses. The positioning of PLHIV in HIV discourse is significant as it has major implications for the response to the HIV epidemic.

Within these discourses, the presentation of an early AIDS patient and the subsequent location of PLHIV in structures of power is explored. Examining where PLHIV are located in the HIV/AIDS discourses assumes and demands the character of opposing marginalisation of PLHIV. This is the central theme of this study: mainstreaming participation of PLHIV in HIV prevention. Michele Foucault's (1978; 1982) understanding of how discourse produces, reinforces and exposes power is employed in the analysis of the politics of HIV/AIDS discourse. The chapter therefore attempts to address two key questions: (a) how (if ever) did the presentation of the early AIDS patient dislocated PLHIV into the margins of society, and (b) in what ways have PLHIV challenged this marginalisation?

According to the culture-centered approach to social change (Dutta, 2011) listening to the voices of the marginalised is one way of bringing them into discursive spaces that limit their possibilities. Participation of PLHIV is now recognised as a very important approach to HIV prevention. For Colin Chasi (2011), society and all its actors cannot do well if they fail to take care of concerns that relate to them. This view finds expression in the ecological approach to HIV/AIDS which suggests that that an effective response to HIV/AIDS, as has been found, takes place when affected communities enact their agency in negotiating structures that limit their choices and capacity to

decide on issues affecting them (Govender, 2011; Stephens, 2004; GNP+, 2004). In this sense, "participatory approaches enable those who may now or previously have been marginalised [PLHIV] to usher in new truths and practices" (Chasi, 2011: 146). However, this is not without power contestations. There may be no better way of understanding the nature of, and power relations characterising the HIV/AIDS discourse than to look at how the early AIDS patient has been imaged since the first HIV/AIDS diagnosis in America. This is confirmed by Singer (1998: 62) who agrees with other scholars that "approaching the HIV epidemic from this vantage is an extension of the insight…that neither the life of an individual nor the history of a society can be understood without understanding both". A historical analysis of HIV/AIDS focusing on the presentation of those afflicted is therefore imperative. The way PLHIV have been perceived historically has in this study's view largely influenced the location of PLHIV at certain levels of the social structure as well as the global response to HIV/AIDS. As with Gill Seidel's (1993) and Cindy Patton's (1997) categorisations of HIV infection mentioned above, I begin by examining the Western pattern.

The Western AIDS patient as a person with an undesirable difference

Complex confusions permeated the earliest public image(s) of an AIDS patient in the Western world. I use the term "AIDS patient" in this chapter deliberately. As I will show later in this chapter, during the first decade after the discovery of HIV, most responses viewed the epidemic as 'medical' requiring a bio-medical response from 'experts' (SafAIDS, n.d). As such, this epidemiological approach crystallised PLHIV as 'patients' who need treatment, care and support. It can be argued that the confusion about the image of the AIDS ill is perhaps still prevailing throughout the world today. Literature shows that in America HIV/AIDS was an epidemic of fear and prejudice first associated with homosexuality (Gilman, 1988). The categorisation of 'AIDS patients' as

suffering from a Gay Related Immune Deficiency Syndrome or "gay compromise syndrome" (Gilman, 1988) is representative of this prejudice.

Compounded by prejudice, lack of knowledge about HIV/AIDS resulted in certain assumptions being made, most of which were later shown to be unfounded. According to Lawrence K Altman (1981), a medical doctor with the Centers for Disease Control (CDC) in America claimed in July 1981 that there was no apparent danger of contracting HIV to non-homosexuals simply because until that time no cases had been reported outside the homosexual community. However, it became clear shortly afterwards that HIV was a sexually transmitted infection that affected other population groups as well.

The term AIDS was coined in 1982 being understood as a subset of STIsbut specifically as "a disease that homosexuals suffered as direct result of their sexual practices" (Gilman, 1988: 247). However, from the beginning the person living with HIV/AIDS was seen as a male homosexual suffering a sexually transmitted infection. As this male homosexual AIDS patient's sexual practice and identity was different from the 'norm', 'he' was thus seen differently from the perceived normal spectrum of other patients (Gilman, 1988). The notion of homosexuals as persons afflicted with the sexual transmitted disease thus became the paradigm through which HIV/AIDS was understood and the AIDS patient perceived in the Western society. For Sander L Gilman (1988), placing the AIDS patient - a carrier of an infectious disease - in a specific sexual orientation whose sexual practices or identities are different from the 'norm' had a marginalising effect on the patient. The PLHIV are thus found on what Julia Epstein (1995: 182-3) refers to as "the public terrain of social prejudice".

In the Western world, HIV/AIDS was thus strongly associated with behaviours which, in the Victorian era were considered deviant. In the United States, HIV/AIDS emerged during a time of political conservation and the homosexual males with whom HIV/AIDS was associated were a highly stigmatised group in

the eyes of the American government (Mawar, *et al.,* 2005; Rossow, 2003). Until today, it is not uncommon in most societies to perceive HIV/AIDS as proof of a certain lacking moral order. The belief that homosexuals are to blame for the epidemic has recently been found to be common (Parker and Aggleton, 2002). This prejudice has since led to ostracism of the HIV-infected or those suspected of being infected.

While sexual orientation remained the salient characteristic used to exemplify the AIDS patient for close to a decade after the first HIV/AIDS diagnosis and the belief that homosexuals are the most group at risk of HIV still persisting today, HIV/AIDS also came to be associated with other socially deviant behaviours such as promiscuous heterosexual behaviour and drug use (Gilman, 1988). Regardless of the epidemiological reality that showed HIV infection among monogamous married women, promiscuous sexual behaviour by (unmarried) women was believed to be responsible for the heterosexual epidemic (Parker and Aggleton 2002).

Prostitution was widely considered as a non-normative female sexual behaviour. As such, women were often identified as vectors of infection (see Mawar, *et al.,* 2005). Associating women with HIV conjures a gender dynamic to HIV/AIDS-related stigma. The gender dynamic to stigma is also articulated by Richard Parker and Peter Aggleton (2002) who observed that as with women, in many settings men are equally blamed for heterosexual transmission because of assumptions about their desire for multiple sexual partners.

Social deviancy was a pre-existing source of discrimination and stigma since the nineteenth century (Brandt, 1985). Associating HIV with socially deviant behaviour thus compounded the marginalisation of the AIDS ill (Mawar, *et al.,* 2005). Victims of the epidemic of gonorrhoea and syphilis had, since the nineteenth century, been condemned as "suffering from an affliction of those who wilfully violated the moral code…a punishment for sexual irresponsibility"

(Brandt, 1985:134; Also see Lindenbaum, 1998). As with the previous epidemics and due to what Erving Goffman (1963) calls 'undesirable difference' from societal norms, those suffering from the HIV epidemic began to be negatively valued in the Western society (Mawar, *et al.,* 2005; Singer, 1998).

HIV/AIDS was thus perceived in the same way as previous epidemics like syphilis and gonorrhoea which had a range of alarming pathological consequences and was assumed to be casually transmitted. There was, therefore, a tendency to use analogy as a means of addressing the new epidemic. Advancing this argument Parker and Aggleton (2002) believe that ostracism of the AIDS ill interact with pre-existing fears about contagion and disease as those posed by syphilis and gonorrhoea. Concern about contagion, for example, resulted in the New York Police Department equipping its patrol officers with masks and gloves for use when dealing with suspected AIDS patients for fear that "they could bring the bug home and their whole family could get HIV" (*New York Times,* 1983). In some cases landlords evicted tenants with HIV while the Social Security department interviewed AIDS patients on telephone rather than face to face (Enlow, 1984).

According to Gilman (1988), in the same Western world, HIV/AIDS was also perceived to be an exotic disease linked to distant geography, race and ethnicity, primarily in Africa. The 'geography' of the disease enabled "tracing the origins of disease since its source, which is always distant from ourselves in the fantasy land of our fears, giving us assurance that we are not at fault but we have been invaded from without" (Gilman, 1988: 262). Thus, as John Iliffe (2006: 3) claims, "the earliest convincing evidence" points to HIV having originated from Belgian Congo - now Democratic Republic of Congo (DRC) - where in 1959 Simian Immunodeficiency Virus (SIV) was found in the blood sample of an unnamed African man in Kinshasa. SIV had elements of the virus found in African green monkeys and chimpanzees. Although this narrative on African origin of HIV/AIDS became a contested issue in the HIV/AIDS debate

since the late 1980s (see Mulwo, *et al.*, 2012) the Western discourse seems to have succeeded in imagining Africa as the source of the HIV epidemic supporting the orthodox view with statistics showing Africa as bearing the inordinate share of the epidemic. Perhaps through John Caldwell, *et al.,* (1989), African permissive sexuality thesis, HIV/AIDS was seen through the "American racist ideology" as an 'African' or 'Haitian' disease (Leibowitch, 1985).

As Laura McGough (2005:2) observes;

> Reactions to HIV/AIDS are...complicated by a wider set of political and cultural associations: initially, with homosexuality and Haiti, then with Africa. Each of these associations brought significant cultural baggage, including the legacy of racism and colonialism.

It is evident in the above observation that HIV/AIDS was characterised as much by Western racist assumptions about African sexuality as it was perceived by African scholars as a disease of the West resulting from the whites' 'immoral behaviour' (Parker and Aggleton, 2002). Quite telling in this discourse are the political power contestations between Africa and the West. The HIV/AIDS narrative thus becomes what Singer (1998:23) calls a product of a continuous compromise between socially contending forces such as classes, gender, ethnic groups and sexual orientation groups rather than the imposition of the powerful upon the powerless.

In the United States, black sexuality was associated with images of STIs and it became a category of marginalisation (Gilman 1988). The history of black people in America is rooted in heavy burdens of slavery, racial discrimination, poverty, malnutrition, homelessness, unemployment and many other vectors of disadvantage (Singer, 1998). These adverse social conditions and the high levels of stress resulting from them contribute not only to the marginalisation of minority population groups but increases PLHIV's vulnerability to HIV/AIDS,

which in turn exacerbates stigmatization and discrimination" (Singer, 1998; Parker and Aggleton, 2002).

Early HIV/AIDS metaphors such as death, horror, punishment, guilt, shame, and otherness among others have exacerbated fears about contagion, reinforcing and legitimizing stigmatization and discrimination (Parker and Aggleton, 2002). Thus, early educational campaigns about the problem of syphilis and gonorrhoea devised by the social hygienists emphasised fear of infection. For Allan M Brandt (1988: 368) these educational efforts "may have actually contributed to the pervasive fears of infection, to the stigma associated with the diseases, and to the discrimination against its victims". In the same way, associating HIV/AIDS with black sexuality in the US entailed stigmatisation of HIV/AIDS, a situation that posed a serious challenge particularly to the bio-medical response to the disease.

To establish and maintain dominance over the poor black population, a negatively valued difference was produced against diseased black people (Mawar, *et al.,* 2005). As Shirley Lindenbaum (1998: 51) observed, the widely held moral thought and experience in the Western world was that "established or governing groups have better health by dint of their position in society". Implied in this thought is the link between infectious disease and social differentiation bound by the notion already noted that HIV/AIDS punishes socially marginal people for their deviant behaviour. This constituted what Parker and Aggleton (2003) surmise as culturally constituted stigmatization.

It is evident from foregoing historical overview that the HIV/AIDS discourse produced in the Western world thrived on prejudice. Wittingly or unwittingly, the (mis)conceptions about both origin and contagion of HIV/AIDS in this discourse seem to also have been reproduced in Africa. As will be discussed below, the discourse about HIV/AIDS in Africa is also replete with misconceptions, not about homosexuality, but misconceptions about the

African culture and its link with HIV/AIDS. Due to these Western prejudices, many years during which prevention measures could have been implemented particularly in Africa were wasted (Gausset, 2001).

Association of HIV/AIDS with marginalised and undesired communities in the US arguably contributed to the erasure of their voices in the discursive spaces where polices on responding to the epidemic were being discussed. The silencing of the AIDS patient and the cultural stigmatisation affected the HIV response in many ways. While doctors in the West could do little to change the wider context of stigma which associated HIV/AIDS with the black colonised (marginalised) Africans (McGough, 2005), in Africa the Western notion of associating HIV/AIDS and homosexuality or drug consumption is argued to have prompted many African governments to deny the reported seriousness of HIV/AIDS in their countries where this behaviour was not common (Gausset, 2001). Although responses to HIV will be dealt with in greater detail in Chapter Four, here it suffices to say that while there is no advocacy for the abolition of homosexuality or intravenous drug use (Western culture associated with HIV/AIDS) in the Western HIV/AIDS discourse, the same discourse prescribes what can be viewed as a 'lethal dose' to Africa by discouraging African cultural practices that they associate with HIV/AIDS. The HIV response, as will be shown later in this chapter, became disastrous perhaps due to the fact that it was prescribed without any effort to understand the African socio-cultural context. It is also pertinent to mention here that the Western HIV/AIDS discourse has had not only a negative impact on global HIV/AIDS-related interventions but it influenced the birth of yet another discourse about HIV/AIDS in Africa.

The African HIV epidemic: Permissive sexuality?
HIV/AIDS has become more prevalent in Africa than in the West. Available statistics continue to show sub-Saharan region as bearing the brunt of the epidemic "with HIV/AIDS-related mortality rates exceeding those of the rest of

the world combined" (Mulwo, *et al.,* 2012). The prevalence of HIV in Africa is generally attributed to the delayed response by most African governments due to other immediate problems facing post-colonial Africa. For Iliffe (2006) when African governments eventually responded to the African epidemic, they modelled the responses to the strategies designed by dominant Western approaches designed for the Western epidemic. The Western strategy as articulated above was designed to counter epidemics in stigmatised minorities as evidenced by the Reagan administration's disdain for deviant minorities (Iliffe, 2006).

Although Africa had no recorded history of blood transfusion, homosexuality, or intravenous drug use that was associated with HIV/AIDS the in the West (Clumeck, *et al.,* 1984, scientists discovered that immunodeficiency in Africa and was similar to that of Western AIDS patients (Kalichman 2009). This realisation stimulated interest among European and American scientists to discover more about the occurrence of HIV/AIDS in Africa (Clumeck, *et al.,* 1984, Kalichman 2009). It is important to highlight that even today, the dominant HIV/AIDS discourse has continued to be led and dominated by Western scholars and institutions such as the Joint United Nations Programme on HIV/AIDS, World Health Organisation, Global Fund, International Monetary Fund and the World Bank amongst others.

As with the Western discourse that isolated the early AIDS patient, the early AIDS patient in Africa had the same fate as their mere proximity was also considered infectious. Hospital staff at Baragwanath in Soweto, South Africa "burned the first patients' clothes, attended them in gowns, masks and theatre boots, and refused to open body bags to enable relatives to identify corpses" (Iliffe, 2006: 66). Also early in the epidemic there were demands for sterilisation of the infected, in Botswana and Zimbabwe many preferred that PLHIV be quarantined, and in Kenya President Moi reported to have ordered quarantining as well (Iliffe, ibid). While public denial of HIV/AIDS was the

general response in Africa, it must be noted that other African governments such as Uganda and Senegal quickly initiated a positive response (Iliffe, 2006).

Be that as it may, the dominant Western discourse about HIV/AIDS has unarguably succeeded in defining what can and cannot be said about HIV/AIDS globally. The severe criticism and subsequent 'whipping into line' of South African ex-President Thabo Mbeki's theory about the link (or lack of it) between HIV/AIDS by the 'disciples of the dominant discourse' is illustrative of how powerful the Western discourse has become in regulating the global HIV/AIDS discourse (see. Tomaselli, 2011). Mbeki's view on HIV/AIDS is based on the question: why has Africa had the world's most terrible HIV epidemic? Contrary to the Western theories that posit that HIV/AIDS in Africa is exacerbated by sexual behaviour, Mbeki blames poverty for the epidemic in the continent. Mbeki's alternative view to HIV/AIDS, dismissed as pseudo-science by the dominant discourse, is explained later in this chapter.

As Foucault (1982) warns, discourse tends to regulate what is right or wrong; it is therefore inevitable that Mbeki denialism about the link between HIV and AIDS - regardless of how sincere it may have sounded to others - was eventually regulated by the dominant discourse. Although this debate signals a need to investigate the sincerity of the Western discourse, the investigation is beyond the scope of this study. Of relevance here, however, is the way the debate illuminates how discourse can be used to marginalise certain communities in society and also justify this marginalisation by silencing dissent.

Although the link between HIV and AIDS and sexuality is now unchallenged, concerns have been raised regarding the treatment of African sexuality in the available literature about HIV/AIDS. However, it has since been observed that most of the early studies on African sexuality were conducted by travellers, missionaries and colonial administrators. The resultant literature is what

Quentin Gausset (2001: 510) calls a "compilation of anecdotes, rumours and de-contextualized data". Due to a "morbid curiosity for exoticism", these studies tended to describe African customs and beliefs as irrational, primitive and immoral (op. cit.). Yet, such description of African customs was done without any effort to understand the broader socio-cultural context in which they were embedded. This is evidenced by Gausset's (2001: 510) observation that "African sexuality was studied only in as far as it was different from our own". As such, an ethnocentric point of view about many aspects of African culture was espoused. No narratives from an African standpoint, or from the African PLHIV themselves are included in this early literature. This silencing suggests a dislocation of the African HIV/AIDS narrative to the margins, a situation which led to misrepresentations of, and development of conspiracy theories about the African HIV epidemic discussed further below.

Whereas HIV/AIDS is associated with drug users, sex workers and homosexuals in the Western discourse, literature reveals that higher levels of sexual promiscuity is put as an explanation for HIV/AIDS in Africa. For Adalbertus Kamanzi (2008: 98) this is perhaps due to the limited knowledge of African cultures and societies by the dominant discourse. An example here is perhaps the first ethnocentric theory that HIV originated from apes. The implication was that the virus could have been transmitted to man through sexual relations between man and ape, or through some cultural practice (Hunt, 1996; Chirimuuta and Chirimuuta, 1997). This conspiracy is perhaps linked to the sexual permissiveness theory explained below.

African permissive sexuality thesis (Caldwell, *et al.,* 1989) articulates a distinct African sexuality that is characterised by high rates of partner change and sexual networking. Caldwell *et al.,* (1989) contend that as opposed to Western Europe systems where moral and religious value is attached to sexual behaviour making it imperative to control female sexuality in order to ensure an acceptable marriage to a person of the same social class, there is a distinct

African system embracing sexuality and marriage. Western scholars also believe that in Africa, non-marital births or marriage dissolution are not greatly frowned upon so much that there is little need to control sexuality and the sexual act. As such, only fertility, reproduction and lineage links are believed to be important than marriage bonds (Caldwell, *et al.,* 1989). Viewing African sexuality from a Western perspective is therefore fraught with misconceptions that are weaved on cultural prejudices (see Ahlberg, 1994).

The African permissive sexuality theory suggests that high degree of permissiveness and little morality on sexuality in Africa allow for multiple partnership and high rates of partner change. This level of sexual networking, according to the theory, makes it easy for HIV to spread (Van Eerdewijk 2007:38; Le Blanc, Meintel and Piché 1991:501). From this viewpoint, Gausset (2001) observes that African cultural practices are identified as culprits in the spread of HIV. The logical consequence was, therefore, an instigation of an agenda by the dominant discourse to fight African cultural barriers and sexualities as a response to HIV/AIDS. Given that in the Western world there had been equally risky cultural practices such as hospital blood transfusions, it is interesting to observe that no efforts were made to stop such practices.

Seemingly, this paradox immensely contributed to the emergence of an alternative view on HIV/AIDS that would challenge the sincerity of the dominant discourse about HIV/AIDS. The theory that HIV had originated from African monkeys was regarded by nationalist politicians and African physicians as a particularly insulting form of racism (Iliffe, 2006). This is perhaps why there still exists, in some parts of Africa, the belief that HIV/AIDS is associated with urban (Western) life. In this light, HIV/AIDS was thus denied by the African elites as "a foreign disease spread on the continent by white homosexuals" (a) "as an attempt to bring down the birth rate by imposing the use of condoms" and (b) "as an attack associated with the puritanism of Christian sects in the face of African traditions such as polygamy" (Carael,

2006: 31). This view sharply contradicts the dominant discourse that associated HIV/AIDS with Africans. For most Africans, HIV/AIDS is thus seen as a result of Western practices, or precisely as a disease brought by White men (Parker and Aggleton, 2003). It is in this sense that Edward Hoopers (2003), countering the blue monkeys and chimpanzees conspiracy theory, suggests that HIV could have originated from the polio vaccine administered to several volunteers in the 1950s in the now Democratic Republic of Congo. Here, the competing African and Western discourses about HIV/AIDS are all too clear. Considering the unethical treatment of black men in the United States Public Health Service (USPHS) Syphilis Study at Tuskegee (1932–72) now infamously known as the Tuskegee Syphilis Experiment, this analysis becomes plausible. The Tuskegee syphilis experiment was a clinical study conducted to study the natural progression of untreated syphilis in rural black men who thought they were receiving free health care from the U.S. government (see Rockwell, *et al.,* 1964).

As shown in the previous section, soon after HIV/AIDS was discovered in the West, it was associated with Africans among other racial groups. Considering the fact that the black population in Europe were discriminated and subordinated, many questions therefore arise: was associating HIV/AIDS with Africa a social production of difference (by the West) for the service of power? If so, then can the African notion of HIV/AIDS as a disease brought by the whites be interpreted as a form of resistance by Africa to challenge Western domination? While the theories about monkey origin were contended in 1987 when WHO described HIV/AIDS as caused by one or more naturally occurring retroviruses of undetermined origin (WHO, 1987), understanding the complex philosophical issues that arise from the above paradox is conceivably plausible in that it extends an insight into the political economy of HIV/AIDS. For Singer (1998) a political economic analysis of HIV/AIDS is concerned with the development of useful knowledge and a commitment to involvement of PLHIV in

the development of effective HIV prevention programmes. This understanding is particularly useful for this study whose aim is to find ways in which PLHIV can be meaningfully involved in strategic communication for HIV prevention. In order to unpack these questions meaningfully, it may be useful to appeal to Foucault's (1982) articulation of discourse in relation to power. Discourse, for Foucault (1978:100), "transmits and produces power; it reinforces it but also undermines and exposes it, renders it fragile and makes it possible to thwart it".

In light of the above, the history of HIV/AIDS, particularly in Africa cannot be complete without engaging with reactions from African academics and opinion leaders particularly Thabo Mbeki's alternative view on HIV/AIDS. This alternative view can possibly be viewed as the first open and deliberate alternative African discourse by a high political figure to challenge the dominant Western discourse about HIV/AIDS. Examining this alternative discourse is particularly relevant not only because this study was conducted in South Africa, but more significantly because HIV/AIDS denialism in South Africa arguably exemplifies the power PLHIV wields when it comes to addressing HIV/AIDS-related social development challenges. This is especially true when one considers the conflicts and court challenges that social movements such as the Treatment Action Campaign battled against the government (see Cullinan and Thom, 2009). Much can be learnt from this discourse as it offers insights into various ways through which PLHIV can meaningfully participate in social change communication for HIV prevention.

It is perhaps clear from the foregoing that the West produced an HIV/AIDS narrative that depicts Africa as a culprit regarding the source of HIV. Wittingly or unwittingly, this narrative appears to have simultaneously created fertile ground for Africa to challenge Western (mis)conceptions not only about the origins of the epidemic but also reasons why it is prevalent in Africa. Whether out of this narrative or not, indeed an alternative discourse that rebukes

Western science on HIV/AIDS for being a mere social production of inequalities in African community to maintain hegemony (colonialism) has been generated (see Mulwo, *et al.*, 2012). However, one can argue that the dominant HIV/AIDS discourse and science catches and deconstructs any alternative views to HIV/AIDS as denialism. Substantiating this argument is Mulwo *et al.'s* (2012) definition of denialism as a term that is used to describe a counter position by individuals, groups, institutions or governments questioning a proposition in which a scientific consensus exists. They note that the Western discourse on HIV/AIDS has used the term in reference to views on HIV/AIDS by Thabo Mbeki who, due to his controversial statements questioning the causal relationship between HIV and AIDS, has become the face of denialism in Africa. The paradox between orthodox and alternative views on HIV/AIDS, as discussed by Abraham Mulwo *et al.,* (2012) leaves discourses about HIV/AIDS not as innocent presentations but contested terrains on what can be surmised as the global *HIV/AIDSscape*. While Mulwo *et al.*, (2012) critically engage with this debate quite extensively, they do not address one of the key questions that drive the present study: where does this leave a person living with HIV/AIDS? Before this question is addressed, it is imperative to look briefly at how the alternative view on HIV/AIDS has been perceived or framed.

Alternative viewpoint: HIV/AIDS denialism

HIV/AIDS denialism has been perceived, understood and mediated differently by scholars. Tomaselli (2011) observes three perspectives from which different scholars have framed denialism discourse. First is an economic perspective which interprets denialism as a way of avoiding costs required for HIV treatment, care and support (see Mbali, 2004; Deane 2005). With an overwhelming number of PLHIV to care for in South Africa, the financial implications on treatment, viewed in light of other competing needs of the country is thought to have led the Mbeki government into HIV/AIDS denialism. For example, in particular provincial health care facilities lacked the "physical,

human and organisational infrastructure to implement even the relatively six month drug treatment for tuberculosis, or the basic immunisation for children, l*et alo*ne the far more complex long term demands of administering complex HIV/AIDS drugs" (Campbell, 2003: 6). Remarkably low percentages of full children immunisation coverage in 1998 (op. cit.) can be attributed to the above challenge.

Secondly, but relatedly is the view that denialism stemmed from government incapacity to manage HIV/AIDS due to inadequate health staff in public health institutions (cf. Buttler, 2005; Altman 2006). Due to a huge staffing deficit of about 30,000 posts in the public health sector, the available members were dealing with hire workloads leading to poor service delivery and long waiting list of HIV/AIDS therapy (Tomaselli, 2011). Writing for the *Mail and Guardian* on May 11, 2000 David McCoy revealed that in the Eastern Cape province the doctor – patient ratio was 1 as to 30, 000. He gives an example of a one *Tshungwana* clinic that served a population of 14, 000 which had no telephone, no running water or electricity and no visiting doctor. While government denial is one of the strategies characterising a pattern of historical responses to infectious diseases, Kalichman (2009) acknowledges lack of clear evidence that support the economic view to Mbeki denialism. However, it is known, as Myron Echenberg (2006: 90) observes, that "during the apartheid years the government of South Africa refused to acknowledge serious cholera outbreaks in the Bantustans to avoid having to build costly water purification plants". Those who subscribe to the economic argument may be viewing Mbeki's denial stance from this historical fact.

The last but most relevant to this study, which many scholars seem to agree, is the perceived notion that the political context of HIV/AIDS in South Africa links denialism to politics (Mulwo, *et al.,* 2012; Gevisser, 2007). This view frames the new South African government's alternative view on HIV/AIDS as a form of resistance to the colonial and post-apartheid discourses on race,

sexuality and disease (Sheckels, 2004; Mbali, 2004; Specter, 2007; Myburgh, 2009). As with the black South Africans' resistance to the apartheid government, this view is particularly relevant to this study because it provides insight into how HIV/AIDS discourse may have subjected PLHIV (and at the same time disposing PLHIV) to resist their placement in the margins of society. It is plausible to reiterate here that the question on how the marginalised can challenge marginality is the avowed goal of the present study.

While reviewing all these frames, Tomaselli (2011) offers yet another frame which dismisses denialism discourse as "sham reasoning and pseudo-science". This resonates well with Kalichman's (2009) view that in all its forms, denialism is inextricably netted with HIV/AIDS pseudoscience. It is, however, neither my intention to review in much detail the arguments advanced for framing the challenge to the Western vies and science on HIV/AIDS in all the perspectives presented above, nor to evaluate which one is most credible as compared to the other. For in doing so one risks becoming a mouthpiece of a particular discourse of which that is not the intention in this study. After all, as Foucault (1977; 1978) warns, knowledge and practices are not objective facts but are historically and culturally specific products. For Foucault, things meant something and were true only within a specific historical context.

However, what is perhaps interesting to understand here and quite useful for the achievement of the study objectives is how denialism can be interpreted not only as a challenge to claims to truth promoted by the Western discourse about HIV/AIDS but as an understanding of (and a form of resistance against) the same discourse. There may be no better way of accounting for this alternative discourse other than an exploration of the much criticised and now suppressed Mbeki's alternative view on HIV/AIDS which, as shown below, considers the Western discourse as a social product linked to colonial power and the aggravation of HIV/AIDS in Africa. This alternative discourse, as Charles Geshekter (2007) would call it, gained such currency that the South African

government under Mbeki was until recently reluctant to provide South African citizens with ARVs.

Thabo Mbeki's Alternative view on HIV/AIDS

There are numerous accounts of HIV/AIDS denialism in South Africa, chief among these being the works of Nicoli Nattrass (2007); Kalichman (2009); Theodore Sheckels (2004) and Mark Gevisser (2007). This review draws heavily on Kalichman's (2009) comprehensive and insightful account of the politics of denialism both in America as well as in South Africa. According to this account, HIV/AIDS denialism in (South) Africa is encapsulated in the anti-science, anti-racist thesis adopted by Mbeki and his government objecting the linking of the origin and spread of HIV to Africans and the Western perceptions that blacks are naturally promiscuous. Mbeki believes that a conspiracy exists to advance HIV as a cause of AIDS, and those "South Africans who espouse the orthodox view that HIV causes AIDS...are financially beholden to drug companies" (Kalichman, 2009:127; cf. Gevisser, 2007). Rather, Mbeki backed the African development of the HIV/AIDS drug, and early in his Presidency, he was involved in a failed attempt to develop Virodene for HIV/AIDS therapy (Kalichman, 2009; Cullinan and Thom, 2009; Sheckels, 2004).

Also espoused in this account is the notion that Mbeki refutes the idea that HIV is the major killer in Africa and believes HIV/AIDS distracts from the real problems Africans face particularly racism and unemployment (see Mbeki, 2000a; 2000b). Mbeki is also convinced that the established science cannot be trusted and must be considered as inconclusive and, therefore new ideas must be entertained in the debate about HIV/AIDS. His government, through the then Health Minister, Dr Manto Tshabalala-Msimang rebuked HIV/AIDS science and was against the use of HIV drugs arguing that they were toxic (Nattrass, 2007).

Mbeki's government is known to have blocked the rolling out of antiretroviral therapy (ART) for preventing HIV from infected mothers to their babies, advocating nutritional approaches instead (see Cullinan and Thom, 2009; Nattrass, 2007). In 2003, Manto - as the Health Minister was popularly known - denigrated drugs such as zidovudine (AZT) and other ARVs as toxic. As a result, she did not believe in handing these drugs to the people (Kalichman, 2009; Nattrass, 2007). The Minister then allowed Matthias Rath, an HIV/AIDS denialist to run clinical trials that saw the removal of AIDS patients from antiretroviral drugs to vitamins (Nattrass, 2007; Kalichman, 2009; Cullinan and Thom, 2009).

It may be important here to stress that rebuking science on HIV/AIDS is not unique to Mbeki or (South) Africa alone as there are other critics of this discourse even within the Western community. According to Kalichman (2009), confusion as to whether HIV is the cause of AIDS is traceable to Peter Duesberg, a leading HIV/AIDS 'denialist' who holds that HIV is a harmless virus that does not and cannot cause AIDS. A number of Americans who share the same view served on Mbeki's presidential panel of HIV/AIDS advisors. Duesberg was also included on this advisory panel.

In her foreword to Kalichman (1999) Nicoli Nattrass mourns that these "denialists" rejected all the available scientific evidence about the efficacy of using antiretroviral drugs for the prevention of mother to child transmission. Duesberg as well as Robert Root-Bernstein, both accomplished and renowned scientist and professors believe that a single virus cannot disable the immune system and cause AIDS. They propose that multiple factors must be at play to cause the collapse of the immune system (Kalichman, 2009: 7).

Mbeki's alternative view to Western science and medicine culminated in his dismissal of the then Deputy Health Minister Nozizwe Madlala-Routledge from office after she, as acting Minister in 2006, accepted and made several public

statements supportive of the benefits of ART (Mybur, 2009; Kalichman 2009). This was an antithesis to the discourse that Mbeki and Manto had produced and sought to promote. This discourse was based on a firm view that HIV therapy requires rigorous scientific testing. Duesberg's question on the causal connection between HIV and AIDS is considered as the basis of Mbeki's South African HIV/AIDS policy which was in part based on the notion that a single virus could not cause a syndrome of diseases (Kalichman, 2009).

Due to the above reason, at least for Mbeki, the devastating impact of HIV/AIDS in Africa, unlike in the West, must be blamed on poverty, not the virus itself. Mbeki was clear to the international world when he maintained his thesis while addressing delegates at an international conference on HIV/AIDS in Durban on July 9, 2000, where he is quoted as having said:

> HIV may technically cause AIDS, but poverty allows the disease and other diseases to have its devastating effects. Thus, we see AIDS predominantly among heterosexuals in Africa, who may take risks in their sexual behaviour but not as many as homosexual males and drug addicts take in the West. Poverty, with its accompanying vulnerability to disease, alters the calculus, causing what would be somewhat risky behaviour in the West to be highly risky behaviour in Africa (Sheckels, 2004: 75).

Although many, through the 'Durban Declaration' refuted Mbeki's claims and remain opposed to his views, Michael Merson, a former head of the Global HIV/AIDS Programme at WHO pointed out at the same conference that much of what Mbeki spoke of was true (Kalichman, 2009). However, following criticism his stance received at this conference, Mbeki removed himself from public HIV/AIDS debate. However, for a while his government policies remained entranced in denialism.

At the heart of the alternative view is a belief that Western scientific claims about the origins, causes and spread of HIV are not facts or simple truths in

any simple sense but social products linked to deeply entrenched white racial stereotypes of black Africans (Myburgh, 2009; Butler, 2005; Sheckels, 2004). This is summed up in an anonymous document (now popularly known as the Castro Hlongwane document) that was circulated in the South African government in early 2002. Here Hlongwane affirms that "Western science of HIV/AIDS was simply an expression of deeply entrenched and centuries-old white racist beliefs and concepts about Africans and black people (Myburgh, 2009: 8; Kalichman, 2009: 134). The document describes how HIV/AIDS promotes stereotypes of Africans as sexually insatiable as well as how poverty is the biggest killer and how rapidly changing societies are exposed to risks if the lower social class becomes overly indulgent.

Questions have been raised as to why Mbeki, an otherwise seemingly intelligent man would come to embrace views that are contrary to scientifically proven theories, medicines and explanations about HIV/AIDS. Alluding to Geshekter (2007), Mulwo *et al.,* (2012) contend that Mbeki's views may be read as an attempt to provide an alternative framework for understanding the HIV/AIDS crisis. Mbeki's public remarks have been viewed as seeking "to promote an understanding of HIV/AIDS in Africa in terms of epidemiology, rather than virology" (Mulwo*, et al.,* 2012: 9; also see van Rijn; 2006). The aim, as they argue, was to redirect attention from the causal link between HIV and AIDS to a broader discussion of factors that underlie the spread of disease in Africa.

However, Kalichman (2009) attributes this position to Mbeki's political philosophy which may have been influenced by the time he spent in Russia (Kalichman, 2009). Hlongwane's articulation of the alternative view on HIV/AIDS, as understood by Kalichman, is replete with Marxist overtones that are akin to Mbeki's political philosophy. This analysis is perhaps useful in appreciating the perspective that frames Mbeki's alternative view on HIV/AIDS within the political economy of HIV/AIDS in the context of (South) Africa.

Indeed, as Lindenbaum (1998); Chasi (2011); Tomaselli (2011) as well as Mulwo *et al.* (2012) observe, there are suggested links between HIV/AIDS and colonisation. For Lindenbaum (1998) - who concurs with Singer (1998) that the HIV/AIDS text if multivocal and fragmented - minority populations reject the orthodox stigmatising narratives about HIV/AIDS. They offer an ideological counter face to the dominant view by considering HIV/AIDS as "genocide in the form of germ warfare [initially] introduced by the United States government...with the purpose of eliminating unwanted persons, specifically homosexuals, drug users and poor inner-city African Americans and Latinos" (Lindenbaum, 1998: 53; also see Cantwell, 1988; 1993). Substantiating this view, notes some historical events such as the Tuskegee Syphilis Experiment where the government was implicated in killing rather than saving black people. Like the Tuskegee experiment, HIV is also believed to have been developed in the US and later introduced to people through Hepatitis B experiments (see Mulwo *et al.,* 2012).

Accentuating the above view and at the same time accounting for how the epidemic ended up affecting other racial groups, Lindenbaum (1998: 54) takes a view by one early AIDS patient at Harlem hospital in the US who felt that "AIDS is a designer disease...designed to hit gays and blacks, but...got out of control and by mistake...hit Rock Hudson and some rich white folks". Similarly, in the early 1990s in Soweto, South Africa, some black Activists who saw disease in this light satirically labelled AIDS as an "Afrikaner Invention to Deprive us of Sex" (Echenberg, 2006: 90) suggesting that HIV/AIDS had been invented by the Boers as a tactic to control blacks sexual behaviour. This thinking evokes memories of the same tactic used earlier by the same white South African government which in the 1890s deliberately imported rinderpest as a "conspiracy to destroy African cattle and drive pastoralists into wage labour" (Echenberg, 2006: 90).

The counteractive view of HIV/AIDS as part of a 'Western' project of 'African genocide' that seeks to annihilate specifically people of African (black) descent is again reaffirmed by Mulwo *et al.,* (2012). Unlike Lindenbaum (1998) who link the African genocide project to the Tuskegee syphilis experiment, Mulwo *et al.,* (2012) point out that HIV/AIDS is argued to perpetuate atrocities engineered by the West on Africans such as slavery, colonialism and neo-colonialism as well as globalization. As Mulwo *et al.,* (2012) argue, the above debate is a battle over the global image of Africa rather than the epidemic itself.

The controversy that has been generated by the scientific debates on the origin and spread of the HIV epidemic, the denial of the link between HIV and AIDS, and the resistance to the roll-out of antiretroviral therapy, has been a battle over the global, especially Euro-American, image of Africa, rather than the epidemic itself (Mulwo, *et al.,* 2012). For Mbeki, assumptions about African inferiority and sexual promiscuity buried within the conventional HIV/AIDS discourse represent Africa negatively as a sick continent, a representation that could lead to Afro-pessimism (Echenberg, 2006). The alternative HIV/AIDS discourse, as posited by Mulwo, *et al.,* (2012), is thus an 'Afro optimistic response' to a socio-economic and socio-political issues that the HIV epidemic and the West brought to Africa. As Singer (1998: 23) argues, this indeed shows that "the HIV/AIDS text is multi-vocal, and includes not only the voice of authority but also the counterhegemonic voice of resistance" not only against the Eurocentric views about HIV/AIDS but against Western domination on Africa.

Alternative view on HIV/AIDS: Africa challenging Western domination?
In the context of South Africa, the alternative view on HIV/AIDS is attributed to the vestiges of apartheid's social and political structures. Citing Anthony Butler (2005), Tomaselli (2011: 29) assents that South Africa's history of apartheid division particularly racist science which serviced apartheid philosophy by justifying racism and domination impelled powerful decision-makers "to doubt

the benevolence and coherence of the bio-medical/mobilisation paradigm". For Tomaselli (2011) this kind of science produced a discourse to explain phenomena to serve a political purpose.

The above sentiments reinforce Kalichman's (2009: 127) assertion that "South African suspicion about a disease that was killing more blacks than whites may have been inevitable following the ruthless wrath of colonialism and Apartheid". As with Foucault's warning that discourse produces, transmits and protects power yet at the same time exposing and making power fragile (Foucault, 1977, 1978), Tomaselli (2011) argues that while bent on resisting domination, Mbeki's view on HIV/AIDS discursively operates in the same way racist science produced a discourse to explain phenomena in the service of power.

While many have dismissed Mbeki's alternative viewpoint on HIV/AIDS as an obsession with race, the argument equating the alternative view to challenging colonial domination is clearly articulated by James Myburgh's (2009) assessment that the key to understanding Mbeki's views lay not in his racial preoccupation but in the African National Congress's promotion of and involvement in an alternative HIV/AIDS cure, Virodene - a drug that was discovered in South Africa in 1997 and was claimed to be a possible cure for HIV/AIDS. For a comprehensive history about Virodene, see Myburgh (2009). The Mbeki government held a strong belief that "this medicine developed in Africa for Africans...would racially affirm the new government, and disprove once and for all Western stereotypes of black African incapacity (Myburgh, 2009: 4). By so doing, the government believed that African medicine "could validate South Africa's black majority in much the same way that Christian Barnard's first successful heart transplant in 1967 affirmed apartheid South Africa to the world" (op. cit.). The drug was therefore a symbol that held the possibility of a kind of racial vindication for the black African majority (Myburgh, 2009: 8).

In the way that Foucault (1982) purports discourse to operate, Mbeki as the national leader propagated discourse of denial explained above, a discourse that had claims of truth to regulate what society must believe and what not to believe about HIV/AIDS, what is true about HIV/AIDS and what is not true about it. This is the same way colonial governments would use claims of "truth" to regulate the masses (Sheckels, 2004).

Remarks made by Mbeki during his famous public lecture at Fort Hare University in 2001 seem to be dismissive of the precepts of the African permissive sexuality thesis that, as discussed earlier, perceives Africans to be promiscuous (see Caldwell, *et al,.* 1989). Perhaps, this can as well be viewed as a form of resistance to the dominant HIV/AIDS discourse. During this lecture, Mbeki bemoaned the fact that the West sees Africans as "natural born promiscuous carriers of germs". He castigated the West for holding wrong convictions that Africans are "but natural-born, promiscuous carriers of germs, unique in the world [and] doomed to an inevitable mortal end because of our unconquerable devotion to the sin of lust" (Mbeki, 2001). Mbeki was not at ease with Western views that depicted Africans as germ carriers, and human beings of a lower order that cannot subject their sexual desires to reason. In Mbeki's view, the ethnocentric views about Africa in the Western discourse presented HIV/AIDS among Africans as a self-inflicted disease.

For Mbeki, whatever lessons Africa may draw from the West about HIV/AIDS, "a simple superimposition of Western experience on African reality, [however], would be absurd and illogical" (Mbeki, 2000a). Rather, he is of the view that as Africans we have a responsibility to respond to the specific threat that faces us. "We will not eschew this obligation in favour of the comfort of the recitation of a catechism that may very well be a correct response to the specific manifestation of HIV/AIDS in the West" (Mbeki, 2000a). For Mbeki (2001), a religious worship of Western prescriptions on African problems would be dangerous. Their appropriateness in the Western context does not necessarily

hold in African context. Here Mbeki echoes Foucault's belief that things mean something and are 'true' only within a specific context. He conceives poverty and inequity as HIV's most potent co-factors in the spread of the disease. For Mbeki, the African solution to the HIV/AIDS problem is poverty alleviation.

Locating the above within the (South) African context, Mbeki's linking of poverty and AIDS has been interpreted by some as a veiled attack on colonialism which in his view is unarguably responsible for poverty in Africa (Tomaselli, 2011). From this perspective, the West is arguably culpable for creating, through its colonial and postcolonial economic policies, the environment that feeds HIV/AIDS (Sheckels, 2004: 75). In this context, the perceived censoring of alternative views on HIV/AIDS by the dominant discourse discussed in the foregoing can be blamed on the above noted West's complicities in creating environments (poverty) that breed HIV/AIDS.

Reminiscent of how post-modernist Marxist thinkers in development communication (Freire, 1970; Servaes, 1999; Gunder-Frank, 1967) debunked dominant theories of development attributing the futility of development in Third World countries to the top down approaches informed by these theories, on April 3, 2000 Mbeki addressed a letter to fellow World leaders impugning imposition of foreign solutions to local problems. He wrote; "It is obvious that whatever lessons we have to, and may draw from the West about the grave issue of HIV/AIDS, a simple superimposition of Western experience on African reality would be absurd and illogical" (Mbeki, 2000a).

Denouncing forces that were aggressively championing the assailing of his alternative view to HIV/AIDS epidemic in Africa, Mbeki in the same letter is quick to link the opposing attitude to colonial domination. He points out that:

> Not long ago, in our own country, people were killed, tortured, imprisoned and prohibited from being quoted in private and in public because the established authority believed that their views were dangerous and discredited…We are now

being asked to do precisely the same thing that the racist apartheid tyranny we opposed did, because, it is said, there exists a scientific view that is supported by the majority, against which dissent is prohibited (Mbeki, 2000a).

Mbeki also believes that a conspiracy exists to advance HIV as a cause of AIDS in the service of capitalism. In the same letter he extends criticism to 'the established world economic order' and, specifically, 'big world drug companies'. For Mbeki, the West insists on the HIV - AIDS link because their drug companies have developed products to fight HIV, as such they need HIV to be the cause of AIDS. If it is not, then their efforts to develop a vaccine would have failed therefore they stand to lose a great deal of money (Sheckels, 2004: 76).

Mbeki expressed this conspiracy again during his address to the African National Congress members of parliament in 2000 saying:

> If we say HIV equals AIDS then we must say equals drugs. Pharmaceutical companies want to sell drugs which they can't do unless HIV causes AIDS, so they don't want this thesis to be attacked. That's one problem. The other one is the international political environment where the CIA has got involved. So, the US says we will give loans to Africa to pay for US drugs (Kalichman, 2009: 80)

The involvement of pharmaceutical companies in this debate is tersely explained by Tomaselli (2011: 31) who, replying to Peris Jones (2005), acknowledges that the pharmaceutical industry was implicated in purposefully propagating false information about HIV/AIDS to promote its products.

For Sheckels (2004), Mbeki's conspiracy theory is sincere because as a trained revolutionary, he is accustomed to seeing the nefarious side of 'established authority'. This again places Mbeki's alternative view as not only as pseudo-science but as an alternative discourse and counter-ideological response to Afro-pessimism (Mulwo, *et al.,* 2012). This perspective of Mbeki's stance is thus

characterised by John Kunda and Keyan Tomaselli (2012) as confusing public health with militant nationalism.

As Tomaselli (2011) posits, Africans believe that accepting white medicine is a way of regarding them (the whites) as more powerful. He brings to light the suspicion and power relations between Africa and the West that are inherent in the former's understanding of Western medicine. For example, the sexual imagery depicting the West as a male and Africa as female conjure these power relations. Indeed, across colonial Africa, medicine was always understood as a vital ingredient in white political power. The needle that penetrates African skin to extract or inject substances into African blood has never been a neutral technology; it is an image that has always been hungry for meaning (Tomaselli, 2011: 30)

The above imagery entails scepticism among Africans about foreign ideas and technologies which, according to Jonny Steinberg (2008), have been agents of corrosion. This mistrust is succinctly shown by Kalichman (2009: 135) who observes that

> [t]he vicious policies of colonialism and Apartheid created an immense distrust of white authority and the West. The Apartheid regime had even worked on biological weapons to control the black population the event of a civil war. African civilisation brought a dream of self-reliance – African solution for African problems.

It is not farfetched, therefore, to suggest that Mbeki's determination to find African solutions to African problems was borne out of this suspicion and can therefore be interpreted as a form of resistance to Western domination. This is consistent with African Renaissance which Mbeki conceived "as a means of having Africans rediscover and affirm their cultural identity" (Echenberg, 2006: 95).

Although it is not the objective of the present study to review frames within which Mbeki's alternative view on HIV/AIDS can be interpreted, the narrative is arguably instrumental in developing a political-economic understanding of HIV/AIDS particularly in the Third World where, as Singer (1998) observes, the epidemic has been viewed as a disease of development and underdevelopment. Alternative views on HIV/AIDS, however, signal and indeed form an integral part of the history and plight of PLHIV. Such views are perhaps inseparable from marginalisation of PLHIV as well as the fight against this marginalisation. This is perhaps the reason why a review of an alternative view to the dominant discourses about HIV/AIDS, particularly in South Africa, was for this study inescapable. Of interest, however, is the position occupied by PLHIV in both the dominant and alternative discourses. These interests can be tersely put in question format as: how are PLHIV constructed in these discourses and with what effect? Do these discourses open up or close down opportunities for action by PLHIV?

It may be difficult to engage with these questions at this point suffice to say that while the alternative discourse unwittingly brought PLHIV into limelight by provoking them into action (see Chapter Five), both the Western and African discourses about HIV/AIDS leave little to imagination as to their stigmatisation of the AIDS patient. The discourses about HIV/AIDS are replete with metaphors contributing to the perception of HIV/AIDS as a disease that affects those who are different or "Others" in terms of sexual behaviour/orientation, gender, race, or socioeconomic status. Associating HIV/AIDS with subordinated groups is so potent in understanding the political economy of HIV/AIDS. It is for this reason that it is important to examine ways in which the above discourses about HIV/AIDS have influenced marginalisation or stigmatisation of PLHIV. Below is an exploration of the concept of stigma with a specific focus on how it has been deployed for the marginalisation of PLHIV and

the effect this has had on the global response to the HIV/AIDS epidemic. Reactions from PLHIV are examined in greater detail in Chapter Five.

HIV/AIDS-related stigma and discrimination

Literature on HIV/AIDS-related stigma and discrimination has largely been influenced by the seminal work of Goffman (1963) that formulates stigma simply as an attribute that significantly discredits a person with an 'undesirable difference'. For Goffman, stigma is conceptualised on the basis of what constitutes difference or deviance and is applied by society through rules and sanctions. This result in what he calls a spoiled identity for the stigmatised individual (Goffman, 1963).

While acknowledging Goffman's influence on the conceptualisation of stigma, sociologists have argued that his formulation of stigma as a discrediting attribute has led to an understanding of stigma as though it is a kind of 'thing' that someone does to another. However, Parker and Aggleton (2003) contend that this conceptualisation may seem logical in highly individualised cultures such as in the West but may not be appropriate in Africa. Their argument is based on the fact that people in the West are taught to be free agents and thus make little sense of their environments whereas in Africa bonds and allegiance to family and community are valued. Stigma in African communities, they argue, cannot therefore be conceived as an individual trait but as a social and cultural phenomenon linked to the actions of the whole community.

It is in this context that this study conceptualises HIV/AIDS-related stigma and discrimination, in the same way that Parker and Aggleton (2003) do. Arguing for a broader conceptualisation of stigma in the context of social construction of individual realities, Parker and Aggleton (2003) propose a focus that takes into account the structural conditions that produce exclusion from social and economic life (see Brandt, 1988). Their argument is based on a view that Goffman's formulation prompted stigma to be seen as something in the

person stigmatised, rather than as a designation that others attach to that individual, a social process that is constantly changing and often resisted (Parker and Aggleton, 2003). In their view, stigma has to be understood as a social process linked to culture, power and difference. They understand stigma to have a history which influences when it appears and the form it takes.

As with Foucault's (1978) conceptualisation of knowledge, stigmatisation therefore takes shape in a specific context of culture and power. In light of this view, there is acknowledgement that the early AIDS patient was assumed to be from members of society who are already marginalized for reasons of sexuality, gender, ethnicity, life-style, or socioeconomic status among other things (Mawar, *et al.,* 2005). From this perspective, it may be intelligible to locate HIV stigma at an intersection with other pre-existing stigma. Figure 3.1 below is illustrative of this. As shown on the Figure, the AIDS patient is related to sexual relations. Here it is presented as gay plague and also linked to sex workers. How sexual practices or identities considered different from societal norms are stigmatised has already been discussed. That HIV is mainly sexually transmitted and that AIDS in the Western discourse was initially linked to homosexuals (an identity that was considered 'different') are perhaps the reasons why PLHIV have been stigmatised. In this regard, HIV/AIDS-related stigma can be conceived as a layer on pre-existing stigma associated with sexuality or sexual deviance.

The AIDS patient is similarly shown closely related to gender relations. Even though in the West, HIV transmission has been linked with homosexuality, the African epidemic is reported to be largely heterosexual. In most African communities, HIV transmission has been blamed on female prostitution which is widely perceived as non-normative female behaviour (Mawar, et al., 2005; Parker and Aggleton, 2002). For Leclerc-Madlala (2001: 42) the "genderification" of HIV/AIDS has seen socio-cultural construction of femininity, in which women are seen as both the sources and disseminators of

HIV/AIDS illness and death. Leclerc-Madlala (2001) believes that the predominant blame on women for the presence and spread of HIV demonises them. This process both reflects and contributes to women's already marginalised and subordinate status in society (Mawar, et al., 2005; Leclerc-Madlala, 2001). In some cases men are blamed for heterosexual transmission where they date young girls or where they are involved in multiple concurrent sexual partnerships. In this context, HIV/AIDS has thus been viewed from a gender relations perspective. Since sexual immorality is considered as behaviour different from the norm, marginalisation of PLHIV can be linked to pre-existing sexual stigma associated with sexually transmitted infections, homosexuality, promiscuity, prostitution, and sexual deviance (Mawar, et al., 2005; Parker and Aggleton, 2002).

Figure 3.1: Social construction of HIV/AIDS-related stigma and its link with pre-existing inequalities (Adapted from Parker and Aggleton, 2002: 3; also see Mawar, et al., 2005: 473)
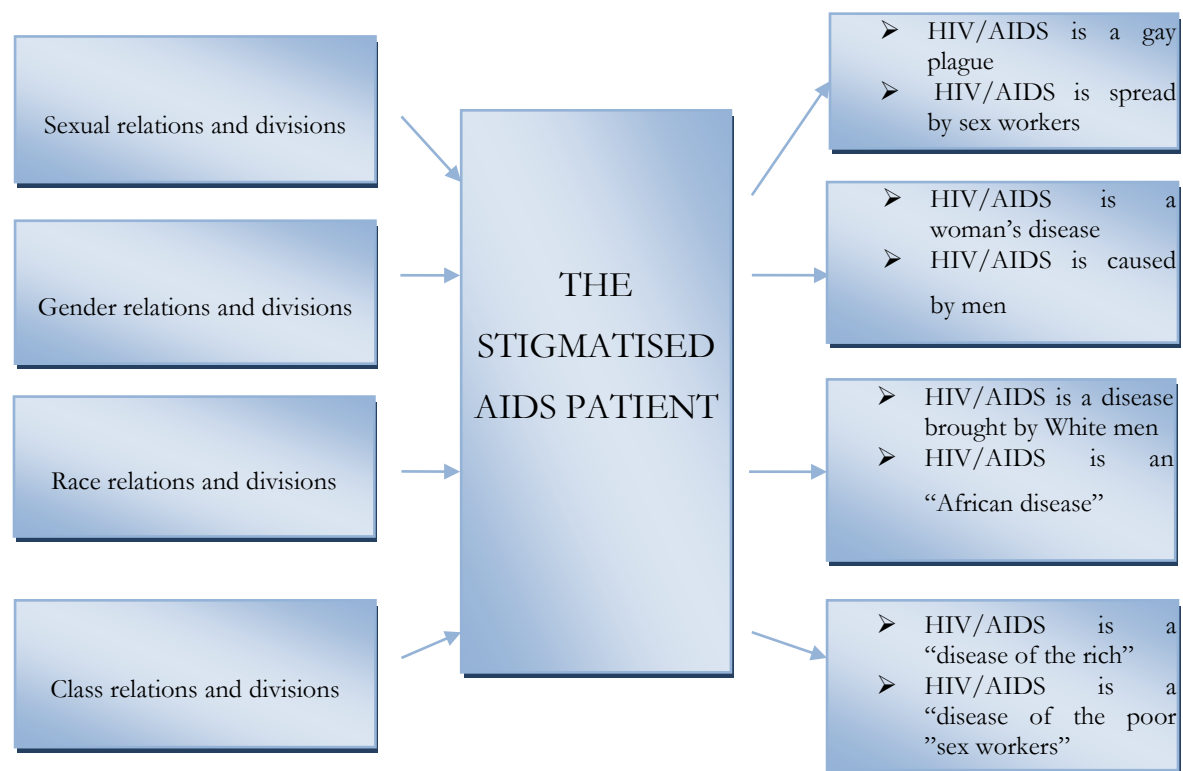
As depicted on Figure 3.1, HIV/AIDS is also associated with class relations. The link between HIV/AIDS and poverty underscores President Mbeki's alternative view on HIV/AIDS. On the other hand, wealthy elderly men and women have often been perceived as vectors of HIV transmission in cases where they are involved in transactional sex with poor young girls and boys. In these circumstances, the former are popularly known in South Africa as "Sugar Daddies" whereas the latter are known as "Sugar Mummies" (Leclerc-Madlala, 2008). These intergenerational sexual relationships have been blamed for the disproportionately high HIV infection rates among young girls aged between 15 and 19 (UNAIDS, 2010). In such kinds of relationships, often stigmatised are particularly the rich and elderly partner.

The AIDS patient is also linked with ethnicity or race relations and divisions. There exist conspiracy theories that view the epidemic as a 'black' or a 'white' disease. Notions about African sexuality in the Western discourse; depiction of HIV/AIDS as a disease of the West caused by the West's immoral behaviour; and also depiction of HIV/AIDS as associated with Western domination and imperialism suggest these conspiracy theories. Marginalisation of the black population in the West has also contributed to the marginalisation of PLHIV (Mawar, *et al.,* 2005).

The above makes apparent how HIV/AIDS-related stigma is layered on pre-existing notions of stigma. For example, studies have shown that there is significantly less sympathy for people living with HIV who use drugs and for people described as homosexual yet there is most sympathy for children and heterosexual women living with HIV (Norman*, et al.,* 2009). The consequence of this assumption is the continued exclusion of PLHIV due to the fact that in some settings, for example, men would fear revealing their HIV status because it will be assumed that they are homosexual. In the same way, women would fear revealing their serostatus because they would be labelled as "promiscuous" or sex workers. The above prompts further complications it results a vicious

cycle where HIV/AIDS is associated with marginalised behaviors (Mawar, *et al.,* 2005; Parker and Aggleton, 2002). The implication is that the already marginalised groups are further stigmatised because they are assumed to have HIV/AIDS.

Considering the foregoing, stigmatisation of PLHIV can be seen as prejudice based on society's pre-existing notions of marginalisation emanating from the past public health approaches to diseases associated with social deviant behaviour. The continued marginalisation or exclusion of PLHIV is consistent with both the African and Western discourses of HIV/AIDS in which PLHIV are viewed as possessing an undesirable difference. HIV/AIDS-related stigma and discrimination continues to be central in the Global HIV/AIDS challenge. This is evidenced by the widespread recognition in the HIV/AIDS literature of the deleterious effect that HIV/AIDS-related stigma has on the social, cultural, economic and political responses to the epidemic. Addressing the challenge of HIV/AIDS-related stigma and discrimination is therefore central in the global response to the epidemic (UNAIDS, 2010).

However, addressing stigma cannot be achievable without an understanding of how it has been and continues to be deployed in different societies. For example, despite empirical evidence that social change - in this case effective response to the epidemic - takes place precisely when affected communities have mobilised themselves to fight back against stigmatisation and discrimination, most interventions that have been developed to respond to HIV/AIDS-related stigma have been aimed at increasing tolerance of PLHIV by the society (Parker and Aggleton, 2003: 16). From a Foucauldian perspective, the discourse of 'tolerance' may be viewed as suggestive (and perhaps a reproduction) of the social inequalities between the 'tolerated' and the 'tolerator' in the social hierarchy. This is precisely because of its potential to cause the former to be devalued and the latter to feel that they are superior. A new way of thinking has thus emerged whose analysis views stigma and discrimination as

an expression of a struggle for power and privilege weaved on patterns of dominance and oppression.

The relevance of Foucauldian discourse in the new thinking, particularly regarding the understanding of how stigma as a discourse has been used to produce and reproduce social inequality or marginalisation of PLHIV, becomes apparent. Here, an analysis of the conceptualisation of stigma as a social process also becomes useful.

Stigma has been defined as a negative attribute mapped onto people with an undesirable difference, "who in turn by virtue of their difference, are understood to be negatively valued in society" (Parker and Aggleton, 2003: 14). Stigma thus plays a key role in producing and reproducing relations of power and control as it causes PLHIV to be devalued and those that are not infected to feel that they are superior in some way. Stigmatisation of PLHIV can thus be conceptualised as what Parker and Aggleton (2003: 16) refer to as a "social processes that can only be understood in relation to broader notions of power and domination".

In this study stigma is understood as a social and cultural phenomena linked to the actions of whole groups of people. It was established earlier that the stigmatisation of the early AIDS patient in both the African and Western societies was due to the association of HIV/AIDS with social deviancy. As such, the desire to look for historical models of dealing with difference or social deviancy therefore acted as important precedents for the fight against the HIV/AIDS epidemic (Brandt, 1988, p.367). The history of epidemics in the West is replete with stigmatisation towards conditions that are threatening, contagious, visible, and associated with deviance behaviour. With HIV/AIDS having all these characteristics, stigma can be argued to have been reproduced as an early response to the HIV/AIDS epidemic. A discussion on how stigma was used as a response to the HIV epidemic is presented in the next chapter.

Here it suffices to note that in their conceptualisation of stigma, Parker and Aggleton (2003) argue that stigma was used by individuals, communities and the state to produce social inequality. For example, when viewed from a Foucauldian perspective, the use of stigma for fear of contagion seen in the Western discourse about HIV/AIDS can be understood as a regime of power that was deployed for the social control or subjectification of the AIDS patient as a conforming subjects or docile bodies. In Foucauldian terms, production of the unnatural is necessary for the definition of the natural (Foucault, 1978; 1977). Similarly, in the context of stigma as a regime of power, it was necessary to mark significant differences between categories of people - stigmatise sexual deviants as having an unwanted difference - for the maintenance of social order. As Parker and Aggleton (2003) seem to suggest, stigmatisation as a regime of power inserted PLHIV in the margins of the structures of power.

As Foucault's adage goes, discourse produces, transmits and protects power yet at the same time it exposes and makes power fragile (Foucault, 1977, 1978). Viewed from this perspective, could it therefore be possible that the experience of stigmatisation by those in positions devalued or stigmatised by the logic of domination could have generated some form of resistance to redefine their position in society or seek transformation of the overall social structure?

It is important here to acknowledge a widespread recognition that both the process of rationalising domination as well as experiences of domination and resistance to power implied in Foucault's axiom above creates some form of identities among the dominated. Manuel Castells (1997) distinguishes three identities that can result from this process namely; legitimising identities, resistance identities and project identities. Whereas legitimising identities are those introduced by regimes of power to legitimise and reinforce domination, resistance identities are generated by the dominated to resist power. Castells

(1997) defines project identities as those formed by social actors to build a new identity to challenge the social order.

