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**The Role of NGOs in Combating HIV/AIDS:**

Case study Juba town.

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*Dedication.*

*This research is dedicated to the millions of people worldwide who have died of HIV/AIDS and those who continue to suffer as a result of Ignorance and lack of access to information.*

*May God rest their Souls in Eternal Peace.*

## ACNOWLEDGEMENTS

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My gratitude also goes to my wife and children who provided me support during the preparation of the study.

May God bless all of them.

## **Abstract.**

The NGOs have been implementing HIV/AIDS programs in Juba for more than a decade with the overall objectives to increase awareness, provide support to victims and try to lower the levels of infection of HIV/AIDS so as to improve the quality of life of the AIDS victims and lead a productive life.

The overall major objective of this study is to investigate the role of NGOs in combating HIV/AIDS. To meet the objectives of this study both primary and data were collected and used. The primary data were obtained through the field survey by means of focused group discussion conducted with staff of the NGOs, youth, women groups, religious and community leaders and people living with AIDS.

The secondary data were obtained from the NGOs reports, official reports, books and other relevant sources.

The major findings of the study are that there has been noticeable effort exerted by the NGOs creating the high level of awareness, provision of support, encouragement of people to turn up for voluntary testing and partially change of attitudes. Despite these achievements, there are major constraints which continue to hinder the fight against HIV/AIDS.

The main conclusion of the study is that although some achievements have been scored, much effort needs to exert to overcome some obstacles facing the NGOs in achieving their goals.

The study strongly recommends the provision of free medical treatment with antiretroviral drugs, implementation of illiteracy campaigns, fight against bad cultural practices that impede the fight against HIV/AIDS, introduction of poverty alleviation programs, more funding by the Government and the International community for further research study in fighting the HIV/AIDS disease.



## **List of ACRYNOMS AND ABBREVIATIONS.**

ACORD	Agency for Co-operation Research and Development.
ADRA	Adventist Development Relief Agency.
ACP-EU	African Caribbean and Pacific-European
AIDS	Acquired Immune Deficiency Syndrome.
APRT	The Rio de Janeiro Prostitutes Association.
CAR	Central African Republic
CDC	Centre for Disease Control
CHEP	Copper belt Health Education.
CPA	Comprehensive Peace Agreement.
DRC	Democratic Republic of Congo
ECS	Episcopal Church of the Sudan.
EU	European Union.
FAO	Food and Agricultural Organisation.
FLAS	Family Life Association Swaziland.
FMOH	Federal Ministry of Health.
GPA	Global Programme on AIDS.
HAI	Help Age International
HIV	Human Immune Virus
ICRC	International Committee of the Red Cross
IDPS	Internal Displaced persons
IDU	Injecting drug users
INGOs	International non Governmental organizations.
KM	Khartoum Monitor.
MCT	Mother to Child transmission
MSF	Medicine San Frontiers
MSM	Men having sex with men.
NGOs	Non Governmental Organisations.
NSP	National Strategic Plan
OCHA	Organisation for Coordination of Humanitarian Agencies.
OECD	Organisation for Economic Co-operation and Development

SAFAIDS	Southern African HIV/AIDS information Dissemination Service
SCC	Sudan Council of Churches.
SMOH	State Ministry of Health.
SNAP	Sudan National AIDS programme
SRCS	Sudanese Red Crescent Society.
STIs	Sexual transmitted Infections.
STDs	Sexual transmitted diseases
TB	Tuberculosis
T.O.T	Trainer of trainers.
UN	United Nations.
UNDP	United Nations Development Program.
UNESCO	United Nations educational Scientific and Cultural Organisation.
UNHCR	United Nations High Commissioner for Refugees.
UNFPA	United Nations Fund for Population activities.
UNICEF	United Nations Children's Emergency Fund.
UNMIS	United Nations Mission in Sudan
RC/RC	Red Cross/Red Crescent
T.O.T	Trainer of Trainers.
US	United Nations
VCTC	Voluntary Counseling and Testing Centre.
WBCs	White Blood Cells
WFP	World Food Program
WHO	World Health Organisation.
YMCA	Young Men Christian Association.

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## **Chapter one**

### **Introduction.**

#### **1.1 Background information.**

According to the United Nations AIDS (UNAIDS) report (2002) on the global epidemic 42 million people are currently living with HIV/AIDS worldwide. Since the virus was discovered two decades ago, around 60 million people have been infected and each year 5 million newly infected cases fall victims to the disease. The death toll already stands at 30 million. It is estimated that the number of Africans currently living with the virus are about **30 million**. Approximately 3.5 million new infections occurred during 2002, while the epidemic claimed the lives of an estimated 2.4 million Africans in the past year.

In four Southern African countries the national adult HIV prevalence has risen higher than thought, possibly exceeding 30%: Botswana (38.8%), Lesotho (31%), Swaziland (33%) and Zimbabwe (33.7%). As for the Sudan a total of 600,000 people are reported to be living with the HIV/AIDS virus (Federal Ministry of Health press release January 2004). The national rate of prevalence of the disease in Sudan is 2.6% infection rate being the highest infected country in North Africa and the Middle East (UNFPA quoted in Khartoum Monitor Vol. 5 Issue No 425 October 2004) while for Juba the rate of prevalence is 3.3% (Accord Socio-Medico survey 2002) among the general population.

#### **1.2 Statement of the problem.**

This research is an attempt to investigate the role of NGO's in combating HIV/AIDS and how far the NGO's have alleviated the suffering of HIV/AIDS victims and their affected families. However, the research is also to attempt to shade light on the social and the economic impact of HIV/AIDS on the affected

individuals and their families as well as the cultural practices that impede the efforts of the NGOs to control HIV/AIDS.

### **1.3 Importance of the study**

This is a new area of study. Very little research/study has been conducted in this field in Sudan. The study therefore may assist policy and decision makers formulate appropriate policies and better decisions in combating the HIV/AIDS in the population and mitigate the suffering of people affected with HIV/AIDS and provide medical, psychological and material assistance to mitigate the suffering of HIV/AIDS individuals and their families.

### **1.4 Objectives of the study**

#### **Overall objectives**

The overall/major objective of this study is to investigate the role of NGOs in combating HIV/AIDS.

#### **Specific objectives.**

- a) To assess the performance of NGOs programmes combating HIV/AIDS in the study area ( Juba Town)
- b) To identify the constraints facing NGOs in implementing HIV/AIDS programmes.
- c) To identify the coping mechanisms of individuals and orphans affected by HIV/AIDS.
- d) To investigate the cultural practices that facilitates the spread of the HIV/AIDS.

## 1.5 Hypothesis

The NGOs have been implementing HIV/AIDS programme in Juba Town for more than a decade in order to create awareness, change the behaviour and sexual practices of the risk groups so as to mitigate the levels of infections and alleviate the suffering of the HIV/AIDS victims in order to improve their quality of life and lead productive lives.

**The hypotheses which the study tries to test are the assumptions that:**

- a) As a result of HIV/AIDS awareness programs there is some change in the sexual behavior of the people.
- b) The NGO's face no constraints in implementing the HIV/AIDS programmes.

## 1.6 Research Methodology and Sources of Data

The research methodology used in the study is both descriptive and analytical in nature.

### **Sources of data:**

The will be drawn mainly from two sources:

#### **(a) Primary data-**

Focused group discussions have been conducted with: NGOs staff/health health personnel), women groups, Youth and some religious leaders and people living with AIDS.

#### **(b) Secondary data:**

The primary data has been supplemented by Secondary data from the following sources: NGOs reports, Sudan National AIDS Programme reports, relevant books, magazine, Journals and News papers.

## 1.7 **Limitation and constraints of the study**

- Weak database on the subject matter as limited study and Research has been conducted in this field in the Sudan. However, sensitivity of the subject matter may not motivate the respondents to provide information freely to the researcher
- 

## 1.8 **Organization of the study**

This research is organized into five chapters as follows:

Chapter one, is an introductory chapter covering, background, statement of the problem, importance of the study , objective of the study, Hypotheses, research methodology and sources of data, limitations of the study and organisation of the research.

Chapter two is literature review. It provides detailed information about the the historical background of the HIV/AIDS, World situation of HIV/AIDS, impact of the epidemic, awareness and behaviour change, the conceptual framework ( the role of NGOs in HIV/AIDS Prevention in International in International experience).

Chapter three provides information about the study area. It includes population size, economy, health services, factors that encourage HIV/AIDS transmission and activities of NGOs in HIV/AIDS prevention in Juba.

Chapter four shows data analysis, findings and discussions

Chapter five provides conclusions and recommendations.

