**The Global Spread of HIV/AIDS:
A Failure of Communications**

By

Niva Shrestha, B.A.

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of
the requirements for the degree of Master of Arts

Department of Mass Communication
Carleton University
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**The Global Spread of HIV/AIDS:
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Submitted by Niva Shrestha, B.A.
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Abstract

Acquired Immune Deficiency Syndrome (AIDS), first documented twenty- one years ago has spread unevenly throughout the world creating havoc. No other disease of public health significance has created so much fear and anxiety among the human population since the days of bubonic plague. The difficulties of developing vaccine and drugs to cure have induced a very high degree fear throughout the world. Since this disease is spread by human behaviour, considered outside the norm, the programs to prevent it have met with varying degrees of opposition ranging from denial to passive resistance.

This thesis focuses on the social and behavioral aspect of men and women in controlling the spread of this disease. Currently extensive behavioural change communication campaigns are the only viable way to prevent the further spread of this disease. Until a cure or effective and affordable antiretroviral drugs are developed and made available to the high risk population groups the only way to prevent the further spread of HIV/AIDS is through behavior change. However, addressing such campaigns must take into account the gender power relationships, accessibility of information, fighting against certain traditional practices, economic and sexual exploitation of the vulnerable population and a good leadership at the decision making level.

Table of Content

List of Abbreviations

Introduction

Health communication: A social vaccine	6
--	---

Chapter 1

Background	17
1.1 What is Acquired Immune- Deficiency Syndrome?	18
1.2 History	19
1.3 In the beginning	20
1.4 Modes of transmission	22
1.5 Who is involved?	24
1.6 Distribution of HIV across the Globe	
Africa	24
Asia	26
Latin America and the Caribbean	28
North America and Western Europe	29
1.7 What are the impacts?	31
The demographic impact	31
The social impact	33
The impact on education	34
The health impact	36
Economic impact	38
Gender dimension of HIV/AIDS	40

Chapter 2

The Political Economy of Treating HIV/AIDS	45
2.1 Why are AIDS drugs so expensive?	47
2.2 Protectionism and the WTO	49
2.3 Generic drugs	51
2.4 Political commitment	52
2.5 Positive steps – HIV/AIDS, NGOs and Civil Societies	53
2.6 Notion of corporate responsibility	55
2.7 Infrastructure, supplies and human resources needed	56
2.8 Affordability of antiretroviral drugs	57
2.9 ARV and the opportunity cost	59

Chapter 3

Why the lack of coverage?	63
3.1 History repeats itself	64
3.2 Construction of the “Other”	66
3.3 Deviant or normal	71
3.4 Stigma: fear of the unknown	74
3.5 Lack of representation	76

3.6	Early AIDS coverage: 1981-1983	77
3.7	Alternative discourse	84

Chapter 4

HIV is preventable without drugs	94
4.1 Why education?	96
4.2 Why prevention?	97
4.3 What is behavioural change communication (BCC)?	99
4.4 How has behavioural change communication been used?	101
4.5 Media advocacy	103
4.6 Information, education, and communication	103
4.7 Voluntary counseling and testing	105
4.8 Diffusion of innovation	107
4.9 Social marketing	111
4.10 Harm reduction	115
4.11 Barriers to effective BCC programming	118
4.12 Success and failure to social marketing for BCC	121
4.13 Holistic approach	127

Discussion and conclusion	131
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Bibliography	141
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List of Abbreviations

AIDS	Acquired immuno-deficiency syndrome
ARC	AIDS-related complex
AZT	Azidothymidine, an antiviral drug
ARV	Antiretroviral drug
ART	Antiretroviral therapy
ASSA	Actural society for South Africa
ASFW	African swine fever virus
ACT UP	AIDS Coalition to Unleash Power
BCC	Behavioural change communication
CBO	Community based organization
CDC	Centre for Disease Control
CMV	Cytomegalovirus
CSW	Commercial sex worker
EFA	Education for all
GDP	Gross domestic product
GNP	Gross national product
HAART	Highly active antiretroviral therapy
HIV	Human Immuno-deficiency virus
IDU	Intravenous drug users
KAP/KAB	Knowledge, attitude, and practices/behaviour
KC	Kaposi's sarcoma
MMWR	Morbidity and Morality Weekly Report
MTCT	Mother to child transmission
NAC	National AIDS Council
NACP	National AIDS Control Program
NEP	Needle Exchange Program
NGO	Non-governmental organization
OI	Opportunistic infections
PCP	Pneumocystis Carinii pneumonia
PLWHA	People living with HIV/AIDS
RT	Reverse transcriptase
STD	Sexually transmitted disease
TASO	The AIDS Support Organization
TB	Tuberculosis bacillus
UN	United Nations
UNAIDS	UN joint program on HIV/AIDS
UNDP	United Nations Development Program
UNICEF	United Nations Children's Fund
WHO	World Health Organization

Introduction

Health communication: A social vaccine

Twenty-one years into the AIDS pandemic, 40 million people are estimated to be living with the human immunodeficiency virus (HIV), acquired immune-deficiency syndrome (AIDS) or AIDS related complexes. Almost twenty-five million people have died as a result of AIDS over the past twenty-one years. And in the absence of a cure the 40 million presently infected people are sure to die in coming years. Although this virus has spread across the globe, Sub-Saharan Africa is by far the worst affected region with an estimated 28.1 million living with HIV/AIDS at the end of 2001. Over 90 percent of people living with HIV/AIDS are in developing countries. Furthermore, experts predict that between now and 2020; 68 million people will die of AIDS if nothing is done to prevent further spread of HIV.¹ HIV/AIDS is hence a critical global problem requiring immediate attention for prevention and mitigation.

The HIV virus has been detected in 152 countries and in some regions the prevalence rate has reached as high as 30%. In many southern African countries such as South Africa, Zambia, Lesotho, and Swaziland, at least one in five adults is HIV positive. In Asia, the prevalence rate is relatively low, with only three countries exceeding one percent prevalence. These countries are Myanmar (Burma), Cambodia, and Thailand. On the other hand the pattern in Latin America and the Caribbean varies according to the modes of transmission; in Argentina and Uruguay the spread is largely concentrated among intravenous drug users (IDU) while in Peru and Mexico HIV spread is predominately amongst the homosexual community. In countries such as Haiti, Honduras, and Guyana it is largely spreading via heterosexual transmission.²

Regardless of the modes of transmission and the region, this disease is having a profound impact on economic growth, income, poverty and death rates among young people to the extent that certain countries have even shown a decline in life expectancy. Researchers have recognized that AIDS threatens to deprive us of an individual and collective future and that it is critical that the global society work together to overcome this disease. Equally necessary is to understand problems surrounding the prevalence of this disease.

Problems surrounding AIDS

There are a number of misconceptions about HIV/AIDS. The most common statement about AIDS is that it *only* happens to drug users, homosexuals, commercial sex workers, truck drivers etc. However, if we look at statistics it is apparent that AIDS has spread to all groups of society; no gender, income range or age bracket is immune. People usually associate HIV/AIDS with “immorality syndrome” reflecting a belief “it cannot happen to me,” thus, creating a category of risky groups with risky behaviours. An important question to address hence is “who is risky” and “who is actually safe?”

Public ignorance and denial are the two main causes of the spread of HIV which has and still is in many countries threatening the lives of millions. The transmission of HIV/AIDS occurs in two main ways. These are unprotected sexual intercourse with an infected person or sharing contaminated needles with an infected person. It is important to emphasize that *anyone* that is having unprotected sex is at risk. HIV may be found in semen, vaginal fluids, blood and breast milk of infected individuals. Furthermore, injecting drugs with a needle used by another person is risky because it can contain their

blood and if that person is HIV positive, you would be injecting HIV directly into your body. Any contact with these bodily fluids puts an individual at risk.

Premarital sexual relationships and having multiple sexual partners are considered immoral in almost all traditional cultures. Society therefore stigmatizes and discriminates against individuals who are HIV positive by isolating and ostracizing them. This stigma and discrimination exists even within families. It is not uncommon to find families that do not want to share utensils with HIV positive family members. Certain families even wash clothes separately and even burn the personal articles of dead family members who were HIV positive. This shows both the magnitude of the fear associated with the disease and the intensity of this fear.

People have placed negative attitudes, beliefs and values toward this disease, which has created a condemning tendency against people living with HIV/AIDS. People either do not have the ability or the desire to approach people living with HIV/AIDS in a nonjudgmental, caring and supportive manner. Due to society's reactions people are reluctant to disclose their HIV status for fear of discrimination, isolation, and condemnation. In many societies people living with HIV/AIDS are often seen as shameful, the infection is associated with minority groups or behaviours. Negative responses to HIV/AIDS continue to exist, as they often feed upon and reinforce dominant ideas of good and bad with respect to sex and illness, and appropriate and inappropriate behaviours.

Due to the nature of transmission we have not been able to talk openly about HIV/AIDS. A culture of silence surrounds sexual practices and reproductive health. Therefore, people cannot openly discuss issues of sexual orientation, promiscuity, sexual

abuse, child abuse, and drug abuse, as these subjects are taboo. Consequently, these issues are entirely ignored or avoided. Additionally, laws and policies increase the stigmatization of people living with HIV/AIDS. For example discriminatory practices such as compulsory screening of “risk groups”, both furthers the stigmatization of such groups as well as create a false sense of security among individuals who are not considered high-risk.³ Specific laws have been developed that insist on compulsory notification of HIV/AIDS cases, as well as restriction to movement/travel of those infected. These laws have been justified on the grounds of public health risk.

The mass media’s coverage of HIV/AIDS has also played a critical role in promoting the stigmatization and discrimination of those infected with the virus. Early media coverage created fear and anxiety worldwide. The use of negative metaphors reinforced stereotypes; the situation was dramatized by the use of certain language, symbolism and images. Rather than breaking the concept of “us” and “them,” this gap was reinforced. The media created articles full of panic, accusing certain groups of people such as homosexuals and commercial sex workers of being responsible for the spread of HIV. Rather than working together with all interested partners to sensitize, educate, and inform the public, the media institutions have used their power to create deception and cause further havoc within society.

In addition, the lack of an enabling environment has furthered spread of HIV. People do want to make changes yet they continue to face resistance from their peers and community. Often health services are inadequate for their needs or insensitive to their situation. People also face economic, cultural, religious, and social pressures that constrain their freedom to choose a healthy and safe option. During the early years of

this pandemic, many heads of state denied having such problems. In recent years South African President Thabo Mbeki's comment that there was no link between HIV and AIDS was received with deep skepticism in scientific communities around the world.

Governments and communities are under obligation to see that global declarations and conventions such as the *Universal Declaration of Human Rights*, *Convention on the Rights of the Child*, *Convention on the Elimination of All Forms of Discrimination against Women* be adopted and turned into actions upheld by law. Implementing and accepting such conventions contributes and creates a supportive environment in which to fight ignorance and confer the rights of every individual. A strong positive social network can improve the quality of life of an HIV positive individual and this can be accomplished through partnership between government, non-governmental organizations, and private agencies. With each agency focusing on its own area of expertise, they can collectively deal with the range of issues at all levels affecting society. Additionally, if support is evident people are likely to transform and adhere to new beliefs and values. Behaviour change is hence critical to mitigate and/or reduce the emergence of HIV/AIDS

Thesis argument

The key argument of this thesis is that HIV/AIDS can be controlled through behavioural changes at the personal and the societal levels. The HIV virus needs a human host to survive. This thesis argues that, if people practice certain behavioural principles whereby s/he engages in safe sexual relationships, avoid contaminated needles, blood and blood products, the transmission rate of HIV can be reduced and eventually be slowed to a stop.

This thesis suggests that each stakeholder has a responsibility in keeping people free from HIV infection. Therefore if governments and communities work together and implement comprehensive National AIDS prevention programs, they can provide accurate information to promote safe behaviour practice. There is a need to accept that individual change is closely related to social change, and that an understanding of social and environmental contexts needs to be incorporated into behaviour change before people can translate information into behaviour. Early and sustained prevention efforts can be credited with the lower prevalence rates in some countries. Examples such as Senegal and Uganda have brought their estimated prevalence rates down to around 7% from a peak close to 14% in the early 1990s with strong prevention campaigns.⁴

Behavioural change communications (BCC) strategies are practical as they emphasize the concept of risk and make people realize that they are vulnerable to the virus. BCC messages are developed according to the target audience such as drug users, commercial sex workers, policy makers, journalists, community and religious leaders etc. BCC programs focus on defining who is at risk, how they can be reached effectively, whether they have access to necessary preventative methods, where and how they can obtain relevant information and resources.

A multifaceted approach

Combating HIV/AIDS needs the combined efforts of all stakeholders. The basic building blocks for this change are education, access to affordable medication, continued research for an HIV/AIDS vaccine and care for those presently suffering from the virus.

All of this is only possible with a supportive environment that promotes change in laws, policies, and deals with issues surrounding stigma.

Prevention, treatment and care consists of a number of different elements including voluntary counseling and testing (VCT), food and nutrition, support for the prevention of onward transmission of HIV, follow-up counseling, protection from stigma and discrimination, spiritual support, treatment of STIs, management of nutritional effects, prevention and treatment of opportunistic infections (OIs), traditional treatment, end of life care, preparing for death, family and orphan support and the provision of antiretroviral drugs.⁵

Focus on one approach will not solve the problem, therefore BCC interventions are effective as they aim to dispel myths and improve the accuracy of HIV/AIDS knowledge. Another goal of BCC is to provide care and support centers to increase voluntary testing of people of all risk levels. In doing this, early treatment for STDs is viable to prevent the spread both through sexual relations and through mother to child transmission. Prevention programs encourage people to know their status, if a person does not know that they are infected, they cannot get any treatment or care. Voluntary counseling and testing (VCT) services provide HIV counseling, testing and follow up counseling and services, as well as manage HIV related illness and opportunistic infections and provide medicines for the treatment of opportunistic infections and HIV related illness.

The focus of prevention programs have been on abstinence (A), being faithful to a monogamous partner (B), and/or condomise (C), which has been identified as the most effective HIV/AIDS preventive strategy. The ABC strategies use mass media interventions to encourage young people to postpone sexual activity, be faithful to one partner, persuade people to get tested and place responsibility not to pass on the disease to others within their community. Abstinence has been a major focus but it is not

necessarily a realistic option given the number of sexually active young people.

Therefore the major focus has been supporting programs that encourage safer sexual behaviour and promote condom use. This has been seen as a good investment in public health, as prevention eventually could reduce the number of cases needing treatment.

Although the number of people that a prevention program serves is small, the number of infections prevented can be large, since the risk of infection is reduced for each client's sexual partner, their partners in turn, and so on. Therefore with lower prevalence rates, the risks of infection decrease for everyone who is sexually active.

Finally, political will and commitment is fundamental: HIV/AIDS must be acknowledged, accepted and understood as a severe threat to human development. Governments at every level must work together to develop a supportive environment to reinforce healthy choices. Commitment between private/public partnerships, civil society mobilization, and collaboration with faith based organizations is critical.

Diseases such as HIV can and do cross borders, therefore every nation, rich or poor is at risk. It is in every country's self interest to attempt to reduce the impacts of this pandemic. A global commitment is essential, with united support, resources, and dedication; the rates of transmission can be reduced.

Rationale and Methodology

To better understand the issues of discrimination and stigma, I have examined articles from Newsweek, Time magazine, New York Times and analysis and reviews from gay publications and scientific journals to provide information from dual perspectives. The use of discourse, myth and ritual analysis help deconstruct how the

information has been constructed in order to produce news. Discourse analysis is relevant as it identifies how this disease has created victims of its sufferer's, in some cases even dehumanized those with the virus. The victims are not created by disease but by the media and its misconceptions. The language used by the media and medical specialists created much fear among ordinary citizens. In addition, there are common ways of portraying illness, or the threat of illness, and these texts incorporate imagery drawn from an identifiable range of ideologies and discourse.⁶ What becomes evident in mainstream coverage of early AIDS is a sub-textual layer of meaning in AIDS discourse. This transforms the state's ideologies into consideration and attempts to control sexual expression in any form not conforming to heterosexual monogamy.

This thesis is primarily based on secondary source data such as published and unpublished literature, reports, policies and guidelines, as it provides a general and conceptual overview of HIV/AIDS. The focus remains on social and behavioural studies, advocacy campaigns, and behavioural change communication strategies, which aim at reducing HIV infection in risk groups. Although primary data and case studies could have advanced the argument of this thesis further; however, due to time constraint research has been limited. Primary research such as holding face to face interventions to discuss problem solving skills and risk reduction education may help to determine how effective BCC interventions are as well as further determine if BCC interventions are an option in overcoming the spread of HIV/AIDS.

The chapter outline

This thesis consists of four chapters. Each chapter illustrates the many problems associated with HIV/AIDS. **Chapter one** looks at the emergence of the disease, its modes of transmission, and its social and economic impact across the world. It is important to recognise that AIDS is a problem involving behavioural practices. It is not solely a health problem. As recommended by experts in the field, the response must be dynamic and react to the pandemic as it evolves. This chapter provides detailed information about the nature of HIV/AIDS, the extent of the pandemic, and its current and likely future impact on such measures of well-being as life expectancy, health, and economic growth. The relationship between economic development, policies and HIV is complex. Current data clearly states that the AIDS pandemic is likely to both affect and be affected by economic development.⁷

Chapter two covers a number of interrelated issues such as the progress of vaccines and antiretroviral (ARV) drugs, affordability of antiretroviral drugs, infrastructure, supply and human resources needed to make these drugs accessible. Although ARV drugs are available, they are not an option for 70% of people infected and living with HIV/AIDS. Medication has also created “false hope” ARV drugs are not a cure for AIDS; rather they are a means of prolonging life. Recently the focus shifted towards treatment and medication as a solution rather than continuing investing and concentrating on prevention.

Chapter three discusses issues of stigma, scapegoats, and deviance. Social discrimination rejects people and this pandemic has taught people about risk groups and behaviour, homosexuality in particular and through fear and ignorance it has enforced

feelings of hatred. Media coverage during 1981-1983 clearly demonstrates how AIDS patients were victimised. Analysis from Newsweek, Time Magazine, The New York Times, certain scientific journals and alternative press revealed certain realities about AIDS and people living with AIDS. This disease labels and blames certain groups of people for spreading HIV. The issues surrounding AIDS goes beyond fairness. It is about human rights, lack of understanding and compassion. AIDS has created fear - fear that continues from generation to generation, as values and beliefs are passed on. The fear of AIDS has irrationally evolved to become a fear of people with AIDS. Regardless of education, people still assume that the virus can be casually transmitted.

Chapter four focuses on behavioural change communication. Behaviour change communication is seen as a good investment in public health, as prevention eventually could reduce the number of cases needing treatment. BCC interventions focus on supporting programs that encourage safe sexual practices such as monogamous relationships, use of condoms, delaying one's sexual debut. This chapter also provides a number of regional examples where BCC interventions have been successful. Therefore BCC interventions are strongly recommended since infection rates can be reduced.

Notes

¹ Stanecki, K.A. (2002). *The AIDS pandemic in the 21st century*. Presented at the XIV International conference on AIDS, Barcelona.

² UNAIDS (2002). *Report on the Global HIV/AIDS Epidemic*. Geneva, Switzerland, UNAIDS.

³ AVERT.org <http://www.avert.org/>

⁴ UNAIDS (2002). *Report on the Global HIV/AIDS Epidemic*. Geneva, Switzerland, UNAIDS.

⁵ AVERT.org <http://www.avert.org/hivcare.htm>

⁶ Ling, J. (1989). *New communicable disease: A communication challenge*. Health Communication (4) 253-260.

⁷ World Bank (1999). *Confronting AIDS: Public Priorities in a Global Epidemic*. Oxford University Press.

Chapter 1

Background

1.1 What is Acquired Immuno-Deficiency Syndrome?

Acquired Immuno-deficiency Syndrome, commonly known as AIDS was not known before 1981. AIDS is not a single disease but a complex syndrome of diseases caused by the weakening and or destruction of the immune system as a result of invasion by the human immunodeficiency virus (HIV), which was identified only in 1984.¹ AIDS paralyses the immune system leaving it helpless so that even the simplest infection becomes fatal. It is an acquired state of health, hence *Acquired Immuno-deficiency Syndrome*. Today there is a broader definition of AIDS, which includes twenty-four different infections and ten cancers.² The mode by which HIV was transmitted was not fully clarified for sometime. Prior to the recognition and labelling of AIDS numerous people had died from it during the 1970s but these deaths were attributed to other symptomatic illnesses. AIDS is defined in relation to other diseases as a person with AIDS is likely to have either *Pnemocystis carinii pneumonia* (PCP) or *Kaposi's sarcoma* (KS).³

The HIV infection has two key characteristics. First, it is fatal; once infected there is no cure. The currently available antiretroviral (ARV) drug treatment can prolong life of HIV positive individuals but there is no known cure or vaccines to prevent infections. Further the associated complications with ARV drug treatment is known to be very serious. Secondly, the disease is totally preventable by breaking the cycle through behaviour change.

1.2 History

HIV infections had been found as early as the 1950s but the widespread dissemination did not appear until the late 1970s.⁴ HIV is a very cunning virus, as “it has more genetic material with which to constantly redesign its surface than any other known virus.”⁵ Therefore, it has the ability to change somewhat, individuate, in virtually each person infected. Once activated, it can replicate itself many times faster than any other viruses and it has the ability to attack the human immune system that people rely on to protect against diseases. For many years this virus was spreading invisibly, as it was an unrecognisable condition.

By early 1981 several homosexual men were found to have registered with unusual complaints with complex disease aetiology and thus it became apparent to the medical community that a distinctive yet nameless *disease* had erupted in homosexual communities in North America.⁶ However, the symptoms varied in different communities. The homosexual community from the East Coast in the United States developed “peculiar purplish spots on their arms, legs, torso, and face.”⁷ Blemishes such as these had rarely been seen before causing further hysteria in the medical community. Additionally, fungal infections appeared in their mouths and cold sores spread across their faces. Meanwhile, members of the homosexual communities from the West Coast developed *Pneumocystus carinii*, which is a rare and exotic form of pneumonia, although the symptoms varied among the men, they, however, all showed signs of an immune system that was rapidly deteriorating. *Pneumocystis carinii pneumonia* is an opportunistic parasite, which only develops in individuals whose immune systems are suppressed due to cancer, leukemia, lymphoma, immuno-suppressed drugs or extreme malnutrition.⁸

Therefore “the appearance of these two diseases in previously healthy young men suggested a common underlying immune deficiency that was related in some way to the life style of gay men.”⁹

The symptoms and pattern of spread witnessed in Africa was, however, very different than in the United States and this may have been the reason why the disease was unrecognised for so long.¹⁰ Over the last century Africa has been dealing with social, economic and health problems such as malaria, tuberculosis, malnutrition, parasitic infestation, illiteracy, poverty, industrial under-development and high population growth. With so many issues of immediate concern to overcome, the presence of HIV/AIDS may have been simply unrecognised or misdiagnosed.