But how is the notion of identities relevant here? For Castells (1997), project identity redefines the position of the dominated in society and seeks to transform the social structure. What this identity implies is that marginalising in a way may cause PLHIV to challenge the system that flung them to the margins of the social structure. But how can they challenge the system? Can the subaltern speak? Even so, how much space is available for the othered to speak? Put simply, is there space for PLHIV to actively and meaningfully participate in the HIV/AIDS discourse, particularly as it relates to preventing HIV transmission? Literature is replete with examples of events that may provide clues to these questions. More than anything, an examination of Zackie Achmat's activism in reaction to the South African government's stance on HIV/AIDS anchored on Mbeki's alternative views could provide a compelling insight into the potential of PLHIV to challenge the system. Achmat is a South African HIV/AIDS Activist who lives openly with HIV. As shown in Chapter Five, Achmat made a name for himself and the movement he founded, the Treatment Action Campaign (TAC) through challenging President Mbeki and his government's public health policy regarding provision of therapy for PLHIV.

It is important to end this chapter by noting that while the foregoing perceptions about the AIDS patient and ensuing stigmatisation and or marginalisation are from an earlier stage of the HIV/AIDS epidemic, they are not without effect. Current literature on HIV/AIDS suggests that some of the early views on HIV/AIDS seem to prevail even today. What is perhaps pertinent for interrogation is the implication of the foregoing presentation of PLHIV in the Western, the African as well as the Mbeki's alternative view on HIV/AIDS to the HIV response. From the above review, it is clear that the presentation was marginalising perhaps as a result of pre-existing notions of inequality. Certainly, this has wide ranging consequences to the global HIV response as

well as gross impact on the quality of life of PLHIV. While a discussion of these consequences is the subject of the next chapter, it is important to highlight how the discourses about HIV/AIDS reviewed in this chapter have impacted on the responses to the HIV/AIDS epidemic.

Because the early AIDS patient came from a population group that was considered to be socially deviant, there was a tendency for many to blame the patient for the disease (Devine, *et al.,* 1999). As such, a discourse of exclusion was generated to symbolically annihilate the societal deviants by dislocating the HIV/AIDS-ill in the margins of society through stigmatisation. PLHIV were thus excluded from participating in in discursive spaces where responses to the epidemic are discussed and decided. This practice is what the culture-centered approach adopted for this study seeks to address.

It is important to note, however, that the erasure of voices of PLHIV from the HIV/AIDS discourses has since been transformed. The adverse effects of HIV/AIDS on development institutions and their programmes in Africa have encouraged the health and non-health development agencies alike to involve PLHIV at the centre of the HIV response and also a more general move to more participatory forms of communication in the public health communication approach to dealing with the epidemic (see Simon-Meyer and Odallo, 2002; Stephens, 2004; Paxton and Janssen, 2009). The HIV epidemic is now being considered as an important cross-sectorial developmental issue bearing far reaching implications for policies and programming, both for the governments and international development agencies from the perspective of PLHIV.

Be that as it may, the inclusion of PLHIV is not without its challenges. It is the nature of this involvement that gave impetus to this study whose objective is to find meaningful ways of mainstreaming involvement of PLHIV in social change communication of HIV prevention. It has been noted in the previous chapter that inclusion is not even placed on the prevention - support continuum. As

will be shown, Thabo Mbeki's view on HIV/AIDS and its ensuing response from PLHIV generated a fierce debate on the issue of accessing treatment. However, it can be argued that the debate on the provision of drugs could have multiplier effects such as drawing energy and attention away from necessary debates around prevention. Alluding to Catherine Campbell (2003), there is still need for all the stakeholders to reaffirm commitment to recognition of the importance of prevention of new transmission in order to contain the epidemic. Different approaches that have been used in this endeavour are reviewed in the next chapter.

CHAPTER FOUR

PRAGMATIC RESPONSES TO THE HIV EPIDEMIC: A SISYPHEAN TASK?

All epidemics comprise not only similar characteristics, but they often elicit similar responses even in different historical and geographical contexts (Rosenberg, 1989; Lindenbaum, 1998). However, unlike other epidemics that have struck humankind, HIV/AIDS is regarded as a postmodern epidemic whose response has generated extraordinary medical research and a variety of institutional interests and approaches (Denis, 2006). The global response to HIV/AIDS has always been a four pronged spectrum focusing on i) prevention from HIV infection, ii) treatment of the HIV infected, iii) caring of the infected and iv) supporting the infected and affected. However, the response has had very limited success with regards to its containment (Iliffe, 2006). Years of engagement with the epidemic has seen not only the continued spread of HIV, swelling number of people living with HIV(PLHIV), and loss of human life but also the growth of HIV/AIDS from an epidemic to a pandemic (Denis, 2006; Singer, 1998). The relentless, but futile, engagement with the epidemic illuminates two important aspects. First is its uniqueness from other epidemics, and second is the question of when and how the epidemic may come to closure. As noted in the introduction of this thesis, based on the futility of the relentless engagement with the epidemic, the second question leaves one wondering if responding to HIV/AIDS is not a mere Sisyphean task. Clearly though, this challenges society to think of nuanced and effective ways of responding to the epidemic.

Along the prevention – support continuum mentioned above, a corpus of approaches have been utilised in the global response to HIV/AIDS. The sub-Saharan Africa region has been presented as an archetype of the tragedies that

the virus has wrought upon human welfare. South Africa, in particular, is a country which is known to bear an inordinate share of the epidemic not only in the continent but the whole world (UNAIDS, 2007). This chapter reviews three approaches that have been employed in the HIV response at the prevention level in South Africa. These are the bio-medical, the behavioural and social change as well as the structural approach. While some successes are attributed to these approaches (Kelly, *et al.,* 2012; Barnett and Whiteside, 2002) the chapter establishes that the engagement effort has been less than satisfactory in containing the epidemic.

The HIV prevention spectrum, comprises of three intervention areas namely; pre-exposure, point of exposure, and treatment for prevention from infection. This study questions the conspicuous absence of voices of PLHIV within these interventions. Most importantly, even when PLHIV are included at the end of the spectrum, they appear only as passive patients, not as active participants in prevention efforts (see Osborne, 2006). From a culture-centered approach to social change (Dutta, 2011); a framework that guides this study, the chapter suggests an approach which, on the HIV prevention spectrum, privileges a deliberate and meaningful participation of the many PLHIV whose number is continuously swelling on a daily basis due to increased access to antiretroviral therapy (ART). Indeed the increased number of people who live longer with HIV forms an incessant and formidable source of infection. This reminds us of a challenge informing the overall objective of this study: exploring ways through which PLHIV can meaningfully participate in HIV prevention efforts.

In order to situate the global response to HIV/AIDS in a meaningful context, the chapter begins by unpacking the history of the epidemic. To achieve this task, HIV/AIDS is viewed in light of other common epidemics in human history particularly exploring their progression and containment. This is done specifically to highlight the uniqueness of HIV/AIDS whose architecture and wide range of responses constitute the remainder of the chapter.

The (dramaturgical) architecture of HIV epidemic: Whither *Act* 4?

Explaining the nature of epidemics, Charles Rosenberg (1989) observes that all epidemics unfold like a *play* [my emphasis]. He points out that epidemics are "episodic" and have a dramaturgical form that "starts at a moment in time, proceed on a stage limited in space and duration, follow a plot line of increasing and revelatory tension, move to a crisis of individual and collective character, then drift towards closure" (Rosenberg, 1989: 2). This analogy is reiterated by Lindenbaum (1998:40) who finds all epidemics to have a "common architecture or perhaps choreography" particularly as it relates to their emergence, progression, impact, public response and containment/closure). For Philippe Denis (2006), this dramaturgical architecture and choreography is characterised by the following four themes unfolding through four different "acts". The first act illuminates a theme of *denial and gradual acceptance* of the epidemic by social and political leaders; the second highlights the *indecisive effort* of the authorities to curb the epidemic; the third concerns *effective and more informed collective action*; and the fourth and last act shows the *containment* of the epidemic with "survivors counting their dead and reflecting on ways of avoiding a similar catastrophe in the future" (Denis, 2006: 20).

Viewing HIV/AIDS from the above perspective entails its placement on par with other epidemics such as the Black Death that plagued Europe around 1340, the Bubonic plague in India during 1896, Kuru in Papua New Guinea around 1930 among other known epidemics that have struck humankind. The Black Death that killed almost a third of the European total population between 1346 -1350, for example, led to the killing of Jews by Christians as a way of controlling it (Singer, 1998). The Jewish population was killed because they were considered a key population responsible for the spread of the disease. Indeed when HIV/AIDS was discovered, it took some time before it was recognised as an epidemic. As noted in the previous chapter, its unexpected

emergence in the West attracted initial responses that were modelled on the existing formulae on how to deal with an epidemic which had previously been employed to respond to past epidemics such as the Black Death. The largely rhetorical formulae included stigmatisation and victimisation of helpless marginalised population groups (Parker and Aggleton, 2002; Epstein, 1995; Gilman, 1988).

However, as Rosenberg (1989) had already observed, HIV/AIDS cannot be entirely placed on par with previous epidemics that have since come to closure. It is a modern and a postmodern epidemic especially looking at the speed with which it spread, the unprecedented medical research it has prompted, and a wide range of interest and anxiety that it has generated. Unlike past epidemics that - like drama - have come to a closure, a solution to the HIV/AIDS epidemic remains an enigma. Indeed, Denis (2006) agrees that the fourth act is no longer pertinent in the history of HIV/AIDS because a devastating toll continues to mount. Years of indecisive response to the epidemic characterised by the continued spread of HIV, swelling number of PLHIV and sheer loss of human life due to HIV/AIDS have all resulted in what I have surmised as a Sisyphean engagement with the epidemic. Most importantly, considerable agreement exists that HIV/AIDS ceased to be an epidemic but has grown to be a pandemic (Denis and Becker, 2006; Carael, 2006; Singer, 1998).

 The uniqueness of HIV/AIDS from other epidemics is an issue. The origins and a stream of social and economic consequences of the HIV/AIDS epidemic are intertwined within an intractable, complex and casual long chain of relationships between the microscopic and the macroscopic worlds. This view is different from the Western scientific approaches that consider an epidemic as a "chance event" or an "unfortunate agglomeration of probabilities" (Barnet and Whiteside, 2002: 70). HIV/AIDS can thus be understood as a post-modernist epidemic which, as these scholars suggest, is not a mere chance but a susceptibility which is tied to the complex economic, political and social

aspects of a society (Campbell, 2003; Barnet and Whiteside, 2002). This complexity is perhaps one of the key characteristics that not only distinguishes HIV/AIDS from other epidemics but possibly make responses to it a Sisyphean challenge.

Perhaps due to its complexity, responses to the HIV/AIDS epidemic are characterised by a variety of institutional interests and a corpus of the approaches utilised but to a limited success. As Shula Marks (2002: 14) remarks, "governments and NGOs, national and international agencies, political parties, patients and their advocates and above all the pharmaceutical industry have all had their own and often conflicting perceptions and agendas in addressing the challenges" presented by HIV/AIDS. These perceptions are conceivably most evident in the ambivalent character of the response to HIV/AIDS. Since the beginning, the response has vacillated between discursive (discourse/communication) and pragmatic (action) interventions.

Having reviewed the discursive responses in the previous chapter, this chapter focuses on the pragmatic side of the response to the African epidemic - a region which, according to Segun Ige and Tim Quinlan (2012: 1) "epitomises the tragedies that the virus has wrought upon human welfare". A comprehensive review of three broader approaches that have been employed in the global response to HIV/AIDS at the prevention level, namely the bio-medical, the behavioural and social change as well as the structural approach is offered. Possibly due to the interconnected web of issues into which HIV/AIDS is woven, found within each approach are multifarious strategies that have been employed by many players - governments and NGOS - in HIV/AIDS programming in their different social, cultural, economic and political contexts as a response to the epidemic.

It is important to mention here that it is the structural approach (Laga and Piot, 2012; George and Sprague, 2011; Coates, *et al.,* 2008) that underlies the

ontological and epistemological underpinnings of this study as embodied in the culture-centered approach to social change (Dutta, 2011). This is precisely because success is deemed likely when affected communities are actively involved in efforts meant to find solutions to their problems. As a key population in HIV/AIDS dynamics, PLHIV therefore need to be involved in finding effective means of bringing the HIV/AIDS epidemic to closure (see Dutta, 2011). The structural approach has thus increasingly become popular due to many reasons. The two most important being; its ecological approach to HIV/AIDS expressed through its inclusion of the social and economic aspects of the epidemic, and its recognition of dialogue as an article of faith that privileges a possibility for listening to the infected, that is PLHIV. According to the culture-centered approach to social change (Dutta, 2011) discussed in Chapter Two, listening to subaltern voices disrupts the status quo through its articulation of alternative narratives which emphasis subaltern agency. One of the key observations of this study, however, is that PLHIV have not been meaningfully involved in efforts deliberately aimed at the prevention of HIV transmission other than in interventions aimed at enabling environment for increased access to treatment care and support. The study argues that the bio-medical approach which gives primacy to treatment has crystallised PLHIV as passive patients who simply require treatment, care and support. Yet, experience and research has shown that (health) policies and programmes which do not respect or engage concerned key stakeholders are doomed to face strenuous resistance and likely failure (see Lubombo, 2012; Storey and Figueroa, 2012; Kincaid*, et al.,* 2007).

It is the above experience that has given impetus to the task this study attempts to undertake: exploring ways in which PLHIV can be meaningfully involved in social change communication for HIV prevention. Here approaches to HIV/AIDS are reviewed the aim being to show the position of PLHIV in these approaches. A meaningful appreciation of these approaches presupposes a

consideration of the nature or rather the epidemiology of HIV/AIDS. Epidemiology refers to a study of "the distribution and determinants of health related conditions and events in populations, and the application of this study to the control of health problems" (Katzenellenbogen*, et al.,* 1997: 5). While epidemiology of HIV/AIDS allows examination of patterns of HIV transmission in terms of who is infected, where and how many they are, it does not reveal the political economy of HIV/AIDS, which is the social, political and economic characteristics which favour its distribution pattern. An understanding of both the epidemiology and political economy of HIV/AIDS, presented below, is quite significant for finding ways in which the transmission can be managed. For Tony Barnet and Alan Whiteside this allows for the designing of effective prevention interventions.

Modes and contexts of HIV transmission

HIV can only be transmitted through contaminated body fluids into the bloodstream. For Barnett and Whiteside (2002), unlike other diseases, HIV is not robust and is therefore hard to transmit. What emerges from this description of HIV is the irony that notwithstanding its 'weaker nature', HIV spreads rapidly among human beings. It is this irony which makes it necessary to examine the modes through, and contexts in which HIV transmission occurs. While there are several ways through which HIV infection takes place, there is general consensus that sexual transmission is the major driver of the global HIV incidence (UNAIDS, 2013). However, it has been found that certain sexual practices such as receptive anal intercourse are more efficient in facilitating HIV transmission than heterosexual sex (Mayer*, et al.,* 2010). It has been noted in Chapter Three that in the West HIV/AIDS was initially discovered among homosexual men and became known as a gay related disease although it was later found among other social groups such as intravenous drug users and prostitutes. The spread of HIV to all these different groups of people is now known. There are various modes of HIV transmission

which expose everyone to the risk of contracting HIV other than those previously suspected. The modes of transmission include unsafe sex, transmission from mother to child, use of infected blood or blood products, intravenous drug use with contaminated needles as well as other modes of transmission involving blood such as bleeding wounds (Barnet and Whiteside, 2002: 38). The degree of risk differs from one group of people to another as there are many other structural aspects such as social, economic, political, and environmental factors that directly affect HIV risk and vulnerability (Gupta, *et al.*, 2008; Campbell, 2002; Singer, 1998). It is acknowledged that poor and powerless people, mostly in underdeveloped communities, are more susceptible to the virus than the rich and powerful. Accordingly, any response that seeks to be effective would therefore employ an epistemological approach that takes into consideration these structural aspects that make people more susceptible to the HIV infection.

Responding to HIV/AIDS continues to be one of the most important challenges facing the world today, especially in sub-Saharan Africa where most communities are poor and those most affected. WHO, during the directorship of Halfdan Mahler as Director-General, is reported to have been slow in its response to HIV/AIDS in the Third World, concentrating on primary health care. Mahler in 1985 dismissed HIV/AIDS as diversion from this focus, arguing that "if African governments continue to make HIV/AIDS a front page issue", this would obscure its real health problems and "the objective of health for all programmes by the year 2000 will be lost" (Iliffe, 2006: 68). This position, however, changed in 1986 when WHO recognised that HIV/AIDS had become a major public health concern as with malaria. This resulted in the creation of the Global Programme on AIDS (GPA) whose key priorities were screening blood supplies in poor countries, training of medical staff in the clinical management of HIV/AIDS and counselling of those tested for HIV, public education for checking the epidemic in the absence of a cure, and preventing HIV/AIDS-

related stigma and discrimination (Iliffe, 2006). It is clear from these focus areas that the view held by WHO in its initial global response to HIV/AIDS through the GPA adopted a bio-medical approach that is discussed further below. While these focus areas were important, HIV has been a complex phenomenon. It has since been established that HIV/AIDS is not only bio-medical but a "social issue located at the interfaces of a range of constituencies with competing actions and interests" (Campbel, 2003: 8)

Response to the HIV epidemic has seen a wide range of approaches being employed over time, beginning from individual focused bio-medical to the ecological and more complex structural approach. In Africa, response to HIV/AIDS has been riddled with governments' slow response which if compared to the dramaturgical structure of the progression of HIV epidemic highlighted earlier can be located in *Act I. T*he choreography of epidemics at this stage is characterised by the theme of denial and gradual acceptance of the epidemic by social and political leaders (Denis, 2006; Lindenbaum, 1998; Rosenberg, 1989). For Ige and Quinlan (2012: 12) the delayed reaction of African political leadership has become an axiom in the recorded history of HIV/AIDS. This is argued to have contributed to the spread of HIV in Africa. While it took longer for South Africa to respond to the HIV epidemic (see Tomaselli 2011), the South African government has recently made the HIV response one of its top national priorities (SANAC, 2011). The National Department of Health (DoH) has put in place a National Strategic Plan for HIV/AIDS and STIs that guides the national response to the epidemic (see SANAC, 2011). The plan outlines four key priority areas including HIV prevention topping the list.

Statistics show that the South African epidemic has reached a holocaust magnitude. According to the fourth population-based household survey that the HSRC has conducted with its partners to assess the state of the HIV epidemic in the country (HSRC, 2014) the overall national estimate for HIV

prevalence among South Africans in 2012 was 12.2%. This shows an increase of almost 1.2 million more PLHIV in South Africa - an increase from 5,253,493 PLHIV in the 2008 to 6,422,179 PLHIV in 2012 (HSRC, 2014: 35). As with any other country or region, there is tremendous heterogeneity in HIV prevalence at different levels in the South African communities disproportionally distributed by age, sex, race, locality type and province (HSRC, 2014). By 2011 prevalence was 3.8% in Western Cape and 15.8% in KwaZulu-Natal (SANAC 2011: 9ff). The majority of adult PLHIV (54%) live in just two provinces, KwaZulu-Natal and Gauteng. Of these, majority are women whose national HIV prevalence rate is higher (17.4%) than men (10%)(HSRC, 2014).

While recent statistics show that the African epidemic continues to be heterosexual, in South Africa HIV incidence is driven by three main factors, namely sexual transmission, injecting drug use and transmission from mother to child (HSRC, 2014; SANAC, 2011). Although other transmission drivers such as medical injections and infection control in health care settings, transmission through blood and blood products are recognised, by 2011 they were under control (SANAC 2011). According to the same report, while South Africa seemed not to have a major injecting drug use (IDU) problem, a problem with crack cocaine, especially among sex workers was growing (SANAC 2011: 12). By 2011, IDU thus seemed a minor contributor to HIV transmission. However, it was interlinked with other risk contexts such as growing homosexuality (SANAC, 2011).

Within the above modes of transmission, there are other important factors that are associated with increased transmission rates and the global inequalities associated with HIV transmission. As mentioned earlier, these are both bio-medical (Mayer, *et al.*, 2010) as well as political and socio economic (Singer, 1998, Barnett and Whiteside, 2002, van Niekerk, 2001). In Africa, the political-economic factors associated with HIV/AIDS relate to unequal class, gender, sexual orientation, and racial relationships. As Singer noted in 1998, it is still

true that HIV/AIDS in Africa is not an isolated threat but a synergy of plagues, a 'syndemic' of intertwined diseases and noxious social conditions (Singer, 1998). HIV/AIDS spreads most easily along several vectors of disadvantage disproportionately striking those already bearing burdens of unemployment, racial discrimination, neighbourhood decay, inadequate housing and homelessness, street violence, poor sanitation, hunger and malnutrition, inadequate medical care, policy maker indifference or outright hostility, and high levels of stress caused by all these adverse conditions (Singer, 1998).

The political economic analysis of HIV/AIDS in Africa insinuates links between the epidemic and colonisation (see Chasi 2011). The disease has unfolded epidemiologically in relation to inequalities of political power and socio economic disparities (Parker, 2012) which are attributable to colonisation in Africa and apartheid in South Africa. Marked differences in HIV prevalence among racial groupings provide concrete evidence to this. In South Africa HIV prevalence is high among the black population as compared to other races that benefited from apartheid (HSRC, 2014). In 2008, white people were 7.8 times less likely to be HIV positive than blacks (SANAC 2011). The socio-economic contexts and differences in sexual partnership patterns, especially sexual concurrency, explain some of the racial differences in HIV transmission and prevalence. With poverty being one of the risk factors for HIV infection as observed by Marie Laga and Peter Piot (2012); Gavin George and Courtenay Sprague (2011); Thomas J Coates *et al.,* (2008); Merrill Singer (1998) and many others, the majority of black South Africans have generally low economic status and they suffer from deprivation spanning from colonial era which was characterised by apartheid. There are also a host of other social factors that influence HIV prevalence heterogeneity among the South African population. These include age at first marriage, level of education, types of residence, and male circumcision among others.

An understanding of the political economy of HIV/AIDS is thus significant not only in understanding the spread of HIV/AIDS and people's responses to it but, correspondingly with the objective of this study, it "includes a driving concern with the development of useful knowledge and a commitment to collaboration with [PLHIV and at high risk to HIV/AIDS] in the development of effective and sensitive programmes" in response to the epidemic (Singer, 1998: 22). The objective of the political economic analysis of HIV/AIDS is consistent with the participatory communication for social change approach within which this study is located.

Contrary to the complex socio-economic system to which HIV/AIDS is part; HIV/AIDS has mainly been viewed from a bio-medical perspective which depicts it as a disease of the body. Kenneth H Mayer *et al.,* (2010) outline a bio-medical view of factors associated with increased transmission rates. These include genital tract infections, stage of infection, presence of sexually transmitted infections, vaccines which can increase viral load, and pregnancy (see Chan and Ray, 2007; Cohen, 2004; Gray and Kigozi, 2005). Also added to this list of determinants of HIV transmission are virus sub-types and male circumcision (Barnet and Whiteside, 2002).

Noticeable from the above bio-medical determinants are parameters of the HIV epidemic which seem to limit it to a mere physical illness. Indeed as Barnet and Whiteside (2002) observe, the above determinants present a Western interpretation of HIV/AIDS as a problem of the body alone. Accordingly, this has implications for what can be done to stem the epidemic not in its complexity but as an infectious sexually transmitted disease. Since the beginning of HIV/AIDS the dominant approach relied "almost exclusively [on] medical science, clinical practices, epidemiological knowledge and behavioural interventions that affect the ways bodies behave towards each other" (Barnet and Whiteside, 2002: 72). So far the biological approach has culminated in the discovery of ARVs, particularly the discovery in 1994 that AZT could reduce

mother to child transmission by 68% (Iliffe, 2006: 141). In Africa, Botswana was the first country to adopt AZT in 1999 followed by Uganda in the same year (Iliffe, 2006). However, due to various reasons discussed in Chapter Three, South Africa delayed until 2002. The different approaches to HIV/AIDS are reviewed below. As shall be noticed in the review, the approach has crystallised PLHIV as passive patients who only need treatment care and support. Contrary to the culture-centered approach to social change (Dutta, 2011), the bio-medical approach is devoid of the agency of PLHIV.

The bio-medical approach

Operationalised by the WHO in its global response to HIV/AIDS, the bio-medical paradigm aimed to mobilise all medical resources to combat the HIV epidemic. With mainly medical organisations being front-line fighters against the epidemic, the first attempts to deal with HIV/AIDS were almost entirely medical and epidemiological (Qamar, 2001; 2003). Hoping that a cure or vaccine would be discovered, the initial response to HIV/AIDS was entirely a responsibility of bio-medical researchers (Mulwo*, et al.,* 2012: 4). During the first decade after the discovery of HIV, most responses viewed the epidemic as 'medical' requiring a bio-medical response from 'experts'. The medical focus can possibly be located in the optimism in science created in 1984 when the US Health and Human Services Secretary Margaret Heckler (owing to the work of Dr Robert Gallo who had just co-discovered HIV) announced that a vaccine would be found within two years (AVERT, 2013). Several short term and medium term medically and epidemiologically driven programmes aimed at containing the spread of the epidemic have since been adopted. The programmes are developed within a framework that views HIV/AIDS as a purely medical problem whose spread could be contained by addressing the determinants already highlighted. A variety of strategies fitting in the bio-medical approach exist. These can be grouped according to the four stages along the prevention continuum shown on Figure 4.1 below.

Figure 4.1: The HIV prevention continuum (Adapted from Webb, 2006: 29)

Prior to exposure	Point of exposure	Post exposure	For the infected
- Behaviour change - Sterile syringe access and drug addiction treatment - STI screening and containment - Vaccines - Pre-exposure prophylaxes - Medical male circumcision (MMC)	- Male and female condoms - ARVs to reduce vertical transmission - Microbicides - Cervical barriers	- Post exposure prophylaxes (PEP) - Treating sexually transmitted diseases - Vocational counselling and testing From this point - Those who contract HIV are PLHIV: Interventions in the previous stages no longer apply - Interventions apply only for the uninfected	- As *patients* they access antiretroviral therapy (ART) to suppress viral load YET - PLHIV continue practicing sexual behaviors that place their partners and themselves at risk for HIV SO? -How can PLHIV participate in efforts aimed at preventing new infections? - What do they think is their role in responding to the epidemic?

As shown on Figure 4:1; there are specific methods targeted at the pre exposure stage, those appropriate at the point of exposure stage, those used at the post exposure stage, as well as those suitable for the already infected. For the sexual transmission of HIV, bio-medical methods falling under the first stage of the continuum include Sexually Transmitted Infections (STI) screening and containment, vaccines, use of ARVs for pre-exposure prophylaxes (PEP) and medical male circumcision (MMC). Sterile syringe access and drug addiction treatment is targeted for intravenous drug users. At the point of exposure, that is the second stage, is found condom use, ART to reduce mother to child or vertical transmission, microbicides and cervical barriers. Just before

the end of the spectrum are strategies used after one has been exposed to the risk of HIV transmission regardless of whether they got infected or not. This is the post-exposure stage consisting mainly of the administration of ART for post exposure prophylaxes as well as encouraging people to get tested. At the end of the continuum is the treating opportunistic infections as well as use of ART by the infected to keep the viral load undetectable low for the purposes of prevention.

Pre exposure stage

Treating sexually transmitted infections: STIs enhance HIV transmission by increasing both susceptibility of HIV negative individuals and the infectiousness of HIV positive individuals (Barnett and Whiteside, 2002). While it may have limited effectiveness in restricting generalised HIV transmission, treatment of STIs is a bio-medical approach that is considered as a pre-exposure public-health intervention (Kelly, *et al.*, 2012; Laga and Piot, 2012). Depending on the stage of the epidemic, treating STIs has shown to be efficacious in preventing HIV. Like any other, this approach is not 100% effective as intervention trials conducted to test the efficacy of improving the management of STIs as an HIV prevention strategy provided mixed results (Mayer, *et al.*, 2010; Barnett and Whiteside, 2002). Correspondingly, DramAidE Health Promoters have encouraged that STI management should thus be seen as an adjunct to other prevention programmes predicated on reduced behavioural risk. For Eline Korenromp *et al.,* (2002) in countries with mature HIV epidemics such as South Africa, STI treatment alone cannot lower HIV incidence without changing risky behaviour. Be that as it may, STI screening and treatment is part of the South African government's strategy for HIV as contained in its latest National Strategic Plan for HIV/AIDS, STIs and TB, 2012-2016.

Medical male circumcision: Another bio-medical approach used at the pre exposure stage is MMC. As the male foreskin contains a large number of HIV

target receptor cells where the virus readily attaches, recent research has shown that its removal can decrease likelihood of becoming infected (Mayer, *et al.*, 2010; Kelly, *et al.*, 2012, Bailey, *et al.*, 2007). Circumcision is also said to reduce males' susceptibility to abrasions and tearing, making them less prone to ulcerative STIs that facilitate viral transmission (Kelly, *et al.*, 2012). Three randomised controlled trials (Auvert, *et al.*, 2005; Bailey, *et al.*, 2007) and other observational studies have shown that male circumcision significantly reduced the risk of HIV acquisition by approximately 60 per cent among uninfected men and partly protect women from human papillomavirus (HPV) (Kelly, *et al.*, 2012). Consequently, WHO/UNAIDS has recommended that male circumcision be considered by countries with hyper endemic scenarios where HIV prevalence exceeds 15% (UNAIDS, 2007). In South Africa, male circumcision (MC) has been shown to reduce men's risk of getting HIV infected by 61% (HSRC 2008). Based on the Demographic and Health Survey of 2003, approximately 45% of men reported being circumcised with highest circumcision rates in the Western Cape (67.5%) and Free State (70%) and the lowest in KwaZulu-Natal (26.8%) and Gauteng (25.2%) (Johnson*, et al.*, 2010). Recent research in South Africa has, however, shown that mean yearly HIV incidence and net reproduction rate of the epidemic was not lower in provinces with higher levels of male circumcision (Garenne, 2008). Other studies have found no link between STI risk and circumcision (Turner*, et al.,* 2008). Beside MMC which was recently introduced and continues to be promoted as a bio-medical response to HIV, in South Africa male circumcision has long been performed on young people among the Venda, Pedi, Ndebele and Tsonga, as well as the Xhosa and Sotho as part of initiation rites of passage into manhood (SANAC: 2011:10). To implement MMC, the South African National AIDS Council (SANAC) has drafted guidelines to provide safe and accessible voluntary MMC. These guidelines also advocate a strategy that institutionalises neonatal and young adult circumcision (Kelly*, et al.*, 2012). In 2010, South Africa rolled out an MMC campaign with the goal of reaching approximately 4.3 million men by 2015.

The government has also included voluntary MMC as an integral part of its HIV counselling and testing campaign (AVERT, 2013). As of 2011, the country had reached more than 250, 000 men through voluntary MMC (SANAC, 2011: 8)

Vaccines: While vaccines are the most effective preventive measures against diseases - having been used effectively against polio, measles, mumps, rubella and other diseases in many parts of the world - the world so far with limited success is still grappling to find a vaccine for the HIV. More than three decades since HIV/AIDS began, efforts are still continuing in search for an HIV/AIDS vaccine which would either protect individuals who are HIV negative from contracting the virus, or may have a therapeutic effect on people already living with HIV/AIDS. The New York based International HIV/AIDS Vaccine Initiative continues to play a leading role in search of the vaccine (Barnett and Whiteside, 2002) although there are also initiatives in Africa such as the South African HIV/AIDS Vaccine Initiative. Many believe that the development of such a vaccine and other prevention options can help contain HIV.

Pre-exposure prophylaxes: The failure of vaccine experiments and other bio-medical approaches to prevent HIV transmission has led to increased interest in the use of antiretroviral pre-exposure prophylaxes (PrEP) (Mayer, *et al.*, 2012). As noted earlier in this section, ART can be used either for preventing HIV acquisition by HIV-uninfected people, or for reducing infectiousness of people who are HIV infected. In the former, ART act as pre-exposure prophylaxis while in the latter it is used as post-exposure prophylaxis (PEP) (Mayer, *et al.*, 2010). As Kevin Kelly *et al.,* (2012: 38) suggested, the oral and vaginal drugs, for pre-exposure prophylaxis and reducing infectiousness among HIV-positive individuals have been assessed with the hope that in the future they may provide valuable female-controlled tools of HIV prevention. Protection may be possible if antiretroviral drugs are taken before a high-risk exposure (Mayer, *et al.*, 2010). According to Kelly *et al.,* (2012), the prophylactic use of

ART in preventing sexual transmission of HIV is a promising development in bio-medical prevention methods.

Sterile syringe access and drug addiction treatment: These are specifically targeted for intravenous drug users. In South Africa, HIV prevalence among people who inject drugs is estimated at 12% (Kelly, 2012; UNAIDS 2010). As with STI treatment, substance abuse treatment has also been used as an HIV-prevention strategy among intravenous drug users (Mayer, *et al.*, 2010). Since substance abuse has been associated with risky behaviour, treating drug users make them less likely to engage in risky sexual behaviours (Needle, *et al.*, 1998) and inject drugs or share needles (Fuller*, et al.,* 2009). In United State of America, substance abuse interventions that impact HIV prevention include pharmacotherapy and provision of sterile syringes (Mayer, *et al.*, 2010). While drug-use and its social contexts is an under-researched area in South Africa, studies have shown a convergence of drug use, sex work and HIV prevalence (Kelly, *et al.*, 2012). Needle-sharing, risky injecting techniques and limited access to sterile injecting equipment have been found to be common among South African injecting drug users (Parry*, et al.,* 2009).

The pre-exposure bio-medical methods discussed above are by no means the only available method. As evidenced above, these are pre-exposure methods only applicable before one is exposed to the risk of transmission. As such, they cannot, at least for the purpose of this study, be related to those who are already infected. Below is a discussion of those methods applicable on the point of exposure, still in the South African context.

Point of exposure
Condom use: If used correctly and consistently, the male condom is considered to be effective in blocking HIV transmission during sexual intercourse (Padian*, et al.,* 2008). Male condom use in South Africa has increased in recent years. Regardless of problems in consistent use or adherence, data from sexual

behaviour surveys suggest that condom usage in South Africa increased substantially since *2005* (see Kelly, et al., 2012). There was a 35% "reported use of a condom during last sexual encounter" in 2005 and this increased to 62% in 2008 (Kelly, *et al.,* 2012). There is an assumed increase in condom usage which is consistent with the timing of increases in the distribution of male condoms in the South Africa. Self-reported condom use increased from 46.1% in 2002 to 55.7% in 2005 and 73.1% in 2008 (Kelly, *et al.,* 2012).

Prevention from mother to child (vertical) transmission: between 15% and 45% of children born to infected mothers will themselves be infected, either before birth, during delivery or after birth through breastfeeding (Barnett and Whiteside, 2002). Use of ART as explained in (d) ii below applies. ART is then used to decrease the mother's viral load in order to inhibit viral replication in the infant thus decreasing chances of MTCT. Regardless of the above purported benefits of this strategy, the South African government under Thabo Mbeki is, however, notorious for its initial belief that ART was more harmful than it was beneficial to PLHIV (Martin-Tuite, 2011). Through the then Health Minister, Manto Tshabalala-Msimang, with assistance from the Presidential HIV/AIDS Advisory Panel consisting of prominent HIV/AIDS denialists such as Peter Duesberg (Martin-Tuite, 2011), the state refused to distribute antiretroviral therapy to South Africans living with HIV/AIDS (Nattrass, 2007). ARVs were then considered as toxic or poisonous and the government promoted vegetables and vegetable products, such as garlic, beetroot, and olive oil. Refusal by the government to provide AZT to pregnant mothers was heavily contested in South Africa notably by the Treatment Action Campaign which, with the support of academics, employed several tactics both in and out of courtrooms to fight for the provision of the drugs to PLHIV in South Africa (Mulwo*, et al.,* 2012). Eventually the government embraced the global bio-medical understanding of HIV/AIDS science and started providing ART to PLHIV. In 2010, the South African government came up with a national prevention from mother to child

transmission (PMTCT) Policy and Guidelines whose aim is to provide guidance towards a reduction in the vertical transmission of HIV. This policy encourages earlier initiation of ART for pregnant women and the introduction of an improved drug regimen for PMTCT. According to the 2010 South African PMTCT Evaluation (Goga, *et al.*, 2012) interventions to prevent mother-to-child transmission of HIV were by 2010 offered in more than 95% of public antenatal and maternity facilities country-wide. In 2011, more than 95% of pregnant women with HIV received treatment to prevent the infection of their child, with yearly infections in children having dropped from 56,500 in 2009 to 29,100 in 2011 (UNAIDS, 2012). The country has adapted as a 20-year vision, zero new infections due to vertical transmission (SANAC, 2011) This is one of the three zeros advocated by the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2012).

Microbicides: Statistics show that women are the fastest growing sub-group of people living with HIV, and most become infected through heterosexual contact (Webb, 2006). Targeted specifically on women, microbicides are a range of substances 'microbe killers' in the form of gels, sponges, films, or vaginal rings that can be applied in the vagina or rectum with the goal of preventing or significantly reducing the risk of acquiring STIs, including HIV (Stein, 1990). Inserted in a vagina prior to sexual intercourse to kill viruses and bacteria, microbicides may provide valuable female-controlled tools of HIV prevention (Webb, 2006, Stein, 1990, Kerry, *et al.,* 2012). By 2012 in South Africa, results of a tenofovir-based gel for women had raised hope that a prevention option for females could soon become viable (Kelly, *et al.*, 2012). A study by the Centre for the HIV/AIDS Programme of Research in South Africa (CAPRISA) found that a microbicide gel reduced HIV infection by 39% and that the gel was both safe and acceptable when used effectively (UNAIDS, 2010).

Cervical barriers: This is one of the bio-medical approaches aimed at prevention. However, Mayer *et al.,* (2010) note that the use of diaphragms and

lubrication, over and above the provision of condoms was discovered to be ineffective as it failed to afford woman added protection from HIV acquisition. These scholars based their judgement on the Methods for Improving Reproductive Health in Africa (MIRA) trial conducted among women in Zimbabwe and South Africa (Padian*, et al.,* 2007) whose findings suggested that the annual incidence among women who received diaphragms, lubricant, and condoms was higher than the annual incidence among women who only received condoms.

While there are many bio-medical methods used for prevention on the point of exposure, condom use remains the commonly used method for sexual transmission while PMTCT is also used among pregnant women. It is at this stage where infection takes place. While in most cases it remains an individual decision to uses methods described above, there are other behavioural, social and structural factors that affect use or not use of these bio-medical methods. In the event of failure to use methods prescribed above, one is eligible to use post exposure methods discussed below.

Post exposure

Post exposure prophylaxes: Post-exposure prophylaxis (PEP) is a bio-medical approach that thwarts the biological course of HIV infection leading to HIV/AIDS. PEP consists of a dose of antiretroviral therapy administered within 72 hours after a possible exposure to HIV (Collings*, et al.,* 2008). The idea is to prevent HIV transmission after accidental exposure to HIV. Research has shown that few cases of HIV transmission have occurred after PEP (Wulfsohn, 2003). The South African government has committed to supporting free provision of PEP in all public health institutions. In 2002 the South African government ratified the protocol of providing emergency post-exposure prophylaxis (PEP) for survivors of sexual violence and people exposed through occupational hazards (Kelly, *et al.*, 2012). In 2005, the DoH launched a policy which included a commitment to the national provision of PEP following a

sexual assault (Kim, *et al.,* 2009). In 2007, the provision of PEP after a sexual assault was legislated via the Sexual Offences and Related Matters Amendment Act No 23, providing for free access to PEP to all survivors of sexual violence (Kelly, *et al.*, 2012).

HIV counselling and testing: While not in and of itself a prevention method, HIV counselling and testing (HCT) makes one aware of their serostatus, the knowledge of which is critical for access to effective prevention and treatment services (Kelly, *et al.,* 2012). HCT is a tool to support other prevention efforts rather than as a prevention method in its own right (ibid). Be that as it may, HCT has been found to be more effective in promoting behaviour change among couples (Pettifor, *et al.,* 2010). Studies have shown that due to HCT, PLHIV who are aware of their serostatus as well as couples are likely to reduce behaviours that might transmit HIV to others (Kelly, *et al.*, 2012). HCT has become increasingly available in South Africa in recent years. The latest National HIV and Testing (HCT) Policy Guidelines in South Africa (2007-2011) targeted to increase people who access HCT services from 25%-70% by 2011. By 2009 only 47% of the national HCT target population had been achieved (Setswe, *et al.,* 2010). In April 2010, a large HCT campaign was launched (SANAC, 2010). According to the HCT Policy Guidelines (SANAC, 2010), vocational testing and counselling (VCT) is offered at over 4500 public health facilities. It is also offered by nongovernmental and faith- and community-based organizations through mobile services and at many other non-medical sites. There are more than 8000 lay counsellors providing HIV counselling at medical and non-medical sites (ibid).

Assuming that the post-exposure methods described above have been used effectively and transmission is aborted, the individual qualifies for previous methods in their next coital experience. However, if the methods fail to work and one is infected, they begin to live with the virus. Effectively they no longer qualify for previous methods that are aimed at preventing infection. The

affected are, however, encouraged to use the methods for preventing reinfection and for preventing transmitting the virus to others. Discussed below are bio-medical methods appropriate for this purpose.

For the infected

Use of ART for prevention: High plasma viral loads are associated with increased infectiousness. Medical research has shown that ART can be used by the already infected for preventing transmitting the virus. The use of ART for prevention has the potential to reduce HIV incidence since effective treatment reduces viral loads and the infectiousness of infected individuals (Kelly, *et al.*, 2012). The approach is attributed to a 2008 consensus statement issued by The Swiss Federal Commission for HIV/AIDS asserting that PLHIV who are on ART and without other STIscannot pass on the virus through unprotected sex; as long as they adhere to the drugs to keep their viral load undetectable (Wilson*, et al.,* 2008). The Commission claimed that a seropositive person on ART with completely suppressed 'viraemia' is not sexually infectious as they cannot transmit HIV through sexual contact (Mayer, *et al.*, 2010; Coates*, et al.,* 2008; Wilson, *et al.,* 2008). These scholars, however, note that while there is increased appreciation that lowering plasma HIV levels may make individuals less infectious, translation of this approach to public health practice is still work in progress. They warn that programmes designed to promote safe sex among PLHIV are extremely important. In South Africa, there is speculation that some of the decline in HIV incidence may be attributable to the impact of ART which has been rapidly rolled out in the South African public health sector since 2004 (SANAC, 2011, Jonson*, et al.,* 2012). ART in South Africa is assumed to have reduced the number of new HIV infections at the start of 2008 by as much as 10 per cent (Jonson, *et al.*, 2012). At this time, adult ART coverage in South Africa was estimated to be only 40%. However, Kelly *et al.,* (2012) note that by 2009 more than 1.7 million PLHIV were in need of ART but not receiving it. In addition, in 2009 an HIV/AIDS treatment policy was

announced for all pregnant HIV-positive women with a low CD4 count or with clinical HIV/AIDS symptoms as well as all infants under a year old to have access to ART. Recently the government expanded the antiretroviral therapy programme which resulted in an increase in ART facilities countrywide to about 2 552 by 2011 (SANAC, 2011). Through its *National Strategic Plan on HIV, Sexually Transmitted Infections (STIs) and Tuberculosis (TB) 2012-2016*, the government aims to initiate "at least 80% of eligible patients on ART, with 70% alive and on treatment five years after initiation" (SANAC, 2011: 12)

It is difficult to review all the existing bio-medical strategies that have been employed to prevent HIV transmission, and also considering that there are even some new and emerging bio-medical prevention methods, the list is just inexhaustible. In light of its (in)effectiveness and limited focus, viewing the bio-medical approach to the epidemic from a dramaturgical perspective arguably places it in *Act II* that concerns indecisive efforts of the authorities to curb the epidemic (Denis, 2006). As evidenced by the unbridled scourge of the epidemic, concerns have been raised over each and every method reviewed above. Many have acknowledged that each of the methods discussed above is not 100% effective. To be effective, scholars and practitioners have noted that bio-medical methods need to be blended with continual behaviour modification (Kelly, *et al.*, 2012; Laga and Piot, 2012; Scalway, 2010; Coates, *et al.*, 2008). For example, male circumcision does not render a man immune from HIV but rather only reduces the risk of acquisition. It therefore requires HIV prevention behaviours by men to avert infection (Coates, *et al.*, 2008).

It is beyond the scope of this study to review the limitations of all the methods suffice to say that the initial interventions had what many have surmised as a narrow bio-medical focus aimed at a passive individual. It is important to highlight here that the import of reviewing bio-medical and other methods to HIV prevention in this chapter lies not in exhausting all the methods, neither does it lie in examining what they do but it is primarily to search for the

position and participation of PLHIV. As I have argued in Chapter Three, and will continue to reiterate, the dominant discourse favouring the bio-medical approach to the HIV response has marginalised PLHIV, crystallising them as patients who only require treatment care and support. It has also been shown, as is now acknowledged in HIV/AIDS literature (Kelly, *et al.*, 2012; Coates, *et al.*, 2008; UNAIDS, 2007; Crepaz*, et al.,* 2006) that excluding concerned communities in addressing problems that affect them has been a major flaw of the responses to the epidemic. It is in this context that this study sets off to explore ways in which PLHIV can be meaningfully involved in this response.

While there have been remarkable advances in the bio-medical approach such as in the case of ART, male circumcision as well as the potential of pre-exposure prophylaxis and microbicides, these advances, for Coates *et al.,* (2008), do (and must) not render behavioural strategies obsolete. As Kelly (2012) observes, supported by existing bio-medical strategies, behaviour change interventions are an integral approach in HIV prevention.

In the global response to the epidemic, the above biological interventions are thus augmented by information and education programmes aimed at creating awareness among individuals about sick role behaviours for example knowledge about diseases and their symptoms, precautions individuals need to take in order to avoid contracting the diseases, places where they can get help after contracting the disease among others.

In the context of HIV/AIDS, such information and educational programmes have tended to influencing behaviour change. Behavioural change interventions centered on admonishing individuals to avoid unsafe intercourse, encouraging individuals to adopt healthy practices (SANAC, 2011). The following section outlines the behavioural and social change approach to prevention and strategies employed in the response to HIV with particular focus on South Africa.

The behavioural and social change approach

This approach attempts to influence behaviour, or practices related to that behaviour, which indirectly or directly promote health, prevent illness or protect individuals from harm. Throughout the world, the social and behavioural approach focuses on a number of goals that complement the bio-medical methods. Informed by psychological theories and models of human behaviour such as the Albert Bandura's (1986) social cognitive theory, Godfrey Hochbaum and colleagues' 1950s health belief model (HBM) among others, behavioural change communication is based primarily on the behavioural and social determinants of the epidemic and implemented mainly through mass information and communication campaigns (Kelly, *et al.*, 2012; Coates, *et al.*, 2008; Crepaz, *et al.*, 2006). In the context of HIV prevention, communication is used to promote behaviour that is aimed, among other things, to see people delaying sexual debut; decreasing number of sexual partners; increasing safe/protected sex; behaviour that encourages people to know their HIV status; that promote adherence to bio-medical strategies for preventing HIV transmission; that decreases sharing of needles and syringes; and that decreases substance use (Kelly, *et al.*, 2012; Johnson, *et al.*, 2010).

Strategies to accomplish the above goals have different levels of focus. These can be individuals, couples, families, peer groups or networks, institutions, and entire communities (Coates, *et al.*, 2008). Whereas bio-medical interventions attempt to block infection or decrease infectiousness, the behavioural and social approach seeks to motivate behavioural change and social practices within individuals or particular groups of people by use of a range of strategies. These may include educational, motivational, peer-group, skills-building approaches, and community normative approaches (Coates, *et al.*, 2008). The approach does not impact directly on HIV prevalence but is rather an ameliorative response that puts communication at the centre to impact on the knowledge, actions, beliefs and social practices which lead to

behaviours that prevent new HIV infections (Kelly, 2012; Campbell, 2002). Figure 4.2 below, adapted from the 2012 - 2016 South African National Strategic Plan on HIV, STIs and TB, highlights key behavioural and social determinants of the HIV epidemic in South Africa and highlights suggested actions to mitigate the impact of the epidemic.

Figure 4.2: Interventions on behaviour and social determinants of HIV (SANAC, 2011: 23)

Sexual debut	• Tailored prevention interventions for the youth to facilitate the delay of sexual debut and sustain protective behaviours.
Multiple sexual partners	• Multi-level interventions that focus on sexual, social, cultural and gender norms and values.
Condom use	• Increase consistent use, especially among key populations, including those involved in sex work.
Intergenerational relationships	• Target prevention strategies at those men and women who have partners much younger/older than themselves, given that significant age discrepancy increases HIV-exposure risk compared to people who reported partners of similar age.
Alcohol and substance abuse	• Interventions to decrease alcohol abuse and other substance abuse, including illegal substances.
Prevention knowledge and risk perception	• Prevention strategies for people who expose themselves to the risk of HIV infection, including education and addressing perceptions of personal risk.

While applicable across all the four stages along the HIV prevention continuum shown on Figure 4.1 - and for both the HIV infected and the uninfected - the behaviour and social change approach seems to be mainly focused on the pre-exposure stage for the seronegative people. HIV prevention typically has referred to protecting individuals from becoming infected with HIV (Gilliam and Straub, 2009; Coates, et al., 2008). A discourse analysis of the language used in Figure 4.2 and its intent is evident to this observation. 'Delaying sexual debut' and 'sustaining protective behaviour' is clearly purported to delay acquisition rather than transmission; condom use is not explicit whether it is aimed to prevent acquisition or transmission; intergenerational relationships

are feared as they 'increase HIV exposure risk'. Also, prevention knowledge and risk perception is for 'people who expose themselves to the risk of HIV infection'.

Kelly et al., (2012), Gilliam and Straub (2009) and Nicole Crepaz et al., (2006) among other scholars note that most HIV prevention interventions have focussed on reducing HIV risk among HIV negative people or those with unknown serostatus but not directly on PLHIV. However, they also note efforts on 'positive prevention', an area of prevention which specifically engages PLHIV in prevention behaviour have recently been acknowledged. Programme planners are beginning to recognise that changing the behaviour of HIV positive people may be as effective as concentrating on HIV negative people (Kelly, et al., 2012; Kalichman, 2005). This approach to prevention is explored in the next chapter.

Due to the fact that the HIV is a sexually transmitted, the initial WHO designed programmes on HIV/AIDS were dominated by a set of psychological models of human motivation and sexual behaviour change (Singer, 1998). These were associated with people's knowledge, attitude and practice (KAP), taking account of what people knew; what their attitudes were; and what practices they had in sexual behaviours (Barnett and Whiteside, 2002). The role of communication or education in behavioural and social change interventions therefore becomes apparent (see Coates, *et al.,* 2008). Regardless of its successes, focusing on behaviour in isolation from the social context that influences people to behave in certain ways has its own limitations. These are discussed later in this chapter.

The first successful examples of the effectiveness of the behavioural change approach emerged from gay communities in the US, Canada, Europe, and Australia and later Thailand (Coates *et al.,* (2008). In Africa Uganda is famous for acknowledging the HIV epidemic fairly early and succeeded in using the

behaviour change approach to reduce rates of HIV infection (Slutkin, *et al*, 2006; Stoneburner *et al.,* 2004). According to various UNAIDS reports, many other countries have also reported decrease in HIV transmission related to changes in sexual behaviour among different population groups. These include Senegal, Brazil, Côte d'Ivoire, Kenya, Malawi, Tanzania, Zimbabwe; rural parts of Botswana, Burkina Faso, Namibia, and Swaziland; and urban parts of Burundi, Haiti, and Rwanda (Coates, *et al.*, 2008). For injecting drug users, the behavioural approach by use of education and access to drug treatment has been successful worldwide in reduction of HIV transmission acquired via sharing of injection equipment (Coates, *et al.,* 2008).

South Africa is a recent example of a country taking aggressive steps to reduce HIV transmission, particularly against its history of HIV/AIDS denialism discussed extensively in Chapter Three. While reductions in HIV transmission in particular risk groups, entire countries or regions "inevitably result from a complex combination of strategies and several risk-reduction options with strong leadership and community engagement that is sustained over a long time" (Coates, *et al.,* 2008: 3), the uptake of HIV prevention behaviours for averting new HIV infections in South Africa has also been mainly attributed to behavioural and social communication programmes aimed at achieving HIV prevention (Johnson, *et al.*, 2013; Kelly, *et al.*, 2012). There is a number of large-scale behavioural and social communication programmes in South Africa such as the *Soul City* TV series*, loveLife, Scrutinize, Brothers for Life*, *Siyayinqoba Beat It!* Among others

Soul City is a television series by The Soul City Institute for Health and Development Communication that deals with health and communication issues through drama. The series is accompanied by a radio drama, health booklets, and intensive advertising, marketing, and advocacy work (World Bank, 2003). Soul City targets both at adults and children through *Soul City* and *Soul Buddyz* respectively. These are two multi-media campaigns that utilise

broadcast, print and outdoor media to promote good sexual health and well-being (Shisana, *et al.,* 2009). In 2011, research into the impact of the Soul City campaign *OneLOve* found that it was having a positive effect on the sexual behaviour of adults that had been exposed to the campaign message (Scalway, 2010; AVERT, 2013).

LoveLife is a national behavioural change programme launched in 1999 by private funders and government (loveLife, 2011). In 2005 donors such as the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria withdrew funding for the programme after it was noted that the programme funding contradicted with the social status of the youth and its impact impinged on several critical aspects concerning how youth sexuality should be addressed (Parker, 2004; AVERT, 2013), *love*Life uses a wide range of media to promote sexual health and healthy lifestyles for young people in South Africa (World Bank, 2003; AVERT, 2013. *love*Life's outdoor media programme had also drawn criticism from HIV/AIDS experts, religious organisations as well as PLHIV regarding its impact on bringing about social and behaviour change as well as how it represented PLHIV and how it was decoded by young people (Delate, 2001; 2012). Now run by The New *love*Life Trust the programme, *love*Life states in its 2012-2013 strategy that it not only considers behaviour change to be the cornerstone of avoiding sexual risk and changing sexual health behaviours (loveLife, 2011; World Bank, 2003), but also employs a combination strategy that recognises the bio-medical prevention methods (loveLife, 2011). As such, it works to increase knowledge, change attitudes, and change sexual behaviour among youth. It specifically encourages young people to delay sexual debut, encouraged condom use by promoting it as a normal part of youth culture. However, evaluations have shown that *love*Life has had unintentional consequences of encouraging sexual interaction by young people. This unintended consequence undermined the original intention of creating spaces where young people can engage and interact in a variety of recreational

activities including learning about sexual and reproductive health (Parker, 2004; Delate, 2012).

Siyayinqoba Beat It! is also a TV show that promotes positive living and HIV prevention. A report on the impact of the programme on HIV HIV/AIDS showed that the Siyayinqoba Beat It programmes reached 47% of the national population. *Scrutinize* and *Brothers for Life* are media campaigns run by Johns Hopkins Health Education South Africa (JHHESA) and its partners. The former was launched in 2008 and involves a series of short animated TV commercials (Scalway, 2010) while the latter is a national campaign that uses interpersonal communication, mass media and advocacy targeting men in promoting health seeking behaviour (Brothers for Life, 2014).

While a number of surveys and meta-analyses show that behavioural social communication is effective and vital for combination HIV prevention response (see Scalway, 2010, Kincaid and Parker, 2008; Shisana, *et al.*, 2009; HSRC, 2008) limitations of behavioural strategies result from the cognitive and individualistic nature of the theories guiding these programmes (Airhihenbuwa and Obregón, 2000). As Coates *et al.,* (2008) argue, the theories guiding most interventions assume that people have the motivation and freedom to adopt protective actions. Central in the designing of prevention programmes with this individual focus are cognitive and motivational variables without any regard to the relational, social and structural influences on individual behaviour (Dutta-Bergman, 2005; Singer, 1998). While cognitive theories are useful at an individual level, they fail to address the fact that HIV transmission is a social event where "many factors other than perceived threat, knowledge, self-efficacy, behavioural intentions, and perceived social norms affect whether or not an individual is going to share needles or have sexual intercourse and then whether or not sexual intercourse will potentially involve transmission risk" (Coates, *et al.*, 2008: 11). Sexual behaviour is complex thus challenging prevention strategies based on the idea of individual rational decisions based

on knowledge about health risks and availability of medical services (Campbell, 2003). This shows limited focus of the behavioural approach that treats an individual as if they are independent from the socio-cultural and economic context as well as other sources of influence such as their families, peer groups, communities and the broader society. It is important to note, however, that cognitive theories are also important at community and society levels as they are integrated into the social change approach that addresses the wider context that influence behaviour (see Kincaid *et al.,* 2007). From a dramaturgical perspective of epidemics discussed earlier, the behavioural and social change approach can arguably be located in the second *Act* of the epidemic *play* explained earlier.

In their comprehensive meta-analytic review of behavioural HIV interventions for PLHIV to determine their overall efficacy, Crepaz *et al.,* (2006) found that few interventions incorporated contextual, societal or structural factors. However, they warn that "while addressing psychological processes, behavioural skills and communication within a relationship is important, socio-ecological models that identify multiple determinants of behaviours…can also be essential because individual behavioural change does not occur in a vacuum" (Crepaz, *et al.*, 2006: 154). The behavioural approach has thus been considered inadequate to respond to the challenges of HIV/AIDS. As such calls have been made to drift towards a social change communication approach that has an ecological approach to health, at the same time recognising culture and agency of the affected individuals. Culture, structure and agency are three key elements of the culture-centered approach discussed in Chapter Two (see Airhihenbuwa, 1995; Dutta, 2011). The relevance of these aspects in social change communication for HIV will be clear in Part Three of this thesis.

Sarah Cardey (2006: 1) suggests that "communication responses to HIV/AIDS must take into account the context in which the epidemic is embedded." The concept of social determinants of ill health is thus now better understood. The

political economic analysis of the HIV epidemic acknowledges that factors such as inequality, poverty and low levels of education compound the behaviour and social determinants of HIV (SANAC, 2011). The fact that HIV/AIDS exists within a complex system warrants need to consider the circumstances surrounding the epidemic as important as the epidemic itself (Airhihenbuwa and Obregon, 2000; Cardey, 2006; UNAIDS, 2009). The UNAIDS framework for HIV/AIDS communication integrates the social change perspective in that embraces social ecological thinking regarding the influence of social context on behaviour (Sallis, *et al.*, 2008). The framework considers an individual as a product of the context such as culture, socio-economic status, government policy, gender and spirituality (Dutta, 2011; UNAIDS, 1999).

Considering health within an ecological context is illustrated in the Social Ecology Model of Communication and Health Behaviour (SEMCHB) (Kincaid *et al.*, 2007). The model suggests that sustainable individual behaviour change is the one that is facilitated and supported by social changes at a higher level (Storey and Figueroa, 2012). For example, regardless of how motivated to change one may be, they cannot sustain this change if there is no complementary support from the family, community and other power brokers in the community. Over and above condom distribution, MMC, treatment and many other bio-medical and behavioural methods, the social change approach also addresses structural elements that impact on HIV transmission (George and Sprague, 2011). These may be physical, cultural, social, community, economic, legal or other policy features of the environment that affect HIV infection risk (Kelly, *et al.*, 2012). Social behaviour change communication is often unsustainable in a restrictive political-economic environment. Consequently, there is another paradigm that conceptualises HIV/AIDS as a development challenge (SANAC, 2011; UNAIDS, 2013). The structural approach thus recognises the socio-economic context in which the HIV epidemics occurs and the inter-relatedness of HIV/AIDS with other development concerns, such

as gender inequality, poverty, unemployment, inequity, lack of access to basic services and lack of social cohesion (SANAC, 2011). This approach can be viewed as drifting towards *Act III* of the dramaturgical nature of epidemics. The theme here concerns effective and more informed collective action about the problem. This is discussed below.

The structural approach

While some individual-oriented interventions discussed above have shown positive results in reducing risk behaviour, recognition that social, economic, political, and environmental factors directly affect HIV risk and vulnerability has stimulated interest in structural approaches to HIV prevention. Geeta Rao Gupta *et al.,* (2008) argue that success in preventing HIV transmission through the above approaches can be substantially improved when HIV prevention addresses the broader structural factors that shape or constrain individual behaviour. Given the relatively limited success gained by the above HIV prevention methods that emphasised on promoting condom use, voluntary HIV counselling and testing, medical male circumcision and treatment among other things as forms of HIV prevention, the history of the HIV response has witnessed a paradigm shift from an emphasis on individual behaviours to structural factors such as poverty and wealth, gender, age, policy, and power (Laga and Piot, 2012; George and Sprague, 2011; Coates, *et al.*, 2008).

This paradigm shift has been influenced by change in the leadership on HIV/AIDS from WHO to the UNAIDS which took responsibility for coordinating broadened international response to HIV/AIDS in 1996 (Iliffe, 2006). Interventions to address these factors are referred to as structural approaches and seek to change the root causes or structures that affect individual risk and vulnerability to HIV (Gupta, *et al.,* 2008). The approach is marked by a broadened response to the epidemic at international level and has a long term focus on the structural determinants that increase vulnerability to HIV acquisition (George and Sprague, 2011). According to Michel Caraël (2006), the

paradigm began around 1995. The approach advocates a 'combination prevention' strategy (Rotheram-Borous*, et al.,* 2009) that blends the bio-medical, behavioural, and structural factors in HIV prevention interventions. These may be physical, cultural, social, community, economic, legal or other policy features of the environment that affect HIV infection risk (Kelly, *et al.*, 2012).

As Gupta *et al.,* (2008) elaborate, structural interventions include structural actions implemented as single or multiple policies or programmes that aim to change the conditions in which people live. For optimal results, these approaches have to be blended with behavioural or medical interventions targeted at individuals. When a structural programme is implemented, it can result in activities or services that affect individual behaviour being delivered to individuals (Kelly, 2012; Gupta, *et al.*, 2008). For example, availing micro-credit programmes to assist sex workers to find alternative work would offer a direct service to individual women; and a social mobilisation programme to oppose a risky traditional practice - such as male circumcision in traditional initiation schools - protects the interest and care of young people (Kelly, *et al.*, 2012, Gupta, *et al.*, 2008). Another example pertinent to South Africa could be reflected in how the Thabo Mbeki administration's HIV/AIDS policies (as structure) limited PLHIV's access to ARVs regardless of the knowledge they may have gained from the bio-medical and behavioural change approaches with regards to the need to take ARVs adherently.