## **CHAPTER TWO**

### **Literature Review.**

#### **Section one: Review of HIV/AIDS and it's Global Impact**

##### **2.1.1 Historical background of HIV/AIDS.**

The HIV virus was first discovered in a blood sample taken from a man in Kinshasa, the Democratic Republic of Congo in 1959. It was not recognized until 1981 when the centre for Disease Control (CDC) in the United States published an article describing unusual clusters of opportunistic diseases among gay men in New York and California. (ACORD quoted in Khartoum Monitor vol 5 issues No 467). Initially, most U.S. AIDS cases were diagnosed in homosexual men, who contracted the virus primarily through sexual contact, or intravenous drug users who became infected by sharing contaminated hypodermic needles. In 1983, French and American researchers isolated the causative agent HIV and by 1985 serological tests to detect the virus were developed. Since the discovery of HIV, several strains of the virus have been identified. In 1985, a related virus was found in parts of West Africa and was called HIV-2 to distinguish it from the earlier virus (HIV-1). The pattern of illness is similar for both HIV-1 and HIV-2. (AIDS/99.31E and Hormazd N.C 2003).

##### **2.1.2 Sexual transmitted diseases HIV/AIDS.**

Sexually transmitted diseases are a large number of different diseases caused by microbial (micro organisms) agents such as bacteria, viruses, fungi and parasites that can be transmitted from one person to another during sexual intercourse. Some of these sexual transmitted diseases are known to mankind since the dawn of history and had had severe impact on human life and history;

such as Gonorrhea and Syphilis. Currently, more than thirty (30) diseases could be transmitted by sexual intercourse; the latest discovered and the most serious being HIV/AIDS. Some of these diseases can also be transmitted through ways other than sexual intercourse (through transfusion with infected blood, transplant of organs or tissues and from mother to child). This later Sub-group includes diseases such as HIV/AIDS, Hepatitis, and Syphilis etc. (Help Age International: 2004).

Sexual transmitted Diseases pose a major Public health problem in most parts of the world. Among the most common STDs are Gonorrhea, Syphilis and Chlamydia, which have far-reaching health, social and economic consequences. STDs stand behind a great deal of cases of inability of reproduction among married couples (infertility), babies born dead (still births), mental illness, malformed babies and even deaths of men, mothers and newborn children. STDs substantially increase the risk of HIV infection. Those infected with STDs have ten times greater chance of contracting HIV infection than those without STDs. Thus, preventing and controlling STDs are key strategies in controlling the spread of HIV/AIDS. (HAI: 2004)

AIDS stands for Acquired Immune Deficiency Syndrome; a fatal transmissible disease of the immune system caused by human immune deficiency virus (HIV). HIV reproduces in the white blood cells (WBC) and slowly attacks and destroys the immune system,( the body's defense against infection), leaving the individual vulnerable to a variety of other infections.

AIDS is the final stage of HIV infection. Most people infected with HIV are still healthy and can live for years with no symptoms or only minor illnesses. Without antiretroviral treatment a person might survive, on average, up to 9-11

years after acquiring HIV. With treatment, survival is substantially longer (UNAIDS/WHO 2002). According to 2001 WHO's estimates HIV/AIDS accounts for 6% of the global pattern of diseases (UNFPA 2003: 9)

### **2.1.3 Modes of Transmission of HIV**

To date there are only four primary routes of transmission:

1) Through unprotected (without the use of condoms) sexual intercourse (vaginal and anal) with an infected person, 2), through infected blood transfusion, blood products, tissues and organs transplants, In the developing world the risk is 5%. In Sudan the risk is 1% ( Help Age International: 2004: 3), the use of contaminated needles, syringes and other piercing instruments and 4), from an infected mother to her child before or during birth. This ranges from 12 to over 40%. There is evidence that breast feeding is also a route of HIV/infection,

### **2.1.4 Main factors Determining the risk HIV/AIDS infection.**

The risk of becoming infected through unprotected sexual intercourse depends on four main factors:

(a) The probability that the sex partner is infected, (b) the type of sexual act (unprotected sex) and the number of sexual partners one has, (c) the amount of virus present in the blood and or sexual secretions (semen, vaginal or Cervical secretions) of the infected partner and (d) the presence of other sexually transmitted diseases and /or genital lesions in either partner can enhance both the acquisition and transmission of HIV.

Other factors may also include age as young girls are physiologically more vulnerable, intercourse before sexual maturity, lack of circumcision for men and intercourse during menstruation increases the chances of infection. The most

common mode of transmission is through sexual intercourse, which is responsible for 86% of infection (UNAIDS: 1999)

#### **2.1.5 Preventing HIV/AIDS transmission.**

There are several precautionary measures that people have to take if they are to prevent themselves from being infected with HIV/AIDS. These includes non sharing of needles, toothbrushes, razor blades or any sharp instruments, those infected with STDs should seek treatment together with their partners.

#### **2.1.6 Pathology of infection.**

The pathology of infection involves three stages

#### **2.1.7 The Primary infection**

The Primary infection is the first stage during which transmitted HIV replicates rapidly. Some persons may experience acute flu-like symptoms, which usually persist for one to two weeks. A variety of symptoms may manifest themselves, including fever, enlarged lymph nodes, sore throat, muscle and joint pain, rash and malaise.( Hormazd 2003: 1)

#### **2.1.8 The a symptomatic phase of HIV-infection,**

The symptomatic period, lasts an average of 10 years. During this period the virus continues to replicate and patients begin to experience opportunistic infections. This is Acquired immunodeficiency syndrome (Mann 2003:4)

#### **2.1.9 AIDS.**

Full blown AIDS is the final stage of HIV infection. The most common opportunistic infections include Pneumocysts carinii, mycobacterium tuberculosis, herpes simplex infection, and bacterial pneumonia. Patients can also experience

dementia and develop certain cancers, including Kaposi's sarcoma and lymphomas and finally death (Serth N: 2003:4)

#### **2.1.10 Vaccines and treatment.**

Scientists are currently developing HIV/AIDS vaccines and trials are already under way in some countries but it is still a long way before an effective vaccine is developed. Vaccines could be the only way to control and eradicate the virus once developed. A Successful vaccine against HIV has not been developed up to now.

#### **2.1.11 Anti retroviral drugs**

Anti retroviral drugs have been found to be effective in reducing the amount of virus in an infected person. Evidence suggests that the drug increases survival by as much as 19 years and improves the quality of life of persons with AIDS. However, the high cost of the drug is a limiting a factor for most of the victims to access the medicines especially in low income countries.

The treatment may alleviate symptoms and return a patient to temporary health, **but even the most comprehensive treatment, including anti-viral drugs, cannot eradicate HIV and cure AIDS.**

#### **2.1.12 People at risk.**

The people at risk of infection with HIV/AIDS include prostitutes of either sex who do not use safer sexually practices( no condoms), people between the ages of 15-49 years who are sexually active and do not do not use condoms and injecting drug users.

#### **2.1.13 World Situation of HIV/AIDS**

The number of people living with HIV/AIDS worldwide is 42 million out of which 38.6 million are adults, 19.2 million are women and 3.2 million are children under 15 years. Newly infected with HIV worldwide in 2002 is 5 million in total. 4.2 million adult, 2 million women and 800,000 children under 15 years. The AIDS epidemic has claimed more than 3 million lives in 2002, (UNAIDS :2002).

**Table ( 2.1) Regional HIV/AIDS statistics and features end of 2002**

	Adults and children living with HIV/AIDS	Adults and children newly infected	Adult prevalence rate	% of HIV positive adults who are women	Main mode of transmission for adults living with HIV/AIDS
Sub-Saharan Africa	29.4 million	3.5 million	8.8%	58%	Hetero
North Africa and Middle East	550'000	83'000	0.3%	55%	Hetero, IDU
South and South East Asia	6.0 million	700'000	0.6%	36%	Hetero, IDU
East Asia and Pacific	1.2 million	270'000	0.1%	24%	IDU, Hetero, MSM
Latin America	1.5 million	150'000	0.6%	30%	MSM, IDU, Hetero
Caribbean	440'000	60'000	2.4%	50%	Hetero, MSM
Eastern Europe and central Asia	1.2 million	250'000	0.6%	27%	MSM, IDU
Western Europe	570'000	30'000	0.3%	25%	MSM, IDU
North America	980'000	45'000	0.6%	20%	MSM, IDU, Hetero
Australia and New Zealand	15'000	500	0.1%	7%	MSM
<b>TOTAL</b>	<b>42 million</b>	<b>5 million</b>	<b>1.2%</b>	<b>50%</b>	

Source UNAIDS/WHO 2002

### **2.1.14 The situation of HIV AIDS in Africa**

HIV/AIDS is by far the leading cause of death in Sub-Sahara Africa. Since the beginning of the epidemic over 15 million Africans have died from AIDS. During 2002 an estimated 2.4 million adults and children died as a result of HIV/AIDS. 71% of the world's HIV positive people live in Sub-Saharan Africa, although the region contains only 11% of the world's population (UNAIDS/WHO: 2002). There is a significant risk that some countries will be locked in vicious cycles as the number of people falling ill and subsequently dying from AIDS has a tremendous impact on many parts of African society, including demographic, household, health sector, educational, work places and economic aspect.