1.3 In the beginning

Between 1981 and 1982 eight hundred and twenty seven people, mostly homosexual men, were diagnosed with this disorder, which was later classified as AIDS. Although AIDS was becoming a medical concern, it was politically ignored until the disease was noted outside the homosexual community. This complex disease was later reported among members of the Haitian community who had recently immigrated to the United States. Nearly all the Haitian patients who reported this complex syndrome were heterosexual, leading to confusion among the scientific community. Further investigations revealed that addicts who shared needles to inject narcotics directly to their bloodstream were also affected. Additionally, the Centre for Disease Control (CDC) revealed that haemophiliacs had also contracted the disease through blood transfusion and new babies born to mothers who were drug addicts were also falling ill with similar

syndrome, signifying that the disease could be passed on during pregnancy or childbirth. With several modes of transmission the disease was no longer believed to be a simple health problem. Questions immediately arose as to whether it was contagious, causing further panic as an extraordinarily deadly virus was on the loose.

The scientific community did not know where, when and how HIV/AIDS originated and perhaps they will never know but speculation on the origins of AIDS has caused much distress among many groups of people. AIDS is blamed on Africans, on gay men and on Haitian immigrants. As a result the Haitian community were severely stigmatised, tourists stayed away and economic investments declined.¹¹ Others believed that the deviant lifestyle resulted in immune suppression, and that the use of amyl and butyl nitrates “poppers” was also the cause of the syndrome.¹² AIDS was considered a stigmatised condition and a social phenomenon that was perceived by the heterosexual community to pollute everyone and everything.

1.4 Modes of transmission

HIV is transmitted from one individual to another through body fluids (blood and blood products, vaginal fluid and semen) by three major routes. Firstly, sexual intercourse through heterosexual, homosexual or bisexual transmission; secondly, direct injection with HIV contaminated needles, blood or blood products. And finally from HIV infected mother to the foetus in the uterus, during pregnancy, childbirth, or during breastfeeding.

HIV is not communicable through contact with inanimate objects or through vectors. Therefore, people cannot catch HIV in the same way as one may catch a cold.

HIV cannot be spread by tears, sweat, coughing or sneezing, or eating from common utensils, drinking glasses, or other objects that HIV infected people have used that are free of blood. Although there are several modes of transmission, heterosexual transmission is the most predominant mode of HIV transmission. As a result millions of young people in the productive age group are at risk or are already affected.

Transmission via saliva have also been speculated yet clinical research show that the concentration of HIV in saliva is very low in comparison to blood, breast milk, semen, and vaginal secretion. The low concentration of virus in saliva may mean that saliva is less likely to cause infection than blood or other body fluids. Additionally saliva contains large sugar protein molecules called glycoproteins, which inhibits HIV and the glycoproteins cause the HIV to form together in giant clumps which are not capable of causing infections.¹³

Scientific evidence shows three patterns of HIV transmission across the world. Pattern one was recognised in the United States, Europe, Australia and New Zealand. Transmission occurred mainly through homosexual intercourse and intravenous drug users (IDU). HIV infection was more prevalent in men than women.¹⁴ Pattern two was identified in the Caribbean and Africa. HIV infected cases was equal between women and men and transmission was mainly through heterosexual intercourse. Pattern three was later discovered in Asia, Eastern Europe, Middle East and North Africa. The transmission varied from blood transfusion, intravenous drug users and both heterosexual and homosexual intercourse.

1.5 Who is involved?

At the global level, UNAIDS is the main advocate for action against HIV/AIDS. Its mission is to strengthen and support an expanded response aimed at preventing the transmission of HIV. UNAIDS provides programming that focuses on “care and support, reducing the vulnerability of individuals and communities to HIV/AIDS.”¹⁵ UNAIDS was formed in 1996, with support of United Nations Children’s Fund (UNICEF), United Nations Development Program (UNDP), United Nations Population Foundation (UNFPA), United Nations Educational, Scientific, and Cultural Organisation (UNESCO), World Health Organisation (WHO) and World Bank. Recently, the International Labour Organisation (ILO) and United Nations Drug Control Program (UNDCP) have also joined the coalition. The support and expertise of each UN agency has enabled UNAIDS to implement a number of effective programs.

Additionally, a network of scientists, university medical researchers, private and public institutions such as Centre for Disease Control (CDC), National Health Institution (NHI), play a critical role in research and implementation of ARV treatment and prevention interventions. Additionally, a number of social scientists and activists are also working with grassroots HIV/AIDS organizations to implement and promote prevention programs. Each organisation provides services and information related to HIV/AIDS, in hope of curtailing the pandemic.

AIDS statistics are gathered by local governments; therefore some of the figures are questionable. The official figures are probably “low estimates” at best, and need to be treated with caution. The question is why there is such a wide discrepancy between the various developing countries governmental statistics and other organisations

estimates? Ultimately it comes down to both practical and political reasons. Many of the developing countries simply do not have the resources available to conduct accurate sampling and estimates for HIV prevalences. There is also a political element that distorts official HIV/AIDS statistics. Many developing governments have denied its HIV/AIDS problems for years, and discouraged accurate monitoring and independent surveillance. In areas with high infection rates, local officials have attempted to cover up independent reporting. This is due partly to the officials concerns about the stigma potentially attached to their region, which could hinder investment and tourism.

1.6 Distribution of HIV across the Globe

Africa

Africa, particularly Sub-Saharan Africa has, been hard hit by this pandemic. In 2001 approximately 3.5 million new infections occurred, totalling to 28.5 million people living with HIV/AIDS in Africa.¹⁶ Africa is home to just about 10% of the world population but it is home to almost 90% of the global HIV/AIDS burden. National HIV prevalence rates vary widely between countries. They range from under 2% of the adult population in some West African countries such as Gabon and Mali to around 20% or more in the southern part of the continent, with countries in Central and East Africa having rates midway between these. However, prevalence rates do not convey people's lifetime risk of becoming infected and dying of AIDS. In eight African countries (Botswana, Kenya, Lesotho, Namibia, South Africa, Swaziland, Zambia and Zimbabwe) where at least 15% of today's adults are infected, studies show that AIDS will claim the lives of around a third of today's 15 year olds.¹⁷

In Africa the sexual transmission is predominantly heterosexual, although there is some homosexual transmission. The heterosexual transmission is further amplified by the high prevalence of sexually transmitted diseases (STDs). Another major concern is that a large number of young people are engaging in sexual activity. Unfortunately this group is often the least educated and therefore know little about how HIV is spread and how infections can be avoided. For example "half of the teenage girls in Sub-Saharan Africa do not realise that a healthy looking person can be HIV positive."¹⁸ A World Bank study indicates that "in 11 population based studies, the average infection rates in teenage African girls were over five times higher than those in teenage boys."¹⁹

Additionally, women and young girls are at a disadvantage because they are taken out of school earlier than boys, as they are expected to help at home, in order to do chores, as well as look after other siblings.

Despite the efforts that have been made in developing educational campaigns, some regions have yet to overcome the painstaking hurdles. For instance condom use among rural men in Zambia remain relatively low, rates estimated at 15% in 2001 compared to 68% for urban men when they last had sex with a casual or paid partner.²⁰ Although male condoms are the best prevention method, it requires male participation and negotiation but since so many negative messages are associated with condom usage, condom use is insignificant.

The challenges continue, as the infection rates soared in all regions of Africa, for instance in countries such as Mali and Senegal in West and Central Africa the HIV prevalence rates are estimated at 1.7%. In urban areas of Cameroon prevalence rates are as high as 4.7% among pregnant women aged 15-19 years old and 12.2% among those aged 20-24.²¹ The prevalence rates in Nigeria are also alarming, as the rates have risen from 1.9% in 1993 to 5.8% in 2001. Today, there are close to three million Nigerians who are already living with HIV/AIDS.²² In nine countries in sub-Saharan Africa, more than 10 percent of the adult population is HIV positive. In Botswana, Namibia, Swaziland and Zimbabwe, 20 to 26 percent of the population aged 15-49 is living with HIV or AIDS. The disease has caused further hardship as hospitals and clinics are facing increasing numbers of patients with HIV/AIDS. Studies conducted by UNAIDS state that in six countries of southern Africa, AIDS is expected to claim the lives of between 8% and 25% of today's practising doctors by the year 2005.²³

AIDS has disrupted the economic and social development of Africa and as a result there have been tremendous loss of trained personnel, deflection of scarce resources, strain on public health and education systems, reduction of tourist revenues, and potential political unrest.²⁴ AIDS threatens to reverse many of the hard won development. Additionally, the spread of the disease comes at a time when many nations are ill equipped to respond as they are affected by famine, civil war, economic misfortune and shortage of resources.

Asia

In 2001 approximately 7.1 million people were living with HIV/AIDS in Asia of whom approximately 6.1 million were in South and South East Asia while 1 million in East Asia and the Pacific.²⁵ Although the virus appeared to have arrived more recently in this region, the HIV infection is spreading rapidly. Peter Piot, the Executive Director of UNAIDS, warns that with 60 percent of the world's population, Asia is showing the steepest infection curve and could fast become the region with the most HIV infections.²⁶

The infection rates are occurring primarily in specific population groups, such as intravenous drug users, commercial sex workers and homosexual communities. During the mid-late 1980s, HIV prevalence was documented among female commercial sex workers (FSW) in Thailand and India (Bombay/Mumbai). In addition, HIV pandemics were also documented in Myanmar, China, Thailand and Cambodia, also known as the *golden triangle* among the IDU population. However, by the 1990s significant heterosexual transmission of HIV was noted between FSW and their clients.²⁷

The 2002 UNAIDS report states that 50% of IDU in Myanmar, Nepal, Thailand and India have already acquired the virus. And as of 2001, Cambodia, Thailand, Myanmar and parts of China and India have an estimated national prevalence rate greater than 1% in their 15-49 year old population. As a result, the annual death rates are expected to increase in these countries by 40%. In addition, nearly 1 million Thais were infected and in the Northern regions of Thailand the leading cause of death was AIDS, whereas in Cambodia 3.7% of married women of reproductive age were HIV positive in 1998.²⁸

China's prevalence rate is also becoming a major concern, although the infection rate is low the number of affected people translate to large number because of the country's population size. UNAIDS estimated the number of people in China, carrying the HIV infection is at about 1.5million. It is believed that most people were infected through intravenous drug use or through transfusion of infected blood and blood products.²⁹ However, if preventive and education campaigns are not enforced, the number of infected people could reach up to 10 million by 2010.³⁰

The prevalence rate of HIV in Asia varies. In some countries the rates have reached 3 percent while in others such as Bangladesh, Laos, Indonesia, and Sri Lanka, the prevalence rate remain low, less than 0.1%. For instance Indonesia, the world's fourth most populous country, fewer than 5 people in 10,000 are living with HIV and in the Philippines, the rate of HIV infection is 7 per 10,000.³¹

Latin America and the Caribbean

At the end of 2001 an estimated 1.9 million people were living with HIV in this region of whom 200,000 people who acquired the virus in 2001.³² Some 1.5 million of these people were in Latin America and 420,000 in the Caribbean. The Caribbean is the second-most affected region in the world, with adult HIV prevalence rates only exceeded by those of sub-Saharan Africa. In several Caribbean countries, HIV/AIDS has become a leading cause of death. Worst affected are Haiti and the Bahamas, where adult HIV prevalence rates are above 4%.³³ The pattern of transmission varies in this region. In some countries it is driven mainly by heterosexual intercourse among young people while in others sex between men is the more prominent route of HIV transmission.

Research conducted by the Interagency Coalition on AIDS and Development indicates that HIV for the most part is spreading rapidly among commercial sex workers. Their studies show that in Georgetown, Guyana, 46% of the commercial sex workers are infected and over a third of these workers have never used condoms with clients and that almost three-quarters did not use condoms with their regular partners either. The probability of the virus passing into the wider population is therefore high. Additionally, in some countries such as Saint Vincent and Grenadines, adolescents are having sex before the age of 14 and more often the young women are having sex with older men. As a result, HIV rates are five times higher in girls than in boys aged 15-19.³⁴

In Costa Rica, Mexico, Nicaragua and parts of the Andean region, sex between men is the more prominent route of HIV transmission. Recent studies among men who have sex with men in Mexico have shown that just over 14% were HIV-positive. Meanwhile, in the Caribbean, prevalence rates are equally alarming among the

heterosexual population. In Haiti the prevalence rate stands at 6.1%, Trinidad and Tobago's prevalence rate is 2.5% and the Bahamas the rate is estimated at 3.5%. These island nations have a relatively small population hence the spread of HIV in heterosexual population is of immense concern. In many Caribbean countries HIV/AIDS patients occupy as many as 25% of available hospital beds.³⁵

However, there are several communities/countries within this region where progress can be seen. For instance studies show that in Brazil where prevention programs have been active among intravenous drug users demonstrate a substantial decline in HIV prevalence. Additionally condom usage among intravenous drug users is also rising; these are clear signs that prevention efforts can have positive results. Other neighbouring countries such as Chile, Paraguay, and Uruguay have also developed similar prevention programs with similar results.

North America and Western Europe

Even after twenty years of awareness and information, the infection rate in the west continues to rise at a steady pace. In 2001, approximately 75,000 people became infected, totalling to 1.5 million people living with the virus. There were an estimated 940,000 adults and children living with HIV/AIDS in the United States and Canada. The adult prevalence rate for this region was 0.6 percent, with women accounting for 20 percent of HIV-positive adults.

The pattern of transmission however, varies according to the region and population. Although homosexual transmission and intravenous drug use was the primary mode of transmission in the 1980s today heterosexual transmission accounts for

a larger number of new infections, among the young especially in disadvantaged communities. The pandemic is moving into poorer and more deprived communities. “Currently AIDS is the top killer of young African American women and is fast becoming a leading cause of death for women aged 18-45”³⁶. For instance in the United States, where African American women make up only 13 percent of the population, account for an estimated 54 percent of new HIV infections in 2000³⁷.

The mode of HIV transmission varies in Western Europe. Although IDU is the main mode of transmission in Spain, heterosexual transmission is also occurring. In France the prevalence rates among intravenous drug users is still ranging between 10 to 23 percent, while Portugal continues to face a serious pandemic among their IDU communities. The UNAIDS report show that of the “3,680 new infections reported in 2000, more than half were caused by injecting drugs use. At 37.3 per 100,000 persons infected with HIV, Portugal’s rate of reported new infections is the highest among all reporting countries in Western Europe”³⁸. In the United Kingdom new HIV infections diagnosed were mainly from heterosexual transmission. It is believed that an increase in unsafe sex is also playing a role in the rise of HIV prevalence “as there has been an increase in reported cases of gonorrhoea among both heterosexual and homosexual males.”³⁹

1.7 Impact of HIV

The demographic impact

The HIV/AIDS pandemic has a tremendous impact on the socio-economic life of people around the world. An estimated 70 percent of the global total of HIV positive people, 28.5 million out of 40 million, live in Sub Saharan Africa. Its impact is already visible in some African countries, particularly in Southern and Eastern Africa. With so many people infected, falling ill due to AIDS or AIDS related complex (ARC), and with many people having lost their lives, the average life expectancy is also decreasing dramatically especially in Sub Saharan Africa, where life expectancy has now been lowered to 47 years, which otherwise would have been 62 years. Nine percent of all adults in Sub-Saharan Africa are HIV positive compared to 0.6 percent of adults in the United States.⁴⁰ Botswana's has already reached negative growth rate and its life expectancy has decreased dramatically from 72.4 years to 33.9 years. The infant mortality rate is also increasing as infants will die either from AIDS or AIDS related diseases. Other countries such as Haiti and Cambodia have also experienced a reduction in life expectancy. Haitian's life expectancy is six years less than it would have been without AIDS while Cambodian's life expectancy had been reduced by four years.

It is estimated that in the 45 most affected countries, between 2000 and 2020, 68 million people will die prematurely as a result of AIDS. Additionally, in countries such as Lesotho, it is believed that a person who has recently turned 15 has a 74% chance of becoming infected with HIV by his or her 50th birthday, while in Guyana where the adult HIV prevalence rate is 2.7% the probability of contracting HIV between the ages of 15 and 50 in 2000-2035 is 15%. Statistics such as these are alarming, as there are at least 12

other countries whose prevalence rates exceed 10% and at least another 12 that hover around 5%. Therefore, one can only envision how many more adolescents will be infected in this region in coming years.

In many developing countries the working-age population (15-49) will be most affected, leaving many children and the elderly. Consequently a whole generation of children will be forced out of schooling to try find work to provide for their families. This will have direct impact on the economic productivity of the entire nation. AIDS weakens economic activity by squeezing productivity, adding costs, diverting productive resources, and depleting skills. The epidemic hits productivity mainly through increased absenteeism, organisational disruption, and the loss of skills and “organisational memory.”⁴¹

Figure 2: Demographic characteristics with and without AIDS: 2002

Country	Growth Rate			Life Expectancy			Child Mortality (Under 5)		
	With AIDS	Without AIDS	Net decrease	With AIDS	Without AIDS	Net decreases	With AIDS	Without AIDS	Net decreases
Botswana	-0.2	2.3	2.5	33.9	72.4	38.5	107.1	30.6	76.5
Kenya	1.4	2.3	1.0	45.5	65.6	20.1	65.7	65.7	29.2
Lesotho	0.2	2.0	1.7	37.1	64.4	27.3	127.7	80.6	47.1
Malawi	2.3	3.3	1.0	38.5	56.3	17.8	184.7	155.0	29.7
Mozambique	1.0	1.8	0.8	32.1	40.0	7.9	304.1	280.9	23.1
Namibia	1.7	2.9	1.1	45.0	65.8	20.9	104.1	59.2	44.9
South Africa	0.2	1.2	1.0	48.8	66.3	17.5	97.3	61.4	35.9
Swaziland	1.1	2.7	1.6	41.4	72.6	31.1	103.5	48.1	55.4
Zambia	1.6	2.9	1.3	35.3	55.4	20.1	170.8	132.7	38.1
Zimbabwe	1.0	2.6	1.6	40.2	69.0	28.8	100.7	47.2	53.4

Source: U.S. Census Bureau, International Data Base

*All figures are for both sexes combined. Growth rate is given as a percent. Crude death rate is deaths per 1, 000 population

The social impact

AIDS has had an astounding effect on households. As parents die from AIDS or AIDS related diseases children are being orphaned and the burden placed on extended family members, particularly grandparents. Globally, since the beginning of the pandemic, more than 13 million children have lost their mothers or both parents to AIDS and many of these orphans may themselves die of AIDS or fall victim to malnutrition or become street children.⁴² The number of AIDS orphans in Asia is small relative to Africa. In Africa 12.1 million children under 15 in Sub Saharan Africa have lost their mother or both parents from AIDS since the beginning of the AIDS pandemic.⁴³

More than 600,000 children were newly infected with HIV in 2001 while some 720,000 died of AIDS in the same year. Approximately one third of infants born to HIV infected mothers worldwide are infected and will develop AIDS and die before they reach their fifth birthday.⁴⁴ AIDS has not only reversed efforts to reduce poverty but has also continued to increase the percentage of people living in extreme poverty from 45% in 2000 to 51% in 2015.⁴⁵ HIV/AIDS poses a potentially major threat to food security and nutrition, as the availability of food diminishes. A study in Cote d'Ivoire showed that when a family member had AIDS, family income fell by 52 to 67 percent and food consumption dropped by 41 percent. Information from Zambia indicated that the pandemic contributed to a doubling of street children between 1991 and 1996.⁴⁶ The UNAIDS study also show that "two thirds of families where the father died, monthly income fell by more than 80%".⁴⁷ The loss of income is not only due to illness but also because other members have to divert more time and effort away from income generating activities.

Eventually families spend all their savings for medical treatments, fees, hospitalisation, transport to health centres, and funeral costs. Studies show that in Cote d'Ivoire, health care expenses rose by up to 400% when a family member had AIDS. The death of a family member has further financial burden as households have reported spending up to 50% more on funerals than on medical care.⁴⁸ Due to costs and the lack of income, younger children will often be removed from school because families can simply no longer afford to pay for their school fees, uniforms, and books. Moreover, these young children will have to help with chores, farming, taking care of other siblings and the sick.

The impact on education

HIV/AIDS has a direct impact on the education sector. Many countries are seeing a decline in school enrolment as children especially young girls are being removed from school in order to help with household chores and help care for sick family members. Additionally, in poorer communities' families remove children from school, as they cannot afford to pay for fees, uniforms and books. For instance the Central African Republic and Swaziland, school enrolment is reported to have fallen by 20-36% due to HIV/AIDS.⁴⁹ The rate of infant mortality is also rising in many countries. Infants are either born infected or contract the virus through breastfeeding; about 15% of children are infected through breastfeeding. In most cases these infected children do not survive long enough to enrol in school.

The disease is having an astounding impact, for instance in the Central African Republic where 85 percent of teachers who died between 1996 and 1998 were HIV

positive, and on average died 10 years before they were due to retire.⁵⁰ In Kenya, teacher deaths rose from 450 in 1995 to 1,500 in 1999 and in other countries HIV positive teachers are estimated at more than 30 percent in parts of Malawi and Uganda, 20 percent in Zambia, and 12 percent in South Africa.⁵¹ As a result, the number of qualified teachers is declining, there is less time for teaching and schedules have been altered due to absenteeism and consequently affecting the quality and quantity of education that a child receives.

