

The challenges meeting children growing up with HIV infection

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Children who are infected with the Human Immune Deficiency virus (HIV) are faced with many challenges in their lives. Some of these may be directly related to the disease itself but a good number of their challenges are related to external factors beyond their control. These include attitude problems from self and society, Government policies that may not favor their immediate comfort and their limited ability to access information or to understand some of what is presented to them. This chapter attempts to highlight some of the challenges met by these children in the societies where they live. The attempts that have been made to overcome these challenges are discussed and the recourse is suggested. For the interested reader sources of information on the topic are listed in the appendix. Among these are simplified links that can be utilized by children. This is intended to benefit the infected child himself to cope and live more positively and protect those around him. Hopefully the uninfected will be sensitized into self protection against getting infected, but also develop empathy for his unfortunate infected colleague. Slowly a more accommodating society will emerge, and together we shall make it.

Introduction

Infection with the Human Immune Deficiency virus (HIV) was first identified in the USA in 1981, among homosexual men who developed symptoms of the late stages of the disease today termed Acquired Immune Deficiency Syndrome (AIDS).¹ Shortly afterwards the disease was noted to affect heterosexual men as well as their sexual partners². A sexual mode of transmission was then concluded. The occurrence of comparable symptoms among the off springs of affected individuals was confusing. The the high death rate among these babies was intriguing.³ Because death seemed to be a definite outcome for all that were infected, survival of their off springs became a desperate social need. Today mother to child transmission of HIV (vertical transmission) is well known world wide. In untreated HIV positive mothers vertical transmission rates range from 15-35%,⁴ depending on the region of survey. The higher rates are in the less developed countries. The survival of the affected infants is very limited. In untreated HIV positive perinatally infected infants, 100% of them would be dead by their 5th birthday.^{5,6} Their short life is characterized by chronic ill health with frequent exacerbations of acute diseases. The high death rate kept the numbers of HIV positive children to a constant

level, a fact that could have masked the true incidence of the disease and the magnitude of the problem.

The discovery of Anti retro viral drugs (ARV), the drugs used to suppress the progression of HIV disease to AIDS, came with a lot of relief as survival and quality of life of the affected individuals were tremendously improved.⁷ It unfortunately took some time before formulations appropriate for children could be developed. It is no surprise that their eventual development brought tremendous relief to the parents of infected children. Because of these drugs the survival and quality of life for these children is also markedly improved.⁸ Another break through that has been achieved after the ARV drugs was the discovery that when given to a pregnant woman at an appropriate time in her gestation, they reduce vertical transmission by about 30-90%.⁹ This practice was undertaken massively under a new program, 'The Prevention of Mother to Child Transmission' (PMTCT). The results from these two discoveries were reduction in the number of babies born with HIV, and survival of the ones that get the infection in whichever way. Because of improved survival chances, children and adolescents are now an ever-growing part of the HIV/AIDS epidemic.^(appendix 2ii) For instance, by the end of 2004 an estimated 2.2 million children were living with HIV, and by December 2006 the number had risen to 2.3 million children.¹⁰ This obviates the need for paying special attention to their unique needs.

Sources of infection in children

While the majority of vertical transmission takes place during pregnancy or during child birth, some few children get infected from breast milk.^{4,11, 12} Older children can get infected by HIV infected sexual molesters. In the hospital setting, infected blood transfusions have transmitted HIV to some children especially in less developed world. A theoretical but possible route may be in the home environment where from accidental cuts and pricks by unsterilized instruments used by infected household members.^{11,12} All the children infected through any of these routes are faced with the challenge of leaving with HIV.

The medical Challenges of HIV disease

It is interesting to note that the largest portion of medical complications in HIV disease is not directly due to the virus itself but rather the conditions are from other opportunistic infections, that take advantage of the weakened immunity, the only direct cause attributable

to HIV. The one condition that is directly related to the presence of the virus in the body is acute viral disease which is experienced by about a third to a half of infected People.¹³ This occurs soon after the individual is infected and is associated with seroconversion. Typically the patient may experience non specific symptoms like headache and fever and general malaise, as the body reacts to the foreign virus by producing immune antibodies directed to the virus. This can fall anywhere between 6 weeks to 6 months after a successful injection of the virus.

