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## The Culture Inspired Hybrid Interpretations of the HIV/AIDS Lived-Experiences

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### 1. Introduction

Over the past two decades of HIV/AIDS disease, there has been a range of research perspectives concentrating on the health related concerns of the epidemic. Parker (2001) stated that like many other disciplines, anthropology failed to distinguish itself in its initial responses to the HIV/AIDS epidemic. Furthermore, anthropologists, especially in Africa, contributed only irregularly to such early research and mobilisation was on the basis of their own individual research initiatives and publications rather than as part of a formal or organised research response. This is evidenced in the paucity of ethnographic empirical research focusing on the management of HIV/AIDS in public schools. This does not mean that there were no important and valuable contributions made by anthropologists to the study of HIV/AIDS (Bolognone 1986).

The dominant paradigm for the organisation and conduct of AIDS research in Sub-Saharan Africa has begun to be perceptible in the past decades. The paradigm that characterised the prevailing studies during this time had a mainly biomedical emphasis and a largely individualistic bias in relation to the ways in which the social sciences might contribute meaningfully to the development and implementation of an HIV/AIDS research agenda (Parker, 2001).

Much of the social sciences research activity that emerged in response to HIV/AIDS in Sub-Saharan Africa during the mid 80s to late 90s, and up to the present, focused on surveys of risk-related behaviours and on the knowledge, attitudes and beliefs about sexuality that are HIV risk associated. The aims of these studies were in Parker's terms, to collect quantifiable data on numbers of sexual partners, the frequency of different sexually transmitted diseases, and any number of other similar issues that were understood to contribute to the spread of HIV infection (Carballo, Cleland, Carael, & Albrecht, 1989; Cleland and Ferry, 1995). Thus, such studies could only pave the way for prevention policies and intervention programmes designed by government to reduce HIV-related risk behaviours.

The limitations of behavioural intervention based on information and reasoned persuasion as a stimulus for risk reduction became evident. In Sub-Saharan Africa, the emergence of cultural studies that have some traces of ethnographic characteristics began to emerge among researchers in Uganda and South Africa. By the late 1990s, it became clear that a far more complex and wider set of social, structural and cultural factors are likely to mediate

HIV/AIDS risks in every population and that individual psychology cannot be expected to explain fully, let alone produce changes in sexual conduct, without taking these issues into account (Obbo 1988, Herdt & Boxer, 1991).

The 1990s witnessed a growing focus on the interpretation of cultural meanings as central to fuller appreciation of HIV/AIDS transmission. In South Africa then, ethnographic studies began to identify culture as key to understanding practices that impact on the high prevalence of HIV/AIDS. These studies viewed cultural/traditional practices as a problem contributing to transmission rather than examining possibilities that might exist for responding to cultural practices through the design of more culturally appropriate prevention programmes. A matter of paramount concern at this time was to examine and explicate what sexual practices mean to the persons involved, the significant contexts in which they take place, the social scripting of sexual encounters, and the diverse sexual cultures and subcultures that are present within different societies. The researchers sought to go beyond the identification of statistical correlates aimed at explaining sexual risk behaviours and conceptions (Leclerc-Madlala, 2005; Abdul Karim, 2000; Parker, 2001).

The focus on sexuality in relation to HIV/AIDS shifted to the knowledge and what informed the knowledge on HIV/AIDS within the society i.e. the cultural setting within which behaviours take place and to the cultural symbols, meanings and rules that arranged it (Ashforth, 2001; Stadler, 2003; Naeme, 2004). It became evident that not just cultural, but also structural, racial, political and economic factors moulded beliefs and experiences. Emphasis was placed on the fact that racial and economic factors have played a key role in determining the shape and spread of the epidemic in South Africa. These studies also focused on the ways in which societies and communities structured the possibilities of sexual interactions between social actors with whom one may have sex, in what ways and under what circumstances.