Continuous investment in education is fundamental, as education is imperative to development. At a time when budgets are tight, governments are likely to reduce their expenditure in the educational sector or divert their spending to the health sector. If spending decreases then the vicious poverty cycle will continue, due to the families' economic status children are deprived of an education, due to the lack of education they will not be able to free themselves from the poverty cycle. Although some may be able to read and write, the majority, mainly girls will not even have the basic survival skills. Studies indicate that "education profoundly affects young people's reproductive lives since better educated women are most likely, in comparison with their peers, to delay marriage and childbearing, have fewer children and healthier babies, enjoy better earning potential, have stronger decision making and negotiation skills as well as higher self esteem, and avoid commercial sex."⁵²

Education has a general preventive impact, as it informs and equips people, especially adolescents on how to make decisions concerning their own lives, as well as bring about long-term behavioural changes. As a result numerous initiatives have been developed over the last decade to provide educational campaigns in schools and efforts

have been made to ensure that every child is sent to school. For instance the education for all (EFA) goal is a commitment taken on by the international community to ensure that *every citizen in every community* has access to and complete free and compulsory education of good quality. The consensus is that an “efficient education system will strengthen a country’s response to HIV/AIDS.”⁵³

The health impact

In many countries across Sub Saharan Africa overall public health spending is less than US\$10 per capita per year. Due to very low expenditure providing basic services such as prevention and care for sexually transmitted diseases (STDs), counselling, and testing prevention of mother to child transmission become impossible. The World health Organisation (WHO) estimates that at least US\$ 34 per capita per year is required to provide basic essential health services in developing countries.⁵⁴ In some areas, hospitals are already operating above capacity. Once the virus progresses to AIDS hospitalisation is essential, as the patient requires appropriate medication and care in order to survive. Studies show that in Tanzania almost 33% of hospital beds were occupied by HIV/AIDS patients. In Zimbabwe 50% of hospital beds were occupied by HIV/AIDS patients.⁵⁵

Figure 3: Causes of mortality among children and young adults in Africa and South Asia

The majority of deaths among children and young adults in Africa and Southeast Asia are due to seven causes, ages 0-44

*Source UNAIDS 2002

Two billion people worldwide are carriers of the tuberculosis bacillus (TB). Every year, about 8.8 million people develop active TB and 1.7 million die of this disease. 99% of all TB patients live in developing countries most of whom are aged between 15 and 54 years. It is estimated that between 2000 and 2020, nearly 1 billion additional people will be newly infected with TB, 200 million people will become sick, and 35 million will die of the disease, unless current efforts to control TB are greatly strengthened and expanded. However, due to their suppressed immune systems, people infected with HIV and tuberculosis bacillus are much more susceptible to developing active tuberculosis. In several African countries, the number of TB cases has doubled or even trebled in the past decade, attributed to HIV pandemic. The number of people infected with TB and HIV has already soared to over 10 million.⁵⁶

Economic Impact

Once infected the individuals in most cases will die within five to ten years, especially in developing countries where people do not have access to antiretroviral drugs. In some countries in Africa the country's Gross Domestic Product (GDP) has been reduced due to loss of working age group population. HIV/AIDS therefore, marks a severe development crisis in Sub-Saharan Africa, which remains by far the worst affected region in the world. In a number of countries a substantial number of people are expected to be lost to HIV/AIDS in coming twenty years. For instance, in Botswana, Mozambique, South Africa and Zimbabwe more than 25% of the current adult population will be lost by 2020 as a result of the prevailing infections. In other countries such as Burkina Faso, Cameroon, Ivory Coast, Nigeria and Togo the adult HIV prevalence rates have exceeded the 5% mark, which will have a direct impact on the country's future development.⁵⁷ South Africa, which represents about 40 percent of the Sub Saharan economy, will also face dramatic changes by the end of this decade. Its real gross domestic product will be 17 percent lower than it would have been without AIDS.⁵⁸

HIV/AIDS will have a tremendous impact on income both at individual and at national level; especially in developing countries. As reported in national AIDS data from many countries, HIV/AIDS affects the population of most productive age (25 years to 39 years). This results in reduction in gross domestic product (GDP) because of frequent and prolonged illnesses associated with HIV/AIDS related infections. In addition individuals, families and the communities are impacted with additional spending on health, which otherwise could have been spent on other development activities. As projected in a UNAIDS report 2002 countries with HIV prevalence of 20% would result

in a drop of GDP by 2.6% points annually. The same report also noted a decrease in GDP between 2-4% annually in many Sub Saharan African counties where HIV pandemic is known to be 20% or more. The most striking data is from South Africa, which is expected to show a reduction in GDP by 17% by 2015, attributed solely to the HIV/AIDS.⁵⁹

HIV/AIDS affects the most productive segment of society, the age group of 25 to 35 years of age. When the individuals of this age group fall victim to long-term illnesses the loss of income affects not only the individuals and families but also the entire nation through loss in productivity and income due to illnesses and early death. The impact has been so severe that even the life expectancy has been reduced from 62 years in 1990 to a projected figure of 42 years in 2010.⁶⁰

In economic terms this reduction in life expectancy has a tremendous negative impact on gross domestic product of the country. In the year 2000, about 5.3 million South African were estimated to be infected with HIV virus, most of whom are economically active adults. The prevalence is different for different age groups: 11.7% in general population, 16.9% among adults above 15 years of age, 21.5% among women of reproductive age (15-49 years) and 24.5% among pregnant antenatal clinic attendants. If there are no changes in behaviour of South African population with regards to HIV, the number of people dying with HIV related causes will increase more than number of people being born annually resulting in eventual shortage of workforce.

The GNP of South Africa is estimated at US\$ 3,918 per capita per year (Human Development Report 2000, UNDP). The Actural Society of South Africa (ASSA) estimated the population of South Africa to be 45.3 million in 2000. Given the projected

decrease in life expectancy of South African population from 62 years to 42 years by 2010, and if all things remain constant, South African economy will lose US\$ 3,549.7 billion in gross national product (Or each individual will lose US\$ 78,360 in life time as a result of early death).

Gender dimension of HIV/AIDS

Of Africa's 28.1 million people living with HIV/AIDS, 15.5 million (or 55%) are women, constituting 88% of the world's women with HIV/AIDS. Africa is the only continent where HIV prevalence is higher for women than for men. The aggregates mask key age/sex differences in HIV prevalence. For every 15-19-year-old boy that is infected, there are five to six girls infected in the same age group. Women under 25 years of age represent the fastest-growing group with HIV/AIDS in Sub-Saharan Africa, accounting for nearly 30 percent of all female HIV/AIDS cases in the Region.

Socio-economic status contributes directly and indirectly to an increased risk of HIV infection among women. Research has shown that the economic vulnerability of women makes it more likely that they will exchange sex for money or favours, less likely that they will succeed in negotiating protection, and less likely that they will leave a relationship that they perceive to be risky.

Gender inequalities are the underlying cause of high HIV/AIDS infection rates in girls and women. These inequalities further speed up the spread of the virus. Currently, women have inadequate access to health care and information regarding prevention, which places them at direct risk of infection.⁶¹ Gender inequality in decision making prevents women from controlling their own sexuality. Consequently, more women than

men are dying of HIV/AIDS. "In Sub Saharan Africa women constitute 55 percent of all HIV infected adults, while teenage girls are infected at a rate five to six times greater than their male counterparts."⁶² A culture of silence surrounds reproductive health in Sub Saharan Africa, and women are faced with significant barriers to obtaining both family planning and reproductive health information and services. In many cases, women are simply denied reproductive health and sexual education because social doctrines believe that knowledge encourages promiscuity, women are therefore ill equipped to make use of condoms even when they are available.⁶³ The lack of information limits women's ability to protect themselves.

The unequal power balance in gender relations that favours men, translates into an unequal power balance in heterosexual interactions, in which ... men have greater control than women over when, where, and how sex takes place. An understanding of individual sexual behaviour, male or female, thus, necessitates an understanding of gender and sexuality as constructed by a complex interplay of social, cultural, and economic forces that determine the distribution of power.⁶⁴

In some countries more than 25% of pregnant women are infected and in others such as Botswana, median HIV prevalence among pregnant women in urban areas had already reached 38.5% in 1997. By 2001 the rate had further risen to 44.9%. Similarly, in Zimbabwe, rates were 29% in 1997 and figures have further climbed to 35% in 2000, while in Namibia rates increased from 26% in 1998 to 29.6% in 2000 and in Swaziland figures soared from 30.3% to 32.3% during the same period.⁶⁵

Many cultural practices increase women's risk of HIV infection. Accepting these practices enhance their social status and security with their partners and within society. These practices include dry sex, polygamy, widow inheritance, child marriages and culturally condoned abuse. Additionally, women are more susceptible to HIV infection because of the vulnerability of the reproductive tract tissues to the virus, especially in

young women. The male – female transmission of HIV is more efficient than female – male transmission, both because infected semen contains a higher concentration of the virus than female sexual secretions and because the exposed surface area of women's reproductive tract tissue is larger than the vulnerable surface area in men.⁶⁶

The predominance of HIV infections in women means that in the coming decades, there will be far more men than women in heavily impacted countries a situation with unknown but clearly worrisome implications, especially for household food security and child care. In Africa, four out of five farmers are women. AIDS has dramatically increased women's economic and social burdens as caretakers, breadwinners and providers of food. When caring for a chronically ill husband, for example, women often have no choice but to spend less time on agricultural production and childcare.⁶⁷ Moreover, when they are sick themselves, women can no longer have the energy to farm. Subsequently women are faced with reduced income, need for food and medicine, social support, which eventually may force them to adopt potentially risky survival strategies such as prostitution, which can easily lead to infection with HIV.

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- ⁶⁷ Morris, J.T. (February 2003). *A New Kind of Emergency: HIV/AIDS and the Crisis in Southern Africa*. <http://usinfo.state.gov/topical/global/hiv/03022704.htm>

Chapter 2

The Political Economy of Treating HIV/AIDS

This chapter will look at the issues surrounding antiretroviral (ARV) drugs that are currently being prescribed to HIV/AIDS patients. The key issue is the production and marketing of these drugs. ARVs for HIV/AIDS are much more costly than other anti-viral drugs for other viral diseases. The pharmaceutical industry plays a critical role in the production, pricing and distribution of ARV drugs to those in need. It is also imperative to analyze the role of governments in developing countries and civil society in relation to the availability of such drugs and their relationship with the pharmaceutical industry. Currently the international economic environment is being shaped not by individual governments but by multinational corporations based in the United States and the European Union countries. Powerful western governments and multinational corporations have the ability to undermine the capacity of smaller companies and less powerful countries around the world. The primary debate is the availability of drugs for public well being versus well being for private profit and trade rules determined by the World Trade Organization (WTO) versus ethical principals of basic health and human rights. This includes access to essential affordable ARV drugs, and finally the duties and responsibilities of a state and the international community.

For many thousands of people living with HIV/AIDS, highly active antiretroviral therapy (HARRT) has extended life and improved health status to a certain extent. These drugs have significantly restored the body's ability to fight infections that once would have been fatal. However, access to ARV drugs is limited and this only reiterates the importance of prevention interventions and behaviour change communication. Currently

70 percent of individuals that are infected do not have access or cannot afford ARV drugs. This thesis stresses the importance of prevention because if prevention is maintained then dependence on ARV drugs is not necessary.

Over the past twenty years millions of dollars have been spent on scientific research to develop an HIV/AIDS vaccine and antiretroviral drugs. As with many viral diseases the development of a vaccine and drugs to treat patients with HIV has been extremely misleading. The antiretroviral (ARV) drugs developed so far are useful to enhance the immune system of HIV patients to a certain extent but developing a cure for HIV is far from a reality. Nevertheless many international agencies and private initiatives (UN Agencies and the Bill and Melinda Gates foundation amongst them) have expressed an interest in funding the procurement of ARV drugs for patients in developing countries. The global fund to fight AIDS, tuberculosis and malaria is one such effort to make ARV drugs available to patients in developing countries. The cost of generic ARV drugs is at least US\$ 1 per day per patient, which in many countries is higher than the daily income of individuals.

As we know from the pharmaceutical industry's pricing policy, high drug prices are artificially maintained to ensure that the cost of research and development is recuperated within as short a timeframe as possible. In recent years this has generated a debate on the ethics of such a policy, especially related to HIV as it threatens the very life of every HIV infected patient without exception. Is it correct to maintain such a policy keeping ARV drugs beyond the financial reach of most ordinary people knowingly that the production cost is much lower than recommended retail prices would suggest?

2.1 Why are AIDS drugs so expensive?

Multinational corporations are increasingly becoming transnational in their operations, spreading different components of their manufacturing processes to different countries where resources and conditions for their operations are optimal.¹ Approximately 300 transnational corporations control at least 25% of the world's productive assets (totaling to US\$5 trillion), but employ only 5% of the global workforce.²

Over the years we have come to see that private interests are prevailing over public needs, therefore it is crucial that private corporations are not left to regulate themselves. At the same time, governments in developing countries, who have the most to lose, are being marginalized by the sheer dominance of western governments and corporations. As recommended by the free market policy of the global economic advisors, including the World Bank and International Monetary Fund, more and more public assets are sold to private companies for the sake of efficiency, which is expected to generate revenue for the governments. This has indirectly made public institutions weaker and less friendly to the general public in developing countries resulting in widening economic gaps between the rich and poor. With the global push for democracy and free market economy inequalities within countries have significantly increased.

In terms of privatization of goods and services the pharmaceutical and telecommunications industries are now so big and complex that regulating them is virtually impossible given the resources that regulating institutions presently have. The global pharmaceutical market is controlled by a handful of corporations such as Pfizer, Bristol-Myers Squibb, Bayer, Merck & Co, Pharmacia, Novartis, Johnson and Johnson, Abbott Laboratories, American Home Products, Eli Lilly, Schering-Plough, GlaxoSmithKline and

Allergan. These companies spend millions of dollars on the research and development of HIV/AIDS drugs as well as on marketing and sales campaigns. The end result is that the cost of research, manufacturing and marketing drives up the price of the end product in an effort to recover the money spent. These companies are publicly traded and so have an obligation to their share holders to recover funds as quickly as possible and to turn a profit as soon as possible. Their market domination has enabled them to dictate drug prices.³ The supply/demand of pharmaceuticals is not influenced by price elasticity as the demand for pharmaceuticals exists irrespective of price. Pharmaceutical companies' profits tend to be high due to limited competition in the pharmaceutical industry caused by strict patent laws and high barriers for small firms (new competitors) to enter the industry.⁴ In addition, through a recent and ongoing wave of mergers and acquisitions the big companies intensify the process of consolidation by limiting competition in the so-called free market even further. Additionally, the more frequent strategic alliances, which are less costly than mergers and acquisitions, are being formed with small biotech companies in order to reap the (new) economic benefits biotechnology offers.⁵ If these large corporations are left unattended, many argue that such transactions could result in unfairly maintained market power by a few industry giants.

The power goes beyond pricing as these companies have the ability to charge countries for breaching WTO's TRIPS Agreement, for instance South Africa was taken to court by 40 pharmaceutical companies for violating the World Trade Organization's rules regarding patents and intellectual property. The pharmaceutical companies are concerned about maintaining control over who can and cannot manufacture the drugs. This creates a form of dependency that will continue to foster inequality. Therefore, policy makers need

to rethink how they assess competitiveness in the pharmaceutical industry so that customers can afford the price of products with due consideration to the issue of profit.

Pharmaceutical companies say they remain committed to research and the development of new drugs. Although several promising vaccines have reached the human trial stage, most experts concede that an effective vaccine remains years off.⁶ But on the other hand, when such a vaccine is discovered, it may be several years before it becomes available to the people who need it most because of high retail price.

2.2 Protectionism and the WTO

The World Trade Organization (WTO) remains a supranational power with an unmatched level of political and economic might led by the United States and the countries of the European Union. It has continued to dominate states and people outside the circle of the most powerful industrialized countries. Its rules and enforcement mechanism protect corporations and defend the interests of powerful companies located in powerful countries. Therefore, when countries sign up to the WTO, they also sign up to protect the patent rights of companies who sell products in their countries. The Trade Related Aspects of Intellectual Property Rights (TRIPS) also requires countries to grant patent protection to pharmaceutical products for a minimum period of 20 years. This clause grants the pharmaceutical companies a global 20 year monopoly and prevents other countries or companies from manufacturing and marketing the same drug. The effect of such overarching patents law confers monopoly upon international drug companies in the production and distribution of their patented drugs. This has serious negative implications for developing countries where such generic version drugs could be produced at a much

cheaper cost. In the context of HIV/AIDS, the ARV drugs, which are manufactured by only a few companies, have a tremendous impact in their availability and affordability to the HIV/AIDS patients in the developing countries.

WTO agreements benefit the pharmaceutical companies and their shareholders. The protection of intellectual property through patenting ensures that profits are made by the pharmaceutical industry in return for investments in research and development.⁷ Additionally, the support of the US government for the WTO and TRIPS is enough to force every developing country to comply for fear of sanctions or trade restrictions by the United States which would cripple the economies of these poor countries. This is an issue of morality versus the motive for profit.

Due to recent public campaigns and a push for basic health rights and access to affordable ARV drugs, the WTO has allowed for some exception on the drug patent law in countries facing HIV crisis by either allowing the import or to produce certain ARV drugs and set prices according to the affordability of the general population. Since the Doha Declaration in November 2001, developing countries have been allowed to manufacture generic drugs on a viable scale and where production is not possible the option of parallel importing and compulsory licensing to import a generic equivalent have been made possible.⁸ When a government institutes legislation allowing for compulsory licensing, it can oblige a patent holder to license rights to a third party to make and sell a product in exchange for royalties determined by that government.⁹ This could allow the governments of developing countries to provide medication to their citizens for much lower prices than if they had bought the medication directly from the patent holder.

Parallel trade occurs when a patent owner sells a product for export to a second country, but the product is then exported without the consent of the rights owner into a third country, which may violate patent rights.¹⁰ Yet for many countries, particularly in Africa, parallel importing and compulsory licensing is currently the most effective way to improve access to ARV drugs, due to the lack of manufacturing infrastructures in most countries.

A 1998 study by the Consumer Project on Technology found prices for GlaxoSmithKline's version of Amoxil was \$8 in Pakistan, but was \$36 in Malaysia.¹¹ Therefore by permitting some form of parallel imports, countries can shop around to obtain better prices. However, the US government at the same time has been trying to put an end to parallel importing as this method ultimately affects the profit margins of American pharmaceutical companies.

2.3 Generic drugs

A number of developing countries (Thailand, Brazil, India, South Africa, etc.) have been manufacturing generic HIV/AIDS drugs to help fight the disease. Generic drugs cost less than one-tenth the price of the patented drugs. The concept of generic drug production and marketing is based on the principle of making drugs affordable to the poor by maintaining low profit margins which also makes a high turnaround of production due to low cost. Article 31 of the World Trade Organization's TRIPS Agreement allows developing countries to manufacture generic drugs if they declare a "National State of Emergency."¹² Under this clause countries such as Brazil, Thailand and India have begun to manufacture and distribute generic ARV drugs to its citizens living with HIV/AIDS.

The Indian government has played a critical role in supporting the development of generic drugs. The government has maintained weak patent laws and encouraged local companies to freely copy and modify drugs that officially belong to pharmaceutical giants like Bristol Myers Squibb and GlaxoSmithKline.¹³ This has eased the availability of most drugs throughout the health care network and has become a threat to the multinational companies which produce patented drugs.

A number of African countries are planning to manufacture generic drugs, with the approval of the WTO. But most of them cannot compete against European and American pharmaceutical corporations which have the knowledge and power to patent and prevent others from using them. Rather than supporting and transferring scientific knowledge, the pharmaceutical companies are forbidding the development of such knowledge and technology transfer. It has become imperative for the international communities to consider changing their policies and share their global goods and prosperity with developing countries.

2.4 Political commitment

Research conducted by UNDP has shown a strong causal relationship between better governance and better developmental outcome.¹⁴ Therefore it is reasonable to conclude that better governance will also lead to more effective AIDS programming. Political commitment is required to support effective action to limit the spread of HIV/AIDS and alleviate the impacts of the pandemic. Ultimately the level of political commitment affects the strategy of HIV/AIDS programs. If world leaders truly understand the consequences of AIDS they will make certain that immediate action is taken. The level

of political commitment also influences the amount of financial resources made available to address the pandemic.

National ownership and responsibility are vital components for effective AIDS responses, and the list of countries that devote significant funds towards combating the pandemic has grown considerably in recent years. The government of Pakistan demonstrated the depth of its commitment by making HIV/AIDS a protected expenditure within the national Social Action Program,¹⁵ most recently countries such as Burundi, Morocco and Peru have shown their commitment by abolishing taxes on imported antiretroviral drugs.¹⁶ Today more and more political leaders are personally overseeing the coordination of national activities, strengthening human and financial resources, and supporting effective decentralization as a means of expanding activities.

2.5 Positive steps - HIV/AIDS, NGOs and Civil Societies

International organizations such as the AIDS Coalition to Unleash Power (ACT UP), Medecins Sans Frontieres (MSF),¹⁷ Oxfam, Pan-African HIV/AIDS Treatment Access Movement and various civil society groups across the world must keep up constant pressure to ensure that the issues around HIV/AIDS are taken seriously by governments and multilateral institutions. Community mobilization and civil society organizations are essential to sustain and maintain meaningful interaction to combat HIV/AIDS. Civil society organizations play an important role in advocacy, participating in policy and programming design and implementation, and in the provision of services especially at the community level.¹⁸ These groups should continue to insist that access to ARV drugs is not only an essential but is also necessary to strengthen further prevention efforts, as it will

increase the number of people visiting voluntary, counseling and testing sites for services. However, emphasis should remain on a strong counseling component for HIV negative clients to stay negative while providing treatment which will reduce the incidence of opportunistic infections. If these groups work together they can force action and ensure greater accountability from various institutions. With a united coalition they can push national political leaders to priorities HIV/AIDS treatment, press multilateral organizations to help implement National AIDS Programs as well as treatment and care programs, advocate for cancellation of debt and ensure continuous reinvestment into social services.

Brazil's success in HIV prevention may be attributed largely to the country's over 600 nongovernmental and community organizations. These organizations have kept the issues surrounding HIV/AIDS in the public realm and continued to put political pressure on the government for action. Additionally, activists from the Treatment Action Campaign (TAC) have become the unofficial heroes of the HIV/AIDS struggle in South Africa, a country with one of the highest HIV infection rates in the world. The TAC won a Constitutional Court case against the government which forced the state to provide antiretroviral drugs to pregnant women and rape victims.¹⁹ TAC Chairperson, Zackie Achmat, who is HIV-positive, has refused to take drugs for his own condition until they are widely available in the public health sector. Achmat attributes the lack of affordable AIDS treatment in South Africa to two major factors: first, the lack of political will on the part of the government and secondly the failure of the patent-owning segment of the pharmaceutical industry to open markets to generic competition.²⁰ Therefore civil society organizations are imperative to building capacity and enabling people and groups to be

active participants.

2.6 Notion of corporate responsibility

The question is: *do the donors and the multinational corporations have a responsibility to fight HIV/AIDS around the world?* The answer is perhaps not a definite no, although the governments in developing countries and the local corporate leaders have a greater role to play. But at the same time, multinational corporations that operate in developing countries should be accountable to their employees. Consequently they should be responsible for providing education, health insurance and universal access to ARV drugs where required. Due to public pressure, companies such as Anglo American, Anglo Gold, and DeBeers have finally agreed to provide AIDS treatment, including ARV drugs to their workers (DeBeers also provides ARV drugs to the worker's partners), and have recognized that they have a responsibility to fulfill the human right to treatment among HIV positive workers and dependents.²¹

As the pandemic progresses, an ever-wider sphere of business operations will be affected. Therefore companies choosing to implement HIV/AIDS policies, offering training and education to their employees, provide support to employees with HIV/AIDS, and contribute to multisectoral efforts to prevent infection or alleviate further harms will gain various direct and indirect benefits. These benefits include improved employee morale, high productivity (by reducing absenteeism), reduction in the cost of rehiring and retraining of new staff (lower rates of employee turnover). Therefore if companies provide efforts to prevent HIV infection and support employees with HIV/AIDS they will ultimately reduce the rate of employee loss due to the disease. By reducing transmission

rates companies can continue to function normally, while providing adequate services and benefits to its employees

2.7 Infrastructure, supplies and human resources needed

In Africa where 28 million people were living with HIV/AIDS in 2001, fewer than 30,000 were estimated to be benefiting from ARV drugs. In contrast 1.5 million people were living with HIV/AIDS in high-income countries and approximately 500 000 people were receiving ARV drugs.²² Access to ARV drugs will remain uneven and compromised until countries are able to afford AIDS related medicines and diagnostic equipment.