The WHO (2008) progress report on priority HIV interventions contends that in almost all areas of HIV prevention programming, rural areas have poorer services. As such, a structural intervention would address structural factors that impede the accessibility of prevention services. Lack of facilities where people can access condoms is a structural barrier to people who might have motivation to use condoms to prevent HIV transmission. A preventive structural intervention for injecting drug users would involve creation of a

policy and legal environment that allows syringe and needle exchange (Gupta, *et al.*, 2008). While structural programmes can take many forms, the underlying goal is to change the social, economic, political, or environmental factors that determine HIV risk and vulnerability in specified contexts (Gupta, *et al.*, 2008).

Due to the fact that many structural approaches address deeply entrenched social, economic, and political factors such as gender or income inequality that are difficult to change, they are considered as long term initiatives that belong within the purview of broader economic and social development as measured through development achievements such as the UN Millennium Development Goals (MDGs) rather than within the scope of HIV prevention. Progress in incorporating structural approaches into HIV prevention has thus been limited (Gupta, *et al.*, 2008).

There has been a range of structural interventions that have been successfully implemented to support vulnerable people in different parts of the world. Notable among these are the 100% condom use policy in Thailand where bar managers and police had a key role in the promotion of condom use (Kumphitak, *et al.*, 2004; UNAIDS, 2000). In Calcutta, India, sex workers were empowered through community mobilisation which resulted in a combination of activities to support HIV prevention (Jana, *et al.,* 1998), while in Tamil Nadu PLHIV have been integrated into women's self-help groups to increase their economic capacity (Cardey, 2006). Uganda, under the leadership of Yoweri Museveni is famous for the political will of government to create a policy framework conducive for a sustainable national response to the epidemic. There are many other examples of successful structural interventions (see Singhal, 2001; Cardey, 2006)

In South Africa, the intervention with microfinance for HIV/AIDS and gender equity (IMAGE) project reduce gender-based HIV violence, women's economic

dependency on men, and women's lack of in-depth information about HIV and its transmission by partnering with a microfinance institution. The intervention enabled women to pursue microenterprises, while offering them HIV education and creating opportunities to discuss and mobilise local action against gender-based violence (Pronyk, 2006). The result was a reduction in levels of intimate partner violence and improved household wellbeing, social capital, and empowerment. However, HIV incidence among participants and unprotected sex among youth in intervention participants' households were not impacted by the intervention (Kim, *et al.,* 2009; Pronsky, *et al.,* 2006).

Unlike approaches that promote behaviour change at the individual level, assessments on the outcomes and effects of structural approaches for HIV prevention have shown that there is no single level of effectiveness in reducing HIV incidence for all structural approaches since they involve different activities in different settings (Gupta, *et al.*, 2008). However, policy changes allowing for needle exchange and methadone treatment programmes have resulted in substantial reductions in HIV risk in areas in which HIV is spread through injected drug use (Gupta, *et al.*, 2008). The falling HIV prevalence throughout the 1990s in Uganda has largely been attributed to how, through a range of actions, the country created an open, enabling, environment for confronting the epidemic. This sharply contrasts to South Africa under Thabo Mbeki. Many different but synergic activities sprung up across Uganda, facilitating involvement of affected communities in establishing specific research centres to inform the response (Gupta, *et al.*, 2008). But whither *Act IV*? When is the HIV epidemic going to be contained? Will it be contained anyway? How? Finding answers to these questions is a continuous effort to which this study is part. It remains to be seen whether this effort is another Sisyphean challenge.

It has been established in the foregoing that a wide range of approaches have been used to try to avert the HIV epidemic but they have had very limited

success. Regardless of its acknowledged limitations, the behavioural prevention remains central to the effort to reduce HIV transmission as compared to antiretroviral therapy that, while having tremendous lifesaving potential, is expensive, does not cure, and may have debilitating side effects for some people (Johnson, *et al.*, 2008). Be that as it may, the bio-medical and behavioural approaches remain a dominant way of responding to HIV. While there are many successes realised through them, the bio-medical and behavioural approaches have, however, been accused of skirting the complexities that are also vital in understanding and curbing the epidemic. Assumptions of this approach such as that information alone would lead to behaviour change and that individuals are always in control of their environment/context and could make decision of their own free will have all been proved wrong. People are not passive receivers of information, nor are they individuals on a level playing field in terms of power. Those in the lower socio-economic segments are most vulnerable to HIV. These and other limitations of the individual focused approaches are addressed from a culture-centered perspective through the social change approach in combination with the structural approach.

While HIV/AIDS cure is still an enigma, and the efforts to find a cure are at the moment conceivably Sisyphean, UNAIDS reports indicate that the global response to HIV/AIDS has of late forced the epidemic into decline. For example, the rate of new HIV infections has fallen, the number of HIV/AIDS-related deaths has decreased due to universal access to HIV prevention, treatment, care and support (UNAIDS, 2013). Access to bio-medical HIV prevention services is reported to have empowered individuals and communities to act in earnest against the disease. In several countries with generalised epidemics, a combination of the reviewed bio-medical interventions is said to have reduced new infections (incidence) for example in Zimbabwe where HIV incidence in urban areas fell from 6% in 1991 to less than 1% by 2012 (UNAIDS, 2013). Regardless of millions of new infections occurring every

day (UNAIDS, 2013), declines in new HIV infections across the world have also been attributed to changes in sexual behaviour (UNAIDS, 2013).

However, there is one particular limitation of the dominant approach to the HIV response which is pertinent to the objective of this study. This relates to its limited view of the complexity of the HIV epidemic. Due to this limitation, the bio-medical approach has not only failed to find a decisive solution to HIV/AIDS but it has rather marginalised PLHIV. Prevention focus efforts have primarily focussed on the seronegative or those who are not aware of their serostatus (Crepaz, *et al.*, 2006) having service providers as those living without HIV and service receivers as those living with HIV (UNAIDS, 2007). This approach created a depersonalised seropositive by shaping what Seidel (1993: 176) calls a "cultural agenda of HIV/AIDS in which the person with HIV/AIDS, as a full human person, is absent".

However, in order to fulfil its vision of zero new infections, the UNAIDS acknowledges that this requires not only a look at the societal structures, beliefs and value systems that present obstacles to effective HIV prevention efforts; poverty, gender inequity, inequity in health and the education system, and unequal resource pathways, but also meaningful participation of PLHIV in the HIV response (UNAIDS, 2010). While this approach has been implemented for two decade since the Greater involvement of people living with HIV/AIDS (GIPA) principle was formulated, it has crystallised PLHIV as patients who needed treatment, care and support. Their involvement has been in efforts meant to access treatment care and support, with prevention efforts being targeted at seronegative people. Yet, as many have argued, without prevention focussed on PLHIV to adopt and maintain healthier and safer behaviours, the growing number of people living longer with HIV forms a potential source of infection (Kelly, *et al.*, 2012; Coates, *et al.*, 2008; Crepaz, *et al.*, 2006). Quite striking here is a challenge on how to undertake effective HIV prevention in the era of more generalised access to antiretroviral therapy which do not cure the

virus but merely make people live longer with the virus. People remain sexually active after they learn of their positive serostatus, "and this is more likely as antiretroviral drugs extend not only life but also quality of life for people living with HIV/AIDS" (Coates, *et al.*, 2008: 14).

Indeed, the objective of this study is to examine ways through which PLHIV can be involved not as patients who fight for treatment but also as active players in prevention efforts as working with PLHIV has become increasingly important in the era of expanded treatment access (Kelly, *et al.*, 2012; Coates, *et al.*, 2008; Crepaz, *et al.*, 2006). The culture-centered approach to social change outlined in Chapter Two clearly articulates the importance of the subaltern agency and voice in the discursive spaces where policies are debated and decided. As a precursor to chapters in Part Three of this thesis that discusses the experiences and feelings of South African PLHIV about their participation in the HIV response that this study sets out to investigate, the next chapter reviews the current programmes involving PLHIV in the HIV response and the policy framework regulating this involvement.

CHAPTER FIVE

GREATER INVOLVEMENT OF PEOPLE LIVING WITH HIV

Due to the expansion of access to antiretroviral therapy (ART), there has been a significant reduction of HIV/AIDS-related deaths resulting in more people living with HIV (PLHIV). According to the Joint United Nations Programme on HIV/AIDS (UNAIDS) calculations, by 2012 a total of 2.5 million deaths had been averted in low and middle income countries since 1995 (UNAIDS, 2013). By the same year about 34 million people were living with HIV worldwide. South Africa has an estimated 5.6 million PLHIV and is host to the world's worst HIV epidemic than any other country (Lurie, *et al.*, 2008) having an annual HIV incidence of about 1.5% (UNAIDS, 2011). The increase of PLHIV has thus been compounded by continued new HIV infections.

Across the world, annual new HIV infections have, however, dropped by about 21% since the height of the epidemic in 1997 (UNAIDS, 2013). The decline in new HIV infections is attributed to prevention efforts through a combination of behaviour changes including reduction in numbers of sexual partners, increases in condom use, and delayed age of first sex. However, prevention interventions have primarily been focused on reducing HIV acquisition risk among the uninfected individuals (Kelly, 2012; Bunnell, *et al.,* 2006; Crepaz, *et al.*, 2006,) who constitute the majority population compared to PLHIV. This is despite the fact that only PLHIV, a much smaller population than all those at risk, are the nexus for HIV transmission (Bunnell, *et al.,* 2006, Osborne, 2006). More so, research has shown that a high proportion of HIV positive men and women aware of their HIV status engage in HIV transmission risk behaviours (Eisele*, et al.,* 2008; Wingood, *et al.*, 2004; Kalichman, *et al.*, 2001; Kalichman,

2000). This suggests that a lot of resources have been used for interventions that target people who may not have power to control HIV transmission

While access to HIV prevention services has empowered individuals and communities to act in earnest against the disease (UNAIDS, 2013), new infections are unabated and the population of PLHIV continues to grow. Deliberate prevention interventions for PLHIV are therefore needed to empower them to maintain behaviours that protect others from becoming infected. Such interventions must, however, not only be *for* PLHIV but *with* PLHIV [my emphasis]. The important contribution PLHIV can make in the response to the epidemic has to be recognised and enhanced. The UNAIDS encourages institutional authorities to create space at all levels within society for the involvement and active participation of PLHIV in all aspects of the HIV response (UNAIDS, 1999). While the importance of involving PLHIV at all levels of programme development and implementation is discussed later in this chapter, it suffices to say that the relevance, acceptability and effectiveness of HIV/AIDS programmes is improved when PLHIV are involved (UNAIDS, 2007, APN+; 2004).

With an estimated global population of 35.3 million people living with HIV by 2012 (UNAIDS, 2013) and the alarming extent of the epidemic in South Africa, the need for prevention interventions that target PLHIV and their sexual partners become apparent. This chapter reviews the involvement of PLHIV in response to the epidemic. It examines PLHIV's involvement in terms of the policy framework that informs it. The chapter highlights important conceptually significant aspects within this policy framework which can be appropriated to the main theoretical framework within which this study is located. In order to situate participation in its meaningful context, the chapter begins by examining PLHIV and their HIV transmission risk practices. This is also because deliberate prevention interventions with any population group presuppose knowledge sharing about all factors that exposes the population to

risk. It is unarguable that understanding patterns of sexual behaviour among individuals who know their HIV positive status remains central to informing such interventions, if ever they have to be relevant.

HIV transmission risk behaviours among PLHIV

Empirical studies examining PLHIV's sexual relationships behaviours are increasing amid concern that HIV positive people who are aware of their status continue practicing sexual behaviours that place their sex partners and themselves at risk for HIV and other sexually transmitted infections. Such behaviours include engaging in unprotected anal and vaginal intercourse, having multiple sex partners, using substances before a sexual encounter, commercialisation of sex, and intravenous drug use (Olley, *et al.*, 2005). That every new HIV infection begins with an infected person in undisputable (see Koester, *et al.*, 2007). With studies having shown that an average of one in three PLHIV continue to practice unprotected intercourse after learning their HIV positive serostatus (Winghood, *et al.,* 2004; Kalichman, 2000), it is worrying that there are as little studies on sexual behaviours of PLHIV in Africa as there are interventions aimed at reducing HIV risky behaviours among PLHIV. Most concerning is the apparent lack of resourcing for such interventions for PLHIV particularly in (South) Africa. This is despite the fact that the region hosts the worst HIV epidemic in the world. Important work in this area has, however, been conducted in the United States of America (US) where researchers have discovered that HIV prevention interventions for PLHIV effectively work in reducing risky behaviour and new infections (see Janssen and Valdiserri, 2004, Janssen*, et al.,* 2001).

While a lot of published research on PLHIV HIV transmission and risk behaviour in industrialised countries such as the US was found (see Kalichman, 2000), in the surveyed literature there was a paucity of such studies conducted in South Africa. Few studies on similar research and interventions conducted in South Africa were found and are tabulated in Table

5.1 below. Findings from the studies suggest that a high proportion of HIV positive men and women aware of their HIV status practice sexual behaviours that place their partners and themselves at risk for HIV and other sexually transmitted infections. The few risk reduction interventions to help PLHIV reduce their risky behaviours in South Africa, as with the US, have proved to be effective in changing risky behaviours among PLHIV (see Cornman*, et al.,* 2008 and Eisele, *et al.*, 2009). Surprisingly, this important observation has failed to generate scholarship interest in such crucial interventions.

Table 5.1: Compendium of Studies on sexual practices of people living with HIV in South Africa

Investigators	Location	Participants	Risk Practices	Risk Factors
Kiene S, *et al.,* 2008	Cape Town	(n=82) 58 women and 24 men	80.17% of sex events were unprotected	Alcohol use by the female, male, or both partners, increased the proportion of sex events
Eisele, *et al.,* 2008	Cape Town	(n=924) 520 on ART (165 men and 355 women) and 404 waiting for ART (150 men and 254 women).	40.1% men and 46.3% women had unprotected sex their last time	Non-disclosure to their partner and ambivalent perception about the relationship between ART and HIV transmission

Simbayi, *et al.,* 2007	Cape Town	413 men and 641 women (903 were sexually active)	55% had unprotected viginal sex with non-concordant partners	Non-disclosure associated with previous HIV/AIDS-related experiences of discrimination
Olley, *et al.,* 2005	Cape Town	(n=149) 44 male and 105 female patients recently diagnosed of HIV	54.4% practiced unprotected vaginal intercourse with the most recent partner	Shorter duration of illness
Shuper, *et al.,* 2008	KwaZulu-Natal	202 PLHIV, 38 female and 52 male sexually active	Among the sexually active, 51.5% men and 37.6% women had unprotected sex	Lower education, alcohol, recent STI treatment, procreation, unemployment, negative condom attitudes, lower HIV stigma, lower power, physical violence.
Kiene, *et al.,*	KwaZulu-	152 patients	30% of the	Alcohol use,

2006	Natal	in clinical care, (69 men, 83 women) 50% sexually active	sexually active reported unprotected anal or viginal sex in the past three months. 39.2% sex events were with uninfected partners	forced sex, sex with a perceived infected partner, and sex with a casual partner
Lurie, *et al.*, 2008	Mpumalanga	(n=1166) 329 men and 837 women patients at first visit to a wellness clinic.	66% men and 69% women reported unprotected sex with recent partner	Non- disclosure poverty, education, alcohol consumption, CD4 cell count
Lurie, *et al.*, 2008	Gauteng	(n=2653) 572 men and 2081 women patients at first visit to a wellness	61% men and 67% women reported unprotected sex with	Non- disclosure poverty, education, alcohol consumption, CD4 cell count

	clinic.		recent partner	
Cornman, *et al.*, 2008: Evaluation of effectiveness of a prevention intervention	KwaZulu-Natal	152 patients assigned to ARV adherence counsellors for a risk reduction intervention in a clinical setting	Despite increased sex event, the number of unprotected sexual events decreased from an average of 2.64 to 0.40	Risk reduction discussions with PLWHA
Eisele, *et al.*, 2009	Cape Town	512 patients (161 men and 351 women) who initiated ART within the last 3 months	Unprotected sex at last sex among patients on ART decreased from 44.7% to 23.2% one year later	Disclosure of one's HIV status, gender inequity, initiating ART, increase in objective health and social status

A study by Thomas Eisele *et al.,* (2008) conducted among 924 HIV positive men and women aware of their status found out that about 40.1% reported having unprotected vaginal sex with the most recent partner. Similar findings are reported by Leickness Simbayi *et al.,* (2007) who found out that 42% of the studied PLHIV had sex with a person to whom they had not disclosed their HIV status in the previous three months. The study also found that participants

who had not disclosed their HIV status to their sex partners were considerably more likely to have multiple partners and unprotected sex with them. Conversely, disclosure of one's HIV positive status would entail otherwise. Unprotected sex and multiple concurrent partnerships (MCPs) are risk practices associated with sexual transmission of HIV.

Many factors contribute to risky HIV transmission behaviours by PLHIV. Susan M. Kiene *et al.,* (2008) studied 58 sexually active HIV positive women and 24 HIV positive men in Cape Town who reported numerous sex events after consuming alcohol. Of these sex events, 80.17% were unprotected and over half (58%) of unprotected sex events were with HIV negative or HIV status unknown partners. The study concludes that drinking alcohol before sex increased the proportion and number of subsequent unprotected sex events. In a separate study, Kiene *et al.,* (2006) assessed the incidence and predictors of unprotected sex among 152 HIV positive patients in clinical care in KwaZulu-Natal. About 50% were sexually active and 30% of those reported unprotected sex. The study found that unprotected sex was associated with alcohol use during sex, forced sex, sex with a perceived HIV positive partner, and sex with a casual partner whereas HIV status disclosure was related to less unprotected sex.

All the above studies confirm early findings from Western countries suggesting that the prevalence of unprotected sex among PLHIV was as high as 30–50% (Kiene*, et al.,* 2006; Olley*, et al.*, 2005). Deliberate interventions for PLHIV to maintain behaviours that protect others from becoming infected have thus been common in the West beginning as far back as 1980s (see Koester*, et al.*, 2007; Kalichman*, et al.*, 2001). A meta-analysis on independent studies carried out from 1987 through 2004 in the US examined self-reported unprotected anal or vaginal sex among PLHIV (Marks*, et al.*, 2005). The analysis indicates that while lower in HIV positive persons aware of their status relative to HIV

positive persons unaware of their status, the prevalence of unprotected sex among PLHIV averaged 53% (Marks, *et al.*, 2005).

Kalichman (2000) reviews studies reporting rates of continued HIV transmission risk behaviours among PLHIV from different geographic areas, populations, and settings. Among infected injecting drug users studied in two settings, in London 42% reported having had unprotected vaginal intercourse with their partners (Rhodes*, et al.,* 1993) while in Sandiego 29% reported unprotected vaginal intercourse in the past six months (Singh*, et al.,* 1993). For men who have sex with men (MSM), in Amsterdam 16% reported unprotected anal intercourse with casual partners (De Vroom, *et al.,* 1998) while in Sydney 29% practiced unprotected anal intercourse (Gold, *et al.,* 1994). Substance abuse also contributed to risk practices. In Los Angeles 26% men and 22% women substance abusers practiced unprotected anal, vaginal and oral intercourse with most recent partner (Marks, *et al.*, 1999). Results from these studies generated interest to change prevention focus from the general populace to PLHIV quite early in the US.

The early and concerted effort to address HIV transmission risk behaviours among PLHIV by the Centres for Disease Control and Prevention (CDC) in the US have largely contributed to the significant decrease in HIV transmission rates in the Western World. As early as late 1990s, the CDC expanded HIV prevention programs for PLHIV to reduce the risk of transmission as a supplement to already existing programs that primarily focused on reducing the risk of acquisition of the virus (Janssen, *et al.,* 2001). This saw CDC launching a serostatus approach to fighting the epidemic (SAFE) aimed at those who are infected with HIV, "linking them to appropriate high-quality care and prevention services, and supporting them in adhering to treatment regimens and in adopting and sustaining HIV risk reduction behaviour" (Janssen, *et al.,* 2001: 1019). SAFE focuses on the infected person with behavioural interventions that have been standard for HIV prevention

programs such as information provision, counselling and testing as well as other HIV/AIDS-related services including treatment and other referral services (Janssen, *et al.*, 2001: 1019). It is thus not solely the bio-medical advances in the treatment of HIV that are responsible for the stabilisation in the reported incidence of HIV/AIDS in the West (Serovich and Mosack, 2003). The SAFE approach also played a pivotal role in this success.

All the studies summarised on Table 5.1 shows important phenomena related to risky sexual behaviour. Key among these is disclosure or non-disclosure of HIV status to sexual partners. It is evident that disclosure of the HIV positive status is one of the important behaviours germane to reducing chances of HIV infections. While non-disclosure allows risky sexual behaviour to occur, disclosure of HIV positive status by the infected partner permits the uninfected one to be involved in the decision-making process that may result in not allowing HIV transmission.

Studies report different motivations for HIV disclosure. These include poor health, reproduction, previous HIV/AIDS-related experiences of discrimination, degree of symptomatology, degree of relationship commitment, number of sexual partners among others (Mlambo and Karl Peltzer, 2011; Simbayi, *et al.,* 2007). However, some PLHIV feel that *'duty'* or a sense of *responsibility* is the key motivating factor for their decisions to disclose. PLHIV who disclose believed that their partners have the *right* [my emphasis] to know, thus disclosure is the responsible thing to do as it is not right to jeopardize the health of others (Serovich and Mosack, 2003). Nowhere is the need/importance for participatory prevention interventions with PLHIV more evident than in this humanitarian compulsion among PLHIV. One has to imagine what would happen if this compulsion is cultivated in every PLHIV. It is, however, concerning that this aspect has been ignored by previous prevention interventions whose focus on the uninfected simply discouraged them from behaviours and practices that put themselves at risk of contracting HIV. Most

of these interventions were modelled on social cognitive theories and fear theories (for example the Social cognitive theory and the Extended parallel process model among others) that evidently prioritise 'self' than 'other'.

The responsibility aspect manifested in the above study appeals to the Denver Principles that declares PLHIV's ethical responsibility to respect the other. The Denver Principles, discussed later in this chapter, remain a foundational principle informing participation of PLHIV in the HIV response. Appealing to these principles to involve PLHIV in prevention interventions may conjure a paradigm shift from self-centered cognitive theories towards ecological theories that put focus on both the 'self' and the 'other'. This is evident in the way the West has responded to the epidemic. Since the Denver principles are founded in a Western context they cannot be divorced from key imperatives within Western moral reasoning. The principle bear a hallmark of Western moral theories such as Immanuel Kant's postulate of 'Categorical Imperative' (CI) which is ingrained in the Western moral discourse (Altman, 2011).

As already shown, the CI is based on the law of autonomous will or self-governing whose presence in each person offers decisive grounds for viewing each other as possessed of equal worth and deserving of equal respect (Wood, 2002). Applied in the South African context, the phenomenon can equally be understood through the African normative theory of *Ubuntu,* discussed in Chapter Two. As already discussed, *Ubuntu* implores oneself not to harm or injure the next person but to respect others. For Kant, imposing risks and harm on another person without their knowledge is impermissible as it violates the respect they deserve as self-determining agents. As such, humans have moral duties to all people by virtue of the fact that they are rational moral agents (Altman, 2011; Wood, 2002). However, rationality in determining health behaviours has been found wanting as health decisions tend to be determined by a broader social and cultural context (Airhihenbuwa, 1995; Dutta, 2008).

In light of the Denver Principles, PLHIV have an ethical responsibility not to transmit HIV. Linked to this are two important conclusions with fundamental conceptual implications for HIV prevention interventions that are worth noting. The first is that continued unprotected sexual intercourse among HIV positive people has potentially grave implications to the spread of HIV. Deriving directly from this is the second conclusion that there is a need to scale up prevention interventions designed to reduce transmission from HIV infected individuals. In this context and in order for such interventions to be effective, there are possibilities of developing social and behavioural change communication interventions for HIV prevention that are modelled on a moral philosophy that is informed by respect for the other. This study thus conceptualises social change communication for HIV prevention involving PLHIV framed within such a moral philosophy. It attempts to capture the essence of morality and ethics in the (South) African context and to elucidate forms of moral wisdom and behaviour grounded in the web of the (South) African community.

However, the central issue is that PLHIV can only perform any moral/ethical duty if they are allowed to participate, that is if communication spaces for their voices are created (Dutta, 2008). Involvement can be viewed here as a catalyst to a sense of duty or responsibility, otherwise continued marginalisation makes one sub-human as it condemns them to subalternity (Dutta, 2011). As has been argued in the previous chapters, activities that are tailored to meet the needs of specific groups are generally successful when attendant communities are involved (see Osborne, 2006).

Involvement of PLHIV is thus important in several significant ways. The first relates to PLHIV's experiences. PLHIV have experienced not only factors that make individuals and communities vulnerable to HIV infection but also HIV-related illnesses and perhaps strategies for managing them (UNAIDS, 2007). This implies that PLHIV cannot only be beneficiaries of the NGO services. This brings us to the second point that their participation gives a personal power

and immediacy to interventions through allowing PLHIV to represent their needs in decision and policy making (UNAIDS, 2007, Cornu, 2006). Due to their personal experience with HIV, PLHIV are likely to understand the epidemic better than anyone.

PLHIV are a nexus for new HIV infections (Osborne, 2006). Containing the HIV epidemic is therefore most likely when PLHIV actively participate in collective action aimed at HIV prevention. This leads to the third reason why involvement is significant. Participation of PLHIV at all levels of programme development and implementation improves the relevance, acceptability and effectiveness of HIV/AIDS programmes (UNAIDS, 2007, APN+; 2004). Apart from this, it is everyone's right to influence policies or to have a say on decisions that affect them. From a participatory communication for social change perspective, when concerned communities actively participate in collective action aimed at addressing common problems; when these communities are proactively involved in determining their own well-being; success is most likely (Bessette 2004; Figueroa *et al* 2002; Tufte and Mefalopulos 2009; Gumucio-Dagron and Tufte, 2006; Melkote and Steeves 2001). Involvement also brings a wide range of personal benefits for PLHIV as it can improve self-esteem and boost morale, decrease isolation and depression, and improve health through access to better information about care and prevention as well as breaking down fear and prejudice against PLHIV (UNAIDS, 2007).

PLHIV were instrumental in influencing the current international and local policies governing their participation in the HIV response. After many years since HIV/AIDS began, PLHIV are now recognised as a key stakeholder whose involvement is critical in any response to HIV/AIDS. However, involvement of PLHIV is more often done to please donors or Activists (Cornu, 2006, Manchester, 2004). To ensure genuine participation, UNAIDS came up with the Greater involvement of people living with HIV/AIDS (GIPA) principle, a cardinal policy which directs the current form of participation of key populations in the

HIV responses. In what follows, I outline the policy framework regulating the involvement of PLHIV.

Policy framework directing PLHIV participation

While the involvement of PLHIV in the HIV response is largely informed by the Paris Declaration popularly known as GIPA, there are many declarations and political commitments on involvement of PLHIV, (see the African Union Commission (AUC) and UNAIDS Declarations and commitments on HIV/AIDS 1987-2007). Since its declaration in 1994, GIPA has since become not only a bandwagon policy slogan but is seen as a model of best practice (Cornu, 2006) informing the policy framework guiding collective action and partnership with PLHIV in responding to the HIV epidemic. However, it is important to note that GIPA is only a 'formalisation' of governments' support of the notion that personal experiences should shape the HIV response, a principle that was first voiced by the PLHIV themselves at Denver, US in 1983 (UNAIDS, 2009). It follows, therefore, that an understanding of GIPA in its meaningful context presupposes comprehension of the Denver Principles. For this reason I begin by exploring the Denver Principles as a way of unpacking GIPA.

The Denver Principles (1983)

PLHIV did not want to spend their lives as exhibits in other people's spectacles of grief, fear, anger, or nihilism, and thus organised themselves to articulate that they had a right to make decisions about their lives, their treatment, how they were treated at every stage of their disease (Wright, 2013). In 1983 PLHIV from across the US gathered for an HIV/AIDS conference in Denver, Colorado and expressed concern about their continued exclusion from discursive spaces where the HIV response policies were debated and implemented. Here PLHIV articulated that their personal experiences should shape the HIV response and this was only possible when their voices were included in these discursive spaces (see Dutta, 2011). Described later as "the Magna Carta of AIDS activism" (Wright, 2013) the Denver Principles whose agenda for PLHIV to claim

an active role in a conversation about HIV/AIDS called for a new relationship between people with AIDS, their health care providers, and the society around them, agreeing on a set of principles that later revolutionised the way the world had responded to the epidemic (Wright, 2013; APNN+, 2004). The advisory committee of the PLHIV attending this conference issued a statement of agreed principles formalized in a foundational document later called the Denver Principles that espouse both the rights, responsibilities and empowerment of PLHIV inasmuch as HIV prevention, treatment, care and support are concerned. According to Joe Wright (2013) the text of the Denver Principles has been reprinted in a number of places. Below is a verbatim text retrieved from the AIDS Coalition to Unleash Power (ACT UP) New York's organization website (ACT Up, 2014).

As can be observed from Panel 5.1 below, the Denver Principles articulate key challenges in the lives of PLHIV and the role of PLHIV themselves in overcoming such challenges by among other things: refusing to be victims and demanding to be involved, asking clinicians to view themselves as subjective individuals, asserting a right to sexuality, demanding freedom from discrimination and stigma, insisting on central social and political roles in society's response to AIDS, and emphasising autonomy and dignity in research, medical care, and end-of-life decisions.

The statement thus consists not only of the rights of PLHIV but also of specific recommendations for both PLHIV and the general populace. Of interest to this study is recommendation number four (4) for PLHIV which calls to all PLHIV to choose to be responsible for their sexual health and to inform all their partners of their HIV status. The recommendation asks PLHIV to "substitute low-risk sexual behaviours for those which could endanger themselves or their partners. We feel people with HIV/AIDS have an ethical responsibility to inform their potential sexual partners of their health status" (Denver Principle, 1983).

This ethical clause, as has been argued earlier and shall herein continue to be highlighted, is at the heart of the conceptual argument of this thesis.

Panel 5.1: The Denver Principles of 1983 (ACT UP, 2014)

Statement from the People with AIDS advisory committee

We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others. We are "People With AIDS."

Recommendations for All People

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.
2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

Recommendations for People with AIDS (PLHA)

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.
2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.
3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
4. *Substitute low-risk sexual behaviours for those which could endanger themselves or their partners; we feel people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status* [my emphasis].

Rights of People with AIDS

1. To as full and satisfying sexual and emotional lives as anyone else.
2. To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status or race.
3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.
4. To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.
5. To die--and to LIVE--in dignity.

Wright (2013) affirms that the influence of the Denver Principles manifests itself in advocacy by PLHIV around the world. This manifestation emerged first in formal associations of PLHIV and then by involvement of PLHIV in roles within broader AIDS Activist movements both local and global, a number of which - as already highlighted in this thesis and is again shown further below - have since persuaded governments and societies to change their responses to the HIV epidemic. Even though by the middle of 1980s PLHIV had already established many community groups not only in the West but in others countries such as Brazil, Senegal, Uganda, and the Philippines to promote prevention and access to treatment, care and support (Merson, *et al.,* 2008; GNP+, 2000), the Denver Principles led to the creation of the National Association of People With AIDS (NAPWA) in the US, and eventually to similar associations in a number of nations including South Africa. It led to the formation of the ACT UP in New York in 1987, a PLHIV advocacy group which, for example, inspired formation of the Treatment Action Campaign (TAC) in South Africa (Wright, 2013; Merson, *et al.*, 2008). The global legacy of the Denver Principles is the Paris Declaration, a formalisation by the United Nations (UN), a decade later, of a political commitment to support the Paris Declaration. Popularly known as GIPA, the Paris Declaration (1994), (see Appendix B) is a principle aimed at increasing the capacity and coordination of networks of PLHIV and ensuring their greater involvement in the formulation and implementation of HIV/AIDS policies and programs (UNAIDS, 1999).

The Paris Declaration

A decade after announcement of the Denver Principles, forty-two (42) United Nations member countries assembled for an HIV/AIDS Summit in Paris, 1994 and issued a declaration in which nation states made a commitment to support "full involvement" of PLHIV in response to the epidemic at national, regional and global levels. The Paris Declaration, referred hereinafter as GIPA, is a principle that calls on governments to commit to the notion of greater

involvement of PLHIV for the realization of their rights, particularly the right to self-determination and participation in decision-making processes that affect their lives (UNAIDS, 2007). GIPA acknowledges the central role of PLHIV as part of the solution rather than of the problem of HIV/AIDS. As such, it binds member states to:

a) Stimulate the creation of supportive political, legal and social environments for the greater involvement of people PLHIV at all levels.

b) Rally the society, public and private sectors and PLHIV in a spirit of partnership.

c) Fully involve PLHIV in the development and implementation of public policies.

d) Ensure that PLHIV enjoy the same level of protection regarding access to care, employment and education, freedom of movement, housing and social security (UNAIDS 1994, 1999).

The endorsement of GIPA through numerous follow up global, continental and regional agreements and declarations of commitment (see UNAIDS GIPA Policy brief, 2007; and African Union Commission (AUC) and UNAIDS Declarations and commitments on HIV/AIDS 1987-2007) is testament to its importance in response to HIV/AIDS. It suffices to note that close cooperation with PLHIV facilitates the achievement of a more effective the HIV response at individual, organisational and community levels (UNAIDS 2006). To realise the greater involvement, the UNAIDS suggested a model that explains how GIPA could be operationalised at a project or organisational level (see UNAIDS, 1999, 'key material' From Principle to Practice). The model specifies a variety of roles that PLHIV can play at different levels of the organisation or project such as shown on Figure 5.1. These include programme planning and implementation, policy formulation, service delivery and programme evaluation.

As shown on Figure 5.1, the model represents GIPA as a hierarchy of involvement. The first strand is the lowest and less involving level where PLHIV are depicted only as target audiences. The last strand is the highest level where PLHIV participate as decision makers who are able to influence and ultimately direct policy. For the UNAIDS and the Global Network of PLHIV (GN+), this level represents complete application of the GIPA principle (UNAIDS, 1999). In between these two levels, PLHIV can also participate as contributors, speakers, implementers or experts. According to the Asia Pacific Network of People Living with HIV/AIDS position paper (APN+, 2004), practical examples of areas where PLHIV can be involved are varied. They include peer education, peer support, advocacy, and counselling, public education, program planning and implementation, public health policy and legislation. It is one of the tasks of this study to examine how and where PLHIV involved in the HIV response in South Africa get involved.

Figure 5:1 Levels of involvement by PLHIV (UNAID S, 1999 'key material' From Principle to Practice)

Target Audiences	Contributors	Speakers	Implementers	Experts	Decision Makers
Activities are aimed at or conducted for PLHIV. Here PLHIV are seen as patients and services receivers	Activities are done with PLHIV. However, involvement is only marginal. Here PLHIV are already known. Examples are using an HIV-positive person on a poster or having relatives of someone who has recently died of AIDS speak about that person at public occasions.	PLHIV are used as spokespersons in campaigns to change behaviors or are brought into conferences or meetings to "share their views". This is often perceived as "token" participation, where the organizers are conscious of the need to be seen as involving PLHIV but do not give them any real power or responsibility.	Involves PLHIV carrying out instrumental roles in interventions, e.g., as caregivers, peer educators, or outreach workers). However, PLHIV do not design the intervention or have much say in how it is run.	PLHIV are recognized as important sources of information, knowledge, and skills. They participate on the same level as professionals in the design, adaptation, and evaluation of interventions.	This is the highest and desirable level of participation representing complete application of the GIPA principle. Here PLHIV participate in decision making or policymaking bodies. Their inputs are valued equally with all the other members of these bodies.

While GIPA and the Denver Principles advocate the rights of PLHIV particularly that of participation, they bear fundamental variations that have theoretical and methodological implications for the participation of PLHIV. Two of these variations are worth noting. The first concerns serostatus disclosure. As already highlighted, the Denver Principles include specific recommendations not only for the general public but specifically for PLHIV. Recommendations for PLHIV clearly state that in order to avoid "endanger[ing] themselves or their partners, they have "an ethical responsibility to inform their potential sexual partners of their health status" (Denver Principles). However, GIPA states that PLHIV "have the right to choose to be involved without making their serostatus public" (UNAIDS, 1999: 3). Here GIPA implies that while there should be nothing to stop PLHIV being open about their serostatus to their colleagues and community, GIPA does not necessarily mean disclosing one's serostatus. It is important here to note that while disclosure is important, it must not be construed as an end as it does not guarantee safe behaviour (Osborne, 2006).

The second variance relates to the general orientation of the two principles. Whereas the Denver Principles focus on both the rights and responsibility of PLHIV, GIPA focuses on "ensuring that all persons living with HIV/AIDS are able to realise the full and equal enjoyment of their fundamental rights and freedoms" (Paris Declaration, 1994). To achieve this, GIPA seeks to address all structural barriers to this enjoyment. For HIV prevention, GIPA seeks to promote "specific risk-reduction activities for and in collaboration with the *most vulnerable populations*, such as groups *at high risk of sexual transmission* [my emphasis" (Paris Declaration, 1994). While this orientation is important, the role of PLHIV in HIV prevention highlighted earlier is ignored (also see Osborne, 2006). In terms of GIPA, involvement of PLHIV is particularly significant in designing policies, laws and enabling environments that protect PLHIV from discrimination; that reduce stigma and that seek to change people's attitudes to HIV/AIDS by giving it a 'human face' so that PLHIV live positively (UNAIDS,

1999). Thus GIPA has a structural change approach that aims at the "creation of *supportive* [my emphasis] political, legal and social environments" (Paris Declaration, 1994). While the structural change approach towards HIV/AIDS strengthens the links between HIV prevention and treatment, care and support of the HIV/AIDS ill, "supporting people living with HIV to live 'positively' [should] include a strong recognition that issues of love, life and intimacy are part of their reality" (Osborne, 2006: 9). To ensure prevention of new infections while supporting the love and intimacy life of PLHIV, they must be involved in prevention interventions.

While the GIPA is elaborate on the rights of PLHIV to enjoy full life encompassing love and intimacy, it is however inarticulate on participation of PLHIV in the prevention of new infections. Yet, on the prevention - support continuum highlighted in Chapter Four, prevention of new infections remains an important aspect in the HIV response (UNAIDS, 2010). This orientation, therefore, illuminates GIPA's strong bias towards inclusion of PLHIV in structural issues with regards to support of PLHIV. While the structural approach is important in HIV prevention as discussed in Chapter Four, involvement of PLHIV in HIV prevention is most important if the epidemic has to be contained. However, this aspect is not clearly articulated by GIPA. This clearly has major consequences in the conceptualisation and application of social change interventions for HIV prevention envisaged by GIPA some of which are reviewed below.

Social change interventions for HIV prevention
The commitment by the UN to involve PLHIV through the GIPA policy framework has seen PLHIV being involved in the response to HIV/AIDS in many ways and at different levels. GIPA has been incorporated into national and international program and policy responses and has been taken up as a model of best practice in the response to HIV/AIDS (Stephens, 2004). However, involvement of PLHIV in promoting their health and well-being in no

personalised ways particularly in developing countries (Maher, *et al.,* 2007) has heightened interests in diagnostic studies on the scope, implementation and evaluation of GIPA in HIV programming in different countries and regions. This effort has however remained a concern for associations representing PLHIV as GIPA has remained subject of relatively little academic research. There is a paucity of academic literature and theorisation of GIPA. The stay of GIPA outside academic scrutiny has prompted an overreliance by this thesis on commissioned research that is less seized with the theoretical aspects of this otherwise fundamental phenomenon which exudes great but untapped potential to halt the HIV epidemic. Lack of GIPA theorisation is perhaps the reason why its conceptualisation and application has remained ambivalent in many communities that attempt to employ it in responding to HIV/AIDS. It is the objective of this study to conceptualise meaningful involvement of PLHIV in social change communication for HIV prevention. From a culture-centered approach to social change examined in Chapter Two, 'meaningful' here relates to personalised participation that is informed by local contexts and grounded in the moral wisdom and web of the affected community. It is participation that emphasise ownership of subaltern agency and based upon their narratives and configurations of what it is to participate, and how should one participate, or simply what is best for them (see Dutta, 2011).

Christophe Cornu's (2003) multi-country diagnostic on PLHIV's involvement in HIV/AIDS service organisations in Burkina Faso, Ecuador, India and Zambia sponsored by the International HIV/AIDS Alliance in partnership with Horizons provides a panoramic view of GIPA implementation in different countries. The study analysed a total of 17 HIV/AIDS service nongovernmental organisations (NGOs) and community based organisations (CBOs) between 1998 and 2001. Except where PLHIV participated as beneficiaries, their involvement in all countries was found to be an economic relationship whereby PLHIV give their time and skills in exchange of financial, material, intellectual/technical and/or

psychological rewards (Cornu, 2003). In all countries, PLHIV took part in three ways. Majority participated as beneficiaries of services of NGOs and CBOs particularly care and support services; some as service providers or implementers of HIV/AIDS activities such as prevention, care and support, and few as decision-makers in the design and planning of activities and services as well as the overall functioning of the organization and its policies.

Cornu's (2003) study shows that as beneficiaries, PLHIV were targets for care and support programs of the participating NGOs yet prevention programmes were targeted at those people who were deemed at risk of infection such as women, the youth, students, sex workers and barbers and the general population. While participation of PLHIV in service provision is encouraged, some PLHIV have questioned whether it is important to have themselves as service providers where an HIV positive person serves another since what is needed is just somebody who is knowledgeable, committed, and not judgemental (see Cain, *et al.,* 2013; Travers, *et al.,* 2008). This view is not irrelevant to the notion of participation as it amply reflects not only a feeling of 'tokenism' that has been reported to exist among PLHIV with regards to their involvement in the HIV response (APN+, 2004; Manchester, 2004) but also a challenge to the implementation of GIPA.

The continuity of the above perspective is also evident in the diverse interpretations that different organisations in different countries in the above study had about what "PLHIV involvement" really means. This resulted in different types of involvement being observed in the participating organisations' programs in all countries (Cornu, 2003). Almost similar to those presented on Figure 5.1, the observed types are a) access: where PLHIV are only beneficiaries; b) inclusion: where PLHIV are not only beneficiaries but are also involved in the implementation of the activities of an organisation; c) participation: where further to access and inclusion, they are actively involved in the planning and designing of organisational activities even though they do

not have the final decision; and lastly d) greater involvement: where PLHIV take part not only in areas of activity of an NGO but also in making managerial decisions that influence policymaking and strategic planning process (see UNAIDS 1999). The first type is the minimum while the last is the maximum level of participation envisaged by GIPA.

Another study evaluated GIPA in five other countries namely Benin, Brazil, Cambodia, South Africa and Ukraine (Stephens, 2004). The study examined the extent to which PLHIV were involved in the design and planning of the national HIV/AIDS strategic framework (Stephens, 2004). It was found that while all countries had a proper understanding of GIPA and PLHIV participated in the national HIV/AIDS strategic planning process, levels of their involvement varied from country to country with Brazil having been able to achieve consistent involvement in national HIV/AIDS strategy and South Africa placing emphasis on involvement of PLHIV in its HIV/AIDS and STD Strategic Plan (Stephens, 2004). South Africa is one of the countries where the UN piloted GIPA and developed the GIPA Workplace Model. The model saw placement of PLHIV in government departments, key parastatals as well as corporate and NGO workplaces where they set up and review workplace policies and programmes among others (Stephens, 2004; Simon-Meyera and Odallob 2002). While this model is explained later in this chapter, it suffices to note that an evaluation of this model found that PLHIV "can add value to workplace HIV/AIDS programmes in a way that is relevant, effective, efficient, sustainable and ethical (Simon-Meyera and Odallob 2002: 471).

The Asia Pacific Network of People Living with HIV/AIDS (APN+, 2004) decried little progress in the participation of PLHIV in programs providing HIV/AIDS care, support, prevention and education after a decade of its promotion in the Asian Pacific. By 2004, relatively few government and non-government organisations had involved PLHIV at national or local levels. Of those involved, most felt exploited rather than inspired by their roles (see Manchester, 2004).

There was also lack of financial support for PLHIV associations and those that receive funding were frequently driven by donor interests instead of the PLHIV they represent. In Uganda, a country famed for its swift and effective response to HIV/AIDS in Africa, recent studies suggest that funding and support problems noted above still persist (see Mi Kim, *et al.,* 2012).

Another GIPA scoping exercise in the Asian Pacific was conducted by the Australian Agency for International Development (AusAID) in eleven countries namely China, Myanmar, Lao PDR, Indonesia, and Vietnam in Asia; and Fiji, Kiribati, Papua New Guinea, Solomon Islands and Vanuatu in the Pacific (Paxton and Janssen, 2009). The study had four major areas of concern: the establishment or availability of PLHIV networks; involvement of PLHIV in national planning; involvement of PLHIV in service delivery and lastly a mapping of supportive policies and programmes. The study concluded that the GIPA implementation in the Asia-Pacific region ranges from tokenistic to genuine partnership and empowerment. In most of the studied countries PLHIV organisations are well-established although several networks were weak and lacking understanding of their role as PLHIV organisation. In Indonesia there was no national PLHIV network and in China organisations representing PLHIV lacked vision and the ability to strategically plan their activities (Paxton and Janssen, 2009). In planning of the national response, PLHIV were involved to some degree in all countries and some even sat on National HIV/AIDS Councils. However, in China and Lao PDR, and in Papua New Guinea the PLHIV on these councils were not representative of other PLHIV. Even though no countries had a specific GIPA policy and had no consensus on its meaning resulting in difficulties to operationalise it into National HIV/AIDS operational plans and budgets, most had supportive structures. The Myanmar National Operational Plan supported establishment of self-help groups; Lao PDR budgeted for GIPA. Also China, Vietnam and Papua New Guinea had legal frameworks supporting the rights of PLHIV. While important shortfalls were

noted in all areas of GIPA programming, capacity building in terms of financial, technical and organisational support for PLHIV networks was evident in all countries. By 2012, most community based organisations that offer material and medical support to local families affected by HIV/AIDS still had limited organizational and technical capacities and frequently operated in isolation from associations of PLHIV (Mi Kim, *et al.,* 2012). Problems charactering GIPA are thus not only in the lack of involvement of PLHIV but also in the involvement process itself.

Many factors have been offered to explain low levels of involvement prevailing in the global response to HIV/AIDS. These include socio-economic differentials, stigma and discrimination, late diagnosis and disclosure, improving counselling, keeping PLHIV alive, and effective representation (Cain, *et al.,* 2013; APN+, 2004; Manchester, 2004; Paxton, 2002, Stephens, 2004). According to the APN+ (2004) it is always difficult to have a small number of publicly active PLHIV leaders being able to effectively represent the diversity of PLHIV. Many HIV positive people come from diverse backgrounds as to those involved in program management or policy development and some may be young whilst required to participate in environments where age is respected. This clearly makes representation difficult (APN+, 2004). Similarly, due to fear of HIV/AIDS-related stigma and its various consequences, tension exists when individual contemplate to disclose their positive serostatus for the purposes and involvement (Paxton, 2002). This is compounded by one's right to confidentiality and personal considerations regarding how and when to diagnose and disclose (Stephen, 2004). Retaining PLHIV is also another challenge to GIPA. Through GIPA, PLHIV gain skills and self-esteem and start making impact on their communities. However, many have fall sick and die, and a wealth of expertise gets lost (APN+, 2004)

As noted earlier, while literature on participation of PLHIV in response to the HIV epidemic is vast, much focus is on involvement in service provision and

policy development, particularly on scaling up treatment, care and support of PLHIV (Maxwell, Aggleton and Warwick, 2008). Involvement of PLHIV in such areas improves quality and enjoyment of life. What is not addressed (though quite significant in the political economy of HIV transmission) is the participation of PLHIV in enacting agency, as provided for in the Denver Principles, in the HIV prevention. Could this be a result of fear of 'blaming the victim' or because of what Nurit Guttman (1997) laments as the "ethical dilemmas in health campaigns?" But who is the victim in the HIV transmission process?

It is perhaps because of GIPA's above-mentioned flaw that the notion of 'positive prevention - initiatives targeted at PLHIV to "avoid transmitting HIV to others" (Osborne 2006: 9) among other things has been suggested. Positive prevention was suggested against the background that prevention efforts have largely targeted those who are HIV negative ignoring the needs and important role of PLHIV who are "the nexus for future infections" (Osborne, 2006: 9). Positive prevention thus becomes a viable alternative prevention method (see Kelly, *et al.*, 2012; Kennedy, *et al.,* 2010; Crepaz, *et al.*, 2006; Kalichman, 2005; Osborne, 2006).

Positive prevention
Positive prevention is an approach that seeks to proactively address the sexual and health needs of people living with HIV through involving them (Osborne, 2006; Kalichman, 2005). The approach links prevention with care, treatment, support and the individual rights approach to HIV/AIDS to help individuals with HIV to avoid spreading it to others (Coates, *et al.*, 2008,). Positive prevention has been implemented from all the different approaches used in HIV prevention with the negative such as the bio-medical approach (Coates, *et al.*, 2008), behavioural and social change approach (Kelly, *et al.*, 2012, Kennedy, *et al.,* 2010, Crepaz, *et al.*, 2006) as well as the structural approach (Osborne, 2006).

The bio-medical approach to positive prevention consists of activities and policies that ensure increased testing (awareness of one's serostatus) and access to treatment by PLHIV. This has two benefits. The first is that HIV testing enable HIV infected persons to get to know their serostatus after which they seek treatment. The benefits of effective use of ART has been discussed in Chapter Four (see Mayer, *et al.,* 2010; Coates, *et al.*, 2008; Wilson, *et al.,* 2008). The second benefit of testing relates to the belief that once they know their serostatus, individuals infected with HIV reduce risk behaviour and take precautions to protect their partners is (Coates, *et al.*, 2008). Kalichman and Lurie (2010) found that serostatus disclosure has a preventive efficacy of 40%. This benefit is, however, offset by risky behaviours of PLHIV. While it is true that people who are unaware of their seropositive status are very likely to transmit a high proportion of infections, it has been noted early in this chapter that HIV infected individuals who know their seropositive status continue practicing risky behaviour. Indeed awareness of one's seropositive status helps them seek treatment for the benefits highlighted above. However, the contradiction on the preventive efficacy of status awareness among the seropositive calls for nuance conceptualisation against which promotion of HIV testing can be modelled. It is unlikely that GIPA can be helpful here for one obvious reason. In terms of involvement of PLHIV, the bio-medical approach to positive prevention where PLHIV are considered as patients who require treatment care and support is at the lowest level and most undesirable by GIPA. However, it is perhaps from the knowledge of one's seropositive status where ethical responsibility espoused in the Denver Principles becomes meaningful, otherwise it makes no sense when people are not aware of their seropositive status.

For preventive efficacy, the challenge has always been to find conceptually compatible theories in which awareness campaigns can be modelled over and above the bio-medical benefits. Given the propensity of PLHIV to continue

practicing risky sexual behaviours, positive prevention "recognises that changing the behaviour of HIV positive people may be as effective as concentrating on HIV negative people" (Kelly, *et al.*, 2012: 51). Positive prevention has thus been posited from a behavioural-social and structural change approach (Kennedy*, et al.,* 2010, Crepaz, *et al.*, 2006), as discussed in Chapter Four. From this perspective, positive prevention specifically engages PLHIV in social and structural issues that promote prevention behaviour. The approach takes into account the mental health consequences of being HIV positive in environments characterised by stigma, discrimination and lack of support (Kelly, *et al.*, 2008). It thus involves PLHIV in activities for and with PLHIV that focus on their physical and mental health, support as well as preventing further transmission of HIV, and that facilitate their participation in leadership and advocacy (Kennedy, *et al.,* 2010, Osborne, 2006).

Consistent with the ethical responsibility aspect of the Denver Principles, positive prevention promotes programmes that aim to ensure that PLHIV disclose their HIV status to their partners (WHO 2008). For Osborne (2006), positive prevention must be based on the realities and perspectives of PLHIV. These include recognition that PLHIV, as with every individual, have right to a satisfying and enjoyable sexual and reproductive life. This conjures the individual rights approach to HIV prevention. If everyone has a right to a satisfying, enjoyable and reproductive sexual life it means therefore that the uninfected have a right to be involved in decision making to choose to or not to be infected. Based on both research and personal experience, Jo Manchester (2004) laments that PLHIV feel used by some interventions that encourage them to disclose. She argues that certain involvement is tokenistic. However, meaningful involvement must be empowering and should be able to instil hope. It is the objective of this study to find out what PLHIV think and feel about their involvement in HIV prevention, if it indeed empowers or instils hope for HIV prevention.

Although behaviour change interventions for HIV negative people have proved useful in reducing self-reported HIV risk behaviours, the efficacy of interventions for PLHIV has not yet been popularised (Crepaz, *et al.*, 2006). However, the efficaciousness of positive prevention has already been demonstrated both in the developed and developing world. The successful implementation of the SAFE approach in the US by the CDC (Wingwood, 2000) and pleasing results from positive prevention behavioural interventions in developing countries are testament to this (Kenneddy, *et al.*, 2010). A study of 366 women living with HIV conducted from 1997 through December 2000 in Alabama and Georgia to evaluate the efficacy of an intervention to reduce HIV transmission risk behaviours and enhance HIV preventive psychosocial and structural factors among women living with HIV (Wingood and Di Clemente, 2000) found that the women reported fewer episodes of unprotected vaginal intercourse, reported greater HIV knowledge and condom use self-efficacy. This was the first intervention with PLHIV in the US which successfully demonstrated that prevention interventions with HIV positive people should be tailored to their unique needs (Wingood and Di Clemente, 2000).

Successive interventions tailored for the special needs and circumstances of PLHIV to prevent HIV transmission in the US include Seth Kalichman (2001) and Mary Jane Rotheram - Borus (2001). As Christopher M Gordon *et al.,* (2005) contend, all these interventions were mainly social cognitive behavioural skill building interventions modelled on the variants of the social-cognitive and structural theories (Gordon, *et al.,* 2005). While behaviour and structural change interventions modelled around cognitive theories may still have important place in HIV prevention interventions including those with PLHIV, the foregoing discussion suggests that attention to SAFE interventions modelled around moral theories needs to be heightened. As highlighted earlier in this chapter, duty, ethical responsibility and respect of the other are

principles that are enshrined in the policy framework that guides participation of PLHIV in response to the HIV epidemic.

In the South African context, the history of participation of PLHIV in the HIV response cannot be complete without mentioning the contribution made by the TAC, an HIV/AIDS Activist organisation established throughout South Africa that advocates access to treatment, care and support services for PLHIV and also involved in HIV prevention campaigns. Originally a project of South Africa's NAPWA (another Denver Principles descendant), it evolved into what Wright (2013: 1795) described as "a militant trade union for HIV-positive people, and as the most successful of a number of social movements that demanded that the post-apartheid government do more for the poor". As with ACT UP in the US, TAC drew on the expertise and energy of a broader constituency representing PLHIV. According to its website (www.tac.org.za) TAC claims to have become the leading civil society force behind comprehensive health care services for PLHIV in South Africa. Since its formation in 1998, TAC has held the South African government accountable for failing to provide ART to AIDS patients. TAC succeeded in pressuring the government to make antiretroviral drugs available in the South African public sector health system (Wright, 2013). It became famous for its court and out of court battles not only against government's reluctance to roll out treatment for PLHIV but also against high drug costs by pharmaceutical companies. TAC also claims on its website that its success manifests not only in the implementation of country-wide mother-to-child transmission prevention and antiretroviral therapy programmes but also in its world-wide acclaim and numerous international accolades, including a nomination for a Nobel Peace Prize in 2004.

It is ironic that TAC was formed the same year when the SA government had begun consolidating efforts to broaden the response to the epidemic by involving PLHIV as recommended in the country's 1994 HIV/AIDS Plan drawn up by the National HIV/AIDS Coalition of South Africa. The then Deputy

President, Thabo Mbeki, on 8 October 1998, made a public call for all sectors of South African society to form a partnership against HIV/AIDS, an opportunity that was seized by the UN to roll out the GIPA Work Place Model in South Africa alluded to earlier (see Simon-Meyer and Odalo, 2002). The model saw different sectors becoming involved in the partnership against HIV/AIDS by selecting, training and placing PLHIV as field workers in sectorial organisations where they would enrich workplace policies and programs on HIV/AIDS (Simon-Meyer and Odalo, 2002). Eight sectors were selected including electricity supply, transport, mining, NGO, international, religious, government and the media. In their respective organisations, the fieldworkers participated at different levels of involvement already discussed (Simon-Meyer and Odalo, 2002). What was particularly important about this model was its recognition of experiences of PLHIV as a special skill at the workplace.

The recognition of experiences of PLHIV as a special skill has continued to appeal to the HIV/AIDS policies of different sectors across South Africa particularly the NGO sector. One of the organisations of particular interest to this study that sees value and utilises experiences PLHIV in the HIV response is DramAidE through its Health Promoters Project (HPP) that is conducted in several higher education institutions throughout South Africa (DramAiDE, 2014). As with the field workers in the GIPA Work Place Model, DramAidE Health Promoters are young people living openly and positively with HIV who work with peer educators to contribute to the reduction of new HIV infections amongst university students, learners in schools and communities in South Africa (DramAidE, 2014; Botha, 2009). According to its website, DramAidE's Health Promoter's Project is located within the framework of existing peer education programmes to provide a face for HIV and demonstrate that it is possible to live positively with HIV (also see Botha, 2009). As already shown earlier, peer education is one of the areas where PLHIV can be involved alongside advocacy, counselling, public education, program planning and

implementation among others (Medley, *et al.*, 2009; UNAIDS, 1999). As contained in the GIPA principles, peer education is an aspect of peer support which facilitates meaningful involvement of PLHIV as peer counsellors, educators, advocates and leaders. DramAidE's Health Promoters formed part of the AIDS Activists who were interviewed for this study. The nature of their involvement, their feelings and perceptions about their involvement in the HIV response are presented in Part III of this thesis.

For the APN+, peer support involves positive people meeting other people living with the virus - peers. This enables PLHIV to share feelings and information as well as providing mutual support. In peer groups PLHIV can educate each other on issues such as use of antiretroviral medication, treatment regimes, adherence issues, and side effects, sexual relationships as well as having children among others (see Medley, 2009). Due to their experience, PLHIV have become experts on these aspects and they can pass this expertise on to peers in ways that are more appropriate (APN+, 2004). Peer support is significant in that meeting peers enables people to realise that they are not alone and can facilitate acceptance of one's status. This can also encourage disclosure whose significance in HIV prevention has already been highlighted.

This section concludes by noting that while GIPA has enjoyed increasing influence over current programmes responding to HIV, application of participation of PLHIV as a response to HIV has remained much focused on treatment care and support of PLHIV and less on prevention. This is regardless the fact that HIV positive people who are aware of their status continue practicing sexual behaviours that place their sex partners and themselves at risk for HIV and other sexually transmitted infections. Two main policy guidelines on participation of PLHIV: The Denver Principles and GIPA have been examined. Both principles recognise that love, life and intimacy are part of PLHIV's reality and therefore call for support and inclusion of PLHIV in the response to the epidemic. However, in order to strengthen links between

prevention of new HIV transmission and treatment, care and support of PLHIV, the former has an ethical and individual rights exhortation on both HIV positive and negative people and the latter adopts a structural change approach to prevention interventions with PLHIV through an approach called positive prevention.

It has also been shown that HIV status disclosure is not an end in itself. However, PLHIV's disclosure of HIV positive status to persons they intend to be intimate with has been suggested as important in mitigating HIV transmission. However, many factors affect serostatus disclosure. One key motivating factor influencing PLHIV's decisions to disclose their positive HIV status to their sexual partners outlined in policy but also manifest in disclosure studies among PLHIV is 'humanism' which is expressed through one's sense of 'duty' or 'ethical responsibility' within human beings. An attempt was made to conceptualise this aspect and the relevance of the Kantian respect for the other as well as the African normative theory *Ubuntu* became apparent. However, regardless of this possible link between moral philosophy enshrined in the Denver Principles and HIV prevention, there is a paucity of literature examining possible use of moral theories such as Kantian philosophy and *Ubuntu* as a conceptual framework through which HIV prevention interventions with PLHIV can be modelled. It is from this conceptual gap that this study draws impetus.

While a careless appeal to moral philosophy as an approach to HIV prevention has potential to be stigmatising, it also has possible benefits. First and most importantly, there is likelihood that the ethical responsibility that PLHIV are asked to embrace by the Denver Principles can be cultivated and increased in all PLHIV. The importance of this aspect in HIV prevention needs no emphasis. Secondly, this value approach is likely to negate the adverse impact that criminalisation of sexual behaviour has on PLHIV. After all, criminalisation of risky sexual behaviour (wilful transmission) is a reactive approach and

therefore cannot be an effective approach to HIV prevention as punishment is only meted after transmission has occurred.

As indicated earlier (also see Introduction), this study elicits perceptions of PLHIV drawn from DramAidE's Health Promoters project at the University of KwaZulu-Natal as well as other HIV/AIDS Activists in KwaZulu-Natal to find ways in which PLHIV (as a nexus to new infections) can be deliberately and meaningfully involved in preventing the transmission of HIV. PLHIV are an integral stakeholder and what I have surmised as a 'factor' whose consideration is germane to the HIV prevention communication. Based on participants' experiences and perceptions, the study culminates in the generation of model for developing HIV prevention communication interventions that factor in the experiences and perceptions of PLHIV thus facilitating the inclusion of voices that have previously been marginalised.

The methodological outline of the study, the findings and the model mentioned above are presented in the next part of the thesis.

PART III

PARTICIPATION AS CONFIGURED BY SELECTED SOUTH AFRICAN PEOPLE LIVING WITH HIV

Cultural codes, symbols, and values embody the essence of meaning that people bring to the production and acquisition of knowledge.

Collins Airhihenbuwa, Health and Culture, 1995.

CHAPTER SIX

METHODOLOGICAL FRAMEWORK

This study elicits views of people living with HIV (PLHIV) in South Africa on what involvement in the HIV response mean to them, and how they perceive their current participation in HIV prevention. Based on an interpretive understanding of their experiences and perceptions, the study is intent on developing a culture-centered conceptual framework (Airhihenbuwa, 1995; Dutta, 2011) that can be used to understand and mainstream meaningful participation of South African PLHIV in social change communication for HIV prevention. The framework has to account for the life conditions, values and cultural circumstances of people in (South) African societies.