Either due to timing or to non specificity of the symptoms the condition is not commonly diagnosed in these babies. When the body mounts an immune response to HIV, it generates HIV specific anti bodies to fight off the infection. Because they now have the indicators of infection they are called HIV positive. To detect these anti bodies, serum is tested hence the coined phrase 'Sero converted or sero positive.' The sero state should ideally refer to any condition that gives antibodies in the serum directed to a specific disease organism but HIV being so widely known, is so far the only condition for which the term has been used outside medical jargon.

The children who are born with or in infancy acquire HIV will, if not treated, get infections related to their deranged long term immunity. This may include conditions like Tuberculosis, meningitis, on and off diarrhea and recurrent febrile illnesses. Acute conditions like mouth fungal growths and ulceration can cause vomiting and weight loss.¹⁴ Presently a vicious cycle of ill health, lack of appetite, vomiting, malnutrition and compromised resistance to common infections, all of which fuels more infections is observed. This state of chronic ill health tends to be associated with growth retardation a situation that is very damaging to the self image of the growing child. Death is a common outcome.¹⁵ This haunts the child as he grows older and appreciates the implication of his circumstances. The realization of his impending death may be heralded by the death of one or both parents, a not rare event among HIV positive families.

Treatment with ARV reduces the progress and the severity of the disease. Those children that have access to ARV have another set of problems. While the ARV reduce most of his medical problems, the regimens are usually complicated and difficult to follow. An undesirable consequence of this is non adherence. Non adherence is associated with development of resistance, so for anyone treated with ARV non adherence should be avoided if the viruses are to be kept under constant suppression. As mentioned above the majority of the children may not be in position to comprehend all this. The pill burden in HIV drug treatment is usually prohibitive, and the life time implication of medication is disheartening to most children. Some of the side effects of the drugs at times mimic HIV related conditions.¹⁶ To make matters worse some of them are more life threatening than HIV itself. To the older child, who takes the medications for a known purpose, this will easily make him loose sense of benefit from the drugs. In those instances wherethe diagnosis as made late, or ARV therapy was started late, there may be a need to take both ARV and additional drugs for inter current opportunistic infections. The unlucky child may still need additional drugs to help him overcome some of the side effects of any of these drugs especially ARV. The more sick the child the bigger and more prohibitive the pill burden, yet tolerance levels are likely to be very low. Among the very young adherence is entirely dependent on adults, who in the majority of situations are foster parents. Since resistance is a sure and fatal outcome of non adherence, all efforts should be made to ensure adherence especially in regions where the supply of drugs is politically intertwined. This is because the availability of these drugs is dependent on complicated and heavily weighed policies. Alternatives are not likely to be accessed. This scenario is more likely to be witnessed in donor- dependent countries, which ironically bear the biggest burden of HIV. The lack of alternative treatments for the non adherent child, who

will by then have built all his hope on taking drugs, will make him despair, as the threat of death becomes as intense to him as it is a fact, when he develops resistance. In many developing countries, the privilege of 2nd line treatment is usually extended to adults at the total exclusion of children. This is because most societies in developing countries would rather invest in individuals from whom they expect some returns rather than young unhealthy ones whom they don't expect to live long enough as to be productive. Worse still the second line drugs are likely not to be free, so the cost benefit is weighed at the family level.