The health systems in developing countries cannot keep up with the growing number of new HIV/AIDS patients. In many countries across Africa, facilities are not available for prompt diagnosis for HIV/AIDS and drug supplies are unreliable. Therefore many people go on living without knowing their HIV status for months, if not years. The early HIV-related conditions and infections are easy to diagnose and inexpensive to treat but due to the lack of facilities many people continue to suffer as their immune systems deteriorate. And when one is admitted to the hospitals it often takes place at the later stages of the illness, when there is little chance for recovery.

African leaders in April 2001 pledged to increase allocation for health care budgets. Emphases were placed on increasing the number of health workers and providing specialty training in HIV/AIDS. At the same time countries such as Malawi and Zambia are experiencing 5-6 fold increases in health workers suffering from HIV/AIDS illnesses. Hundreds of school teachers and health workers have died of HIV/AIDS. Many countries are simply unable to replace the human resources that they have lost. Countries are not

able to produce health workers and school teachers to compensate for the attrition. The HIV/AIDS pandemic is already a huge burden on the health sector in southern Africa. More people living with HIV are expected to fall ill over the next decade and the situation is likely to become even worse. Maintaining the quality of health services will require substantial investments in health facilities and human resources, which will be impossible without significant external aid.

2.8 Affordability of antiretroviral drugs

In early 2000, the price of combination ARV drug treatment for one patient for one year was between US\$10,000 and US\$12,000 worldwide. By the end of 2000, after negotiation with manufacturers, prices of US\$500 to US\$800 per year were being discussed, however, by December 2001 prices were further reduced for certain generic combination drugs for as low as US\$350 per person per year.²³ Some of these companies plan to sell ARV drugs, specifically Combivir just above manufacturing costs, which amounts to US\$3 a day. Many of the pharmaceutical have had to reduce the ARV drug prices in order to continue competing as south to south cooperation on drugs access is increasing. For instance India and South Africa signed a declaration of intent to cooperate in a variety of health fields, including technology transfer and importation of inexpensive HIV/AIDS related drugs, while Thailand and Ghana have developed similar agreements.²⁴

Additionally Indian generic drug manufacturer, Cipla Ltd., which manufactures generic drugs, has offered to sell selected ARV drugs (Stavudine, Lamivudine and Nevirapine) at a considerably lowered price to Doctors Without Borders (MSF) for its work in Africa. They have negotiated to sell the ARV drugs to government programs at a

price of US\$ 600 dollars per person per year.²⁵ Bristol-Myers Squibb Company of the US holds the patent on Stavudine; Britain's Glaxo-Wellcome holds the patent on Lamuvidine while Germany's Boehringer Ingelheim holds the patent on Nevirapine and these multinational companies sell the drugs in the western markets at between US\$10,000 and US\$15,000 dollars per person per year.²⁶

The price reductions, however, still do not benefit those most in need as the lowest prices of ARV drugs still exceed the annual per capita health expenditure of most middle-income countries and average annual per capita income of most low-income countries.

In Kenya even after a price reduction of 85%, without donor support, the price of treatment is still out of reach for the average citizen, where average income is \$270 per year. Annual spending in poor countries on health is only about \$16 per person on average (the total health expenditure per capita ranges from US\$ 3 in Kenya to US\$ 203 in South Africa) and in middle-income countries, annual health spending is about \$160 per person; while in industrialized countries per capita spending on health is at least \$2,300 per person per year.²⁷

A number of countries in the last two years have developed treatment policies for AIDS in consultation with various agencies including the World Health Organization. UNAIDS state that as of May 2002, 39 countries had completed, or were close to completing, national care and treatment plans for HIV/AIDS patients with technical assistance from the United Nations.²⁸ Subsequently a number of African, Caribbean, and Latin American countries have reached agreements with manufacturers in reducing the retail prices of the drugs. Five of the world's leading pharmaceutical companies, Glaxo-Wellcome, Boehringer Ingelheim, Bristol-Myers Squibb, Hoffman-La Roche, and Merck and Co. have also reached agreements with Botswana, Chad, the Democratic Republic of Congo, and Malawi to provide ARV drugs at a reduced price.²⁹ Through this initiative they plan to fund extensive research trials, train more than 200 physicians and help non-

governmental organizations bolster community AIDS-prevention and treatment programs. On the other hand this initiative allows the five pharmaceutical companies to control the supply of ARV drugs and to stave off competition from generic producers. Additionally, they will have the ability to impose themselves and their vision of drug competition on developing countries, as well as influence local doctors to prescribe specific drugs combination.³⁰ Ultimately the companies' core strategies revolve around controlling market price restrictions on developing countries for accessing generic drugs.

2.9 ARV drugs and the opportunity cost

With mass protest on the high price of ARV drugs in several countries the cost has been substantially reduced. But one question still remains. Are ARV drugs the best investment governments can make in their fight against HIV/AIDS? We know that these drugs improve the immune system of the HIV patients to a certain extent hence the governments have decided to invest scarce resources to obtain ARV drugs. Perhaps not to do so would be an *unethical* decision. But on the other hand we also know that cost of one year of ARV treatment for one patient can perhaps prevent 10 or 20 or more infections by investing these funds in HIV prevention programs through improved behaviour change communications programs. These are some of the hard choices that politicians, policy makers and decision makers have to make. Additionally, ARVs is perhaps inducing false hope among HIV infected patients for a cure which as yet does not exist. It is therefore likely that by investing in ARV drugs, the HIV/AIDS control program may be prolonging the life span of a few HIV/AIDS patients by few years at the cost of prevention of new

infections with HIV with the same resources. The value of this opportunity cost cannot be underestimated.

Prevention programs are relatively inexpensive in comparison to treatment costs. As studies show that there are a number of benefits on other health conditions besides HIV/AIDS.³¹ For instance needle exchange programs have resulted in a reduction in hepatitis B, while consistent condom use not only prevents HIV infection but also reduces the rate of sexually transmitted diseases and unplanned pregnancies. Prevention interventions that use a combination of information, education and communication strategies demonstrate that behaviour change is possible. Many of these programs focus on providing support through peer education and community outreach programs to help high-risk clients to use condoms correctly, communicate safe sex practices and learn to recognize and avoid high-risk situations.

Prevention programs that address a low HIV prevalence population are necessary if the prevalence rate is rapidly rising and do not yet reflect current high-risk behaviours. Additionally, prevention interventions that are already established often show decreased risk behaviours and HIV prevalence. But these programs need to be maintained so that new infections do not recur. Field experiences show that treatment and prevention efforts are both necessary and complementary strategies are fundamental for reducing, if not eliminating further spread of HIV. As programs without care increase the isolation of those infected and deny respect as well as imply that those who are infected have themselves to blame. Consequently this is counter productive; as it makes those uninfected or untested more convinced that "AIDS does not happen to people like me" thus making prevention messages ineffective.

The issue of HIV/AIDS reinforces the age old saying - *prevention is better than cure*. In absence of vaccine to prevent and drugs to treat only the effective behavior change communication program can cut off the cycle of HIV infection. The most important fact in HIV/AIDS pandemic is that it can be prevented. The HIV virus does not live in the air unlike many other human disease agents. The HIV virus lives inside the human body. Only human beings are able to stop this virus from transmitting from one person to another. An effective behavior change communication program can deliver this message in a language that is understood by all.

Notes

¹ Kamalipour, Y.R. (ed). (2002). *Global communication*. Canada: Wadsworth Thomson Learning.

² Greer, J. and K. Singh. (2000) *A brief history of transnational corporations*. Global Policy Forum. <http://www.globalpolicy.org/soecon/tncs/historytncs.htm>

³ Drug pricing depends on a set of interrelated factors such as the availability of competitive rival products, competitive substitutes, market size and cost of development. Another essential factors, often unacknowledged, are the industry's political weight and secret (price) agreements between big companies.

⁴ The high entry barriers for small firms are due to substantial economic, regulatory, legal, and even personnel obstacles, as well as, according to industry, the heavy expenditures on research and development. It can take years and years to develop new drugs. However, many innovations still originate from small firms.

⁵ US Business Reporter. (2001). *Industry analysis: Pharmaceutical industry*. http://www.activemedia-guide.com/pharmaceutical_industry.htm

⁶ Esparza, J. *An HIV vaccine: how and when?* Bulletin of the World Health Organization, 2001, 79 (12)

⁷ UNAIDS 2002 p148

⁸ Elliott, B.V. (2002). *Perceptions after Doha*. Axios International. <http://www.thinkaids.org/about/Secondmeeting/DohaBrian16-04-02.ppt>

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- ¹⁷ Doctor's Without Borders/Medecins Sans Frontieres. *DWB/MFS's goals*.
<http://www.doctorswithoutborders.org/advocacy/access/msf.html>
- ¹⁸ UNAIDS Report 2002 p178
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- ²⁰ Letter to the South African President, Minister of Health and all Members of Parliament, concerning the development of a treatment plan and the declaration of a health emergency
<http://www.cptech.org/ip/health/sa/tacsag03142001.html>,
http://www.mask.org.za/sections/HIV/lovebytes/news/news_07.htm
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- ²² UNAIDS (2002). *Report on the Global HIV/AIDS Epidemic*. Geneva, Switzerland, UNAIDS
- ²³ Ibid. p146
- ²⁴ Ibid. p.148
- ²⁵ Pilot program that will provide ARV drugs to 10, 000 adults and 5,000 children, people in the treatment plan will be expected to pay US\$120 per year and the rest will be covered by the government.
- ²⁶ Firm To Sell Low-Priced AIDS Drugs For African Patients. Panafrican News Agency. 8 February, 2001.
<http://allafrica.com/stories/200102080015.html>
- ²⁷ UNAIDS (2002). *Report on the Global HIV/AIDS Epidemic*. Geneva, Switzerland.
- ²⁸ Ibid.
- ²⁹ Companies reduce prices for HIV drugs in developing countries. New England Journal of Medicine; New resolutions on HIV/AIDS announced at the 53rd world health assembly, World health report 2000: improving health systems performance: vol. 78, number 6, 862-863.
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Chapters 3

Why the lack of coverage?

“The stigma of AIDS is a result of ignorance. We are too lazy to read; lazy to be aware; lazy to know...Incorrect information is also a virus. People live with it, and stigma is attached to it.”

Joshua Formetera, founder of *Positive Action Foundation Philippines*

The debate concerning AIDS goes beyond medicine, sexuality, deviance, prevention and intervention. From the onset of this pandemic, people have learned in a relatively short time to categorise, rationalise, stigmatise, and persecute those living with HIV/AIDS. By focusing on categorising of people, we have made it possible for society to rationalise that HIV/AIDS belongs to somebody else. Consequently people living with HIV/AIDS face social disapproval regardless of how the disease was transmitted. Due to fear, the pandemic has further segregated the marginal groups of society, as AIDS patients have lost their jobs and have to deal with a series of social perceptions and attitudes that encourages further bigotry, even medical professionals have (and some still) refuse to treat AIDS patients. The public response to the disease has also been accompanied by a rise in attacks on homosexuality, most notably during a period when paramedics refused to resuscitate men they suspected might be homosexual¹. Mainstream media have powerfully shaped our understanding of AIDS and its implications. Unfortunately the media have failed to accurately report on the situation promoting public hysteria, only now, after years of high profile scientific research has this hysteria begun to fall. The fear surrounding AIDS in the early 1980s was beyond transmission, the main concerns were about homosexuality, as AIDS threatened heterosexuality. As a result homosexuality itself was feared as if it were a communicable lethal disease.²

There was an obsession with the gay angle “homosexual hazards” “gay bowel syndrome”³ the focus of the syndrome was on sexual orientation and lifestyle, namely the open promiscuity of the homosexual community, rather than contraction of specific infections. Sweeping generalisations were common and little attempt was made to deconstruct the stereotypes. An unjustified belief that illness in gay men was directly related to their promiscuity emerged.

The way societies respond to problems reveals their deepest cultural, social and traditional values, which shape human perception and actions. AIDS has been shaped not only by biological forces but also by behavioural, social and cultural factors, as diseases are socially constructed and as a result relate to public health, science, and especially social and cultural values⁴.

3.1 History repeats itself

All human societies have suffered from infectious diseases as the concept of contagions has a long history. Due to the lack of understanding of the modes of transmission a number of inappropriate measures have taken place in the past⁵. Between the fourteenth and nineteenth centuries, society had to deal with a number of diseases such as leprosy, the plague, syphilis, cholera and tuberculosis. Like AIDS, these diseases were also judged, for instance leprosy was believed to be a result of breakdown of moral values and therefore a punishment for sexual transgression. The Black Death was blamed on the Jews, who were thought to have poisoned the wells, while cholera was blamed on the poor by the rich and in the case of polio, the *infected bodies* were quarantined so that they could not infect others. Additionally, it was also believed that venereal diseases such as syphilis

were easily transmitted by drinking cups and shared utensils. Consequently, people who handled daily domestic work were tested for venereal diseases. Similarly those with the Bubonic plague in Rome were confined to one area of the city and left to die. We have always believed that danger come to us from outsiders and as a result associated diseases with foreigners⁶.

During the Bubonic plague, Roman officials patrolled the seaports and borders, inspecting all ships entering the harbour; they looked for sick-looking crewmen and travellers. Rome in the seventeenth century was a densely crowded city, its streets were packed with street vendors, merchants, beggars and few obeyed the public health orders to deposit their rubbish in the designated areas. Instead, the rubbish was dumped along the riverbanks and streets. Consequently the poor residents of the riverbanks were the first to be affected; their homes were infested with spiders, mice and vermin. Due to the lack of space people were forced to huddle together, living conditions degenerated to the point that the city was soon infested. However, public health officials took strong measures against them immediately. The sick were shipped off to an island (St. Bartholomew) while their homes were either demolished or cleansed by burning sulphur, pine, juniper, cleaners dressed in special vests and sponges covered in vinegar entered the contaminated premises and removed all of their personal belongings which were also destroyed. Family members were also quarantined in fear that they would further contaminate the city. However, those that died from the plague were all buried in mass graves outside the city. Bodies were covered with lime and soaked in vinegar. Clothes and personal belongings were also burnt as a measure of prevention⁷.

The main factor that distinguishes the situation with AIDS today from prior pandemics is the role the media are playing. Due to the power and reach of the media, information, accurate or otherwise can be disseminated across the globe in a matter of hours. The power of communication is clear, it influences how people vote; persuades people to consume and even how people behave. Therefore once messages such as “AIDS is a plague” “AIDS is a homosexual disease”⁸ have been disseminated, AIDS is easily translated as a “strange and mysterious disease that is threatening our society.”⁹ Since the emphasis is placed on certain characteristics such as *plague*, *mysterious* and *homosexual*, the real facts, however, such as HIV is difficult to transmit and occurs in other communities besides the homosexual community becomes obsolete and difficult to relay. Media coverage between 1981 and 1983 placed little emphasis on the modes of transmission, subsequently the fear intensified amongst the public, fuelled by a lack of understanding of the disease.

3.2 Constructing the “Other”

The symbolism around HIV/ AIDS has been constructed and mediated through various channels such as the media, art, and scientific research aimed at protecting society against the invasion of foreign bodies-in this situation viral or human *other*.¹⁰ “AIDS has brought back panic, fear, and terror of the ‘Other’, condemned and damned, at a time where our Western societies, armed with the miracle of antibiotics, sanitary hygiene, self-surveillance and the presence of the providential state, seemed to have repressed the fear of deaths.”¹¹ As Sontag further reiterates “AIDS has turned out, not surprisingly to be one of the most meaning-laden disease.”¹² Society has made specific moral judgements and

constructed AIDS as an illness that afflicts certain groups of people, the construction of the *deviant other*, and the victim. The belief that “these people think in different forms, act in different patterns, cling to different truths” became the general belief of an average society. The notion that disease is a form of punishment that “he is the architect of his own misfortune” became an accepted justification of the situation. By emphasising the difference, society reinforces the status quo “those who control the state and socio-economic elite continually use various kinds of structural and direct violence to exercise and maintain power, especially against those who challenge the status quo.”¹³

The mass media play a critical role in shaping how scientific controversies are interpreted and adjusted, as “mainstream journalists construct an elaborate societal hierarchy, placing various kinds of people in specific inter-relationships of dominance and subservience.”¹⁴ Since the beginning of the pandemic, anxiety and fear have predominated as major subtexts of this construction. The language used to describe the pandemic and those associated with it serve as sufficient demonstration. In the early years, we spoke of the “AIDS crisis” a sense of clearly separated boundaries is reinforced by the construction of two camps: “risk groups” and the “general population.”¹⁵ The heterosexual family unit, consists of one man, one woman, and their children, this became the focus of Victorian sexual values and various arrangements of sexuality. The fact remains that heterosexual versus homosexuals is the fundamental dividing line by which sexual identities are constructed in our culture. By positioning ourselves on one side of that line or the other, individuals as well as communities shape their social and sex lives. Everyone has a sexual identity and this identity is in fact very important both to individual psychological development and to one’s social relations. Heterosexuals tend to socialise with other

heterosexuals, a practice that reinforces the view that the only normal form of identity is heterosexual.¹⁶

Since homosexuals do not fit the characteristics of the general heterosexual public, they are immediately isolated and excluded from ordinary legal rights and protection. In Western societies where AIDS has spread rapidly among the sub-culture of male homosexuals and intravenous drug users, an infectious disease whose primary means of transmission are deviant sexual conduct and the use of illegal intravenous drugs is easily incorporated within the model of divine retribution for sin¹⁷. Blame and disgrace are attached to both homosexuality and intravenous drug users. It is believed that the deviant minorities are getting what they deserve for their behaviour and practices.

Religion also plays an important role in constructing the notion of *other*, as Christian beliefs promote certain values and these values do not coincide with the ideologies of homosexuality. "Interpretations of illness as the consequences of sin are deeply embedded in the religious dimensions of North American society"; therefore people come to believe that AIDS is God's judgement on a society that does not live by His rules.¹⁸ Preachers such as Archbishop John Foley who is the President of the Vatican's Pontifical Council for Social Communications has identified AIDS as a *sanction*; claims have also been made by two other leading Brazilian clerics, Bishop Falco of Brasilia, who has declared AIDS to be the *consequences of moral decadence* and the Cardinal of Rio de Janeiro, Eugenio Sales, describes AIDS as "God's punishment and homosexuality is a choice and a perversion, a blasphemy against the laws of God."¹⁹ Zion states religious communities blame the victim for the threat of AIDS as they assume that gay relationships are not based upon monogamy, as being homosexual enables liberation and freedom from

all restraints that are imposed by a heterosexual situation²⁰. Additionally, Rene Girard, has identified the notion of sacrifice of “trouble makers” as the cure of religious practice “a means of healing society by destroying those who would threaten it.” This idea is further reiterated as it is believed that those who do not abstain from all sexual activity outside heterosexual marriage will be punished and condemned.²¹ Due to the lack of understanding, heterosexuals draw clear lines as to what is and is not acceptable. They place themselves favourably while putting homosexuals in the other category. As Zion states “the accusation that gays are effeminate only reveals a latent hatred for the feminine itself as that which real men must avoid in themselves while the masculine females are scorned as they threaten men and their masculinity”.²² This is why patriarchal ideologies are enforced and why traditional Catholics view homosexuals as such a perverse and evil phenomenon. As men are not following the roles that are expected of them from society, consequently “gays and lesbians are considered to be traitors to the cause and indeed, moral heretics of human society.”²³ Yeo further reiterates these ideas, as he suggests AIDS proves that homosexuality is morally wrong and requires (at the very least) the premise that nature is somehow constituted in such a way as to punish so-called immoral behaviour²⁴. Therefore creating distinctions such as *them* and *us* inevitably only has a brutalising effect upon society.

History has taught us that blaming the victims of a pandemic disease is easier when they can be conceived as *different*.²⁵ The distance that is created between one’s *self* and the *other* allows rumours to persist long after factual information is provided. Mass media have the ability to symbolically portray good and bad, right and wrong, winners and losers in society.²⁶ Coverage between 1981 and 1983 clearly labelled people that were being

affected as *promiscuous homosexual males*; obviously the coverage suggested that only distinct groups such as, American homosexual males were affected and therefore every other American (or non-American) should not worry if they did not fall into this specific category.²⁷ Mainstream media in the first two years, especially Newsweek, Time and The New York Times' reinforced the message that this "unknown, deadly disease" may be contagious therefore one must avoid association with these high-risk groups. Creating the condemnation of homosexuality, the drawing of distinctions between innocent and guilty people with AIDS, the denial of risk to the general population, and metaphors associated with plague, death and divine retribution, were all clearly evident in media coverage of the time. However, the idea of unprotected sex was one that was not clearly illustrated; rather the notion of *several/multiple* partners was the focus, which helped to develop the frenzy and hysteria around promiscuity and homosexuality.

Due to the myths surrounding HIV/AIDS, those who have acquired the illness are often viewed with disgust, hatred and treated as social outcasts; in addition, the fear of contracting HIV/AIDS denied homosexual patients proper medical care. Since the virus was near invisible, it was difficult to detect making it essential to make assumptions as to where the virus might be located. Society was quick to point fingers and place labels. This created further distorted images and myths of the carrier. At first people feared both the disease and the person carrying it, as it was believed to be contagious. People then feared the infected body, which was no longer considered as human and could transmit the virus simply by coughing, touching, shaking hands, or kissing. Although, the transmission isn't as simple as this, Barbour and Huby state that scapegoats are an essential and common function within our social structure. Blaming those most affected such as homosexuals,

ethnic minorities and drug users became essential.²⁸ Rushing proclaims that there is a “universal human penchant for attributing the origin of an unfamiliar nasty disease to foreigners.”²⁹ These specific groups of people were already seen to be different due to their race and sexual preference; in effect Patton states that anyone opposing the dominant paradigm is an apt candidate for acquiring the disease.³⁰ Since the disease was considered to be *dirty*, the AIDS hotline received many alarming phone calls as people were afraid that they could contract AIDS from holding subway straps or using toilets seats used by gays, sharing an apartment building’s laundry room with gay tenants. The irony of the reports from the early 1980s is that it tried to encourage people not to shun any groups of people, but simultaneously placed the blame on the homosexual community. This glaring contradiction further alienated victims from the general public.

3.3 Deviant or normal

AIDS can be seen from two perspectives: disease or illness. Disease is understood as a biological malfunction (the break down of immune system), which can be *cured* by science.³¹ Diseases described by Sontag and Feldman holds several socially constructed meanings. AIDS is seen as a “sickness” in terms of a psychological disorder as opposed to the feeling of illness. This sickness is due to the devious behaviour one engages in.