### **2.1.15 Situation of HIV/AIDS in Sudan and neighboring countries.**

Sudan is the largest country in Africa with an area of 2.5 million square kms. Sudan is boarded with nine African countries namely: Egypt, Ethiopia, Eritrea, Kenya, Uganda, the Democratic Republic of Congo, Chad, Central African Republic and Libya. Some of these countries form what is known as the AIDS belt in Africa and have high prevalence of HIV/AIDS-Kenya 6.7%, C.A.R 13.5%, Ethiopia 4.4%, Eritrea 2, 7% Uganda 4.1%, and DRC 4.2%. Chad 4.8% and Sudan varying between 2.3% (UNAIDS: 2004). Sudan and the nine neighboring countries account for a combined population of around 295 million people. The estimated total number of people who are living with the HIV/AIDS in the ten countries of this sub region is near 7.5 million while the estimated number of those who lost their mothers, fathers or both parents to AIDS and who were alive and under the age of 15 at the end of 2001 was around 4 million (Bol : quoted in frame work for Development of Post war South Sudan:2004:322 ).

The first case of HIV/AIDS was diagnosed in Soba the Sudan in 1986 followed by the second case in Sennar in 1987 (Khartoum monitor Vol 5, Issue 425, 2004).

According to studies conducted by SNAP in 2003, the prevalence among women attending antenatal clinics was 1%, among the refugees was 4% while the prevalence of the high risk groups tested varied 4.4% among prostitutes, 1.6 among T.B patients, and 2.5 % among tea sellers and was 25% among the suspected people living with HIV/AIDS (SNAP: 2003). According to UNFPA Sudan is currently the highest infected country in North Africa and the Middle East with a 2.6% prevalence rate (Khartoum Monitor Vol.5 Issue No 425 October 2004). The infection rate is higher among tea sellers, taxi drivers, sex workers, IDPS and refugees (SNAP: 2003)

**Table ( 2.2) HIV/AIDS Estimates in the Sudan Relative to Neighbouring Countries.**

<b>Country</b>	<b>Prevalence Rate 2004.</b>	<b>PLWHIV/AIDS</b>	<b>Number of Orphans</b>	<b>Number of Deaths 2003</b>
<b>Sudan</b>	2.3	400,000	NA	23,000
<b>Kenya</b>	6.7	1,200,000	650,000	150,000
<b>Ethiopia</b>	4.4	1,500,000	720,000	120,000
<b>Eriteria</b>	2.7	60,000	28,000	6,300
<b>Uganda</b>	4.1	530,000	940,000	78,000
<b>DRC</b>	4.2	1,100,000	770,000	100,000
<b>CAR</b>	13.5	260,000	110,000	23,000
<b>Chad</b>	4.8	200,000	96,000	18,000

Source JAM Report Feb 2005

**Table (2.3) HIV/AIDS Surveillance Sudan (1993-2003)**

Year	Number of Cases
1993	198
1994	201
1995	250
1996	221
1997	270
1998	511
1999	517
2000	625
2001	678
2002	630
2003	271
Total	4372

Source SNAP 2003

#### **2.1.16 SITUATION of HIV/AIDS IN JUBA and other towns in South Sudan.**

Studies conducted by SNAP in Juba among STD patients between 1994 and 1996-showed HIV prevalence rate of between 2-4%. Another study among ante-natal attendants in 1996 revealed prevalence rate of 5% reflecting the rate among sexually active female population. Another survey conducted December 1997 – January 1998 by SNAP/UNAIDS revealed a prevalence rate of 3.3% in the general population.

. Another study in same period conducted by UNDP in various locations in South Sudan reveal the following: Chukudum 3.8%, Meridi 8.6%, Malakal 1.0%,( HIV/AIDS Policy and Control strategies New Sudan 2001: 6 ). Yambio 7% and Yei 2.7% in 2003 (Khartoum Monitor Vol 5 Issue 557 2004)

### **2.1.17 Factors that encourage the spread of HIV/AIDS**

There are several factors that contribute to the spread of HIV/AIDS among which are poor governance, political instability, poverty, powerlessness and social instability, population movement due to conflicts, physical and sexual violence following the breakdown of law and order and the mixing of civilians with armed forces which increases the risk HIV transmission particularly in times of conflict e.g the case of South Sudan (UNAIDS/WHO: 2002)

UNAIDS estimates that HIV infection rates among armed forces personnel are on average higher than among their civilian counterparts. A study in Uganda in 1997 found that the national adult prevalence rate was 9.5% while prevalence among Ugandan soldiers was 27% (UNAIDS 2002)

### **2.1.18 The Impact of HIV/AIDS in Africa.**

#### **i The Impact on households**

The toll of HIV/AIDS on households can be very severe. Although no part of the world is unaffected by HIV, it is often the poorest that are the most vulnerable to HIV/AIDS and on whom the consequences are most severe. In many cases, the presence of AIDS means that the household will dissolve, as parents die and children are sent to relatives for care and upbringing. A study in Zambia, revealed that 65% of the households in which the mother had died and dissolved.

HIV/AIDS strips the family of assets and income-earners, further impoverishing the poor.

#### **ii The impact on the household income**

A study in three countries, Burkina Faso, Rwanda and Uganda, has calculated that AIDS will not only reverse efforts to reduce poverty, but will increase the percentage of people living in extreme poverty, from ( 45% in 2002 to 51%

) In Botswana household income for the poorest quarter of the household is

expected to fall by 13%. Income earners in these households are also expected to take on an average four more dependants because of HIV/AIDS.

### **iii The impact on basic necessities.**

A study in South Africa found that already poor households coping with an AIDS Sick member were reducing spending on necessities even further. The most likely expenses to be cut were reducing spending on necessities even further. The most likely expenses to be cut were clothing ( 21%), electricity(16%), and other services (9%). Falling incomes forced about 6% of the households to reduce the amount they spend on food and almost half of the households reported having insufficient food at times.

### **iv .The impact on food production**

It is estimated that in Burkina Faso, 20% of rural families have reduced their agricultural work or even abandoned their farms because of AIDS. In Ethiopia, AIDS Affected household were found to spend 11-16 hours per week performing agricultural work, compared with an average 33 hours for non AIDS affected households.

### **v. Illness**

Taking care of a person sick with AIDS is not only an emotional strain for household members, but also a major strain on household resources, loss of income, additional care, related expenses, the reduced ability of care givers to work ,and mounting medical expenses and funeral expenses together push affected households deeper into poverty. According to a study in Cote d'Ivoire health expenses rose by up to 400% when a family member had AIDS ( [www.avert.org](http://www.avert.org) the impact of HIV/AIDS on Africa 2003: 3)

## **Vi Funerals.**

The financial burden of death can also be considerable, with some families in South Africa spending three times the total household monthly income on a funeral.

## **Vii The impact on children**

Children whose parents are affected with HIV/AIDS are traumatized and face hardships. Not only does HIV/AIDS mean children lose their parents or guardians, but, sometimes it means they lose their childhood as well. As parents and family members become ill, children take on more responsibility to earn an income, produce food and care for family members. It is harder for these children to access adequate nutrition, basic health care, housing and clothing. Fewer families have the money to send their children to school. Often both of the parents are HIV/AIDS positive in Africa. This has resulted that AIDS more children have been orphaned by AIDS in Africa than anywhere else. Also many of the children will be part of a generation to be raised by their grand parents or left on their own in child-headed households.

**Table (2.4) HIV/AIDS Orphans statistics**

Region	Total number of orphans since the epidemic began
Sub-Saharan Africa	11 million
Global Total	14 million

Source [www.AVERT.ORG](http://www.AVERT.ORG)

## **viii The Impact on life expectancy.**

In many countries of sub-Saharan Africa, AIDS is erasing decades of progress in extending life expectancy. Life expectancy reflects the conditions in a community, but also life expectancy affects conditions in the community. A average life expectancy in Sub-Saharan Africa is now 47 years, when it would

have been 62 years without AIDS. Life expectancy at birth in Botswana has dropped to a level not seen in Botswana since before 1950. In less than ten years time, many countries in Southern Africa will see life expectancy fall to near 30 levels not seen since the end of the 19<sup>th</sup> century

**Table ( 2.5 ) Average life expectancy in 11 African Countries**

Country	Before AIDS	2010
Angola	41.3	35.0
Botswana	74.4	26.7
Lesotho	67.2	36.5
Malawi	69.4	36.9
Mozambique	42.5	27.1
Namibia	68.5	33.8
Rwanda	54.7	38.7
South Africa	68.5	36.5
Swaziland	74.6	33.0
Zambia	68.6	34.4
Zimbabwe	74.4	34.6

Source: UNAIDS Report on the global HIV/AIDS Epidemic 2002.