The challenges of disclosure

In the world of HIV, disclosure tends to refer to telling a person their tested results of an HIV status. It carries a lot more meaning for the HIV positive as the implications of the test very many, and usually unpleasant.^{17, 18} In the case of children, disclosure of the HIV status is a complicated situation. It calls for balancing the medical and ethical legal issues against bridging of confidentiality, in case of an HIV positive mother who does not want to disclose her status.¹⁹ The role and of the parent in this becomes more complicated as more knowledge is required by the child if he is to understand his body and take the necessary precautions. To make the pressure on the unwilling parent worse, this same information is vital to this infected child if he is to prevent transmission to those around him, most likely his siblings. The process itself is difficult. It is not clear who should disclose the status to the child, and at what age. The unwillingness to disclose sero status to the child is a social barrier that has been identified. For instance Research and clinical reports suggest that many HIV-infected children, particularly those younger than 13 years, do not know they are HIV infected. This has been attributed to parental concerns about the impact of this information on the child's mental health.^{20,21} Data from several centers indicate that between 25% and 90% of school-age children with HIV Infection /AIDS have not been told they are infected²² It has however been noted that non disclosure is commoner among parents who themselves are still in states of insecurity or denial^{1,20,21,22} This conspiracy of silence surrounding children infected with HIV may isolate them from potential sources of support. In the unfortunate event of the death of a parent, the opportunity is lost for children to discuss their illness with that parent. Children also may inadvertently learn of the nature of their illness in a manner that is not supportive^{23,24} In the African context, cultural norms preclude free discussion of sexuality and sexual behavior. Needless to say HIV in the African context, being a predominantly heterosexual disease, is inadequately addressed.²⁵ In Uganda non government organizations have sprang up in aid of people living with HIV. These include 'The Aids Support Organization' TASO and the Mild may treatment center for childhood AIDS^(Appendix 1,2) which are the most famous organizations that are involved with HIV positive individuals, in Uganda. These organizations have created platforms over which disclosure to HIV infected children can be done smoothly. The school syllabus in Uganda is constantly upgrading the contents of family life and sex education and sexually transmitted infections, depending on the perceived need in the country. Their stance is that of compassion for the affected and prevention for the uninfected. This is a starting step on alleviating the anxiety associated with disclosure of HIV status and it enhances coping skills in the affected.

Psychological challenges

At all stages of development, emphasis put on secrecy of a child's HIV status only serves to increase his associating the condition with shame. The child will have more unanswered questions because of lack of a platform to express his doubts. This will compound his confusion. The strain tends to be worse when the care givers are foster parents- a common phenomenon in Africa. Stigma in all its domains is a challenge to the child and gets worse as he grows into an adolescent. Stigma can present as associative or internalized stigma. The associative stigma that stems from the people or circumstances that are linked to his condition is destructive. In the developed countries, the association of HIV with homosexuality, an orientation initially scoffed, at as well as the association with intravenous drug use have damaged the attitude masses have of HIV. In Africa promiscuity and sexual permissiveness have surpassed the role that cultural practices might have played in the transmission. Children with AIDS find themselves associated with these marginalized essentially adult populations²⁶ Stigma is particularly damaging when it becomes internalized, which occurs when a person is aware of a social stigma and accepts, or internalizes, society's negative views. This damages the person's self-esteem resulting in a negative sense of self worth. Stigma management describes the routes that the child may take to overcome or minimize stigma. These can at times be detrimental to him. The children are less likely to seek social support for fear of rejection and isolation. In some areas, stigma has been reduced through education and outreach. In many parts of the under developed world, however, stigma is still a harsh reality, which sometimes may bar children from school and other community activities.^{26,27,28}

Orphan hood is common among HIV infected children. By 2005 of 1 million orphans in Uganda 45% had been orphaned from AIDS.²⁹ The process of dying of parents has strenuous and depressive effects on most children, before facing the consequences of the death.¹⁹ On top of the insecurity felt at the loss of parents, another challenge faced by these children is the feeling of being a social burden. The assumed unconditional love of biological parents is gone for ever. The uncertainty of the future keeps the child in a constant state of anxiety. Death of a parent is a constant reminder of their own impending death. This can lead to loss of hope and overt fear. The situation is worsened by the common habit of not making succession plans for the off spring after ones demise.