Gender inequalities in sub-Saharan Africa were identified as the seeds of social and cultural rules and regulations placing specific limitations on the female's potential for negotiation in sexual interactions. These rules and regulations conditioned the possibilities for the occurrence of sexual violence and the patterns of contraceptive used and sexual negotiation (Visser, Schoeman, & Perold, 2004; Naeme 2004). Consequently, the dynamics of gender power relations have become a major focus for recent research such as mine. Although most studies concentrated on reproductive health, some social anthropological studies voiced concerns about gender relations especially among the rural women. This body of research has drawn attention to the need for structural changes aimed at highlighting, in a wider perspective, a focus on cultural influences. The findings of these studies channel the attentions of these researchers towards critically envisioning the search for effective mediation of HIV/AIDS and People living with HIV/AIDS (PLHIV) towards cultural and religious practices. Similarly, it moves the focus from the usual biomedical constructs investigation to investigation of the lived experiences of the members in order to get clues for the way forward especially now that the existing strategies seem neither effective nor efficient.

In this chapter, I have drawn attention to overlaps between various beliefs and practices that characterised the HIV/AIDS lived experiences of the members of education workplaces. Though some studies refer to these constructs, they do not explicitly identify the combination, or what I identified as 'hybridisation', of these constructs in the understanding and practices around HIV/AIDS and PLHIV. HIV/AIDS academic analysts have rarely looked at these combined lived experiences that characterise HIV/AIDS. However, in the

South African public schools' cases, I saw that there is no one approach or strategy that individuals use to mediate the epidemic. I also note that while there are various ways of experiencing the disease: people combine two or more approaches.

Firstly, there is evidence confirming that members of these education institutions have relatively good biomedical and legal knowledge of the epidemic, such as is provided in the National Policy document. A closer look at the HIV/AIDS lived experiences at the individual level confirms the inadequacy of the biomedical and legal approaches to the epidemic. Although most of the educators and principals draw their experiences mostly from the biomedical and legal approaches, most of them also integrate aspects of religious, gender and indigenous cultural beliefs and practices. Also, despite the fact that biomedical and legal approaches are officially recommended, members of these education institutions see these strategies as insufficient, inefficient and ineffective in providing solutions or answers to several questions. Because these two approaches (biomedical and legal) have some attributes which instead of solving the problems, encourage several forms of emotional torment from their high costs, and because of the culture of secrecy and privacy, alternative measures were incorporated by these individuals to deal with the multifaceted challenges of HIV/AIDS.

The experiences narrated in this chapter have pragmatic implications for how people experience the disease and PLHIV in education workplaces. The first category of the respondents, presents the narratives of an educator who *was* very knowledgeable in biomedical approaches to HIV/AIDS, but who chose to embrace religious beliefs and practices in her lived experiences. This educator seems to have successfully maintained her claim on the religious approaches whilst acknowledging the biomedical and other cultural practices relating to the epidemic and PLHIV. There does not appear to have been any significant disaffirmation by her of HIV/AIDS lived experiences; rather, it is the aspiration to the search for a cure and protection from stigma that led her to choose to give up the biomedical approaches to the disease. Her lived experience with the disease has reinforced her sense of being someone who is able to deal with the HIV/AIDS related circumstances in her school. What emerges very powerfully from this respondent's narrative is the centrality of belief, particularly religious belief in dealing with HIV/AIDS in the work place. This theme appears throughout my research but in a variety of forms. I abandoned the assumption that biomedical and legal constructs are truly accurate versions of a participant's beliefs, actions and practices towards HIV/AIDS and PLHIV. From the above, the challenges seem to revolve around the treatment of the infection and dealing with the stigma associated with it.

The second category that switched from treatment to protection against the infection. One of the educators in this category demonstrated considerable dissatisfaction at the western-medicine approach to protection against the disease. It was his experience of his ethnic practices, which provided understanding and meaning to what he prefers to use to protect himself and his wife. He was able to develop this new protective strategy by adhering to his indigenous cultural practices. With this new experience, he was able to protect his family from the disease which carries unbearable shame for someone like him. From this respondent, I posit that people construct their own beliefs and practices towards protection against the epidemic, some of which are in contrast to the protective strategies laid out by the biomedical discourses.