### **ix The economic impact of HIV/AIDS**

Through its impact on the labour force, households and enterprises, HIV/AIDS can act as a significant brake on economic growth and development. Besides the human cost, HIV/AIDS is having deep effects on Africa's economic development. The impact of HIV/AIDS on the economies of African countries is difficult to measure. The economies of many of the worst affected countries were already struggling with development challenges, debt and declining trade before

HIV/AIDS started to affect Africa. Together with other factors, HIV/AIDS has had a devastating effect on many countries economies. HIV/AIDS has an impact on labour supply, through increased mortality and morbidity. This is multiplied by the loss of skills in key sectors of the labour market. Long periods of AIDS related illness reduce labour productivity. Government income also declines, as tax revenue fall, and governments are pressured to increase their spending, to deal with the rising prevalence of AIDS, as result creating a potential financial crisis. One review reported that the annual cost associated with sickness and reduced productivity as a result of HIV/AIDS varied from US\$ 17 per employee in Kenyan manufacturers firm to US\$ 399 in the Uganda Railways Corporation.

#### **2.1.19 AIDS awareness and sexual behaviour change**

In South Africa, for pregnant women under 20, HIV prevalence rates fell to 15.4% in 2001(down from 21% in 1988 UNAIDS/WHO:2002:16). This along with the drop in Syphilis rates among pregnant women attending antenatal clinics down to 2.8% in 2001, from 11.2% four years earlier suggests that awareness campaigns and prevention programmes are bearing fruit.

A decline in HIV prevalence has also been detected among young inner –city women in Addis Ababa in Ethiopia. Infection levels among women aged 15-20 attending antenatal clinics dropped from 24.2% in 1995 to 15.1% in 2001. Uganda continues to present proof that the epidemic does yield to human intervention. Recent HIV infections appear to be on the decline in several parts of the country as shown by the steady drop in HIV prevalence among the 15 -19 years old pregnant women. Trends in behavioral indicators are in line with this apparent decline in HIV incidence. Condom use by single women aged 15- 24 almost doubled between 1995 and 2000/ 2001, and more women in that age group delayed sexual intercourse or abstained entirely.

Recent studies in Ethiopia (Teka: 1977) show increased knowledge about methods of AIDS in Prevention 62% to 80% .The study also revealed that student awareness of condoms for AIDS prevention increased from 69% to 84%. Increases in AIDS related knowledge were also observed in Zimbabwe and Nigeria among University students (Akande :1994) and in rural communities in Senegal and Kenya.

Increasingly safer sex behavior has been observed in countries which have had aggressive HIV/AIDS awareness campaign, for example, HIV/AIDS campaign led to increases in condom use in Zaire and Mexico, more careful partner selection, preference for monogamy and avoidance of high risk groups by students in Alberta, Canada and reduction in number of sexual partners in Senegal.

A study in Durban, Kwazulu –Natal, among black female prostitutes showed that 29% of the central city prostitutes and 14% of the Suburban prostitutes reported always using condoms with clients. In Soweto, it was found out that female adolescents increased their condom use from 38 to 53% between 1996 and 1997. In Senegal, where prostitution has been long legalized about three quarters of all Dakar's official sex workers reported always using condoms.

In Uganda studies carried out in the early 1990s showed that knowledge of AIDS was high because of the government's open policy towards HIV (kirumira: 1992) Knowledge about AIDS in Uganda has now become universal.

#### **2.1.20 Knowledge, attitude, behaviour and practice in Africa.**

The majority of community beliefs that males are by nature sexually polygamous. These beliefs arise out of the nature of the traditional society. Men's unlimited sexual freedom in and out of marriage in keeping with a situation in which a man can be the husband of several wives and this can result into the spread of

HIV/AIDS. Polygamy is on a large scale in Sub-Saharan Africa than elsewhere in the world.

In most of West Africa 40-50% of the currently married women are found in polygamous marriages, 30% in East Africa and 10% or less in Southern Africa. (Lesthaeghe, et al 1989 quoted in *towards the containment of the AIDS Epidemic* )

Earlier campaigns for AIDS awareness in Uganda have achieved improvements in sexual behaviour. A study in 1999 in Uganda observed favourable changes in sexual behaviour and marriage, and positive attitude towards HIV testing. These positive changes in behaviour are associated with significant declines in HIV prevalence currently observed in Uganda. Similar positive behavioral changes have been observed in Thailand. However, despite growing knowledge about AIDS and positive behavioral change, accurate information about HIV/AIDS is still lacking in Uganda. Asera et al 1997 give evidence of this, observing that many people feared contracting HIV through such activities as eating and shaking hands with those infected. They also suspected a wide range of common symptoms such as rashes, cough, fever and sore throat as indicator of HIV/infection.

Other studies have revealed that behavioral change leading to safer sex may be limited by socio-cultural and economic factors relating to gender, class and power relations. Kiseka (1992) in a study of Baganda and Hausa people, observed that women had little or no bargaining power in sexual matters because they were poor, ill educated and economically dependent on their sexual partners, though women derived rights from being married, they lacked property or inheritance rights and at the death of their spouses many widows were banished and disinherited of their possessions. These widows tend to marry again or engage in sex work for survival, which puts them at high risk of HIV infection. A recent study by Ntozi et al (1999)

in northern Uganda showed that widow inheritance has not stopped thus pointing to the cultural and economic vulnerability of women.

## **Section Two**

### **Conceptual Frame work.**

#### **The Role of NGOs in HIV/AIDS Prevention ( International experience).**

##### **2.2.1 Definition of NGOs**

The World Bank ( 2001) defines NGO's as "Private Organizations that persue activities to relieve suffering, promote the interests of the poor, protect the environment, provides basic social services and undertake community development"(http/wbloo 18-worldbank.org). The term NGO's is also used as denominator, for all organizations within the aid channel that are institutionally separated from state apparatus and are not primarily commercial or profit making , have their own procedures for self governance and serve public purpose (Terje 1998: 12-13). More than 19 million people work for NGO's worldwide and they spend at least US dollars 1.1 trillion a year (Sue : 2000:5)

##### **2.2.2 Types of NGOs**

Non Governmental organizations are classified into three catergories which are :

###### **International NGOs**

These are organizations which are based in the donor countries and work abroad mainly in the third world countries conducting emergency and development work. Sometimes they work with national or local NGOs as partners in the countries where they are operational. ( Terje, 1998:1.)

International NGOs are currently active in global humanitarian aid and development activities, collectively spending US \$ 9-10 billion annually supposedly reaching 250 million people living in abject poverty. Over the last two decades, aid has increasingly been channeled through international NGOs by bilateral and multilateral agencies fearful of government bureaucracies and inefficiencies.

### **National NGOs**

These are organizations created within a country and operate within its national boundaries only. For example in the Philippine there are 21'000 non profit national organization, Chile 27'000 (1994), Bangladesh 16'000 (1993) in Brazil 100'000 Christian communities based action groups (Terje, 1998:22), Ethiopian 100 (1984/85). According to the guide of the voluntary organizations in the Sudan issued by HAC there are more than 300 registered voluntary organizations in the Sudan. Most are active in the area of relief, health, education and agriculture (SRCS: 2003:16)

### **Local NGOs**

These are mainly grass root or community based organizations, which work at the local level with the local communities.

## **3.5 The Role of NGOs in HIV/AIDS Prevention**

NGOs work mainly in development and emergency aid. Their mandates vary from organization to organization.

NGOs have assumed a central role in activities involving human rights, complex humanitarian emergencies, the global environment, the international women's movement, and AIDS prevention. Based on a close

scrutiny of goals, and operational methods, it has been deduced that NGOs play two broad roles in society.

- 1) Operational roles and,
- 2) Educational and advocacy roles.

The role of NGOs in society cannot be ignored. This is true also in the field of prevention and treatment of HIV/AIDS. In areas of the industrialized world hardest- hit by AIDS, NGOs helped set trends that have now been institutionalized within AIDS prevention:

- Advocacy for persons living with HIV/AIDS, targeting educational materials to specific groups, improved access to experimental drug trials and health care and Peer education
- In the developing world, the NGO response to AIDS emerged somewhat more slowly, reflecting a lack of both resources and experience, and a widespread reluctance to recognize or acknowledge the threat. Publicly for fear of stigma. However, as the epidemic has progressed both well established and newly organized NGOs have been among the first to respond by advocating, the need for persons with AIDS and HIV to have access to counseling, support and health care. They have mobilized impressive efforts for training, education, and other supportive services.

The WHO's global programme on AIDS (GPA) has developed extensive links with a wide range of NGOs, and now supports their efforts to combat AIDS at global, national and local levels. A 1989 resolution from the world Health Assembly supported the importance of NGOs in the global strategy for the prevention and control of AIDS, acknowledging that their commitment,

knowledge and experience can make a special impact on individuals and society regarding AIDS and the needs of the HIV/AIDS victims.

There is a growing list of NGOs projects for AIDS prevention and cure that are providing critically needed services in many different settings.

Examples included:

**1 The AIDS organization (TASO) – Uganda** provides urgent needed medical, emotional and practical support for people with HIV/AIDS and their immediate families.

**2. Bombay Dost-India** reaches out to people with alternate sexuality in the city of Bombay e.g. the gay community and a lack of information about AIDS and other STDs.

**3. The Rio de Janeiro prostitutes Association (APRT) - Brazil:** Encourages people for regular medical check ups with Brazil's largest private family planning agency to provide condoms.

