Context and Cross Cultural Response to AIDS: A Review of the Literature

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Summary

The response to the AIDS epidemic varies cross-culturally. In Euro-America, AIDS is viewed as a disease of the gay, and minorities. The major social response has been blame, ostracization and finally, activism. In Cuba, AIDS is viewed as a disease of marginal people. The major response has been putting the victims in quarantine. In Asia and Latin America, it is viewed as a problem of homosexuals and IV drug users. The major response has been blame and ostracization, to a considerably much less extent than in North America. In Africa, it is viewed as a disease of prostitutes and truck drivers. These groups are blamed for the disease, but still, to a much less extent than in the United States of America. Except for activism, the social response to AIDS was not biomedically appropriate, for it neither led to the eradication of the virus nor did it stop the man-virus contact.

Introduction

HIV/AIDS is a fatal condition which has been a cause of untold suffering to its victims, claiming numerous lives and disrupting societies. In the absence of a known cure, hope only lies in prevention. Prevention implies culture change which involves modification of those behaviours and practices which predispose society to the disease, and building on those aspects which protect them. This paper is mainly an analysis of literature sources. It examines how different cultures in context responded to the AIDS epidemic and whether these responses are ideal biomedically. This study contributes to our understanding of the dynamics of cultural adaptation to deadly diseases and HIV/AIDS prevention and management.

Cross-Cultural Perception of and Response to AIDS

Since the identification of AIDS in the early 1980's in the United States of America (McCombie 1990), the virus believed to cause the scrounge has spread in virtually all societies of the world, and has reached epidemic proportions in some. Faced with the epidemic, societies in different contexts have viewed and responded to AIDS in a number of ways.

In Euro America, and especially in North America, AIDS was first reported in the gay community, and later among haemophiliacs who had received blood transfusion with a gay origin. It therefore came to be viewed as a gay disease. Before AIDS, the gay community was already stigmatised. Come AIDS and there was a tendency to move slowly to combat the epidemic because it was a gay disease anyway, and the gays were the undesired minorities (Felman 1994, Shilts 1987). Gay bashing characterised the first decade of the epidemic, with the introduction of all sorts of segregation targeted at the small population. AIDS was also noted among haemophiliacs and IV drug users who are also a minority and Haitians. These groups were categorized as the 'risk groups'. As long as one did not belong to this risk groups, they were thought to be free from the danger of contracting AIDS.

This categorisation and the risk group approach, entailing emphasis on the risk group's had far reaching effects. First it is a known case that everyone can get AIDS if they engage in risk behaviour. A large segment of the population was left out in AIDS prevention efforts because they

were not from the said risk groups.

In 1982, 32 Haitians residing in North America were diagnosed having opportunistic infections which came to be later known as AIDS (Farmer 1991). The 32 denied ever having had any homosexual contact, however, it was assumed that they had been homosexuals and that indeed, all Haitians and AIDS and were a risk group. The consequences were that Haitians were avoided by all means. They could not find jobs in the United States of America, and people were afraid and hostile to them. Genuine Economic and Political refugees from Haiti, which then was experiencing political problems could not get a fair hearing in the United States, or be accommodated because of the misconception that as Haitians, they had AIDS.

There were calls from various corners in the populations of Europe and North America to restrict international travel due to fear, and flight from AIDS. The venue of the 1992 international AIDS conference scheduled for Harvard University in the United States of America had to be changed to Amsterdam because the United States government could not issue visas to the HIV positive participants. In certain societal learning and other institutions like the military, gays and HIV positive people were ostracised and generally kept away. AIDS in the United States was used to add another leaf to justifying why the gays, the IV drug users and minorities should be segregated against and deprived of their rights, because they were seen as the agents of doom by the mainstream society.

In the second decade of the epidemic, AIDS is becoming more a problem of the minority groups such as Latinos, African-Americans and women. It is making its way in the heterosexual minority groups (Ulin 1992, Schiller 1994, Roman 1993). After 15 years in existence, and with the going public of Basketball star player Magic Johnson and Tennis star the late Arthur Ashe, society is beginning to accommodate AIDS even though stigmatisation still continues. In an interview with a sample of ten HIV positive persons from all walks of life at a Los Angeles medical centre in February 1994, nine out of ten respondents observed that what the American society could do to make their lives more comfortable was 'not to fear us' but to 'accept us'.

AIDS has brought a fair amount of mistrust between minorities particularly black Americans who view it as genocide by the mainstream population (Farmer 1994, Guinan 1993, Singer 1994, Felman 1994, Hereh and Capitano 1994).

While the mainstream Euro-American society was slow to respond to AIDS initially, the gay community mobilised itself politically, pressing for more research funding, fighting discrimination and promoting condom use as well as stepping up the dissemination of preventive messages. By the late 1980's the high transmission rates among the gay men had reduced, thus political mobilisation had a positive effect even though the gains are being lost because young gay men are showing a willingness to take more risks even when they know it is dangerous (Jones 1993).