Another example of religious beliefs is one of extended eschatological Christian beliefs and practices. This notion by some identified Christians suggested that HIV/AIDS is God's ways

of venting His anger on the generation that has turned their backs on Him. This view does not necessarily provide opportunity for people to learn from their mistakes. People living with the disease have been condemned to pay for their 'sin' by death which is their 'wage' for not listening to God's messages and instructions.

The fourth category offered an example of an educator who is struggling to accept the challenges of being infected. She started with bitterness, blames and anger towards the society that seems to appreciate the males more than the females. She took this position because it was difficult for her to forgive a man who traditionally married three wives and yet was promiscuous. She has now resigned to a life of shame for her while alive and for her children when she is dead. These narratives highlighted important culturally-related concepts such as 'curses' 'dirt' and 'pollution'. Some educators also see the disease as dirt and the infected as polluted with dirt. Douglas (1966) asserts that such feelings introduce the concept of sacredness whereby the society isolates the sick person who then keeps his or her distance from other people.

Obviously, the practices of '*sacredness*' in relation to the illness and the infected ushered in the understanding of 'dirt' as associated with HIV/AIDS. At this juncture, I must emphasise that those infected are not treated as taboo or outcasts openly but are indirectly stigmatised. Not all respondents treat them so. According to Stein's (2003) theory of the 'latest changing faces of HIV/AIDS stigma', it can be accepted that symbolic stigma (i.e. stigma based on moral condemnation regarding sexual behaviour) is instrumental or useful here because it serves to distance the individual or group from the fear of infection by facilitating denial of own risk (*It will not happen to me because I am a good person/part of a good group of people*).

The fifth respondent's attitude constructs the epidemic as a taboo, not discussed or easily talked about. She suggests that some members of the education sector use blame and resignation to mediate HIV/AIDS. The failure to speak openly about the epidemic, irrespective of biomedical knowledge of the disease acquired through training and based on the construction of gender was revealed. Her responses help highlight the influence of gender according to which the women are socialised not to freely discuss death and sex.

Finally, a new perspective on the disease emerges from the youths which contradict in every way the fears, shame and condemnation consistently found in the responses of the interviewees. Taking different perspectives and routes to understand and mediate the epidemic, they appear to attempt to distance themselves from the entire mystifying HIV/AIDS-related stigma because of death. They provide models for reclaiming their desired HIV/AIDS lived experiences. Their sexual relationships and the socialisation practices they engage in provide completely new and contradictory views of their friends and acquaintances living with HIV/AIDS and the epidemic.

What do we learn from this rather long expedition into the realities of the HIV/AIDS lived experiences? I argue that in order to effectively deal with the challenges people face as a result of the epidemic, we need to know the diverse ways people understand and experience the disease. I have presented information that not only do people mediate the epidemic in diverse ways; they also combine constructs in their HIV/AIDS lived experiences. I also showed that biomedical and legal discourses are not taken very seriously in the practice of HIV/AIDS treatment and protection against the epidemic by the members of education work places. The culture of secrecy and privacy located within the biomedical and legal discourses strengthens the HIV/AIDS-related stigma which I identified in the narratives as '*residential*' (in the epidemic) and '*translated*' (not only for the PLHIV but also their children when they are dead).

The HIV/AIDS and PLHIV understandings have been the subject of avid interest and curiosity in this section. The section presented a significant sampling of responses from the semi-structured interviews and the focus group discussions with the participants, and explored both their HIV/AIDS narratives and meaning.

Many participants would still subscribe to the biomedical theory in understanding HIV/AIDS and PLHIV; many think that there will always be 'confusion, strife and dispute' in making sense of the disease and PLHIV especially considering that there is still no cure for the epidemic. The fact is that today neither biomedical nor legal discourses (common with researchers and policy designers) are satisfactory in explaining issues around HIV/AIDS and PLHIV. But the question is to know whether there are alternative ways people understand or make meaning of the epidemic and those infected that may explain the existing implementation gaps between HIV/AIDS policies and practices in the South African schools.