As noted in the previous chapters, the HIV epidemic is not a mere health problem but a social development challenge whose impact is felt across all sectors of society. It has occasioned different forms of basic and applied research not only in health science but across disciplines including social sciences, education, and communication among others. Consistent with the primary objective of research to generate or increase knowledge on a particular aspect (Saunders, Lewis and Thornhill, 2009), HIV research has also attempted to generate knowledge about the epidemic and its various facets such as the clinical, behavioural, social and its political economy as well as on ways to prevent new HIV infections so as to contain the epidemic. As a cultural studies and development communication scholar with research interests in communication for social change and stakeholder engagement, I am interested in people's lived experiences and narratives as to how their social development challenges can best be addressed. Thus views of South African PLHIV on what involvement in the HIV response mean to them will give insight into how PLHIV

can participate meaningfully in social change communication for HIV prevention. In order to reach this understanding, the study is guided by the following key questions:

a) In what ways are South African PLHIV involved in the HIV response?
b) How (if ever) is their participation different from the global framework guiding involvement of PLHIV in HIV prevention?
c) What are their perceptions and feelings about the global framework guiding involvement of PLHIV in terms of HIV prevention?
d) How should PLHIV, participate in social change communication for HIV prevention?

The above questions seek to provide an understanding of the philosophy upon which involvement of South African PLHIV in social change communication for HIV prevention is and should be based. This chapter outlines the research methodology deployed for the execution of this inquiry, beginning by explicating key issues relating to research philosophy in order to enlighten discussion on the concept of methodology. As the study was conducted in a specific context in KwaZulu-Natal South Africa with a small number of particular people, the findings cannot be generalised. However, for credibility and transparency of the findings as well as transferability of the study, this chapter provides a thick description of the systematic process through which the study was executed, explaining the research context and assumptions that were central to the study.

Philosophy of research

Research is defined as a systematic process involving use of particular methods of collecting and analysing data in order to generate knowledge (Saunders, Lewis and Thornhill, 2009). Two aspects underlying this conceptualisation: 'systematic' and 'knowledge' are worth noting as both are core elements underlying the philosophical debate in social science research and the

methodological developments arising from it. The former relates to the process of conducting research (methodology) while the latter relates to the outcome of research (knowledge construction). A methodological framework therefore explains how research was conducted not only in terms of principles, methods and procedures and purpose of a particular social inquiry but also in terms of researcher assumptions (Harding, 1987; Schwandt, 2001). An attractive explanation of what research methodology entails is offered by Norman Denzin and Yvonna Lincoln (2005: 21) who state that "the gendered, multiculturally situated researcher approaches the world with a set of ideas, a framework (theory, ontology) that specifies a set of questions (epistemology) that he or she then examines in specific ways (methodology, analysis)".

Research in different disciplines is either qualitative or quantitative, the two dominant windows into knowledge construction (Cohen, Manion and Morriso, 2000; Creswell 1994; Denzin and Lincoln 2005). Each of these paradigms holds different views about the nature of knowledge. The sections ahead explain the methodology deployed for this study from the perspective of cultural studies scholarship about what there is to know about the world (ontology) and how to know about the world (epistemology).

A detailed explication of these two important aspects of knowledge creation is provided further below. Here it is important to outline, as tabulated below, the methodology employed for this study. As illustrated on Table 6.1 below, the study is a social inquiry whose ontological and epistemological positions employ the qualitative window to knowledge construction not simply because it is attractive to cultural studies but also because it allows for an indepth understanding of experiences of PLHIV, offering a critical social analysis on how involvement of PLHIV in preventing new infections can be improved in a meaningful way.

Table 6.1: The methodological outline for this study (Adapted from Lubombo, 2012:7)

Research Paradigm: Qualitative Research

Attempt to make sense of, or interpret phenomena in terms of the subjective verbal and written expressions of meaning given by research participants

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Ontology: Reality is subjective

Reality is created from the perceptions and consequent actions of the social actors. The study subscribes to the coherence or inter-subjective theory of truth which holds that truth can only be gauged in a consensual rather than an absolute way.

Epistemology: Interpretivism

A phenomenon is not independent from the behaviour of the researcher and participants. Both are co-creators of the knowledge. A social researcher has to explore and understand phenomena through interacting with the participants

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Research Approach: Cultural Studies

Cultural studies places emphasis on experiential data in order to provide an enriched understanding, description and explanation of human experience. It believes that events and understandings are mediated and made real through discourse, interaction and tales from the field.

Data Sources: Qualitative Interviews

Qualitative interviews allow for a natural conversation that proceeds as a professional conversation in which qualitative knowledge is constructed through the interaction of the researcher and the participants

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Analysis: Interpretive

Focus on understanding the interpretations that social actions have for the people being studied.
Integrates hermeneutics, reflexivity, and realist investigation of context

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This study elicited views of PLHIV in order to obtain a deeper understanding of what participation means to them, and what perceptions they have about their

current participation in HIV prevention. This is consistent with the cultural studies perspective that events and understandings are mediated and made real through discourse, interaction and tales from the field. For this reason, the quantitative window to knowledge construction was ontologically and epistemologically untenable to generate what cultural studies, discussed further below, consider to be real or adequate knowledge. This is especially so because researchers who work within the quantitative or positivist paradigm examine meanings in terms of quantity, amount, intensity or frequency (Denzin and Lincoln, 2005). Often privileged as hard or empirical science, the positivist approach seeks knowledge based on probabilities derived from the study of numbers, rates and percentages of cases to communicate meaning (Hesse-Biber and Leavy, 2006; Denzin and Lincoln, 2005). The approach, however, has been used effectively in studies examining for example continued (risky) sexual behaviour among PLHIV and levels of stigma, among other interests. For a catalogue of such studies, see Table 5.1 in Chapter Five.

The qualitative window into knowledge construction

For Denzin and Lincoln (2005), qualitative researchers are committed to the naturalistic perspective and the interpretive understanding of the world or human experiences. Unlike quantitative research that places emphasis on numbers, qualitative research attempts to make sense of or interpret phenomena in terms of the subjective verbal and written expressions of meaning given by research participants as windows into their inner lives. Poststructuralists however, argue that there is no clear window into the inner life of an individual as any gaze is filtered through the biographical positions of both the researcher and participants, that is "the lenses of language, gender, class, race and ethnicity" (Denzin and Lincoln, 2005: 21).

Qualitative research is "a naturalistic, interpretive approach concerned with understanding the meanings which people attach to phenomena within their social worlds" (Snape and Spencer, 2003: 3). There are six key characteristic

features of qualitative research that are worth highlighting. These characteristics, as shown on Panel 6.1 below, contrast sharply with quantitative research whose ontological position is that knowledge exists independent of the research process; with its epistemology also holding that researchers should attempt to distance themselves from the studied phenomena.

Panel 6.1: Common characteristic of qualitative research (Snape and Spencer, 2003: 3)

a) It aims to provide an in-depth and interpreted understanding of the social world of the studied individuals by learning about their social and material circumstances, their experiences, perspectives and histories
b) Participants are relatively few and are purposively selected
c) Data collection methods usually involve close contact between researcher and participants, allow for interaction and allow for emergent issues to be explored
d) Extract detailed data, rich and extensive information
e) Analysis allows for emergent concept and ideas, may produce detailed description and classification, identification and association of patterns as well as development of typologies and explanations
f) Its output tends to focus on the interpretation of social meaning through mapping and re-presenting the social world of research participants.

The significance of the above characteristics is useful in explicating the following two key aspects of the philosophy of research whose discussion is germane to the understanding of the methodological outline of this study.

Ontology

In the hard sciences the dominant 'theory of truth' is correspondence theory which holds that there is a match between observations or readings of the natural world and an independent reality (Snape and Spencer, 2003). However,

studying of the social world, indeed as the present study does, functions within coherence or intersubjective theory of truth which holds that reality can only be gauged in a consensual rather than an absolute way (Snape and Spencer, 2003). The theory therefore privileges conversations with the participants as a way of constructing reality. From a culture-centered approach to social change discussed in Chapter Two, here the researcher becomes a facilitator; the reality and explanations developed are those of the members of the culture in dialogue with the researcher (Dutta, 2011; Airhihenbuwa, 1995)

That there is a match between observations or readings of the natural world and an independent reality is problematic in two ways. Firstly, reality can be elusive and truth can be difficult to determine as researchers' conception of reality and theories of truth differ (Snape and Spencer, 2003; Patton, 2002). The second way in which this is problematic relates to the contestations surrounding different views on what knowledge is. Researchers in different traditions hold different views and assumptions about the way that the world operates. These views are known as ontology (Saunders, Lewis and Thornhil, 2009). A key ontological debate relating to this study concerns whether social reality exists independent of human conceptions and interpretation. This also relates to how reality is constructed.

Two contradicting versions of the nature of reality namely objective reality and the subjective reality have divided disciplines (Hesse-Biber and Leavy, 2006). The former can be described as a positivist approach to knowledge that is commonly associated with quantitative research. It concerns possibility of a real world out there with a singular, predictable and verifiable reality or truth that researchers set out to observe. Subjective reality, on the other hand, portrays that reality is created from the perceptions and consequent actions of the social actors and is believed to be the cornerstone of qualitative research. It honours the inevitability of multiple socially constructed realities based on multiple perspectives or diverse points of view (Hesse-Biber and Leavy, 2006;

Patton, 2002). As a qualitative study functioning within the coherence theory of truth framework, this study ontologically conceives reality as subjective.

Epistemology

Epistemology is understood as a theory of knowledge concerned with what knowledge is and how it is constructed (Cater and Little, 2007; Hesse-Biber and Leavy, 2006; Denzin and Lincoln, 2005). For Stacy M Cater and Miles Little (2007) epistemology becomes visible in knowledge production through its influence in three ways. Firstly, it influences methodology which in turn makes particular demands on the researcher including methods they choose (Cater and Little 2007; Denzin and Lincoln, 2002). Here epistemology may be considered as axiological in that it is normative or prescriptive. It is these values in epistemology that form the basis of validity and sources of justification of the obtained knowledge (Cater and Little, 2007; Denzin and Lincoln, 2002).

Secondly, epistemology influences and manifests itself in the implementation of the selected methods, particularly in the relationship between researcher and participants. Depending on the epistemological position regarding whether or not phenomena is independent from the behaviour of the researcher, participants may be considered either as co-creators of the knowledge; or as passive subjects of the study (Rubin and Rubin, 2005; Cater and Little, 2007; Snape and Spencer, 2003, see also Tomaselli, Dyll-Myklebust and van Grootheest, 2013). The qualitative approach is usually associated with the former.

Lastly, epistemology influences the form, voice and representation in the analysis and writing. Two resultant formats are the active voice usually popular among qualitative researchers particularly in cultural studies where the researcher is heard within the narrative as they are considered part of the research. The other format is a depersonalized narrative where the researcher

is absent from the analysis and narrative (see Dutta, 2011; Cater and Little, 2007).

In addition to the above three ways, epistemology also manifests itself in methods of analysis through two main options; inductive analysis and deductive analysis (Snape and Spencer, 2003). Inductive analysis involves using findings as the genesis for a conclusion whereas deductive analysis uses evidence in support of conclusions. Both ways of analysis are applicable to qualitative research although the former is interpretivist and the latter is positivist (Denzin and Lincoln, 2002).

This study falls within interpretivism which holds that a social researcher has to explore and understand phenomena through interacting with the participants (Rubin and Rubin, 2005; Snape and Spencer, 2003). The epistemological position allowed for interaction with South African PLHIV on the nature and meaning of their participation in the HIV response. In light of principles of the interpretive epistemology, below is an outline of the methodological approach that was deployed for the execution of this study.

Disciplinary and paradigmatic location of study

Regardless of the ambivalent disciplinary status of cultural studies which Stuart Hall (1980) calls 'theoretical noise (because it appropriates theories and methods from other conventional disciplines) the study is ontologically and epistemologically located within the cultural studies interpretive perspective (Denzin and Lincoln, 2005) informed by Paula Saukko's (2005) integrative analytic framework that interlaces different epistemological positions within the qualitative research paradigm.

Located in the qualitative research paradigm, this is an interpretive study that utilised a cultural studies perspective to find out from PLHIV in South Africa what involvement in the HIV response means to them, and their perceptions on

their current participation in the HIV response. The purpose was to make an interpretation of these people's experiences in responding to the HIV epidemic so as to explore ways in which South African PLHIV can meaningfully participate in social change communication for HIV prevention. In order to achieve this task, the inquiry was guided by four key research questions outlined earlier in this chapter. The questions reflect a commitment to the naturalistic perspective and the interpretive understanding of a phenomenon: the PLHIV's experiences of their involvement in response to the HIV epidemic. The aim is to make sense of this experience in terms of the subjective verbal expressions of meaning given by (South) African PLHIV. This methodology is consistent with the culture-centered conceptual approach (Airhihenbuwa, 1995; Dutta, 2011) explained in Chapter Two.

Participation of PLHIV in the global HIV response, as reviewed in the literature section of this thesis, has Western origins linked to the Denver Principles of 1983 in Colorado, and subsequently the United Nations sponsored Greater involvement of people living with HIV/AIDS (GIPA) Principles of 1994. As discussed early in this chapter, providing an in-depth and interpreted understanding of the social world of the studied individuals by learning about their experiences, perspectives and histories is a key characteristic of the qualitative approach. It is also consistent with the objectives of this study. As already discussed, experiential data or people's lived experiences, is only possible through a qualitative window to knowledge.

According to Ziauddin Sardar and Borin Van Loon (1997) cultural studies consists of the five distinguishable characteristics, one of which is not only relevant to the study of the HIV epidemic but also underpins the objective and the conceptual framework (culture-centered approach to social change) of this study. This characteristic relates to its attempt:

To expose and reconcile the division of knowledge, to overcome the split between tacit (that is intuitive knowledge based on local cultures) and objective (so called universal) forms of knowledge. It assumes a common identity and common interest between the knower and the known, between the observer and what is being observed (Sardar and Van Loon, 1997: 9).

Deploying a cultural studies perspective for this study was therefore appropriate to understand, from the perspective of the local people, what participation means in responding to the (South) African HIV epidemic. This perspective was useful for this study that took seriously an important but often ignored aspect, participation of PLHIV in HIV prevention, trying to understand it from the point of view of South African PLHIV against the backdrop of their dislocation in the margins of society that was created by the Thabo Mbeki administration discussed in Chapter Three.

As with the interpretive approach and its epistemologies in their various forms, what cultural studies perspectives also have in common is the emphasis on experiential data; the focus being to provide an enriched understanding, description and explanation of a human experience. In order to achieve this, qualitative researchers collect intense, full and saturated descriptions of the experience under investigation (Polkinghorne, 2005; Patton, 2002). The methodological implication for this theory of knowledge is that in order to gather such data a social researcher has to interact with people "who have directly experienced the phenomenon of interest" (Patton, 2002: 104).

In order to understand (a) the perspective of South African people living with HIV regarding what participation in the HIV response means, (b) the nature of their current participation, and (c) interpret the meaning of their experiences in ways that can facilitate meaningful participation of PLHI in social change communication for HIV prevention, interviews were conducted with selected South African AIDS Activists, that is men and women who live openly with HIV

and are involved in the HIV response. The selected Activists are experienced and therefore knowledgeable about the topic under investigation. The assumption was that such people were best suited to yield information required to achieve the above objectives.

Selection of participants

Donald Polkinghorne (2005: 139) points out that that participants and documents for a qualitative study are selected to provide "substantial contributions to filling out the structure and character of the experience under investigation". Such contributions can only be drawn from fertile exemplars of the phenomena under investigation (Polkinghorne, 2005, Rubin and Rubin, 2005). The phenomenon under investigation is participation of PLHIV in HIV prevention. As such, exemplars could only be PLHIV. They have experience with HIV and are therefore knowledgeable about it. Their varied perspectives enhance credibility to the study (Rubin and Rubin, 2005).

Two categories of participants were utilised, one comprising of Drama in AIDS Education (DramAidE) Health Promoters (HPs) selected from a DramAidE's health promotion project which involves PLHIV in the HIV response. The other comprised of AIDS Activists who are variously involved in the HIV response in their individual capacities. DramAidE was introduced in the last chapter. All participants were drawn from Durban, KwaZulu-Natal. Although the initial plan for the second category of participants was to include AIDS Activists from different AIDS associations across South Africa, inadequate funding for the research prompted a revision of the original sample upon which this study protocol was based. However, this did not compromise the credibility of this study as a variety of experienced and knowledgeable Activists were found.

Credibility was also not compromised because after all the focus of qualitative research is not to study participants in order to make any generalisations about a larger population or place from which participants are selected but to

obtain a deeper understanding of their experiences and perspectives about a phenomenon under investigation (see Panel 6.1; Rubin and Rubin, 2005). The concern for this study is not the number of participants but whether the selected participants are able to provide sufficient, rich and extensive information that can substantially provide insight into their experience and configuration of participation in response to the HIV epidemic. As already noted, participants in qualitative research are relatively few and are purposively selected, with data collection methods involving close contact between researcher and participants (Rubin and Rubin, 2005; Snape and Spencer, 2003).

Over and above experience and knowledge, consideration in this study was given to participants availability, willingness and ability to "reflectively discern aspects of their own experience and to effectively communicate what they discern through [a mutually intelligible] language" (Polkinghorne, 2005: 138). For the above reasons, a total of thirteen (13) purposively selected adult participants consisting of four (4) DramAidE Health Promoters (HPs) and nine (9) AIDS Activists participated in this study. All the participants are located in Durban. Two HPs are based at the Durban University of Technology (DUT) and the other two at the University of KwaZulu-Natal (UKZN). One HP is a full time DUT employee and the other three work for DramAidE. One is placed at the DUT, one at UKZN Howard College campus and the other one at UKZN Pietermaritzburg campus

As a Shona speaking person from Zimbabwe who is not conversant in the local IsiZulu language, the inclusion criteria used to satisfy the above considerations was to choose participants who - further to being an HIV positive adult involved in the HIV response - are expressive in English. However, during the interviews, I learnt that communicating one's experience is not only a language issue as one of the English speaking Activists had partial access to her thoughts and lacked the discourse to express them. She was willing to talk but

she just could not express her thoughts regardless of repeated probing. The same happened with one black Activist who was also taciturn irrespective of the probes. Compared to other interviews, information generated from these two interviews lacked the depth and breadth required for the production of worthwhile qualitative findings. Interviews with these two participants confirmed the poststructuralist argument noted earlier that there is no clear window into the inner life of an individual as any gaze is filtered through some lenses such as that of language (Denzin and Lincoln, 2005). Integrating different methods of analysis - as will be discussed further below - was an intelligible way of ensuring credibility of the findings in light of this limitation. Thoroughness with other Activists in investigating all the options which the above Activists had difficulties in articulating also assisted in closing the above gap and ensuring credibility of the findings. Disparate views on all aspects were gathered through follow up questions when any evidence was missing

As the goal of qualitative research which is to enrich the understanding of a phenomenon under investigation from the perspective of the participants; in this study Activists were purposively selected (see Polkinghorne, 2005). In deciding on participant selection criteria for the study, consideration was given to various factors mentioned above. Purposive selection was therefore not only found attractive but it allowed for selection of participants with relevant information needed for achieving the goals of this study. The HP project was chosen because it involves people who live openly with HIV.

Gaining entry to the DramAidE Health Promoters was only possible through gatekeepers. These included DramAidE management who run the HP project. Gatekeepers are those persons through whom entry to participants is gained or those who volunteer assistance as key actors or key insiders (Greig, *et al.*, 2007). DramAidE management gave permission to study the HP project and facilitated entry to participants by assigning me to a focal person who initiated my contact with the participants. For the other Activists who were not part of

the DramAidE Health Promoters' project, they were reached through two (2) female AIDS Activist whose initial contact was established through what Shanade Barnabas (forthcoming) calls 'providential stumbling'. Initial contact with the first Activist, a black female Activist (referred hereinafter as *BFA* 1) was made at an HIV/AIDS Candle Lighting ceremony where she was a guest speaker. She gave an inspirational talk about her life as a person living with HIV. After the ceremony, she was approached and a request was made if she could be part of this study, a request which she accepted without hesitation. She expressed interest to share her experiences of living with HIV, and to link me with other PLHIV.

Contact with the second participant, a coloured female Activist, university lecturer and author (referred hereinafter as *CFA*), was made through her student who was familiar with this study, and being my friend, and introduced me to her. As with *BFA*1, she also recommended other Activists whom she knew would be best for the study. Eventually, all other participants were recruited through these two initial contacts. The process of asking one participant to recommend relevant others for participating in a study as described above is known in qualitative research as snowballing (Polkinghorne, 2005). This strategy is used to locate and recruit participants who purposively fulfil the data needs of a study. There are different snowballing strategies that can be deployed depending on the aim of the research. These include maximum variation, homogeneous sampling, typical sampling, deviant sampling, convenience sampling among others (Polkinghorne, 2005).

For the first two participants named above, their selection was convenient as they just happened to be available. Convenience selection is the use of people who happen to be available to the researcher as participants (Polkinghorne, 2005). No conscious decision was made to select participants from different racial groupings, but it was providential that they were stumbled upon. Since HIV prevalent rates are reported to be different among racial groups in South

Africa (see Chapter One), a racial mixture allowed for narratives on participation in the HIV response from different perspectives. It is on this basis that maximum variation selection strategy was later adopted to enrich the information. This strategy involves selection of participants with divergent forms of experience (Polkinghorne, 2005). Through *BFA1* and *CFA*, a total of 13 participants of different gender, race and sexuality were eventually selected. Of these eight (8) were female and five (5) were male; six (6) were black; four (4) coloured and three (3) white. Only three (3) identified themselves as gay.

Although Indian participants who form a significant part of the Durban population were not found, this did not detract from achieving the objective of the study which aimed not at statistical representation but wanted an in-depth account of the thoughts and perceptions of those PLHIV who participated regarding their involvement in the HIV response. Delarise Mulqueeny and Madhu Kasiram (2013) also failed to secure Indian participants in their study on dating and sexual challenges faced by PLHIV in KwaZulu-Natal. However, the obtained variations produced rich accounts that allowed for an understanding of what all participants may suffer in common but often approach in a different way. Essential aspects of what participation means across the participants of different race, gender and sexuality, and also some aspects where the meaning differed were noticed. Moving beyond a single view produced a varied and rich understanding of PLHIV's thoughts and perceptions about their participation in the HIV response.

Data collection methods

Gathering information from the above participants was a process that involved careful consideration of ways through which required information could be generated. There are different ways through which qualitative information can be generated. Polkinghorne (2005) points out three main methods for generating useful qualitative information namely interviews, observation and document study. Information for this study was collected using in-depth

qualitative interviews (Hesse-Biber and Leavy, 2006; Rubin and Rubin, 2005; Kvale, 1996). The section below describes the interview format, process and reasons for choosing the method.

In-depth Interview*s*

Also known as qualitative interviews (Hesse-Biber and Leavy, 2006; Rubin and Rubin, 2005; Kvale, 1996), in-depth interviews seek qualitative knowledge or what Polkinghorne (2005: 138) calls 'languaged data'. In whatever format it may take - face to face, telephone or various forms of electronic interviews (Saunders, Lewis and Thornhill, 2009) - the interview proceeds as a professional conversation in which knowledge is constructed through the interaction of the researcher and the participants (Rubin and Rubin, 2005; Kvale, 1996). From a culture-centered approach to social change within which this study is framed, by talking to the marginalised participant, the researcher finds an outlet for the voices from below within the dialogue between the researcher and the subaltern speaker (Dutta, 2011). This allows for a deep understanding of a phenomenon under investigation from the perspective of the affected people whose voices had been erased from discursive spaces where their problems are discussed and solutions to these problems are decided.

While the researcher usually brings a schedule of questions or aspects they want participants to describe, the questions are flexible so much so that the conversation becomes a give-and-take dialectic in which the interviewer "follows threads opened by the interviewee and guides the conversation towards producing a full account of the experience under investigation" (Polkinghorne, 2005: 142). The researcher has an opportunity to probe and ask follow-up questions which may not be appearing on the original schedule. Thus compared to other information collecting instruments such as questionnaires that consist of structured questions; interviews are normally flexible, iterative and continuous such that they provide both the researcher and the participant

with an opportunity to enjoy some flexibility and freedom (O'Leary 2004; Robson 2000; Patton 2002).

Although the content, sequence, and wording of the questions (formulated around the research objective) are usually in the hands of the interviewer (Cohen, Manion and Morrison 2000; Leedy and Ormrod 2005; Robson 2000), for this study a dry run of the interview was conducted with one of the participants in order to revise the interview schedule before commencement of recorded interviews with other participants. Participants had to be involved in revising the questions primarily because HIV/AIDS is a sensitive subject whose discourse intractably regulates what to and what not to be said especially when talking to or about PLHIV. It was therefore necessary, with assistance from a knowledgeable participant, to structure the interview questions in a way that was ethical and acceptable within the discourse and, as Mulqueeny and Kasiram (2013) also warn, an interview schedule was needed that was not going to cause painful issues to surface among the participants. Not harming participants is an ethical consideration that the study consciously and consistently attempted to avoid. *CFA*, the participant who participated in the dry run interview is an AIDS Activist who has researched and published academic and personal work on HIV. The dry run with *CFA* was quite fruitful to avoid harming participants as some adjustments were made to the interview schedule (see Appendix A).

It was also during the dry run that a decision was made to include Activists from the main racial categories represented in South Africa. Indeed *CFA* linked me to a white female Activist (WFA 1) as well as coloured male Activists who participated in the study. The formula for participants names used in this thesis (colour, gender, race and number formula: for example *HP1*) was also decided during the dry run. Be that as it may, due to the flexible character of qualitative interviews, the schedule remained fluid. Eventually, interview

questions varied as they were adjusted based on the individual being interviewed.

Choosing interviews as the means of collecting information from participants was inescapable as all methodological choices are epistemological manifestations informed by the researcher's position on how knowledge is constructed (Cater and Little, 2007; Willig, 2001). As a construction site of knowledge, the interview has become the most widely used approach to generate qualitative information (Polkinghorne, 2005). Interviews are thus epistemologically related to five characteristics of the postmodern cultural studies philosophy that conceives knowledge as conversation, as narrative, as language, as context, and as interrelational between interviewer and the interviewee (see Kvale 1996). This philosophy thus accepts the qualitative interview as the basic mode of knowing as it aims to produce - through conversation between interviewer and interviewee - a detailed narrative account of languaged data that - although developing in a general area of interest of the researcher - pictures the life-world of the interviewee in its natural context (Leedy and Ormrod 2005; Polkinghorne, 2005; Kvale, 1996).

The Interview *process*

Interviewing for this study involved collecting information relating to how PLHIV configure their involvement in the HIV response. A total of thirteen (13) recorded in-depth individual interviews lasting between forty-five (45) and seventy-five (75) minutes were conducted with participants at pre-arranged venues preferred by the participants. Six (6) were conducted at the participant's work places, four (4) at their homes and three (3) in a parked motor vehicle in instances where participants were met at public places where, due to noise and presence of many other people, it was difficult for the interview to proceed. As per the normal practice in qualitative interviewing (Polkinghorne, 2005), and with consent of participants, all the interview sessions were audio recorded. Recording of the interviews ensured

transparency of the information which adds to the credibility of this study. Long interviews allowed for clarifying information and contradictions to enhance believability of the findings and overall credibility of the study (see Rubin and Rubin, 2005).

As the experience under investigation was personal and sensitive, introduction to participants by gatekeepers or trusted friends was not enough. A relationship with participants was cultivated so as to create a fertile ground for a natural conversation. Establishing relationships allowed for generation of worthwhile findings from the interview sessions, believable information of sufficient quality which for Polkinghorne (2005) can be produced if researchers attend to establishing a trusting open relationship with participants. Indeed Herbert Rubin and Irene Rubin (2005) acknowledge that central to qualitative interviewing is the understanding that the interviewer and the interviewee as co-creators of knowledge are in a relationship in which there is mutual influence. Here, knowing participants well and they knowing the researcher well, there is tendency to be reasonably truthful and to tell the whole story (Rubin and Rubin, 2005). This ensures believability of the findings.

Another useful method to generate believable and worthwhile findings was to engage with participants in more than a one-shot interview session. For Irving Seidman (2012), one-shot interviews are not sufficient to produce rich descriptions of experience. He suggests that a sequence of three (3) interviews with one participant is more likely to produce sufficient data. Here the first interview is focused on getting acquainted, developing rapport, and laying out the area the researcher would like the interview to explore. The second shot is where the experience is explored in depth after which recorded sessions will be transcribed before the last shot focused on follow up questions to fill in and clarify the account.

Only the first and second interviews of the above typology occurred in this study. After being introduced to the participant, participants were called or emailed requesting for an initial meeting. All the emails were accompanied by an interview schedule and a detailed consent form that included an explanation of the study, its purpose, risks and benefits; what the participant were expected to do, what their rights were, issues of confidentiality among other ethical issues. Even though participants were reached through gatekeepers, individual informed consent was sought and secured from all those who participated in the interviews. For some participants contacted by phone, the interview schedule and consent form were issued during the initial meeting where acquaintance was established. This process enabled all the participants to study the interview schedule well before the commencement of the long interview session. Times between the first contact meeting and the long interview varied. For most participants, several meetings were held and rapport was established before the interview started. Informed consent was signed by participant on the day of the interview moments before the interview started.

Rubin and Rubin (2005) warn that because qualitative interviewing is based on mutual and personal relationship mentioned earlier, where the researcher receives the participant's time, thoughtfulness and openness, the researcher is also bound by norms of reciprocity and ideally the interview process must leave the interviewee better off. The researcher must ensure that the interview process is pleasant and fun. The relationship established with the AIDS Activists in this study was reflected not only in the free and flexible conversation that ensued but also in the way they became more and more interested in the study after the interviews. While some voluntarily recruited participants on my behalf - more than required - enquiring if more interviews were required - others sent relevant literature and website links that this study has also relied upon. Perhaps their interest was out of the fact that the social

significance of the study is to attempt to overcome the problem that they are also seized with by making it visible to the public, interventionist or policy makers (see Rubin and Rubin, 2005).

Ethics require kindness and gentleness (Rubin and Rubin, 2005). At a personal level, two Activists called when they were bereaved. I shared their grief and reciprocated by offering some assistance. Others often call to enquire on the progress of my work. It is important to note here that the dialogic process with these participants did not compromise my ethical obligations such as the obligation to report the interviews correctly, and the commitment to not harm the participants. Our conversations did not lead to any degree of therapeutic interaction of which I am not qualified to perform. If anything, the relationships provided the solid and deep understanding of their perceptions about participation and how they were involved in the HIV response.

After information was generated through the above described process, the next step was to transcribe the interview recordings. Transcribing is a process of structuring the oral interview conversations into a written format that is amenable for closer analysis (Kvale, 1996). Transcribing is argued to be the first stage of analysis where researchers can have an overview of the data by immersing themselves in it. In order to immerse myself in and have an overview of the data, I did the transcribing myself so as to remember the interviews and make extensive analysis of them. To ensure accuracy and transparency of the findings, interview recordings were played back for during the transcribing process. While verbatim transcriptions are considered most loyal and objective (Kvale, 1996), some statements in the transcripts for this study were rephrased and condensed in order to present participants views in a correct written and more readable form. Also, my interest was not in sociolinguistic analysis that is interested in verbatim transcriptions including intonation, repetitions and even pauses (Kvale, 1996) but the interest was to understand what PLHIV configure their participation as well as to

understand/theorise these configurations. However, transcriptions for this study are not edited versions but are as close as possible to audio recordings. Only in few instances was rephrasing required. They are not complete verbatim transcriptions in as much as intonation, repetition, and pauses among other conversational aspects are concerned. These were left out as they were not going to yield important material for interpretation for this study.

Dozens of pages of interview transcripts were generated. These transcripts were viewed as a representation of PLHIV's experiences. Denzin and Lincoln (2005:21) argue that participants are seldom able to give full explanation of their actions or intentions but all they can offer are accounts and reasons of what they have done. In an attempt to secure an in-depth understanding of these accounts, the transcripts were analysed through a mosaic of lenses described below. To ensure credibility and transparency, direct quotes from the interviews are presented in this thesis to support conclusions derived from the analysis.

Methods of analysis

As with the methods of data collection discussed above; the analytic framework deployed for this study is influenced by the culture-centered approach to social change. As with the CCA, the study views truth in interactive terms as happening in the dialogic space between a demographically situated researcher and demographically situated participants. As such, the study takes local realities seriously, so much so, that the findings were obtained through dialogue with PLHIV. The aim was to capture PLHIV's perceptions about their participation in HIV prevention in the context of their life conditions, values and cultural circumstances.

While the current framework guiding participation of PLHIV in the HIV response has its own historical context, the way PLHIV participate and perceive participation cannot be divorced from their life conditions, values and cultural

circumstances (see Dutta, 2011). It follows, therefore, that findings of this inquiry are complex, and require a combination of multiple analytic perspectives to comprehend. Saukko (2005) offers such a framework. Her integrated analytic approach combining three methodological programmes used in cultural studies is employed as an analytic framework to secure a deeper understanding of what meanings PLHIV give to their participation. The approach (illustrated in Table 6.1) interlaces three realities arising from dialogue between researcher and participants; lived experiences of the participants; as well as the historical context in which these experiences are located. To fully understand these realities, the findings of this study are, therefore, analysed from (a) a hermeneutic/dialogic focus on participants' lived realities, (b) a (post)structuralist/reflexive critical analysis of discourses that mediate both the participants' experiences and my assumptions of reality; and also from (c) a contextual/realist investigation of historical, social and political structures of power.

Table 6.2: The three methodological programs in cultural studies (Saukko, 2005: 344)

	Contextual Validity	*Dialogic Validity*	*Self-Reflexive Validity*
Contextual dimension	**Social reality**	Local realities in social context	Research shapes 'real' social processes
Dialogic dimension	Local repercussions of social processes	**Local realities**	Local awareness of social shaping of reality
Self-reflexive dimension	Research shapes social processes or reality	Local realities are socially shaped	**Social shaping of reality**

In order to appreciate the lived realities of participants as expressed through dialogue or the interview conversations, a hermeneutical interpretation was used (Saukko, 2005; Kvale, 1996). While a pure dialogic sense of hermeneutics in cultural studies entails involvement of research participants in the project of capturing of constructing their reality as co-workers involved in designing, executing and reporting on the study (Saukko, 2003; Denzin, 1997), it was applied in this study to analyse the experiences of PLHIV as captured in the dialogic interactions.

As the participants and I are biographically positioned social actors, the study views the dialogue as influenced by the way social discourses or our cultural values shape or mediate how people should relate to each other as human beings. In order to appreciate this, a poststructuralist view of truth is used. This entails a self-reflexive or critical reflection on how social discourses shape or mediate how we experience ourselves and our environment (Saukko, 2005; Willig, 2001). This approach allows for a critical engagement with the politics embedded in the discourses through which reality is construct and perceived; in this case what participation in HIV prevention means or should mean for the participants. The participation of PLHIV is reflected against other cultural and political frames of reference that lie in participatory communication for social change particularly with regards to the rules of community engagement (see Lubombo, 2011).

The other focus in this analysis according to the above integrative framework (Saukko, 2005) is the contextual and realist notion of truth which is concerned with an analysis of the historical and social reality. The interest of this study here is to examine how the history or context in which the policy framework guiding participation of PLHIV (see Chapter Five) resembles or differs from the local contexts of the participants. Assessing contextual developments is a key characteristic of cultural studies whose aim is to expose and reconcile the division of knowledge, to overcome the split between tacit (that is intuitive

knowledge based on local cultures) and objective (so called universal) forms of knowledge (Sardar and Van Loon, 1997). Contextual realities are also at the core of the culture-centered approach to social change which provides a conceptual lens to this study.

The above analytic approach presents a mosaic of realities at whose intersection a comprehensive and critical understanding of phenomena should occur (Saukko, 2005). Exploring issues in a broader way enriches a systematic analysis that paves way for an inclusive and multidimensional response (Saukko, 2005). Integrating the dialogic focus, the context and self-reflexivity is consistent not only with cultural studies preoccupation with "exploring the nexuses between the local and the global, the cultural and the real, and the personal and the political" (Sardar and Van Loon, 1997) but is also useful in providing an improved insight into the views of PLHIV in South Africa about their participation in HIV prevention in the context of both the GIPA framework of participation (which is global) and the social reality of the South African epidemic. The integrated analytical framework is therefore deployed as a strategy to secure an in-depth understanding by adding rigour, breadth; richness and depth to the analysis presented in the chapters that follow.

CHAPTER SEVEN

DISCONNECT BETWEEN GLOBAL THEORY AND LOCAL PRACTICE

SOUTH AFRICAN PLHIV'S PARTICIPATION IN SOCIAL CHANGE COMMUNICATION FOR HIV PREVENTION

Framed within a culture-centered approach (Airhihenbuwa, 1995, 2004; Dutta, 2008; 2011) which takes local realities seriously in interpreting meanings people attach to phenomena, the purpose of this study is to (a) explore how South African people living with HIV (PLHIV) participate in social change communication for HIV prevention; (b) examine what participation means to South African PLHIV who are involved in the HIV response and (c) understand how participants feel about the normative precepts of participation in HIV prevention. The overall aim is to develop a conceptual framework that can be used to mainstream meaningful participation of South African PLHIV in social change communication for HIV prevention in ways that account for their local realities and cultural circumstances.

Perhaps as a prelude to the findings below, it is important to remind the reader that participation of PLHIV in the global response to the HIV epidemic is guided by the Greater involvement of people living with HIV/AIDS (GIPA), a policy framework for collective action of PLHIV in responding to the HIV epidemic. In order to ensure involvement of PLHIV, the Joint United Nations Programme on HIV/AIDS (UNAIDS) developed a model (presented in Chapter Five) that explains how GIPA could be universally operationalised. Through its best practice collection (UNAIDS, 1999), UNAIDS identifies a variety of ways and roles that PLHIV can play in the HIV response at a project or an organisational level.

The GIPA model arguably falls within the same taxonomy of participation such as Sherry Arnstein (1969), Norman Uphoff (1985) and Jules Pretty's (1995) typologies of participation that view participation as inclusion of people at different levels of development projects. The model thus presents GIPA as a hierarchy of involvement with strands ranging from low to high where in this order PLHIV can participate as target audiences – contributors – speakers – implementers or experts – decision makers.

Participation as target audience is considered the lowest form of participation while decision making, where PLHIV are able to influence and ultimately direct policy, is considered the highest and desired level of participation. The limitation of such a model is that it excludes what should be the important part of GIPA: the efforts of individuals at a personal level. Individual contribution to social mobilisation and participation in HIV prevention forms a significant portion of the worldwide response to the HIV epidemic. Indeed as scholars have suggested, motivation or self-mobilisation of those who adopt and practice participatory approaches is an important factor in shaping social change interventions (see Hart, 1992; Pretty, 1995; Cornwall, 2008).

It is perhaps pertinent to reiterate that social change communication for HIV prevention should ideally be a "process of sharing decisions that affect one's life and the life of the community in which one lives" (Hart, 1992:5). For Roger Hart (1992:5), the principle behind participation is motivation as "involvement fosters motivation, which fosters competence, which in turn fosters motivation for [social mobilisation]". This is the nature of social change espoused by the culture-centered approach which holds that the change process is more likely to be sustainable when the affected people are involved in initiating and promoting it (Dutta, 2011).

The findings presented in this and the following chapters provide a window to understanding what South African PLHIV consider as participation, and what

motivates their participation. An interpretive analysis of these findings seeks to identify contexts and values that must be placed at the core of effective intervention programs to mainstream their meaningful participation in social change communication for HIV prevention. In this chapter, the nature of participation as configured by the interviewed Activists is described. The nature of their involvement provides a perspective into what participation means to them.

Particular focus in this chapter is paid to the gaps that exist between the global framework guiding participation of PLHIV and the configuration of same by the interviewed Activists. Premised on the ontological position that who we are is a function of the historical circumstances and community in which we find ourselves (Airhihenbuwa, 2007), the chapter employs a hermeneutical analysis (see Chapter Six) to obtain at a holistic interpretive understanding of PLHIV's participation in relation to the normative precepts of involvement as well as the social and cultural contexts or values that nurture their participation.

The nature of participation described by participants is categorised in three different ways namely (a) participation as an economic relationship with AIDS Service Organisations (ASOs), (b) participation as a service to humanity, and (c) participation as being visible (serostatus disclosure). Although the nature of participation configured by participants conjures elements of GIPA, it challenges some of its key precepts. This not only begs questioning the presumed global relevance of the conventional framework for the greater involvement of PLHIV but also suggests that there are some unique values or motivations that nurture participation as configured by participants. Thus corresponding (*Ubuntu*) values are identified, and ways in which these values can be applied to mainstream meaningful participation of PLHIV in HIV prevention is discussed in Chapter Nine.

Participation as an economic relationship with AIDS Service Organisations

While the individual AIDS Activists and DramAidE Health Promoters (HPs) who form part of this study are all from KwaZulu-Natal, their programmes are not limited to their locations as they often visit different parts of the country. Some even have an online presence as well as other promotional means. An example of such is one white female Activist (*WFA1* Interview: October 21, 2013) and coloured female Activist (*CFA* Interview: October 8, 2013) who, apart from public speaking, training, and community outreach in and outside KwaZulu-Natal, have an online presence. The former runs a website *Cindy Pivacic and my journey* and the latter has published a book about her experience with HIV and also conducts 'junk email' campaigns by which she forwards emails to different people educating them about HIV/AIDS. The book *My HIV journey as a woman of colour in South Africa* (Mulqueeny, 2013) was published soon after our interview. In the book, the author shares her experiences from the day she was diagnosed and chronicles how she has managed to live with the virus. She also shares her thoughts about many issues around HIV. Most interestingly is her emphasis on 'responsibility' and the quality of 'being human' which she thinks everyone, including PLHIV should possess if HIV has to be contained.

Participation of DramAidE Health Promoters (*HP1*, *HP2*, *HP3* and *HP4*) is different from that of other AIDS Activists in that the former are employed to participate. For its HP programme, DramAidE employs HIV positive young people who are open about their HIV status to raise awareness about HIV prevention, stigma-reduction, HIV testing and positive living so as to limit the progression of the HIV epidemic. Functioning differently at respective institutions where they are placed, HPs personalise the epidemic by being open about their status (see DramAidE, 2014; Botha, 2009; Myers, 2012).

As they are employed to participate, it can be argued that HPs' involvement is primarily based an economic relationship with their employer DramAidE - an

ASO which benefits from HPs' time and skills in exchange with financial and material gains for the HPs. While this, as shall become evident below, is not solely so; the differences in the nature of participation between HPs and other Activists who do not consider their participation as employment is significant in demonstrating the way meaningful participation is configured by the participants.

Indeed HPs shared that their involvement is a paid job for which they applied. The minimum requirement for the job, as shared by HPs is a seropositive person who is willing to disclose their serostatus. "It's a job that I applied. They stated in the advertisement that they wanted people who are disclosing openly about their status. So I said this is my work, and then you can educate the students and can motivate and teach" *(HP4* Interview: November 7, 2013*)*. The same was also reiterated by *HP3* who stated that "the job was advertised and then I applied. They wanted specifically someone living with HIV" *(HP3* Interview: November 12, 2013*)*.

One of the suggested ways of strengthening GIPA is to pay a living wage to PLHIV who are involved in the HIV response. Incentivising PLHIV is widely recognised as one way of empowering PLHIV and to ensure their participation in the HIV response (Cornu, 2006; 2003; Gooey, 2006). Commenting on the relationships between ASOs and PLHIV under their employ, non-African PLHIV respondents working in Eastern and Central Africa reviled lack of incentives for volunteer PLHIV whose expertise in ASOs need to be recognized and compensated (Gooey, 2006).

The economic nature of PLHIV's participation is an underlying assumption encoded in GIPA that places emphasis on improving the welfare of PLHIV to enable them to meaningfully participate in responding to the epidemic (UNAIDS, 1999). While HPs referred to their involvement as a job and are indeed being remunerated for their participation, they revealed that an

economic focus on their involvement is limiting as their interest is in preventing HIV transmission. For *CFA (*Interview: October 8, 2013*)* while money may make HIV management easier as compared to a poor seropositive individual who cannot afford medical care, transport, food and shelter, "it cannot cure HIV or prevent someone from being infected" (also see Mulqueeny, 2013: 90). However for those PLHIV, who maybe engaged in transactional sex or commercial sex work due to poverty, empowering them through income generating projects can be helpful in halting HIV transmission by improving their life styles (see Fenton, 2004).

Deconstructing the widely held political economic view that associates HIV transmission with poverty (HSRC, 2014; UNAIDS, 2010), *CFA* (Interview: October 8, 2013) questioned why it is that not all poor people are HIV positive, and why some individuals with basic capabilities of life such as food, clothing, and shelter are also infected. The same observation is also made by Chasi's (2012) analysis of the risky sexual behaviour involving two affluent people: a South African Sports Minister Fikile Mbalula and a Johannesburg model who admitted to have engaged in unprotected (extramarital) sex. For Chasi (2012), this case is instructive as it demonstrates that HIV/AIDS not "only needs to be understood in strict terms related to poverty and social capital [as] Mbalula lives a handsomely privileged life as government minister to whom much social capital accrues" (Chasi, 2012: 313). Chasi observes from this case that human beings are not merely subject to social conditions so much so that their behaviours are merely dependent on conducive medical, economic or other social conditions. This analysis makes sense especially considering that some areas with a stable economy such as Botswana and South Africa have the highest cases of HIV as compared to poor countries in the same region. As such, addressing poverty and undernourishment among marginalised communities including PLHIV cannot therefore be enough to contain the epidemic.

Temples' (1959) assertion quoted on the first page of thesis which suggest that behaviour is based upon a logical system of thought and a complete positive philosophy of life becomes instructive in understanding Chasi's (2012) observation above. Indeed, the task that this thesis sets out to achieve is to understand this philosophy which shapes the South African PLHIV's configuration of participation in the HIV response, and suggest this as the viable alternative framework upon which mainstreaming participation of PLHIV in social change communication of HIV prevention must be based. Also in light of the above paradox, the interviewed Activists believe that a logical approach for sustainable HIV prevention is "taking responsibility for one's actions and loving one's self" (*CFA* Interview: October 8, 2013; also see Mulqueeny, 2013: 91). This is a shared sentiment among HPs and other Activists who expressed passion about their job so much so that even if it is not paid, they will continue to work as volunteers: "I think if it was not a paid job, if I was not working and they advertised I would volunteer like at McCord Hospital" (*HP1* Interview: October 18, 2013). As shall become clear in the next chapter, these views by the Activists can best be described as expressive of what *Ubuntu* stands for.

HPs are involved in what Hart (1992: 10) terms 'regime instigated' social change mobilisation as they did not initiate participation themselves. However, their narratives, as shown above, demonstrate that they are well informed about their involvement. They feel real ownership of the HP project as they are personally concerned about the problem of HIV in their communities. HPs have also demonstrated that they even have some critical reflection about the problem and their involvement in addressing it. While *HP1* above does not give reasons why she would volunteer her services, *BFA1* clearly stated what motivates her involvement. She echoed *CFA* quoted earlier expressing that money was not her major concern but human life: "My participation is not driven by money. I go places and talk without any payment. It is not about money, it is about life, saving another person's life. Once a person sees us, they

get inspired by how we manage our lives and feel like doing the same" (*BFA1* Interview: October 12, 2013).

Thus self-mobilisation from intrinsic motivation prompts Activists like *BFA1* to become volunteers in different ASOs. The above demonstrates that regardless of the economic relationship they may have with any ASO, the Activists have a high degree of personal investment, motivation, dedication and commitment to servicing humanity. Notable here is that regard for the other person is not articulated by GIPA whose atomist nature appears to be centered on improving the welfare of individual PLHIV (UNAIDS, 1999; Paris Declaration, 1994). This focus depicts GIPA as an individualistic and inward looking instrument whose adequacy in mainstreaming the kind of participation configured by the Activists can be questionable. The Activists demonstrated PLHIV's possibilities and responsibilities that arguably exceed and are outside the realms of the GIPA scope. It can be argued, therefore, that the nature of participation of PLHIV configured in this study deconstructs the normative precepts of GIPA. Addressed throughout this and the next chapter, this contention forms the basis upon which not only the tittle but the logic of this thesis is formulated.

Lessons learnt from the Activists' personal experiences with the epidemic as well as influences from family and community serve as visible prods for the Activists' desire to transform other people's lives through giving advice on the management of HIV and prevention of new infections. The selfless attitude reflected by the Activists through their "desire to sow a positive seed in another human being's life" (*CFA* Interview: October 8, 2013) by helping society to deal with the epidemic is described by the Activists as acts of humanness and friendship. For *CFA*, "humanness and friendship is all about being with a person" (*CFA* Interview: October 8, 2013). The most important way by which the Activists are involved in social change communication for HIV prevention is through being responsible to the other person, "touching peoples' lives in a positive way; to make a notable difference in the lives of others; to educate and

empower more people about HIV" (*CFA* Interview: October 8, 2013). As shown below, the Activists are not exclusively concerned about their welfare but are also committed to helping other people. As expressed by *CFA* above, participation in this way is an expression of PLHIV's humanity. The concept of being human, though not exclusive, is of great importance in the African worldview (Chabal, 1999).   As discussed in Chapter Two, the African conceptualisation of personhood acknowledges that a person consists not only of the body, spirit, and soul, but should also have humaneness, that is *Ubuntu;* which for Le-Roux (2000) as with *CFA,* above is the most important quality for authentic human existence. African philosophy suggests that a person possessing *Ubuntu* has a spirit of caring for each other's well-being and can harmoniously relate with others (Tutu, 1999). From a culture-centered approach to social change, effective models for social change must take into account people's values as all knowledge is provincial and every theory, regardless of its Global reach, is anchored in culture (Airhihenbuwa, 2007).

Participation as service to humanity

That PLHIV have been crystallised as service receivers who depend on ASOs for treatment care and support is not debatable, (see SafAIDS, n.d; UNAIDS, 2007). What has been, and is still of concern among PLHIV scholarship and associations is to identify strategies to mainstream meaningful participation of PLHIV in ways that not only break this binary, simplistic and false assumption of service givers as seronegative people and service receivers as the seropositive, but also in ways that contribute to halting the HIV epidemic (see Gilliam and Diane, 2009). Indeed the Activists in this study shared that they are actively involved in implementing or facilitating HIV/AIDS programmes aimed at helping society deal with the HIV epidemic. In a manner that may be viewed as deconstructing the dependistas discourse which depicts PLHIV only as service receivers (see SafAIDS, n.d; UNAIDS, 2007), participants' activities depict PLHIV as service providers and not receivers. The Activists reported that

due to their experiences of HIV-related illness, they are now not only aware of factors that make individuals and communities vulnerable to HIV infection but they have also developed strategies for managing the virus for "our purpose in life...is to make a difference in other human beings' lives" (*CFA* Interview: October 8, 2013*)*.

Realising their purpose in life, the Activists feel compelled to share their experiences and new insights about life with others in order to help society deal with the epidemic.

> When I was diagnosed the issue of HIV was very traumatic in our communities and people were not only stigmatised but discriminated. There was physical discrimination in our families. People were not accepted immediately after they were diagnosed with HIV especially when symptoms start to develop. That was a difficult and sad part. When I learnt what HIV is and how to live with HIV, it became my mission that I need to educate and inform other people that HIV is a virus which you can live with and there are possible ways to try and delay AIDS in your body and then live your life as normal. That was the only reason. From my experience of seeing people being discriminated and stigmatised because of HIV, I felt that I need to be involved in the struggle and enlighten and inform people and be a face of people living with HIV (*HP3* Interview: November 12, 2013).

The above narrative by *HP3* highlights the tremendous influence that local realities in families and communities have in people's behaviour. The link between an individual and their communities is also evidenced by other participants who reported that their infection marked a significant turn in their lives, "changing the way I thought, lived, ate, slept, had relationships, related to other people and also changing with who and where I socialised" (*WFA1* Interview: October 21, 2013). The Activists reported that their experience with the virus made them realise how important it was to transform their society concerning the HIV epidemic. For *CFA*, as with *BFA2* and *CMA*;

Living a life with HIV has made me realise the true meaning of success. It has taught me that real success is not driving a sports car or living in an upmarket suburb. It's about managing to accomplish actions that allow and enable me to touch other people's lives with positive traits like love, honesty, respect and most of all, hope…It has made me to understand and survive various crises in my life and I have come out triumphant and eager to impart my surviving skills to others in similar situations (*CFA* Interview: October 8, 2013).

Sharing their experiences and information about HIV with others aimed to ensure that other people are better informed about the epidemic. Here PLHIV are involved not as beneficiaries of the NGO services but as service providers to other people. According to participants, information about HIV/AIDS is shared through involvement in different activities such as HIV awareness programmes, health promotion programmes, HIV counselling as well as HIV information and education campaigns. Activities of PLHIV were pertinently outlined by one white female Activist as follows:

I run a non-profit organisation for people living with HIV/AIDS in Pine town. I am a counsellor and Activist. In a nutshell; I am a facilitator on HIV information and education. I do go out and do awareness talks. I do not like to be referred to as an inspirational, motivational speaker. I prefer to be called awareness creator. That is what I do. I create awareness around HIV/AIDS be it people living with the virus or to people affected of which everybody is and that is my focus (*WFA1* Interview: October 21, 2013).

In most of her activities, *WFA1* works with *WFA2*. The two white women claimed that they had been exposed to the virus (at a very late age of forty-six (46) for *WFA1)* by the same person who consciously infected them. As with these two white females, two other the Activists from other racial groups (*CFA* and *BFA*2) had also been deliberately infected by their partners. Recollecting her experience, *WFA2* confided how she was deliberately infected. "I slept with a man who did not tell to me that he was HIV. I should have been given the

choice to choose if I wanted to be with him or not because I don't think I would have slept with him if I knew that he was HIV positive" (*WFA2* Interview: December 4, 2013*).

While *WFA2* spoke from a liberal "choice" and rational "I don't think I would" perspective, reviling wilful transmission of HIV is a central theme in all participants' discussions on awareness as they believe - regardless of their different races - that infecting someone is tantamount to putting potential death sentence on other people. The Activists feel that they would never be at peace with themselves if they are to infect another person. This is evidenced by the contrite *BFA2* who unwillingly infected her boyfriend and therefore is finding it difficult to face not only the boyfriend but also his family. The convergence of both blacks and white Activists on the notion of 'doing good' suggests that reverence for the wellbeing of the other is not only present in *Ubuntu* – an African cultural logic used by some black Activists to image their participation - but also features strongly in other cultural perspectives. However, that *WFA2* spoke from an atomist view of a rational individual and *CFA* spoke from a relational perspective conjures a pertinent difference discussed earlier between Kantian philosophy which places emphasis on rational choices and *Ubuntu* which is relational (see Chapter Two).

Consistent with their desire to help society as an expression of humanity, the Activists consider themselves as sources of motivation for other infected people. While *WFA1* does not like to be addressed as a motivational speaker but as a 'knowledge creator', other Activists stated that they are involved in motivational speaking. Most Activists reported giving motivational speeches not only during public events such as World AIDS Day that take place annually on the 1st of December or the International AIDS Candlelight Memorial which takes place every third Sunday in May but they also give speeches in other organisations and institutions. One black female Activist reported that she is a motivational

speaker who gets invited by different organisations to address people on HIV/AIDS issues.

> Companies and organisations invite me to come disclose and do motivational speaking especially on World AIDS Day. What I do is like I tell them about where I come from with regards to my status, my fears and how I overcame. I will be there to motivate them that yes, HIV is here but it does not kill any one. Life doesn't stop. You live as a normal person (*BFA2* Interview: November 19, 2013).

I met *BFA1* and *HP3* in 2013 at the International AIDS Candlelight Memorial held at the University of KwaZulu-Natal where they were giving motivational talks. As with other Activists, they consider their lives as sources of inspiration for other seropositive people in various ways. They claimed that among other positive behaviour outcomes, their lives and activities have made other people get tested for HIV, get on treatment, accept their positive status, disclose their status for "wherever they are they are alive because of me. They listen to what I say to them, and then they look at me and say they can manage like me" (*BFA1* Interview: October 12, 2013). It is precisely for this reason that involvement for all the Activists began with publicly disclosing their seropositive status. For them this is a way of demonstrating to people that it is possible to live positively with HIV.

HPs are thus employed to provide a 'face for HIV' to university students, an arrangement that for most HPs is quite beneficial for infected students.

> It's one of the benefits of this institution of having health promoters who are living with HIV and are open about it which has led to a support group for students with HIV. The environment at the University in many cases puts so much pressure and stigma for one not to be comfortable to share their HIV status. I can tell you that through health promoters, because of our life style and our information that we render to the University, it has allowed students to

be free to come forward and want to learn how to live with HIV (*HP3* Interview: November 12, 2013).

The DramAidE HP project, as mentioned earlier, is implemented in institutions of tertiary education across South Africa (Myers, Kelly and Motuba, 2012; DramAidE, 2014). HPs who participated in this study are based at the University of KwaZulu-Natal as well as Durban University of Science and Technology. As part of their jobs HPs coordinate different programmes meant to educate HIV positive students on issues such as acceptance, balancing their status and academic work, issues of antiretroviral medication and adherence to treatment as well as the issue of disclosure and its importance (*HP4* Interview: November 7, 2013).

Since the HP project is designed by DramAidE, there are no major differences in the nature and way the project is being implemented by HPs in respective campuses where they are placed (see Myers, Kelly and Motuba, 2012; Botha, 2009). In terms of programme development HPs have no influence over other programmes such as the World AIDS day and other national or international programmes. However, they have some influence over local programmes some of which they have designed themselves.

> I have developed other brochures before, but then all the brochures I have developed like I said, they mostly talk about other things and not positive people. I have done discordant couples; I have done the LGBTI (Lesbian, Gay, Bisexual, Transgender and Intersexual) and their prevention regarding HIV/AIDS. So I am coming to the positive people now, what they can do to prevent HIV (*HP2* Interview: November 5, 2013).

That PLHIV must be involved in the decision making processes of their respective organisation is a widely acknowledged GIPA key objective (see Cornu, 2006, UNAIDS, 1999). However, it is not the objective of this thesis to examine how DramAidE is constituted in terms of representation of PLHIV in

its management structure. The objective of the study is to explore how PLHIV are personally involved in social change communication for HIV prevention.

Implied in the earlier statement by *HP2* is the undisputed fact that HIV transmission begins with an infected person (also see Koester, *et al.*, 2007). *HP2's* misgivings about the current focus of prevention programmes stem from the milieu that an average of one in three PLHIV continues to practice unprotected intercourse after learning their HIV positive serostatus (see Winghood, *et al.,* 2004; Kalichman, 2000). However, *HP2* bemoaned that while there are campaigns and awareness events that talk about prevention, more often they talk about prevention from the perspective of a negative person, ignoring the HIV positive person. Against this background, she confided that at the time of the interview she was busy developing a brochure for PLHIV as she is aware that it is impossible to contain the epidemic without involving PLHIV. Insisting on this view, she feels strongly that efforts to contain the HIV epidemic will remain fruitless "if we are not talking to them. We are saying do not talk about us, talk to us. Involve us!" (*HP2* Interview: November 5, 2013).

In the above, *HP2* echoes Kelly, *et al.,* (2012), Rebecca Bunnell *et al.,* (2006) as well as Crepaz *et al.,* (2006) among others who have observed that HIV prevention interventions have primarily focused on reducing HIV acquisition risk among the uninfected individuals (see Chapter Five). This is despite the fact that PLHIV, a much smaller population than all those at risk, are the nexus for HIV transmission (Bunnell *et al* 2006, Osborne, 2006). Compounding the HIV epidemic is also that a high proportion of these HIV positive men and women who are aware of their HIV status do engage in HIV transmission risk behaviours (Eisele, *et al.*, 2008; Wingood, *et al.*, 2004; Kalichman, *et al.*, 2001; Kalichman, 2000). What *HP2* agitates for - and is indeed involved in - are deliberate prevention interventions for PLHIV that seek to empower PLHIV to maintain behaviours that protect others from becoming infected. As *HP2* categorically stated as shown above, prevention interventions must not only be

for PLHIV (talking about us) but must involve them (talk to us *(HP2* Interview: November 5, 2013*).*

It is in light of the above that *HP4* is involved in the *Right to Respect* campaign that is targeted at seropositive people as well as the other community members. The campaign, as enunciated by *HP4* is *"about understanding yourself first, your partner and what you are doing" (HP4* Interview: November 7, 2013*).* As discussed in Chapter Five, deliberate interventions for PLHIV to maintain behaviours that protect others from becoming infected have been common in the Western world particularly in the US where the Centres for Disease Control (CDC) championed the serostatus approach to fighting the epidemic (SAFE) that linked PLHIV to prevention services and used communication and other means to support PLHIV in adopting and sustaining HIV risk reduction behaviours (see Janssen, *et al.,* 2001).

As discussed in Chapter Five, it is important to reiterate here that for HIV prevention, GIPA seeks to promote "specific risk-reduction activities for and in collaboration with the most *vulnerable populations*, such as groups *at high risk of sexual transmission*" [my emphasis] (Paris Declaration, 1994). Here it is clear that the focus is on the 'seronegative vulnerable groups at risk of transmission'. While this orientation is important, the role of PLHIV in HIV prevention is not articulated. In terms of GIPA, involvement of PLHIV is significant in designing policies, laws and enabling environments that protect PLHIV from discrimination; that reduce stigma and that seek to change people's attitudes to AIDS by giving it a 'human face' so that PLHIV live positively (Paris Declaration, 1994). GIPA thus has a structural change approach that aims at the "creation of supportive political, legal and social environments" (Paris Declaration, 1994). While the structural change approach towards the HIV epidemic strengthens the links between prevention and treatment, care and support of the infected, "supporting people living with HIV to live 'positively' [should] include a strong recognition that issues of love, life

and intimacy are part of their reality" (Osborne, 2006: 9). To ensure prevention of new infections while supporting their love and intimacy life, effective frameworks for involvement of PLHIV must therefore articulate ways in which PLHIV can participate in HIV prevention.

In their participation in HIV prevention programmes to help society deal with the epidemic, the Activists are involved in two different but equally important ways: (a) as experts sharing knowledge gained from personal experiences with the virus, and (b) as audiences conferring with peers (other PLHIV) on how to manage the virus and protect others from infection.

Expert service providers

PLHIV can become experts on HIV issues, owing to their personal experience with the virus. The Activists in this study indeed consider themselves as such. They indicated that HIV infection has been a transformative window in their lives and their experiences with it taught them much about the HIV epidemic. "I always say that when you have got the virus you develop a seventh sense, not just a sixth sense. You are so sharp to anything that is happening around you. You are just too sharp" (*CMA* Interview: November 29, 2013). This sentiment was also echoed by other participants. For *CGA2* (Interview: December 3, 20132) HIV made him a better person as brought him to his senses.