In Cuba like everywhere else AIDS is viewed as a dangerous disease, but the official response of the Fidel Castro regime has been extreme. The response fits best to what UNAIDS calls AIDS apartheid (Piot 1995). In addition to blaming the victims, the regime tests and quarantines all known HIV positive people to stop transmission (WorldAIDS 1991). Even though Schepper-Hughes (1991) after a Cuban sponsored visit is in praise of this, no where else has the freedom of association and rights of HIV positive persons been violated as much as in Cuba.

The perception and response to AIDS in Haiti was different from that of Cuba and the United States of America. In a Haitian village, Farmer (1991) observes that AIDS was believed to have been caused by evil spirits, (voodoo). AIDS patients were treated with more compassion than in the United States. In a case which Farmer (1991) discusses a case where, as one patient declined and withdrew from social life; his friends

felt that he was ignoring them and until his death, he had villagers around him helping him seek treatment despite the fact that he had been confirmed as having AIDS, and just like everywhere, AIDS is feared.

In the Caribbean which is generally settled by people from varying cultural backgrounds, majority of whom are of African descent, AIDS, was introduced through the interaction with the USA and Europe. Initially, it was seen as a homosexual/ bisexual problem, then later as an heterosexual problem reflecting its mode of transmission (Wheeler and Radcliffe 1994).

The literature available on AIDS in Asia and Latin America suggests that AIDS is viewed as a gay, prostitute and IV Drug users disease. The general population sees AIDS as something that affects others, as opposed to themselves. AIDS is seen as originating from the US, particularly among the gays. The pattern of fear, blame and ostracization is seen although not to the same extent as in the United States of America (Hannovan et al. 1992 Carrier 1988, Parker 1989). In Nicaragua, Low et al (1993), states that even though the epidemic was several years behind that of USA, a combination of war and poor health services serves to see its fast spread. Due to poor sexual behaviour and cultural values such as 'Machismo', HIV is spreading fast in heterosexual communities. This is the case in other Latin American communities.

AIDS in Africa was initially seen as a disease of prostitutes and truck drivers because its first serious outbreak was among these groups, but today, it has permeated all segments of society. It is viewed as a disease which originated in Euro America, and possibly intended to reduce the high population of Africans after the failure of population planning (Latham 1993), or as caused by witchcraft. During the initial stages of the AIDS epidemic, it was argued that AIDS originated in Africa (Felman 1990, Parkard and Epstein 1991). Reports followed that all prostitutes and majority of people in Africa were HIV positive, even though this leading hypothesis has not been proven. Even though other prevalence reports may have been exaggerated at the time, they influenced the perception of a response to AIDS.

First, it was denial that people who went down with the disease actually died of AIDS. In fact, today, death certificates in Africa do not show the cause of death as AIDS related for people who die from it. Secondly, at the country level, it was denial that AIDS was a problem. Up to November 1993 for instance, the government denied that AIDS was a problem in the country (*Weekly Review* 1993). This was probably to avoid discouraging tourism which is a major source of foreign exchange earnings for Kenya and avoid stigma.

As the government 'ignored' AIDS, its spread continued. In the mid 1980, it was reported that AIDS was common among prostitutes and truck drivers. Compared to the United States of America, patients were stigmatised and sometimes ostracised.

Another response in Africa is that of rationalising of behaviours thus putting people at risk and the localisation of the epidemic. First people have come up with erroneous ideas that they cannot catch the AIDS virus from a prostitute during a weekend fling; that fat women do not have HIV; that AIDS is caused by the Nile Perch, or that it is a curse from God. Such erroneous beliefs crop up on day today basis and people in Africa and elsewhere have resorted to alternative medicines to try to manage AIDS.

In Africa a category of traditional healers claiming to cure AIDS using Chameleons drugs or even soil have come up but the effectiveness and efficacy of their remedies is questionable.

Variations and Regularities in Cross-Cultural Response to AIDS

The variations on how AIDS is viewed and responded to in different cultures reflect is based

on the local context. For example, in Siaya, Kenya, it is believed that the Nile Perch causes AIDS which is not the case in Zaire where they do not have the Nile Perch. In Africa where the number of gays are relatively few, and where AIDS is as much a mans problem as it is a woman's problem, gay bashing is absent. The point here is that, the social-cultural response to AIDS is unique to every culture and nothing short of a local context approach suffices in understanding the social response to AIDS cross-culturally.

Despite the localisation of the response to the AIDS problem in different cultures, there are certain socio-cultural response features which appear constant across cultures. The first is fear, flight or what McGrath (1992) calls the avoidance response. As information and knowledge about AIDS spreads, stigmatisation moves in a normal curve in all societies.