Biomedical and legal understandings notwithstanding, no one discourse explains the HIV/AIDS and PLHIV understandings of these participants. The truth is that these individuals engage more than one realm of ideas in making sense of the disease. Indeed, even with the most extreme religious and indigenous theories, it is possible to demonstrate the existence of a rivalry between these two discourses and one or two other discourses. It is clear from the extracts discussed in this chapter that there is more than one alternative way people make sense of the disease in their individual schools. But these understandings are very ambiguous and unconventional.

These interpretations do not unfold on a conventional level of understanding of the disease. Further, no one theory has ever seemed sufficient to define how people make meaning of the disease, to furnish in itself the key to human explanations of the disease, or to express the totality of a situation (especially with PLHIV) that it only helps to define. These realms of ideas are products of their lived experiences and belief systems. Based on these systems of understanding, the concept of 'hybridisation' as identified in the lived experiences summarises ways these individuals make sense of the epidemic and PLHIV.

Hybridisation theory in this context suggests that people combine one or more views to make sense of the disease. With biomedical knowledge as top on the list, there is less evidence of or emphasis on the legal discourses in these narratives. People combine one or more of these alternative discourses with their existing biomedical knowledge of the disease. These alternative discourses are; indigenous (including witchcraft), religious, eschatological and racial discourses. It is vain to apportion praise or blame to any of these theories. The hybrid theory for explaining the disease and attitudes towards PLHIV will go on as long as the biomedical discourse fails to discover the cure for HIV/AIDS. These men and women fail to recognise a single system of understanding as the ultimate in explaining the epidemic.

For a long time there have been efforts to disguise this misfortune (complicated understanding of the epidemic and PLHIV) in South Africa. For example, the indigenous theory of the epidemic has been accused of escalating HIV/AIDS transmission. No one has been able to pinpoint the fact that it is first one way individuals make sense of the epidemic and PLHIV; the religious and eschatological views have not received much recognition and the constructions of the racial discourse was not very different from the legacies of apartheid. However, the innumerable conflicts that set biomedical discourse against others (which I described as 'alternatives') come from the fact that neither is prepared to offer credible, effective and efficient explanations for the consequences of this epidemic.