**4. Project Hope for family life Association (FLAS) Swaziland:** FLAS, a local NGO is collaborating with project Hope, an international NGO for AIDS awareness and preventing programme. FLAS staff develops training programmes and educational materials for non - literate adults, out –of school youth, staff of family planning clinics, and traditional healers, train 60 HIV-AIDS counselors in Swaziland, and organize nationwide networks of regional counseling support groups.

**5. EMPOWER- Thailand** offers support, assistance and access to education for women workers in Pat Pong, the entertainment district of Bangkok, Thailand. EMPOWER also provides referrals and health counseling on sexually transmitted diseases, nutrition, exercise, safe drug use and family planning.

**6. Copper belt Health Education project (CHEP) Zambia:** CHEP offers street children a five day survival skills course directly responding to immediate needs and long term concerns including job training, Small business management, staying within the law, avoiding drug and also alcohol abuse, and preventing STDs and AIDS. CHEP also runs training workshops for health, workers and community leaders.

**7. The NGO consortium Kenya:** NGOs formed a national consortium of organizations concerned with improving HIV-AIDS prevention and care ensuring regular dialogue between NGOs and the AIDS programme Secretariat, a government supported national AIDS committee. The sharing of information skills between NGOs leads to records for the role of NGOs played in the AIDS programme.

**8. The European union in collaboration with MSF-Belgium** and the government of Ethiopia has drawn up a policy, which aims to reduce the level of HIV transmission by 25% within five years. It includes improving the quality of public services and access to them, dealing with sexual transmissible diseases, de-stigmatizing persons living with HIV/AIDS, and promoting the use of condoms. Drama in the public health centres, and the Universities, prisons and among the female sex workers are part of the efforts to reduce the infection.

**9. The YMCAs** better life options programme in South Africa allows young people to educate others about the issues involved. They raise awareness through drama and music, out reach support, and work with young offenders and local advocacy initiatives. There are currently programmes in more than 30 schools in four regions, training dozens of peer educators every year. Each peer educator's

works with around 25 young people every week promoting drama and music performances, which focus on HIV/AIDS education. They can also raise awareness of youth issues and rights, gender and family related problems and HIV/AIDS information and advice.

**10. The Straight NGO** called the straight talk foundation in Uganda publishes the “straight talk” and “Young talk” magazines, which aim to give young people, and their adolescent’s clear information about their perils of unprotected sex. The two magazines have huge coverage in Uganda. 160, 000 copies of straight talk are distributed monthly while Young talk has approximately 200,000. The foundation estimates that over 90% of secondary children read straight Talk, which is distributed by schools, health centres and NGOs and is inserted into Uganda’s biggest daily News paper the daily New Vision.

Straight talk tries to educate adolescents about the changes; they are going through and the dangers of unsafe sex. It also aims to change traditional attitudes towards relationships. Young talk is aimed at 10-14 years old and promotes key messages such as assistance, children rights and the importance of staying in school.

The straight talk in Uganda has been adopted as a model by other countries like Zimbabwe, Kenya, Namibia and a handful of other countries.

In Senegal which is 95% Muslims during Friday prayers, the Imams talk about AIDS and solidarity with patients.

The religious associations, the Christian and Muslims NGOs have set up an alliance of religious figures and medical experts to fight the disease, and 2002-2006 action plans has been put into place.

**11. Mekdim a local NGO based in Addis Ababa** and supported by the Irish aid agency, Concern offers a wide range of services to its clients who are either HIV

positive themselves or are living with people who are infected with HIV. The organization provides:

- Pre-and Post- Test counseling to HIV/AIDS victims, supports Aids orphans, Out reach services for home based care for HIV-positive people who are housebound by the disease, pilot project providing milk, enhanced with extra protein and vitamins, to some of the patients who are suffering from additional illness-to which their weakened immune systems make them vulnerable, Financial support to those who need medication, Fund for rent support, School support for children in the care of HIV-positive persons and for essential items such as sheets and blankets. The organization has music and a theatre group consisting of Aids orphans, HIV-positive people and volunteers. They stage an impressive range of songs and drama about HIV/AIDS. As part of their educational performance, HIV-positive members of Mekdim often tell the story of their lives and their infection on stage. They believe that openness and awareness is vital to combating the disease (the Courier Sept-Oct 2003).

**In Haiti NGOs offer:**

- Screening tests and free health care for those infected, Promote counseling sessions for people who test positive and have set up a pilot project to prevent mother – infant transmission,. conduct seasonal campaigns on world AIDS Day, Easter and summer holidays. These are periods when there are large numbers of people out on the streets, and they are more active sexually, handout condoms together with advice and information leaflets, set up a nutrition workshop for HIV-positive women

- The aim is to enable them to fight the virus for a longer period through eating better food and through introducing them to a manual activity such as leatherwork or embroidery. That sort of thing keeps their spirit up and prevents them becoming depressed and allowing themselves just fade away.

**12. Environ-care in Tanzania** is currently involved setting up local committees to deal with human rights abuses, such as the abuse of young girls in the belief that having sex with a virgin will cure Aids commonly held belief in Tanzania. The door to door campaign for women at home, because they have no access to information.

This is despite the fact that their husbands might have a radio, buy newspapers and watch T.V in bars. Women are particularly vulnerable to HIV infection because of this lack of information and their general position in society.

#### **2.2.4 Constraints facing NGOs in combating HIV/AIDS**

The constraints facing NGOs in combating HIV/AIDS generally could be listed as follows:

##### **Poverty, illiteracy and Ignorance**

Poverty forces some young people into the sex industry. In Asia women who are abandoned by men, or whose husbands are unemployed, have to earn money themselves, when they fail to get work in the market they turn to prostitution. In the Philippine, the number of prostitutes is estimated at 600,000 and India has the largest number of child prostitutes in the world with a figure that varies between 400,000 and 575,000 some of whom no more than 10 years of age. In conditions of poverty, immediate well being or survival takes precedence over the benefit of the long protection. Poverty forces women to exchange sex for food, money, the opportunity to attend School.

## **Use of Condoms**

The lack of knowledge on the use of condoms by men makes them reluctant to use Condoms because of their cultural association with promiscuity and prostitution. Rejection by religious people on use of condoms saying that such recognition would imply approval of immoral and prescribed acts. Many people still refuse to use condoms even with prostitutes or multiple partners. The Orthodox Church maintains that in Philippines out of 2.5 million people in sexual relations, 80% use no Condoms. In Sub-Saharan Africa, UNAIDS estimates that there is only 50% use of condoms with casual partners on account of social, cultural and religious beliefs.

## **The culture of silence and denial.**

People with HIV/AIDS suffer isolation, stigma and trauma in Africa. Some countries still deny the existence of HIV/AIDS in their countries.

## **Inability to accept homosexuality and lesbians as non existent in Africa.**

Inability to accept homosexuality as non existent in Africa yet research reveals that the practice is widely spread in the continent and is one of the ways by which HIV/AIDS spread through homosexuals. These practices are usually concealed within society. The practice exists in Angola, South Africa, Uganda, and Zanzibar, Kenya.( Sapper quoted in the courier Sept-Oct : 2001)

## **The culture of widow Inheritance.**

The culture of widow inheritance is widely practiced in Africa and this is one way by which HIV is spread. Lack of information, ignorance, prejudice and misinformation is rife.

### **-Sexual transmitted diseases**

There is limited knowledge by parents about sexuality, contraception or sexually transmitted diseases and many beliefs that earlier marriage will protect their daughters from being infected with HIV/AIDS.

### **-No Media campaign.**

There is lack of recognition and support of the problem by the governments in many countries. There is also no media campaign.

### **-High cost of drugs.**

Lack of vaccines and provision of treatment to everyone with HIV due to high cost of retroviral drugs. Many millions are not receiving medicines to treat opportunistic diseases especially in low income countries.

### **Difficulties faced by AIDS orphans.**

There are serious difficulties that face HIV/AIDS orphans. These include emotional suffering due to illness and death of the parents, stigma and rejection, sexual exploitation and abuse. social isolation,. Malnutrition and lack of health care.

Orphans assume family responsibilities following death of parents. They become care takers and bread winners. They take the role of both the mother and the father looking after siblings and caring for ill or dying parents ([www.avert.org](http://www.avert.org) 2003 : 4 )

## **Chapter Three.**

### **The study area.**

#### **3.1 Introduction**

Chapter three provides the general information about Juba town, its population, economic activities ethnic composition, some cultural practices related to the people, health services in Juba and the activities of the NGOs interventions in the fight against HIV/AIDS.

#### **3.2 Profile of Juba town**

Juba is the largest town in South Sudan and is the capital of Bahr el Jebel state, which is one of the Equatoria states bordering Uganda, Democratic Republic of Congo, Kenya, and the Central African Republic, which are considered to be the Aids belts in Africa.

A large number of people from different states in Equatoria have fled to Juba as a result of the 21 civil war living in internal displaced (IDPS) people's camps and adding more burdens to the existing infrastructure.