The Activists also have strong opinions on their ability to share their experiences with peers in ways that are more appropriate as compared to HIV negative individuals. This is due to the fact that "we know better than anyone, so we are an example. We have to set an example to other people out there. I am positive so I am the one who knows better. The more you are an example to people, you make sure you do everything right. Not for yourself but for the other people" (*BFA2* Interview: November 19, 2013). Because they consider personal experience with the virus as expertise on HIV/AIDS issues, the

Activists are not happy with the involvement of seronegative HIV counsellors. Instead, they prefer seropositive HIV counsellors.

> I strongly believe that even at a clinic like this positive people should be the counsellors because people who do not have the virus do not understand how you feel, how you deal with it and also do not have pertinent questions for us. The feeling has to come from deep within, from being infected, feeling of knowing the type of question that are going to come from a positive person. If that person is not infected, they do not have those questions. I think I am going too far with this, but I think it's good because I feel I have to tell you everything (*CGA2* Interview: December 3, 20132).

Commenting on the same notion, *WFA1* contended that since PLHIV have acquired much information on how to take care of themselves and are now able to manage the virus, they have a wealthy of information to share for the benefit of other people. She believes that "positive people have so much to share but sadly there is only a few of us that want to go out and speak about it because they perceive that there is still stigma" (*WFA1* Interview: October 21, 2013). *WFA1* also believes that while seronegative people, including medical doctors may have information to share, there are limits to their ability to support the needs of PLHIV as they cannot articulate issues in the same way a seropositive person can do. This is because

> someone who is actually HIV has lived it. Negative people honestly they don't know. Even the general practitioners actually don't have all the knowledge of what I have been through. Somebody who has been living with it might not know the medical terms of it but the living terms of it. That is why I believe I have to go through all that I can share, vocalise and hopefully support and direct other people (*WFA1* Interview: October 21, 2013).

The significance of lived experience was also echoed by *BFA2* who recounted how her experience with the virus grew her mind, making her quite knowledgeable about HIV/AIDS issues, things that she believes seronegative

people have not experienced. For her, when one has the experience of being positive, their mind grows and they "see life in a very different way. You do everything like it's the last time. You grow more out of HIV. You have responsibility, you know this is the way how I want to live, and this is how I protect other people" (*BFA2* Interview: November 19, 2013). This view was supported by *HP4* who because of her experience also believes that she understands and executes her job better than other seronegative people.

HP4 bemoaned involvement of seronegative HIV counselors who, without lived experiences, qualify on the basis of receiving professional training. In her view, if one talks about HIV and test other people, they know how it feels because they "have been there before. Testing is just a short course taught over 10 days after which you qualify to get a job in government. So the [negative] people just do the course because there are no jobs. They just go for money" (*HP4* Interview: November 7, 2013). Elaborating on the importance of lived experience in the HIV response, *BFA1* feels that it is better to talk about something one has firsthand experience "because when I do my presentation I do not read from a paper but I talk about my experience. I have been sick. I had full blown AIDS and then I survived" (*BFA1* Interview: October 12, 2013).

Due to personal experiences with HIV and reported deeper understanding of HIV/AIDS issues, the Activists are involved not only in their formal jobs (for HPs) and public talks but also in their communities, where they belong to support groups for PLHIV (see Botha, 2009). Here they provide peer support to other positive people. One gay Activist stated that he is a co-founder of a support group "called blue buddies where we empower one another through social activities. I also run another support group at one of the churches for PLHIV. Next year we will be open a gym because we are promoting health living through exercise" (*CGA2* Interview: December 3, 2013*2*).

The reviewed literature (see Chapter Five) suggests that participation of PLHIV at all levels of programme development and implementation improves the relevance, acceptability and effectiveness of HIV/AIDS programming. Conceptually, this is what the culture-centered approach to social change espouses (Dutta, 2011). Evidence has shown that when key stakeholders such as PLHIV actively participate in collective action aimed at addressing the epidemic; when they are proactively involved in determining their own well-being; success is most likely (also see Lubombo, 2011; Bessette, 2004, Figueroa, *et al.,* 2002). This aspect is best illustrated in the following assessment by *HP4*:

> If clients say we prefer to see an HIV person or we prefer to see me because we are peers, therefore I will be always on a better position than someone who is HIV negative. Because an HIV negative person can run a workshop, can train him and everything, living with HIV is not about someone training you. It's about the experience that I share with the client. So I don't think an HIV negative person will succeed in terms of dealing with HIV stigma that we cover. Neither will he succeed in allowing people to speak freely about HIV without him personalising it. They have not experienced it. My work does not only involve professionalism, it involves my testimony, my life which do not involve the education. That is what people living with HIV want. I have people living with HIV in the University they are most appreciating having a person like me around because I am a light to them; I bring hope to them working as a person like them. Most people feel more comfortable to come and talk to me about their HIV status and trusting me because they see how I am taking care of myself, they believe I can transfer it to them and be able to live life like I am doing (*HP4* Interview: November 7, 2013)

The above valuation conjures rudiments of peer support whereby PLHIV support other seropositive people. As with peer support, the above statement suggests that making use of PLHIV in programmes aimed at addressing and involving seropositive people ensures trust, influence, support and

understanding (see Medley, 2009). The information that *HP4* provides is readily accepted by the 'clients'. This tangibly suggests that his or such programmes are likely to succeed especially because the clients (other PLHIV) identify with the service provider. As outlined in the GIPA implementation guide (UNAIDS, 1999), peer education as an aspect of peer support is important in facilitating meaningful involvement of PLHIV as peer counsellors, educators, advocates and leaders.

Involvement of seronegative people in the HIV response as discussed above also reflects inherent gap between theory and practice; especially considering contradictions that exist between the realm of GIPA as a global framework for involvement of PLHIV in the HIV response, and the meaning and experiences of participation among the geo-culturally positioned Activists reported in this study. In particular, the lack of faith in the participation of seronegative people displayed by the participants lays bare and deconstruct GIPA's definition of PLHIV as including those affected by HIV. This further suggests need to bridge this gap by finding localised culturally appropriate ways of mainstreaming participation of PLHIV in social change communication for HIV prevention.

The above reflections by PLHIV unarguably provide not only an insight and space for understanding conventional approaches (that is the realm of structures constituting participation of PLHIV) but also an avenue for deconstructing and transforming the assumptions encoded in the global approach, reconstituting them with local realities and cultural values. Ways in which participation can be reconstituted within local realities is demonstrated ahead in Chapter Nine. Below I discuss ways in which PLHIV reportedly participate as audiences in HIV social change communication for HIV prevention.

Contrary to GIPA that configures participation of PLHIV in a hierarchical structure that depicts 'participation as audiences' as less important and not

meaningful by placing it at the bottom (UNAIDS, 1999, Cornu, 2006), the Activists believe that conferring with other PLHIV is equally if not most important. In her study on youth participation in HIV interventions in KwaZulu-Natal, Eliza Govender (2013) also found that participation can occur at any level of the hierarchy. Developing her model set up to enhance active participation of the youth through body mapping, she disapproves 'levels-of-participation' taxonomies that depict participation "in a linear process suggesting that people on the bottom of the level are not participating, while people on the top are participating" (Govender, 2013: 261). She argues that the level of participation does not mater but what matters is how participants understand participation to mean. This for Govender (2013) is the pivotal indicator of whether participation happens.

The Activists in this study were concerned about the lack of information among PLHIV who may still be involved in HIV risky behaviours. As such, dialoguing with PLHIV at any level is considered useful to find solutions to the problem. As noted in Chapter Two, dialogue is a cardinal principle for social change and is fundamental to the journey that humans collectively travel towards finding solutions to their problems. Also noted, and is central to the culture-centered approach (Airhihenbuwa, 1995; Dutta, 2011) is that a key characteristic of social change is participation of those who are most affected by the problem. Through dialogue, concerns, ideas and opinions of all the people are able to occupy space in any public discussion through the everyday language, understanding, and way of life of the concerned people (see Dutta, 2011). In *Ubuntu*, "what your neighbour has to offer in terms of experiences, knowledge and ideas is essential to your own growth" (Blankenberg, 1999: 46). Integrating expert knowledge with experiential knowledge of PLHIV has been noted as fundamental in communication for social change in the context of HIV/AIDS.

Audiences conferring on prevention and management of the virus

In the GIPA model, PLHIV participate at different levels as target audiences - contributors - speakers - implementers or experts - decision makers. Here participation as target audience is considered lowest or less involving as compared to decision making which is considered most important. The dialogical engagement I had with the Activists, however, shows that PLHIV can also meaningfully participate in social change communication for HIV prevention as audiences in dialogue with others. In light of the above, participation is configured by the Activists in yet another way that tangibly contradicts GIPA, making clearer the gap between global theory and local practice.

While not invalidating the relevance of GIPA in particular contexts, the Activists pointed out that conferring with others enables PLHIV to learn ways by which they can not only protect other people but also manage the virus. Finding solutions in dialogue is perceived by the Activists as an important way in which PLHIV can contribute to society's efforts to contain the HIV epidemic. The importance of PLHIV's participation in dialogue is illustrated by how other PLHIV reportedly benefited from lived experiences of *WFA1*, *WFA2*, *CFA* and *BFA*2 who had been deliberately infected by their sexual partners. Based on her experiences, *WFA1* challenges other PLHIV on why they would choose to consciously infect other people: "How dare you? How dare you putting somebody's life at risk? What gives you the right, knowing your status, to wilfully infect other people? Do not tell me that it is denial. That is the easy way out" (*WFA1* Interview: October 21, 2013*).* Consciously infecting other people with the virus has been described by the Activists as inhumane. Terms used to describe the behaviour include among others 'murdering', 'harming', 'killing' and 'risking' the other person's life. For them such behaviour is not only distasteful but an indication that people lack knowledge.

It is, therefore, important to dialogue with other PLHIV educating one another on possible ways in which further HIV transmission can be halted. Expressing

concern that PLHIV are the nexus for HIV transmission, and therefore need to be educated on HIV prevention, the forthright *CGA*2 unequivocally stated that "it's the people who are positive that are making other people positive. So we need to get hold of all the positive people and say hey, you are the ones that can make other people positive because of the secret that you still keep" (*CGA2* Interview: December 3, 2013*2*). *CGA2* here is certain that there are other PLHIV who expose other people to HIV infection because their partners do not query their status. Asked on what therefore needs to be done, he believes that PLHIV need to be educated: "Get all the positive people together and keep educating them on the importance of having protected sex … to stop them from infecting others because soon the country will not have enough ARVS to give everybody" (*CGA2* Interview: December 3, 2013).

Engaging with key stakeholders or affected communities is at the core of the culture-centered approach to social change (Dutta, 2011). Through this process voices of PLHIV are brought to the forefront as they articulate questions and solutions in ways that are meaningful to them. To engage with more PLHIV, the Activists indicated that their messages are (also) aimed not only at those in support groups to which they belong but even among the general populace where they give their public talks. As expressed by HP2 below, the Activists have reservations about the current framing of HIV prevention messages that are predominantly targeted at the seronegative.

> Ok, most of the time we talking about prevention looking at it in a negative person's perspective ignoring the HIV positive person. I do not know why... I have developed other brochures before, but then all the brochures I have developed like I said, they mostly talk about other things... so I am coming to the positive people now, what they can do. I am busy developing a brochure, for people living with HIV because we cannot get to zero if we do not talk to them (*HP2* Interview: November 5, 2013).

That HIV prevention efforts have been focused on the general populace paying relatively little attention to PLHIV has been highlighted in Chapter One. This view has recently been noted in the WHO consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations (WHO, 2014). The guidelines note that this is painfully true in sub-Saharan Africa which is home to 71% of the 35.5 million global population of PLHIV. Considering the fact that PLHIV are the nexus for new HIV infections, Osborne (2006: 9) argues that excluding them from dedicated prevention efforts is indeed "not conducive to successful global prevention". Logically, HIV/AIDS educational programmes cannot succeed without participation of PLHIV. Their voices, as the culture-centered approach to social change holds, must be listened to as social change programming ought to locate the affected people's culture and local contexts at the centre of the process (Dutta, 2011) If this is true, it follows therefore that trivialising participation of PLHIV as audiences in discursive spaces only serves to undermine meaningful participation of PLHIV. Tellingly, experiences of the Activists indicate that participation of PLHIV as audiences in these discursive spaces where HIV/AIDS issues are discussed is equally important as with their participation as service providers.

While involving the seropositive in HIV prevention dialogue remains important particularly considering continued new infections, the Activists have not only enjoined other PLHIV to protect other persons but they also educate them on better ways of managing the virus so that they live healthy and prolonged lives. Emphasising the importance of addressing PLHIV from this perspective, *WFA1* explained what she deals with in her programmes with other PLHIV. "I am more specific about their vitamins, their intake and the quantities because people do feel that generally need to take absolutely everything not knowing that it can do damage to their bodies" (*WFA1* Interview: October 21, 2013). *WFA1* was, however, quick to point out that seropositive people who do not disclose their status cannot fully benefit from these programmes. She deplores

the culture of secrecy among seropositive people who have not disclosed their status. She indicated that because of this culture, the first thing she does whenever she gives her presentations is to encourage seropositive people to disclose. Castigating the culture of secrecy which for her puts them at a disadvantage in terms of their health, *WFA1* believes that "people living with the HIV virus we are our own worst enemies by not disclosing our status" (*WFA1* Interview: October 21, 2013). The benefits of disclosure are discussed in the next chapter.

Also justifying the participation of PLHIV in dialogue, *HP1* bemoaned the lack of information among PLHIV which for her results in them compromising their health. Warning other seropositive people who, after knowing their status, continue with HIV risky behaviours such as unprotected sex, *HP1* fears that they risk reinfection. "I think they are ignorant and they need more knowledge and to be educated on what happens when they sleep with others without wearing condoms, because that time when you sleep without a condom you doing cross infection" (*HP1* Interview: October 18, 2013).Similarly, but also being mindful of the fact that there is no law that forces people to disclose their serostatus before having sex with someone, *HP3* echoed the above sentiments and added that the most important thing that PLHIV should know is that they not only pass HIV to the next person but may also be re-infected. His message to PLHIV is, therefore, to always use protection (*HP3* Interview: November 12, 2013). Using protection is important particularly for him because by the time of the Interview: he had been married to a discordant partner for at least five years. Because of his experience, his appreciation of condom use is well informed. His experiences are also important to other serodiscordant couples who could be lacking information on how to maintain their status.

Still demonstrating the significance of participation of PLHIV in dialogue, the Activists recalled that many other PLHIV who listen to their presentations enrol on antiretroviral therapy (ART). They indicated that they would continue being

involved in HIV/AIDS educational activities in the hope that more seropositive people will emulate how they have managed to live with the virus. One black Activist reported that some PLHIV see her as their role model. "Wherever they are they are alive because of me. They listen to what I say to them, and then they look at me and say they can manage like me" (*BFA1* Interview: October 12, 2013). The information sessions they hold with other PLHIV serve as a forum to share personal experiences from which many seropositive people learn. This was succinctly put by one participant who said that through these sessions "we share stories like where we come from, where we are and most of those stories are successful stories. Each time we share those stories new people learn from that" (*HP3* Interview: November 12, 2013*).* For *WFA1*, many seropositive people appreciate and value her sessions. Many of those who would have not disclosed have also opened up through these dialogues. "People have come to me and talk to me about their HIV status, telling me that I am the first person that they are revealing their status to in 10yrs. For me if somebody tells me that they are HIV positive, it shows that they listen to my message" (*WFA1* Interview: October 21, 2013).

The above excerpts serve as illustrations of how the Activists feel about involving other PLHIV in discursive spaces where HIV/AIDS information is shared and educational programmes take place. By so doing, HIV prevention is situated within local contexts, and participation in social change communication for HIV prevention is here configured by looking at meanings and experiences of PLHIV and not through GIPA precepts. While the Activists in this study are involved in the HIV response at both institutional and interpersonal levels, their particular focus is to influence other PLHIV and their communities in general to become responsible people who, because they are humane, can protect others from being infected. The Activists are thus personally involved in interacting with other PLHIV as well as the general populace who are beneficiaries of their expert services. Consistent with the

varied practical areas of involvement of PLHIV noted by the Asia Pacific Network of People Living with HIV (APN+, 2004) the Activists are involved in peer education, peer support, advocacy, counselling, public education, as well as program planning and implementation. From what has been pointed out in the foregoing, for social change or HIV prevention to occur, cooperation between the infected ensures their voices are heard and information is shared through peer exchanges among other things.

While DramAidE Health Promoters are employed to participate, involvement of other Activists is not on contractual basis. However, the Activists revealed that they are recognised by different tokens of appreciation when they do presentations. Reasons for participation are almost the same among the Activists regardless of race or gender. All the Activists have an intrinsic motivation for their involvement. As such they have some convictions that are seemingly inconsistent with some conventional principles governing participation of PLHIV such as those espoused by GIPA, for example their convictions about serostatus disclosure explained below.

Participation as disclosure

Notwithstanding the fact that it does not guarantee safe behaviour, disclosure has been suggested as one of the important behaviours that are germane to reducing chances of continued HIV infections (see Chapter Five). However, that GIPA does not insist on serostatus disclosure as a condition for participation is not in dispute. The UNAIDS key material, *GIPA: From Principle to Practice* (1999) states that while PLHIV are free to disclose, GIPA "does not mean no visibility = no involvement". Rather, PLHIV "have the right to choose to be involved without making their serostatus public" (UNAIDS, 1999: 3). Its focus seems to be on the positive aspects and protection of rights of PLHIV such as autonomy and privacy rather than negative consequences of confidentiality.

Two observations about serostatus disclosure that are fundamental to the present discussion were made in Chapter Five: that non-disclosure in sexual relationships allows risky sexual behaviour to occur; and conversely, that disclosure by the infected partner corresponds with safer sex practices as it permits the uninfected partner to be involved in the decision-making process that may result in not allowing HIV transmission to occur. PLHIV who participated in this study believe that participation of PLHIV in HIV prevention should begin with disclosure of sero positive status. Thus for *CFA*, other PLHIV should know that choosing to use protection goes with disclosure. "It may entail disclosing to your partner as you now have to use condoms. Is it really worthwhile not using protection and ultimately infecting others? Honesty should be the only policy no matter how hard it is, but it does bare positive fruits in the end" (*CFA* Interview: October 8, 2013).

According to *CFA (*Interview: October 8, 2013) omission of information (non-disclosure) means lies. For her, disclosure means that deceit and lies are gone. As such, all the Activists subordinate their participation to disclosure. For *HP2*, without disclosure it is inconceivable to prevent new infections and stigma. Because of her conviction, no one prompted her to disclose as she "just felt that it was something I needed to do for myself and for the community. For me disclosing was to desensitise and de-stigmatise HIV" (*HP2* Interview: November 5, 2013).

In contradiction to GIPA principles that disclosure is an individual choice, the Activists believe that in order to prevent HIV transmission, seropositive people must disclose their status primarily to those they intend to be intimate with, and also to those around them in order to get necessary support. However, it is evident in the way the Activists articulated their convictions that they are also aware of the precepts of the conventional approach to the involvement of PLHIV which does not enjoin PLHIV to disclose. While stressing that seropositive

people must disclose their status to protect the other, the Activists were cognisant of the principle that disclosure is their individual choice.

> At the end of the day it is still my choice. If I decide to keep quiet about my status, it's my choice. You not gonna force me to. Then as much as it is my responsibility to make sure that you are protected, it is also your responsibility to protect me because at the end of the day, it is not about me infecting you but it is you re-infecting me (*HP2* Interview: November 5, 2013).

The above sentiments can be described as encompassing two contradictory views that the Activists have about disclosure: that (a) it is one's choice not to disclose their status although (b) people have a responsibility towards each other. As PLHIV, the Activists feel that this responsibility can be enacted at least by disclosing seropositive status to other people so as to allow them an opportunity to take precautions to avoid HIV infections, either primary or secondary. These two contradictory views epitomise the two competing frameworks to the HIV response, a challenge that this thesis sets out to address. The latter view listed above as (b – responsibility to disclose) can be described as mirroring the way Africans conceptualise personhood as discussed in Chapter Two (see Metz, 2007b, Tutu, 1999). The former view listed above as (a – choice to disclose) can also be described as mirroring the individual rights discourse espoused by GIPA.

However, that the view 'disclosure is responsibility' is dominant among the Activist is unarguable. That the participants are aware that disclosure is a choice can be viewed neither as an unexpected finding nor contradictory as it simply demonstrates the influence of the dominant Western discourse on HIV/AIDS among African people whose worldview allows for collective interlocution and sharing of burdens (see Airhihenbuwa, and Iwelunmor; 2012; Airhihenbuwa and Webster, 2004; Dube, 2009). The usefulness of the dominant discourse in addressing the African epidemic is, therefore, argued in

this study as doubtful. This argument is further illustrated in the next chapter which discusses disclosure as responsibility to protect self and the other.

Here it is important to note that due to their convictions on disclosure, all the Activists have publicly disclosed their seropositive status as an initial step to their involvement as 'knowledge creators', a term that *WFA1* prefers to 'motivational speaker'. Disclosure for the Activists is necessary as it enables them to educate others through presenting themselves as living testimonies of both what HIV can do to one's body and also of how possible it is to manage the virus and live a healthier and prolonged life with the virus. Feeling strongly about this, *CGA2* affirmed that "I am here disclosing my status. I am showing you AIDS as it is. I just think that once you get AIDS, you show what AIDS is" (*CGA2* Interview: December 3, 2013*2*).

Through their testimonies (disclosure) the Activists educate different people in different places across the country. As with *CGA*2 above, another coloured gay Activist also stressed the importance of disclosure in their HIV knowledge creation work. He would want "people to know what this thing [AIDS] does to you. I know the dangers of it so I inform them, also letting them see what it can do to a person. That's what I do. Why not showing you the gory scenes, not just glossing over it" (*CGA1* Interview: November 27, 2013*,* Interview: November 27, 2013)*?* These views suggest that for the interviewed Activists, disclosure is none negotiable and integral aspect of their participation in HIV prevention programmes. This was a strong and common feeling among the participants. Thus, as *HP1* expressed, disclosure is the second important thing that she urges other seropositive people to do after accepting their status.

According to Laura Myers *et al.,* (2012), DramAidE Health Promoters have succeeded in changing the 'face' of HIV in their respective communities (also see Myers, 2011). By openly declaring their serostatus, these HPs have managed to change perceptions among members of their communities who now

understand that PLHIV cannot be identified merely by looking at a person. Thus for *HP1* disclosure has resulted in students understanding that HIV testing is imperative especially those who once thought that they could detect if a person is positive. "So if I start and say that I am positive, they laugh and say I am lying" (*HP1* Interview: October 18, 2013). Living openly with HIV thus enables HPs to challenge dominant conceptions of what it means to live with HIV.

Regardless of their insistence on disclosure, the Activists were however cognisant of the fact that disclosure is compounded with many challenges. Regardless of their awareness that it is better to disclose early they were aware that it is not easy to disclose in the community because of stigma. As such, some took time to disclose. "I was diagnosed in 1996 but I disclosed to the public in 1999. Now anywhere I go, I disclose my status. If they ask me to come and do a presentation on HIV, I disclose to them" (*BFA1* Interview: October 12, 2013). The challenges to disclosure include domestic violence, rejection, divorce, stigma and discrimination among others (see Mlambo and Peltzer, 2011; Paxton, 2002; APN+, 2001).

While it is not the focus of this study to investigate these, the Activists indicated that in addition to fear of being left by their partners, the social environment and other circumstances affect decisions to disclose. According to *BFA2* challenges to disclosure are linked to various social ecological influences. They "start at the family level. There you have got values, you have got religion. Well, in the family you need to be accepted, you need support in order to get used to the fact that you are positive. Once you get support and people accept you, you live freely" (*BFA2* Interview: November 19, 2013).

Because of various challenges affecting disclosure such as those outlined above many PLHIV end up engaging in relationships without disclosing to their partners. As noted below, Larry Kincaid *et al.,'* (2007) Social ecology model of

communication and health behaviour is illustrative of the influence that the context has on one's behavioural choices. The behavioural choices that people make happen not because they want it that way but because they would be forced by circumstances. This is illustrated by *CGAI* who troubles with the issue of disclosure each time that he gets in a relationship with somebody. His issue is whether one discloses to the partner immediately or they have to wait and tell them when the sex is about to happen. "I do not think I can at the moment, maybe I should not tell anybody. That is how I see my life going at the moment. There are people who you are just like, can this person handle or you think maybe he is HIV positive as well" (*CGA1* Interview: November 27, 2013*).

During the time of the interview *CGA1* had since 2009 "not really" been sexually active and the number of his partners was perhaps a "count of the fingers of my hand, so few" (*CGA1* Interview: November 27, 2013). However, prior to that period he was involved with multiple sexual partners. In most of his sexual encounters, he was often under the influence of alcohol.

> Everybody and anybody you name it, if you wanted it, let's get it on (laughs). On disclosing to the partners, somehow I don't think it was convenient for me to say anything. Every time I had a sexual encounter it was with liquor. So who is going scrutinizing a person? But when I am not drunk definitely, I just tell them. But as I said lately it's been so few that is why I have always been able and everybody seems to be minding (*CGA1* Interview: November 27, 2013).

In the excerpt above, *CGA1* highlights another challenge to disclosure; that regardless of a person's willingness to disclose, there are other factors that may affect their decision and ability to do so. For him, alcohol consumption is one such factor. As discussed in Chapters Four and Five, there are many other social, political and cultural factors that affect people's behaviour or attitude to health - either positively or negatively. As with *CGA1*, other Activists in this study and indeed every human being are not spared by these factors.

The challenges to performance of certain behaviours, regardless of one's motivation, are explained by Kincaid *et al.'s* (2007) meta-theoretical model, the Social Ecology Model of Communication and Health Behaviour (SEMCHB) that draws attention to the influence that social context has on behaviour. According to this model, these contexts include institutional and cultural variables. As such, the model takes into account the interconnected influence of family, peers, community and society on behaviour (Storey and Figueroa, 2012; Sallis, *et al.*, 2008). The culture-centered approach within which this study is framed acknowledges the influence that culture has on people's behaviours and seeks to utilise culture to address social change (Airhihenbuwa, 2007, Dutta, 2011). It is in this context that this study aims to understand the local realities and cultural contexts that inform the Activists' configuration of participation so as to apply these for mainstreaming South African PLHIV in social change communication for HIV prevention.

For example, there is need to unpack a philosophy that accounts for the difficulty that the Activists have shown in trying to understand those who do not disclose for fear of being rejected by their loved partners (*HP2* Interview: November 5, 2013) and end up quietly infecting them,. *CFA* questioned such PLHIV who chose to base 'love' on deception or non-disclosure. For her, relationships involve love, caring and responsibility towards each other and non-disclosure is thus an antithesis of love. She does not believe that deception is the manner in which one displays their love for a person. "Is deception the basis for any relationship? Should the person love you more for lying to them? Love means honesty, truthfulness and kindness. Love does not hurt" (*CFA* Interview: October 8, 2013). *CFA* was quite categorical that she conceptualises human beings as relational, and as such she reminds other PLHIV not to be selfish beings lest they cease to be human.

The question that this thesis attempts to answer is: what local contexts or culture can be used to explain the conception of being alluded by *CFA* (and

indeed by all other Activists in this study) above? As illustrated by the SEMCHB model highlighted above, the Activists indicated that their views to disclosure are influenced by their values which are shaped by their experiences with HIV both personally and among their families and communities. The conclusion arrived in this thesis, as suggested in the thesis title and illustrated in Chapter Nine, is that the type of relationship envisaged by *CFA* above conjures an *Ubuntu* ethic and African conceptualisation of being. Meanwhile, it may be important to examine in accordance with the Kincaid *et al.'s* (2007) SEMCHB model, what the Activists' personal, family and social experiences influence them to publicly disclose their status and become involved in social change communication for HIV prevention the way they do.

Personal experiences as prods to disclosure

The Activists described how their experiences with HIV fuel their high degree of personal investment, motivation, dedication, and commitment to participate in the HIV response. Describing her experience, *HP4* explains how HIV incidents in her family act as visible prods that prompted her to disclose and participate in the HIV response.

> In my family, we have 8 people who died of AIDS. Because of this, I became desperate to study about HIV to update myself about HIV. Because I had this concern to help people, I was doing the volunteering work all the time because I was trying to understand about the virus. In 2005, I started working with Usiyanqoba community base educating people in the community about HIV/AIDS. I also worked with street kids and sex workers, educating them about HIV/AIDS (*HP4* Interview: November 7, 2013).

As with *HP4* above, two other black female Activists (*BFA1* and *BFA2*) have similar experiences. For *BFA1,* the notorious killing of her close friend Gugu Dlamini for having disclosed her HIV status to the public inspires her participation in the HIV response. According to the AIDS Foundation of South Africa website (www.aids.org.za) Gugu Dlamini had realised that the secret to

overcoming the impact of being HIV positive was to talk about it. As such she had dedicated her life to educating, motivating and encouraging others to reveal their HIV status and talk about the epidemic.

However, in 1998 she was stoned to death by a group of men from her home township, *KwaMashu* in Durban for disclosing her HIV status to the public. She had realised that the secret to overcoming the impact of being HIV positive was to talk about it, and had made a bold decision to dedicate her life to educating, motivating and encouraging others to reveal their HIV status and talk about the epidemic. A year after Dlamini's murder, *BFA1* publicly disclosed her positive serostatus, marking the beginning of her participation in response to the epidemic *(BFA1* Interview: October 12, 2013*)*.

The Activists' personal experiences with the virus also play a central role in their decisions to publicly disclose and participate in the HIV response. In a country like South Africa where the government was once reluctant to provide antiretroviral therapy to its citizen (see Chapter Three), most Activists had developed full blown AIDS and had faced many challenges in managing their lives. However, their experiences with AIDS taught them important things about the epidemic and they feel compelled to share with the public so as to provide information on how to deal with HIV/AIDS. One Activist realised that

> there was a serious lack of information. My general practitioner for instance did not give me the information. To this day I have never pre- or post- counselled. And I have a very strong personality and I could just imagine just how other people with a more sensitive disposition than me must be having serious issues dealing with the situation. This kind of prompted me, after I had gone through all the various stages of AIDS. I have had shingles, had pneumonia, meningitis, cancer I had two strokes. By the time I went public six years ago I had gone through all those acquired diseases. I thought that I was in a position to assist or direct other people at least on how to manage their viruses. That is what prompted me, the lack of information (*WFA1* Interview: October 21, 2013).

Also due to her personal experience, *WFA1* is concerned that 'unsuspecting' elder women, whose marriages may have failed but continue wanting to date, are at risk of infection. This is typical of her personal experience. Together (but at different occasions) with *WFA2* who is also an elderly woman, they contracted HIV from the same man whom they trusted and never suspected would infect them. *WFA2* confided that she trusted him so much so that they did not discuss condom use. From such experiences, *WFA1* considers elderly white women as a group that need to be educated to enable them to be vigilant in protecting themselves from HIV infection. For her, "they come from trusting environment. They are two polite to ask you to wear a condom because they think they are insulting you" (*WFA1* Interview: October 21, 2013).

While *WFA1* said that she protected but their condom burst, her claim that white women are trusting was reiterated by *WFA2* who confided that because she is from a 'trusting community', she did not discuss condom use with her infector. She believes that "when you meet somebody, you do not want to talk about such things. It's like saying that person is positive. That person does not know infection. How do you say it? Do you say, 'are you HIV positive" (*WFA2* Interview: December 4, 2013)*?* While *WFA2's* view does not suggest low condom use among the white population in South Africa, her fear to discuss HIV issues during intercourse is linked to HIV/AIDS-related stigma. Participants revealed that this problem is still rampant among the white communities. *WFA1* claimed that in her community, stigma is high because members are ignorant and do not consider themselves at risk of HIV. She bemoaned that this problem is compounded by national HIV/AIDS campaigns which seem to target the black population, perpetrating the fact that only black people are HIV positive. "You see we people who are living with it see that sort of thing. As a white person, I'm willing to see white people as well on the adverts. I'm more than willing to go and sit with that sister and tell them that yes man I'm HIV positive" (*WFA1* Interview: October 21, 2013).

However, the above reflections differ from experiences of women from other racial groups. Non-white women Activists including those who were also deliberately infected by their partners indicated that they always insist on condom use, an acknowledgement that their perception of risk is high. One such participant, *CFA* confided that she is "a condom person" but on that day "my infector convinced me otherwise. I blame myself for having given my life to somebody else by agreeing not to condomise. That is why I do not blame him. I do not say he infected me but I say 'We' infected me" (*CFA* Interview: October 8, 2013).

BFA2 who was also deliberately infected also indicated that even though she is insistent on condom use, she confided that black men do not like to use condoms. She thus believes that disclosing seropositive status is one way of reminding these men to use condoms. However she acknowledged that some still insist on unprotected intercourse even after disclosing to them. "You know black men. Black men! They don't want to use condoms. It is better to tell the person that I am HIV positive. But, hey, hey; in the bedroom there is something else" (*BFA2* Interview: November 19, 2013).

The above sentiments were also echoed by *HP4* who without mentioning racial identities indicated the most men don't like condoms, or at least do not use condoms all the time. "They do not use condoms so you have to disclose to him, to say I am HIV positive and you go and check your status and we can continue. But some of them just say we claim to be positive because we want to stop them from having unprotected sex" (*HP4* Interview: November 7, 2013).

While the above clearly affirms the notion that disclosure does not equate prevention, it is important to note that the Activists consider serostatus disclosure as integral in social change communication for HIV prevention. For other Activists like *HP1,* disclosure has worked to protect condom-averse male partners from getting infected. "If I had not disclosed to him, you know men,

they will not agree to have sex with a condom. So I tried to disclose so that we use a condom so I do not end up infecting him" (*HP1* Interview: October 18, 2013).

Many reasons for disclosure were given but, as shall be shown in the next chapter, they revolve around respect and consideration of the self and the other. The reported Activists' experiences are examples of circumstances which prompt the Activists to be involved in the HIV response. The way the Activists were infected, the subsequent opportunistic infections, and beliefs previously held are common experiences which influence the Activists' involvement particularly regarding their activities and messages to their audiences. These personal experiences are closely linked to the personal investment, motivation, dedication, and commitment that, as already shown, motivate the Activists' involvement in social change communication for HIV prevention.

The nature of participation configured in the foregoing suggests a notable disconnect or incongruence that exists between how the Activists make sense of participation, and the tenets of the global framework governing involvement of PLHIV in the HIV response. Contradictions have been observed between the way the Activists are and prefer to be involved *vis-à-vis* the GIPA precepts which do not make it an obligation for PLHIV to disclose serostatus as a pre-condition for involvement.

The above brings the other important question this study sets out to address: how do the Activists feel about their current participation in the HIV response? As presented in the following discussion, it suffices to highlight that while the Activists expressed interest, passion, commitment and some satisfaction about their involvement, there are other issues they are not happy about.

Perceptions about their participation

As already highlighted in the preceding sections, the Activists were contented that as PLHIV with lived experiences they are personally involved in the HIV response. This is particularly because HIV/AIDS is a phenomenon that they understand and can talk about not from prepared speeches but from personal experience. Most if not all the Activists had been sick and survived full blown AIDS. As *WGA* stated, he feels good to participate in the HIV response "because well, we know what it is like to be told that you have AIDS" (*WGA* Interview: October 29, 2013). Asked on how he feels about his participation, *HP3* also shared the above sentiments. "I think for me, it's that, I always feel good when I do the work of HIV whether it's for the university or not. I am passionate about what I am doing" (*HP3* Interview: November 12, 2013).

The Activists are content with the progress that has been made in involving PLHIV and the positive impact that their involvement has made on other PLHIV. Enchanted by the fact that PLHIV have now acquired much knowledge as compared to the time she got infected, *WFA1* commended that nowadays PLHIV have gained hope and courage to continue with life. "Support groups for example encourage people to be more open. People that come to my support group have been much quicker to sharing their status with family and friends than I was" (*WFA1* Interview: October 21, 2013). This development is attributed to, among other things, the involvement of PLHIV in responding to the epidemic. Indeed this is what the culture-centered approach to social change (Dutta, 2011) grapples with. The impact that PLHIV have made to society in terms of addressing HIV/AIDS-related stigma as well as access to treatment was highlighted by *HP3* who acclaimed how his aspirations to fight HIV/AIDS-related stigma have been fulfilled.

> I am glad that my decision that I took many years ago is fulfilled because today as much as we still talk about stigma in our community, there is improvement as compared to the stigma that was there 18 years ago although a lot still has

to be done. In my days, we had no access to treatment. Treatment was expensive, we were discriminated in our families, and there was no education, there was nothing. We were the first group to come out to say we want to take the risk (HP3 Interview: November 12, 2013).

The history of the contribution PLHIV have made to the HIV epidemic response in South Africa as indicated by *HP3* above cannot be complete without acknowledging the work of Treatment Action Campaign (TAC) whose contribution in the struggle for the rights of PLHIV has been discussed in Chapters Three and Five. *HP3* revealed that he was initially involved with TAC. Here it suffices to note that TAC's contribution revolutionised South African government's response to the HIV epidemic. As with many other African governments whose response to the epidemic was slow, the above reflections by *HP3* suggest that progress has been made in addressing the challenges for which GIPA was established such as (in)access to treatment, HIV/AIDS-related stigma and discrimination, laws and structures enabling involvement of PLHIV in all spheres of activity, welfare of PLHIV among other issues GIPA was set out to address. From the Activists' reflections, nowadays these issues are no longer at current debate of responding to the HIV epidemic. What remains a challenge, however, is finding effective ways of containing new HIV infections. Today's *AIDSscape* is undoubtedly different from how it was when GIPA was formalised in 1994 (see Part II of this thesis). While GIPA remains useful, if the above is anything to go by there is need to find ways that appeal to both current challenges and the aspirations of PLHIV.

These aspirations can be gleaned from both the challenges they are facing as well as from what they want to be addressed. While the Activists eulogised their involvement, there are some pertinent issues that they are equally concerned about. In addition to lack of involvement of many PLHIV who are reluctant to disclose but continue spreading the virus, the other challenge relates to exploitative economic relationships PLHIV often have with ASOs (Gooey, 2006).

BFA1 bemoaned the exploitation she suffered in the hands of a previous ASO that she had been involved with. While the ASO financially benefited from her testimonies, lack of recognition or payment by the organisation made her feel exploited so much so that she was left with no choice but to leave the ASO and work as an individual.

> It is true that we are being used a lot. Me too I am one of those who have been used. If you are living with HIV and people who are doing their business with you, they will be just doing it for themselves. You are just like a slave. They call you and you go there and present a motivational speech or play a certain part about HIV/AIDS and they will say thank you, bye. And then it's finished like that, no assistance or nothing but the NGO will be collecting money under your name. That's why I left. I used to go to Mozambique and everywhere they were invited they would send me to go and do a talk. And then I eventually queried with the company that had invited us. The guy was surprised that I was never given anything as they had paid my organisation a lot. That's when I stopped working with them (*BFA1* Interview: October 12, 2013).

Here, as with many other PLHIV, *BFA1* was expected to be a volunteer, with no incentives or any financial or material benefits. So disheartening for her was the fact that whenever she gave a talk, her organisation would receive payment yet she was not compensated or recognised for her testimonials. Indeed, being involved in ASOs as volunteers without being paid has been perceived by PLHIV as manipulative or exploitative (see Cornu, 2006; Gooey, 2006, Manchester, 2004).

*CGA*2 is another participant disappointedly involved with an ASO. Asked on what he feels about his involvement, he did not hide his disappointment in the lack of PLHIV involvement in his organisation's management structure. His position, together with three (3) other PLHIV employed by the ASO is at the bottom of the structure so much so that the ASO is run by people who do not have personal experiences with the virus. He revealed that among the employ

of the ASO, "there are four (4) of us out of twenty-nine (29). I am the maintenance guy, the one is in support staff in the kitchen, and the other one is in administration. No one in management, I find that a problem" (*CGA2* Interview: December 3, 20132).

Concern was also raised regarding inadequate resource allocation that, according to the Activists, stifles their capacity to grow. Literature suggests that in order to practice the GIPA principle effectively, PLHIV must not only be present but be capacitated to participate effectively and meaningfully (Alliance and GNP+, 2010, Cornu, 2006, UNAIDS, 1999). In terms of resources, *CGA2* remonstrated that due to his menial duties he has little time to engage in HIV/AIDS-related activities. The ASO only allows him to engage with other PLHIV during the late afternoon after his maintenance work.

> This is between me and you. Right now I cannot get the rest of the members to feel from their hearts as to what is really needed to reach out to the person who is positive. I find life very important that you actually want to take a step further so much so that after your working hours you still raring to go. I find that there is this closure. Support groups run from 7:30 am to 4:00pm. After that you don't want to partake in anything else. I find that that is the major problem (*CGA2 Interview: December 3, 2013).*

The issue of resources was also echoed by *HP3* who feels that at the university he is based, he has not been given what he would have loved to have in order for him to improve his work related capacities through sharing with other networks of PLHIV for example through local and international conferences.

> In terms of the investment to PLHIV, the resources that are being put to us are little. The resources for me to go out and search for more information, you know that there are so many conferences that are happening around. So being the only seropositive person who is employed by the university on fulltime basis, if there are conferences that talk about HIV around the country no other parson

can legitimately claim that they want to attend the conference on behalf of PLHIV. But do I get access, do I get resources? International conferences are happening but the authority is not on me. I am just booked when there are students coming to my office and every day because I am being paid every month but not seeing the bigger picture that resources need to be put so that I can improve (*HP3* Interview: November 12, 2013).

The above reflections by PLHIV highlight an issue that is widely recognised to have, and continues to affect PLHIV; that is lack of capacity development and recognition by ASOs they work under (see Gooey, 2006). As shown by *HP3* above, inadequate resources stifle the Activists' capacity to grow. The International HIV/AIDS Alliance and GNP+ (2010) suggests that in order to make sure that participation of PLHIV is meaningful, there is need to support PLHIV in terms of developing their capacity to participate effectively. As implied by *HP3* above, capacity building may be enhanced through attending conferences to share skills and knowledge across communities. These are the discursive spaces where policies are debated that the culture-centered approach to social change advocates inclusion of the affected communities (see Dutta 2011). There remains a challenge to alter these structural barriers such as resource constraints that limit inclusion of the affected communities in these discursive spaces. Any model that seeks to address inclusion of the marginalised in these spaces - like the *Ubuntu* model outlined in Chapter Nine - has to seek to manipulate, or at least be able to speak to these structural challenges.

Regardless of the above challenges, the Activists were determined and self-driven to continue with their work in order to help society deal with HIV/AIDS. Incongruence between their preferred way of involvement and the conventional framework regulating involvement of PLHIV in the HIV response, especially on the principle of disclosure amply demonstrates their self-drive. It also suggests presence of some other values or principles that nurture their conception of

participation. In contrast to GIPA which accords them an option to participate without having to disclose, the Activists concurred that meaningful participation of PLHIV involves serostatus disclosure. This stance is evidenced by the fact that they are living openly with HIV. The notion of disclosure and challenges to it are addressed in the next chapter.

Many reasons may be proffered as to why the Activists configure participation as presented in this chapter. Here an appeal to the culture-centered approach may be enlightening in providing a perspective through which such a configuration can be understood. According to this approach, our lives and behaviour, our thoughts, feeling and actions as individuals are largely influenced by what our society considers important (Airhihenbuwa, 2007; Dutta 2011). From this perspective, people's cultural values are central to the ways in which they conceptualise problems and the developed solutions to these problems. It is in this context that *Ubuntu* has been offered in this thesis as a transcendent framework for mainstreaming participation of PLHIV in social change communication for HIV prevention in African communities.

The next chapter further explores the Activists' configuration of disclosure in relation to the GIPA principle of visible participation. The chapter interrogates why the Activists predicate their involvement to disclosure. To answer this question, the chapter appeals to the culture-centered approach to social change which holds that the way the Activists configure participation cannot be divorced from local realities that include life conditions, values and cultural circumstances.

CHAPTER EIGHT

SOUTH AFRICAN PEOPLE LIVING WITH HIV'S CONFIGURATION OF PARTICIPATION IN THE HIV RESPONSE

Serostatus disclosure to sexual partners has been shown to correspond with safer practices. Scholars who endorse this view have found that disclosure has the capacity to reduce the risk of transmission by about 40% (Kalichman and Lurie, 2010). The last chapter discussed AIDS Activists who participated in this study as having a considerably high regard for visible participation predicated on disclosure. It has also highlighted that this configuration of participation challenges the Greater involvement of people living with HIV/AIDS (GIPA) principle which holds that PLHIV have the right to choose to be involved without making their serostatus public (see UNAIDS, 1999). This palpable contradistinction is a significant aspect underlying the intent of this chapter to understand the contextual filters that shape participants sense making and configuration of meaningful participation as that predicated on disclosure. To account for this contrast, this chapter argues that the context, present realities and concerns that the interviewed AIDS Activists encounter today are not necessarily the same with those within which GIPA was formulated and set to address. Indeed, as the culture-centered approach to social change holds, local filters bear and account for the Activists' configuration of participation as well as their understanding of disclosure.

Informed by the contextual and realist notion of truth whose underlying assumption is that we can neither understand nor influence behaviour unless we understand the structures and systems that influence personal behaviours and practices (Airhihenbuwa, 2007), this chapter examines contextual factors and values that influence the Activists' (a) equation of involvement to disclosure

and (b) perception of non-disclosure as problematic. Assessing contexts is thus important in reconciling the above conundrum: the conceptualisation of participation through the conventional/global framework such as GIPA, versus the way the Activists configure participation as shown in Chapter Seven.

In light of the findings presented in the previous chapter, this study finds GIPA's principles of 'invisible' participation to be not only inadequate but unhelpful in the task of mainstreaming participation of South African PLHIV in HIV prevention. The way the interviewed Activists configure participation suggests that mainstreaming their involvement in social change communication for HIV prevention is likely to be successful through an approach that premiums disclosure. The sections below examine the Activists' accounts that reflect their understanding of disclosure as well as its relevance in relation to social change communication for HIV prevention. Ways in which the Activists find non-disclosure problematic are also highlighted.

On (in)visible participation: The problem of non-disclosure

Disclosure; hereinafter referred to as visible participation (see UNAIDS, 1999) is a popular and common practice upon which the Activists predicated their involvement. In sexual relationships, they consider serostatus disclosure not only as a signifier for safer sex intentions but also functions as a motivation to stimulate dialogue with sexual partners on how to protect each other from infection and re-infection (*CFA* Interview: October 8, 2013). In the work place, the Activists consider disclosure as a signal of concern for people around as it enables them to follow appropriate safety procedures necessary in cases wherewhere physical contact waswas involved *(BFA2* Interview: November 19, 2013*; CMA* Interview: November 29, 2013*).* Such a practice by the Activists can be attributed to a sense of responsibility towards other people that they reported to have. A sense of responsibility prompts them to feel obliged to inform people around them about their positive status in order to ensure that they are protected.

As discussed in Chapter Two, responsibility towards the wellbeing of other people is a central aspect of *Ubuntu*. People possessing *Ubuntu* should have a conscience that is oppositional to causing harm on other people, a conscience of which manifests in self-respect as well as respect for the dignity of the other person (see Tutu, 1999). Disclosure is thus deemed not only important in limiting harm (infection) on other people but also as a sign of respect for self and the other people. In this light, non-disclosure or invisible participation is deemed unhelpful and therefore undesirable. Because of this conviction, visible participation is not only exemplified by the way the Activists are involved in the HIV response but disclosure is a central message in their discussions with their audiences *(BFA1* Interview: October 12, 2013*)*. The Activists in this study not only articulated beneficial aspects of disclosure but they actually frown upon non-disclosure.

According to *WFA1 (*Interview: October 21, 2013*)*, PLHIV involved in sexual relationships must disclose their serostatus as a way of giving their partners a choice to decide whether to continue with the relationship or not. For her, partners have a right and they need to decide for themselves whether to be involved with a seropositive person. Dialogue between two partners is deemed important as it affords each one an opportunity to participate in deciding on relationships and other matters that affect their lives. Democratic participation and decision making is a cardinal principle for social change (see Dutta, 2008; Freire, 1970). Engaging in dialogue suggests that both partners value each other as well as their freedoms to make decisions about any behaviour that can expose them to the risk of HIV. Here disclosure is important because partners can discuss safety matters that need to be taken into consideration if they decide to carry on in the relationship *(WFA1* Interview: October 21, 2013*)*. This view was further reiterated by *BFA1* who stated that people must be in a position to decide whether they would like to be involved with someone who is HIV positive and take the necessary precaution. "I must not hide my status

because when you are in a relationship, you make sure that it goes sexual. So I need to disclose my status to him so that we protect" (*BFA1* Interview: October 12, 2013).

As indicated by *BFA1* above, protecting one another is one important reason that drives her visible participation. The interviewed Activists believe that disclosure of seropositive status to a person one intends to be intimate with is one of the important behaviours germane to reducing chances of infecting them. Here disclosure is presented as having potential to allow partners to take precautions to protect themselves from HIV infections (see also Kalichman and Lurie, 2010). Conversely, confidentiality or non-disclosure does not afford an opportunity for protection. It is for this reason that confidentiality is shunned and discouraged. It was noted in Chapter Seven that sero-conversion prompted the Activists to realise the value of life, and therefore saw a need to educate and protect others. Consideration of each other shown by the Activists is not different from the African worldview that values coexistence and sensitivity to the wellbeing of the other discussed in Chapter Two (see Metz, 2007b; Tutu, 1999; Shutte, 1994).

From the same African worldview, visible participation is also considered by the Activists as very important in sexual relationships especially between partners who want to bear children. Activists indicated that sexual intercourse is associated not only with procreation, but that child bearing was invaluable in their communities. This was succinctly put by *HP2*, who said that regardless of the fact that she lives with HIV, one day she will find someone who wants to date her or make an honest woman of her. For her the problem is:

> If you are not talking prevention, if you are not talking disclosure then that becomes a problem. Because at the end of the day, we as African believe that if someone comes and say I want to marry you, yes we know they are marrying you for love but then at the end of the day they are marrying you so that you

can make sure that umuz' ka baba [the husband's generation] doesn't die. You have to bear children and lots and lots of children. So bearing children requires not using protection at some point and it is gonna put someone in danger. By not disclosing you are only putting yourself and your partner in danger (*HP2* Interview: November 5, 2013).

It is apparent from the above that *HP2'*s worldview places importance on child bearing and views that as every woman's duty. That condom use is no option for those intending to fulfil this obligation is unarguable. As unprotected sex exposes people to the risk of HIV infection - as *HP2* is clearly aware and afraid of - she (as with other the Activists) believe that it requires a respectful and caring seropositive person to avoid transmission by insisting on protection, or at least by disclosing to the partner. It is in such scenarios where the Activists deem non-disclosure by infected partners extremely indecorous and problematic. *HP2*'s concern, as with all other Activists, is that by not disclosing seropositive status in such scenarios, PLHIV put their partners in danger. As with the *Ubuntu* ethic discussed in Chapter Two, above *HP2* is not only concerned about herself but is equally sensitive to the well-being of the others.

Child bearing is a concern not only for *HP2* but for other the Activists as well, especially black Activists. Neither is it mere rhetoric for them. During the time of the interviews, *HP4* was nursing a 3 month old seronegative baby. During the night of 11 November 2013, few hours before our interview the following morning, *HP3* - who is married to a serodiscodant partner - featured on *SA.fm* radio program discussing with his wife and family doctor various issues including plans to have a child. As he would share with me the following morning, disclosure, love and caring for the wellbeing of each other are the key values that sustain their marriage and ensuring that the wife remains uninfected. Also, *BFA2* had a pair of ten year old seronegative twin daughters whom she conceived after learning about her seropositive status.

The desire to bear children was not the only factor reported to be affecting condom use as experienced by the Activists. Black women Activists reported general aversion to condom use by their black male partners. Speaking from experience, *BFA2* warned thus: "You know black men; they don't want to use condoms. So it is better to tell the person that I am HIV so that he knows and we protect" (*BFA2* Interview: November 19, 2013).

Because of their sensitivity to the welfare of the reported condom-averse men, women Activists as such as *BFA2* consider disclosure as an important motivation that stimulates discussions on safe sex with the men. According to most the Activists, disclosure can ensure that partners are protected from infection. Inversely, non-disclosure is viewed as being insensitive to the wellbeing of partners as no effort would be taken to prevent HIV transmission. As indicated earlier and shall be shown throughout this chapter, sensitivity to the welfare of the other as well as respecting the dignity of other people are central values of *Ubuntu*. Such values that are believed to inform social practices and relations among African people are clearly epitomised by, and find strong expression in the Activists' configuration of disclosure. However, it is important to reiterate that not all Africans l*et alo*ne PLHIV possess these values. Be that as it may, *Ubuntu*, as already shown in Chapter Two and will further be shown is a social conscience that is imparted through socialisation (see Munyaka and Motlhabi 2009; Kamwangulu, 1999, Prinsloo, 1996). What this suggested is a possibility that these values can still be implanted in others who don't have them.

In her previous marriage, *BFA2* was recklessly infected by her (black man) husband who did not use protection regardless of his knowledge about his seropositive status. Similarly, unprotected sex in her current relationship resulted in the infection of her (condom-averse black man) boyfriend. *BFA2*'s experience lays bare two important points which had concurrence among other the Activists. Firstly, her experience demonstrates that non-disclosure allows

risky sexual behaviour to occur. The husband did not disclose to her, and she subsequently failed to disclose to her current boyfriend. Secondly, her contrition and convictions suggest that disclosure of HIV positive status by the infected partner to people they intend to be intimate with permits the partners to be involved in the decision-making process about whether to allow HIV transmission to occur or not. Even though she had been deliberately infected by her previous partner, *BFA2* is contrite for having infected her current boyfriend. Her contrition can, therefore, be associated with a conscience that is oppositional to inflicting harm on the other person, a conscience that has an inclination to the sensitivity to the wellbeing of other people espoused by *Ubuntu.*

Further lessons can be learnt from *BFA2*'s experience as both the 'infected' and the 'infector'. The dominant discourse about the African HIV epidemic presents women as powerless people who cannot negotiate sex with their male partners (Leclerc-Madlala, 2001). They are often presented as victims of callous and often elderly opulent men who cajole them into sex and as a result infect them with HIV (Mawar, et al., 2005; Leclerc-Madlala, 2008). Generally women do not necessarily have the power to force their partners to wear a condom (AVERT, 2014). Amply demonstrating this view are cases of *BFA2, CFA, WFA1* and *WFA2* as 'victims' in the hands of their male partners who recklessly infected them without disclosing their known seropositive status. However, this taken for granted truth is faulted by *BFA2*'s experience with her latest boyfriend whom she infected because she did not disclose her known seropositive status. While the boyfriend's behaviour affirms both notions that black men do not like condoms, and that women cannot negotiate sex, here the same powerful man is victim to the same powerless but seropositive woman. While the 2012 South African National HIV Prevalence, Incidence and Behaviour Survey (SHSRC, 2014) suggest that condom use has generally decreased, black Africans are

reported to use condoms more (41.9%) than the other race groups with white (14.7%); coloured (18.4%), and Indian (14.4%) (SHSRC, 2014: 73).

In light of the foregoing discussion about the potential function of disclosure as a motivation for safer behaviour, it can be argued that seropositive people - regardless of gender, age, social status – have power to cause partners and people around them to take safety precautions by disclosing their status. However, this view is faulted by the argument that it is not solely the responsibility of PLHIV to protect the negative as each person must be responsible to protect themselves against HIV infection. Considering procreation obligations noted earlier as well as the power relations enacted in heterosexual relationships (Mawar, *et al.,* 2005), shared responsibility in such unions becomes an impractical reality. It is in this context that this study argues that disclosure can transform a seropositive person to become more powerful when it comes to influencing discussions and decisions that can result in preventing HIV transmission. This is because it is only the 'infector' who is a factor in the transmission matrix, otherwise without an 'infector' there is no transmission to talk about (Kalichman, 2005). By pursuing this argument, the study attempts to make a case that if it is true that no one wants HIV, then it is a seropositive partner who has power to decide whether transmission takes place or not by disclosing to the partner. Unless the negative partner consciously allows it to happen, no transmission can happen.

However, the power envisaged above is possible to enact if PLHIV possess what the Activists described as conscience, self-respect and if they respect other human beings. As noted in Chapter Two, these are values that people can acquire through socialisation. As the Activists would concur, had *BAF2* been sensitive and respectful enough and disclosed her seropositive status to her current boyfriend, safer sex decisions could have been taken and transmission avoided. Women Activists indicated that in cases where they have no power to negotiate, they appeal to disclosure as a means of preventing HIV transmission.

As with *BFA2,* other Activists (*WFA1, WFA2, and CFA*) revealed that they had also been deliberately infected by their partners who were already aware of their status. Here it is important to note that the fact that only women revealed that they were deliberately infected does not suggest that male participants cannot be deliberately infected too. Perhaps, unlike the above female Activists, it could be that men did not have a chance to discover that the partners who infected them already knew about their seropositive status. While the deliberately infected female Activists are not happy about what happened to them, they do not have any intention to pass on the virus to other people. This is because, as *CGA1* stated, they do not want anybody to go through the same experience they have had with HIV. "I do not want somebody else to go through what I went through. I mean who wants to get sick? So I do not want to pass it on. I just cannot do something that puts someone's life in danger, getting the virus" (*CGA1* Interview: November 27, 2013).

The reason why the Activists do not like to pass the virus is indeed their sensitivity to the wellbeing of other persons. Because they have been deliberately infected by their partners, they have a choice to infect other men as a form of revenge. Due to their self-worth and conscience, they have chosen to educate people about HIV. This was aptly put by CFA who said that "I had a choice every day to go out and infect every man that I come across, and yet I choose to educate every man that I come across and that's the responsibility I have, and that's what I want to transfer to other people" (*CFA* Interview: October 8, 2013).

Non-disclosure of HIV infection was reported to have devastating psychological effects on a person. The Activists believe that silence about one's sero-conversion, keeping that information as a secret, can be stressful and burdensome among the infected who always contemplate ways of coping with the new condition. If not changed, stress results in the rapid deterioration of one's health, a situation that can lead to premature death (Manchester, 2004).

However, for all the Activists, disclosure provides relief to this burden and has a cathartic effect. This was clearly put by *BFA1* who said that "I needed to take out this thing in me because it was stressing me a lot. Disclosing helped me a lot. After disclosing, everything was going well with me. I got well" (*BFA1* Interview: October 12, 2013). The same sentiments were echoed by *WGA* who indicated that he had witnessed how other people suffered because they were scared, having nobody whom they felt they could talk to about their status. He does not wish to be like them. For him, silence "was next to a burden on their shoulders. Since I disclosed, I felt at harmony" (*WGA* Interview: October 29, 2013). The above sentiments mirror Manchester' (2004) findings from her conversations with African positive women who were among the first in their respective countries to publicly disclose their serostatus. The African women's activism is reported to have been possible because of disclosure, which according to one of Machester's participants was "like a huge weight off their shoulders. They feel really different because they are not alone" (Manchester, 2004: 89)

Compounding the burden of secrecy is the fact that seropositive people delaying accessing treatment as a result of hiding their status. *CGA1* has a low opinion on PLHIV who keep their status secret because they are afraid of being noticed.

> You are stupid because nobody wants to go to Blue Roof [an AIDS Service Organisation that dispenses antiretroviral drugs] because if you go there people will know you are positive. So I think about it and say, ooh my God can you die for no reason, because you are too afraid to let people see you get treatment (*CGA1* Interview: November 27, 2013).

The above discussion presents different situations that for the interviewed AIDS Activists warrant disclosure. The devastating impact of non-disclosure both to self as well as to other people has been highlighted. Because of this

impact, the Activists subordinate their participation in the HIV response to disclosure or visible participation which is driven by a wish not only to help other PLHIV to cope with the virus but also to share their stories so much so that other people are made aware about the existence of HIV and are educated about it the ultimate aim being to prevent new infections.

In light of the above, and in accordance with the objectives of this study that is to mainstream participation of PLHIV in HIV prevention, below are the Activists' accounts of what disclosure means to them in the context of HIV prevention. Here it is important to note that visible participation in the HIV response is considered by the Activists as extremely important in HIV prevention in many ways. In sexual relationships for example, disclosure to sexual partners is considered as (a) giving partners an opportunity to participate in deciding whether transmission takes place, (b) a sign of respect for the humanity of the other person whom they do not want to harm; conversely non-disclosure (c) is a burden on the shoulders of the infected, and it also (d) limit opportunities for the seropositive to access treatment and support. Indeed disclosure is not only important in the context of sexual relationships (see Manchester, 2004; Paxton, 2002). As such, different views were expressed as to why disclosure is important. However, that sexual transmission is dominant in the (South) African epidemic is not in dispute (see HSRC, 2014; UNAIDS, 2013). Below is a discussion on what the Activists feel about disclosure in the context of prevention, mainly but not exclusively through sexual relationships.

Granting others an opportunity to make choices
The Activists in this study view HIV/AIDS as a critical condition that they would never wish other people to have. For them it is inconceivable to be in a relationship that exposes another person to harm due to non-disclosure. As such, they consider disclosure as granting the other person an opportunity to make choices. *CMA* admonished seropositive people who engage in sexual

relationships with others and consequently infect them due to non-disclosure of their serostatus. He first considers this as a sign of disregard for self. "Going around infecting other people is stupid. You don't respect your own self. You don't respect your own life. I can tell you. You see me; I am going to die of old age. The medication is there. This thing of going around; you end up infecting yourself and shorten your lifespan" (*CMA* Interview: November 29, 2013). Regard for each other in a relationships as well as each other's opinion allows for freedom of expression and articulation of choices that are beneficial to both parties *(HP3* Interview: November 12, 2013*).*

Respecting self is thus considered as a precondition for respecting the other person. In the context of HIV prevention, the Activists believe that respecting the other entails giving them an opportunity to decide if they wanted to be involved in a relationship with an infected person, rather than infecting them without their knowledge, or as *WFA1* - who was wilfully infected by her partner who did not disclose to her – puts it, non-disclosure denies the partner an opportunity to decide if they want to continue a relationship with an infected person. "You have to be in a position to decide whether you would like to be involved in someone who is HIV positive and take the necessary precaution" (*WFA1* Interview: October 21, 2013).

It is important to note here that while the Activists maintained that PLHIV must disclose in order for the other partner to decide, this does not suggest that all seronegative people always opt out of relationships when their (prospective) partners disclose their seropositive status. Indeed the most challenge PLHIV face after disclosure is abandonment by their partners (sees Manchester, 2004) However, two male Activists who participated in this study *(HP3 and CMA*) are married to discordant or seronegative partners. They disclosed their seropositive status to these women prior to the commencement of their relationships, and they consciously decided to establish the relationship.