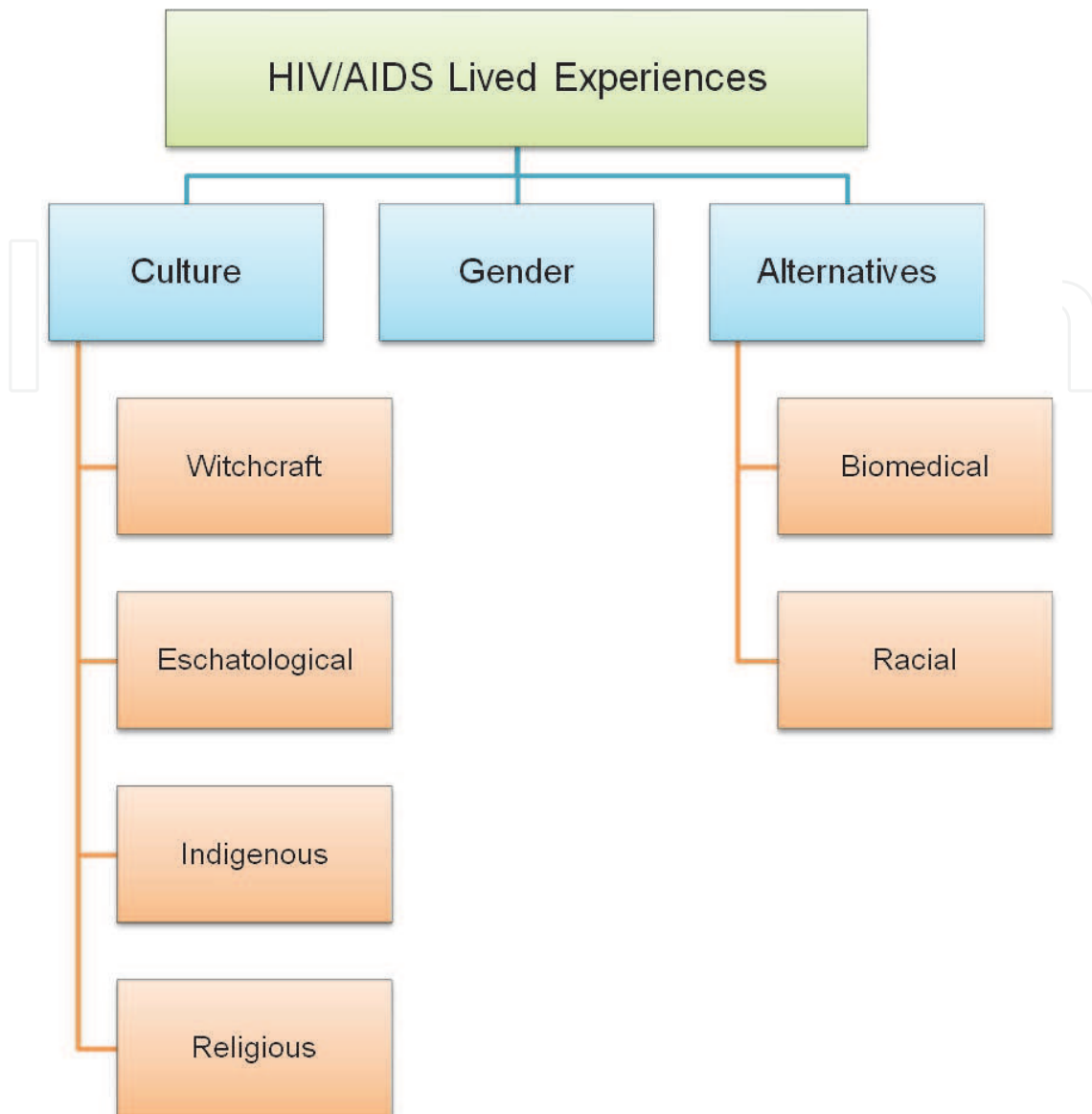


Fig. 1. Diagrammatical representation of the interconnectivity of the impact of culture and gender on HIV/AIDS lived experiences

At the commencement of the research from which this chapter is written, I accepted the premise that there are several factors that directly or indirectly influence the HIV/AIDS lived experiences and how people make sense of the epidemic and PLHIV. Having accepted this, I created relationships and situations which might offer members of South African public schools the possibility of narrating and describing their HIV/AIDS lived experiences in interviews and discussions with me and each other. From the findings, I identified the defining experiences and perceptions as 'conventional' and 'alternatives'. I also identified the systems by which these conventions and alternatives function together, as 'hybridisation' processes. I attempted to create scenarios and situations which would offer the participants opportunities for revealing these. The focus of my attention was on;

- Individual HIV/AIDS lived experiences
- The background events, practices, knowledge and beliefs which might highlight the individual's lived experiences

- The background perceptions and circumstances which might stimulate the likelihood of cultural response to their HIV/AIDS lived experiences
- The respondents' interactions, responses and non-verbal communication

I concluded that culture has immense influence in the HIV/AIDS lived experiences of the majority of the members of South African public schools in the following ways;

- Understanding of the epidemic and PLHIV
- Their treatment approaches
- Their methods of caring
- Their prevention strategies
- Beliefs and practices

I further concluded that;

- Gender constructs are embedded in the cultural discourse so as to impact HIV/AIDS lived experiences of individual members of these institutions
- Biomedical discourse is inadequate in providing detailed explanations for and interpretations of the HIV/AIDS lived experiences of these individuals
- There are alternative realms of ideas and practices that these people engage in making sense of and dealing with the epidemic and PLHIV
- Members of these educational institutions engage in a process of 'hybridisation' of the diverse discourses that are prevalent in HIV/AIDS related study in understanding and experiencing HIV/AIDS and PLHIV
- Most of these 'alternative' approaches are unconventional and may be seen as authentic or contrived. However, they provide these people with other ways of mediating the epidemic than the biomedical discourse
- The National Policy also created conflicts and complications in understanding and dealing with the epidemic through its linguistic constructions

Although I drew these conclusions, my attempts to generalise findings were not successful. Diverse experiences and understandings in a society that is very diversified (such as exists in Gauteng province; South Africa) in terms of culture and beliefs made it impossible. I am therefore forced to accept that the findings in this study may yield different or more consistent results if conducted in a society with the same or similar culture and belief systems.