The three stages of puberty may not be well lived by children with HIV. Adolescence is a stage when self worth and esteem are judged on physical appearance. The HIV positive teenager who is stunted and has the tell tale signs of AIDS in form of skin rashes and healing scars, is bound to have a very low self esteem. Poor academic performance and possibly inconsistent tuition as well as constant absenteeism due to ill health, will lay a good back ground for a high school drop out. The teenagers social, financial and psychological needs become compounded.

Conflicting social expectations

The desire to reproduce one self is natural to man, HIV positive individuals inclusive. As demonstrated by Azondekon et al, 50% of HIV positive children of ages as early as 6 to 14 years were concerned about their fertility when told about their HIV sero status.²⁵ While the commonest intervention considered effective is prevention, the HIV positive child has a problem joining the campaigns knowing he is supposed to be the one to be the infection source. Worse still this individual in his late teens has to sort out his feelings about mating and reproduction, feelings society around him does not excuse him for entertaining. To add to his problems research has demonstrated that childhood HIV is associated with varying degrees of delayed sexual maturity or in cases frank hypogonadism.^{30,31} Even when he is on ARVs there is no sure escape as it is also documented that the Protease inhibitor type of ARVs are associated with male sexual dysfunction.³¹ In the HIV positive adolescent who already has problems with self esteem, sexual dysfunction may feel like the last straw. Because of societal concerns about transmission of HIV this child is bound to find a problem expressing his concerns about his sexual inadequacies to anyone.

Policy Issues

Political will is important in the management of any public health problem like childhood HIV disease. The policies set will be influenced by the estimates of cost effectiveness and cost of the different interventional programs. For instance, it has been estimated that the incremental cost per year of life gained for an individual given standard treatment for HIV is \$1,180. If the first line treatment fails and one develops resistance, introducing 2nd line drugs increases an individual's life expectancy by 30%.³² Although these figures are encouraging they are measured on adults only. In many African settings children with HIV disease will not have such estimates because of the lack of expected benefits from them. For the resource scarce countries Masaki asserts that prevention of transmission is more cost effective than treatment of infected individuals.³³ The fact is likely to result into policies that disfavor the HIV infected children. Another research finding that would result in formation of health policies that are in disfavor of the infected children was done by Kafiriri et al in Uganda. She demonstrated that stake holders prioritized health interventions differently from HIV infected individuals. Some Stake holders ranked PMTCT lower than ARV therapy which still was ranked lower than treatment for malaria and diarrhea disease. On the other hand the HIV positive individuals consistently ranked treatment of opportunistic infections and ARV therapy as number one in priority. This conflict of interest demonstrates the high possibility of setting health policies that are not in favor of the HIV positive children.³⁵ When consideration is put in research ethics, the guidelines stipulate that trials in children can only be done after ascertaining toxicity, efficacy and effectiveness in adults.³⁴ Safety driven, as this guideline may be, it creates a lag in development of drugs for children. At the government level, PMCTC program reduces vertical transmission. The program policy on those children who are born HIV positive is so ill defined and vague.

What has been done so far

Different actions have been taken at different levels in different regions. The most important action that has been taken is acknowledging the magnitude of the problem and