The main routes of access to Juba are air transport, barges along the Nile from Kosti, road from Uganda through Yei South west of Juba, route from Lokichokio linking through Kapoeta and Torit to Juba. Following the signing of the CPA in Naivasha Kenya on the 9<sup>th</sup> of January 2005, there is freedom of movement. Landmines, however, threats to farmers and cattle keepers and those who go to fetch firewood. Occasionally people are blown up by landmines especially people who go to gather wood, straw, burning charcoal or tendering their animals and harvest work.

### **Population size.**

The main ethnic group in Juba is Bari who are the original inhabitants of the area, but as Juba has developed into a major town and also the seat of the previous governments of Southern Sudan and the state government it has attracted other tribes from within the state, other locations from South Sudan and the north of Sudan to settle in Juba. Most of these tribes have moved to Juba as employees of the government while others are involved in commercial activities.

According to the census conducted in 1995 by Humanitarian agencies the population of Juba was put at 145'200 people (Accord socio medic survey). Other estimates put the population of Juba at 259'000 (Source Annual Needs Assessment 2003 – 2004 WFP/Juba). Out of these 28'066 are considered to be IDPS (OCHA JUNE 2003) The IDPS are settled in camps according to areas of origin and tribes. Following the signing of the CPA the population movement has considerably increased making the town's population unpredictable.

### **Economy and employment**

The government is the main employer for the majority of population in Juba town but the humanitarian agencies also provide some limited employment. The majority of the people are also involved in informal small-scale trade. The coping mechanism for most of the people including some of the working class include sell of firewood, charcoal, grass, (straw) for thatching tukuls, sell of beer, tea, water and cultivation, working as house maids and in restaurants. As Juba was a town under siege, it has a war economy in which prices are distorted by the costs of transport and scarcity and thus great profits are being made in the sale of basic food commodities.

Poverty is widely spread within the population as manifested by high levels of illiteracy, malnutrition, poor sanitary and living conditions and limited access to education, training, employment and market opportunities. The vast majority of the

population depends on subsistence agriculture and a few on livestock which absorbs most of the labour force. Agricultural production which is the backbone of the local economy is, however, at a minimum due to a number of factors which include inaccessibility to fertile land, poor rainfall, drought, soil exhaustion as the same land is cultivated every year and pests. All the above factors provide a fertile ground for poverty and exacerbate the spread of HIV/AIDS.

### **3.3 Health facilities HIV/AIDS Services in Juba.**

The health services in Bahr El Jebel State are not adequate but rather very poor considering the destitute population of the area. There are three (3) hospitals in Juba, 10 health centres, 12 dispensaries and 23 primary health care units

A report by UNICEF published in June 2004 estimated that there was only one Doctor per 100,000 people in Southern Sudan (KM vol.5 issue Nr.550). The state ministry of health has a reference Laboratory that carries out HIV/AIDS blood tests for patients referred from the health facilities and also conducts tests for those who voluntarily would like to determine their HIV/AIDS status. The health facilities are ill resourced in terms of manpower, drugs and equipment including infrastructure. A voluntary testing and counseling centre (VCTC) was inaugurated in January 2004 which provides testing and counseling services for individuals, married couples and those intending to get married and volunteers who would like to determine their HIV status. All tests previously referred to Khartoum for confirmation are now done in Juba.

### **3.4 factors affecting HIV/AIDS transmission in South Sudan.**

Most people in Sudan know little about HIV/AIDS HIV/AIDS-mode of transmission and prevention. This is compounded by poverty and cultural practices such as polygamy, wife inheritance and scarification. The population is also because, of cultural inhibitions, less than 1% use condoms. In addition they are vulnerable because of the prevalence of

sexually transmitted infections since these are commonly associated with HIV/AIDS. People with STIs will have difficulty in obtaining effective treatment since health facilities lack appropriate drugs and trained health providers. South Sudan does not have a standard system for surveillance .

The huge presence of soldiers in towns like Juba have created a destructive environment to family life. Teenage pregnancies are common resulting very high number of School drop outs rate among girls in schools. Communities close to the border are also exposed to the free movements of people from neighbouring countries that have high HIV/AIDS prevalence's such as Kenya, Uganda, and Democratic Republic of Congo. Following the signing of the peace agreement many refugees will also return from these countries.

### **3.5 Activities of NGOs in HIV/AIDS Prevention in Juba**

There are about twenty-five NGOs and agencies in Juba. They comprise of UN agencies, International non-governmental organizations, National and local organizations. These agencies are involved in the implementation of various activities in all the accessible areas in Bahr el Jebel. The activities range from capacity building, food security, livelihood, water, and environmental sanitation, health, emergency preparedness, and response, relief and rehabilitation, education, information, and advocacy, HIV/AIDS, mine risk education.

The agencies and NGOs mainly involved in HIV/AIDS activities are ACORD, the Sudan Council of Churches, Help Age International, and the Episcopal Church of the Sudan. Other actors include SNAP, Scouts and the girl guides association, UNICEF, WHO and the Anti AIDS students association and the Sudanese Red Crescent Society.

## **OBJECTIVES OF NGOS HIV/AIDS PROGRAMMES**

(a) To enlighten people on facts about HIV/AIDS and its impact on their lives and community,(b) to create awareness about modes of transmission and how to prevent infection with the virus,(c) to encourage home based care for people living with HIV/AIDS and how caretakers can protect themselves,(d) to reduce stigma in people living with AIDS and orphans orphaned by the disease, (e) to encourage and promote voluntary blood testing among the population (f) to promote safe sex behaviour (use of condoms)

### **Agency for Co-operation and Research in Development HIV/AIDS**

#### **Activities**

**ACORD'S** Juba HIV/AIDS programme started in 1995 with the aim of awareness raising and counseling services in the residential and slum areas of Juba. The target group included students and school dropouts , indigenous Bari communities living in the villages around Juba, IDPS, Orphans orphaned by HIV/AIDS, People living with AIDS (PLWAs)

ACCORD's main areas in the fight against HIV/AIDS included the following, enlightenment campaigns to raise awareness on the mode of transmission and prevention of HIV/AIDS spread within the population, provision of critically needed food and non food items to the PLWA's to improve their nutritional status and provide cover against cold by providing blankets etc, educational support in terms of fees and School materials to AIDS orphans, capacity building (counseling) i.e training volunteers as counselors to provide counseling to AIDS victims, distribution of condoms to infected couples, coordination, networking and advocacy with other agencies working in a similar area. ACCORD has trained 32 counselors between 1997 and 2000.

ACCORD also conducts research on HIV/AIDS. The last research conducted was in 2000.

### **Sudan Council of Churches (SCC).**

The SCC initiated the HIV/AIDS programme in 1995. The S.C.C conducts the following activities counseling, awareness raising. The youth group within S.C.C performs drama and sings songs to enlighten people has provided capacity building (T.O.T) for 150 counselors, and 300 volunteers as awareness campaigners who conduct dissemination of HIV/AIDS information within the general population and through the local radio using local languages and Juba Arabic to reach the wide audience and distributes material and financial assistance to HIV/AIDS victims to purchase drugs for the treatment of opportunistic disease and educational support to orphans. The S.C.C, ,however, discourages the use of condoms as it is alleged to encourage promiscuity among the youth. This is in line with church policy, which only encourages abstinence from sex as the only way out of the problem .

### **ECS HIV/AIDS program.**

The Episcopal church of the Sudan ( ECS) started the HIV/AIDS program in 1995 with the overall aim of awareness creation. The activities of ECS include the following: Drama performance by youth groups, awareness campaigns by volunteers, counseling of HIV/AIDS victims, support to 50 orphans orphaned by HIV/AIDS. The implementation of these activities, however, face some constraints which include lack of financial resources, the churches policy of not allowing the use of condoms, strong cultural influence in relation to widow inheritance, polygamy, people are afraid to talk about the disease openly and the lack of support from local political leaders as they do not see HIV/AIDS as a priority.

### **The Catholic Archdiocese of Juba.**

The Catholic Church has dedicated youth groups who are actively involved in the implementation of the HIV/AIDS program. The program targets mainly the youth aged between the ages of 15 to 49 years old as they are considered to be the active sexually and therefore need awareness campaigns in order to pass specific messages which are important for protection and prevention of the HIV/AIDS. Other activities include counseling services, capacity building for volunteers in areas of HIV/AIDS and support to victims of HIV/AIDS victims. The church's policy just like any other religious institution discourages the distribution of condoms to the public the church beliefs that this will promote promiscuity and prostitution within the population.

### **Help Age International**

Help Age International is a British based organization which is focused on helping elderly people. It started the HIV/AIDS programme in Juba in 2001 for two reasons.

(a) The elderly people carry the burden of taking care of their grandchildren who are orphaned by AIDS, (b) To create awareness among the elderly and the general as some of them are sexually active and could still infect or be infected with HIV. The awareness campaigns are also extended to the general public.