Theoretical assumptions that inform the research were greatly challenged as I continued to explore these HIV/AIDS lived experiences and how people actually understood the disease and PLHIV. I realised that available ideas and existing metaphors are not adequate in projecting the lived experiences and various interpretations that plagued the research content: HIV/AIDS, culture, gender, and lived-experiences. When I analysed my data, I reacted to more than the few theories that touched on the subjects of my interest. As well, I note during data collection that people react differently from the prescriptions of most of the theories that seemed to offer reasonable interpretations in some aspects. I concluded that there are immense complexities, complications and conflicts in interpreting how HIV/AIDS and PLHIV are experienced and understood. Having adopted this position, I then concluded that no one approach or discourse could offer adequate interpretations to the HIV/AIDS and PLHIV lived experiences and understandings. Individuals make sense and deal with the epidemic and those infected not only through the biomedical paradigm but also following their cultural precedents. I therefore posit that the intricacies associated with HIV/AIDS brought about by lack of a cure would be said to have initiated the combinations



of world views in dealing with and understanding the epidemic and PLHIV even among members of the education sector.

I explored the empirical elements of persistent cultural and gender themes in HIV/AIDS transmission and treatment debates vis-à-vis the personal epistemologies of the members of education workplaces that deal with HIV/AIDS and PLHIV. I focused on participants' narratives, to study the identified social and cultural variables that shaped and nurtured the participants' experiences which inform their practices and attitudes towards the disease and PLHIV.

I reviewed the empirical literature for HIV/AIDS culture and gender and the National HIV/AIDS Policy, with particular emphasis on the education workplace. Although there is a paucity of literature in this regard, some high quality evaluation designs informed the methodological strengths of some aspects of the data collection tools and analysis. For example, I borrowed the use of 'rumours and gossip' from an incredible study on HIV/AIDS by Stadler (2003). Most of the HIV/AIDS and culture literature offers exposure to the exacerbated impact of culture in mediating HIV/AIDS especially with respect to gender construction. While I admit that this literature offers extensive insight on the topics, the external validity of these studies for HIV/AIDS lived experiences was difficult to ascertain.

On the HIV/AIDS programmes in the public schools, there is no evidence that cultural issues are considered in the curriculum. However, it is notable that cultural issues influence the transmission of the knowledge especially in the gender, sex and death related topics which chiefly characterise HIV/AIDS. The evidence for cultural effects on learners and other members of the education sector is inconclusive. This is because there is no study that directly examined the concepts of culture, gender, and HIV/AIDS lived experiences in South African public schools. Conclusions were drawn in this area based on the assumptions that members of these education sectors constitute part of the society where most of these studies were carried out. It is very difficult to accept such conclusions as valid considering that most of the studies were conducted in the rural areas and with less educated people. This therefore suggested that if some of those studies were replicated in urban areas where diversity is high and levels of education are of a reasonable standard (such as in Gauteng), the study would yield different results.

Several carefully designed qualitative HIV/AIDS studies demonstrated the considerable effects of cultural influence in the education sector. One of the studies not done in South Africa highlighted that culture impacts not only on the individuals' HIV/AIDS lived experiences but also the ways HIV/AIDS related issues are dealt with in public schools in sub-Saharan Africa (Mirembe and Davis, 2001). My study indicated that because of the intrinsic presence of cultural beliefs and practices in the schools, many HIV/AIDS related programmes and taught curriculum were not effective. Most of these findings locate this deficiency in the gender-related restrictions induced by cultural perceptions of sex and death. Whether the combination of the impact of culture and gender on HIV/AIDS educational programmes in schools is sufficient to justify the schools' inability to openly state how they are dealing with the epidemic and PLHIV (UNESCO/UNAIDS, 2000), there is evidence that the choice to ignore the cultural influence by education sectors does not exclude its presence. It is rather a choice not to deal with the challenges associated with these cultural influences.