the intensity of the challenges faced by the individual HIV positive children. Data has been collected on the prevalence and incidence rates of childhood HIV. Other epidemiological studies have been done on a regional level W.H.O prevalence estimates are made basing on data given by each country. It may however be pointed out that these estimates are most accurate where birth, clinical and death records and other vital statistics are well documented. In those countries where these statistics are incomplete, under estimates are very likely. This is more likely to be the case in developing countries. An example of interventions done in developed countries is by the American Academy of Pediatrics which has put down recommendations on disclosure of HIV status to children. According to the academy, parents and other guardians of an HIV-infected child should be counseled by a knowledgeable health care professional, about disclosure to the child of their infection status. Also that disclosure of the diagnosis to an HIV-infected child should be individualized putting onto consideration the child's cognitive ability, developmental stage, clinical status, and social circumstances not forgetting to address their fears and misperceptions. Coping skills need to be imparted on to the children. Adolescents should be fully informed to appreciate consequences for many aspects of their health; including sexual behavior.²⁴ Efforts to address the problem have been on as early as 1987. In the Report of “The Surgeon Generals Workshop on Children with HIV Infection and Their Families’ held in Philadelphia, some recommendations were made regarding the management of childhood HIV. Emphasis was laid on prevention of infection and addressing the needs of the infected children.³⁶ Many organizations are now formed that address the specific need of HIV positive children. Some of these are private non profit organizations and some are individual projects while others are religious based. Examples of these include Barnado’s Planning Scheme, Children with Aids Charity, Grandma’s and Support for Adults with AIDS, in the UK.³⁷ In developing countries too some work is being done among the HIV positive children. Aka et al in Coted’Ivoire brought out the good that the Yopougon Child program of “agence Nationale de rechercher sur le Sida” that was launched in Abidjan in 2000 has done to this end.³⁸ In Uganda ‘The Aids Support Organization’ TASO and the Mild may treatment center for childhood AIDS spear headed the patient based management of HIV using a multidisciplinary approach. The interaction they have with government plays a major role in the health policies regarding HIV positive individuals. On a wider perspective the school syllabus in Uganda is constantly upgrading the contents of family life and sex education and sexually transmitted infections, depending on the perceived need in the country. Their stance is that of compassion for the affected and prevention for the un infected. The association of Uganda Women Medical Doctors disseminate information to schools in form of talks and brochures on the topic of HIV prevention STI, Risk behavior and home management of HIV disease. One could safely say that the intervention that has been of highest public health value as far childhood HIV is concerned was the decision to operationalise research through PMCT. This preventive measure has reduced incidence of perinatal HIV hence lowering the numbers on which the available resources can be spent. This is relevant where resources are scarce.^{39,40}

The way Forward

There are many ways in which childhood HIV can be handled. The areas that need recourse include prevention of transmission and improvement of quality of life for the

affected individuals. Setting priorities is important depending on the specific problems faced by each region. For instance 63% of all persons living with HIV are found in Sub-Saharan Africa^(appendix 2 i) While rates are stabilizing or falling in some countries other areas are experiencing an increase in the rates of HIV. Another factor to take into consideration is the risk behavior patterns in each region. While heterosexual transmission is the biggest mode of transmission in Africa^(appendix 2ii) both homosexuality and heterosexuality as well as injection drug use all pose risk in the developed countries.^(appendix 2iii) Evolving risky behavior in an unsuspecting population is a bigger risk than a known behavioral trait. Examples of this include the emergency of injection drug use among youths in Tanzania and Nigeria, and the recently discovered practice of homosexuality in Cambodia China India Nepal and other areas famous for their high moral and sexual codes of conduct.¹⁰ Such communities pose an unrecognized danger of transmission to the boy child and the youth in general. Information gathering on these of information regarding these risky behaviors and how they affect the children is most important before intervening.

Prevention

Prevention of transmission is the most difficult but most realistic intervention in the management of childhood HIV infection.

Since the biggest burden of HIV is in the sub Saharan Africa it will be used here to demonstrate the way forward.

Information and education are the best weapons that societies need to be able to effectively assimilate these children. Information regarding transmission prevention and disease progression in HIV can be accessed formally or informally. Talks to the masses about the causes, risk factors transmission, prevention and management of HIV disease. Such education messages may be passed through the schools, the media and political sub units. In Uganda the local political subunits have a child and youth representative. These would be instrumental in dissemination of education messages. In clinic waiting lounges information posters and billboards can all be used. Clarity and simplicity of language is emphasized.

Statistics: Numbers and facts are vital if proper planning is to be done. Collection and documenting vital statistics has to be revitalized and done every where all the time. ^(ppendix 2)

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Research: Research to reduce further vertical transmission is still needed. The health policies set should put these HIV positive youths into consideration. Sharing of information and experiences by different countries will help uplift the overburdened ones for the better.