H.A.I conducts awareness campaign on modes of transmission and prevention, capacity building (training of counselors (16 trained) and community mobilisers 21), drama performed in market areas to educate the population about the dangers of HIV/AIDS, provision of material in support of victims and 165 orphans with school materials and Condom Distribution particularly among the youth who are sexually active and vulnerable to infection by HIV. The

organisation performs drama on weekly basis in markets on special occasion like the world AIDS day. Help Age was only able to distribute 144 pieces of condoms during the year 2004

#### **The United Nations Agencies.**

The UN agencies which work in the field of HIV/AIDS prevention comprise of WHO/UNICEF which mainly provide technical assistance in form of training in the areas of counseling, testing for HIV/AIDS status, surveillance, blood safety and treat in HIV/AIDS and training of staff in Anti-retroviral therapy(ART) and provision of support and educational materials and financial support to the NGO's in the promotion of HIV/AIDS programs It is foreseen that in the year 2006, WHO will provide ARV for the treatment of advanced AIDS diseases, tuberculosis and malaria procured using funding from the global fund for AIDS. The total cost of the drugs bought is US\$ 7.8 million for the initial two years. The funds from this can only provide treatment for about 1,300 adults and children per year. The medicines will be distributed through the following Hospitals Omdruman, Bashaer, Khartoum, Gaderef, Nyala, Juba and Wau .ART services will also be extended to Kassala, Port Sudan, el Obeid, Kaduguli, Malakal and Wad Medeni Hospitals. WHO will receive US\$ 20.8 million foreseen for the next three years and another US\$ 112.5 million for another five years.( vol.1, Issue 52)

#### **4.6.7 The Sudan family planning Association.**

The Sudan family although not directly involved in the fight against HIV/AIDS provides condoms to the population as part of it's family planning, prevention of unwanted pregnancy and STDs including HIV/AIDS. In a period of five years the organisation has distributed 63,381 condoms.

**Table( 3.1) Condoms distributions**

<b>Year</b>	<b>Condoms Distributed in pieces</b>
<b>2000</b>	<b>28'263</b>
<b>2001</b>	<b>12'158</b>
<b>2002</b>	<b>11'484</b>
<b>2003</b>	<b>11'476</b>
<b>2004</b>	<b>11'381</b>
<b>Total</b>	<b>63'381</b>

**Source Sudan Family Planning :2004**

**The Scouts and Girl guides Association.**

The scouts and girl guides association started the HIV/AIDS programme in 1994 as partners with the Norwegian church AID.

The scouts and girl guides association focuses mainly on the dissemination of basic facts about HIV/AIDS transmission, prevention and how the disease is not transmitted, Perform drama and songs to the general public in public places and particularly on important public days like the World's AIDS day when large crowds gather to commemorate the special day which is observed worldwide and marked with colorful events. The Scouts also show video films on AIDS especially to the youth and also conduct the distribution of condoms mainly to the soldiers. During the period 2000-2003 the association reported having distributed 10,000 condoms to the military, during the same period 24 T.O.T have been trained. The main constraints facing the scouts association is lack of financial resources, other factors include bad cultural practices like scalirification, lack of female condoms, people still belief that AIDS caused by witchcraft and those fall sick are referred to traditional healers other than to the Hospital to get the appropriate

treatment for the treatment of opportunistic disease and the removal of the milk teeth (false teeth) children by traditional healers using one instrument for all children who happen to be brought for this kind of operation.

### **The Sudanese Red Crescent Society.**

The SRCS runs a First AID and health promotion program in the IDPS camps in Juba. The HIV/AIDS program is integrated into the first AID and health promotion activities. The program targets patients who come mainly to attend consultations at the primary health care facilities which are run five days a week in seven health facilities. The sessions are conducted twice a week and run by seven volunteers. This program is run by volunteers of the Sudanese Red Crescent Society.

**Table (3.2) HIV/AIDS awareness sessions.**

Year	Number of sessions	Audience
2000	195	7'715
2001	140	5'651
2002	158	6'840
2003	143	5'931
2004	182	7'049
Total	818	33'186

Source: SRCS Juba 2004

**Table( 3.3) Distribution of NGOs working in HIV/AIDS.**

UNICEF	Health, Water and Sanitation, Education,HIV/AIDS
WHO	Health/HIV/AIDS
UNDP	Rule of law.
UNHCR	Refugees, Protection.
OCHA	Coordination of Humanitarian activities.
UNAMIS	Peace Keeping and civil affairs
<b>RC/RC Organisations.</b>	
ICRC	Surgical and Medical activites Juba Hospital.I, Tracing and family reunion,IHL, Protection
Sudanese Red Crescent Society SRCS	PHC, Relief, Tracing, Dessimination, Membership and Volunteers Recruitment,HIV/AIDS
The Dutch Red Cross	Technical Support to SRCS PHC programme.
<b>INGOs</b>	
Oxfam	Water and Peace building.
Help Age International	Health,Peace building,capacity building/AIDS
Swedish Free mission	Health, Water, Sanitation and Agro-forestry
Action Contra Lafaim ACF	Water/Sanitation, Health,Food security,Income Generating Activities/AIDS
ACCORD	HIV/AIDS, Food Security, Capacity building.
International Rescue Committee	Peace building, Sanitation,
War child	Rehabilitation of war children
Usratuna.	Rebilitation of handicapped children.
ADRA.	Health/HIV/AIDS, Education and monitoring population movement.
Islamic Relief World wide	Rehabilitation of Schools.
Royal Dutch	Drilling of bore holes
<b>National and local organisations</b>	
Sudan Council of churches	Coordination of Church Activities, Relief, education, HIV/AIDS and radio broadcast.
Sudan AID/Archdioces of Juba	propagation of Christianity, Relief/AIDS
Munazamat Dawa El Islamia	Propagation of Isam, education.
Nile Assistance for the Disabled	Orthopaedic activities
NICODO	Assistance to pastoralists
ACCOMPOLISH	livestock, relief, Education.
Women Self Help.	Capacity building, Income generating Activities, Food Security
SLIRI. Sudan landmine Information Response Initiative	Mine risk Education.
Scouts and girl Guides Association. ANTI AIDS Students Association HIV/AIDS, propagation of christianity,education Coordination of HIV/AIDS activities	Training of Scouts, HIV/AIDS programs HIV/AIDS activities campagns among students.

Source field work Juba July 2005.

## **Chapter four.**

### **Data Analysis, findings and discussions.**

**4.1** chapter four is concerned with data analysis, findings and discussions.

focused group discussions were conducted with the staff of the NGOs, women groups, youth and religious leaders and the issues discussed included the following:

#### **i Categories of people affected with HIV/AIDS.**

According to discussion held with the different groups they mentioned that most of the people affected by HIV/AIDS are women and men of middle ages.

The women were those associated with the armed forces. Some of these are sex workers who sell their bodies in exchange for money. Most girls and boys start practicing sex at an early age ( 15 years ) and some are forced to marry at an earlier age of 17 years. Some of these girls are forced into prostitution for their own survival as their parents cannot provide their needs. This situation is dictated on the women due to high level of poverty that is wide spread within the population.

#### **ii Level of awareness within the population.**

The various groups mentioned that the level of awareness on understanding the knowledge and mode of transmission of the HIV/AIDS was generally high (above 70%). They said that the increase in the level of awareness was due to continuous efforts by the NGOs in creating awareness through radio, direct dissemination of knowledge of HIV/AIDS to the general population. They however, commented that although the awareness level was high there are misconceptions about the

cause of the disease. A substantial number of people believe that AIDS is caused by witchcrafts.

### **iii Stigma.**

According to the various groups met stigma is reported to be strife within the population. People are afraid to share food with AIDS victims. They believe that HIV/AIDS can be transmitted through sharing of food with AIDS victims. AIDS victims are looked upon as people who have led a corrupt life.

### **iv Constraints.**

The NGOs personnel mentioned that the main problems that face the agencies is the lack of continuous flow of funds to sustain the program.

Both the NGOs personnel and the focused groups mentioned the following as the main factors that hinder the smooth implementation of the HIV/AIDS programs: a) the high level of illiteracy within the population, it is estimated that 90% of women in the South are illiterate (Sudan Millennium Development Goals 2004:64) b) cultures and traditions that encourage widow inheritance i.e. practice where by if your brother dies and leaves a widow, (a brother has to assume the responsibility of the deceased wife as his wife), c) scarification (tribal cuttings on the face/body), d) removal of milk teeth from children as people believe they are responsible in causing diarrhea in young children) the lack of access to information as most of the people cannot read, f) The reluctance of men to use Condoms (less than 1%) because they associate condom use with infidelity and they also look at it as something foreign and not acceptable by their culture, g) there is lack of political support from the Political leadership, h) the opposition by religious leaders in the use of condoms as they claim that the use of condoms promotes promiscuity, (This has created confusion in the minds of the people as the audience receives two conflicting messages from two different sources concerning

condoms), i) the lack of anti retroviral drugs for the victims as they are quite expensive and the NGOs and the government are not in position to provide the drugs, j) the influence of traditional healers (“kujur”) in the South play an important role in the lives of the people especially those who are sick despite the huge costs involved in the treatment of the patients. In most cases they demand money and animals like sheep, goats to be given them to perform some rituals before they can embark on the treatment of the patients. Most people who are affected by HIV/AIDS and even their relatives prefer to take the sick to such people in the belief that they have either been bewitched by their neighbours or in the places of work and therefore traditional healing and sacrifices by slaughtering animals would provide the necessary treatment and cure for the sick person, k) Polygamy is also widely practiced in the South whereby some people end up marrying more than 10 women whom they cannot satisfy sexually and therefore some of these women may go astray and in the process becoming infected as a result the rest of the co-wives become infected and in this way the disease can spread from one person to another and l) Circumcision using a single tool on several children has been cited as a concern in the spread of the HIV/AIDS. The spread of the disease is exacerbated by population movements especially across the borders from Uganda, the Democratic Republic of Congo and Kenya including the movement of IDPS.