Foucault states that modern society such as ours depend upon the acceptance of certain principles. He used the “panopticon” as a metaphor to describe the way people police themselves, as they feel they are being watched and therefore they act appropriately to avoid punishment. He argued that people exercise power over other people; as everyone has a little power. For instance mental asylum, hospitals and reformatory system are tools

of domination which incarcerate us and inflict surveillance and control society. He states in the panopticon prison, the warden sits in darkness observing the inmates without their knowing. Eventually, the degree of control would be such that the watchtower would no longer be necessary as the inmates would behave as if under constant surveillance and discipline themselves. The term discipline is very important, as he argues that people subscribe to a particular discipline. Consequently, people become imprisoned by that discipline, as people are controlled through regulation, be it the panopticon, religion or society itself.

Accordingly, deviance is defined by social control, as deviants do not exist except in relation to those who attempt to control them. Therefore deviants are viewed as living outside the boundaries of acceptable social life, outside the “common sense of society itself.” The majority see them as evil, dirty, dangerous, sick, and immoral. Consequently deviants and those participating in deviant acts are fined, beaten, incarcerated, hospitalised, and labelled and subsequently we fear them since they threaten the control of society. The more consensus there is among the reactors, the more intensity they display in their reactions, and the more power they are able to deploy in response, the more serious the deviance is considered to be.³² Therefore, with new forms of knowledge about people came new ways of exercising power over people.

Society has developed formal (medical and legal institutions) and informal (ostracising and stigmatising) methods of controlling people who have been pigeon-holed as deviant. These institutions are actively involved in determining which behaviours and people should be classified as deviant and deciding how they should be dealt with. Due to societal pressures conformity is a basic fact of social life. Most people choose to conform

and follow the social rules that are expected of them. As human beings we want to be accepted and liked by others. However, there are some people who question the norm, as their judgment and values may differ slightly but at the same time they don't want to be *different*; therefore they try to act within the roles prescribed by society, going against their personal beliefs.

Within society, specific methods have been developed to deal with deviant individuals: institutionally and behaviourally³³. Institutionally, those who are disobedient and do not adhere to laws are dealt through the judicial system while others who do not comply are labelled *sick* and treated by the medical system (through social work and psychiatry). In terms of behaviour, society often tries to correct behaviour "by segregating the deviant individual from the abnormal, rehabilitate the individual and later reintegrate them into the social system."³⁴ Society believes that it is essential to isolate the deviant individual as the deviant behaviour may be contagious and as a result may further disrupt society.³⁵ Society also expects the deviant individual to do whatever it takes to get back to being normal, as our immediate reaction is to fix it and normalise the situation. However, with AIDS and people living with the virus, there is confusion as to how society should respond to the person as well as the disease. The majority of victims have contracted the disease by engaging in immoral acts, such as homosexual relationships or intravenous drug use which in the eyes of the heterosexual law is seen to be illegal. Due to society's homophobia, punishing the deviants behaviourally for instance by scapegoating, segregation, and control enable us to maintain the status quo. The person is perceived to be *sick* not only because they have AIDS, the disease, but they are consider sick due to their devious behaviour. However, due to the complexity of AIDS, some individuals can

be infected yet show no symptoms and continue to function within the norm among others. As a result, those who have AIDS are treated as criminals and are stigmatised, the person is denied the sick role described by Parson.³⁶ The sick role model enables the sick to be “exempt from their usual roles and obligations, they are not responsible for their incapacity, they are obliged to see technically qualified help and to co-operate in the prescribed therapy.”³⁷ AIDS the illness is perceived to be the result of some serious deviation from social rules and norms and as a result the person is blamed, since “sexually transmitted diseases are medically labelled as illness, due to the non monogamous sexual relations, which are acts of moral deviance” and AIDS as a disease which is also sexually transmitted is clearly included in this category of illnesses that are considered to be illegitimate.³⁸

3.4 Stigma: Fear of the unknown

Stigma is defined as “the situation of an individual who is disqualified from full social acceptance” therefore a person with a stigma is not quite human³⁹. Erving Goffman (1963) in *Stigma: Notes on the Management of spoiled identity* identifies three types of stigma, all of which can be connected to AIDS. The abomination of the body, the blemishing of individual character and the identification with a particular group such as race, nationality or religion. Through stigmatisation negative stereotypes are developed and people are placed in social categories of “them” and “us.” Consequently the rights of people living with HIV/AIDS and their families are violated simply because they are known or presumed to have HIV/AIDS. The stigma is built upon, and reinforces, existing

prejudices which strengthen existing social inequalities. The inequalities allow for some groups to be devalued while others are empowered and given more social control.

Stigmatization takes place at a number of levels, political, social and even amongst highly educated medical doctors. Activists like Shilts blamed the government for not taking a leading role in the education process as the Reagan administration ignored AIDS and AIDS related issues until the late 1980s, "the federal government viewed AIDS as a budget problem. Local public officials saw it as a political problem, gay leaders considered AIDS to be a public relations problem and new media regarded it as a homosexual problem that would not interest anybody else."⁴⁰ The public had to rely on the mass media for information.

Dominant discourses reinforce and support certain actions, however, homosexuals and intravenous drug users do not fit within the hegemonic beliefs of the dominant discourses, therefore they are stigmatized and perceived to be "them". It is assumed that they have crossed some boundaries that make them less than human and essentially dangerous and as a result they are labeled high-risk groups. By categorizing them we have the ability to question their life style, values, and morals, which also allows us to blame them without guilt: "victims of AIDS thus suffer the biological consequences of a terrifying, fatal disease as well as a deep social stigma."⁴¹ Media coverage is focused on positioning negative images of high-risk groups; portrayed as passive and pathetic victims or as irresponsible and threatening villains.

3.5 Lack of representation

Representation was limited, especially between 1981 and 1983. Throughout those years gay men were dying in several hundreds as a result of AIDS and their plight was rarely given sympathetic press attention. AIDS was seen as a disease of deviance and governments seemed reluctant to fund research. Stuart Hall's reception theory is applicable as he argues that the dominant ideology is typically inscribed as the preferred reading in a media text. However, he states that the reader may not automatically adopt this dominant reading. He suggests that the audience does not necessarily accept the textual meaning intended by the creator/producer, rather, the audience is likely to negotiate the meaning within the text, by applying their own experiences with the meaning that is provided to the audience.⁴² However, in the case of AIDS, readers with fundamental religious beliefs and people with homophobic views may accept the dominant principle that "gay men are receiving retribution for their sexuality." Whereas gay men and liberal heterosexuals may reject this reading as they may believe that people have the right to express their own sexuality and AIDS is not a consequences of their sexual orientation. During this time of crisis the dominant reading must have been favourable as many people look up to the state and support their views. However, mainstream media did not allow much room for negotiation, as the texts have been produced in such a structure that it is difficult to engage in an oppositional discourse.

3.6 Early AIDS coverage –1981-1983

If a scientific issue is not in the mass media, then it is not news, and if it is not news, then it does not become a public issue. AIDS did not make it onto the U.S mass media news agenda for four years. During 1981 and 1982, very little mass media attention was given to the AIDS pandemic, although the Centre for Disease Control (CDC) reported over 800 AIDS cases diagnosed and over 350 deaths by the end of 1982.⁴³ There was brief coverage during mid-1983 but the issue of AIDS was still not on the media agenda. The first two years (1981-1983) have been chosen for analysis. The information that was available was mainly associated with the homosexual community. The sample size is not extensive but adequate information can be compiled from mass media, alternative magazine articles and medical journals to illustrate that a certain discourse was taking place. Specific magazines, newspapers and journals have been chosen as I am interested in examining how news was constructed around this unknown disease at the time.

Newsweek, Time and The New York Times have been chosen specifically, as they are international mainstream magazines and newspapers that are strongly influenced by American values. Consequently their ideologies are influenced by the state and the conservative fundamentalists that operate therein. Karim states “the news magazine’s writers ritually framed information about events to fit the dominant cognitive model regarding such situations; there was little in the way of an alternative discourse.”⁴⁴

The media played a prominent role in raising social and medical awareness about AIDS; sadly the reporting consistently misrepresented the basic concepts of HIV/AIDS and sensationalised faulty research and selectively reported on conflicting data. Even medical journalists framed their articles around the possibility of a gay disease. Scanning

the early headlines regarding AIDS reveals that at least eight main metaphors were used to describe the nature of the first victims of the disease. Some of these metaphors included "The AIDS Hysteria"⁴⁵, "Homosexual plague"⁴⁶, "Gay cancer,"⁴⁷ and "The Gay plague."⁴⁸ From the beginning of the pandemic, AIDS was rhetorically framed as a lethal, violent, plague-like disease caused by homosexual "deviance."⁴⁹ Patton states that scientists tried to dispel the myth of early cognitive symptoms, but the damage had already been done.⁵⁰ The idea of "AIDS madness" provided the popular imagination with a pseudoscientific basis for the longstanding fears of the psychologically impaired homosexuals or the crazed junky.⁵¹

The victims were not created by disease but by the media and its misconceptions. This was accentuated through popular uses of polarity of words, such as homosexual/heterosexual, the other/self, deviant/normal, and illness/health, natural/unnatural, normal/perverted to mention a few. Such polarities created images of good and bad distorting society's concept of the disease. These words often appeared in the title of articles and provide a stepping stone for the reader to associate certain ideologies with certain groups of people. We are continuously bombarded with information, therefore it became difficult to separate the good from the bad. In addition, there are common ways of portraying illness, or the threat of illness, and texts incorporate imagery drawn from an identifiable range of ideologies and discourses.⁵² Their presence suggests certain societal anxieties and concerns about gender relations and sexuality, the domination of science and technology in western society, and the state's control and surveillance.⁵³ What becomes evident in mainstream coverage of early AIDS is a sub-textual layer of meaning in AIDS

discourse. This transforms the state's ideologies into consideration and attempts to control sexual expression in any form not conforming to heterosexual monogamy.

Until the beginning of 1983, only three articles mentioning AIDS appeared in *Newsweek* and *Time*, and these articles appeared within the medicine section of the magazine, limiting readership. *Newsweek* was one of the first newsmagazines to cover the pandemic; the first story appeared in December 1981, coverage escalated only in 1983 with a cover story, which was significant as this was the first time a national publication was giving the pandemic important play. The articles suggested AIDS was a phenomenon of importance only to special groups. There was a suggestion that this new disease could be related to a tropical disease, as physicians had not seen anything like this before. Also, the association with the tropics can imply that disease is far away in Africa (associating with the green monkey) and therefore unlikely to harm us in North America. Foreign countries, particularly Africans ones (articles mention Congo and Angola) were defined as a prime area of infection. It was also implied that black North Americans and foreigners (particularly Cubans and Haitians) were the most susceptible.

The New York Times has a relatively large readership (within the United States and internationally) and is seen to be very influential and trustworthy among decision-makers and politicians. Although a very powerful agenda setter, the Times did not think AIDS was a story worth highlighting; in fact it had virtually ignored the health crisis. The newspaper published its first page 1 story about AIDS on May 25, 1983, "12 months later than the *Los Angeles Times*, 10 months later than the *Washington Post*, 11 months after the *Philadelphia Inquirer*, and 11 months after the *San Francisco Chronicle*."⁵⁴ AIDS demanded mainstream news media to deal with formally taboo subjects such as

homosexuality, drugs, and sex. The language surrounding AIDS is difficult to deal with, as there are several interpretations, beyond medical definition. The major concern was not to offend the “average” American family with coarse language and vulgar stories of the pandemic, as it was believed that the pandemic did not affect the average reader in the United States.⁵⁵ The few stories that did appear during 1982-1983 were not detailed and often rather misleading. The emphasis remained around blame and the modes of transmission were rather ambiguous. Kinsella,⁵⁶ in *Covering the Plague*, points out that one of the main reasons The New York Times did not cover the pandemic closely was because Abe Rosenthal (ex executive director) did not like homosexuals. And under Rosenthal “according to a number of top editors and reporters, homosexuals and the “Gay Plague” stood a poor chance of making it on the front page, or almost anywhere in the Times.”⁵⁷ According to Kinsella, those interested in covering AIDS would face career consequences “if reporters (during Rosenthal’s tenure) got to be known as excessively interested in homosexuals or were themselves thought to be homosexual – something would happen to them.”⁵⁸ Subsequently the pandemic was ignored for many years. Although New York City had the highest percentage of cases of the disease in the United States, its coverage was marginal. One of the earliest mentions in The New York Times was in 1982 “New Homosexual Disorder worries Health officials” provided in-depth look at the crisis. However the article was placed in the science segment far from the eyes of millions of New Yorkers. Obviously, the person who determines what news belongs on the front cover did not see the pandemic as news worthy. As long as AIDS seemed to be confined to fringe groups, it was simply a medical curiosity.

From its beginning, AIDS was a baffling and misunderstood disease. The headlines clearly connected the disease to gay men "A puzzling new syndrome afflicts homosexual men,"⁵⁹ "Homosexual plague strikes new victims,"⁶⁰ The continuous reminder that it is through promiscuous liberated sex that this unknown disease in contaminating communities and possibly infiltrating non-fringe groups. The explosion of AIDS only divided society. The coverage seen in both Newsweek and Time demonstrate this clearly, especially in the articles from 1983: "The change in gay life style,"⁶¹ "The AIDS hysteria,"⁶² AIDS Public enemy No.1,"⁶³ "Homosexual plague strikes new victims"⁶⁴ and "AIDS dilemma."⁶⁵ Headlines such as these only scared the public and further segregated the homosexual community as "the police department began issuing plastic resuscitation devices and rubber gloves in response to officers' fears that they might be infected during the course of first aid care."⁶⁶ Such dramatic use of language and images startled the public and generated more anger and emotions, as people were unable to understand the spread of the disease.

Concerns among citizens increased during the early coverage of AIDS, Patton explains that there had been an incident related to a man who watched a television documentary on AIDS in April 1983. Following this he had developed an irrational conviction that he was incubating AIDS. The man had suicidal thoughts from the fear of contaminating others. At the same time another man complained of acute depression and other AIDS related symptoms, in each of these cases the conditions were caused by particular media coverage of the AIDS pandemic.⁶⁷ Due to the inconsistent coverage, people were confused as how the disease was transmitted and its symptoms. Although the people described in Patton's research represent extreme cases within society, however,

there must have been others who were also sceptical, during this period the media played an important role in providing information about AIDS, accurate or otherwise. Klusacek and Morrision state, “as much as AIDS has been an pandemic of disease and death; it has also been an pandemic of metaphors and symbols that separate people. AIDS is not a nice sickness; seldom do the uninfected people want someone with AIDS near them.”⁶⁸

The articles have used a lot of loaded words, one that appears frequently is promiscuity and it has been directed specifically at the homosexual community. Although the word means to have multiple sexual partners, popular discourse has given it a new meaning, one that implies the lack of self-control, violating one's morality. By the creation of new metaphors such as these, when one reads the article one can immediately attach negative sentiments to high risk groups and the disease. Other words and phrases that appear frequently and created further panic are *lethal, mystery, and untouchable, sweating in terror, rare cancer, plague, and creeping out*. Additionally, the photographs used also reinforced the difference, as many homophobics are uncomfortable seeing homosexual men in sexual positions. The majority of images show men in close contact, holding hands and laughing, images that portray their relationships as equally loving as heterosexual relationships. The photographs enable us to have a mental image of what a stereotypical homosexual behaviour looks like. Therefore when we see someone in our daily lives with similar features to those in published photographs we can immediately associate to them as being homosexual. This creates further barriers as individuals go on living questioning those they see in the public. Not only is he homosexual but he may have AIDS. Therefore people fear sitting next to someone on the bus or the subway as the uncertainty creates further paranoia.

AIDS in every article continues to invoke stigmatisation, discrimination, panic, racism, with images associated with plague and sin. As Watney argues AIDS has been used to articulate profound social fears and anxieties in a dense web of racism, patriotism, and homophobia.⁶⁹ “The web is constructed by blood, lust, contempt, hatred and hysteria, which hangs across the entire media industry of the western world and beyond.”⁷⁰ Articles begin by emphasising the nature of the disease, how it began, who in the population has it, why they have it and how they got it. In fact it has become a ritual process for journalists reporting on AIDS. The ritual only creates further ignorance and casts out the people with AIDS and carriers of HIV. The emergence of AIDS enabled dominant discourse to reinforce what is considered normal and abnormal sexual behaviour in explicit detail in the public sphere. By demoralising abnormal behaviour, it becomes easier to place blame on the other, as this method becomes a way of maintaining social control.

Every article includes professional opinions and this is largely because society has placed a great deal of importance on authority figures such as immunologists. Their diagnosis is of great value to us. Therefore statements such as: “it is not a disease of normal young adults... something unusual and frightening is happening... no modern cities should have this many cases” was made by Dr. Michael Gottlieb, an AIDS specialist working at UCLA medical centre, his explanations had an enormous effect on the readers.⁷¹ Medicine has always played an important role in society, as the general belief has been that science can conquer anything. We live in a society where we fear the unknown, reading articles such as these only creates further fear not only from the unknown disease but also the possibility of death.

Previously, sexual conduct was an issue that was discussed in the private realm, but with the explosion of AIDS, private information became public knowledge. The coverage focused on the victim's sexual activity and quoted information such as the number of sexual partners "engaged in sex with more than 1,000 partners" information such as this leaves no room for sympathising since previous articles that have clearly stated that due to promiscuity one is transmitting the disease. Therefore one can only assume that many heterosexual people believed the media when they state "gay men are receiving retribution for their sexuality." There are several discourses that are occurring within these articles and because the dominant readings are obvious it becomes harder to identify the alternative.

3.7 Alternative discourse

Lupton's research indicates that the gay press was the first to bring this unknown disease to the attention of its audience.⁷² The first story was reported in May 18, 1981 "the six-inch story was easily overlooked on page seven of the *Native*, hidden away in a lower left hand corner."⁷³ By the end of 1981, almost every gay newspaper had published reports about this new *disease*; community and national alternative newspapers such as *The New York Native*, Boston's *Gay Community News*, Washington D.C.'s *Blade*, and the *Advocate* which was the biggest and most successful nationally distributed gay newspaper.

Although the number of gay men checking into the hospitals by 1981 was increasing little was being covered in both medical and mainstream media whereas the *Advocate* and *Native* began covering the outbreak of Kaposi's sarcoma (KS) and *Pneumocystis carinii* pneumonia (PCP) reports such as "Cancer in the Gay Community"

appeared in the front cover of the *Native* by July 1981. Although it was not clear what, why and where this cancer came from, there was significant coverage of KS lesions, images were graphic and the community acknowledged that there was a health crisis fast approaching them. By the end of the summer, activist such as Larry Kramer a well-known playwright in New York City and his friends who were already diagnosed with KS held a meeting and felt it necessary to warn other men of this new startling cancer that was spreading amongst their community.⁷⁴ The group “agreed to make thousands of photocopies of Mass’s article with the frightening KS photos and distribute them on the island. It was the first official act of the Gay Men’s Health Crisis.”⁷⁵ By the end of 1981 the aim among those affected by KS was to get national attention focused on the pandemic. Kinsella states “The *Native* was becoming known as ‘The AIDS paper’ it was the first publication in American to list high-risk behaviour” and discussed the potential danger of the disease being spread by a virus.⁷⁶ Additionally, Dr. Larry Mass, who was reporting part time for the *Native*, later became known as one of the most authoritative reporter covering the crisis as he asked each individual to question one’s lifestyle and make certain behavioural changes otherwise he stated gay men would have no future on this earth. “Kramer was putting out the call, once again, to gay men to get involved in concerted and coordinated efforts to lobby government and change their own lifestyle.”⁷⁷ His reporting brought attention to other activists across the country; especially in the west coast where the coverage was very different, as “the *Examiner* and the *Chronicle*, had been covering all sides of the AIDS issue for months, earlier than many gay publications.”⁷⁸ The homosexual community had more political influence in the west coast, as many of the leaders themselves were homosexuals, additionally a large portion of the voting population

were homosexuals therefore it was in their best interest to accommodate the needs of their community.

By 1983, several issues related to AIDS were being covered in the alternative press besides the consequence of lifestyle for instance the connection between AIDS and African swine fever virus (ASFV). Etiologically the two diseases were very similar. It was believed that eating uncooked pork might have infected humans, since ASFV previously had been transmitted to a small population in Haiti. Other discussions such as the pandemic of acquired immuno deficiency in Rhesus monkeys, as well as the lack of interest of the Reagan administration were extensively covered. The coverage focused mainly on questioning why and where the pandemic had risen, rather than placing blame, which is clearly evident in mainstream media.

Mainstream medicine does set the agenda for medical news, as certain medical organisation and medical journals controlled the amount of information in the news about AIDS, and the type of information. A number of detailed reports and studies were available in medical journals such as the Centre for Disease Control's *Morbidity and Mortality Weekly Report* (MMWR), *New England Journal of Medicine*, *The Lancet*, the *Journal of American Medical Association*, and *American Journal of Epidemiology*. Although the research was largely neutral, at times the coverage did focus on the *gay angle*. During 1981 the number of publications was limited. However by 1983 the literature grew as the scientific interest developed as the death rates increased. Additionally, the question of etiology and epidemiology was still open, as little was understood beyond the KS lesions or PCP. However, what is interesting is that scientists rather than revealing their results and findings, concealed information for the fear that once

their studies were revealed “they would not be published in more prestigious journals.”⁷⁹ The scientists, primarily at *The New England Journal of Medicine* were controlled by the *Ingelfinger Rule*,⁸⁰ which enabled editors to control the flow of news and information therefore with the knowledgeable people silent, it becomes easier to understand why mass media developed their own tangent on the pandemic, as they were not given any guidance. General belief among activists was that scientists should not be striving to make the front page but instead should be working together to advance scholarly information⁸¹. Additionally, the lengthy review process meant that there was a long waiting period before the articles could be published, and such rules slowed down the research process.

The Centre for Disease Control (CDC) in the MMRW was the first to cover the pandemic with reports on KS and PCP in June 1981; however, the pandemic only became an issue among other medical journals after late 1982. Criticisms by AIDS activists were made due to the lack of reporting and therefore by 1983, they shortened the time frame spent on peer review. By June 1983, eleven articles were published in the *New England Journal of Medicine*, fourteen in the *Lancet*, more than half a dozen in the *Journal of American Medical Association*, and at least six in the *American Journal of Epidemiology* dealt directly with AIDS while several others dealt with AIDS related opportunistic infections. However, controversies continued among the scientific community, as it was believed that important research was often overlooked because the work was not from a well-known scientist or doctor, as a result much research was overlooked for lack of credibility.⁸² Besides the internal political controversies, the coverage during 1983 was extensive and detailed. Despite limited funding significant amounts of scientific knowledge and understanding were developed in a short period of time.