Orphans: Since HIV positive children imply an HIV positive mother and very likely father, parents should be facilitated in passing information to their children, and educating them and feeding them. Where the children are orphans nations should make policies that assist all HIV related orphans especially in terms of education. Scouts that look out for the common needs of orphans can recommend additional assistance.

VCT and Family planning: Most perinatal infections happen to babies whose mothers didn't know they were infected at the time of conception. Voluntary counseling and testing and family planning clinics should be made more available for women in the reproductive age. Male (husband) involvement in reproductive health may help in raising the information level in society.

All in all as countries strive to better the lives of present HIV positive children the ultimate hope is of ending the problem of childhood HIV. The journey is still long.

Health care professional: These being the direct contacts with patients should build a network of information sharing. Continuous medical education for care givers should be mandatory. The collaboration between care givers and the health care workers is very important.

Globally as a vaccine for HIV is undergoing trial ⁴¹ plans and research should be done to find out exactly how the HIV came to man. This may be the information that help in prevention of the next strain from reaching humans.

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Appendix 1: Where to look for more information

Statistics about childhood HIV

1. Until There's A Cure: Until There's A Cure® is a national organization dedicated to eradicating HIV/AIDS by raising awareness and funds to combat this pandemic.
<http://www.until.org/statistics.shtml>

2. Averting Aids. Sub Saharan Africa. HIV and AIDS Statistics:
<http://www.avert.org/subadults.htm>

3. CDC Basic statistics: <http://www.cdc.gov/hiv/topics/surveillance/basic.htm>

4. Interact Worldwide: <http://www.interactworldwide.org/>
Interact worldwide works in collaborative partnerships with local and national organisations and governments, to improve the sexual and reproductive health and rights, including maternal health care, family planning and HIV/AIDS services, of some of the poorest and most marginalised people in the world.

Medical challenges in childhood HIV

1. Respite Care for Children with HIV-related Condition: fact sheet number 5
<http://www.archrespite.org/archfs5.htm>

2. Treating Opportunistic Infections Among HIV-Exposed and Infected Children - December 3, 2004:
<http://www.google.com/search?hl=en&q=opportunistic+infections+in+HIV+children.&btnG=Search>

3. Guidelines for preventing opportunistic infections among HIV-infected persons--2002. Recommendations of the U.S. Public Health Service and the Infectious Diseases Society of America.
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12081007&dopt=Abstract

4. ARV Treatment fact Sheet 06. Side effects. Detailed information. This explains the cause of the side effects to the ARV and how the patient should manage them.

5. WHO Comprehensive HIV Care (Uganda) Care Giver booklet gives advise on how to manage an HIV patient at home with local remedies for common distressing symptoms.

Problems of disclosure

1. A family support programme on disclosure to children with HIV. Donaghy S, Waugh S.
<http://gateway.nlm.nih.gov/MeetingAbstracts/102251722.html>

2. Talking to your children about HIV: An interactive site

<http://www.thebody.com/content/living/art12753.html>

2. Living With AIDS/HIV. <http://library.thikquest.org/j003087F/favorite.htm>, 2007. This teaches a person who has just known their HIV status all they want to know about HIV and AIDS including positive living.

General

1. Frequently Asked Questions about HIV and AIDS (Comprehensive site)

http://www.capegateway.gov.za/eng/pubs/public_info/F/87102/1: This covers all topics plus more in simple language.

2. The AIDS Support Organisation (TASO)

3. J Adv Nurs. 1999 Jan; 29(1):4 Mildmay AIDS center uganda

Specific for children and adolescents

1. Young People & HIV/AIDS : <http://www.thebody.com/index/whatis/children.html>
Discusses relevant topics of interest to the young

2. Voices of the youth. Be in the know

http://www.unicef.org/voy/explore/aids/explore_1360.html.
games about HIV for kids

For The Very Young

1. Jimmy and the Eggs Virus Explains the AIDS virus through a story. Can be read by parents to children to aid their discussion of HIV.

2. *How Can I Tell You* by Mary Tasker, MSW

Offers case examples of families' disclosure process.