A social-cultural feature that appears constant across cultures is the assignment of blame or scapegoating (McGrath 1993, Farmer 1990, Nelkin and Gilman 1988), which involves blaming an individual, a group or class of individuals or an institution for the occurrence and continuation of the epidemic. Those who are blamed tend to be the ones who are already deemed blameworthy within society. In the United States, such groups have been the homosexual men and IV drug users. In Africa, prostitutes and truck drivers are blamed. Blame appears to enforce social prejudices without leading to a disruption of the social system. Everywhere there has been blame, it appears to reflect the structure of power relations in society with majority groups blaming minority/marginal groups, and minorities blaming those who discount them (e.g. Gay men blaming the government for causing and not doing enough to combat AIDS). Ugandans blame Tanzanians for bringing AIDS with raids across the border during the war in 1980's while on the other hand Ugandans blame Tanzanians for bewitching them with AIDS (McGrath 1992). Africais blamed for originating the disease while Africa thinks AIDS is from Euro America (Schoepf 1991, Packard and Esptein 1991).

At another level, in all societies, individuals are considered to be responsible for their own disease (Ankar 1992, Rosenberg 1988) due to their lifestyle. The degree of responsibility attributed to individuals differ from society to society, however, innocent victims like children are exempt from this response. In situations of high infections as in Kampala, Uganda where 20 per cent of the population may be infected (Goodgame 1990), or West Hollywood where many gay men are, it might be difficult for the group to assign blame to the individuals.

Another constant response has been the creation of risk categories and who to ostracise. In the United States, being homosexual is enough to lead to the assignment of risk. Anything perceived to be related to being homosexual, such as a single male hairdresser or dancer suggests risk regardless of the fact that risk depends on specific behaviours as opposed to sexual orientation (McGrath 1989). In Uganda, persons who have certain symptoms such as being thin febrile or having diarrhoea for a sustained period of time were ostracised. While these may be AIDS symptoms, some people who inhabit desert like conditions may be naturally thin. Due to the poor health and feeding habits of some communities in Africa, these symptoms may represent another disease.

After almost 15 years of the existence of AIDS, there has been resignation or acceptance of death or disease in majority of the societies where AIDS is a problem (McGarth 1989). There is some degree of societies settling in to accept AIDS as a routine and eventually a fatal disease much like serious cases of cancer and heart disease (Bowser 1991). However, despite this being a significant social response, it should not be taken to mean AIDS has became fully socially acceptable. The point is that AIDS is becoming just another social problem.

Inter and intra-group conflict is another social response to AIDS. Whereas conflicts are common in all societies, their specifics are shaped by the local context. AIDS has led to conflicts over how to respond to it (Shilts 1987, Lang 1989, Panem 1988, Singer 1994, Farmer 1994, Herek and Capitanio 1994). In the USA, gay men felt that AIDS deserved more attention and research funding that the government was giving. This led to the rise of activism groups such as ACT UP. In Kenya, Know AIDS society and Society for People with AIDS are the equivalent. Africa's fights have been different in degree with those of Euro America because they involve the state and the church. There are those groups which oppose provision of condoms while others advocate for the availing of clean condoms and needles, even to school children.

Activism has led to the social response, and recognition by governments. For example, one of President Clinton's campaign promise was to ensure more funding for the AIDS cause. President Museveni of Uganda has actively participated in AIDS prevention, while President Moi of Kenya regularly calls on certain ethnic communities to avoid practices such as wife inheritance which increase risk.

Another social response has been research focusing on AIDS and sexuality. The scientific community has spent millions of dollars in AIDS research and funding for research is increasing. Many conferences to lay out strategies to combat the epidemic have been held.

Culture change is the other social response. Societies have changed values which prohibit the open discussion of sexual matters to tackle the issue of AIDS, and practices such as wife inheritance among the Luo of Kenya are changing. Societies have been influenced by the scrounge to incorporate activities highlighting issues such as the danger of AIDS, the World AIDS day, candle light memorials, concerts of rap songs, drama, and a variety of other activities reflecting the particular culture (Global AIDSNEWS 1995).

Conclusion

The cultural responses to HIV/AIDS epidemic draws heavily on the limitations in biomedicine and the deficiencies of many interpretations of culture in anthropology (Frankenberh 1994). It is a reflection and a true testimony of the profound influence of society, on health and disease and vice versa as Singer 1994 would agree. Variations in response to AIDS in different cultural areas are adaptations to the local context and the groups affected. Despite the local situation, literature of response to AIDS shows many constants across cultures. It is important however, to note that except for the case of activism, and to a small degree cultural change over 15 years after, the social responses to AIDS have not succeeded in stopping the HIV epidemic and may even have contributed to its continuation, because they have failed to get rid of the virus among the infected, and have not even stopped the man-virus contact adequately.

Recommendations

Cultural beliefs and values, fear and blaming each other that characterise the response to the AIDS epidemic are inappropriate in AIDS prevention. These need to be confronted with appropriate AIDS education and STD prevention programs, to curb AIDS spread. In doing so, particular attention should be paid to the context, both micro and macro because the beliefs and values are contextual. Nothing short of a contextual approach can be effective in curbing AIDS. Many forms of concoctions, beliefs and taboos purported to be an AIDS cure have come up all over the world. The efficacy of these need to be established.

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