As noted earlier, disclosing to people with whom one intends to be intimate allows the other person to make a conscious decision about whether or not to engage in sexual relations with them. The way the Activists consider the autonomy of other people mirrors the Kantian philosophic configuration of human beings as autonomous agents who have the right to take own decisions (see Chapter Two). By virtue of them being rational autonomous agents, Kant postulates that human beings have dignity and thus deserve to be respected (Paton, 2005) at least in this case by affording one an opportunity to decide not to deliberately infect them.

For *HP2* her respect for self stems from *Ubuntu* values that were imparted in her by her parents and community.

> I grew up in a coloured family. My grandmother is coloured and she made sure that *Ubuntu* uyasebenza [*Ubuntu* is applied]. You know it takes a whole village to raise a child. If I did wrong my grandmother did not mind having a neighbour come and spank me. Right now it is very difficult. But if we go back to loving ourselves, that is where we have lost it…If you love yourself, you will know that by going around infecting other people, you are re-infecting yourself, you are reducing your chances of living a long life. So that on its own should mean something to a person (*HP2* Interview: November 5, 2013).

Consistent with the view that *Ubuntu* is a collective social conscience created by socialisation through generations (Nussbaum, 2003) *HP2* above points out that it was not only the responsibility of her biological parents but the whole community to make sure that proper values are instilled in them. From an ecological perspective to health communication, *Ubuntu* as a social conscience and its influence on individuals finds expression in Kincaid *et al.*'s (2007) SEMCHB model that has already been outlined. The model is in accordance with *Ubuntu* values which, as has been discussed, privileges interdependence, collective responsibility through values such as sisterhood, brotherhood and sharing. These values enjoin individual persons not only to respect the dignity,

but also to become sensitive to the wellbeing of other people. By so doing, one affirms their own and others' humanity.

In *Ubuntu* self-worthiness is a cardinal principle which is emphasised not by perceiving an individual as an isolated static self but as a person with a shared identity and communal sense of self as illustrated by *HP2*. Here, one sees everyone as their kin - other people's children as their own, other men as brothers and other women as sisters. The foregoing suggests that health decisions that individuals make - as illustrated by the social ecology model of communication and health behaviour - are therefore made not only in regard to the other person but in regard to the societal norms and values. Here the relevance of the culture-centered approach to social change within which this study is framed becomes apparent.

Regard for the other was also emphasised by the interviewed AIDS Activists that regardless of whether the other partner is already infected, disclosure remains necessary as the partner's status does not absolve one from their own responsibility. This was aptly put by *BFA2* who, rueing the day she infected her boyfriend, regretted that "even if he had his own HIV, I am living with a guilty conscience because I did not give him a chance to decide for himself if he wanted to use a condom or want to carry on with the relationship" (*BFA2* Interview: November 19, 2013). While BFA2 claimed that it was a mistake on her part, other Activists noted with concern that some PLHIV do not disclose as they would be suspecting that their partners are also infected. However, there was concurrence disclosure was an individual responsibility which must be enacted regardless of whether others are infected or not.

Thus *BFA2* was contrite for not having given her boyfriend a chance to decide. An ability to take own decision is known as self-determination and is one of the desired outcomes of social change. In both *Ubuntu* and Kantian postulates, self-determinism is a basic goal that ought to be preserved out of respect for

the dignity of the person (see Metz, 2007a; Altman, 2011). However, as argued in Chapter Two, the Kantian conception of a person as an isolated and static self cannot not adequately explain what constitute humaneness in interdependent African societies that privilege shared identities. Shared values are deemed a critical ingredient for social change where self-determination is achieved through dialogical and respectful communication between the people seeking to address a common problem to achieve a common goal (see Figueroa *et al.,* 2002; Dutta, 2011).

By regretting the consequences of her non-disclosure to the well-being of her boyfriend, *BFA2*'s story above tangibly illustrates why the Activists encouraged disclosure. Equally telling were stories of *CFA, WFA1* and *WFA2* who were deliberately infected by their men also due to non-disclosure.WFA2 quoted earlier claimed that she slept with a man who did not disclose to her that he was HIV positive. Affirming the view that disclosure grants others chance to decide, she believes that she should "have been given the choice to decide if I wanted to be with him or not because I don't think I would have slept with him if I knew that he was HIV positive" (*WFA2* Interview: December 4, 2013). Because of the lessons learnt from experiences such as that illustrated by *WFA2,* the Activists encourage other PLHIV to disclose so as to create opportunities for their partners to actively participate in relationships. *WFA1* encourage other PLHIV to "give the partner a choice to decide whether to continue the relationship or not. They need to decide for themselves pretty much" (*WFA1* Interview: October 21, 2013).

In the context of *Ubuntu,* a person's freedom depends on personal relationships with others in the community as one's desire for freedom is realised to the full the more they are fully involved with others. *WFA1* above conceptualises people as relational beings who depend on one another for their development. Ford *et al.* (2003) suggest that communication begins with dialogue between people who respect each other, a dialogue without which social change becomes

difficult to achieve. It is in this sense that the Activists interviewed in this study also view disclosure as respect for the other.

As discussed in Chapter Seven, the above Activist views by sharply contrast GIPA precepts on disclosure. In this study's view, GIPA precepts bear hallmarks of extreme liberal ideologies that privilege freedom of the sacred self from intrusion by others. It appears that GIPA even goes beyond Kantian postulates which, while also giving prominence to individual decisions, can be interpreted in this context to mean that a decision not to disclose can only be deemed right if it is out of a good will. The spirit of good will can perhaps be viewed as not different from the spirit of sisterhood and brotherhood that find expression in the Activists' subordination of involvement to disclosure, a practice that not only signals safer intentions but also their aversions to causing harm on other people by infecting them with HIV.

Brother/sisterhood and sensitivity to the well-being of the other

The AIDS Activists also consider disclosure significantly as an expression of the values of brother/sisterhood inherent in communal societies. In African cosmology embodied by *Ubuntu*, the universe is built upon the principles of coexistence depicted through the relational nature of persons (Mets, 2007; Shutte, 1994). Here individuals are linked to the collective through values of brotherhood or sisterhood, sharing, caring, respect, being sympathetic, and sensitive to the needs of others (Tutu, 1999). Ideally, *Ubuntu* grants people their human dignity so much so that people possessing *Ubuntu* values are averse to actions that are harmful to other people. Harmful actions include deliberate transmission of HIV.

Although the Activists do not view HIV as a killer, they perceive it as a critical condition that they would not want other people to have. Transmitting HIV is thus regarded synonymously with a death sentence for the other person; a behaviour they all claimed does not conform to brother/sisterhood values

implied by *HP2* when she said "I do not want to be the cause of my brother being HIV infected, because of my negligence" (*HP2* Interview: November 5, 2013). Such values, illustrated further below, are shared among all the Activists regardless of their racial category. A white Activist warned that one "should not put anybody else at risk…I would hate to think that I put potential death sentence into somebody" (*WFA1* Interview: October 21, 2013).

That the act of disclosure by the Activists signals a safer intention is unarguable. The practice, as highlighted earlier, is aimed to protect seronegative people around them. The Activists all agree that no person is ready to contract HIV, and as such they are not prepared to be agents for their infection. This attitude among the Activists reflects their sensitivity to the dignity of other people. As such, the Activists importune other PLHIV to disclose to all people around them as means to instigate protective behaviour. Dube (2009) also found that keeping serostatus confidential at personal level - as advanced by GIPA- is tragic in most African cultures who view individual health as inseparable from the others. She gives an example of a common practice among African communities where family members and relatives take care of their kin. Here if they do not know the sick relative's status, they risk being infected. This illustrates the incompatibility of the confidentiality principle espoused by GIPA.

Interviewed Activists also expressed the same fear as above. Thus *CMA* felt obliged to disclose to his colleagues as a way of protecting them. "We work with grinders and drilling machines. There is a possibility of accidents. In the event of an accident somebody jumps on to assist you not realising the dangers. So I let them know in case they get to assist me. They have to keep a safe distance (*CMA* Interview: November 29, 2013).

Similarly, other the Activists such as *CGA2* also encouraged PLHIV to disclose in consideration for the people they live with. In case of emergency they need to

know what they can and cannot do. The Activists, however, expressed concern that because PLHIV were uncertain about other people's reaction when they disclose to them, most PLHIV do not disclose. Be that as it may, the Activists suggested that in sexual relationships if one thinks that their partners will not accept their status, there are ways to protect them from infection least of which is to end that relationship rather than infecting the partner without their knowledge (*CMA* Interview: November 29, 2013; *WFA1* Interview: October 21, 2013).

Indeed reflecting a sense of typical brotherhood and sisterhood which does not encourage confidentiality at personal level, *HP2* believes that infecting somebody literally meant that you will have infected your brother or sister.

> For me, I would not want a person to be in any kind of harm because of me. I would not want any person to be sad, depressed or anything because of me. So I make sure I do unto others as I would want them to do unto me because if I am going to infect you, believe me, probably we separate for whatever reason. You then go out and date someone. I did not tell you that I am positive, and you did not go for tests. You date someone and infect that person. Eventually it will come back to one of my family members. I do not want to be the cause of my brother being HIV infected, because of my negligence, because of me being selfish (*HP2* Interview: November 5, 2013).

There is no doubt that HP2's worldview above resonates with *Ubuntu* values already discussed. Indeed she indicated (as quoted earlier in this chapter) that she was raised through *Ubuntu* values. In light of GIPA's incompatibility highlighted earlier, what *HP2* suggests above is the possibility that *Ubuntu* has in mainstreaming participation of PLHIV in HIV prevention. This is the central argument that this thesis posits and the rationale informing the proposition of an *Ubuntu* model outlined in Chapter Nine. The point that not every person in Africa possesses *Ubuntu* values has already been made. Its reiteration here is necessary in so far as it suggests that if more PLHIV are socialised to embrace

values as expressed by *HP2* above, it is likely that a change to the course of the (South) African epidemic might be enhanced.

While the Activists clearly expressed that in as much as they might have accepted living with the virus, they indicated that they are not happy with it. Due to the physical and emotional pain they endure, the Activists believe that no one wants to be infected. Expressing this concern, *CGA1,* as with HP2 above*,* indicated that he does not like to be an agent for other people's suffering.

> I am not happy I got the disease but I am just accepting but really I do not want somebody else to experience what I have gone through. I mean who wants to get sick? So I do not want to pass it on. I do not like it, so I do not like anybody else to go through the same thing. So why would I knowingly pass on something that I am not happy with. So you always consider the next person considerate. I just cannot do something that going to put someone's life in danger, getting the virus (*CGA1* Interview: November 27, 20131).

The above shows not only a sense of brotherhood depicted through one's sensitivity to the dignity and welfare of other people but also reiterates a common view among the Activists that disclosure is important in social change communication for HIV prevention. What this further suggests is that utilising GIPA precepts to mainstream participation of PLHIV with such a view on disclosure cannot change the course of the African epidemic. In light of the foregoing, if the course of the African epidemic is to be changed, there has to be a structural system that not only allows but conventionalises the notion of disclosure as a sign of respect, responsibility, interdependence and a sign of brotherhood and protection of others.

According to the interviewed Activists, participation in the HIV response means protecting each other against HIV infection. To achieve this task, disclosure is deemed important as it is believed to result protection. Indeed it has been

noted earlier that disclosure has a protective efficacy of up to 40% (see Kalichman and Lurie, 2010). Thus *BFA1* believes that by disclosing to her partner, "I want him to know that I am HIV positive so that we protect. It is better to disclose to your partner because the person will understand and use protection during sex. It is also important for prevention of secondary transmission because you don't know if that person is taking ARVs or not" (*BFA1* Interview: October 12, 2013).

As a signal for safe intention, disclosure was synonymous with protecting each other, the already infected as well as the negative person. The discourse of protection is again not foreign in *Ubuntu*. The whole essence of brotherhood and sisterhood is to be there for each other, to affirm the humanity of the other as it is "only in terms of other people [that] the individual becomes conscious of his being, his own duties, his privileges and responsibilities towards himself and towards other people" (Mbiti, 1969: 108). Regard for each other thus involves protecting each other from danger. Thus people with *Ubuntu* find satisfaction and fulfilment when they affirm the dignity or - as *HP2* quoted earlier demonstrates - protect others.

Fulfilment manifests itself among the Activists in the form of life with a free conscience. Conversely, people who act contrary to this principle never have free lives (see Manchester, 2004). Thus *WGA* asserted that because of his conscience, he would never infect another person as he would never forgive himself. "It is so disheartening for somebody to say 'You! I am sick because of you'. You know... Yeah, I wouldn't want that. I took a great interest and say I have HIV but I don't want my friends to die of it" (*WGA* Interview: October 29, 2013). It is *WGA*'s purpose in life - as with *CFA* noted in Chapter Seven - to encourage other PLHIV to live their lives with the knowledge that they are not infecting anyone. Because of this resolve, *WGA* is open about his status and has informed all his partners. He indicated that he has always disclosed to his partners because confidentiality does not stop them from insisting on not using

a condoms, a situation that puts them at risk of HIV. He declared therefore that he will not allow that to happen, and has never allowed it *(WGA* Interview: October 29, 2013*)*.

Also illustrative of the above are *HP3* and *CMA's* stories who, as already mentioned, are both married to serodiscordant partners. *CMA* indicated that he met and confided in his wife about his serostatus. For him, disclosure helped they both know the precautions that have to be undertaken. "How could I be in a relationship with her and everyday condomising when she doesn't know? I mean she is my wife. I would end up infecting her. I gonna make sure that she is protected" (*CMA* Interview: November 29, 2013). Evidently, it is because of his sensitivity to the welfare of his wife that through disclosure *CMA* manages to protect his wife from infection. *CMA* and other the Activists such as *BFA2* and *CGA2* have disclosed at their workplaces as they believe that it allows other people around to be careful so much so that they do not put themselves in risk of contracting HIV whenever they are in physical or possibly even sexual contact with them.

It can be argued in light of the foregoing that the presented Activists views can plausibly be described as mirroring the interpersonal humanity espoused by the *Ubuntu* dictum 'I am because we are'. This is possibly true when looking at their warning that everyone has a responsibility to protect their partners and people around them as well as the fear that if you infect someone, you will have infected your brother or sister. From an *Ubuntu* perspective which embodies aspects of interdependence, communalism, sensitivity towards and caring for others, an individual is born out of and into the community and is always part of the community. As such, "whatever happens to the individual happens to the whole group, and whatever happens to the whole group happens to the individual. The individual can only say "I am because we are; and since we are, therefore I am" (Mbiti 1969: 108):

I am because we are? Responsibility to protect the the other

Although the acknowledgement that PLHIV have a responsibility to protect their partners is not articulated in GIPA, the injunction on PLHIV to protect people around them is not new. It finds expression in the original manifesto of the participation of PLHIV, the Denver Principles whose fourth recommendation for PLHIV clearly states that "…we feel people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status" (Denver Principles, 1983). Indeed this same view characterises the configuration of participation by the Activists interviewed for this study who subordinates their involvement in the HIV response to disclosure because they understand it not only as a sign of responsibility by PLHIV towards themselves as well as to people around them. Here disclosure is a signal for safe intentions which is arguably driven by good will to protect others from infection.

However, as *HP2* indicated, responsibility is not for PLHIV alone but has to be reciprocal. "As much as it's my responsibility to make sure that you are protected, it is also your responsibility to protect me because at the end of the day it is not about me infecting you, but you re-infecting me" (*HP2* Interview: November 5, 2013). There may be no better way of illustrating the extent to which the Activists embrace the *Ubuntu* dictum 'I am because we are' than through this statement by *HP2*. As shall be further demonstrated ahead, the notion of responsibility is considered highly by the Activists if PLHIV are to meaningfully participate in social change communication for HIV prevention.

While no research is known to have been conducted to assess the impact the responsibility clause in the Denver Principle has in containing the Western epidemic, initiatives aimed at inculcating such values were initiated in the 1980s by the US Centres for Disease Control and Prevention (CDC). Notable among these initiatives is the serostatus approach to fighting the epidemic (SAFE) programme explored in the previous chapters and mentioned again early in this chapter. Even though the containment of HIV in the West can be

attributed to different initiatives, SAFE is acknowledged to have played a pivotal role in the stabilization of the Western HIV epidemic (see Serovich and Mosack, 2003; Janssen, *et al.,* 2001).

If indeed the reported contribution of SAFE to the success of the HIV response in the West is true, the Activists' reflections reported in this study - that are indeed similar to those made at Denver four decades ago - may not only be helpful but can be considered as a long overdue and appropriate approach to be applied in response to the sub-Saharan epidemic. This conclusion is based on the fact that the approach resonates with the cultural context in the region which believe not in individual but in shared confidentiality as one's health is inseparable from others (Dube, 2009). That these reflections seem to embody *Ubuntu* values which articulate the same principle of responsibility, a proposition is made in the next chapter as to how the region can take advantage of the *Ubuntu* values to mainstream participation of PLHIV in social change communication for HIV prevention.

Intimating values akin not only to *Ubuntu* but also to those articulated through the Denver Principles especially with regards to disclosure, *WFA1* holds that if one values their own integrity, they should not put anybody else at risk. "I would hate to think that I put potential death sentence into somebody, I could not live with myself. Me as a person I was honest with myself. I would rather not to be in a relationship than not to tell the other person which is what happened with me" (WFA1 Interview: October 21, 2013).

As shown above, the act of disclosure serves two functions. It firsts serves to avoid inflicting harm on the other person (putting potential death on somebody), an act that for *WFA1* is indicative of one's integrity. As such, disclosure secondly is also indicative of self-respect. Respecting self and the dignity of the other by not transmitting HIV to them was described by the Activists as responsibility to self as well as to the next person. According to

WFA1, if one does not have respect for themselves, they cannot respect someone else, "it's not possible. You obviously do not value your own life. If you value your own life it means you value the lives of people around you, including your family. It always begins with you" (*WFA1* Interview: October 21, 2013).

Responsibility to self and the other manifests itself through understanding and loving oneself as well as taking care for oneself and other people. As *HP4* indicated, respect helps in HIV prevention because if people understand themselves, if they love themselves, they do not sleep around without protection *(HP4* Interview: November 7, 2013*)*. Also during one of her workshops on HIV prevention, *CFA* was appalled by revelations by a seropositive gay man who participated in the workshop. Her participant reported that he had unprotected sex with other men, exposing them to HIV without disclosing to them. Due to her values that can be described as resonating with Ubuntu, CFA had difficulty in understanding how he consciously chose to have unprotected sex with men, married or not knowing that he was positive.

> He knew the men belonged to families and had wives and children, yet he chose to subject them to STIs and HIV. Did their wives and children deserve that? I know there are two bodies in an intimate relationship so I could not eliminate the married man's sense of responsibility. I thought about whether or not they cared about infecting their wives (*CFA* Interview: October 8, 2013).

Echoing the above sentiments, *WFA1* described people who consciously infect others as irresponsible sub-humans who do not have self-worth and respect for the other. If infecting the other makes one 'sub-human' as WFA1 suggests, then indeed one's self worthiness, as *Ubuntu* holds, can be achieved only through dignifying the other (see Mbiti, 1969). Infecting the other is characteristic of a person that has no self-respect, nor respect for people around. For *WFA1* "probably they are psychopath, there may be other issues

that you may have no conscience to do but something like that there is no excuse. If you can talk, you can state the fact. So there is no excuse of infecting somebody if you know your status" (*WFA1* Interview: October 21, 2013).

The ultimate goal of a self, according to *Ubuntu* should be to become fully human (Shutte, 1994, Tutu, 1999). Individual humanness here is measured in common with others. Fully human beings with *Ubuntu* as stated by *HP2* are averse to harming other people. She does not feel good hurting other people and always makes sure that does not get on something that at the end of the day is going to hurt somebody. "I am not a saint, I am not an angel. I am just a human being who got and sees *Ubuntu* in everybody and tries to protect each other in every way possible" (*HP2* Interview: November 5, 2013).

Indeed as she admits that she possesses and sees *Ubuntu* in every person, the *Ubuntu* consciousness embodied in the dictum 'I am because we are' is evident in the way *HP2* seems to be averse to causing harm on other people. It is not surprising, therefore, to find that she and other Activists view those who disregard the wellbeing of others less human, and lacking *Ubuntu.* Fully human beings protect each other because they are aware that their being is because of other people's being (see Mbiti, 1969).

As previously noted in Chapter Seven, *WFA1* challenged other PLHIV who have no regard for the wellbeing of others, including her infector who was prosecuted for deliberately infecting other people with HIV. It was inconceivable for *WFA1* and indeed other the Activists that one can put somebody's life at risk particularly if they are aware of their seropositive status. For *HP4*, engaging in unprotected sex when you know that you are infected is not respecting yourself and the other person because the infected person can also further contract STIs *(HP4* Interview: November 7, 2013).

Having realised the absolute need to sensitise people to respect one another as a normative social change principle, the Activists' key strategy to mobilise society towards changing the course of the HIV epidemic in their communities was to predicate their involvement on disclosure. Both white female Activists pertinently put this as follows:

> Me telling other people about my status made them aware of the danger out there, to be more careful, to condomise, being aware that there are people out there lying about their status. That is the biggest reason (*WFA2* Interview: December 4, 2013).

> First of all I say we are our worst enemies by not disclosing our status. Secondly...know that you are putting somebody else at risk. If you respect yourself you would make sure that you know your status because you can at least do something about it (*WFA1* Interview: October 21, 2013).

When presenting to other people, the above Activists thus urge PLHIV to always disclose as disclosure is not only deemed beneficial to the negative but to the positive person as well. In their configuration, disclosure is thus not only a sign of acceptance of seropositive status but an intention to protect people around them. Being open about one's HIV status means that PLHIV are focused on HIV prevention as prevention methods will likely be used. Without disclosure, partners might insist on unprotected as black men were reportedly accustomed to do.

For *HP3*, telling somebody "I love you" means that you must protect them. Failure to practice this is perceived by the Activists as being irresponsible, carelessness and inhumane. This is a serious concern for *CFA* who thinks that by keeping their seropositive status secret, some PLHIV "have forgotten how to be human and have replaced compassion with self-centeredness and in the process become selfish beings (*CFA* Interview: October 8, 2013). This view is consistent with the *Ubuntu* notion that a fully human being is selfless, have

compassion, do care and they affirm their humanity through others (Metz, 2007a; Tutu, 1999).

The Activists indicated that HIV can be a very isolating and lonely disease which is devastating for PLHIV particularly considering issues of stigma and discrimination. Because of this reason PLHIV feel discouraged to disclose finding support from GIPA and other structural policies and legislation that seek to protect confidentiality of PLHIV. *CFA, (*Interview: October 8, 2013*)* however, indicated that non-disclosure can make HIV doubly isolating and may compound feelings of helplessness and despair among PLHIV. As such, those PLHIV who are responsible for their own wellbeing would disclose as this has several benefits for them (also see Manchester, 2004).

Questions may therefore be posed as to whether *Ubuntu* values have provisions to address stigma. This issue is discussed in Chapter Nine where ways in which *Ubuntu* can be applied as a framework to mainstream participation of PLHIV in social change communication for HIV prevention are suggested. Here it is pertinent to highlight what the AIDS Activists suggested as benefits of disclosure for PLHIV. Among other things, it was indicated that disclosure allows PLHIV to freely access treatment and take medication in the presence of anybody. This also enables them to get necessary support from people to whom they will have disclosed to. PLHIV who have not disclosed were reported to find it extremely difficult to take their medication in presence of other people, a situation which often results in some failing to adhere to treatment regimens. Thus, according to *HP3*, the best that PLHIV who love themselves can do is to open up (*HP3* Interview: November 12, 2013). By opening up, PLHIV become exposed to the other part of life they were not aware of, as well as to other benefits. The Activists concurred that living openly with HIV relieves one of a burden of secrecy thereby preventing immature death.

Flaking off the burden of secrecy

Manchester (2004) found out that disclosing one's HIV status is like a double-edged sword in that it can be daunting yet it can also help to shift and lessen the overwhelmingly negative feelings. The GIPA liberal principle which allows one to keep their seropositive status confidential at personal level (UNAIDS, 1999) is in the present study considered burdensome by the Activists. Instead of keeping it as a secret, *HP4* thinks that it is "good to disclose because you get peace with yourself" (*HP4* Interview: November 7, 2013). The burden of secrecy, for example, is a painful reality in *BFA2*'s experience highlighted earlier in this chapter. *BFA2* ruefully lives with a burdensome secret of having infected her boyfriend with whom she had unprotected intercourse without disclosing her seropositive status. While she acknowledges that she is not perfect, she indicated that her behaviour at that point was not deliberate and that it is against her values that she had unprotected intercourse with the boyfriend.

> I want to tell you that I am not perfect. I know about this HIV and I know we have to take precautions about it. But then you know, sometimes there are things that happen so fast. Me, the first time I meet you, whoever asks me out I always disclose my status. But with my current boyfriend, I don't know what happened. One thing led to another and no one stopped it. And it happened. Now if he has to hear that I am HIV, what will happen...It's like I always have this guilty. When I look at him I say Oh God! Sometimes I don't feel like talking to him. For a week I would not call him, I wouldn't want to see him. Because I am living a lie and I just want to run away (*BFA2* Interview: November 19, 2013).

The above statement alludes to the idea that the aspect of secrecy is entangled with another important aspect about sexual transmission of HIV: that sexual intercourse is a compulsive human activity that can be made on the spur of the moment without involving deliberate cognitive evaluation. According to Dutta-Bergman (2005) affective laden choices are not accommodated within cognitive

based theories and models. Although *BFA2* above indicates that she knows about HIV and the precautions that must be taken, remedy to the risky behaviour that she did cannot be solely based on her knowledge and attitude as provided by, for example, the Health Belief Model. However, her point, which affirms Dutta's argument here, is that 'things happened so fast' that she forgot about the precautions that must be taken. With clear indications that GIPA is equally based on such theories as it grants PLHIV to choose where to disclose on the basis of their cognition, there is need for consideration of a social change communication approach for involving PLHIV premised not on cognitive theories but on a philosophy that espouses affective values and also focusing on everyday life of the people (see Dutta-Bergman, 2005).

Focusing on people's way of life is particularly important for this study that is located in South Africa where HIV is overwhelmingly transmitted through heterosexual contact, where women, especially married women are disproportionately affected, where men hold power and where poverty is widespread (Dunkle, 2008; UNAIDS 2010). Here it becomes pertinent to raise questions on whether one should have a right to information about the serostatus of people with whom they intend to be intimate. The Denver principles at least attempt to address this question. However, GIPA neither emphasises nor acknowledge it. That the above concern is not different from the Activists' motivation for visible participation in HIV prevention, and that their reflections find adequate expression in the *Ubuntu* dictum 'I am because we are' is a case this chapter attempts to make and argue.

Coming back to the issue of disclosure or non-disclosure, a general feeling among the Activists is that nondisclosure is a burden that PLHIV who respect themselves must flake off. As with the rest of other the Activists, *BFA2* intimated that disclosure is the only way of relieving this burden. HIV was described by Activists as a sensitive issue that an individual cannot deal with alone (*HP1* Interview: October 18, 2013). Non-disclosure or keeping one's

seropositiveseropositive status as a secret is thus described as a number one killer (*GMA2*). This view can best be illustrated by *BFA1*'s account on why she disclosed:

> I needed to take out this thing in me because it was stressing me a lot. Disclosing helped me a lot. After disclosing, everything was going well with me. I got well. I never had that – like something that I am hiding within myself. I was not like keep on thinking about myself, I just disclosed to live my life openly because one you keep something in your heart, it gives you a problem (*BFA1* Interview: October 12, 2013).

It is in light of the above that the Activists suggest that disclosure is another way of taking care of oneself. Disclosure is indicative of the fact that one loves themselves as keeping secrets, according to *HP3*, has disastrous social and psychological consequences and thus affects their general wellbeing. He warned that when people are not aware of your HIV status either in the work place or family, they can say negative things about PLHIV "without knowing that they are talking to you. The moment people talk about HIV negatively, you are affected. Therefore disclosure allows the environment to be conducive for you" (*HP3* Interview: November 12, 2013). This is also true for all other Activists and it is this very same danger that they seek as AIDS Activists to avert among other PLHIV.

When *CMA* initially found out about his status, he could not sleep because all he had in in mind was 'death, death, death'. The notion of disclosure, as suggested by *CMA (*Interview: November 29, 2013*)* is however relative as he believes different people views it differently. He is certain that people from different cultures might have different ways of handling disclosure.

> You have got to understand where we come from in terms of race. Amongst the Indian people it might not be a good idea. Amongst the blacks it might not be a good idea because there are different ways of looking at life. There is still so

much taboo associated with this virus. For me it is easy to talk, it is easy to be open…You don't carry the load alone. Even now as I am talking to you I am leaving a little bit of my load with you. You sleep better at night (*CMA* Interview: November 29, 2013).

South Africa is famed for its brand as a rainbow nation. Its population consists of different racial groups although the majority are black. While this is not a quantitative study, most Activists interviewed were black. Whites and coloureds were equally represented and there were no Indians. However, it is important to note that all the Activists in their diversity concurred that disclosure was important and, therefore, encouraged every other PLHIV to disclose so as to flake off the burden of secrecy. CMA above brings about two key aspects that are significant in this study: a) the fact that different cultures view disclosure differently, and that b) he considers disclosure as sharing the burden.

The first point raised above is significant in that it reflects the weaknesses of GIPA which appears to disregard this important fact and encourages PLHIV to keep their serostatus confidential as it is their right. We have already noted the dangers this brings in the African context where each individual has a stake in their brother's health. Here one's health is bound to the health of the community. This brings to the second important point, that of sharing. The value of sharing has been shown as one of the key characteristics of *Ubuntu.* Values of *Ubuntu* have also been shown to be inherent among, and as the worldview of African people. As CMA rightly points out, sharing includes not only wealth and other goods, but concerns including health. The common belief as noted by Mbiti (1969) is that what happens to an individual happens to everyone. As such, from an *Ubuntu* perspective, whole community shares its concerns including the health of its members (see Dube, 2009). What this implies is that confidentiality of serostatus as espoused by GIPA is not helpful in African conception of health as indicated by *CMA* above. It is in this context

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that this study attempts to transcend GIPA by proposing a culture-centered *Ubuntu* model to mainstream participation of South African PLHIV in social change communication for HIV prevention.

However, in what seems to be a contradictory finding, yet important, the Activists are aware that disclosure is an individual choice. For *HP2 (*Interview: November 5, 2013*)* that they are 'encouraging' others to disclose means that they are 'giving people a choice to do so'. Their recognition of individuals' right to or not to disclose is consistent with the GIPA principles which states that PLHIV "have the right to choose to be involved without making their serostatus public" (UNAIDS, 1999: 3). Here GIPA implies that while there should be nothing to stop PLHIV being open about their serostatus to their colleagues and community, disclosing one's serostatus is not necessary. This sounds contrary to the previous finding that Activists consider disclosure as a responsibility or an obligation. That disclosure is a choice suggests that one is not obliged to do so.

GIPA continues to guide global participation of PLHIV in response to the HIV epidemic. Indeed as a show of their "determination to ensure that all persons living with HIV/AIDS are able to realize the full and equal enjoyment of their fundamental rights and freedoms without distinction and under all circumstances" (The Paris Declaration, 1994), many governments including South Africa have not enacted any legislation that enjoins PLHIV to disclose their status to anybody. In my view, the enacted laws are consistent with GIPA as they protect PLHIV by providing that disclosure is voluntary.

However, the Activists in this study are aware that if a PLHIV knowingly infects someone, they are criminally liable for reckless or intentional transmission of HIV *(HP3* Interview: November 12, 2013*).* It is helpful to note here that many governments have targeted to prosecute rather than educate PLHIV as an approach to involve them in HIV prevention. An increasing number of PLHIV

are being prosecuted for recklessly or intentionally infecting other people with HIV. For example, the man who infected both *WFA1* and *WFA2* was prosecuted, convicted and sentenced to serve a jail term for recklessly infecting other people (*WFA1* Interview: October, 21 2013). The practice and consequences of criminalisation of HIV transmission presents numerous challenges to HIV prevention efforts and has constantly been under attack by both PLHIV as well as other progressive minds seeking effective ways of HIV prevention (Avert, 2014). That prisoners engage in sexual activities among themselves is undisputable. With people in prisons and other closed settings recognised as 'key population' in terms or HIV (WHO, 2014), it is not far-fetched to argued that during his incarceration the man who infected the above ladies might as well have infected other inmates.

Furthermore the practice also counters HIV counselling and testing as it leaves people afraid to be tested knowing that if they do find out their status they risk liability to prosecution (Avert, 2014). Given that law appears to have little effect on people's sexual behaviour, sanctioning or prosecuting PLHIV as a preventative measure seems incongruous. What has been suggested as appropriate is prevention education targeting PLHIV ensuring that they adopt risk reduction behaviour (see Kennedy, *et al.,* 2010; Coates, *et al.*, 2008; Crepaz, *et al.*, 2006). Successful approaches such as SAFE, mentioned before, place emphasis on the responsibility to protect each other. In the context of this study, this can mean studying PLHIV to find if they relate to any values and if so, finding ways in which these values can be appropriated not only to maximise their participation in social change communication for HIV prevention. As already indicated, this is the task this study has attempted to undertake. It has been suggested that the principles of *Ubuntu* are central to implementing this alternative approach, the ways through which are discussed in the next chapter.

Here it is important to also highlight that the Activists' knowledge about the conventional frameworks, legal provisions and discourses about HIV/AIDS do not entirely influence the manner in which they configure their involvement in social change communication for HIV prevention. The overwhelming evidence presented in the foregoing discussion suggests that the Activists possess an intrinsic sense of responsibility towards the other. This sense manifests itself in their sensitivity towards the wellbeing of other people. The Activists' reverence for humanity prompts them not only to predicate their participation on disclosure but also their aversion to spreading HIV. They consider their experiences with the virus as not only as expertise but mandates to service humanity through educating and empowering others to deal with the HIV epidemic (see Chapter Seven).

From the evidence presented in this and previous chapters, there may be no better way of understanding the Activists' configuration of involvement and disclosure, their reverence of human dignity as well as attitude towards other people than through the *Ubuntu* precepts particularly the dictum "I am, because you are". For example, consideration of 'the other' expressed and lived by the Activists and manifested through their insistence on treating other people as humans who deserve to be respected is illustrative of this conclusion. Against the dictates of the conventional global framework guiding participation of PLHIV in the HIV response, disclosure is for the Activists out of consideration and respect for self and the other, an inherent characteristic of *Ubuntu* ideals.

Consideration of the other is agreed as a common characteristic among societies commonly found in sub-Saharan Africa (Metz, 2007a). Considering the inordinate share of the global epidemic the region continues to bear, applying liberal principles of participation such as GIPA in such communal societies may be inconsequential (see Dube, 2009). Indeed, different communities have unique value systems, beliefs and behaviours that are

determined by their unique ways of looking at the world. The culture-centered approach to social change acknowledges that people's worldview is critical in the way they maintain their well-being and deal with illness, handicaps or death (Airhihenbuwa, 2005; Dutta, 2011). In such circumstances applying GIPA in its universal format will therefore be eccentric. What is required rather is a culturally appropriate approach that can provide unique solutions to unique situations.

In light of the above, and from a culture-centered approach to social change (Dutta, 2011), utilisation of *Ubuntu* values is outlined as an alternative approach for mainstreaming participation of South African PLHIV in social change communication for HIV prevention. In the next chapter a model that illustrates ways in which *Ubuntu* can be appropriated for this process is outlined.

CHAPTER NINE

BRIDGING THE CONCEPTUAL GAP

TOWARD AN *UBUNTU* FRAMEWORK FOR MAINSTREAMING PARTICIPATION OF PLHIV IN SOCIAL CHANGE COMMUNICATION FOR HIV PREVENTION

The apparent absence of behaviour change in the face of evident risk is a truth that social scientists have struggled to understand (Chasi and de Wet, 2005). The fact that the way people conceptualise their being determines their actions can be an important aspect to consider when theorising social change communication for HIV prevention. With an emphasis on stimulating the creation of supportive political, legal, and social environments for the involvement PLHIV, programmes seeking their participation in the HIV response the world over have been buoyant on the individual rights discourse emphasised by Greater involvement of people living with HIV/AIDS (GIPA). This is despite the fact that the historical and philosophical origins of individual rights are rooted in Western libertarian traditions (London, 2003) whose relevance in addressing social development challenges in non-Western societies have long been challenged. As such, new approaches rooted in local cultures (the culture-centered approach) have been suggested (Airhihenbuwa, 1995, Dutta, 2011). Indeed GIPA's present day embodiment under the Joint United Nations Programme on HIV/AIDS (UNAIDS) and its emphasis on rights of PLHIV - including that of keeping their serostatus confidential at an individual level – appears to have Kantian hallmarks that represent a construction deeply rooted in the Western philosophical origin.

The above further illustrates the argument made in Part II of this study that the HIV response continues to operate under the strong and direct influence of

the dominant liberal Western tradition. Yet, in (South) Africa, communitarian responses to illness are important (Chinouya and O'Keefe, 2008; Dube, 2009). Individualistic approaches therefore seem at odds when it comes to HIV prevention in Africa where the epidemic, as Martha Chinouya and Eileen O'Keefe (2008) argue, is a threat to both communal and individual health; or as Dube (2009) points out, where the cultural beliefs are such that individual health is inseparable from the others. The fact that GIPA has resulted in increased participation of PLHIV in developing support structures, policies and programs that have helped reduce HIV/AIDS-related stigma and discrimination (see HSRC, 2014), with little success in mainstreaming participation of PLHIV in HIV prevention suggests a need to indigenise or appropriate exogenous frameworks in ways that are appropriate to local cultures (see Dube, 2009).

Based on the notion that people's perceptions about health comprise of the knowledge, attitude, values and beliefs that may facilitate or hinder motivation to change (Airhihenbuwa, 1995), this study set out to integrate perceptions of PLHIV about HIV prevention, elements of the policy framework guiding participation of PLHIV as well as selected South African PLHIV's participation experiences as a way of making sense of the philosophy upon which their involvement in social change communication for HIV prevention is and should be based.

The previous two chapters dealt with the interviewed AIDS Activists' reflections on their experiences of participation as well as their perceptions about involvement in the HIV prevention response. The findings demonstrate a configuration of participation in social change communication for HIV prevention that is rooted in a philosophy that conceptualises persons as social or relational beings. That society's collective existence and values shape individual thinking and actions (Airhihenbuwa, 2007), and that behaviour cannot be permanent unless it is based upon a logical system of thought, philosophy of man and of the things which surround him (Temples, 1959)

plausibly locates the rationale for such a configuration in a philosophy that nurtures the humanity of the Activists. In light of the justifications provided by the Activists; *Ubuntu* which is an African philosophy that confers human beings with a code of conduct with other human beings (Mbiti, 1969) has been surmised as the most possible framework through which the Activists' configuration of involvement can be understood and perhaps be mainstreamed.

Ubuntu is a key term in the contemporary South African discourse so much so that appealing to it has a great effect on the likely success of the interchange of ideas (Rampersad, 2007). Besides, it is an old philosophy and way of life that has, for many centuries, sustained the African communities in South Africa in particular, and in Africa as a whole (Munyaka and Motlhabi, 2009). That *Ubuntu's* emphasis on respect, humanity and the interconnectedness of beings are mirrored in the Activists' configuration of their participation suggest that it can be a useful framework for mainstreaming participation of PLHIV in HIV prevention. Premised on this view, this chapter sets out to demonstrate *Ubuntu's* applicability not only in social change communication for HIV prevention in the South African context but also in enabling a supportive environment for their participation. The chapter suggests possible ways through which *Ubuntu,* in comparison with GIPA, can be employed as an alternative framework to guide participation of PLHIV in ways that account for South African people's sociocultural circumstances. It is hoped that through this framework, HIV prevention interventions may be developed that involve PLHIV while emphasising not only individual rights but also stressing normative values of participation and social change namely: respect, equality, and dialogue which both literature on disclosure (Paxton, 2002; Mlambo and Peltzer, 2011, Yonah, *et al.,* 2014) and the interviewed Activists suggest as important for HIV prevention. If embraced by the communities, *Ubuntu* values are likely to provide motivation among community members to manipulate the environment so much so that structural barriers that affect participation of

PLHIV in HIV prevention are altered. James Jaccard *et al.,* (1990) suggest that altering or manipulating structural features in the environment to provide opportunities for adoption of alternative behaviours is one of the strategies for social mobilisation, for example mainstreaming participation of PLHIV in social change communication for HIV prevention. Based on *Ubuntu* values, the outlined model for participation of PLHIV in social change communication for HIV prevention gives primacy to harmonious relations so much so that an environment that is inimical not only to infecting other people with HIV but also to HIV/AIDS-related stigma and discrimination is fostered. The model is not intended to counteract extant frameworks but it is hoped to localise GIPA in ways that account for the cultural contexts of South African PLHIV. As with GIPA, the model not only acknowledges the role that structural determinants related to policy and power play in HIV transmission, but also suggests ways in which *Ubuntu* can be applied in communication programmes to address, in culturally appropriate ways, these structural barriers to HIV prevention.

While models represent processes, for credibility they are often developed upon theoretical grounding. This study's *Ubuntu* model incorporates elements of social ecological models of behaviour such as Kincaid *et al.*'s (2007) social ecology model for communication health behaviour (SEMCHB) among others. Its construction is, however, deeply rooted in African philosophy of life, *Ubuntu*, described in Chapter Two. Theoretically, it is based on Metz's (2007a) formulation of *Ubuntu* as a normative theory for African ethics. The theory outlines some moral injunctions that specify values and virtues that are considered paramount to a worthwhile life of an African, values of which can serve as action guides for individuals and groups' behaviour and actions.

Recognising *Ubuntu* as a normative theory the model is also mindful of the level of applicability of *Ubuntu* in different contexts, even in (South) Africa. For example, the discourse of denialism and its associated 'African response' that characterised the Thabo Mbeki's presidency, can arguably be thought of as a

structural challenge to fostering *Ubuntu* as a premise upon which prevention strategies may be founded. As noted in Chapter Three, the anti-science and anti-racist discourse, which was part of Mbeki's African Renaissance (to which *Ubuntu* is closely associated), was ironically and inadvertently detrimental to the lives of South African PLHIV (see Tomaselli 2014, Mulwo, *et al.,* 2012; Nattrass, 2007). Antiretroviral therapy (ART) was viewed as "Western" and had to be avoided, thus jeopardising the wellbeing of many PLHIV (Chasi, 2012; Nattrass, 2007). This is one of the limitations of this study's model which are discussed at the end of this chapter.

### *Ubuntu* normative theory for African ethics

While *Ubuntu* is regarded more as a philosophy (Temple, 1959; Mbiti, 1969; Shutte, 1994) than a theory, Metz's (2007a) formulates an *Ubuntu* normative theory for African ethic. It is only from the Metzian perspective that *Ubuntu* is herein referred to as a theory. In his theoretical formulation, Metz (2007a) begins by articulating moral intuitions that are universally accepted in modern constitutional democracies. From these he singles out those which he argues to bear an African pedigree. According to Metz (2007a), it is universally immoral to kill; steal; have sex with someone without their consent; deceive people; violate trust/break a promise; and to discriminate. Immanuel Kant's (1724 – 1804) Categorical Imperative (CI) was discussed in Chapter Two as an example of universal moral law. While it is purely Western, Kantian philosophy has come to be accepted as universal and as a standard of reference for moral philosophies of all persuasions (see Altman, 2011; Wood, 2002).

Be that as it may, Kant's characterisation of a moral act as presented in Chapter Two is insightful in understanding Metz's (2007a) formulation of *Ubuntu* as a normative theory as well as its potential in mainstreaming participation of PLHIV in social change communication for HIV prevention. Pertinent here is the following Kantian characterisation of a moral action:

a) Good will is the power determining moral action

b) Action is morally good as long as it is decided upon, and motivated by duty to do good. The results the action attains or seeks to attain are not important.

c) Only reverence for the law enables humans to struggle other influences or obstacles.

It is also important to note that reverence of the law, according to Kant, is a self-produced feeling within a rational being, which emanates from his or her consciousness that their will is subordinated to a universal law (Paton, 2005). Figure 9.1 below is an attempt to schematically illustrate, as presented in this study, Kant's universal moral law as the sole motivation for moral action.

Figure 9.1: Illustrative model of universal moral law as a motivation for right action
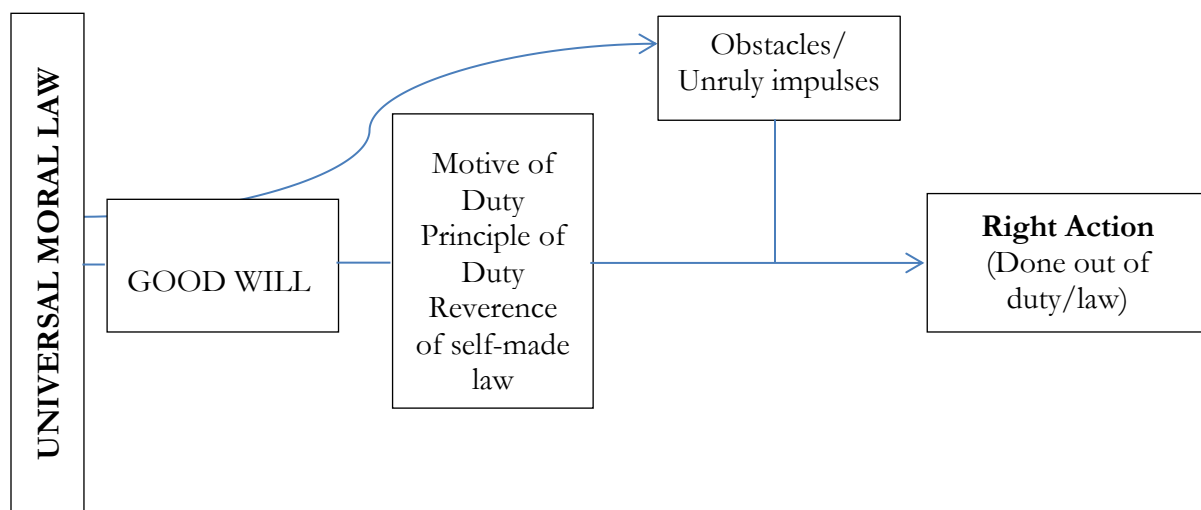
In the above figure, the so called universal law (at the far left) and its cardinal principle 'good will' as determinants for a moral or right action are illustrated. Good will is shown as consisting of three principles; motive of duty, principle of duty and reference of the law. These are the characteristics of good will and the maxims upon which moral action is deontologically decided and measured, not

from the results it attains or seeks to attain (Patton, 2005). The arrow that zigzags from universal law through good will illustrates the fact that only reverence for the law diffuses barriers and capacitates humans to struggle against these obstacles in their desires to do good.

Criticising its deontological nature, Metz (2007a) argues that the universal law is cold and dead because it does not have any intention. The law is devoid of provisions for affective aspects such as love, feeling, or inclination. As shown on Figure 9.1, it is merely out of a sense of reverence of law that a good man seeks to do good. It is not difficult to notice similarities of this formulation to GIPA, particularly its emphasis on the rights of PLHIV to satisfying sexual relations without any responsibility on the self (see Paiva, *et al.,* 2003). This is where universal intuitions differ from *Ubuntu* as they are devoid of values that are given prominence among Africans such as brother/sisterhood or shared identity. Rationality in such contexts becomes less important. Universal law neither includes activities coordinated to realise common ends nor any "we-ness" (Metz, 2007a: 338). Since universal law is deontological, its intuitions do not place emphasis on acting for the sake of others. This is contrary to the collective identities and values that the AIDS Activists interviewed in this study idealise.

As the context for defining personhood in the African worldview is community, the isolated and static self of universal law as conceptualised through Western philosophy (Christians, 2004) such as Kantian ethics may be insufficient to explain what constitute humaneness in the African context. While Kant, at least within Western moral reasoning, remains useful in explaining participation of PLHIV as enshrined in the Denver Principles, it is the above inadequacy of the universal intuitions to explicate Africa issues that *Ubuntu* becomes relevant. In this regard, it is plausible to argue that an understanding of *Ubuntu* moral ethos can provide valuable insights on mainstreaming

meaningful participation of PLHIV in HIV prevention in the (South) African context in the same way *Ubuntu* was used to entrench colonialism in Africa.

According to Father Placide Tempels (1959:14) "the European needed to understand the African worldviews and belief systems so that the missionary message and civilizationary projects could be implanted in the vital nodes of the structures of faith and the existential inferiority of the African". For meaningful participation of PLHIV in social change communication for HIV prevention to succeed in a self-sustaining manner, one must therefore work through this ontological system.

In his development of the *Ubuntu* normative theory, Metz (2007a) identifies six practices that Africans generally find morally objectionable namely: (a) decision-making in the face of dissent, (b) retributive punishment, (c) competitive economics, (d) rights-based allocation of wealth, (e) isolation from a community's way of life, and (f) failure to procreate through marriage. Before an explication of these practices in detail, it is pertinent to note here that finding some practices morally objectionable does not, however, suggest that Africans at all times exemplify all those values that are considered to be humane. Although associated with Africans, *Ubuntu* values may be quite scarce among many African communities. However, absence of such values must not be viewed as implying the impotency of *Ubuntu* in addressing the HIV epidemic in a manner outlined in this thesis. *Ubuntu* is a social consciousness whose principles are fostered through socialisation (Munyaka and Motlhabi 2009; Nussbaum, 2003; Kamwangulu, 1999, Prinsloo, 1996).

Policy decisions in the face of dissent

In African thought, a cooperative activity that is achieved through consensus by the presence of a person to person is the ultimate purpose of a community (Shutte, 1993). While this again does not always materialise, in the political realm, *Ubuntu* prizes unanimity so much so that if there is no unanimity over

an issue, discussion are expected to continue until consensus is reached or a compromise is found (Nussbaum, 2003). The African thought is thus understood to have an almost infinite capacity for the pursuit of consensus (Teffo, 1994) where all involved in the discussion have to agree with the outcome. As Metz (2007a) outlines, unanimous decision making is not only constitutive of shared identity but it is (in the long run) likely to promote both shared identity and good will more than majoritarianism since the minority would feel excluded from the political process.

Indeed democracy in the *Ubuntu* worldview does not simply boil down to majority rule but operates in the form of a discussion or and *indaba* where consensus has to be reached (Louw, 2001; Shutte, 2008). While this aspect does not feature in the findings of this study (understandably because of what the study sets out to unravel), consensus elucidates the web of moral wisdom upon which community based societies, such as what African communities are believed to be, are grounded. This culture best illustrated by the notion of '*pungwe*', a forum that is common among African communities that allows for all people to air their concerns and propose ideas and solutions in response to the question of 'what shall we do' (see Shutte, 2005; Blankenberg 1999; Teffo, 1994).

Prizing retribution over reconciliation in criminal justice
Retribution as a way of punishing offenders is linked to the fact that one justly deserves condemnation because of, and to the same degree as, his having done wrong in the past. African communities, however, believe it appropriate to respond to crime with the expectation of a good result (Metz, 2007a; 2010). Traditionally, Africans in such circumstances would seek to appease angry ancestors thereby protecting the community from their wrath, or to mend a broken relationship between the offender, his victim and the community. In South Africa, this approach is usually credited for helping to ground a restorative rather than punitive response to apartheid-era political crimes

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(Metz, 2007a). More so, Chapter 15 of the Constitution of The Republic of South Africa, Act 200 of 1993 states that in order to transcend the divisions and strife of apartheid South Africa and its transgression of humanitarian principles "there is a need for understanding but not for vengeance, a need for reparation but not for retaliation, a need for *Ubuntu*, but not for victimisation" (RSA Constitution, 1993: 251).

Similarly, sentiments were echoed by the Activists in this study that ruthless spreading of HIV on the pretext that one contracted it from another is morally and legally objectionable. Pertinent examples are cases of *WFA1*, *CFA*, and *BFA2* who after being recklessly infected by their partners sought no retribution. Rather they all forgave their infectors. While bitter about her infection, *CFA* in her book tells us that she had forgiven her infector even though "I didn't see any reason why I had to go and see him. Forgiving him didn't mean I had to go and look into his eyes and tell him that I had forgiven him, [nor that] I needed to eat ice cream with him" (Mulqueeny, 2013: 101). In the Interview: she revealed that she rather chose to educate other men about treatment and taking care of themselves. Ideally, this is how a person with *Ubuntu* should conduct themselves with others. It is unarguable that if this feeling of forgiveness gets fostered among many PLHIV, reckless infections such as the above could be minimised.

Creating wealth largely on a competitive basis

In the spirit of its value of sharing, *Ubuntu* prescribes that wealth should benefit others. Metz (2007a/b) asserts that in many traditional African societies land is co-owned and labour ought to be undertaken for the sake of the community, neither in order to make a profit in light of demand nor simply to care for one's immediate family. Economically, to compete with fellow citizens on labour and consumer markets with an eye to maximising self-interest is held as not acting for the sake of others, and hence lacks good will (Metz, 2007a; Shutte, 2008). As noted in Chapter Seven, participation of PLHIV in the

HIV response through HIV/AIDS Service Organisations (ASOs) is sometimes for economic benefits. It has been demonstrated that the Activists are engaged with ASOs not because the want economic gains but as they are motivated by a good will to service humanity. These actions are therefore comparable to the *Ubuntu* principle of acting not to maximise self-interest but in the interest of others.

Distributing wealth on the basis of individual rights

Metz (2007a) argues that among Africans, it is immoral to distribute wealth on the basis of individual rights as opposed to need. *Ubuntu* holds that one is morally obligated to help others to the extent that one can, and that others need (Nussbaum, 2003; Bhengu, 1996). Rights do not figure into the analysis of how much one ought to transfer wealth, time or labour. Rather, *Ubuntu* prescribes generosity and forbids a stingy reference to individual rights to keep goods regardless of whether they are unneeded by the possessor and others need them (Metz, 2007a, Nussbaum, 2003). One mutually beneficial transaction based on sharing wealth in the interests of building the community in South Africa is a tradition called '*ukusisa*' where one family would 'lend' a cow and a bull to a newly married couple and wait until a calf was produced and reared for a while before taking back the original cow and bull. The offspring would stay with the new family leaving them with their own 'seed capital' and their dignity (see Sayers, 2010). Here good will rules out greediness. While wealth distribution was not the focus of study, generosity manifests in so far as the Activists volunteer to work in communities not for economic gain. As demonstrated above, the Activists are motivated by good will that sees them all wanting to help other PLHIV to manage the virus in ways that do not further put themselves and others at risk of infection.

Ignoring others and violating communal norms

Ubuntu's central dictum prescribes that people ought to acknowledge others, *umuntu ngumuntu ngabantu* (a person's humanity is, through others) (Bhengu,

1996; Shutte, 1994; 2008). It is common among Africans to think that one has some moral obligation to engage with one's fellows and to support the community's way of life. This does not mean that African values forbid individuality, creativity or nonconformity nor does it mean that the same values are absent in other philosophies of the world. However, it does mean that in the African context, *Ubuntu* is the filter through which some weight in moral thinking is given to whether one's actions upsets communal norms (Metz, 2007a; Louw, 2001). In this study, the fear of upsetting communal norms is also raised by the Activists. Referring to serostatus disclosure in communities against the backdrop of HIV/AIDS-related stigma, *WFA1* said:

> I'm open about it now. I realised that in as much as it sounds horrible...I can tell anybody who is willing to listen now, almost in the sense that I want to see what their reaction is going to be. Not a single soul has showed me a horror sign on their faces they kind of take their hats off to you because you are openly taking about it and that is the community that I am in. I know in other communities it's not always like that, they fear they are going to be ostracised in their culture (*WFA1* Interview: October 21, 2013).

Reference to community norms and values by the Activists amply affirms the above intuition that individual action is influenced by their community values and beliefs. As *WFA1* alludes above, one risks being ostracized if they violate communal values. In the African thought, communal consequences of an offence are an extension of the consequences felt by the recipient. The relative harm caused by the event spreads throughout the community: the more severe the consequences, the greater the discord within the community (Verhoef and Michel, 1997).

Failing to marry and procreate

Many African people think there is some strong moral reason to create and extend familial relationships by finding a (heterosexual) spouse and having children (see Broodryk, 1997). Polygamy is often permitted, and indeed

welcomed, because of its effectiveness at generating more children than monogamy would. Bearing children enables one to expand the range of a common sense of self, to enlarge the scope of a "we" (Metz, 2007b, Mbiti, 1969). This notion was succinctly expressed by *HP2* as follows: "we as African believe that if someone comes and say I want to marry you tomorrow…they are marrying you so that you can make sure that *umuz'ka baba* doesn't die, so you have to bear children and lots and lots of children" *(HP2* Interview: November 5, 2013).

It is pertinent here to note that *Ubuntu* values are one thing, and possessing or living them is quite another. While the values outlined above are commonly revered in African societies as compared to other societies, Metz (2007b; 2009) cautions that not all societies, l*et al*one all individuals in Africa hold *Ubuntu* values. However, it has been noted in Chapter Two that *Ubuntu* can be engraved in African people's hearts as part of their socialisation (Munyaka and Motlhabi 2009; Nussbaum, 2003; Kamwangulu, 1999, Prinsloo, 1996). It was also noted that working through *Ubuntu* helped Europeans to effectively and sustainably colonise Africa (Tempels, 1959; Eze, 1998). This sustains the argument in this study that due to the fact that *Ubuntu* grounds and regulates the daily ethical, political and economic existence of the African (Temples, 1959; Mbiti, 1969) there is strong epistemic reason for (South) African PLHIV to be motivated to participate in social change communication for HIV prevention by *Ubuntu* values.

In light of the foregoing, below is Metz's (2007a) formulation of a normative theory that best accounts for the core values associated with *Ubuntu*. The theory is premised on the principle that what is right is what connects people together; what separates people is wrong (Mbiti, 1969). Metz (2007a) expounds harmonious relationships in Kantian terms as "constitutive of the good that a moral agent ought to promote" (Metz, 2007a: 334). His theory offers a prescription to produce harmony in terms of the requirement to promote

identity and solidarity. The theory provides a foundation upon which this study's *Ubuntu* model to mainstream participation of PLHIV in social change communication for HIV prevention outlined further below is based.

Tenets of *Ubuntu* normative theory

The *Ubuntu* normative theory accounts for the core values associated with *Ubuntu.* It is formulated on the proposition that "an action is right just insofar as it produces harmony and reduces discord; an act is wrong to the extent that it fails to develop community" (Metz, 2007a: 334). Harmonious relations, according to this theoretical tenet are premised on the following three key elements namely (a) shared identity, (b) good will and (c) a combination of shared identity and good will (Metz, 2007a). Since the theory has been formulated by Metz (2007a), this section heavily relies of this text and his several other works including Metz (2008; 2009; 2010) among others.

Shared identity

This involves sharing a common sense of self which entails an individual thinking of themselves as part of a group and vice versa. Here the theory assumes that people share identity when they have common ends and motives that underlie them. As already illustrated in Chapter Two, instead of the self being 'I', distinct from others, the self becomes 'We' (Shutte, 2008; Mbiti, 1969). Shared identity consists of people in the group coordinating their activities in order to realize their ends. The principle here is that an individual is inextricably bound to their community and is enjoined to always think of themselves as part of a group (Metz, 2007b; 2009; Dube, 2009). The theory postulates that the greater the common sense of self, the more people think of themselves as interconnected; the more ends they share; the higher they rank these ends; the more they share the same reasons for adopting these ends; and the more they will sacrifice to achieve these ends (Metz, 2007a). The shared identity construct however appears problematic when viewed in the context of the political and social context of HIV/AIDS. Appealing merely to a shared

identity on the basis of humanity may be viewed as denying individuality or the unique circumstances within which behaviours are enacted. Another danger with this theoretical construct is that shared identities can be formed for illicit reasons such as community sanctioned HIV/AIDS-related stigma (for example in the case of Gugu Dlamini who, as discussed earlier, was stoned to death by the community members). Be that as it may, the theory seems to concede to these flaws by stating that without good will, shared identity in itself is not morally important (Metz, 2007a). Harmonious relationships which unite and bind members of a community as beings are "the ultimate meaning not only of the unity which is personal to each man (person) but of that unity in multiplicity, that totality, that concentric and harmonic unity of the visible and invisible worlds" (Battle, 2009: 110).

Good Will

A relationship of good will presupposes caring or support for each other. The theory states that such a relationship thrives so far as one: wishes another person well (conation); believes that another person is worthy of help (cognition); aims to help another person (intention); acts so as to help another person (volition); acts for the other's sake (motivation); and, finally, feels good upon the knowledge that another person has benefited and feels bad upon learning they have been harmed (affection) (Metz, 2007a). The assumption here is that the greater the good-will; the stronger the desire that others benefit, the firmer the belief they are worthy of it, the higher the ranking of one's end of helping others, the larger the sacrifice on others' behalf, and the greater the empathy with their flourishing or injury (Metz, 2007a).

Ubuntu normative theory holds that shared identity and goodwill are distinct relationships. Shared identity is not always a result of good will in as much as good will does not always entail shared identity. The theory, however, holds that even though good will without shared identity is morally valuable, it is better still with shared identity as harmony is achieved through close and

sympathetic social relations within others (Metz, 2007a). Here the assumption is that harmonious relationships are anchored on both good will and shared identity. The theory thus espouses a third formulation which combines shared identity and good will.

Combination of Shared Identity and Good Will

According to the *Ubuntu* normative theory, good will and shared identity entail harmonious relationships achieved through close and sympathetic social relations (Metz, 2007a/b). To be part of the community is constituted through sharing an identity whereas to be sympathetic or realise the well-being of others is constituted through good will. The theory postulates that a combination of good will and shared identity is the most attractive conception of harmony where people have a common sense of self and are inclined to act for one another's sake as implied by the dictum "I am because we are" (Mbiti, 1969). Here, every member is expected to consider him/herself an integral part of the whole community and to play an appropriate role towards achieving common goals. The enriched variant of the *Ubuntu* theory which account for the combination of shared identity and good will states that "an action is right just insofar as it promotes shared identity among people grounded on good will; an act is wrong to the extent that it fails to do so and tends to encourage the opposites of division and ill-will" (Metz, 2007a: 338).