However, what is astonishing is that even the first few reports developed by CDC focused on sexual orientation. The reports stated that the disease was a result of “the fact that these patients were all homosexual” and infections such as PCP and KS were associated with “some aspect of a homosexual lifestyle” as they acquired the disease through a sexual contact.⁸³ Emphasis was made on sexual frequency with and multiplicity of partners. However, other specialists such as Dr. Alvin Friedmankien, Professor of dermatology and microbiology at New York University Medical centre suggested that the possible role of amyle nitrite or butyl nitrite inhalants, also know as “poppers” which could have immuno suppressive effects.

By 1983, it was understood that AIDS could be transmitted only by three main methods, sexual contact, through blood or blood related products, and through breastfeeding. However these discoveries were not recognized to be significant by the mass media as the lines of miscommunication and misinformation continued. Scientific research clearly showed that if frequently exposed to infected blood products, one could consequently have a higher risk of developing hepatitis B, Cytomegalovirus (CMV) and other infections including AIDS. Additionally, the CDC advised, “sexual contact with known AIDS patients should be avoided, that homosexual males should limit the number of their partners, and that steps should be taken to exclude high-risk subjects from donating blood or plasma.” Yet, important information such as this was not clearly transferred to the mainstream media, as the popular press is often out of bounds for scientists.

Unfortunately even some of the early articles within the medical journals did not differ from those seen in *Newsweek*, *Time*, and *New York Times* as the research focused on comparing diseases already seen in Africa to AIDS, an attempt to connect the American

virus to Africa. Additionally a number articles focused on the pandemic from a homosexual perspective, with titles such as "Unusual cytoplasmic body in lymphoid cells of homosexual men with unexplained lymphadenopathy"⁸⁴ "Immune-cell augmentation (with altered T-subject ratio) is common in healthy homosexual men"⁸⁵ "Herpes simplex virus proctitis in Homosexual men"⁸⁶ "Preliminary observations on the effect of recombinant leukocyte interferon in homosexual men with Kaposi's sarcoma."⁸⁷ Even after doctors began seeing PCP cases among intravenous drug users and young children, the focus continued on the homosexual suffering, since homosexual males who have many partners are likely (more than the general population) to contract sexually transmitted diseases. Their hypothesis matched previous research that had already been developed during the 1960, which state that there has been an explosion of venereal sexually transmitted diseases among gay men since the onset of the sexual revolution. Therefore seeing the new immune dysfunction it becomes easier to make conclusions from previously developed knowledge.

Although the scientific journals covered the pandemic in-depth not everyone had access to the information, furthermore the information presented is very complex and very difficult to understand. However, even with sufficient information, prevention policy and programs were not developed in the United States until 1987, six years after the first person was diagnosed. By this time it was far too late for 32,000 people, as the decision makers spent far too much time placing blame rather than accepting the problem at hand and overcoming it. The modes of transmission were clearly outlined in various medical journals by mid-1983, even though the virus was not understood, prevention programs should have been developed to stop further transmission.

During the early 1980s, the general public largely perceived AIDS as confined to gay men or intravenous drug users, causing many people to be either indifferent or outright hostile to the people with the disease. This is partly due to the irresponsible media coverage of AIDS. The media neglected the issue for a long time and not until April 18 1983; issues surrounding AIDS finally appeared on mainstream media. AIDS has finally become news fit to print; however, by this time, the blame had been placed on everyone but the media for creating fear among society. Early AIDS reporting has affected how one sees the homosexual community as certain beliefs continue to pass from generation to generation. Although homosexuals are no longer associated directly with AIDS, they continue to be stigmatised for deviating from the norm. Present emphasis has been focused on women and children within third world countries and their struggle to evade this deadly disease as it destroys innocent lives.

Notes

¹ *The AIDS Hysteria*. Newsweek. May 30, 1983.

² Brandt, Allan M. "AIDS: From Social History to Social Policy," in *AIDS: The Burdens of History*, ed. by Elizabeth Fee & Daniel M. Fox (Berkeley CA: University of California Press, 1988), pp. 147-71.

³ Epstein, S. (1996). *Impure Science: AIDS, activism, and the politics of knowledge*. Berkeley, Los Angeles: University of California Press

⁴ Feldman, D.A. (ed). (1990). *Culture and AIDS*. New York: Praeger

⁵ Overall, C. and W.P. Zion. (eds). (1991). *Perspectives on AIDS: Ethical and social issues*. Oxford: Oxford University Press.

⁶ Ibid.

⁷ Fee, E and D.M. Fox. (eds) (1988). *AIDS: The burdens of history*. Berkeley CA: University of California Press.

⁸ *The AIDS Epidemic: The search for a cure*. Newsweek. April 18, 1983.

⁹ Feldman, D.A. (ed). (1990). *Culture and AIDS*. New York: Praeger. P 19

¹⁰ Klusacek, A. and K. Morrison (eds). (1992) *Leap in the Dark: AIDS, Art and Contemporary Cultures*. Vehicule Press

¹¹ Ibid. p1

¹² Sontag, S. *AIDS and its metaphors*. Harmondsworth: Penguin. P 64

¹³ Karim, K. (2000). *Islamic peril: Media and global violence*. Montreal: Black rose books. p20

¹⁴ Ibid. p27

- ¹⁵ General population is a code for white, Western, heterosexuals, positioned itself as natural but also general however, it does not include gay men, IV-drug users, African, Asian, or Latino heterosexuals, haemophiliacs as they have further categorised into sub-groups, such as gay community or African American community. As a result, the general population is a limited sphere of potential identities.
- ¹⁶ Brym, R.J. (1998) *New society: Sociology for the 21st century*. University of Toronto. Harcourt Brace and Company, Canada.
- ¹⁷ Newsweek – December 21, 1981. And Klusacek, A. and K. Morrison (eds). (1992) *Leap in the Dark: AIDS, Art and Contemporary Cultures*. Vehicule Press
- ¹⁸ Zion, P.Z. "AIDS: ethics and religion in *Perspectives on AIDS*" eds. Christine Overall and William P. Zion (Oxford: Oxford University Press, 1991), pp p43
- ¹⁹ Ibid. pp43-54
- ²⁰ Ibid. pp43-54
- ²¹ Ibid. pp43-54
- ²² Ibid. pp45
- ²³ Ibid. p46
- ²⁴ Yeo. M. "Sexual ethics and AIDS: A liberal view in *Perspectives on AIDS*" eds. Christine Overall and William P. Zion (Oxford: Oxford University Press, 1991) p75
- ²⁵ Sontag, S. (1989). *AIDS and its metaphors*. Harmondsworth: Penguin.
- ²⁶ Karim, K. (2000). *Islamic peril: Media and global violence*. Montreal: Black rose books.
- ²⁷ *Opportunistic Disease*. TIME. December 21, 1981.
- ²⁸ Barbour, R.S. and G. Huby (eds). (1998). *Meddling with mythology: AIDS and the social construction of knowledge*. New York: Routledge.
- ²⁹ Rushing, W.A. (1995). *The AIDS epidemic: Social dimensions of an infectious disease*. Westview Press Inc.,
- ³⁰ Patton, C. (1990). *Inventing AIDS*. New York: Routledge.
- ³¹ Unlike other diseases AIDS requires the presences of other opportunistic infections (OI), like other diseases foreign pollutants invades the body and attack the body's immune system. The virus (HIV) attacks all cells within the body, deteriorating the immune system, the body cannot fight the OI since its already weak and as a result the person is likely to die in a matter of months from numerous OI also known as AIDS related complex (ARC). AIDS has so many meanings for so many people, some see it as a gay sickness, others see it for what it actually is: an immune deficiency and some describe it in terms of the various opportunistic infections. Depending on the person's age, gender, socio-economic status and sexual orientation the four letter acronymic will carry a different meaning
- ³² Pontell, H.N. (ed). (1999). *Social deviance readings in theory and research*. Prentice Hall: New Jersey
- ³³ Parson, T. (1951). *The social system*. London: Routledge.
- ³⁴ Feldman, D.A. (ed). (1990). *Culture and AIDS*. Praeger: New York. p32
- ³⁵ For instance alcoholics are sent to rehabilitation and AA before they are considered to be sober.
- ³⁶ Parson believes that people have various rights and duties, which they must fulfil and society is maintained by people following their social roles, norms and values and deviation from these roles and norms is met with some form of social control. As a result Parson sees society as a system
- ³⁷ Richman, J. (1987). *Medicine and health*. New York: Longman
- ³⁸ Quam, M.D. "The sick role, stigma, and pollutant: The case of AIDS" in *Perspectives on AIDS* eds. Christine Overall and William P. Zion (Oxford: Oxford University Press, 1991) p32
- ³⁹ Goffman, E. (1963). *Stigma; notes on the management of spoiled identity*. Englewood Cliffs, N.J., Prentice-Hall
- ⁴⁰ Shils, R. (1987). *And the band played on: Politics, people, and the AIDS epidemic*. New York: St. Martin's.
- ⁴¹ Brandt, A M. (1987). *No magic bullet: a social history of venereal disease in the United States since 1880*. New York: Oxford University Press p156
- ⁴² Hall, Stuart. "The television discourse: Encoding and decoding" pp.28-34 in *Studying Culture: An introductory Reader*, 2nd ed., (eds). Ann Gray and Jim McGuigan. (1997)
- ⁴³ Edgar, T, M.A. Fitzpatrick, and V.S. Freimuth (eds). (1992). *AIDS: A communication perspective*. London: Lawrence Erlbaum Associates, Publishers
- ⁴⁴ Karim, K. (2000). *Islamic peril: Media and global violence*. Montreal: Black rose books p89
- ⁴⁵ *The AIDS Hysteria*. Newsweek. May 30, 1983

- ⁴⁶ *Homosexual plague: Strikes new victims*. Newsweek. August 23, 1983 p10
- ⁴⁷ *The AIDS Epidemic: The search for a cure*. Newsweek. April 18, 1983 p74
- ⁴⁸ *The AIDS Epidemic: The search for a cure*. Newsweek. April 18, 1983 p74
- ⁴⁹ Lander, E. (1988) *AIDS coverage: Ethical and legal issues facing the media today*. Journal of Mass Media Ethic. 3 (2, Fall) 66-72
- ⁵⁰ Patton, C. (1990). *Inventing AIDS*. Routledge: New York.
- ⁵¹ Patton, C. (1990). *Inventing AIDS*. Routledge: New York.
- ⁵² Ling, J. (1989). *New communicable disease: A communication challenge*. Health Communication (4) 253-260.
- ⁵³ Sontag, S. (1989). *AIDS and its Metaphors*. Harmondsworth: Penguin
- ⁵⁴ Edgar, T, M.A. Fitzpatrick, and V.S. Freimuth (eds). (1992). *AIDS: A communication perspective*. London: Lawrence Erlbaum Associates, Publishers. p183
- ⁵⁵ 1) Between 1981-1987, 65% of new AIDS cases were homosexual men, by 1993-1995 the rate had decreased to 45% 2) Between 1981-1987, 3% of new AIDS cases were the result of heterosexual contact, by 1996-1995 the rate has increased to 10% 3) Between 1981-1987, 17% of HIV infection were due to IDUs, by 1993-1997 the rate had increased to 27%
- ⁵⁶ Kinsella, in "Covering the plague" focuses on a number of media institutions and their coverage of AIDS. His book looks at US journalism and how poorly they handled the epidemic.
- ⁵⁷ Ibid. p60
- ⁵⁸ Ibid. p60
- ⁵⁹ *Opportunistic Disease: A puzzling new syndrome afflicts homosexual men*. Time. December 21, 1981 p67.
- ⁶⁰ *Homosexual plague: Strikes new victims*. Newsweek. August 23, 1983 p10.
- ⁶¹ *The change in gay lifestyle*. Newsweek. April 18, 1983 p80.
- ⁶² *The AIDS hysteria*. Newsweek. May 30, 1983.
- ⁶³ *AIDS: Public enemy No. 1*. Newsweek. June 6, 1983.
- ⁶⁴ *Homosexual plague: Strikes new victims*. Newsweek. August 23 p10.
- ⁶⁵ *AIDS dilemma: Need for long-term cure*. TIME. October 24, 1983.
- ⁶⁶ *Gay America in transition*. Newsweek. August 8, 1983 p30.
- ⁶⁷ Patton, C. (1990). *Inventing AIDS*. New York: Routledge.
- ⁶⁸ Klusacek, A. and K. Morrison (eds). (1992) *Leap in the Dark: AIDS, Art and Contemporary Cultures*. Vehicule Press. p23
- ⁶⁹ Watney, S. (1997). *Policing desire: Pornography, AIDS and the media*. Cassell: London.
- ⁷⁰ Ibid. p1
- ⁷¹ *Gay America in transition*. Newsweek. August 8, 1983.
- In 1981 Dr. M Gottlieb first identified AIDS in five Los Angeles patients; he has been one of the pioneers in AIDS research.
- ⁷² Lupton, D. (1994). *Moral threats and dangerous desires: AIDS in the news media*. Taylor and Francis Inc.
- ⁷³ Kinsella, J. (1989). *Covering the plague: AIDS and the American media*. Rutgers University Press: New Brunswick. p28
- ⁷⁴ Ibid.
- ⁷⁵ Ibid. p.30
- ⁷⁶ Epistine, S. (1996). *Impure science: AIDS, activism, and the politics of knowledge*. Berkeley, Los Angeles: University of California Press.
- ⁷⁷ Kinsella, J. (1989). *Covering the plague: AIDS and the American media*. Rutgers University Press: New Brunswick.
- ⁷⁸ Ibid.
- ⁷⁹ Ibid.
- ⁸⁰ The aim of this policy was to discourage the public announcement of research findings before publication in a scientific journal, as well as to discourage the growing practice of redundant publication. The publication would run no manuscript that had been reported in detail anywhere else, including the popular press.
- ⁸¹ Shilts, R. (1987). *And the band played on: Politics, people, and the AIDS epidemic*. New York: St. Martin's.

⁸² Epstein, S. (1996). *Impure Science: AIDS, activism, and the politics of knowledge*. Berkeley, Los Angeles: University of California Press

⁸³ Ibid.

⁸⁴ New England Journal of Medicine. April 7, 1983 "Unusual cytoplasmic body in lymphoid cells of homosexual men with unexplained lymphadenopathy"

⁸⁵ New England Journal of Medicine. April 7, 1983. Immune-cell augmentation (with altered T-subject ratio) is common in healthy homosexual men

⁸⁶ New England Journal of Medicine. April 14, 1983. "Herpes simplex virus proctitis in homosexual men"

⁸⁷ New England Journal of Medicine. Mar 5, 1983. Preliminary observations on the effect of recombinant leukocyte a interferon in homosexual men with Kaposi's sarcoma

Chapter 4

HIV is preventable drugs!

HIV/AIDS is a health problem emanating out of certain kinds of individual behaviour. Solving the problems of HIV requires changes in social behaviour, individually and amongst groups. Education and knowledge are imperative to solving this problem but they are not enough. Combating this issue requires changes in attitude.

The leading primary HIV/AIDS prevention today is education and teaching people on how to adjust their behaviour to reduce or eliminate HIV exposure. The goals of educating people about HIV infection and AIDS are to promote social understanding, compassion towards those living with HIV/AIDS, deal with issues of stigma and discrimination and to change people's sexual behaviour and drug habits. Health specialists suggest that "health communication is a crucial element in disease prevention and health promotion is the primary social process that can empower individuals to take charge of their own health."¹ The aim of this strategy is to help targeted audiences to recognise the consequences of HIV/AIDS, levels of risk, ways to avoid and take appropriate measures to motivate people to make effective decisions. Knowledge, nevertheless, does not guarantee sufficient motivation to change sexual behaviour or drug habits. One cannot assume that exposure to the health communication campaigns will lead people to immediate behavioural change.

Behaviour change is a long and complex process; therefore long-term strategies must be considered - ones that build on previous campaigns as well as new and different prevention messages, targeting a number of audiences beyond the high-risk groups.² Behaviour change requires communication strategies that encompass locally appropriate

information, training in negotiating and decision-making skills, and social and legal support for safer behaviours, access to the means of prevention such as access to condoms and/or clean needles and motivation to change behaviour. For instance education has not stopped teenage pregnancy, nor has knowledge about cigarettes causing cancer stopped people from smoking. Moreover, why should people who depend on the sex industry for daily survival care about safer sex practices when it might lead to rejection by their customers, consequently putting an end to their livelihood.

There must be a perception of personal health risk before behaviour changes. The pandemic must be made concrete, real, and personal, and not simply something out there distant and remote from an individual's daily life. Many believe that once people actually see the geographic dynamics of the pandemic, when they see it all around them they then begin to reflect carefully upon the possibility of their own personal danger.³ As Ostrow found traditional motivational appeal such as fear, force, pleasure and altruism are insufficient to encourage desired change but rather a variety of psychological, educational and institutional support with adequate resources are necessary for people to make behavioural changes.⁴ The focus should remain on highlighting that it only takes one infected partner and engaging in one incidence of unprotected sexual activity to become HIV positive. And to remind people that the AIDS pandemic is not a problem that will go away on its own and that it does and will potentially affect each person across the world.

4.1 Why education?

Education leads to increase in knowledge not only about HIV/AIDS but also about other reproductive health information. Education enables one to understand why it is important to drink clean water, use mosquito nets to prevent malaria, use condoms consistently to avoid pregnancy and HIV infection. The World Bank report states that education is a proven means to prevent HIV/AIDS; through education people have the ability to make healthy decisions concerning their lives and give people the opportunity for economic independence and hope.⁵ Education has had a tremendous impact on women in developing countries, as they are more informed and have the knowledge to make positive decisions regarding family planning, be more economically independent, and delay marriage. Additionally, “education is highly cost effective as a prevention mechanism, because the school system brings together students, teachers, parents and the community and preventing AIDS through education avoids the major AIDS related costs of health care and additional educational supply.”⁶ Consequently many programs, which initially worked with youth over thirteen years, now included primary school aged children, recognising the needs of younger children as well as the value to intervention before typical adolescents risk situation arises. These programs focus on life skills, which are necessary both in everyday circumstances and particularly in specific risk situation, as young people need skills to adapt to the social, economic, and political realities of their world, to make decisions that will enhance their opportunities. Life skills are psychosocial competencies such as decision making, critical thinking, effective communication, problem solving are a few to mention, skills that enable individuals to think and behave in a proactive and constructive way in dealing with themselves and relating to others in order to succeed.⁷

Life skills are fundamental to operate in everyday society as this approach is a teaching and learning approach, the emphasis remain on process as opposed to content; how something is learnt as opposed to what is learned; and how to think as opposed to what to think.

However, it is fundamental to have an enabling environment where change is possible; even if people are motivated and develop the necessary life skills, they will continue to face a range of barriers to attaining good health such as resistance from family, peers and community, as well as religious, cultural, economic and social pressures. Furthermore, due to the lack of structural and legislative support people do not have the freedom to make healthy and safe decisions. Communication, development and change must occur at all levels, from individual, community, to societal in order to overcome the HIV/AIDS pandemic. These issues will be discussed within this paper.

4.2 Why prevention?

In absence of vaccines and drugs for treatment prevention is the only option available for eradicating HIV or at least reducing transmission. Effective programs that are targeted to specific audiences can be highly cost effective and impact the course of the AIDS pandemic.

Communication influences how people behave, vote and even determine what people buy. These strategies supplemented by interpersonal intervention and face-to-face communication can bring about behavioural change. Therefore, today the focus is placed on sharpening our understanding of human behaviour and attitude so that we can create and develop effective communication strategies targeted at the specific groups of people.⁸

On the other hand, finding the keys to motivation, that spark of energy, which spurs people to change and consolidate those changes, has become increasingly difficult. A number of theories assume that awareness of risk motivates action. However, the actual form action taken depends on outcome expectations of the advised behaviour, in combination with self-efficacy expectations about performing that behaviour.⁹ Therefore, efforts to change deeply held values have a low success rate, as a person's sense of identity and wellbeing is rooted in his or her basic values. But through informative communication strategies, knowledge, values and social norms can be disseminated so that discussion of formerly taboo topics, such as HIV/AIDS, in community meetings and on television and radio can greatly reduce the embracement of talking with friends and family members about prevention methods. Purposefully designed messages in the mass media can help change the way people perceive HIV/AIDS and ultimately lead them to adopt preventive methods and plan for positive behaviour when engaging in sexual activity.

Behavioural change is harder to achieve than cognitive or a single action change as, people have to abandon old habits and learn new habits and maintain the new patterns of behaviour.¹⁰ Behavioural change is very complex as it involves several decisions. Awareness does not lead to immediate behavioural change/outcome. For example a woman may have good intentions to using condoms, but 1) she may not have money to purchase condoms, 2) she may have the money but may not have access to condoms (health centres or clinics or shops, 3) clinics or health centre or shops may deny her services, 4) she is concerned about safe sex practices but discouraged to use a condom due to the attitudes within her community, 5) she might not be able to convince her partner into

wearing a condom, 6) even if she discusses with her partner he may refuse her request.

Each of these situations affects the success rate of HIV prevention campaigns.

A number of models have been used to inform the public about HIV/AIDS. Top-down health education models are increasingly being replaced with more participatory approaches. Getting people to change their behaviour and maintain that new practice or attitude is the essential task of the communication strategies. Therefore a number of strategies are used, which include behavioural change communication (BCC), information, education, and communication (IEC) strategies, diffusion of innovation, social marketing of condoms and HIV/STDs, and harm reduction. These strategies have been used in order to promote positive health messages across the world. Communicators often mix elements from each of these strategies, evolving into a multi-disciplinary mix of communication, education, social marketing, advocacy and social mobilisation.

4.3 What is behavioural change communication (BCC)

“Behavioural change communication is an interactive process with communities (as integrated with an overall program) to develop tailored messages and approaches using a variety of communication channels to develop positive behaviours; promote and sustain individual, community and societal behaviour change; and maintain appropriate behaviours.”¹¹ BCC strategies use a variety of interventions such as, mass media, advocacy at various levels, inter-sectorial collaboration, involvement of non-governmental organisations, and voluntary counselling and testing (VCT), peer education, support groups, counselling and interpersonal communication. This strategy also focus on providing a supportive environment where behaviour change is possible, with access to

treatment, information, condoms, needles and medication for curing sexually transmitted disease (STDs). BCC has incorporated a number of behaviour change models in order to develop effective programs and activities (Everett Rogers' Diffusion of Innovations, the stages of change model by Prochaska, DiClement and Norcross, and the self-efficacy model by Bandura). Effective BCC promote essential attitude change, reduce stigma and discrimination, create a demand for information and services, advocate an effective approach from policymakers and opinion leaders, promote services for prevention, care and support and improve skills and sense of self-efficacy.¹² By using the various strategies, the goal of BCC is to increase condom usage, reduce the number of partners, and increase the number of people enquiring for help, increase the adoption and continued use of safer sex practices, prevention, and care for STDs and delay adolescents' first sexual debut.