Describes stages families' progress through in the process of disclosure.

Helps providers assess where a family may be in the process of disclosure.

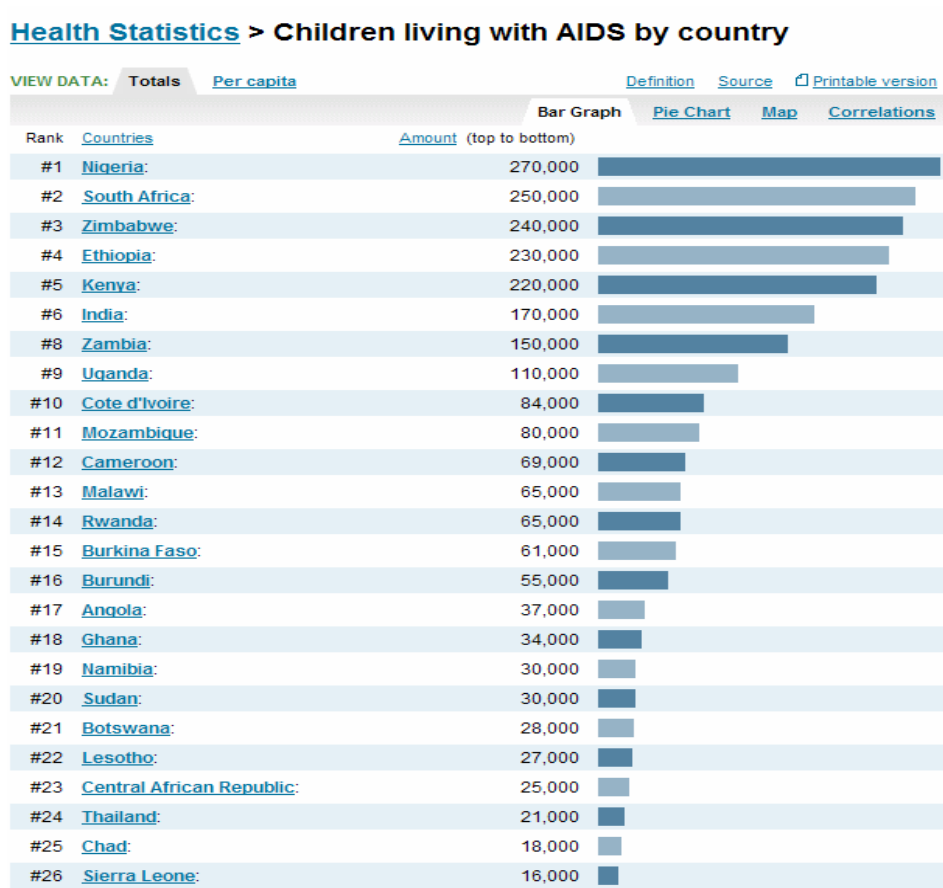
3. *What's Best for You: Families Living with HIV: Talk About Disclosure* A videotape depicting families and children discussing their experience with disclosure.

Provides a personal view of the HIV disclosure process for parents and children.

Depicts a range of experiences from unplanned to planned disclosure. Depicts the role of different systems (e.g., counselors, school nurses, support groups, peers) in the process of disclosure.