#### **v. Copping mechanisms for HIV/AIDS victims/Orphans**

Copping mechanism means a defense mechanism or an active way for solving problems and methods of handling stress ( self help). Copping also means how to adjust for whatever reasons when normality switches to abnormality.

A focused group discussion was also held by some members of the association of people living with HIV/AIDS on how they are coping with disease. The association of people living with AIDS in Juba at the moment has a membership of

about 36 AIDS sufferers who have come out openly and declared themselves. They have a chairman and other office bearers. The main objectives of the organisation is to seek recognition and advocate for their case so that they can get support from the government and the NGOs. The chairman of the association reported that the major problem facing them is how to maintain themselves and their families as their ability to work has been very much reduced with the sickness. Currently the people living with HIV/AIDS who have come out openly receive food assistance package from the World Food program on monthly basis to improve their nutritional status, for those who are working in the government departments they continue to get their salaries, NGOs working in the HIV/AIDS program like ACCORD and S.C.C. provide some limited financial assistance to enable them buy some medicines for the treatment of opportunistic diseases like malaria, tuberculosis but there are no anti retroviral drugs that are being provided to the AIDS victims as the NGOs say the cost is very high. One course of the drug which is estimated to cost about 15,000 Sudanese Dinnars and yet a patient is required to take so many courses throughout his life time. There are several AIDS cases within the population but they are afraid to come out simply because of stigma. The orphans whose parents have died are always taken of by the extended family system. Those whose relatives are not in a position to accommodate them simply because they are poor end up as street children. At the moment there are 264 AIDS orphans who have been registered by NGOs and are being provided with support particularly School materials, School fees and food from WFP and other agencies. All the different focused groups agreed that although the NGOs were conducting awareness sessions within the population, behaviorally change is limited.

The religious leaders reported that one of the ways by which the victims were coping is the spiritual aspect whereby the clergy are always invited to pray for the bed ridden patient or by going to a divine leader locally known as “kujur” to look

for treatment. For most women upon the death of the husband they migrate to urban areas and get remarried or return to their parents homes. Others turn to prostitution and in the process the disease is spread to others.

All the groups mentioned that the mass media especially the local radio was important tool in the dissemination of HIV/AIDS information to the general public as it can reach a lot of audience at the same time and that most of the broadcast over the radio are done in local languages and Juba Arabic which can be understood by the illiterate people. All the groups also agreed that despite the efforts exerted by the NGOs in combating the HIV/AIDS, little change in terms of behavior and increased use of condoms has not been observed within the population.

#### **4.2 Findings:**

In the assessment of the performance of the NGOs activities in combating HIV/AIDS the following were the findings:

1. No antiretroviral drugs provided to the victims yet they are the only drugs currently that can prolong the lives of the victims
2. Cultural practices like widow inheritance, scarification, polygamy, removal of the children's milk teeth and use of "Kujur" for rituals is still wide spread within the population.
3. A substantial number of people still belief that AIDS is caused by witchcraft.
4. Stigma is rife within the population as some people still fear sharing food or drink with HIV/AIDS victims.
5. There is lack of flow of funding for sustainability of most HIV/AIDS programs.
6. No commitment from the political leadership in the state.

7. limited use of condoms
8. Weak data base and surveillance on HIV/AIDS.
9. Provision of materials ( food) to improve the nutritional status of the victims and financial assistance for the purchase of drugs for the treatment of opportunistic disease.
10. Provision of counseling services to the HIV/AIDS suffers and their care takers.
11. Promotion of awareness campaigns through the use of radio, volunteers, with information on how the HIV/AIDS is transmitted, the use of condoms so that the people can protect themselves against infection by the HIV/AIDS virus.
12. Performance of drama and composition of songs in local languages so that the message can reach the illiterate.

## **Chapter Five.**

### **Conclusions and Recommendations**

#### **5.1 Conclusions**

The NGOs working in the fight against HIV/AIDS have been disseminating a lot of information to the population in Juba for the last eleven years in order to change the behavior, attitudes, sexual practices and increase the use of condoms in order to lower the levels of infections within the population. The NGOs have established themselves as the major institutions that are propagating information and providing material assistance in support of HIV/AIDS victims in order to alleviate their suffering.

The NGOs have developed some competency in areas such as promotion of awareness, encouraging people to go for voluntary testing, formation of an association for people living with HIV/AIDS, counseling, providing financial support to victims and AIDS orphans.

Despite these achievements by the NGOs, there are a number of shortcomings which face the agencies in achieving their objectives among which are, bad cultural practices, high level of illiteracy, poverty, lack of financial resources to provide antiretroviral drugs to the HIV/AIDS victims and lack of support from the state governments .

The findings therefore show that the hypotheses (assumptions) are partially proven true because there is some level of awareness about the disease in the population, some limited medical support is being provided and there are factors that hinder the smooth implementation of the NGOs activities.

## **5.2 Recommendations.**

In the light of the findings arrived at the study recommends the following:

1. Provision of free medical care including anti-retroviral drugs to all HIV/AIDS victims.
2. Stepping up of prevention by creating awareness campaigns and management of patients.
3. Provision of resources for those involved in the campaign.
4. Introduction of an “anti-AIDS” component in all socio economic development projects and programmes, particularly in sectors such as women, youth and Schools etc.
5. The government should formulate legislation to discourage bad cultural practices ( like widow inheritance, removal of milk tooth from children etc) that impede the fight against HIV/AIDS.
6. To promote the use of condoms especially among the most active sexually age groups
7. Formulation of laws for respect of people living with HIV/AIDS.
8. The National NGOs should mobilize local resources from the local business people to supplement what they receive from donors.
9. The NGOs should produce publications, newsletters and leaflets containing HIV/IDS information and to be distributed on monthly basis in Schools as as part of awareness campaign.
10. The NGOs and the government should introduce poverty alleviation Programs to reduce the level of poverty within the population.
11. Further studies should be conducted to generated new information that could help in the fight against HIV/AIDS.

12. The government should set up HIV/AIDS testing centres along the borders to screen all people entering into the country.

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## **Appendix**

### **Guided Questionnaire**

#### **For NGOs**

- (1) When was the HIV/AIDS programme initiated within the Organizations programmes ?
- (2) What are the objectives of the HIV/AIDS programme ?
- (3) What HIV/AIDS activities does the NGO implement?
- (4) Does the NGO distribute condoms? If yes
  - (i) Who are the beneficiaries?
  - (ii) How many do you distribute per month?
  - (iii) How do the people perceive the use of condoms?
- (5) What are the constraints impeding the organisation efforts in achieving its objectives ?
- (6) Does the NGO publish magazines/news letters/information leaflets on HIV/AIDS?
- (7) **Counseling** activities

How many counselors trained since the start of the programme ?
- (8) **Medical assistance.**
  - (i) Do you provide drugs to HIV/AIDS victims? If yes
  - (ii) What kind of drugs do you provide?
  - (iii) To how many people?
  - (iv) Are the drugs free of charge?

(9) Does the NGO provide material assistance to the HIV/AIDS victims?

(i) If yes what kind of assistance?

(10) does the NGO provide assistance to **AIDS orphans**? If yes

( i) What kind of assistance ?

( ii ) What is the number of orphans being assisted ?

( iii ) With whom are the orphans living in the event that they have lost both parents ?

(11) Do you sometimes use the local radio and T.V. to disseminate HIV/AIDS information ? If yes

(i) What medium of communication do you use ?

(12) Traditional healers could be a source of of HIV/spread while performing their work. Have you ever attempted to discuss with them matters related to the spread of HIV/AIDS ?

**For community leaders, youth and women groups etc.**

(13) Are the people aware about HIV/AIDS, its mode of transmission and how to prevent themselves against infection.

(14) Are people's behaviour changing in relation to safer sex behaviour ?

(15) How do people perceive the use of Condoms?

(16) Are Condoms available to people freely?

( 17 ) How do people those infected with HIV/AIDS ?

(18) What are some of the bad cultural practices that contribute to the spread HIV/AIDS?