Figure 1: A framework for behaviour change communication design

Source: Family Health International

BCC has different yet related roles to play in implementing AIDS programming as effective BCC should create a demand for information and services and should encourage people to reduce risk. Behaviour change takes place at individual, community, and institutional level and goes through a series of steps, hoping to proceed forward to achieve the desired behaviour. Different channels have shown to be effective at different stages of the continuum and for achieving different goals. For instance the use of mass media was found to be effective to disseminate information and increase awareness but the interpersonal communication is more effective to discuss (post) counselling and option for treatment and care. When an individual or community is ready to adopt new attitudes, policies and the larger social environment become more important, as the services and or products being promoted must be available to them.¹³ Such support must also be part of BCC.

4.4 How has BCC been used?

Behaviour change through communication has achieved some success in some of the health fields such as reducing diarrhoea-related infant and child mortality. In a number of developing countries across Africa, mothers refuse to administer water or any fluid to children with diarrhoea thinking that liquid is bad for diarrhoea without realising the fact that diarrhoea causes dehydration, which eventually leads to child death.¹⁴ Starting from early 1980s, health workers launched a global campaign to change the feeding behaviour of mothers and family members to promote giving of fluids to children with diarrhoea as a result the infant and child mortality rates have been reduced by 50% by the end of 2000.

Similar behaviour change communication campaigns have been launched in many countries for promotion of condoms for family planning but with less success.

A number of BCC campaigns for prevention of HIV have been implemented in a number of countries in all continents. The key messages for behaviour change were focused on abstinence, remaining faithful to partners (monogamous), use of condoms, and preventing the sharing of needles amongst the intravenous drug users. The successes have been mixed so far. In the Netherlands the government implemented a free needle exchange program and the prevalence of HIV has notably declined. In Uganda where the government accepted the existence of diseases and promoted the use of condoms the prevalence of HIV has been reduced dramatically from 18.5 percent in 1995 to 5.0% in 2001.¹⁵

The key problem in behaviour change program appears to be the reluctance by people and governments to accept the fact that the problem of HIV exists in their countries. This delayed the entire process of program design and targeting the risk group. Southern Africa has been devastated by HIV and is expected to lose almost 25% of the entire population in coming two decades, yet the political leaderships in much of Southern Africa has refused to recognise the problem.¹⁶

Another key concern is the vertical transmission of HIV from mother to child during pregnancy, delivery and breastfeeding. Administration of *nevarapine* to pregnant women just before delivery and to infants after the delivery is expected to prevent the HIV in newborn infants. However, there still exist the risks of HIV transmission to 15 to 25% of infants through breastfeeding.¹⁷ This can be prevented by introducing replacement feeding. But in many developing countries, women who do not breastfeed their children

are not socially accepted. Therefore, how could such behaviour and tradition be influenced?

4.5 Media Advocacy

Media advocacy is an innovative strategy to advance public policy. Its purpose is to promote public health goals by strategically using the media, especially the news media, to apply pressures for changes in policy.¹⁸ Media advocacy focuses on social, political, and economic issues. Its three specific goals are setting the agenda, shaping debate, and advancing a policy approach over time. “The goal of media advocacy is to empower the public to participate more fully in defining the social and political environment in which decisions affecting health are made.”¹⁹ ACT UP (AIDS Coalition to Unleash Power) is an activist group that has used media advocacy to effect change in AIDS public policies. ACT UP has grown tremendously over the last fifteen years, although ACT UP New York remains the largest, a number of other chapters across the United States and Europe have been formed. Their commitment is to provide people with information on AIDS treatment and support, safer sex, and intravenous drug use. At the heart of ACT UP’s message is that many of the AIDS deaths thus far have been needless and therefore focus on bringing the issue of AIDS into the lives of every American, pointing out that no one is safe and that AIDS is everyone’s problem.

4.6 Information, education, and communication (IEC)

Information, education and communication (IEC) strategies are crucial element to BCC as IEC initiatives concentrate on raising awareness, improving knowledge and understanding among the general public about HIV/AIDS infection and STDs, routes of

transmission and methods of prevention.²⁰ The aim of these initiatives is to promote desirable practices such as abstinence, avoiding multi-partner sexual relationships, condom use, and sterilisation of needles among intravenous drug users, as well as to create a supportive environment for the care and rehabilitation of persons with HIV/AIDS. There are several components to IEC initiatives. It uses a multidisciplinary and client-centred approach such as the use of interpersonal communication, counselling session or group discussions, community meetings and events or mass media communication such as radio, television and other forms of one way communication, such as leaflets, posters and visual aids are a few to mention.

It is essential to develop IEC messages that are effective, relevant, short and accurate. The information should be disseminated in the language of the target audience, as localisation is crucial. It is also important to develop several versions of the same message, as each target audience must be addressed, as their perception of problems is different, and their needs and priorities are different. Communication can be both verbal and non verbal. It is also important to avoid jargon, medical and other sophisticated technical terms that may only confuse the message. Non-verbal communication can also communicate as much as words. Service providers must be aware of their own body language and the signals they may be unknowingly sending to their clients, as it is important that the attitudes conveyed must be compassionate and not judgemental.

Communication is a fundamental component of IEC strategy, as good communication between the client and service provider is essential, given the sensitive nature of some of the issues that are addressed such as sexual violence, dealing with discrimination and contraceptives. Building trust and developing rapport with clients

enable service providers to obtain information, their needs, priorities and concerns.

Beyond developing linkages with service providers, it is also essential to develop dialogue with influential individuals within the community. Peer education prevention programs also play critical role in raising awareness and help spread the message and change community norms as well as encourage behavioural change. Peer education prevention programs recognise that people in their own communities has tremendous power of persuasion and can be effective agents of change.²¹ These individuals are familiar with the environment as they too live and come from the same community, additionally they may already play a leading role within the community therefore their opinions are respected (examples have been seen in refugee camps across Africa). Consequently, they become role models for disseminating information and educating the community for desired behaviours and actions.

4.7 Voluntary counselling and testing (VCT)

The global scientific community promoted the concept of voluntary counselling and testing (VCT) as one of key intervention strategies to prevent the spread of HIV. Voluntary HIV counselling and testing are key components of prevention and care programs. VCT is a combination of two activities, counselling and testing.²² Many studies have found that VCT is effective as a strategy for facilitating behaviour-change around both preventing HIV and early access to care and support. VCT helps people to learn how HIV is transmitted, practice safer sex, information as to where and why to get an HIV test, as well as how to take the steps to avoid becoming infected or infecting others.²³ Through the care program, people are directed towards relevant counselling (pre-test and post-test),

care and support services so that they can seek further information to treat sexually transmitted disease, opportunistic infections, and obtain antiretroviral drugs for prevention of mother to child transmission.²⁴

However, promoting VCT for behaviour change, as a prevention strategy alone will not work if services or referrals are unavailable for those found to be positive. Therefore a referral for care and support program must be established, with medical, nursing and home care services available for medical, nutritional, and psychological support. Additional support for antiretroviral drugs (ARV), prophylaxis for common infections, post-testing counselling should also be available at each VCT centre. Currently the services available in developing countries are limited due to the lack of trained staff; health infrastructures, access to adequate laboratory facilities, and where services are available people are reluctant to visit the sites due to issues surrounding stigma, discrimination, and confidentiality. There is clearly the need to strengthen and expand VCT services with access to ARV for treatment and prevention of mother to child transmission (PMTCT). It is essential that all communities have access to VCT programs and encourage people to know their HIV- sero status. It is critical that testing be supported by effective counselling with adequately trained counsellor as interpersonal communication support is fundamental within a user-friendly locale, with guaranteed confidentiality.²⁵ It is strongly believed that by embracing and incorporating VCT programs in all care and prevention programs will lead to greater openness about HIV/AIDS, consequently leading to less stigma and discrimination within society.

Studies show that between 15 to 30 percent of pregnant women transmit HIV virus to their infants during pregnancy, delivery or through breastfeeding during infancy.²⁶

Therefore pregnant women with high-risk behaviour are encouraged to go for counselling and testing for HIV. Advocacy for this program has been very difficult to implement as submitting for counselling and testing is an indirect acceptance that they have been unfaithful to their partner/husband therefore they run the risk of being accused of infecting their partner/husband. As reported in various news paper reports, once the partner/husband discovers that their partner/wife has gone for pre-test counselling they are likely to beat their wife/partner, abandon them, or neglect them, as a result only a handful of women agree to be tested for HIV. Under such circumstances how can BCC be made more effective?

In Ghana for example 2,636 pregnant women in a HIV sentinel site agreed to be tested for HIV after counselling.²⁷ Out of this 232 (12.2%) were found to be HIV positive. These women were advised to bring their husbands for testing and only a small number of women managed to actually even tell their husbands. However, a portion of them were beaten, while majority were either divorced or were kicked out of the house. Under such circumstances no one will ever know if the husband gave the virus to the wife or wife gave the virus to husband assuming husbands are HIV positive. Finally such attitudes are deadly for any BCC programming.

4.8 Diffusion of innovations

The Diffusion of innovations is a theoretical model developed by Everett Rogers, this model explains the progression over time, by which members of a community or society adopt new, or different, ideas and practices.²⁸ Diffusion is a “process by which an innovation is communicated through certain channels over time among the members of a

social system.”²⁹ And innovations are new ideas or practices such as technologies, attitudes and behaviour and policies that are adopted.³⁰ Innovations are communication through mass media and/or interpersonal communication. Rogers states that there are six types of groups. Innovators act on information they get through the media and peers outside their community. Early adopters act if convinced by the media and innovators that the new practice “works.” Early and late majority adopters rely heavily on information from their peers. Late acceptors and resisters require extensive peer group education.³¹

Characteristics of Innovation

Rogers states that “newness in an innovation need not just involve new knowledge,” as some people may have known about an innovation for sometime but not yet developed favourable or unfavourable attitudes toward it, nor have adopted or rejected it.³² Some innovations take a relatively short time to adopt such as cell phones and personal computers, while others require decades to reach complete use, such as the use of seat belts in cars, drinking and driving and smoking. He states that the characteristics of innovation as perceived by individuals help to explain their different rate of adoption.³³ The adoption of new and different behaviour is more likely to happen if we can emphasise the benefits over the negative outcomes of a desired change. The innovations, at the beginning of the campaign are not seen to be necessary, useful or important. However, the adoption rates do generally increase slowly, once a few people try the idea, it gradually develops and spreads before the mass becomes more accommodating. He also states that an individual goes through five types of consideration before making a decision to adopt the new idea, or different behaviour, and these innovation characteristics are 1) relative advantage, 2) complexity, 3) compatibility, 4) trialability, and 5) observability.³⁴

Relative advantages can be measured in economic terms, social prestige, convenience and satisfaction. The individual's perception of the new innovation is fundamental, for instance, condom campaigns have not been as effective because of the negative attitudes associated with condom usage. Many believe that condoms reduce pleasure, break easily and the perception that women or girls who ask their partners to use condoms are either unfaithful or are planning to be, as a result women don't ask as they fear reprisal. Moreover, those that are interested to use condoms often may not be able to afford to buy them regularly as the major problem faced by many is the lack of access to retail outlets. Compatibility is the degree to which an innovation is perceived as being consistent with the existing values, past experiences, and the needs of potential adopter's.³⁵ For example, condom usage is not compatible with the norms and values of many traditional believers, as religious beliefs discourage use of condoms as it is seen as a contraceptive method, rather than prevention from STDs and HIV. Complexity is the degree to which an innovation is perceived as difficult to understand. Some innovations are very easy to understand and consequently adopted more rapidly than those that require the adopter to develop new skills and understanding. For some people condom usage is complicated, as one has to go and purchase it first, then learn how to use it, often negotiate it with a partner as to whether to use it or not and in many cases, couples have to deal with private issues that are often uncomfortable to discuss. Ultimately many disregard this new innovation entirely, due to the complexity. Trialability is the degree to which an innovation may be experimented with on a limited basis, as an innovation that is trialable represent less uncertainty to the individual as this enables them to learn by doing. Rogers states new ideas that can be tried on the installment plan will generally be adopted more

quickly than innovations that are not divisible.³⁶ Finally, observability is the degree to which the results of an innovation are visible to others. If the adopter sees immediate results they are likely to adopt the innovation faster, consequently leading to further discussion among peers who may also adopt the new innovation as the results are positive and immediate.³⁷ Previous research from various areas such as family planning, oral rehydration treatment (ORT), weight loss programs, smoking campaigns show that these five qualities are crucial before an innovation is adopted.

However, before an innovation can be adopted it has to be communicated; diffusion is therefore a particular type of communication, during this process the message that is exchanged between two individuals is related to the new innovation. In essence, diffusion process is the information exchange. Diffusion process consists of four ideas, these are 1) the innovation, the idea or practice that is perceived as new and one that should be adopted, 2) communication channel, the means by which messages are exchanged, 3) time or process, and 4) social system, the structure and function of relations among a set of individuals.

Communication was originally conceptualised as a one-way process of messages from source to a receiver, focus was placed on the production of the message rather than the content. This approach reflected the norms of the modernisation paradigm that emphasised transferring technology and norms from the developed to the developing countries. However, communication has since been redefined as a two way interactive process where receiver and sender participate in both the encoding and decoding process. As Piotrow et al. states “in the process, there is convergence of both the idea and the behaviour of the participants... The distinction between the sender and receiver disappears

because all participants have the opportunity to be both senders and receivers.”³⁸

Participatory communication projects aim to empower individuals and communities to take control of their lives. Information flows both ways between sender and receiver. Effective communication is only possible if the target audience continues to participate, as it is critical to have their feedback since target audience needs vary, consequently their way of thinking must always be incorporated in order for the communication message to be successful. Messages therefore must be based on information obtained from target audience and pre-tested on them before introducing it to the larger group, in order to make sure that the design is accurate. This dialogue is critical, as information cannot just be created and disseminated without understanding the target audience. If the messages have been developed accordingly, the target audience is likely to adopt the new behavioural practices faster.

A basic notion of diffusion is that a new idea is adopted slowly during the early states and eventually accepted. People do not suddenly begin to do something they have never done before. They learn, weigh the benefits and see if anyone else is doing it. They acquire the skills needed for the new behaviour, apply it to their own lives and evaluate whether it is worthwhile continuing. They may reject the behaviour, or encourage others to follow their lead.

4.9 Social marketing

Social marketing is defined as “the design, implementation and control of programs designed to ultimately influence individual behaviour in ways that the marketer believes are in the individual or society’s interest.”³⁹ The aim of social marketing for HIV/AIDS

prevention is to promote lifestyle changes, for instance to encourage intravenous drug users not to share needles and to promote condom education so that people practice safer sex. However, many of these behaviours occur in the private realm therefore difficult to measure or observe changes directly. Social marketers place great emphasis in providing accurate and effective information to their target audience, as information can create awareness and recommend alternative health practices. Previous AIDS information communication campaigns were not effective in the United States as most Americans were not HIV positive and did not know anyone who was. This led to the *not me syndrome* as people stopped paying attention to AIDS related information. Consequently a different approach was later established with the focus on “anybody who practices certain behaviours may be at risk, but everybody is not at risk” this message focused on the behaviour, rather than on the person or the society.⁴⁰

Social marketing strategies are very similar to merchandize marketing strategies. The *product* is often the idea, practice or service, (positive behavioural change) in the present context enquiring about HIV transmission, using condoms, dental dams, getting an HIV test and demonstrating empathy towards HIV individuals. The *price* is beyond monetary value, as the adoption of new product/service will enable the person to live a longer and healthier life, save money, embarrassment, and pain.

Place refers to the distribution channel used to make the product or service available to the target audience. Some examples in the current context are the community health centre, hospitals and clinics. Finally, the *promotion* is what makes the consumers aware of the product/services and encourages them to develop positive attitudes towards behavioural change. A social behaviour is an intangible product, which can be sold using

techniques that are similar to those applied to selling tangible products such as soap and shoes.⁴¹ For instance condom social marketing campaigns have dramatically increased sales of condoms in some regions. In Zaire, *Prudence* a condom designed and priced to be culturally sensitive and affordable increased significantly within one year of the prevention campaign; today the word *Prudence* has become a generic substitute for the word condom.⁴²

Market research is a crucial element, as the existing knowledge, attitudes and practices/behaviours (KAP/KAB) must be understood of the potential clients. Additionally, generating baseline data is equally important in allowing communicators to measure progress. It is also essential to maintain good relations and understand the target audience, "as the social marketer's task is to learn about and then use the contents of the choices set to design effective interventions."⁴³ Research enables marketers to accommodate needs and priorities of both infected as well as general population. Market research also enables social marketers to determine who is aware and unaware of safe sexual practices and whether people know about HIV/AIDS and what they know about HIV/AIDS. Once this information is gathered they are able to develop communication strategies accordingly, as one communication campaign will not be sufficient to lead people from awareness through to trial of new behaviour. Segmentation also helps to determine how many messages and what types of messages must be developed to reach the target audiences.⁴⁴ Different channels of media must be used at different stages of awareness. For instance television campaigns are appropriate for relaying basic informational messages as it is able to reach a large number of people at one time,

however, interpersonal communication is fundamental when providing counselling services and further information about care and prevention.

It is also critical to have good public relations and involve opinion leaders at all times. For example in the Philippines, a national program was developed in order to educate all opinion leaders and media personnel, the workshop showed the dangers of journalistic misinformation and how it can create people's fear and anxiety of HIV/AIDS.⁴⁵ The workshop illustrated why it is important to provide accurate information about HIV transmission. Another series of workshops were held to provide information for industry, education, health administration, advertisers and other groups whose jobs influence top down public opinion.⁴⁶ By having educated policy makers and opinion leaders, positive steps can be made in order to move forward.

Social marketers often develop several types of educational campaigns according to their target audience. Messages developed for the general public must be informative and directed to other resources in order to obtain further detailed information. However, messages focused on specific target audiences such as homosexual communities, intravenous drug users, and commercial sex workers, the information developed for these audiences are very specific to their behaviours and habits. The groups will immediately understand the language used and the message communicated is usually very direct and effective. The aim of social marketing like behavioural change communication is to make people aware of positive behavioural change, motivate them to change, try new behaviour and eventually sustain their new behaviour. Consider the social issues of convincing people to stop smoking; people already know that smoking is harmful for one's health yet they continue, as they do not know how to quit. Those who have tried only fail; however,

social marketers' goal is to target potential smokers with messages that indicate where one might go for help in quitting.⁴⁷ Communication strategies that give the information people need are more effective. One assumption made in condom social marketing is that people do not use a condom because they do not know about them. However, studies suggest that in many cases people do know about condoms and are willing to use them but in many cases they don't know the correct procedures and as a result the use become ineffective.⁴⁸ Therefore the goal of social marketing is to promote lifestyle change and assist its audience to make these changes by providing them with healthier alternatives.

One of the major focuses in Sub-Saharan Africa has been supporting programs that encourage safer sexual behaviour and promote condom use. This has been seen as a good investment in public health, as prevention eventually could reduce the number of cases needing treatment. Although the number of people whom a prevention program directly serves is small, the number of infections prevented can be large, since the risk of infection is reduced for each client's sexual partner, this partner in turn will, and so on. Therefore with lower infection rates, the risks of infection decrease for everyone who is sexually active.

4.10 Harm Reduction

Harm reduction is another preventive method that is increasingly being used. It arose in response to the growing AIDS crisis. Many countries have recognised the need for more practical and adaptive strategies to reduce the risk of HIV transmission among intravenous drug users and to their partners through sexual intercourse. Harm reduction programs began operating in Europe as early as 1984. In Canada these strategies are only

just being incorporated in a few provinces. Few states in the US and in some developing countries have also introduced this program recently. In the United Kingdom and the Netherlands, needle exchange programs and medical prescription of addictive substances has been an effective way to combating further HIV transmission.⁴⁹ Services such as the Methadone bus (in the Netherlands) SITE van in Ottawa has been established in order provide door-to-door services for needle exchange, (clean needles in exchange for dirty needles).⁵⁰ SITE does not encourage drug use, rather its goal is to help those who are already using illicit and licit drugs access to clean needles. The program's goal is to keep the community safe by collecting the needles instead of leaving the dirty needles in public parks where it might harm the public. The program also provides testing for HIV, hepatitis B, C and tuberculosis, referrals to health centres and counselling on site.

Prior to the introduction of needle exchange programs bleach was distributed as part of the harm reduction approach. Users were taught to clean their drug injection equipment (hardware) to kill HIV and other harmful diseases. Bleach distribution programs were chosen instead of needle exchange, since bleach was legal and widely available, additionally politicians and authoritarian figures believed providing needle exchange only encouraged people to continue to engage in licit and illicit drugs. Although bleaching presented a solution to eliminating HIV, this process, however, can be very dangerous and can cause further health risks if the bleach is not flushed from the syringe. Ultimately the program has limited results, as it requires several conditions such as knowledge, time (as it takes at least three minutes to undergo the cleaning process), transporting the bleach and uncontaminated water for cleaning the syringe process.

Harm reduction strategies have been designed to minimize the harmful consequences of drug use and associated high-risk behaviours; this movement is quickly becoming a public health alternative, as the program focuses entirely on client needs.⁵¹ Harm reduction programs include four areas of services 1) treatment, 2) care, 3) control, and 4) education. This strategy offers a variety of different ways of assisting people to help themselves by reducing the harm and suffering associated with licit and illicit drug use. Harm reduction encourages the individuals to set their own goals, including goals of abstinence or moderation, instead of being forced to accept goals set by treatment providers.⁵² The goal is to meet the users where they are at and to help them reduce any harm associated with their drug use, unlike the traditional substance abuse programs based on power relationship in which the professional care giver holds all the power over the patient and the focus remains on the program and not the client. However, in order for this strategy to be a success, firstly we must accept that licit and illicit drug use is part of some people's lifestyle and allow the users to voice their opinions in the creation of programs and policies designed to serve them.

However, for the majority of the population harm reduction strategies question many of our beliefs as it advocates of taboo concepts such as needle exchange programs, rations of alcohol and drugs, medical marijuana-potentially changing our zero tolerance laws. The director of the North American Syringe Exchange Network stated "harm reduction is more an attitude than a fixed set of rules or regulations, the attitude is a humanitarian stance that accepts the inherent dignity of life and facilitates the ability to see oneself in the eyes of others instead of judging or condemning them."⁵³

4.11 Barriers to effective BCC programming

When developing BCC programming for Voluntary Counselling and Testing services, Information, Education and Communication strategies, Harm reduction or condom social marketing it is essential to consider fundamental social and other contextual factors such as gender roles, individual expectations within a given cultural setting, sexual practices, issues of economic inequalities, dependence, violence, and empowerment.