The *Ubuntu* prescription for harmony - the requirement to promote identity and solidarity - is a normative principle of right behaviour that may serve as an action guide for individuals and groups (Metz, 2007b; Verhoef and Michel, 1997), thus conferring people with a code of conduct with other human beings. This theoretical viewpoint was instructive in the formulation the *Ubuntu* model (described further below) for mainstreaming participation of PLHIV in social change communication for HIV prevention. From this theoretical perspective, individuals are enjoined to demonstrate utter respect for practices that govern harmonious relationships with other human beings for being human is to be

with-others (Shutte, 1994, Metz, 2007a). Being-with-others is encapsulated in the expression *umuntu ngumuntu ngabantu* which presupposes dependence of a human being upon other people. Mkhize (2008) argues that 'self' is defined in relation to the quality of one's participation in a community. For Setiloane (1986: 14) "the essence of being is participation in which humans are always interlocked with one another". Such interlocution provides opportunities for the creation of communicative spaces for a two way flow of knowledge that serve humanity.

The *Ubuntu* normative theory outlined above shows that one is connected to their community by offering a service to humanity through positive acts that create harmony (see Verhoef and Michel, 1997). According to Mluleki Munyaka and Mokgethi Motlhabi (2009) such acts are aimed at furthering self and the other's wellbeing thereby alleviating human suffering. Here the injunction is for one to respect and provide assistance to the other human being where the stronger helps the weaker or those in advantaged positions help the disadvantaged. Such acts "bring sense not only to one's own life but also to the life of others" (Broodryk, 1997: 74).

It can be argued from the above that *Ubuntu* normative theory can provide a useful starting point for modelling social change communication for HIV prevention through respect for the dignity of the other, an aspect from which liberal philosophies such as Kantianism and other cognitive frameworks guiding participation of PLHIV in the HIV response such as GIPA are evidently devoid. Understanding how Africans value connections with each other might serve as a mechanism for mainstreaming meaningful participation of South African PLHIV in social change communication for HIV prevention interventions as compared to the individual based frameworks that undermine the cultural and political contexts that shape behaviours. This study's *Ubuntu* model outlined further below draws on three aspects: motivation for the visible participation configured by the Activists as presented in Chapters Seven and

Eight; recommendation (4) of the Denver Principles (1983), and the notion of creating supportive environment to enhance participation of PLHIV as espoused by GIPA (UNAIDS, 1994). The idea is to model a framework suggesting how *Ubuntu* can serve not only to motivate PLHIV to participate in social change communication for HIV prevention, but also to illuminate its potential to alter structural barriers that hinder such participation. Foreseen challenges that may arise with the model are examined at the end of the chapter. Below is an explication of the above mentioned three key elements of the model.

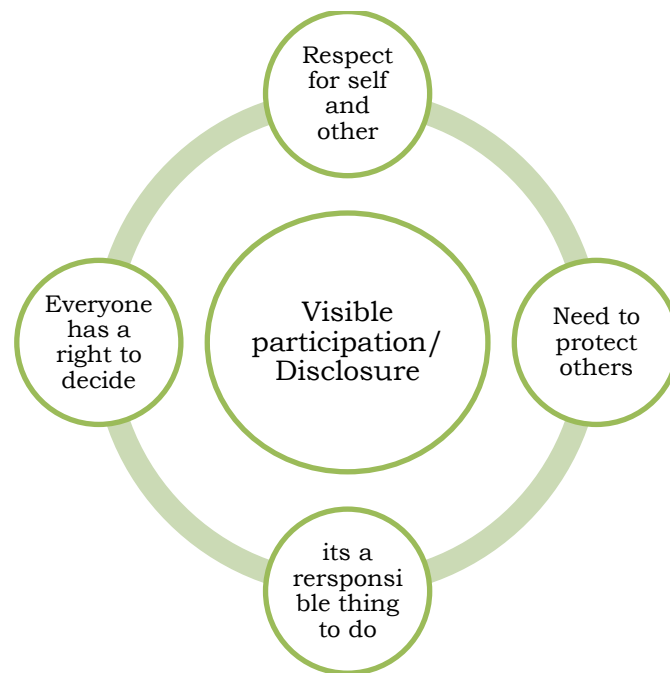**Participation of PLHIV in the HIV response through *Ubuntu***

As presented in the previous two chapters, there are four key values underlying the Activists' visible participation. As noted, their motivation is good will which manifests itself in their consideration of the wellbeing of the other. The Activists have a desire to serve humanity by assisting both other seropositive people on how to manage the virus, protecting others from infection, as well as seronegative people to be cautious so much so that they maintain their seronegative status. Passing on HIV is viewed as a death penalty on somebody and the only (a) responsible thing to do by PLHIV is to disclose their serostatus. Motivation for disclosure include the Activists' (b) felt responsibility to respect self and other human beings who have (c) a right to enact their agency in deciding whether to allow transmission to take place or not. The Activists thus have a (d) common goal of protecting other people from HIV infection and helping the already infected to manage the virus. Figure 9.2 below illustrates these four values which act as a motivation for the Activists' configuration of participation as just outlined. These values, namely: respect, responsibility, shared goals and agency are also embodied not only in *Ubuntu* as illustrated earlier, but also in social change as demonstrated in Chapter Two.

If viewed in light of the *Ubuntu* theory presented in the foregoing, the four elements shown above depict a harmonious interlocution involving different

people who dialogue respectfully with each other in order to achieve a common goal. Collective action among PLHIV helping other people to manage the virus as well as to protect others from infection is bound by the shared goal to save life of other people. Figure 9.2 below is used to illustrate the above mentioned aspects that function as motivation for the Activists' visible participation.

Figure 9.2: Motivating factors for visible participation by PLHIV

Respect for self and other

Everyone has a right to decide

Visible participation/ Disclosure

Need to protect others

its a rersponsi ble thing to do

As noted in Chapter Two, it is only when people espouse common goals, and engage with each other respectfully through dialogue, that collective action to transform their situations is made possible (see Figueroa *et al.* 2002; Bessette 2004; Freire, 1970). For Freire (1970), collective action or social praxis which involves affected people assumes that harmonious relations are a central defining feature of human life and a necessary condition of social change. This, for Freire (1970) enhances people's capacity to be self-defining subjects by providing necessary conditions for each person to be conscious of their situation. This notion of life is true among Africans whose humanity is

understood to complete only in recognition of the wellbeing of the other (Murove, 2009; Ramose, 2009; Shutte, 1994; Mbiti, 1969).

The above worldview contradicts the supposed universal philosophy that, as shown on Figure 9.1 conceives a person as a static being whose self-worthiness depends on reverence of the law without regard to the role of the other (see Airhihenbuwa, 2007). This is particularly true in the context of serostatus disclosure where onus is placed on an individual as an autonomous being with a right and freedom to keep their serostatus confidential to themselves (UNAIDS, 1999).

It is against the above background that *Ubuntu* is suggested as an alternative framework to mainstream participation of PLHIV in social change communication for HIV prevention. Figure 9.3 below is an illustration of this model. It adopts a socio-ecological approach (see Sallis, *et al.*, 2008) that shows possibilities of *Ubuntu* to influence the individual, their community, society and how this provides opportunities for PLHIV to visibly participate in the HIV response. Unlike Figure 9.1, the *Ubuntu* model illustrated below incorporates both 'self' and 'other' in a harmonious relationship aimed at achieving common goals. This conjures the very same values shown on Figure 9.2 that are reportedly behind the visible participation of the interviewed Activists as discussed in the previous two chapters. These values also find expression not only in *Ubuntu* but in the philosophy of social change discussed in Chapter Two.

Due to the fact that three determinants of HIV prevention namely risk-reduction information, motivation, and behavioural skills have been, and continue to be central in influencing different approaches and responses to the HIV epidemic (Kelly, *et al.*, 2012; Coates, *et al.*, 2008; Crepaz, *et al.*, 2006). The *Ubuntu* model outlined here takes a social-ecological approach that addresses motivation and skills for performing certain practices in relation to broader

context within which they are performed. As motivation, *Ubuntu* functions as a catalyst for PLHIV to protect others from HIV infection. To capacitate PLHIV with skills for protecting others from infection, *Ubuntu* confers PLHIV with a code of conduct with other human beings (Mbiti, 1969; Louw, 2001), the cardinal code of which is to treat others with respect and dignity. In the same vein, *Ubuntu* here can be seen as having capacity to influence the alteration of hostile or stigmatising environment and creates harmony so as to enable motivated PLHIV to practice behaviours that protect others from infection. Here the model derives from the character of *Ubuntu* which as Dirk J Louw (2001: 14) notes, does not only describe human being as 'being-with-others' but also prescribes how we should relate to others, that is what 'being-with-others' should be all about. The model thus employs *Ubuntu* as both a factual description and a rule of conduct.

Figure 9.3 below illustrates *Ubuntu* as a source or basis of feelings of responsibility, care and compassion among other traits that are responsible for producing harmonious relations - at an individual, community and societal levels - by influencing people to become sensitive to the well-being of others. As with good will in Kantian terms, the model shows *Ubuntu* functioning as force whose presence in each person offers decisive grounds for viewing each as possessed of equal worth and deserving of equal respect as expressed through the dictum 'I am because we are'. Here, *Ubuntu* confers PLHIV who aware of their serostatus (top left) and seronegative people, including those infected but not aware of their status (bottom left) with a code of conduct with one another. In other words, it prescribes how PLHIV should relate to others and what being-with-others should mean. However, these individuals, as with any other person in a community, are presented with multilevel barriers that influence their behaviours, actions and practices. The panel marked 'BARIERS' describes different forms of these barriers as individual, community; social and structural (see Kincaid, *et al.,* 2007).

Figure 9.3: Ubuntu model for mainstreaming participation of PLHIV in SCC for HIV prevention
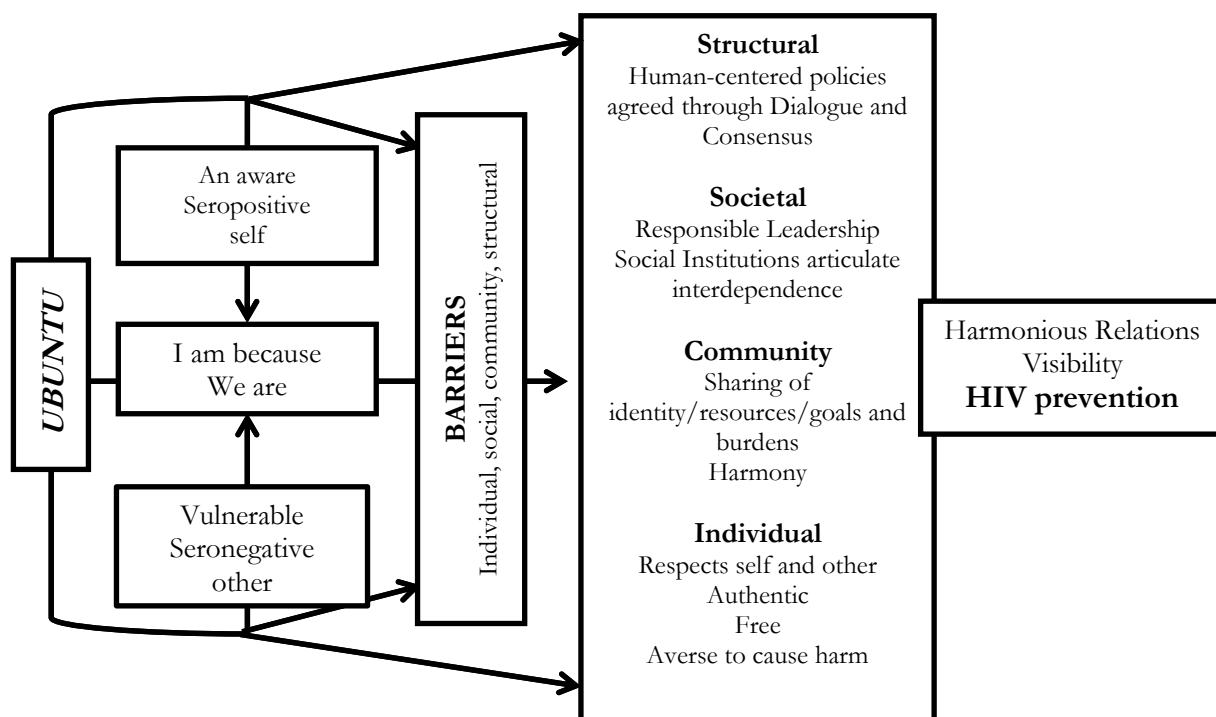
For example, while the seropositive individual may be aware of their status, challenges such as HIV/AIDS-related stigma and discrimination, poor political leadership on HIV/AIDS as in the case of Thabo Mbeki's government among other barriers that can hinder participation of PLHIV in social change communication for HIV prevention (see Tomaselli, 2014; Chasi, 2012; Mulwo, *et al.,* 2012). These challenges were real among the Activists such as *BFA1* and *HP3* who were diagnosed during the Mbeki denialism period. Other Activists revealed that they have experienced stigma and some have been abandoned by their partners after disclosing their status. They reported that most PLHIV therefore keep their status confidential, situations that usually end up in their partners being infected as was the case of *BFA2* (also see Manchester, 2004; Paxton, 2002). Similarly, the seronegative individual also has unique barriers that expose people to HIV infection. The literature section of this thesis has examined main factors that make different South Africans vulnerable to HIV

infection. These include power relations related to intergenerational relationships, gender and socioeconomic status among others (see Laga and Piot, 2012; George and Sprague, 2011; Coates, *et al.,* 2008; Zungu-Dirwai, *et al.,* 2007).

Just before the 'BARRIER' panel, two boxes in the middle left of Figure 9.3 represent *Ubuntu* and its cardinal principle "I am because we are". Dark arrows that originate from the boxes represent *Ubuntu* in its function as the technology for sociability where individuals and groups are conferred with a code of conduct with other human beings. It is here where community members who have grasped *Ubuntu* and become sensitive to the wellbeing of the other can lobby for policy changes by governments. This may result in the alteration or manipulation of the environment so much so that structural barriers that affect participation of PLHIV in social change communication for HIV prevention are altered. While this may be a difficult challenge in reality, changes in the Mbeki's denialism discourse and polices are attributed to the activism by organisations such as the Treatment Action Campaign (TAC) (Mulwo and Tomaselli, 2012; Kalichman, 2009). That TAC is driven by sensitivity to the wellbeing of PLHIV is unarguable. The interconnectedness of the HIV epidemic with structural issues such as access to resources which often results in different power relations among people has seen an increase in social ecological approaches to HIV prevention that place emphasis on the environmental and policy contexts of human behaviour such as Kincaid *et al.*'s (2007) model discussed earlier that recognise need to alter structural barriers in the environment so as to provide opportunities for safe practices.

At the top of Figure 9.3 are three *Ubuntu* arrows: one socialising the seropositive individual, the second defusing the barriers and the third showing the impact of *Ubuntu* at different levels of society. At the bottom of the Figure are also the same *Ubuntu* arrows, first socialising the seronegative, then

defusing barriers and finally showing the impact that this has on the individual and their environment or at different levels of society.

The large panel where the three *Ubuntu* arrows end characterise a society that has embraced *Ubuntu*. It shows from the bottom: the prescribed conduct of an individual with *Ubuntu*, their inter-relational community, nature of societal institutions and leadership, and lastly how policies and laws are formulated. Far right in the middle is the outcome of an *Ubuntu* manipulated environment and defused structural barriers with regards to meaningful participation of PLHIV. It represents motivated individuals and a community capacitated to relate harmoniously with each other thereby creating opportunities for social mobilisation of PLHIV to visibly participate in HIV prevention. Regardless of its limitation discussed further below, the model presents *Ubuntu* as what Pieter Boele van Hensbroek (2001: 5) describes as an African technology of sociability whose function and power as an instrument is to overcome differences and creating a harmonious community (also see Van Binsbergen, 2001; Shutte, 1993).

The above characterisation is based on both the Activists' perceptions presented in the preceding two chapters as well as the *Ubuntu* precepts discussed earlier in this chapter as well as in Chapter Two. Below is a further illustration of how *Ubuntu* motivates and capacitate PLHIV in social change communication for HIV prevention as shown on Figure 9.3 above.

Before doing so, it is perhaps pertinent to again reiterate the point stressed earlier that while *Ubuntu* is associated with Southern African people, this does not suggest that every individual in Southern Africa adequately represents or is a true embodiment of its values (see Letseka, 2013a/b). *Ubuntu* is a moral conscience that is acquired through socialisation (Nussbaum, 2003; Broodryk, 1997). However, it has been used to mobilise society at different levels and for different purposes as shown below. For *Ubuntu* to be embraced, advocacy work

has to be undertaken at all levels of society, beginning with the family (see Letseka, 2013a/b).

Individual motivation: *Ubuntu* as law of autonomous will

The cardinal principle of coexistence espoused by *Ubuntu* enshrines in an individual an appreciation and recognition that one's humanity is dependent upon the well-being of the others (Tutu, 1999). Here, a culturally sound method of communication that encapsulates *Ubuntu* values is interpersonal communication among Africans. One such method namely home visits has been used successfully by Chinouya and O'Keefe (2008) among Africans in England where individuals are regarded as autonomous beings with rights to keep serostatus information confidential at an individual level. The home visits strategy involves health professionals or peer educators visiting PLHIV into their private homes where they use language and a set of values that they identify with (Chinouya and O'Keefe, 2008). Visiting neighbours is a practice rooted in the principle of sharing ideas and supporting each other which promotes neighbourliness or harmony (Chinouya and O'Keefe, 2008; Metz, 2007a). As outlined on Figure 9.3, at an individual level *Ubuntu* regulates the conduct of PLHIV with others, also functioning as a source of motivation and capacity to:

a) *Treat others with dignity and respect*: Treating all people with respect entails granting them their human dignity. Here an individual possesses values, attitudes and feelings of collective shared-ness, brotherhood, solidarity, interdependence, hospitality and caring (Bhengu, 1996; Shutte, 2009, Mkhize, 2008). Caring and sharing for others create an environment of collegiality where everyone would like to be appreciated, valued, and respected for their contributions. Clearly this is an antithesis of stigma which, as discussed in Chapter Three, sanctions viewing of PLHIV as undesired and different from other human beings (see Goffman, 1963; Parker and Aggleton, 2003; Mawar, 2005). Here respect implies a positive attitude to other people and a rejoicing in their welfare. For PLHIV, Chapters Seven and Eight have shown that this entails not

only an aversion to transmitting HIV, but also a motivation to educate the already infected on how to manage the virus so as to live a healthy and prolonged life. For the Activists in this study, this involves visible participation or public disclosure of one's positive serostatus.

b) *Be visible and authentic:* Thus through the above values, PLHIV do not keep their status confidential to themselves but share the information with others. Disclosure or visibility, as discussed in Chapters Seven and Eight is beneficial to both the seronegative and the already infected. For the seronegative, disclosure was reported to encourage safe practices that protect them from infection. For the already infected, disclosure by the Activists gives them inspiration to want to manage the virus the way the Activists do. As shown in Chapters Seven and Eight, one way of managing the virus is disclosure. This means more PLHIV end up disclosing and participating in HIV prevention as with their role models as; borrowing from Colin Chasi and Gideon De Wet (2007), an authentic being chooses in freedom to be as they communicate. This implies that PLHIV who visibly participate in the HIV response become authentic to themselves as well as during their personal engagement with others. In contrast, a person without *Ubuntu* is likely to be unauthentic and can choose, as accorded by GIPA and individual rights, not to disclose and act in the bad faith of pretending not know their status yet transmitting HIV to other vulnerable and unsuspecting individuals as in the cases of *CFA*, *WFA1* and *WFA2* discussed in Chapters Seven and Eight.

c) *Be sensitive to the wellbeing of others:* A person with *Ubuntu* is prescribed to live in harmony with others, being sensitive to their well-being. In the context of HIV prevention, respect and dignity enjoin PLHIV to protect others by not exposing them to HIV. As shown in Chapters Seven and Eight, this code of conduct is not foreign to South African PLHIV as their experiences shows that sensitivity to the wellbeing of others is central to their worldview. The interviewed Activists are averse to transmitting HIV as this is seen as calamitous. This aversion is evidenced by their readiness to disclose their seropositive status not only to people they intended to be intimate with but also to the general public. Here serostatus disclosure is seen as a signal for safer intentions. On the other hand, sensitivity to the wellbeing of the other confers on seronegative individuals a conduct that is fundamental in addressing stigma. Instead of seeing an undesired different when looking at PLHIV, communities embracing this *Ubuntu* principle are likely to deploy love, care and empathy for PLHIV as individuals are sensitive to the wellbeing

of the other. The relevance of this in addressing HIV/AIDS related stigma is quite apparent and needs no emphasis.

d) *Be free:* High-risk HIV behaviours are choices that an individual makes (Chasi and De Wet, 2007). In as much as *Ubuntu* seeks collectiveness and interdependence, it also protects the freedoms of every individual within the collective, particularly the freedom of expression (Christians, 2004). While the individual rights discourse embodied in GIPA values one's freedom from intrusion by others and therefore allows them to keep their serostatus confidential to themselves, here one's freedom is dependent on personal relationships with others in the community where one is free to voice their concerns without restriction (Shutte, 1994; Christians, 2004). The Activists reported that disclosure gives other people an opportunity to decide if they want to be involved with a PLHIV or not. It also gives them an opportunity to decide whether to allow transmission to occur of not. Freedom therefore means a person is able to freely articulate issues of importance without restriction or censure. Serostatus disclosure is also considered as freeing PLHIV from the burden of secrecy. Disclosing seropositive status is for *CMA* equivalent to sharing the burden (*CMA* Interview: November 29, 2013). As another participant said, disclosure made her well *(BFA1* Interview: October 12, 2013).* One's desire for freedom is realised to the full the more one is fully involved in community with others (Shutte, 1994). While cultural freedom is a collective freedom, here *Ubuntu* is the condition for individual freedom to flourish. It guarantees freedom as a whole.

Due to its social ecological focus and location in the culture-centered approach to social change (Dutta 2008, 2011), the *Ubuntu* model for mainstreaming participation of PLHIV in social change communication for HIV prevention seeks to mobilise participation of PLHIV in two ways; the first being motivation which has just been described above. The second way is environmental manipulation which seeks to alter environmental forces such as HIV/AIDS-related stigma that hinder PLHIV from meaningful participation in the HIV response. It has been noted already that while one of the strategies for social mobilisation is altering structural features in the environment to provide opportunities for adoption of alternative behaviours, this may be challenging.

Despite these challenges, the following sections demonstrate how *Ubuntu* can possibly achieve its potential.

Creating a supportive environment for PLHIV: *Ubuntu* as the technology for sociability

Figure 9.3 depicts *Ubuntu* as capable of altering social and structural barriers to provide conditions that allow PLHIV with various opportunities that are favourable to their increased participation in social change communication for HIV prevention. These include opportunities for care and support as well as shared-ness that impact on determinants of HIV such as stigma and discrimination; power relations/inequalities related to age, gender, and economic status noted earlier (Gupta, *et al.*, 2008; Coates, *et al.*, 2008). As social determinants of HIV include influences beyond the individual level, a culture-centered approach to social change requires capacity of communities to engage as a collective with a shared identity organised around a specific issue (Dutta, 2011). Within this *Ubuntu* framework, meaningful social change communication strategies will include public communal meetings and events where PLHIV engage with communities and leadership on various aspects affecting their participation, debating issues in good faith, respecting each other's views until consensus is reached and policies are made (see Dube, 2009; Nusbaum, 2003, Blankenberg 1999). *Ubuntu* is depicted here as what Boele van Hensbroek (2001:5) calls a 'time-tested African technology of sociability' which functions "as an instrument to overcome differences, and reconcile by creative redefinitions of identity; they can create a new moral community". As such it is assumed to have potential to alter the environment and provide various opportunities for participation of PLHIV including:

a) *Opportunity for care and support:* According to the *Ubuntu* normative theory outlined in the foregoing, caring communities characterised by harmony is the outcome of an *Ubuntu* driven community. Harmony is achieved when community members care about each other, when they

sympathise and empathise with each other, and when there is love (Letseka, 2013b; Tutu, 1999). Presence of these values in communities creates an environment that allows easy disclosure by PLHIV as they are assured to receive love instead of hate, care instead of dereliction, and support instead of stigma (see Museka and Madondo, 2012). This is likely to see increased visible participation of PLHIV in HIV prevention. As discussed in Chapters Seven and Eight, stigma and discrimination as well as fear for rejection are the main factors that PLHIV keep their serostatus confidential to themselves as there is no sharing of health concerns. In light of this model, whatever misfortune or illness that happens to an individual, they are a concern to the whole group, and whatever happens to the whole group is a concern to the individual (Mbiti, 1969).

b) *Shared-ness:* An *Ubuntu* driven community conceives being human as always sharing life with others (Mbiti, 1969, Shutte, 1994). Achieving the state of humanness, which every community member aspires to be, is constituted by positively relating to others, a connectedness embodied in the principle 'I am because we are' which appears in the middle left of Figure 9.3. This connectedness implies a shared life where there is no unnecessary competition but equal sharing of wealth, resources and health concerns. Gill Seidel (1996) observed that shared confidentiality, which is sharing of confidential serostatus information in communities, was preferred by health workers in KwaZulu-Natal as it ensured care and social support for PLHIV. This sentiment was echoed again by the Activists (Chapters Seven and Eight) that disclosure often results in them not only receiving appropriate care and support but also protection of other people.

c) *Power inequalities*: As drawn from the moral intuitions of *Ubuntu* presented earlier, the *Ubuntu* dictates that wealth should benefit others. In *Ubuntu* driven communities the principle is that one cares not only for their immediate family but for the whole community (Metz, 2007a). Sharing of resources will ensure that poverty-related barriers to participation of PLHIV are altered. Coupled with care and sympathy for others, power relations related to social status inequalities are also altered as *Ubuntu* prescribes generosity as already illustrated. Also since people will be averse to causing harm to others, like one affluent Activist who drives expensive cars envied by young girls, no PLHIV will maliciously infect others. He said, "I value who I am, I value my family. That is why I am not prepared to die soon because I value my family, my

self and other people. When you are passionate about life you make sure that you protect other people" (*HP3* Interview: November 12, 2013). Intergenerational sex is one of the drivers of HIV in South Africa where older men commonly known as sugar daddies go for younger girls and infect them (see Leclerc-Madlala, 2008). Here the right to keep one's seropositive status confidential without any responsibility to protect others compounds the vulnerability of young and powerless girls by widening the already existing power gap. This is disempowering on the part of the girl as she cannot force the older man to disclose. Her vulnerability is further compounded by the fact that African women, worst still young ones are dominated by men in negotiating (safe) sex (AVERT, 2014). *Ubuntu,* as illustrated in the above model has possibility to alter such power relations and other social influences. Being sensitive to the wellbeing of the other finds expression in sexual relationships where partners feel as their duty to accept the other as an equal partner and to allow them especially the weaker to participate in decision making. In a similar situation as the above, but under different conditions - for example when the young girl is seropositive and the sugar daddy is seronegative - an *Ubuntu* motivated young girl who is averse to causing harm can signal safer intentions by disclosing her seropositive status to the man. *Ubuntu* value of being sensitive to the welfare of the other empowers and prompts her to disclose so as to stop HIV transmission.

d) *Structural barriers*: As discussed early in this chapter, *Ubuntu* can also provide helpful guidelines relating to developing policies. Communities with *Ubuntu* generate culture-centered policies that are developed through dialogue and consensus, not in the face of dissent (see Blankenberg 1999; Nussbaum, 2003; Metz, 2007b). Participation is essential for social change for what your neighbour has to offer in terms of experiences, knowledge and ideas is essential to your own growth (Blankenberg, 1999). Here respect for each other's views equalises each community member's potential contribution to policy formulation by being able to assert themselves as active citizens rather than as passive subjects (see Tomaselli, 2003). The outcomes are policies that promote freedom among and care for members including PLHIV, an environment that allows increased participation of PLHIV in social change communication for HIV prevention. When PLHIV are cared for they are likely to become involved in being more open about their status and taking HIV protective precautions in their sexual behaviour (Botha, 2009;

Campbell, *et al.*, 2007). However, it is important to note that policy makers cannot legislate respect, nor can they coerce people to behave respectfully. What they can do is to enshrine *Ubuntu* as one of the pillars on which the society is founded (see Servaes, 2007). As has been noted already, *Ubuntu* is a conscience that is imparted on people and acquired through socialisation (Nussbaum, 2003; Saule, 1996; Munyaka and Motlhabi 2009; Broodryk, 1997). It becomes imperative to establish and strengthen social institutions to instil in society the moral injunction to respect communal relationships characterised by sharing a way of life and caring for others' quality of life. By so doing, challenges such as stigma among others can easily be addressed. To foster *Ubuntu*, Dube (2009) suggests need for curriculum transformation and community-oriented teaching and research as possible means to bring *Ubuntu* into the public discourse. By so doing, institutions will be able to promote harmony in community thereby influencing alteration of different barriers that limit participation of PLHIV in social change communication for HIV prevention.

For *Ubuntu* to work, social change communication for HIV prevention has to be informed by its values. Appealing to *Ubuntu* to involve PLHIV in prevention interventions may conjure a shift from inward looking cognitive approaches towards ecological approaches that recognise the other. Such interventions would encourage sharing, neighbourliness, mutual respect and sensitivity to the wellbeing of the other. Such a code of conduct would undoubtedly result in increased visible participation of PLHIV in their struggle for recognition; against HIV/AIDS-related stigma, and also contribute to HIV prevention.

In conclusion, it is pertinent to note that in matters involving health beliefs and practices, *Ubuntu* may be considered by some as belonging to traditional societies that have been displaced by modern societies. This, according to Airhihenbuwa (1995), is particularly true among persons who are products of colonial or postcolonial realities who are "conditioned to believe that everything good about themselves and their cultures existed only in the past and should remain there" (Airhihenbuwa, 1995: 14). However, the success of health

promotion in Africa, he argues, "rests with the degree to which [intervention] are based on the sociocultural realities of Africans" (op. cit.).

It can be argued from the foregoing that an understanding of *Ubuntu* may provide valuable insights on mainstreaming meaningful participation of PLHIV in social change communication for HIV prevention in the (South) African context the same way it was used to sustain colonialism in Africa. Here again, Temples' (1959) argument for the need for colonialists to understand *Ubuntu* so as to inculcate docile behaviour among Africans is instructive. That behaviour cannot be permanent unless it is based upon a logical system of thought and a philosophy of man and of the things which surround him suggests that *Ubuntu* remains an important resource that can be meaningfully applied for mobilization of African communities around social development challenges such as HIV/AIDS. As with logics which justify models and theories applied to HIV/AIDS prevention often refer to a Western scientism and empiricism for their legitimisation (Airhihenbuwa, 2007), people engage in sense making using beliefs and values as filters to understand the world (Chasi and De Wet 2005). It is therefore not difficult to see how *Ubuntu* which dominates, penetrates and informs African thought (Temples, 1959) cannot succeed to orientate (South) African PLHIV to participation in social change communication for HIV prevention. It can be argued that the way the Activists configure participation as presented in Chapter Eight locates their sense making firmly in *Ubuntu*.

It is also important to end by noting that the model outlined in this chapter is by no means a definitive solution to the African HIV epidemic. What it attempts to do is to contribute, based on African ways of knowing, to the effort of meeting challenges of local realities in the context of global transitions. In the face of the un-abating sub-Saharan HIV epidemic whose response has been based on Western programmatic interventions by national and international authorities which have since been considered inadequate, the outlined model becomes relevant as it resonates with local experiences.

Caveat

In light of the foregoing, it is pertinent to reiterate here that while *Ubuntu* values of caring, sharing, compassion, warmth, understanding, humanness among others that have been used to formulate the above model find intense expression among Africans, this does not suggest that they are exclusively African (see Enslin and Horsthemke, 2004; Prinsloo, 1996; Ramphele, 1995). As Louw (2001) warns, suggesting that the above values are uniquely African would be ethnocentric as the same values also feature strongly in other philosophies in the world including Kantianism and Christianity already noted earlier. Be that as it may, Louw (2001) concedes that for Africans, the concept of *Ubuntu* serves distinctly as an African rationale and code of conduct on what being with others mean. He agrees that *Ubuntu* gives a distinctly African meaning to, and a reason or motivation for a fraternal attitude towards the other (also see Airhihenbuwa, 1995; 2007). It can, therefore, be argued from this that appealing to *Ubuntu* in programmatic interventions such as mainstreaming participation of PLHIV in social change communication for HIV prevention is likely to be successful among Africans as - to echo Chasi and De Wet (2005) - it is the filter that African people use when engaging in sense making to understand the world. This again does not suggest that the above outlined model which seeks to achieve this task is not without limitations.

Limitations of the *Ubuntu* model

It can be argued that the *Ubuntu* model suggested above sounds plausible in its articulation of possibilities of *Ubuntu* to serve as a conceptual framework for mainstreaming participation of (South) African PLHIV in social change communication for HIV prevention. It can also be advanced that it appears strategically important for interventionists attempting to mainstream participation of PLHIV in social change communication interventions for HIV prevention. However, it is worthwhile to mention that the model is not definitive, hence it has some limitations.

Firstly, while suggesting broad examples of interpersonal communication strategies encapsulating *Ubuntu* values, the model does not provide clear guidelines as to how such communication programmatic interventions are designed and implemented. However, it has been made clear from the outset that this study is located within the culture-centered approach to social change communication. Growing literature in this area suggests ways in which such interventions can be made (see Dutta, 2011; 2008; Airhihenbuwa, 1995). To mitigate this limitation, the model can also be read in light of other ecological models of communication such as Kincaid *et al.'s'* (2007) Social Ecology Model of Communication and Health Behaviour (SEMCHB) as well Storey and Figueroa's (2012) Global Model of Health Communication and Competence, among others. The SEMCHB model offers communication guidelines at each level. Different ways to address the structural barriers to participation of PLHIV in social change communication for HIV prevention identified earlier - including HIV/AIDS related stigma - could also be located in the different levels of these social ecological models.

Another possible limitation of the model relates to feasibility of its application in modern and globalising democracies such as South Africa where *Ubuntu* has arguably become a dream about the past (see Van Binsbergen, 2001). In accordance with the globalised and modernised South Africa, the value orientation of the village and the kin group is not within easy reach of the globalized and urban population that has become standard in Southern Africa (Van Binsbergen, 2001). Further, the capitalist relations of production of the modern South Africa, the constitutional democracy and liberal policies promoting individual property rights and confidentiality at individual level appear to have been deeply entrenched. These appear to be an antithesis of an environment within which the outlined model can possibly and usefully be implemented. Influence of such liberal policies is evident in the Activists' indications that disclosure is an individual choice. The strong emphasis on

freedom and equality in the South African constitution (Republic of South Africa, 1996) presents an immediate antithesis to the notion of visible participation embodied in the model. The South African constitution is widely admired for protecting a range of rights, including privacy and choice (Enslin and Horsthemke, 2004). Behaviours are choices that individuals make. As such, emphasising community over individual rights to privacy "denies the individual the possibilities of choice and freedom that are implied by human agency" (Chasi and de Wet, 2005: 124)

In the context of the South African HIV epidemic, some may argue that a call for an *Ubuntu* model for mainstreaming participation of PLHIV is no different from former President Thabo Mbeki's African renaissance dream whose achievement, as Chasi (2012) notes, demanded of others the "commitment to creative resourcefulness", the effort of which resulted in him questioning medical orthodoxy in ways that had genocidal consequences. Questions have been raised such as where *Ubuntu* was when millions of South African PLHIVs were denied treatment (see Kunda and Tomaselli, 2012). This criticism is also compounded by the fact that Mbeki was a leader who, in the African context, can be regarded as a model and custodian of culture. Chasi (2012) argues that in the face of HIV/AIDS; the actions, behaviours and motivations of the post-apartheid South African political leaders has shown that calling for political leadership to act as role models to direct how the country should face the epidemic may be disappointing.

It is important, however, to note here that viewing the model outlined in this chapter in light of Mbeki's AIDS leadership and his vision which Chasi (2012: 317) describes as a "Sisyphusean effort" for an African renaissance will be a misunderstanding of *Ubuntu*, particularly the way it is purported to be understood in this thesis. Even though African Renaissance and *Ubuntu* share a resonance of being weighty subjects which address fundamental and often ignored aspects of African development (Boele van Hensbroek, 2001) the

concepts are not the same. The former is political with the aim of inspiring and legitimate the bold development efforts of the post-colonial Africa, and the latter is cultural and philosophical which refer to past African life-forms as a foundation for African development (Boele van Hensbroek, 2001)

Indeed Mbeki's renaissance effort politicized HIV/AIDS and questioned science in ways that tragically delayed the government administration of antiretroviral programmes in the country resulting in the death of many South Africans (see Chapter Three). While it is correct to argue that the consequences are contrary to what *Ubuntu* stands for, that is respect for human life, it can be observed from the above that Mbeki's intentions and approach were political rather than cultural. His focus was on systems of governance and international relations (Makgoba, 1999). Kunda and Tomaselli (2012) also correctly note that his was militant nationalism which ended up compromising public health. That *Ubuntu* is cultural has already been noted. Neither did Mbeki himself claim that his challenging of orthodox science was *Ubuntu*.

The above are just some of the possible limitations of the outlined model. Other limitations may not necessarily be related to the inadequacy of the model in itself but may derive from the scope and epistemological framework of the study, the limitations of which are addressed in the next chapter. Further problems and limitations may become visible when the model is put to trial. As it is, the model remains open for further development and revision in ways that seek meaningful participation of South African PLHIV in social change communication for HIV prevention. As such, the identified limitations can be viewed not only as limitations but as pointers to instances of further research.

CHAPTER TEN

CONCLUSIONS

The objectives that this study set out to achieve can be described as a preoccupation with the need to bridge the gap between theory and practice in social change communication. The thesis explored the nature and meaning of, as well as views that selected South African people living with HIV (PLHIV) have about the involvement of PLHIV in the HIV response. Based on the disconnect between participation as configured by the interviewed AIDS Activists and the principle of Greater involvement of PLHIV (GIPA), a global framework that guides participation of PLHIV in the HIV response, the aim of the thesis was to make sense of the philosophy upon which the involvement of South African PLHIV in social change communication for HIV prevention is and should be based. The premise is that making sense of the filters that shape the meanings that people give to phenomena is critical for the design of meaningful social change communication interventions.

The thesis in its endeavour to achieve this task was guided by the following four key research questions:

a) In what ways are South African PLHIV involved in the HIV response?
b) How (if ever) is their participation different from the global framework guiding involvement of PLHIV in HIV prevention?
c) What are their perceptions and feelings about the global framework guiding involvement of PLHIV in terms of HIV prevention?
d) How should PLHIV participate meaningfully in social change communication for HIV prevention?

In its endeavour to explicate the above questions, the thesis has been arranged in three different but coherent parts that help locate the questions in a meaningful context. Part I provided an overview of the global HIV epidemic,

interrogating the positions occupied by PLHIV in the dominant HIV/AIDS discourse. It is also in this part that the social change philosophy and the African moral philosophy of *Ubuntu,* the conceptual framework within which the study is located, are explained and critiqued.

The thesis went on to review the global responses to the HIV epidemic in Part II where both the discursive and pragmatic responses to the HIV epidemic are critiqued with the intent of demonstrating the lack of agency of PLHIV or the absence of their voices in the discursive spaces where the HIV response strategies are discussed and determined. The concept of GIPA was then interrogated examining the extent to which PLHIV have managed to enact their agency to challenge the dominant HIV/AIDS discourse. A conclusion was drawn here that while PLHIV are now recognised in the HIV response, no signs of success have been recorded in containing the sub-Saharan epidemic through GIPA as it places much emphasis on other aspects of the response such as access to treatment, care and support.

The methodology and findings of the study are presented in Part III of the thesis where the configuration of participation in HIV response by the selected South African AIDS Activists is outlined and interpreted. Based on the configuration of participation by the Activists, lessons learnt from their experiences with the virus, and also some elements of the policy framework guiding global participation of PLHIV in the HIV response, a culture-centered framework dubbed an *Ubuntu* model for mainstreaming participation of PLHIV in social change communication for HIV prevention has been developed from the point of view of selected AIDS Activists. The model is based on African ways of knowing and accounts for South African PLHIV's values and cultural circumstances that influence their meaning and experiences of health.

Several conclusions have been drawn from this thesis, the key of which is a confirmation of the apparent disconnect between global frameworks for social

change and the ways in which social change is configured in some parts of the World. While engagement with HIV/AIDS should not be simplistically reduced to the application of local solutions divorced from global science, this study has proposed an *Ubuntu* model for mainstreaming participation of PLHIV in social change communication for HIV prevention. The model is based on the configuration of participation by the interviewed Activists. A hermeneutic and dialogic analysis of such a configuration has been described as an embodiment of the philosophy of *Ubuntu* whose cultural beliefs hold that an individual's wellbeing is inseparably bound to one another. This view sharply contradicts GIPA's present day embodiment under the Joint United Nations Programme on HIV/AIDS (UNAIDS) and its emphasis participation of PLHIV based on the rights as human beings, an approach whose historical and philosophical origins appear to be rooted in Western libertarian traditions. The relevance of such approaches in addressing social development challenges in non-Western societies has long been challenged. Alternative approaches such as the culture-centered approach upon which this thesis is based have since been propounded.

While the individual rights perspective has been helpful in mainstreaming participation of PLHIV in the HIV response, particularly with focus on addressing HIV/AIDS-related stigma and discrimination, the elevation of individual liberties over communal interests in the individual rights discourse was seen by the Activist as downplaying responsibilities of PLHIV to other people. The filters that the Activists appeared to use to make sense of their World have been interpreted as an embodiment of *Ubuntu* whose cultural belief places emphasis on obligations and duties to the other instead of simply pursuing individual self-interest conferred by the individual rights discourse.

It can also be concluded that the problem of the unabating sub-Saharan HIV epidemic is not because of the permissive sexuality or promiscuity of African people. Neither is it solely because of poverty or patriarchy. It may as well be a

result of the de-centered approach that is being used for its response which, as noted above, represents a construction deeply rooted in the Western philosophical origin. However, instances were noted where some like former President Thabo Mbeki have attempted to challenge Western medicine in the form of ARVs, a situation which sadly had consequences which some have described as genocidal (see Tomaselli, 2011; Chasi, 2012).

This has thus sought not to supplant but to complement GIPA in a way that re-locates South African PLHIV as subjects who have agency in informing frameworks upon which their involvement in social change communication to HIV prevention can be based. The developed model thus envisages social change communication interventions for HIV prevention that are premised on moral philosophies that are comparable to the Kantian respect for persons which has come to be accepted as universal. Here the *Ubuntu* maxim that 'a person is a person through other persons' (Metz 2007a) can be read within the Kantian postulate of 'Categorical Imperative' which is based on the law of autonomous will or self-governing whose presence in each person offers decisive grounds for viewing each as possessed of equal worth and deserving of equal respect (Paton, 2005). The thesis has argued that participation of South African PLHIV in social change communication for HIV prevention can equally be understood, and possibly mainstreamed from the *Ubuntu* philosophy.

While it can be concluded that the African worldview suggest that Africans naturally exhibit *Ubuntu*, it has been stressed throughout the thesis that not all Africans let alone PLHIV possess these values. However, *Ubuntu* is understood as a social conscience that can be fostered on individuals through socialisation. What this suggested is a possibility that these values can still be implanted in others who don't have them. While assumptions can be made that fostering *Ubuntu* may not be difficult among Africans through different ways including those suggested by Dube (2009) and Letseka (2013a/b), it may be interesting a point for further research to find ways in which practitioners can

facilitate the development of *Ubuntu* amongst those including non-Africans who do not naturally exhibit its values.

It is important to end by noting that the findings of this study are by no means more definitive than a particular perspective, and cannot therefore be generalised. It is possible that different findings could have been obtained, for example, had the number of participants been increased and scope of study been enlarged. I, as a researcher, have not been actively involved in the HIV response more than being an academic. My approach therefore is nothing more than theoretical. That researchers and practitioners often conflict is widely acknowledged (see Obregon and Tusfte, 2013). Being a biographically positioned researcher with no practical experience of the phenomenon under investigation, and at the same time a key instrument of this study, the questions that I chose to ask, and perhaps the way the questions were asked have unarguably defined and limited what could have been found. Although a combination of quantitative and qualitative research methods could have generated more informed information, the interest of this study was to make sense of the meanings that selected participants make of participation.

Be that as it may, the prospect of transferability of this study cannot be totally rejected. Even though the findings are applicable to a small number of AIDS Activists from KwaZulu-Natal in South Africa, the conclusions derived may as well be applicable to other populations elsewhere. The methodological outline presented in Chapter Six, and the conceptual framework outlined in Chapter Two, provide a thick and concise description of the context within which this study was undertaken. This may be insightful to those who, if they believe that their situations are similar to those described in this study, wish to transfer the conclusions to their own contexts (see Bassey, 1981; Lincoln and Guba, 2001).

While the findings reported in this study creates a new direction for mainstreaming participation of PLHIV in social change communication for HIV, it may be interesting, as a further study, to find out how other PLHIV who are not necessarily involved in the HIV response think about disclosure as a signal for safer intentions. It has been found that Activists who were recklessly infected by their partners forgave them and they seek no retribution. Rather they view as morally objectionable the notion of spreading HIV on the pretext that they were infected by someone else. It will be interesting as a point for further study to find out if this feeling of forgiveness is the widely accepted reaction among PLHIV.

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APPENDICES

A: INTERVIEW SCHEDULE

'Getting to Zero' Mainstreaming participation of PLHA in social change communication for HIV prevention.

INTERVIEW GUIDE
This is a confidential interview that seeks to elicit views of PLHA involved in HIV/AIDS response on their experiences in HIV/AIDS related work and also their thoughts about their involvement in HIV prevention. The objective is to find ways in which PLHA can be meaningfully involved and their capacity for self-determination enhanced for halting new HIV infections.

A. Personal Information
    1)   Gender; Age; Association/Organisation/Project; Position; Relationship

B. Disclosure of positive serostatus
    2)   Please explain when and what prompted you to disclose.
           (Was it an external influence or something from within?)
    3)   What, in your opinion, are the benefits or dangers of disclosing one's sero positive status?
    4)   In what way does disclosure (if ever) assist in HIV prevention?
    5)   In most instances HIV is transmitted through an act of expression of love. What is your opinion on disclosing to a sexual partner/person one intends to be intimate with?
    6)   Would you encourage other HIV positive people to disclose their seropositive status to their sexual partners/those they intend to be intimate with? (WHY)
    7)   What in your opinion should an act of true love entail?

C. Involvement of PLHA in HIV/AIDS response
    8)   Please explain your (current) involvement in the response to HIV/AIDS.
           (How long has it been; on what capacity; what are the roles/activities)
    9)   At what level of society/organisation/programme are you involved?
    10) Were you involved in developing the content of your programme/role? Who developed it?
    11) Explain how you become involved? (invited, voluntary, job etc)
    12) How you feel about your involvement

D. Importance of Involvement of PLHA in HIV/AIDS communication
    13) Participation of PLHA stems from the need for collective responsibility in responding to HIV/AIDS. In this light, what in your view is the responsibility of (1) HIV+ and (2) HIV- people?
    14) (Why) Is there a need to involve PLHA in communication about HIV?
    15) To whom can PLHA communicate about prevention of HIV?
          a.   (Other PLHA (peers), sexual partners, family, community, general public)
    16) What, in your opinion, are the benefits of involving PLHA in HIV communication?
          b.   (To other people with HIV/AIDS; to the general community; to the target community of your programme; to the health profession/general AIDS response)
    17) Tell me about the power/influence that PLHA have in HIV prevention?

E. Challenges to preventing HIV transmission
    18) Please describe what you consider to be the major challenges to your and other PLHA's participation in HIV prevention communication.
    19) What do you thing needs to be done to address these challenges?

F. Way forward
    20) It is believed that we cannot effectively address HIV/AIDS unless we draw lessons from experiences of PLHA. What is your final comment on this and as we go forward?

END/

B: THE PARIS DECLARATION

The Paris Declaration

Paris AIDS Summit - 1 December 1994

We, the Heads of Government or Representatives of the 42 States assembled in Paris on 1 December 1994:

I. Mindful

- that the AIDS pandemic, by virtue of its magnitude, constitutes a threat to humanity,
- that its spread is affecting all societies,
- that it is hindering social and economic development, in particular of the worst affected countries, and increasing the disparities within and between countries,
- that poverty and discrimination are contributing factors in the spread of the pandemic,
- that HIV/AIDS inflicts irreparable damage on families and communities,
- that the pandemic concerns all people without distinction but that women, children and youth are becoming infected at an increasing rate,
- that it not only causes physical and emotional suffering but is often used as justification for grave violations of human rights,

Mindful Also

- that obstacles of all kinds - cultural, legal, economic and political - are hampering information, prevention, care and support efforts,
- that HIV/AIDS prevention and care and support strategies are inseparable, and hence must be an integral component of an effective and comprehensive approach to combating the pandemic,
- that new local, national and international forms of solidarity are emerging, involving in particular people living with HIV/AIDS and community-based organizations,

II. Solemnly Declare

- our obligation as political leaders to make the fight against HIV/AIDS a priority,
- our obligation to act with compassion for and in solidarity with those with HIV or at risk of becoming infected, both within our societies and internationally,
- our determination to ensure that all persons living with HIV/AIDS are able to realize the full and equal enjoyment of their fundamental rights and freedoms without distinction and under all circumstances,
- our determination to fight against poverty, stigmatization and discrimination,
- our determination to mobilize all of society - the public and private sectors, community-based organizations and people living with HIV/AIDS - in a spirit of true partnership,
- our appreciation and support for the activities and work carried out by multilateral, intergovernmental, non-governmental and community-based organizations, and our recognition of their important role in combating the pandemic,
- our conviction that only more vigorous and better coordinated action worldwide, sustained over the long term - such as that to be undertaken by the joint and cosponsored United Nations programme on HIV/AIDS - can halt the pandemic,

1

III. Undertake in our national policies to

- protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV/AIDS, through the legal and social environment,
- fully involve non-governmental and community-based organizations as well as people living with HIV/AIDS in the formulation and implementation of public policies,
- ensure equal protection under the law for persons living with HIV/AIDS with regard to access to health care, employment, education, travel, housing and social welfare,
- intensify the following range of essential approaches for the prevention of HIV/AIDS:

  - promotion of and access to various culturally acceptable prevention strategies and products, including condoms and treatment of sexually transmitted diseases,
  - promotion of appropriate prevention education, including sex and gender education, for youth in school and out of school,
  - improvement of women's status, education and living conditions,
  - specific risk-reduction activities for and in collaboration with the most vulnerable populations, such as groups at high risk of sexual transmission and migrant populations,
  - the safety of blood and blood products,
  - strengthen primary health care systems as a basis for prevention and care, and integrate HIV/AIDS activities into these systems, so as to ensure equitable access to comprehensive care,
  - make available necessary resources to better combat the pandemic, including adequate support for people infected with HIV/AIDS, non-governmental organizations and community-based organizations working with vulnerable populations.

IV. Are resolved to step up international cooperation through the following measures and initiatives:

We shall do so by providing our commitment and support to the development of the joint and cosponsored United Nations program on HIV/AIDS, as the appropriate framework to reinforce partnerships between all involved and give guidance and worldwide leadership in the fight against HIV/AIDS. The scope of each initiative should be further defined and developed in the context of the joint and cosponsored program and other appropriate for a:

- Support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations. By ensuring their full involvement in our common response to the pandemic at all - national, regional and global - levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments.
- Promote global collaboration for HIV/AIDS research by supporting national and international partnerships between the public and private sectors, in order to accelerate the development of prevention and treatment technologies, including vaccines and microbicides, and to provide for the measures needed to help ensure their accessibility in developing countries. This collaborative effort should include related social and behavioural research.
- Strengthen international collaboration for blood safety with a view to coordinating technical information, proposing standards for good manufacturing practices for all blood products, and fostering the establishment and implementation of cooperative partnerships to ensure blood safety in all countries.
- Encourage a global care initiative so as to reinforce the national capability of countries, especially those in greatest need, to ensure access to comprehensive care and social support services, essential drugs and existing preventive methods.

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- Mobilize local, national and international organizations assisting as part of their regular activities children and youth, including orphans, at risk of infection or affected by HIV/AIDS, in order to encourage a global partnership to reduce the impact of the HIV/AIDS pandemic upon the world's children and youth.
- Support initiatives to reduce the vulnerability of women to HIV/AIDS by encouraging national and international efforts, aimed at the empowerment of women: by raising their status and eliminating adverse social, economic and cultural factors; by ensuring their participation in all the decision-making and implementation processes which concern them; and by establishing linkages and strengthening the networks that promote women's rights.
- Strengthen national and international mechanisms that are concerned with HIV/AIDS related human rights and ethics, including the use of an advisory council and national and regional networks to provide leadership, advocacy and guidance in order to ensure that non-discrimination, human rights and ethical principles form an integral part of the response to the pandemic.

We urge all countries and the international community to provide the resources necessary for the measures and initiatives mentioned above.

We call upon all countries, the future joint and cosponsored United Nations programme on HIV/AIDS and its six member organizations and programmes to take all steps possible to implement this Declaration in coordination with multilateral and bilateral aid programmes and intergovernmental and non-governmental organizations.

3

BIBLIOGRAPHY

ACTUP. (2014). *The Denver Principles 1983*. Retrieved October 18, 2014, from ACT UP: AIDS Coalition To Unleash Power: http://www.actupny.org/documents/Denver.html

Ahlberg, M. B. (1994). Is there a distinct African sexuality? A critical response to Caldwell. *Africa: Journal of the International African Institute, 64*(2), 220-242.

Airhihenbuwa, C. (1995). *Health and culture: Beyond the western paradigm.* Thousand Oaks: Sage Publications.

Airhihenbuwa, C. (2007). On Being Comfortable With Being Uncomfortable: Centering an Africanist Vision in Our Gateway to Global Health. *Health Educ Behav, 34*(1), 31-42.

Airhihenbuwa, C., & Iwelunmor, J. (2012). Why culture matters in reducing the burden of NCDs and CDs in Africa. *Commonwealth Health Partnerships*, 107-111.

Airhihenbuwa, C., & Obregón, R. (2000). A Critical Assessment of Theories/Models Used in Health Communication for HIV/AIDS. *Journal of Health Communication, 5*(supplement), 5-15.

Airhihenbuwa, C., & Webster, J. (2004). Culture and African contexts of HIV/AIDS prevention, care and support. *SAHARA-J: Journal of Social Aspects of HIV/AIDS, 1*(1), 4-13.

Alliance, & GNP+. (2010). *Greater Involvement of people living with HIV (GIPA): Good Practice Guide.* Retrieved May 10, 2012, from http://www.aidsalliance.org/resources/283-good-practice-guide-greater-involvement-of-people-living-with-hiv

Altman, C. M. (2011). *Kant and applied ethics: The uses and limits of Kant's practical philosophy.* West Sussex: Wiley-Blackwell.

Altman, D. (2006). Taboos and denial in government responses'. *International Affairs, 82*, 257.

Altman, L. (1981, July 3). *Rare cancer seen in 41 Homosexuals*. Retrieved October 18, 2014, from The New York Times, US: http://www.nytimes.com/1981/07/03/us/rare-cancer-seen-in-41-homosexuals.html

APN+. (2001). *Lifting the burden of secrecy: A Training Module for HIV-Positive Speakers.* Retrieved August 15, 2013, from http://catalogue.safaids.net/publications/lifting-burden-secrecy-training-module-hiv-positive-speakers

Arnstein, S. (1969). A Ladder of Citizen Participation. *Journal of the American Planning Association, 35*(4), 216-224.

Asia Pacific Network of People Living with HIV/AIDS. (2004). *Asia Pacific Network of People Living with HIV/AIDS (APN+) Position Paper 2: GIPA.* Asia Pacific Network of People living with HIV. Retrieved April 18, 2012, from www.hivasiapacific.apdip.net

Auvert, B., Taljaard, D., Lagarde, E., Sobngwi-Tambekou, J., Sitta, R., & Puren, A. (2005). Randomized, controlled intervention trial of male circumcision for reduction of HIV infection risk. *The ANRS 1265 Trial. PLoS Medicine, 2*(11), 298.

AVERT. (2013). Retrieved January 25, 2014, from http://www.avert.org/news/national-hiv-counselling-and-testing-hct-campaign

AVERT. (2014). *Criminal Transmission of HIV*. Retrieved June 10, 2014, from AVERT: Averting HIV and AIDS: http://www.avert.org/criminal-transmission-hiv.htm

Bailey, C. R., Moses, B, S., Parker, C., Agot, K., Maclean, I., & Krieger, J. N. (2007). Male circumcision for HIV prevention in young men in Kisumu, Kenya: A randomised controlled trial. *The Lancet, 369(9562), 643-656., 369*(9562), 643-656.

Bailey, R. C., Moses, S., Parker, C., Agot, K., Maclean, I., Krieger, J., & Ndinya-Achola, J. (2007). Male circumcision for HIV prevention in young men in Kisumu, Kenya: A randomised controlled trial. *The Lancet, 369*(9562), 643-656.

Barnett, T., & Whiteside, A. (2002). *AIDS in the twenty-first century: Disease and globalization.* New York: Palgrave Macmillian.

Bassey, M. (1981). *Pedagogic Research: On the relative merits of search for generalisation and study of single events.* Oxford Review of Education 7 (1), 73-93.

Battle, M. (2009). *Ubuntu: I in you and You in me.* New York: Church Publishing.

Bentham, J. (1781). *Introduction to the Principles of Morals and Legislation.* Kitchener: Bantoche Books .

Bessette, G. (2004). *Involving the Community: A Gide to Participatory Development Communication.* Ottawa: International Development Research Centre.

Bhengu, M. J. (1996). *Ubuntu: The Essence of Democracy. Cape Town.* Cape Town: Novalis.

Bhengu, M. J. (2006). *Ubuntu: The Global Philosophy for Humankind.* Cape Town: Lotsha Publications.

Blankenberg, N. (1999). In search of a real freedom: *Ubuntu* and the media. *Critical Arts, 13*(2), 42-65.

Boele van Hensbroek, P. (2001). Philosophies of African renaissance in African intellectual history. *Quest, 15*(1-2), 147-162.

Botha, P. (2009). The Application of Paolo Freire's Pedagogy in renegotiating HIV Stigmatised Identities: A Study of DramAidE's Health Promotion Project (HPP) at the Durban University of Technology (DUT). Durban: Unpublished Masters Dissertation: University of KwaZulu-Natal.

Brandt, A. M. (1985). *No Magic Bullet: A Social History of Venereal Disease in the United States since 1880.* New York: Oxford University Press.

Brandt, A. M. (1988). AIDS: From Social History to Social Policy. In E. Fee, & D. M. Fox (Eds.), *AIDS:The Burdens of History* (pp. 147-171). Los Angeles: University of California Press.

Broodryk, J. (1996). Is *Ubuntu*ism unique? . In J. Malherbe (Ed.), *Decolonizing the mind: Proceedings of the 2nd Colloquium on African Philosophy* (pp. 31-37). Pretoria: UNISA Research Unit for African Philosophy.

Broodryk, J. (1997). *Ubuntu*ism as a worldview to order society. PhD Thesis: University of South Africa.

Brothers for Life. (2014). *About Brothers for Life*. Retrieved August 7, 2014, from http://www.brothersforlife.org/about-brothers-life.html

Bujo, B. (2001). *Foundations of an African Ethic: Beyond the Universal claims of Western Morality*. New York: Herder & Herder.

Bujo, B. (2009). Ecology and Ethical Responsibility from an African Perspective. In M. F. Murove (Ed.), *African Ethics: An Anthology of Comparative and Applied Ethics* (pp. 291-297). Scottsville: UKZN Press.

Bunnell, R., Mermin, J., & De Cock, K. M. (2006). HIV Prevention for a Threatened Continent. *JAMA: The journal of the American Medical Association, 296*(7), 855-858.

Butler, A. (2005). South Africa's HIV and AIDS Policy, 1994-2004: How can it be explained? . *African Affairs , 104*, 591-614.

Cain, R., Collins, E., Bereket, T., George, C., Jackson, R., Li, A., . . . Travers, R. (2013). Challenges to the involvement of people living with HIV in community-based HIV/AIDS organizations in Ontario, Canada. *AIDS Care, 26*(2), 263-266.

Caldwell, J., Caldwell, P., & Quiggin, P. (1989). The Social Context of AIDS in sub-Saharan Africa. *Population and Development Review, 15*(2), 185-234.

Cambell, C., Nair, Y., Maimane, N., & Nicholson, J. (2007). Dying twice: a multi-level model of the roots of AIDS stigma in two South African communities. *Journal of Health Psychology, 12*(3), 403-416.

Campbell, C. (2003). *Letting them Die: Why HIV/AIDS Intervention Programmes Fail.* Indiana: Indiana University Press.

Campbell, C., & MacPhail, C. (2002). Peer Education, Gender and the Development of Critical Consciousness: Participatory HIV Prevention by South African Youth. *Social Science & Medicine, 52*(2), 331-345.

Caraël, M. (2006). Twenty Years of Intervention and Controversy. In P. Denis, & C. Becker (Eds.), *The HIV and AIDS Epidemic in sub-Saharan Africa in a Historical Perspective* (pp. 29-40. Accessed May 2, 2013 @ http://www.refer.sn/rds/article. php3?id_article=245). Online edition: Senegalese Network "Law, Ethics, Health" .

Cardey, S. (2006). From Behaviour Change to Social Change: Planning Communication Strategies for HIV/AIDS. Cairo: Paper prepared for presentation at the International Association for Mass Communication Research, The American University in Cairo.

Castells, M. (1997). *The Power of Identity.* Oxford: Blackwell Publishers.

Cater, S., & Little, M. (2007). Justifying Knowledge, Justifying Method, Taking Action: Epistemologies, Methodologies, and Methods in Qualitative Research. *Qualitative Health Research, 17*(10), 1316-1328.

Chabal, P. (2009). *Africa: The Politics of Suffering and Smiling.* London: Zed.

Chan, D. J., & Ray, J. E. (2007). Quantification of antiretroviral drugs for HIV-1 in the male genital tract: Current data, limitations and implications for laboratory analysis . *Journal of Pharmacy and Pharmacology, 59*(11), 1451-1462.

Chasi, C. (2011). Why participation . In K. Tomaselli, & C. Chasi (Eds.), *Development and Public Health Communication* (pp. 137-150). Cape Town: Pearson Education.

Chasi, C. (2011). *Hard Words on HIV/AIDS Communication.* Johannesburg: Real African Publishers.

Chasi, C. (2011). Why Participation. In K. Tomaselli, & C. Chasi, *Development and Public Health Communication* (pp. 137-150). Cape Town: Pearson Education.