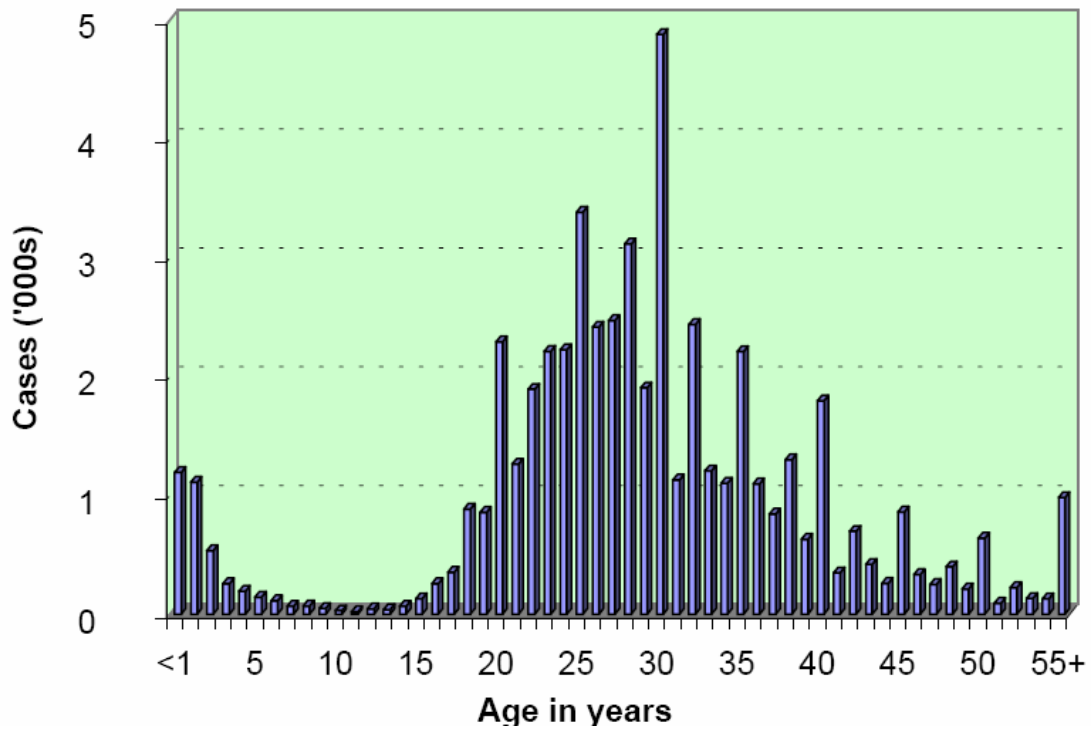
Appendix 11. Statistics for selected countries

(i)



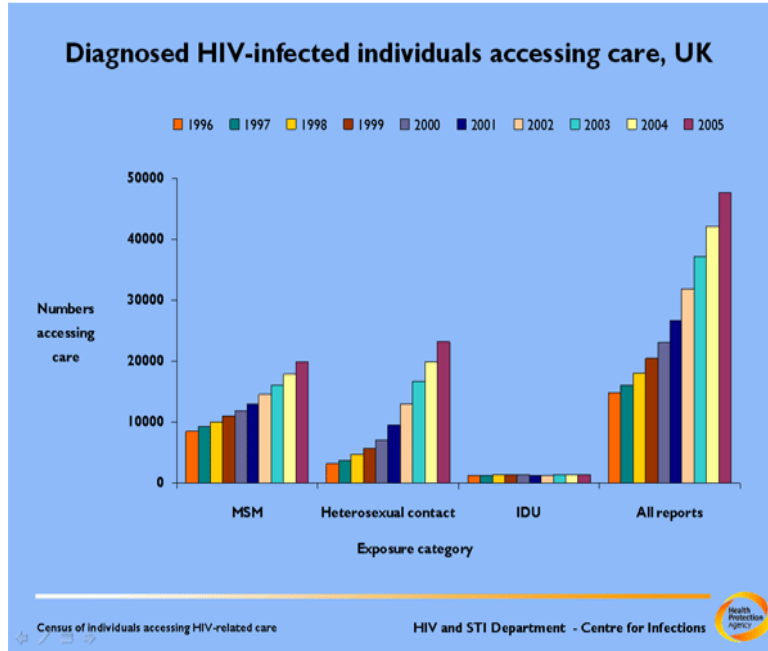
Part of a graph depicting the countries with the highest prevalence of HIV in the world (Predominantly Sub Saharan Africa)

Graph 16: Age of Ugandan AIDS cases



(ii)

The risk factors for HIV are mainly heterosexuality and vertical transmission



(ii)

The risk factors in UK include homosexuality heterosexuality Intravenous drug use.

NO information for vertical transmission