The policy decision to allow independent autonomy for implementation guideline design may be based on the cultural diversity that characterises South Africa. Based on the

literature on National Policy, there is substantial indirect evidence that there are other factors that may impact the HIV/AIDS implementations in public schools. However, the key question is whether other factors other than biomedical, legal and risk metaphors, would yield any better results in mediating between the HIV/AIDS lived experiences and the practices of the National Policy. On this matter, the literature presented very little evidence. Very few studies have been done on the experimental evaluations of alternative approaches to the National Policy-identified metaphors. Moreover, the study that measured the impact of the National Policy often neglected to collect the additional data needed to obtain information on the influence of cultural beliefs and practices. The literature review on policy implications suggest that more systematic and detailed research is needed to find the most effective way to deal with cultural implications in the implementation of the National Policy in public schools, especially those with high cultural diversity.

My study advanced the existing knowledge in this field of research through the following arguments that proceeded from the findings. First, in this study, I posit that dealing with HIV/AIDS in education workplaces is not only complex and complicated but seems impossible because of the manner in which the members of the public school institutions experience the disease. In other words, the policy documents, the biomedical knowledge, their elitism, exposure and training in relation to the disease seem, perhaps, overshadowed by their cultural backgrounds, other world views and perceptions.

Second, from the findings of this study, I reveal that there are various ways members of the education workplaces in South African mediate HIV/AIDS, the PLHIV and those affected. Most of these strategies are based on individual experiences, personal belief systems, personal attitudes, biomedical exposure and the official policies for understanding and dealing with the disease, PLHIV and those affected. At this juncture, I must reiterate that not all the stakeholders share the same experiences but the extent to which their experiences differ is still based on their various cultural beliefs and practices. Again, no one of them uses one world view to arbitrate the epidemic. They share the strategy of combining more than one world view to deal with the epidemic.

## 2. Conclusion

I note from the findings that HIV/AIDS lived experiences in public schools are generational. There is significant variation in the ways and manner in which the youths (learners) and educators understand and deal with the epidemic. While there is not much distinction in their understandings, their HIV/AIDS lived experiences are conspicuously different. The conceptions of stigma also differ considerably. While the adults (educators and school governing board members) experience stigma in a more in-depth manner, the youths (possibly because they do not have a really good sense of death) demystified the HIV/AIDS related stigma.

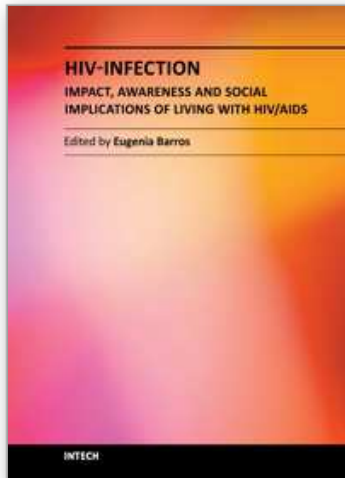
Again, I suggest, based on my findings, that due to the complications, tensions and complexities associated with HIV/AIDS lived experiences, most members of the schools identified boundaries between those who claimed to be HIV/AIDS negative and those they assume to be positive. Identifying these boundaries means creating distinction-maintaining strategies to deal with the PLHIV in these public schools. I conclude therefore that most members of the public schools deal with PLHIV through symbolic boundary maintenance. I judged this boundary maintenance as a complication arising from their inability to deal with the unknown especially when it touches constructs considered culturally as taboo such as death and sex.

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## **HIV-infection - Impact, Awareness and Social Implications of living with HIV/AIDS**

Edited by Dr. Eugenia Barros

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The past few decades have seen the escalation of HIV-infections and the 'frantic' search for new drugs to treat the millions of people that live with HIV-AIDS. However because HIV-AIDS cannot be cured, but only controlled with drugs, and the Antiretroviral (ARV) treatment itself results in some undesirable conditions, it is important to generate wider awareness of the plight of people living with this condition. This book attempts to provide information of the initiatives that have been used, successfully or unsuccessfully, to both prevent and combat this 'pandemic' taking into consideration the social, economic, cultural and educational aspects that involve individuals, communities and the countries affected.

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