Chasi, C. (2012). Role models in politicians will disappoint you: Cautionary notes on Aids leadership in post-apartheid South Africa. *Communicatio:*

South African Journal for Communication Theory and Research, 38(3), 312-328.

Chasi, C., & de Wet, G. (2005). Communication, choice and freedom with reference to risk in aspects of communication on HIV/AIDS, Communicatio. *South African Journal for Communication Theory and Research, 31*(2), 119-136.

Chasi, C., & Omarjee, N. (2014). It begins with you? An *Ubuntu*-centred critique of a social marketing campaign on HIV and AIDS. *Critical Arts: South-North Cultural and Media Studies, 28*(2), 229-246 .

Chinouya, M., & O'Keefe, E. (2008). Pachedu-Zenzele in the Diaspora: Promoting Sexual Health Amongst Zimbabweans in England. *International Migration Vol, 46*(5), 71-93.

Chirimuuta, R., & Chirimuuta, R. (1987). *AIDS, Africa and Racism.* London: Free Association Books.

Chitando, E. (2008). Religious Ethics, HIV and AIDS and Masculinities in Southern Africa. In R. Nicolson (Ed.), *Persons in Community: African Ethics in a Global Culture* (pp. 45-63). Scottsville: UKZN Press.

Christians, C. G. (2004). *Ubuntu* and communitarianism in media ethics. *Ecquid Novi: African Journalism Studies , 25*(2), 235-256.

Clumeck, N., Sonnet, J., Taelman, H., Mascart-Lemone, F., De Bruyere, M., Vandeperre, P. J., . . . Noel, H. (1984). Acquired immunodeficiency syndrome in African patients . *New England Journal of Medicine, 310*(8), 492-497.

Coates, T. J., Richter, L., & Caceres, C. (2008). Behavioural strategies to reduce HIV transmission: How to make them work better. *Lancet, 372*(9639), 669.

Cohen, L., Manion, L., & Morrison, K. (2000). *Research Methods in Education* (5th ed.). London: Routledge.

Cohen, M. S. (2004). HIV and sexually transmitted diseases: Lethal Synergy. *Topics in HIV medicine: A publication of the International AIDS Society, USA, 12*(4), 104-107.

Collings, S. J., Bugwandeedn, S. R., & Wiles, W. A. (2008). HIV post-exposure prophylaxis for child rape survivors in KwaZulu-Natal, South Africa: Who qualifies and who complies? *Child Abuse and Neglect, 34*(4), 477-483.

Cornman, D. H., Christie, S., Fisher, W. A., Shuper, P. A., Pillay, S., & Fisher, J. D. (2008). Clinic-based intervention reduces unprotected sexual behavior among HIV-infected patients in KwaZulu-Natal, South Africa: Results of a pilot study . *Journal of Acquired Immune Deficiency Syndromes, 48*(5), 553.

Cornu, C. (2006). *Enhancing the Greater involvement of people living with HIV (GIPA) in NGOs/CBOs in India.* New Delhi: The International HIV/AIDS Alliance in India.

Cornu, C., & Attawell, K. (2003). *The Involvement of People Living with HIV and AIDS in Community-based Prevention, Care and Support Programs in Developing Countries: A Multi-country Diagnostic Study.* New York: The Population Council Inc. and the International HIV/AIDS Alliance.

Cornwall, A. (2008). Unpacking 'Participation': Models, Meanings and Practices. *Community Development Journal, 43*(3), 269-283.

Craig, G., & Mayo, M. (1995). Community Participation and Empowerment: The Human face of Structural Adjustment or Tools for Democratic Transformation. In G. Craig, & M. Mayo, *Community empowerment: A reader in participation and development* (pp. 1-11). London: Zed Books.

Crepaz, N., & Marks, G. (2002). Towards an understanding of sexual risk behavior in people living with HIV: a review of social, psychological, and medical findings . *Aids, 16*(2), 135-149.

Crepaz, N., Lyles, C., Wolitski, R., Passin, W., Rama, S., Herbst, J., . . . Stall, R. (2006). Do prevention interventions reduce HIV risk behaviours among people living with HIV? A meta-analytic review of controlled trials. *AIDS, 20*(2), 143-157.

Creswell, J. (1994). *Research design: Qualitative and quantitative approaches.* Thousand Oaks: SAGE.

Creswell, J. (2002). *Qualitative Inquiry and Research Design.* Thousand Oaks, CA: SAGE.

Cullinan, K., & Thom, A. (2009). *The virus, vitamins and vegetables: The South African HIV and AIDS mystery.* Sunnyside: Jacana Media.

De Vroom, E., de Wit, J., Stroebe, W., Sandfort, T., & van Griensven, G. (1998). Sexual behavior and depression among HIV positive gay men. *AIDS and Behavior, 2*(2), 137-150.

De Wet, G., & Chasi, C. (2007). Existence, communication, violence and a mainly Kierkegaardian existential approach to communication on HIV/AIDS. *Communitas, 12*, 175-188.

Deane, N. (2005). The political history of AIDS treatment . In S. Abdool, & Q. Abdool, *HIV/AIDS in South Africa* (pp. 538-47). Cambridge : Cambridge University Press.

Delate, R. (2001). The struggle for meaning: A semiotic analysis of interpretations of the loveLife HIS & HERS Billboard Campaign. *Unpublished Honors Paper.* Durban: University of Natal.

Delate, R. (2012). US and Them: loveLife, Commercial Brands and Everyday Life. In E. Durden, & E. Govender (Eds.), *Investigating Communication, Health and Development: 10 Years of Research inThe Centre for Communication, Media and Society* (pp. 372-388). Sunnyside: Jacana Media.

Delia, J. (1977). Constructivism and the study of human communication. *Quarterly Journal of Speech, 63* , 66-83.

Denis, P. (2006). Towards a Social History of HIV and AIDS in sub-Saharan Africa. In P. Denis, & C. Becker, *The HIV and AIDS Epidemic in sub-Saharan Africa in a Historical Perspective* (pp. 13-26). Senegalese Network "Law, Ethics, Health": Online edition. Accessed May 2, 2013 @ http: //www.refer.sn/rds/article. php3?id_article=245.

Denis, P., & Becker, C. (2006). *The HIV/AIDS epidemic in sub-Saharan Africa in a Historical Perspective.* Senegalese Network "Law, Ethics, Health": Online edition. Accessed May 2, 2013 @ http: //www.refer.sn/rds/article. php3?id_article=245. .

Denzin, N., & Lincoln, Y. (2002). *The Qualitative Inquiry Reader.* (N. Denzin, & Y. Lincoln, Eds.) London: SAGE.

Denzin, N., & Lincoln, Y. (2005). Introduction: The Discipline and Practice of Qualitative Research. In N. Denzin, & Y. Lincoln (Eds.), *The SAGE Handbook of Qualitative Research* (pp. 1-19). London: SAGE.

DramAidE. (2014). *The Health Promoters project.* Retrieved July 31, 2014, from http://www.dramaide.co.za/index.php?option=com_content&view=article&id=58&Itemid=74

Dube, M. (2009). 'I Am Because We Are': Giving Primacy to African Indigenous Values in HIV/AIDS Prevention. In M. Murove, *African Ethics: An Anthology of Comparative and Applied Ethics* (pp. 188-217). Scottsville: UKZN Press.

Dube, M. W. (2009). I Am Because We Are: Giving Primacy to African Indigenous Values in HIV and AIDS Prevention . In M. Murove, *African Ethics: An Anthology of Comparative and Applied Ethics* (pp. 188-217). Scottsville: UKZN Press.

Dunkle, K., Stephenson, R., Karita, E., Chomba, E., Kayitenkore, K., Vwalika, C., . . . Allen, S. (2008). New heterosexually transmitted HIV infections in married or cohabiting couples in urban Zambia and Rwanda: An analysis of survey and clinical data. *Lancet, 371*, 2183–2191.

Dutta, M. (2008). *Communicating Health: A culture-centred approach.* Cambridge: Polity Press.

Dutta, M. (2011). *Communicating Social Change: Structure, Culture, and Agency.* London: Routledge.

Dutta-Bergman, M. (2005). Theory and Practice in Heath Communication Campaigns: A Critical Interrogation. *Health Communication, 18*(2), 103-122.

Echenberg, M. (2006). Historical Perspectives on HIV/AIDS: Lessons from South Africa and Senegal. In P. Denis, & C. Becker (Eds.), *The HIV and AIDS Epidemic in sub-Saharan Africa in a Historical Perspective* (pp. 89-96. Available at http: //www.refer.sn/rds/article. php3?id_article=245.). Online edition: Senegalese Network "Law, Ethics, Health".

Eisele, T. P., Mathews, C., Chopra, M., Brown, L., Silvestre, E., Daries, V., & Kendall, C. (2008). High levels of risk behavior among people living with

HIV Initiating and waiting to start antiretroviral therapy in Cape Town South Africa . *AIDS and Behavior, 12*(4), 570-577 .

Eisele, T., Mathews, C., Chopra, M., Lurie, M., Brown, L., Dewing, S., & Kendall, C. (2009). Changes in risk behavior among HIV-positive patients during their first year of antiretroviral therapy in Cape Town South Africa. *AIDS and Behavior, 13*(6), 1097-1105.

Enlow, R. (1984). Special session. (S. IJ, T. AS, & H. SZ, Eds.) *Annals of The New York Academy of Sciences: Acquired Immune Deficiency Syndrome, 437,* 290-311.

Enslin, P., & Horsthemke, K. (2004). Can *Ubuntu* provide a model for citizenship education in African democracies? . *Comparative education, 40*(4), 545-558.

Epstein, J. (1995). *Altered Conditions: Disease, Medicine, and Storytelling.* New York: Routledge.

Epstein, S. (1995). The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology & Human Values, 20*(4), 408-437 .

Epstein, S. (1996). *Impure science: AIDS, Activism, and the Politics of Knowledge* . Berkeley, CA: University of California Press.

Eze, E. (1998). *African philosophy: An anthology.* Oxford: Blackwell Publishers.

Eze, E. (1998). Modern Western Philosophy and African Colonialism . In E. Eze (Ed.), *African Philosophy: Anntology* (pp. 213-221). Oxford: Blackwell Publishers.

Farmer, P. (1999). *Infections and inequalities: The modern plagues.* Berkeley: University of California Press.

Fenton, L. (2004). Preventing HIV/AIDS through poverty reduction: the only sustainable solution? . *The Lancet, 364*(9440), 1186-1187.

Figueroa, M., Kincaid, D., Rani, M., & Lewis, G. (2002). *Communication for Social Change: An Integrated Model for Measuring the Process and Its Outcomes.* New York: The Rockefeller Foundation.

Ford, N., Odallo, D., & Chorlton, R. (2003). Communication from a Human Rights Perspective: Responding to the HIV/AIDS Pandemic in Eastern and Southern Africa A Working Paper for use in HIV and AIDS Programmes. *Journal of Health Communication: International Perspectives, 8*(6), 599-612.

Foucault, M. (1977). *Discipline and Punish.* New York: Pantheon.

Foucault, M. (1978). *The history of sexuality Vol. 1: An introduction.* New York: Random House.

Foucault, M. (1982). The Subject and Power. (H. Dreyfus, & P. Rabinow, Eds.) *Critical Inquiry, 8*(4), 777-795.

Foucault, M. (1990). *The History of Sexuality* (Trans. Robert Hurley ed.). London: Penguin.

Fourie, P. (2007). Moral philosophy as the foundation of normative media theory: The case of African *Ubuntu*ism. *Communications, 32*(1), 1-29.

Fourie, P. (2008). *Ubuntu*ism as a framework for South African media practice and performance: Can it work? . *Communicatio: South African Journal for Communication Theory and Research, 34*(1), 53-79.

Freire, P. (1970/2005). *Pedagogy of the Oppressed* (30th Anniversary ed.). London: Continuum.

Fuller, C., Ford, C., & Rudolph, A. (2009). Injection drug use and HIV: Past and future considerations for HIV prevention and interventions. In K. Mayer, & H. Pizer (Eds.), *HIV Prevention: A Comprehensive Approach* (pp. 305-339). London: Elsevier.

Garenne, M. (2008). Long-term population effect of male circumcision in generalised HIV epidemics in sub-Saharan Africa. *African Journal of AIDS Research , 7*(1), 1-8.

Gausset, Q. (2001). AIDS and cultural practices in Africa: the case of the Tonga (Zambia) . *Social Science and Medicine , 52*, 509 – 518.

George, G., & Sprague, C. (2011). HIV prevention in the world of work in sub-Saharan Africa: Research and Practice . *African Journal of AIDS Research, 10*(1), 291-300.

Geshekter, C. (2007). Myths and misconceptions of the orthodox view of AIDS in Africa. *Ethics & Politics , 9*(2), 330–370.

Gevisser, M. (2007). *Thabo Mbeki: The dream deferred.* Cape Town: Jonathan Ball.

Gilliam, P., & Straub, D. (2009). Prevention With Positives: A Review of Published Research, 1998-2008. *Journal of the Association of Nurses in AIDS Care, 20*(2), 92-109.

Gilman, S. L. (1988). *Disease and representation: Images of illness from madness to AIDS.* London: Cornell University Press.

GNP+. (2000). Evolution of GIPA - The road to Nairobi from Paris via Denver. *Informal Consultative Meeting on GIPA, 28 February–1 March. 2000.* Nairobi: Global Network of Persons Living with HIV and AIDS.

GNP+. (2004). Greater Involvement of People Living with HIV and AIDS (GIPA) in National Response to HIV and AIDS in India. Strategy Paper. New Delhi: Global Network of Persons Living with HIV and AIDS (GNP+).

Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity.* New York: Simon & Schuste.

Goga, A., Dinh, T., & Jackson, D. (2012). *Evaluation of the Effectiveness of the National Prevention of Mother-to-Child Transmission (PMTCT) Programme Measured at Six Weeks Postpartum in South Africa, 2010.* Pretoria: South African Medical Research Council, National Department of Health of South Africa and PEPFAR/US Centers for Disease Control and Prevention.

Gold, R., Skinner, M., & Ross, M. (1994). Unprotected anal intercourse in HIV infected and non-infected gay men. *Journal of Sex Research, 31*(1), 59 - 77.

Gooey, S. (2006). The Greater Involvement of People Living with and Affected by HIV and AIDS (GIPA) NGO Experiences and Implications for the Work of

Oxfam International and Oxfam Australia. HIV POLICY.ORG. An Online Database of HIV/AIDS Policies for the Asia Pacific Region. Available at http://www.hivpolicy.org/bib/HPP001513.htm. Retrieved from http://www.hivpolicy.org/bib/HPP001513.htm

Gordon, C., Forsyth, A., Stall, R., & Cheever, L. (2005). Prevention interventions with persons living with HIV/AIDS: State of the science and future directions . *AIDS Education & Prevention, 17*(Supplement A), 6-20.

Govender, E. (2013). *Processes and participation in HIV and AIDS Communication: Using bodymapping to explore the experiences of young people.* UKZN: Unpublished PhD Thesis.

Governder, E. M. (2011). Development and health communication for HIV and AIDS prevention. In K. Tomaselli, & C. Chasi (Eds.), *Development and Public Health Communication* (pp. 51-76). Cape Town: Pearson Education.

Gray, R., & Kigozi, L. (2005). Increased risk of incident HIV during pregnancy in Rakai, Uganda: A prospective study. *Lancet , 366*(9492), 1182 - 1188.

Gray-Felder, D., & Deane, J. (1999). *Communication for social change: A position paper and Conference Report.* Retrieved October 13, 2014, from http://www.communicationforsocialchange.org/publications-resources?itemid=14

Greig, A., Taylor, J., & MacKay, T. (2007). *Doing Research With Children* (2nd ed.). London: SAGE.

Gumucio-Dagron, A., & Tufte, T. (2006). *Communication for Social Change Anthology. Historical and Contemporary Readings.* New Jersey: Communication for Social Change Consortium.

Gupta, G., Parkhurst, J., Ogden, J., Aggleton, P., & Mahal, A. (2008). Structural approaches to HIV prevention. . *The Lancet,, 372*(9640), 764 - 775.

Guttman, N. (1997). Ethical Dilemmas in Health Campaigns. *Health Communication, 9*(2), 155 -190.

Hall, S. (1980). Cultural studies and the Centre: Some problematics and problems. In *Culture, Media, Language: Working Papers in Cultural Studies* (pp. 1972-1979). London: Hutchinson.

Hall, S. (1999). Cultural Studies and its Theoretical Legacies. In S. During (Ed.), *The Cultural Studies Reader* (pp. 99-108). London: Routledge.

Harding, S. (1987). The Method Question. *Hypatia, 2*(3), 19-35.

Hart, R. (1992). *Children's Participation: From Tokenism to Citizenship.* Florence: UNICEF International Child Development Centre.

Hesse-Biber, S., & Leavy, P. (2006). *The Practice of Qualitative Research.* London: SAGE.

Hintika, J. (1962). Cogito, ergo sum: Inference or Performance? . *The philosophical review, 71*(1), 3-32.

Hoopers, E. (2003). AIDS and the Polio Vaccine: Edward Hoopers finds New Evidence. *London Review of Books , 25*(7), 22-23.

HSRC. (2008). *South African National HIV Prevalence, Incidence, Behaviour and Communication Survey, 2008: A Turning Tide among Teenagers?* Cape Town: Human Sciences Research Council Press.

HSRC. (2014). *South African NationalHIV Prevalence, Incidence and Behaviour Survey, 2012.* Cape Town: Human Sciences Research Council.

Hunt, C. (1996). Social VS. Biological: Theories on the Transmission of AIDS in Africa. *The Journal of Social Science and Medicine, 42*(9), 1283-1296.

Ige, S., & Quinlan, T. (2012). HIV and AIDS Rhetoric in Africa. In S. Ige, & T. Quinlan (Eds.), *African responses to HIV and AIDS: Between Speech and Action* (pp. 1-8). Scottsville : University of KwaZulu-Natal Press.

Illife, J. (2006). *The African AIDS epidemic: A history.* Athens : Ohio University Press.

International HIV/AIDS Alliance . (1999). Enhancing the involvement of people Living with HIV'AIDS. *Alliance Newsletter, 4*(2).

Jaccard, J., Turrisi, R., & Wan, C. (1990). Implications of behavioral decision theory and social marketing for designing social action programs. In J. Edwards, R. Tindale, L. Heath, & E. Posavac (Eds.), *Social influence processes and prevention* (pp. 103-142). New York: Plenum .

Jana, S., Bandyopadhyay, N., Mukherjee, S., Dutta, N., Basu, I., & Saha, A. (1998). STD/HIV intervention with sex workers in West Bengal, India. *AIDS, 12*(Suppl. B), 101-108.

Janssen, R., & Valdiserri, R. (2004). HIV prevention in the United States: Increasing emphasis on working with those living with HIV . *Journal of Acquired Immune Deficiency Syndromes, 37*(Sup 2), 119-121.

Janssen, R., Holtgrave, D., Valdiserri, R., Shepherd, M., Gayle, H., & De Cock, K. (2001). The Serostatus Approach to Fighting the HIV Epidemic: Prevention strategies for Infected Individuals. *American Journal of Public Health, 91*(7), 1019.

Johnson, L., Hallett, T., Rehle, T., & Dorrington, R. (2012). The effect of changes in condom usage and antiretroviral treatment coverage on human immunodeficiency virus incidence in South Africa: A model-based analysis. *Interface Journal of The Royal Society, Online Accessed January 18, 2012@ rsif.royalsocietypublishing.org on.*

Johnson, S., Kincaid, D., Figueroa, M., Delate, R., Mahlasela, L., & Magni, S. (2013). *The Third National HIV Communication Survey, 2012.* Pretoria: Johns Hopkins Health Education South Africa.

Johnson, S., Kincaid, L., Laurence, S., Chikwava, F., Delate, R., & Mahlasela, L. (2010). *Second National HIV Communication Survey 2009.* Pretoria: Johns Hopkins Health Education South Africa.

Johnson, W., Diaz, R., Flanders, W., Goodman, M., Hill, A., Holtgrave, D., . . . McClellan, W. (2008). Behavioral interventions to reduce risk for sexual transmission of HIV among men who have sex with men (Review). *(3).* The Cochrane Library.

Jones, P. (2005). A test of governance: Rights-based struggles and the politics of HIV and AIDS policy in South Africa. *Political Geography , 24*, 419 – 47.

Kalichman, S. (2000). HIV transmission risk behaviors of men and women living with HIV-AIDS: Prevalence, predictors, and emerging clinical interventions. . *Clinical Psychology: Science and Practice, 7*(1), 32-47.

Kalichman, S. (2005). *Positive prevention: Reducing HIV transmission among people living with HIV/AIDS.* New York: Kluwer Academic/Plenum Publishers.

Kalichman, S. (2009). *Denying AIDS: Conspiracy theories, pseudoscience and human tragedy.* Ney York: Springer.

Kalichman, S., & Lurie, M. (2010). Positive prevention Interventions. In S. Abdool-Karim, & Q. Abdool-Karim, *HIV/AIDS in South Africa* (pp. 250-267). Cape Town: Cambridge University Press.

Kalichman, S., Ntseane, D., Nthomang, K., Segwabe, M., Phorano, O., & Simbayi, L. (2007). Recent multiple sexual partners and HIV transmission risks among people living with HIV/AIDS in Botswana. *Sexually Transmitted Infections, 83*(5), 371-375 .

Kalichman, S., Rompa, D., Cage, M., DiFonzo, K., Simpson, D., Austin, J., . . . Graham, J. (2001). Effectiveness of an intervention to reduce HIV transmission risks in HIV-positive people. *American journal of preventive medicine, 21*(2), 84-92.

Kamanzi, A. (2008). Evolution of HIV and AIDS discourse among the Haya on ten landing sites on the western shores of Lake Victoria, Tanzania: Need for a shift from a bio-medical to a meaningful life discourse . *UMU Press , 6*(3), 95-101.

Kamwangamalu, N. (1999). *Ubuntu* in South Africa: A sociolinguistic perspective to a pan-African concept. *Critical Arts, 13* (2), 24-41 .

Kant, I. (1978). *Anthropology from a Pragmatic Point of View.* (V. Dowdell, Trans.) Carbondale: South Illinois University Press.

Kant, I. (2002). Groundwork of the Metaphysics of Morals. In A. Wood (Ed.), *Rethinking the Western Tradition: Groundwork for the Metaphysic of Morals. Immanuel Kant* (pp. 1-63). London: Yale University Press.

Kaphagawani, D. (2004). African Concepts of a Person: A Critical Survey. In K. Wiredu (Ed.), *A Companion to African Philosophy* (pp. 332-342). Oxford: Blackwell Publishing.

Karenga, M. (2004). *Maat, the moral ideal in ancient Egypt: A study in classical African ethics.* New York: Routledge.

Katzenellenbogen, J., Joubert, G., & Karim, S. (1997). *Epidemiology: A manual for South Africa.* Cape Town: Oxford University Press.

Kelly, K., Freeman, M., Nkomo, N., & Ntlabati, P. (2008). The vicious circularity of mental health effects of HIV/AIDS: symptom and cause of poor responses to the epidemic. In V. Møller, & D. Huschka (Eds.), *Quality of Life and the Millennium Challenge* (pp. 223-237). Dordrecht: Springer.

Kelly, K., Mkhwanazi, N., Nkhwashu, N., Rapiti, R., & Mashale, R. (2012). *HIV prevention situation analysis in KwaZulu-Natal, Mpumalanga and Gauteng provinces, South Africa. USAID Sexual HIV Prevention Programme in South Africa (SHIPP).* Cape Town: Centre for AIDS Development, Research and Evaluation (CADRE).

Kelly, M., Desmond, C., & Cohen, D. (n/d). *The impacts of HIV and AIDS on Development. Module 1.1.* Retrieved November 13, 2012, from http://www.iiep.unesco.org/fileadmin/user_upload/Cap_Dev_Training/pdf/1_1.pdf.

Kennedy, C., Medley, A., Sweat, M., & O'Reilly, K. (2010). Behavioural interventions for HIV positive prevention in developing countries: a systematic review and meta-analysis. *Bulletin of the World Health Organization, 88*(8), 615-623.

Khobotlo, M., Tshehlo, R., Nkonyana, J., Ramoseme, M., Khobotle, M., Chitoshia, A., . . . Fraser, N. (2009). *Lesotho HIV Prevention Response and Modes of Transmission Analysis.* Maseru: Lesotho National AIDS Commission.

Kiene, S., Christie, S., Cornman, D., Fisher, W., Shuper, P., Pillay, S., & Fisher, J. (2006). Sexual risk behaviour among HIV-positive individuals in clinical care in urban KwaZulu-Natal, South Africa . *Aids, 20*(13), 1781-1784.

Kiene, S., Simbayi, L., Abrams, A., Cloete, A., Tennen, H., & Fisher, J. (2008). High rates of unprotected sex occurring among HIV-positive individuals in a daily diary study in South Africa: The role of alcohol use. *Journal of Acquired Immunodeficiency Syndrome, 49*(2), 219-226.

Kim, J., Askew, I., Muvhango, L., Dwane, N., Ambramsky, T., Jan, S., . . . Watts, C. (2009). Comprehensive care and HIV prophylaxis after sexual assault on rural South Africa: The Refentse intervention study . *British Medical Journal, 338*, 1559 -1564.

Kim, J., Gear, J., Hargreaves, J., Makhubele, B., Mashaba, K., Morison, L., . . . Watts, W. (2002). Social interventions for HIV and AIDS: Intervention with Microfinance for AIDS and Gender Equity. *IMAGE Study Evaluation Monograph: Intervention*(2). IMAGE. Retrieved from http://www.aidsportal.org/atomicDocuments/AIDSPortalDocuments/Intervention_monograph_no_pics.pdf.pdf.

Kincaid, D., & Figueroa, M. (2009). Communication for participatory development: Dialogue, collective action and Change. In L. Frey, & K. Cissna (Eds.), *Handbook of Applied Communication* (pp. 505-530). New Jersey: Laurence Erlbaum Associates.

Kincaid, D., & Parker, W. (2008). *National AIDS communication programs, HIV prevention behaviour, and HIV infections averted in South Africa, 2005.* Pretoria: Johns Hopkins Health Education South Africa.

Kincaid, D., Figueroa, M., Storey, J., & Underwood, C. (2007). *A social ecology model of communication, behaviour change, and behaviour maintenance. Working paper.* Bloomberg: Centre for Communication Programs, Johns Hopkins Bloomberg School of Public Health.

Koester, K., Maiorana, A., Vernon, K., Myers, J., Rose, C., & Morin, S. (2007). Implementation of HIV prevention interventions with people living with HIV/AIDS in clinical settings: Challenges and lessons learned . *AIDS and Behavior, 11*(1), 17-29.

Korenromp, E., Sudaryo, M., de Vlas, S., Gray, R., Sewankambo, N., Serwadda, D., . . . Habbema, J. (2002). What proportion of episodes of gonorrhoea and chlamydia becomes symptomatic? *International Journal of Sexually Transmitted Diseases and AIDS, 13* (2), 91 - 101.

Kumphitak, A., Kasi-Sedapa, S., Wilson, D., Ford, N., Adpoon, P., Katkaew, . . . K. (2004). *Involvement of people living with HIV/AIDS in treatment preparedness in Thailand: Case Study.* Retrieved October 2014, 2014, from World Health Organisation: http://www.who.int/hiv/pub/prev_care/thailand/en/

Kunda, J., & Tomaselli, K. (2012). Confusing public health with militant nationalism: South Africa's AIDS policy under Thabo Mbeki. In S. Ige, & T. Quinlan (Eds.), *African responses to HIV/AIDS: Between speech and action* (pp. 109-123). Scottsville: UKZN Press.

Kvale, S. (1996). *Inter-Views: An Introduction to Qualitative Research* Interview*ing* . New Delhi: SAGE.

Laga, M., & Piot, P. (2012). Prevention of sexual transmission of HIV: Real results, science progressing, societies remaining behind. *Aids , 26*(10), 1223-1229.

Le Blanc, M., Deirdre, M., & Piché, V. (1991). The African sexual system: comment on Caldwell *et al.*, in . *Population and Development Review, 19*(3), 497-505.

Leclerc-Madlala, S. (1997). Infect one, infect all: Zulu youth response to the AIDS epidemic in South Africa . *Medical Anthropology, 17*(4), 363-380.

Leclerc-Madlala, S. (2001). Demonising women in the era of AIDS: On the relationship between cultural constructions of both HIV/AIDS and femininity. *Society in Transition, 32*(1), 38-46.

Leclerc-Madlala, S. (2008). Sugar daddies and HIV: Is it really about money, money, money. *Human Science Research Council Review, 6*(3).

Leedy, D., & Ormrod, J. (2005). *Practical Research: Planning and Design* (8th ed.). New Jersey: Prentice Hall .

Leibowitch, J. (1985). *A Strange Virus of Unknown origin. trans. Howard R. New York: Ballentine Books.* (R. Howard, Trans.) New York: Ballentine Books.

Le-Roux, J. (2000). The concept of '*Ubuntu*': Africa's most important contribution to multicultural education? . *Multicultural Teaching, 18*(2), 43-46.

Letseka, M. (2000). African Philosophy and Educational Discourse. In P. Higgs, N. Vakalisa, T. Mda, & N. Assie-Lumumba (Eds.), *African Voices in Education* (pp. 179-193). Cape Town: Juta.

Letseka, M. (2013a). Anchoring *Ubuntu* morality . *Mediterranean Journal of Social Sciences, 4*(3), 351-359.

Letseka, M. (2013b). Educating for *Ubuntu*: Lessons from Basotho indigenous education. *Journal of Philosophy, 3* (2), 337-344.

Lincoln, Y. S., & Guba, E. G. (2001). Naturalistic Inquiry. VALLES, M. Técnicas.

Lindenbaum, S. (1998). Images of catastrophe: The making of an epidemic. In M. Singer (Ed.)*, The Political Economy of AIDS* (pp. 33-58). New York: Baywood.

Lindenbaum, S. (2001). Kuru, prions, and human affairs: Thinking about epidemics . *Annual Review of Anthropology*, 363-385.

London, L. (2003). Can Human rights serve as a tool for Equity: Equinet Discussion Paper 14. *14*, Available @ http://www.equinetafrica.org/bibl/docs/POL14rights.pdf. Cape Town: Regional Network for Equity in Health in Southern Africa (EQUINET) & UCT School of Public Health and Family Medicine.

Louw, D. (2001). *Ubuntu* and the Challenges of Multiculturism in Post Apartheid South Africa. *QUEST: An African Journal of Philosophy, 15*(1-2), 15-36.

Louw, D. (2003). *Ubuntu: An African assessment of the religious other.* Retrieved October 10, 2014, from https://www.bu.edu/wcp/Papers/Afri/AfriLouw.htm

loveLife. (2011). *Annual Report 2011.* Johannesburg: New loveLife Trust.

Lubombo, M. (2011). Stakeholders and their impact on community development. The case of OneVoive South Africa Schools Programme. In K. Tomaselli, & C. Chasi (Eds.), *Development and Public Health Communication* (pp. 104-119). Cape Town: Pearson Education South Africa.

Lubombo, M. (2012). *Theorising participation: Appropriating Stakeholder Theory in participatory communication for social change interventions in South Africa.* Saarbrucken: LAP Lambert .

Lurie, M., Pronyk, P., de Moor, E., Heyer, A., de Bruyn, G., Struthers, H., & Klipstein-Grobusch, K. (2008). Sexual behavior and reproductive health among HIV-infected patients in urban and rural South Africa. *Journal of Acquired Immune Deficiency Syndrome, 47*(4), 484-493 .

Maher, L., Coupland, H., & Musson, R. (2007). Scaling up HIV treatment, care and support for injecting drug users in Vietnam. *International Journal of Drug Policy, 18*(4), 296-305.

Makgoba, M. (1999). *African Renaissance: The New Struggle.* Johannesburg: Mafube.

Manchester, J. (2004). Hope, involvement and vision: Reflections on positive women's activism around HIV. *TRANSFORMATION*(54), 85-103.

Mangaliso, M. (2001). Building competitive advantage from *Ubuntu*: Management lessons from South Africa. *The Academy of Management Executive, 15*(3), 23-33.

Marks, G. (2005). Positive Prevention: Reducing HIV Transmission among People Living with HIV/AIDS (Book Review). *The New England Journal of Medicine, 353*(5), 353-356.

Marks, G., Burris, S., & Peterman, T. (1999). Reducing sexual transmission of HIV from those who know they are infected: The need for personal and collective responsibility. *AIDS, 13*(3), 297-306.

Marks, G., Crepaz, N., & Janssen, R. (2006). Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA. *Aids, 20*(10), 1447-1450.

Marks, G., Crepaz, N., Senterfitt, J., & R, J. (2005). Meta-analysis of high-risk sexual behavior in persons aware and unaware they are infected with HIV in the United States: implications for HIV prevention programs. *Journal of Acquired Immune Deficiency Syndromes, 39*(4), 446-453.

Marks, S. (2002). An Epidemic Waiting to Happen? The Spread of HIV and AIDS in South Africa in Social and Historical Perspective. *African Studies, 61*(1), 13-26.

Martin-Tuite, P. (2011). Whose Science?" AIDS, History, and Public Knowledge in South Africa. *Intersect, 4*(1), 8-25.

Mawar, N., Sahay, S., Pandit, A., & Mahajan, U. (2005). The third phase of HIV pandemic: social consequences of HIV/AIDS stigma & discrimination & future needs. *Indian Journal of Medical Research, 122*(6), 471-484.

Maxwell, C., Aggleton, P., & Warwick, I. (2008). Involving HIV-positive people in policy and service development: Recent experiences in England. *AIDS Care, 20*, 72-79.

Mayer, K., & Pizer, H. (2009). *HIV prevention: A comprehensive approach.* London: Academic Press.

Mayer, K., Skeer, M., & Mimiaga, M. (2010). Bio-medical approaches to HIV prevention. *Alcohol Health & Research World, 33*(3), 195-202.

Mbali, M. (2004). AIDS discourses and the South African state: Government denialism and post-apartheid AIDS policy-making. *Transformation, 54*, 104-22.

Mbali, M. (2005). The Treatment Action Campaign and the history of rights-based, patient-driven HIV/AIDS activism in South Africa. *Democratising development: The politics of socio-economic rights in South Africa*, 213-244.

Mbeki, T. (2000a, April 3). *Letter by President Mbeki: The complete text of South African President Thabo Mbeki's letter to world leaders on AIDS in Africa.* Retrieved October 14, 2014, from Virus Myth. A Rethinking AIDS Website: http://www.virusmyth.com/aids/news/lettermbeki.htm

Mbeki, T. (2000b, July 9). *Speech at the Opening Session of the 13th International AIDS Conference.* Retrieved October 14, 2014, from The Presidency Republic of South Africa: http://www.thepresidency.gov.za/pebble.asp?relid=2644

Mbeki, T. (2001, October, 12). *"He Wakened to his Responsibilities" Address by President Thabo Mbeki at the Inaugural ZK Matthews Memorial Lecture, University of Fort Hare.* Available @ http://www.unisa.ac.za/contents/colleges/docs/2001/tm2001/tm101201.pdf

Mbiti, J. S. (1969). *African Religions and Philosophy.* Oxford: Heinemann.

McGough, L. (2005). HIV and AIDS Stigma: Historical Perspectives on Sexually Transmitted Diseases. *Ethics Journal of the American Medical Association, 7*(10).

Medley, A., Kennedy, C., O'Reilly, K., & Sweat, M. (2009). Effectiveness of Peer Education Interventions for HIV Prevention in Developing Countries: A Systematic Review and Meta-Analysis. *AIDS Education and Prevention, 21*(3), 181-206.

Melkote, S. R., & Steeves, L. H. (2001). *Communication for Development in the Third World: Theory and Practice for Empowerment.* Thousand Oaks, CA: Sage Publications.

Merson, M. (2006). The HIV–AIDS pandemic at 25—the global response. *New England Journal of Medicine, 354*(23), 2414-2417.

Merson, M., O'Malley, J., Serwadda, D., & Apisuk, C. (2008). The history and challenge of HIV prevention. *The Lancet, 372*(9637), 475-488.

Metz, T. (2007a). Toward an African Moral Theory. *The Journal of Political Philosophy, 15*(3), 321–341.

Metz, T. (2007b). The Motivation for Toward an African Moral Theory. *South African Journal of Philosophy, 26*(4), 331-335.

Metz, T. (2009). African Moral Theory and Public Governance: Nepotism, Preferential Hiring and Other Partiality. In M. Murove (Ed.), *African Ethic: An Antology of Comparative and Applied Ethics* (pp. 335-356). Scottsville: UKZN Press.

Metz, T., & Gaie, J. (2010). The African ethic of *Ubuntu*/Botho: Implications for research on morality. *Journal of Moral Education, 39*(3), 273-290.

Mi-Kim, Y., Kalibala, S., Neema, S., Lukwago, J., & Weiss, D. (2012). Meaningful involvement of people living with HIV/AIDS in Uganda through linkages between network groups and health facilities: An evaluation study. *Psychology, Health and Medicine, 17*(2), 213-222.

Mill, J.S. (1985). Essays on Ethics, Religion, and Society. In M. JS, & J. Robson (Ed.), The Collected Works of John Stuart Mill (Vol. X). London: Routledge.

Mill, J.S. (1963-91). *The Collected Works of John Stuart Mill.* Toronto: University of Toronto Press.

Mkhize, N. (2008). *Ubuntu* and Harmony: An African Approach to Morality and Ethics. In R. Nicolson, *Persons in Community: African Ethics in a Global Culture,* (pp. 35-44). Scottsville: UKZN Press.

Mlambo, M., & Peltzer, K. (2011). HIV Sero-status Disclosure and Sexual Behaviour among HIV Positive Patients who are on Antiretroviral Treatment (ART) in Mpumalanga, South Africa. *Journal of Human Ecology, 35*(1), 29-41.

Mngadi, S., Fraser, N., Mkhatshwa, H., Lapidos, T., Khumalo, T., Tsela, S., . . . Odido, H. (2009). *Swaziland HIV prevention response and modes of transmission analysis.* Mbabane: National Emergency Response Council on HIV and AIDS.

Mulqueeny, D. (2013). *My HIV Journey as a woman of colour in South Africa.* Durban: Delarise Mulqueeny.

Mulqueeny, D., & Kasiram, M. (2013). Dating and sexual challenges faced by HIV-positive people in KwaZulu-Natal, South Africa. *Social Work/Maatskaplike Werk, 49*(3), 354-368.

Mulwo, A., Tomaselli, K., & Francis, M. (2012). HIV/AIDS and discourses of denial in sub-Saharan Africa: An Afro-optimist response? . *International Journal of Cultural Studies, 15*(6), 567-582.

Munyaka, M., & Motlhabi, M. (2009). *Ubuntu* and its Socio-moral Significance. In M. Murove, *African Ethics: An Anthology of comparative and applied ethics* (pp. 63-84). Scottsville: UKZN Press.

Murove, M. (2009). An African Environmental Ethic based on the Concepts of Ukama and *Ubuntu*. In M. Murove, *African Ethics: An Anthology of comparative and applied ethics* (pp. 315-331). Scottsville: UKZN Press.

Museka, G., & Madondo, M. (2012). The quest for a relevant environmental pedagogy in the African context: Insights from unhu/*Ubuntu* philosophy. *Journal of Ecology and the Natural Environment, 4*(10), 258-265.

Myburgh, J. (2009). In the beginning there was Virodene. In K. Cullinan, & A. Thom, *The virus, vitamins and vegetables: The South African HIV and AIDS mystery* (pp. 1-15). Sunnyside: Jacana Media.

Myers, L. (2011). *HIV positive leadership and entertainment-education within South African higher education: Lessons from the DramAidE's Health Promoters programme.* New Delhi: 5th International Entertainment Education Conference, 17-20 November 2011.

Myers, L., Kelly, K., & Motuba, T. (2012). *An 'appreciative inquiry' into the DramAidE Health Promoters project. Cape Town: CADRE.* Cape Town: CADRE.

Nattrass, N. (2007). *Mortal Combat: AIDS denialism and the struddle for Antiretrovirals in South Africa.* Scottsville: UKZN Press.

Needle, R., Coyle, S., Normand, J., Lambert, E., & Cesari, H. (1998). HIV prevention with drug-using populations - current status and future prospects: Introduction and overview. *Public Health Reports, 113*(Sup 1), 4-18.

Nicolson, R. (2008). Persons in the community: *Ubuntu* in the global village. In R. Nicolson, *Persons in Community: African Ethics in a Global Culture* (pp. 1-14). Scottsville: UKZN Press.

Norman, L., Abreu, S., Candelaria, E., & Sala, A. (2009). The effect of sympathy on discriminatory attitudes toward persons living with HIV and AIDS in Puerto Rico: A hierarchical analysis of women living in public housing. *AIDS Care, 21*(2), 140-14.

Nussbaum, B. (2003). African culture and *Ubuntu. Perspectives, 17*(1), www.barbaranussbaum.com/downloads/perspectives.pdf.

Nussbaum, B. (2003). *Ubuntu*: Reflections of a South African on our common humanity. *Reflections. The SoL Journal, 4*(4), 21-26.

Nussbaum, B. (2009). *Ubuntu* and Business: Reflections and Questions. In M. Murove, *African Ethics: An Anthology of Comparative and Applied Ethics* (pp. 238-258). Scottsville: UKZN Press.

Nussbaum, B. (2009). *Ubuntu*: Reflections of a South African on Our Common Humanity. In M. Murove, *African Ethics: An Anthology of comparative and applied ethics* (pp. 100-109). Scottville: UKZN Press.

Obregon, R., & Tufte, T. (2013). Towards a paradigm shift in Entertain-ment-Education: Exploring the emergent conceptual underpinnings. *African Communication Research*, 6(1) 33-64.

O'Leary, Z. (2004). *The Essential Guide to Doing Research.* London: SAGE Publications.

Odora-Hoppers, C. (2004). *Culture, Indigenous Knowledge and Development: The Role of the University.* Johannesburg: Centre for Education Policy Development.

Olley, B., Seedat, S., Gxamza, F., Reuter, H., & Stein, D. (2005). Determinants of unprotected sex among HIV-positive patients in South Africa. *AIDS care, 17*(1), 1-9.

Osborne, K. (2006). Positive prevention. *Contact, 182*, 9-11.

Ovens, M. (2003). A criminological approach to crime in South Africa. *Acta Criminologica, 16*(3), 67-80.

Padian, N., Buvé, A., Balkus, J., Serwadda, D., & Cates, W. (2008). Bio-medical interventions to prevent HIV infection: Evidence, challenges, and way forward. *The Lancet, 372*(9638), 585-599.

Paiva, V., FE, V., Santos, N., Novaes, L., & Segurado, A. (2003). The right to love: The desire for parenthood among men living with HIV. *Reproductive health matters, 11*(22), 91-100.

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

Parker, R., Aggleton, P., & Horizons, F. (2002). *HIV/AIDS-related stigma and discrimination: A conceptual framework and an agenda for action.* New York: Population Council.

Parker, R., Easton, D., & Klein, C. (2000). Structural barriers and facilitators in HIV prevention: A review of International Reseach. *AIDS, 14*(sup 1), 22-32.

Parker, W. (2004). Ideology, hegemony and HIV/AIDS: The appropriation of indigenous and global spheres. Durban: Unpublished PhD thesis. University of Kwazulu-Natal.

Parker, W. (2012). The politics of AIDS in South Africa. In S. Ige, & T. Quinlan, *African responses to HIV and AIDS: Between Speech and Action* (pp. 225-244). Scottsville: UKZN Press.

Parry, C., Carney, T., Petersen, P., Dewing, S., & Needle, R. (2009). HIV-risk behaviour among injecting or non-injecting drug users in Cape Town, Pretoria and Durban, South Africa. *Substance Use & Misuse, 44*(6), 886-904.

Paton, H. (2005). *Kant: The Moral Law.* New York: Routledge Classics.

Patton, C. (1997). From nation to family: Containing African AIDS . In M. Di Leonardo, & R. Lancaster, *The gender/sexuality reader: Culture, History, Political economy* (pp. 279-290). New York: Routledge.

Patton, M. (2002). *Qualitative Research & Evaluation Methods* (3rd ed.). London: Sage Publications.

Paxton, S. (2002). The paradoxn of public HIOV disclosure. *AIDS Care, 14*(4), 559-567.

Paxton, S., & Janssen, P. (2009). *AusAID GIPA Scoping Report.* AusAID Health Resource Facility.

Perkins, D., & Zimmerman, M. (1995). Empowerment Theory, Research and Application.. *American Journal of Community Psychology, 23*(5), 569-579.

Pettifor, A., MacPhail, C., Corneli, A., Sibeko, J., Kamanga, G., Rosenberg, N., . . . Cohen, M. (2010). Continued high risk sexual behaviour following diagnosis with acute HIV infection in South Africa and Malawi: implications for prevention. *AIDS and Behavior, 15*(6), 1243-1250.

Pojman, L. (2006). *Ethics: Discovering right and wrong.* London: Thompson Wadsworth.

Polkinghorne, D. (2005). Language and Meaning: Data Collection in Qualitative Research. *Journal of Counseling Psychology, 52*(2), 137-145.

Pretty, J. (1995). Participatory learning for sustainable agriculture. *World Development, 23*(8), 1247-1263.

Prinsloo, E. (1996). The *Ubuntu* style of participatory management. In J. Malherbe, *Decolonizing the mind: Proceedings of the Second Colloquium on African Philosophy* (pp. 112-127). Preotoria: UNISA Research Unit for African Philosophy.

Pronyk, P. (2006). *Development finance social capital and HIV and AIDS: The intervention with microfinance for AIDS & gender equity.* London: The IMAGE study London School of Hygiene and Tropical Medicine.

Qamar, M. (2001). The HIV epidemic: An unusual challenge to agricultural extension services in sub-Saharan Africa. *Journal of Agricultural Education and Extension, 8*(1), 1-11.

Qamar, M. (2003). *Facing the challenge of an HIV epidemic: Agricultural Extension Services in sub-Saharan Africa.* Rome: Food and Agriculture Organization of the United Nations.

Ramose, M. (2009). Ecology through *Ubuntu.* In M. Murove, *African Ethics: An Anthology of Comparative and Applied Ethics* (pp. 308-314). Scottsville: UKZN Press.

Ramose, M. (2009). Towards Emancipative politics in Africa. In M. Murove, *African Ethics: An Anthology of Comparative and Applied Ethics* (pp. 412-426). Scottsville: UKZN Press.

Rampersad, R. (2007). *Corporate Social Investment and HIV/ AIDS in South Africa.* University of Zululand: Unpublished PhD Thesis.

Ramphele, M. (1995). *Ubuntu doesn't mean a friendly greeting to your greeting to your gardener. What it does mean is another question … .* Sunday Independent, 24 September.

Rhodes, T., Donoghoe, M., Hunter, G., & Stimson, G. (1993). Continued risk behavior among HIV positive drug injectors in London: Implications for intervention. *Addiction, 88*(11), 1553-1560.

Robson, C. (2000). *Real World Research* (2nd ed.). Oxford: Blackwell Publishers.

Rockwell, DH., Yobs, A., & Moore, M. (1964). The Tuskegee Study of Untreated Syphilis The 30th Year of Observation. *Archives of Internal Medicine , 114*(6), 792-798.

Rosenberg, C. (1989). What is an epidemic? AIDS in Historical Perspective. *Daedalus, 118*(2), 1-17.

Rossow, M. (2003). The plague over time: A longitudinal study of how newspaper type and community location have influenced AIDS coverage in Minnesota. In L. Fuller, *Media-Mediated AIDS* (pp. 75-96). Creskill: Hampton Press.

Rotheram-Borous, M., Swendeman, D., & Chovnick, G. (2009). The past, present, and future of HIV prevention: Integrating behavioral, bio-medical, and structural intervention strategies for the next generation of HIV prevention. *Annual Review of Clinical Psychology ,* 143-167.

Rotheram-Borus, M., Lee, M., Murphy, D., Futterman, D., Duan, N., Birnbaum, J., & Lightfoot, M. (2001). Efficacy of a preventive intervention for youths living with HIV. *American Journal of Public Health, 91*(3), 400-405.

Roy, C., & Cain, R. (2001). The involvement of people living with HIV/AIDS in community-based organizations: Contributions and constraints. *AIDS care, 13*(4), 421-432.

RSA. (1993). *Constitution of the Republic of South Africa.* Pretoria: Government Printers.

Rubin, H., & Rubin, I. (2005). *Qualitative* Interview*ing – The Art of Hearing Data* (2nd ed.). Thousand Oaks: Sage Publications.

SafAIDS. (n.d.). *Mainstreaming the principle of Meaningful Involvement of People Living with or Affected by HIV and AIDS (MIPA) into HIV and AIDS programming.* Retrieved October 14, 2014, from SafAIDS: http://www.safaids.net/content/mainstreaming-principle-mipa-hiv-and-aids-programming-brochure-safaids

Sallis, F., Owen, N., & Fisher, E. (2008). Ecological Models of Health Behavior. In K. Glanz, B. Rimer, & K. Vismanath (Eds.), *Health behavior and health education : Theory, research, and practice* (pp. 565-485). San Francisco: Jossey-Bass.

Samkange, S., & Samkange, T. (1980). *Hunhuism or Ubuntuism: A Zimbabwe indigenous political philosophy.* Salisbury: Graham Publishers.

SANAC. (2010). *The national HIV Counselling and Testing campaign.* Pretoria: South African National AIDS Council.

SANAC. (2011). *National Strategic Plan for HIV and AIDS, STIs and TB, 2012-2016. South African AIDS Council.* Pretoria: South African National AIDS Council.

SANAC. (2011b). *The HIV epidemic in South Africa: What do we know and how has it changed?* Pretoria: South African National AIDS Council.

Sardar, Z., & BV, V. L. (1997). *Introducing Cultural Studies.* New York: McPherson's Printing Group.

Saukko, P. (2005). Methodologies for cultural studies: An integrative approach. In N. Denzin, & Y. Lincoln (Eds.), *The Sage Handbook of Qualitative Research* (pp. 343-356). London: SAGE.

Saule, N. (1996). *Images in some of the literary works of SEK Mqhayi .* Pretoria: Unpublished PhD Thesis, University of South Africa.

Saunders, M., Lewis, P., & Thornhill, A. (2009). *Research Methods for Business Students* (5 ed.). London: Financial Times Prentice Hall.

Sayers, H. (2010). *UBUNTU! The Spirit of Humanity.* Oman : Oasis Human Resource Development.

Scalway, T. (2010). *Presenting the evidence for social and behavioural communication.* Pretoria: Johns Hopkins Health Education South Africa.

Schwandt, T. (2001). *Dictionary of qualitative research.* Thousand Oakes: SAGE.

Seidel, G. (1993). The competing discourses of HIV and AIDS in sub-Saharan Africa: Discourses of rights and empowerment versus discourses of control and exclusion. *Social Sciences and Medicine, 36*(3), 175-194.

Seidel, G. (1996). Confidentiality and HIV status in Kwazulu-Natal, South Africa: implications, resistances and challenge. *Health Policy and Planning, 11*(4), 418-427.

Seidman, I. (2012). Interview*ing as qualitative research: A guide for researchers in education and the social sciences.* New York: Teachers College Press.

Serovich, J., & Mosack, K. (2003). Reasons for HIV disclosure or nondisclosure to casual sexual partners. *AIDS education and Prevention: Official publication of the International Society for AIDS Education, 15*(1), 70-80.

Servaes, J. (1999). *Communication for development: One world, multiple cultures.* Cresskill: Hampton Press.

Servaes, J. (2007). Harnessing the UN system into a common approach on communication for development. *International Communication Gazette, 69*(6), 483-507.

Setiloane, G. (1986). *African Theology: An Introduction.* Johannesburg: Skotaville Publishers.

Setswe, G. D., Akpan, F., Phala, A., Asmal, S., Kollipara, A., & Bishop, M. (2010). *Know your HIV prevention response (KYR) analysis: Report on the review of HIV prevention policies and programmes in the Gauteng Province.* Commissed by WorldBank/UNAIDS.

Sheckels, T. (2004). The Rhetoric of Thabo Mbeki on HIV and AIDS: Strategic Scapegoating? *Howard Journal of Communications, 15*(2), 69-82.

Shisana, O., Rehle, T., Simbayi, L., Parker, W., Zuma, K., Bhana, A., . . . Pillay, V. (2005). *South African national HIV prevalence, HIV incidence, behaviour and communication survey, 2005.* Cape Town: HSRC Press.

Shisana, O., Rehle, T., Simbayi, L., Parker, W., Zuma, K., Bhana, A., . . . Pillay, V. (2009). *South African National HIV Prevalence, Incidence, Behaviour and Communication Survey 2008: Turning the tide among teenagers?* Cape Town: HSRC Press.

Shutte, A. (1993). *Philosophy for Africa. Cape Town: UCT Press.* Cape Town: UCT Press.

Shutte, A. (1994, July). The *Ubuntu* project. . Durban: Unpublished paper presented at the 22nd Congress of Philosophical Society of Southern Africa, University of Natal.

Shutte, A. (2008). African Ethics in a Globalising World. In R. Nicolson, *Persons in Community: African Ethics in a Global Culture.* (pp. 15-34). Scottsville: UKZN Press.

Shutte, A. (2009). Politics and the Ethic of *Ubuntu* . In M. Murove, *African Ethics: An Anthology of Comparative and Applied Ethics* (pp. 390-399). Scottsville: UKZN Press.

Simbayi, L., Kalichman, S., Strebel, A., Cloete, A., Henda, N., & Mqeketo, A. (2007). Disclosure of HIV status to sex partners and sexual risk behaviours among HIV-positive men and women, Cape Town, South Africa. *Sexually Transmitted Infections, 83*(1), 29-34.

Simon-Meyer, J., & Odallo, D. (2002). Greater involvement of people living with HIV/AIDS in South Africa. *Evaluation and program planning, 25*(4), 471-479.

Singer, M. (1998). *The political economy of AIDS.* New York: Baywood Publishing Company Inc.

Singh, B., Koman, J., Catan, V., Souply, K., Birkel, R., & Golaszewski, T. (1993). Sexual risk behavior among injection drug-using human

immunodeficiency virus positive clients. *International Journal of the Addictions, 28*(8), 735-747.

Singhal, A. (2001). *Facilitating community participation through communication.* New York: UNICEF.

Slutkin, G., Okware, S., Naamara, W., Sutherland, D., Flanagan, D., Carael, M., . . . Tarantola, D. (2006). How Uganda reversed its HIV epidemic. *AIDS and Behaviour, 10*(4), 351-360.

Stein, Z. (1990). HIV prevention: The need for methods women can use. *American Journal of Public Health, 80*(8), 460-462.

Steinberg, J. (2008). Aids and Aids treatment in a rural South African setting. *Institute for Security Studies Monographs, 149,* 1-55.

Stephens, D. (2004). Out of the Shadows: Greater Involvement of People Living with HIV/AIDS (GIPA) in Policy. *USAID POLICY Working Paper Series, 14.*

Stoneburner, R., & Low-Beer, D. (2004). Population-level HIV declines and behavioral risk avoidance in Uganda. *Science, 304*(5671), 714-718.

Storey, D., & Figueroa, M. (2012). Towards a Global Theory of Health Behavior and Social Change. In R. Obregon, & S. Waisbord, *The Handbook of Global Health Communication* (pp. 70-94). London: John Wiley & Sons, Inc.

Teffo, L. (1994). *The concept of Ubuntu as a cohesive moral value.* Pretoria: *Ubuntu* School of Philosophy.

Teffo, L. (1996). The other in African experience. *South African Journal of Philosophy, 15*(3), 101-104.

Temples, P. (1959). *Bantu Philosophy.* Paris: Africaine.

Times, N. Y. (1983, May 22). *San Fransisco seeks to combat fear of AIDS.* Retrieved October 14, 2014, from The New York Times, US: http://www.nytimes.com/1983/05/22/us/san-francisco-seeks-to-combat-fear-of-aids.html

Tomaselli, K. (2003). Our Culture'vs 'Foreign Culture'An Essay on Ontological and Professional Issues in African Journalism. *Gazette, 65*(6), 427-441.

Tomaselli, K. (2011). Application and Case Studies. Introduction. In K. Tonaselli, & C. Chasi, *Development and Public Health Communication.* Cape Town: Pearson Education South Africa.

Tomaselli, K., Dyll-Myklebust, L., & van Grootheest, S. (2012). Personal/Political Interventions via Autoethnography: Dualisms, Knowledge, Power and Performativity in Research Relations. In A. T. Holman, & C. Ellis, *The Handbook of Autoethnography* (pp. 576-594). California: Left Coast Books.

Travers, R., Wilson, M., Flicker, S., Guta, A., Bereket, T., McKay, C., & Globerman, J. (2008). The greater involvement of people living with AIDS principle: Theory versus practice in Ontario's HIV/AIDS community-based research sector. *AIDS Care, 20*, 615-624.

Tufte, T., & Mefalopulos, P. (2009). Participatory Communication: A Practical Guide. *World Bank Paper 170.*

Turner, A., Morrison, C., Padian, N., Kaufman, J., Behets, F., Salata, R., . . . Miller, W. (2008). Male circumcision and women's risk of incident chlamydial, gonococcal, and trichomonal infections. *Sexually Transmitted Diseases, 35*(7), 689-695.

Tutu, D. (1999). *No future without forgiveness.* New York: Random House.

UNAIDS. (1999). *'key material' From principle to Practice: Greater Involvement of People Living with or Affected by HIV and AIDS (GIPA).* Geneva: Geneva: Joint United Nations Programme on HIV/AIDS.

UNAIDS. (2000). *Enhancing the Greater Involvement of People Living With HIV or Affected by HIV/AIDS (GIPA) in sub-Saharan Africa - A UN response: how far have we gone? .* Geneva: Joint United Nations Programme on HIV/AIDS.

UNAIDS. (2001). *The UN Declaration of commitment and people living with HIV(PWAs).* Geneva: Joint United Nations Programme on HIV/AIDS.

UNAIDS. (2007). *The Greater involvement of people living with HIV and AIDS: Policy Brief, Africa.* Geneva: Joint United Nations Programme on HIV/AIDS.

UNAIDS. (2010). *Global Report: UNAIDS Report on the global AIDS epidemic.* Geneva: Joint United Nations Programme on HIV/AIDS.

UNAIDS. (2010). *Non-discrimination in HIV responses: 26th Meeting of the UNAIDS Programme Coordinating Board.* Geneva: Joint United Nations Programme on HIV/AIDS.

UNAIDS. (2013). *UN World AIDS Day Report 2013.* Geneva: Joint United Nations Programme on HIV/AIDS.

UNAIDS. (2011). *UNAIDS Terminology Guidelines: Revised Version.* Geneva: Joint United Nations Programme on HIV/AIDS.

UNAIDS. (2012). *World AIDS Day Report.* Genever: Joint United Nations Programme on HIV/AIDS.

UNDP. (2004). *From Involvement to Empowerment: People Living with HIV/AIDS in Asia Pacific.* Geneva: United Nations Development Programme.

Uphoff, N. (1985). Fitting projects to people. In M. Cernea, *Putting People First: Sociological Variables in Rural Development* (pp. 359-391). New York: Oxford University Press.

Van Binsbergen, W. (2001). *Ubuntu* and the Globalisation of Southern African Thought and Society. *QUEST. An African Journal of Philosophy, 15*(1-2), 53-90.

Van Eerdewijk, A. (2007). *The ABC of unsafe sex: gendered sexualities of young people in Dakar (Senegal).* Nijmegen: Radboud University.

Van Niekerk, A. (2002). Moral and social complexities of AIDS in Africa. *The Journal of Medicine and Philosophy, 27*(2), 143-162.

Van Rijn, K. (2006). The politics of uncertainty: The AIDS debate, Thabo Mbeki and the South African government response. *Social History of Medicine, 19*(3), 521-538.

Venter, E. (2004). The notion of *Ubuntu* and communalism in African educational discourse. *Studies in Philosophy and Education, 23*(2-3), 149-160.

Verhoef, H., & Michel, C. (1997). Studying morality within the African context: A model of moral analysis and construction. *Journal of Moral Education, 26*(4), 389-407.

Webb, R. (2006). Microbicides and their role in HIV prevention. HIV PREVENTION: Current issues and new technologies. *Contact, 182,* 28-30.

WHO. (2008). *Towards Universal Access: Scaling Up Priority HIV and AIDS Interventions in the Health Sector. Progress Report 2008.* Geneva: WHO Library Cataloguing-in-Publication Data.

WHO. (2014). *Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations.* Geneva: WHO Library Cataloguing-in-Publication Data.

Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method.* Philadelphia: Open University Press.

Wilson, D., Law, M., Grulich, A., Cooper, D., & Kaldor, J. (2008). Relation between HIV viral load and infectiousness: A model-based analysis. *The Lancet, 372*(9635), 314-320.

Wingood, G., & DiClemente, R. (2000). Application of the theory of gender and power to examine HIV-related exposures, risk factors and effective interventions for women. *Health Education and Behaviour, 27*(5), 539-565.

Wingood, G., DiClemente, R., Mikhail, I., Lang, D., McCree, D., Davies, S., & Saag, M. (2004). A randomized controlled trial to reduce HIV transmission risk behaviors and sexually transmitted diseases among women living with HIV: The WiLLOW Program. *JAIDS Journal of Acquired Immune Deficiency Syndrome, 37*(Sup 1), 58-67.

Wood, A. (2002). *Groundwork for the Metaphysics of Morals. Rethinking the Western Tradition.* London: Yale University Press.

World-Bank. (2003). *Education and HIV/AIDS: A Sourcebook of HIV/AIDS Prevention Programs.* Washington DC: World Bank.

Wright, J. (2013). Only Your Calamity: The Beginnings of Activism by and for People With AIDS. *American Journal of Public Health, 103*(10), 1788-1798.

Wulfsohn, A., Venter, W., Schulze, D., Levey, M., & Sanne, I. (2003). Post-exposure prophylaxis for HIV after sexual assault in South Africa. Atlanta: Unpublished data presented at the 2003 National HIV Prevention Conference, Atlanta.

Yonah, G., Fredrick, F., & Leyna, G. (2014). HIV serostatus disclosure among people living with HIV/AIDS in Mwanza, Tanzania. *AIDS Research and Therapy, 11*(5).

Zungu-Dirwayi, N., Shisana, O., Louw, J., & Dana, P. (2007). Social determinants for HIV prevalence among South African educators. *AIDS Care, 19*(10), 1296-303.