Unequal gender relations can be seen in many ways in every structure of society. Gender bias against women, however, is especially pervasive in the poorest developing countries such as those in the Sub-Saharan Africa. Gender is socially constructed and shapes the opportunities one is offered in life, the roles one might play, and the kinds of relations one might have. All these factors strongly influence the social norms in the spread of HIV.⁵⁴ Society also determines how and what men and women are expected to know about sexual behaviour. Women are often poorly informed about reproduction and sex. Women in most traditional African societies do not have the power to break free from traditional roles. Women learn from a young age through socialisation that their first loyalty must be to their kin and families; this causes them to act in ways that reinforce rather than challenge female subordination.⁵⁵ Gender related laws and policies that prevent women from owning land; property and other resources support discrimination. Essentially, this promotes women's economic vulnerability to HIV, as they are dependent on men.⁵⁶

Currently, women and adolescents have inadequate access to health care and information regarding prevention, which places them at direct risk of infection. A culture of silence surrounds reproductive health in Sub-Saharan Africa where the infection is

affecting the population at an alarming rate and women are faced with significant barriers to obtaining both family planning and reproductive health information and services.

These barriers have a variety of sources, including the breakdown of traditional information system and negative or ambiguous governmental policies. In many cases, women are simply denied reproductive health rights and sexual education because social doctrines believe that knowledge encourages promiscuity, women are therefore ill equipped to make use of condoms even where/when they are available.⁵⁷ Women are afraid to seek sexual health information, as they are afraid to be labelled by the other members of the community. As a result, women and young girls are poorly informed and lack of information limits women's ability to protect themselves. Due to the lack of information, women tend to accept the symptoms related to STDs as an inevitable part of their womanhood, or sometimes act of God and therefore do not seek treatment or help.

Gender stereotypes (machismo and marianismo) also allow women to be blamed for spreading HIV/AIDS, as men often report to be infected by sex workers or casual girlfriends, while less blame tends to fall on men than women who have multiple partners.⁵⁸ In addition dominant ideologies of masculinity which emphasizes male sexual pleasure, value the display of sexual ability and encourage men to have multiple sexual partners whether they are married or not, as this is culturally accepted. Some of these views are entrenched by initiation ceremonies and the whole process of socialisation, for instance female genital mutilations.⁵⁹ Sex for many men has become a matter of recreation at the expense of moral duty and responsibility. In the context of HIV/AIDS, such cultural views and gender disparities continue to present serious hazards. Researchers and

specialists within the field of development argue that until women have a status equal to men, HIV transmission will continue at the same rate.

Cultural norms such as the ones mentioned above make it difficult for African women to reduce their risk of HIV infection, as they are confined to appropriate behaviour and regulated gender roles. These culturally defined gender roles must be taken into consideration when developing BCC programming. For instance making men responsible, as majority of the campaigns have focused on women and women's need; therefore, men, whether they are heterosexual or homosexual must be made to understand how their behaviours contribute to the spread of HIV. Men are important since they control most of the power and therefore their changes in attitudes and behaviour can bring about the required difference. Since they have the power in decision-making, economic, political, social and other spheres, the lives of the society are firmly in their hands. Therefore HIV prevention programs focusing at men should be implemented at a local level across the continent.

Men have a lot to learn in order to become responsible partners and citizens, in fact research also shows that many men in rural areas of Sub-Saharan Africa have not heard of AIDS and therefore do not practice safe sex.⁶⁰ However, there are some people who know that unprotected sex is risky yet continue to engage in risky behaviour, as they believe that it will not happen to them. Therefore, it is important to personalise the disease, emphasising on the self so that the message will be received positively.

4.12 Success and failure of social marketing for BCC

In absence of vaccines and curable drugs, the only viable mode of controlling or reducing the transmission of HIV is behaviour change. Marketing of this information with a view to influencing people's knowledge, attitude, behaviour and practice is therefore key to the success of HIV/AIDS control program.

A number of preventative campaigns have been successful across the world; one that has set the standards is Switzerland's STOP AIDS program, which has been the longest running social marketing program for AIDS prevention in the world.⁶¹ Their prevention campaigns focused not only on condom use and distribution but changing attitudes towards the pandemic, anti-discrimination and needle exchange programs. Condom promotion and needle exchange programs were promoted on local radio and television; additionally community groups were organised and new distribution points were open throughout the country for condoms and for counselling and testing. Condoms were made the central focus, promoting their use as the most reliable and effective method of preventing the spread of HIV. The campaign focused on convincing people that AIDS should not be feared and the price of risky behaviour was too high, with positive support from every governmental level they were able to increase condom use, encourage people to voluntary test as well as talk about AIDS in public. Therefore by 1990, the condom use among 17-30 year olds had increased from 8% in 1987 to 50%.⁶² Early interventions have had a tremendous impact; the campaign was based on the learning method, a concept that assumes that individuals are capable of both changing their behaviour and taking responsibility for protecting themselves.⁶³

Another campaign that has been very successful in condom promotion and able to maintain the AIDS prevalence rate is that of Thailand's 100 Percent Condom Program. Implementation of the Thai Prevention Program expanded from the public health sector to social and economic sectors as well, since this pandemic was one that entailed socio-economic factors as well as health factors. As a result Thai government began sponsoring health clinics in promotion of condom use and launched the "100% Condom Use Program" by supplying 60 million free condoms to clinics.⁶⁴ The goal of the program was to make condom use universal among commercial sex workers. However, if a client refused to use a condom, the commercial sex workers were supposed to refuse sex and to return the money. The Thai government played an important role in promoting safe sex interventions, as they embarked on large-scale mass media AIDS awareness campaigns and they closed brothels that did not abide by the program.⁶⁵ The mass media campaign and free condom distribution has helped to slow the AIDS pandemic as studies show that behavioural change was possible as condom use from 1989 to 1994 in commercial sex establishments increased from about 25% of all sex acts to more than 90%. Additionally, STD rates among commercial sex workers decreased by more than 85%.⁶⁶

Similar programs have been implemented in Cambodia since 1994, where "Number One" brand condoms are marketed nation-wide. The program has focused on social marketing strategy to disseminate messages using mass media, including television, radio, newspapers, point-of-sale materials, and special events such as comedy shows and music concerts. A number of communication strategies including puppet shows and participation in televised programs, a radio soap-opera, HIV/AIDS and family planning discussions on the popular "Super Game" and "SMART" television shows, a radio call-in show, and

collaboration with CARE on HIV/AIDS prevention activities in garment factories.⁶⁷ There has been a steady decline in the infection rate, current infection rate among adults 15-49 years old is 2.8%, the drop has occurred in all age groups, especially among adolescents.⁶⁸ To date the campaign has had a profound influence, as condom use has increased dramatically while decreasing the level of HIV prevalence rate to 2.7% at the national level.⁶⁹ The prevalence rate among high-risk groups have also decreased substantially; additionally Population Service International/ Cambodia with the government have continued to implement new prevention programs, together with the military effective HIV/AIDS prevention initiative have been implemented to target the army, police and security forces.⁷⁰

On the contrary in a number of countries in Africa many governments are still grappling with the issue of HIV/AIDS. Many countries are simply ashamed to accept that HIV even exists in their country. Despite the existence of polygamy and other forms of multiple sexual partnerships prescribed in their traditional cultural practices many countries want to portray their countries as pure and in the process deny the existence and spread of HIV. Even when the problems were diagnosed these were assigned to as imported from other countries! With the exception of Uganda this feeling was the norm in almost all African countries. If one does not accept the existence of a problem no solution can be introduced. Hence the BCC programs in Africa continue to face numerous difficulties.

Only Uganda has seen remarkable success due to early interventions. According to the Ministry of Health data, prevalence rate among pregnant women has declined consistently since the early 1990s at all of the country's sentinel sites.⁷¹ Uganda's falling

prevalence rate is mainly due to a number of behavioural changes that have been identified in several qualitative studies. These include changes in sexual practices, reduction in casual and commercial sex, reduction in number of sex partners, and increase in condom use. The head of state, president Yoweri Museveni, recognised the problems that were arising due to HIV/AIDS and consequently made a proactive commitment to prevention programs. He emphasised that fighting AIDS was a patriotic duty, he advocated for openness and communication among his citizens.⁷² “His charismatic directness in addressing the threat placed HIV/AIDS on the development agenda, and encouraged constant and candid national media converge of all aspects of the pandemic.”⁷³

By 1986, Uganda established a National AIDS Control Program (ACP) and an aggressive behavioural change communication campaign was launched with print and radio information, education, and communication materials that focused on community based face to face and culturally appropriate materials. In addition, thousands of community based AIDS counsellors, health educators, and peer educators have been trained since 1994.⁷⁴ Uganda also addressed the problem with political and democratic means. The programs were decentralised giving adequate powers to local government and the communities. In addition, the leading political parties also attempted to empower women and youth by giving them more political voice, including in Parliament where by law, women must make up a minimum of one-third of the parliament members. Similarly the parliament also has youth representation which is an important component of society.⁷⁵

Programs were also developed to overcome stigma and discrimination against those living with HIV/AIDS. The AIDS Support Organisation (TASO) was formed to provide support to people living with AIDS. TASO with other community based organisations,

and non-governmental organisations played a central role in contributing to prevention efforts, providing care, counselling and education in addition to supporting people living with AIDS. There has been support from every sector, including faith-based organisations that have also played a critical role in the response to the pandemic. More people became also interested in knowing their status, which resulted in expansion of VCT. Finally, condom sales too increased significantly. Studies show that Ugandans are reporting fewer partners.

The success in Uganda is largely due to immediate interventions, which have been implemented across the country. The high-level political support, decentralised planning and multi-sectorial responses have helped to decrease the national prevalence rate.

Senegal has also shown progress. The Ministry of Health has created safe blood banks for transfusion, promoted blood testing for syphilis and hepatitis since 1987 and appropriate support and resources for HIV testing.⁷⁶ Commercial sex workers are expected to register and required to undergo quarterly health check ups and receive treatment for STDs. This process has enabled to directly educate commercial sex workers on practicing safe sex. Additionally, the National AIDS Control Program with assistance of international development agencies have focused on distributing free condoms to commercial sex workers, patients with STDs, and adolescents.⁷⁷ Information, education, and communication programs have been developed and targeted at specific groups such as truck drivers, vendors, migrant workers as well as women, children, school children, and men. All these interventions were made possible with active involvement of the community, political, and religious leaders from the beginning of the program. The government also established effective collaboration with both Muslim and Christian

religious organisation since 1989 to discuss AIDS prevention strategies. All groups have been actively involved in making decisions and providing support, additionally, antiretroviral drugs have been made available to pregnant women at certain clinics in Dakar.

Other communities within Africa have also had some success in behavioural change, although their successes have not been at a national level. Communities have implemented effective information, education and communication strategies, advocacy at the community level, and condom social marketing have made it very easy for people to accept change and be more aware of HIV transmission and its consequence. In Zimbabwe, more and more adolescents are voluntarily getting tested since the implementation of *New Start* centres, which provide counselling and testing services.⁷⁸ The centres have been equipped with recent technologies, which allow clients to know their status within an hour. Previous testing technology required clients to wait for a week in order to receive their result, consequently many never returned. With new technology and access to immediate and better services people are willing to get tested. *New Start* counsellors are trained with pre and post-test counselling sessions that include referrals. The centres have been established in high traffic areas or at institutions that already provide health-related services, in order to reduce the uneasiness many VCT clients feel due to the stigma of HIV. The main reason for the success of VCT is due to the effective communication campaigns, which target to certain groups. Messages have been developed to reach certain groups via television, radio and print. Additionally interpersonal communications is also utilized to communicate messages about VCT services and the benefits of knowing one's HIV status.⁷⁹

4.13 Holistic approach

Communications play a central role in changing the opinion as well as behaviour of individuals. Communications campaigns when combined with the appropriate development skills and the provision of an enabling environment will have a holistic impact in changing people's perception of practically anything, ranging from simple marketing of soap to changing individual personal behaviour such as the sexual practices of individuals. Such profound social transformation requires three main strategies. These strategies are political and social leadership commitment by all stakeholders; building partnership and alliances with civil society organisations and private sector and finally developing appropriate communication materials to suit the level of the target audience. If communities can be reached with these three key components, they can be influenced on how people think and what people do in a particular circumstance, including changing their behaviour pattern as has been noted in South East Asian countries.

We know and believe that every community has their own culture and traditional beliefs. We also know and have witnessed changes in traditional cultures under the influence of external factors. The key again is how we target and who we target. In the case of HIV/AIDS if we target the young, we have much higher chances of achieving our aim of behaviour change. Once the young people form their views and set their ideas as they grow into adulthood it will be difficult to change their viewpoints. It is therefore imperative that we target young people with proper information before they set their ideas and concept on HIV. Consequently, once they form their views based on anecdotes and baseless stories it may be too late.

Notes

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Discussion and conclusion

Despite the advancement in clinical research leading to discoveries in new vaccines and drugs to fight infections and degenerative diseases people have been left helpless when it comes to HIV/AIDS, at least for the moment. While the scientific community now know more about the virus than they have ever done much remains unknown. It is in the unknown area that we believe there is scope for the creation of a vaccine to prevent HIV or at least its spread. Until then only individual behaviour can prevent HIV from spreading. The most basic fact about HIV is that it can be fully prevented and to do so people do not need to take medication or be vaccinated. It simply requires people to practise certain behavioural principles.

The origins of the virus itself are not fully understood. The fact of the matter is that AIDS is now widespread and something has to be done fast. The first action has to be the prevention of the spread of this virus. Studies show that in 2001, three million people died of AIDS, while five million people were newly infected, with a total of 40 million adults and children now living with AIDS who are expected to die in coming years.¹

We have adequate knowledge to understand the mode of transmissions and methods to prevent it. In order to holistically address the issue of HIV/AIDS programming should focus on the following areas:

- Behaviour change communication, educating the unaffected population
- Overcome issues of stigma and discrimination
- Voluntary counselling and testing of people of all risk levels
- Prevention of mother to child transmission
- Assistance to persons living with AIDS
- Assistance to the orphans of AIDS

No other disease has caught the imagination of so many people in such a short time. This can be attributed probably to the fact that it affects a very personal aspect of human being - reproduction. Even though HIV can be transmitted through other routes such as sharing of contaminated needles, use of infected blood and blood products, the most common mode of transmission is through conventional sexual relations with multiple partners. The other important aspect of this pandemic is that it affects the economically most productive age group, as this group is also the most sexually active.

A comparison of HIV prevalence between the various parts of the world clearly indicates the gravity of this problem in Africa, and followed by India and China where the absolute number of HIV positive cases is expected to rise in coming decade, not because of high percentage of HIV positive population but because of the sheer magnitude of the actual populations.

The table below is based on the HIV/AIDS data published by UNAIDS in 2002 according to which sub Saharan Africa carries the burden of 8,895 cases of HIV positive adult individuals for every 100,000 adult population followed by the Caribbean.²

Table 1: Cases of HIV per 100,000 adult population by Region*

Region	Estimated cases of HIV positive in adult population (15-49 yrs.)	Adult population (15-49 years)	Adult HIV positive cases per 100,000 adults
Sub Saharan Africa	26,000,000	292,310,000	8,895
Caribbean Islands	400,000	17,183,000	2,328
North America	940,000	161,413,000	582
South & Central America	1,400,000	262,151,000	534
South & South East Asia	5,400,000	1,031,463,000	523
Eastern Europe & Central Asia	1,000,000	209,038,000	478
Western Europe	540,000	200,286,000	270
North Africa & Middle East	460,000	180,506,000	255
Australia & New Zealand	14,000	11,845,000	118
East Asia & Pacific	970,000	833,058,000	116
Global	37,100,000	3,198,252,000	1,160

* Based on Report on global HIV/AIDS epidemic, pp 189. UNAIDS, Geneva 2002

This scenario can, however, change. Only a decade ago many political leaders and communities were denying the existence of HIV/AIDS in many countries. Today the many heads of state are the patrons of national HIV/AIDS control programs. Furthermore, a number of civil society organisations have shown keen interest in developing partnerships with governments and international institutions to fight HIV/AIDS. Global alliances have been forged between countries, research institutions, financial institutions, developmental organisations such as UNAIDS and private philanthropic institutions such as the Bill and Melinda Gates foundation. These alliances demonstrate the existence of political will, technical knowledge and resources. Only time will tell if these partnerships against HIV/AIDS are effective.

Overcoming social barriers

National AIDS programmes must strive to overcome social barriers and remove barriers that have impeded HIV prevention efforts. Tackling the epidemic requires more than money and treatment, it requires knowledge and the desire for

change. HIV-related stigma is often layered upon pre-existing stigma concerning socially marginalised and vulnerable groups. Stigma builds upon and reinforces earlier fear and prejudices. Consequently people with HIV/AIDS have become the object of enormous social stigma and as a result many do not seek help, therefore the virus continues to spread from community to community.

Discriminatory actions include: denial of employment, denial of the right to marry, violence and death, segregation in schools and hospitals are a few to mention. Issues such as these must be dealt with immediately; if ignored, prevention efforts will have no meaning. Adequate information must be made available to eradicate misconceptions; once this has been accomplished people are likely to use services such as voluntary counselling and testing. Prevention programs should persuade people within communities to work together to encourage adoption of positive behavioural practices. Only by having a supportive community it is possible to facilitate change in behavioural practices. This will also encourage people to talk about issues of HIV openly as well as disclose their status.

Pitrow et al illustrate this point further with an example seen in Korea³. Two Korean women are both illiterate, married with two children, and are twenty-nine years old. Both husbands are literate, with farms of five acres, therefore we might assume that both women would be about equally likely, or unlikely, to adopt a contraceptive method. However, the main difference is that they live in different villages, where the adoption rates of family planning methods differ (village A 57% while village B 26%). Although the innovation had been promoted equally in both villages by the national family planning program in Korea, it is likely that the woman living in village A with 57% adoption rate is likely to adopt a contraceptive method as her community is likely to encourage her.

This case study determines how social structure can affect the diffusion and adoption of innovations. Additionally, the different norms of each village can help explain why adoption of contraception varies. Norms are the established behaviour patterns for the members of a social system and they define desirable behaviour, as a result making the use of contraceptives the norm is hugely beneficial to communities worldwide.

Assistance to persons living with AIDS

Persons living with HIV/AIDS (PLWHA) were obscure entities until recently. Increasingly PLWHAs have been recognised as an important resource in the fight against AIDS although stigma against AIDS patients is still a reality in many countries. There are two issues that PLWHAs must be supported on. First is to honour their *human rights*, which includes treatment, care and support. This will involve participation of families, communities and the institutions with support of the government. Secondly the PLWHAs must be educated and protected so that they do not cause further harm to themselves or to their families and communities. This requires proper education and counselling for PLWHAs and their families so that the stigma attached to AIDS is minimised. PLWHAs also require resources for opportunistic infections and proper nutritional support so that they remain healthy. Resources required for this component of HIV/AIDS programmes are not always fully addressed.

Assistance to women and children

Women have a slightly higher rate of infection than men and women also facilitate both antenatal and postnatal transmission of the virus to their children.

About 15% of women who are HIV positive are known to infect their children at some stage during pregnancy or breastfeeding. This transmission cycle increases the number of children living with the virus and the number of children who become orphans as they eventually lose their HIV positive mothers. The cost of treatment, care and support requires large amounts of resources, which become a drain on family resources.

Currently there are approximately 14 million orphans worldwide (who have lost one or both parent to AIDS) of which 11 million are in Africa.⁴ However, studies estimate that there will be 40 million orphans by 2020 if the problems surrounding HIV/AIDS are not resolved.⁵ This becomes a social issue in many countries as orphans end up becoming exploited in different ways including becoming street children. The orphans also face educational and economic uncertainty, along with a higher risk of malnutrition, illness, abuse and sexual exploitation.⁶

It is therefore extremely important that mother to child transmission of HIV be stopped or at least minimised to avoid the suffering of children. This can be done by the implementation of effective screening programmes of all women who consider themselves to be at risk. Action must be taken at three levels. First, those who are HIV positive and are not pregnant must be discouraged from becoming pregnant. Secondly, those who are HIV positive and are pregnant must be counselled properly on the various possibilities including supplementary feeding as an option to stop the vertical transmission of HIV through breastfeeding. The mothers must also be put on *Niverapin* therapy just before delivery.

Cost effectiveness of HIV prevention versus treatment

Treatment interventions may alleviate short-term problems but prevention interventions have long lasting impacts. Studies show that the cost effectiveness of HIV prevention in Sub-Saharan Africa indicates that prevention is at least 28 times more cost effective than highly active antiretroviral therapy (HAART).

Education is imperative, for learning to know, to do, and to be. Through education knowledge is developed, values and beliefs are passed on from person to person and generation to generation. Education enables individual empowerment, which is prerequisite of HIV prevention. Consequently, preventative interventions are being focused on the very young, as they are more likely to learn and change than adults who may have already adopted certain ideas and values. Prevention efforts that focus on teaching negotiation skills and communication techniques that facilitate discussion about sexuality among peers, partners, and children have shown to transform people's lives. Additionally, overcoming issues surrounding stigma is critical, as well as providing psychological support for patients and families. Once people living with HIV/AIDS are accepted by society people are more likely to enrol in the ARV treatment programs.

Furthermore, messages that target a person's multiple identity are more effective. For instance prevention programmes in Mexico targeted at commercial sex workers for increased condom use showed that women were not motivated by the idea "I want to live" they were more concerned about providing the next meal for their family than the possibility of dying of AIDS five years later. However, their research showed that these women were very concerned about their children's welfare. Therefore messages were created around the importance of using condoms in order to protect their children and their future. These messages are believed to have

encouraged immediate behavioural change, as a noticeable number of women came forward enquiring about condoms and issues surrounding HIV/AIDS.

Overview of comprehensive HIV/AIDS care program

Source: Eric van Praag, FHI/IMPACT

These components not only compliment but also mutually reinforce each other. Prevention of STDs and HIV is very simple in theory. But maintaining and sustaining behaviour change is difficult. A holistic approach will have an effective long-term impact. Implementation of rights and policies that are non-discriminatory and provide care and support for infected individuals and affected families. As well as be responsive to the needs for other treatment and care options for certain opportunistic infections (OIs).

Education and communication is vital, as it is through communication that people initiate, develop, maintain and change their personal relationships. Continuous evaluations of communication strategies are essential, programs that focus on the needs of people are likely to be more successful and effective.

One of the greatest challenges is to maintain public interest in HIV/AIDS. Without public interest there can not be public support. Without this support it is unlikely that political leaders will take any significant action as they are accountable to their electorates. AIDS is no longer a new disease but it cannot be forgotten as it continues to take lives. It must be a priority for every community, nation and region. Ignoring it can only cause more harm. Awareness must be linked with adequate support to protect the affected. Priority must be give to those who can amplify and transmit key messages, such as governmental leaders, representative of the media, religious and community leaders. They must continue to speak out and influence the public's attitudes toward the situation and call for active involvement. Despite scientific advances in the fight against HIV/AIDS the greatest obstacle remains to be the mindset of the public. Given that we live in the information age the opportunity is there for policy makers to take decisive action to fight the pandemic. Ironically the mass media, the same institutions responsible for early hysteria and misinformation on the subject of HIV/AIDS, may be the best means of re-education in the fight against HIV/AIDS.

Notes

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