

UNIVERSITY OF PORT HARCOURT

**PAEDIATRIC HIV, TOTALLY
PREVENTABLE – CHALLENGES IN
MANAGEMENT; ARE WE EQUAL
TO THE TASK?**

An Inaugural Lecture

By

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ORDER OF PROCEEDINGS

2.45 pm. Guests are seated

3.00pm. Academic Procession begins

The Procession shall enter the Ebitimi Banigo Auditorium, University Park, and the Congregation shall stand as the Procession enters the hall in the following order:

Academic Officer

Professors

Deans of Faculties/School

Dean, School of Graduate Studies

Provost, College of Health Sciences

Lecturer

Ag. University Librarian

Ag. Registrar

Deputy Vice Chancellor Research and Development

Deputy Vice Chancellor Academic

Deputy Vice Chancellor Administration

Vice Chancellor

After the Vice Chancellor has ascended the dais, the Congregation shall remain standing for the University of Port Harcourt Anthem.

The Congregation shall thereafter resume their seats.

THE VICE CHANCELLOR'S OPENING REMARKS.

The Ag. Registrar shall rise, cap, invite the Vice Chancellor to make his opening remarks and introduce the Lecturer.

The Lecturer shall remain standing during the Introduction.

THE INAUGURAL LECTURE

The Lecturer shall step on the rostrum, cap and deliver her Inaugural Lecture. After the lecture, she shall step towards the Vice Chancellor, cap and deliver a copy of the Inaugural Lecture to the Vice Chancellor and resume her seat. The Vice Chancellor shall present the document to the Registrar.

CLOSING

The Ag. Registrar shall rise, cap and invite the Vice Chancellor to make his Closing Remarks.

The Vice Chancellor's Closing Remarks.

The Vice Chancellor shall then rise, cap and make his Closing Remarks. The Congregation shall rise for the University of Port Harcourt Anthem and remain standing as the Academic [Honour] Procession retreats in the following order:

Vice Chancellor
Deputy Vice Chancellor Administration
Deputy Vice Chancellor Academic
Deputy Vice Chancellor Research and Development
Ag. Registrar
Ag. University Librarian
Lecturer
Provost, College of Health Sciences
Dean, School of Graduate Studies
Deans of Faculties/School
Professors
Academic Officer

PROTOCOL

- ❖ The Vice Chancellor
- ❖ Past Vice Chancellors
- ❖ Deputy Vice Chancellor, Administration
- ❖ Deputy Vice Chancellor, Academic
- ❖ Deputy Vice Chancellor Research and Development
- ❖ Past Deputy Vice Chancellors
- ❖ Members of the Governing Council
- ❖ Principal Officers of the University
- ❖ Provost, College of Health Sciences
- ❖ Dean, School of Graduate Studies
- ❖ Deans of Faculties
- ❖ Heads of Departments
- ❖ Distinguished Professors
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- ❖ Captains of Industries
- ❖ Cherished Friends and Guests
- ❖ Unique Students of UNIPOINT
- ❖ Members of the Press
- ❖ Distinguished Ladies and Gentlemen

DEDICATION

This lecture is dedicated to:

- Almighty God, My Rock,
- My mother and late father, my inspirer
- My darling husband and children, the important persons in my life
- My patients and their caregivers, my source of joy

ACKNOWLEDGEMENT

With heart full of praise and gratitude, I thank the Almighty God who has guided me this far and without whom I will not be where I am today.

My special thanks to my husband, brother and friend, Sir, Engineer Ikechukwu Raymond Ugwu, (Chief Nwachinemere of Obige Obukpa) for his love and support throughout my career progression. I also express my gratitude to my children Regina, Richard, Raphael and Robert for their patience and understanding.

I am grateful to Prof. Ndowa E.S Lale the 8th Vice Chancellor of the University of Port Harcourt for appointing me Professor of Paediatrics and Paediatric Infectious Disease in 2015.

My sincere gratitude to Prof. Owunari A. Georgewill the current Vice chancellor of this Unique institution for granting his approval for me to present this Inaugural lecture. I am grateful indeed Sir.

I will forever be grateful to my academic mentors Prof. Raphael Oruamabo, Prof. Kanu Nkanginieme and Prof. Augusta Eneh who believed in me and encouraged me to do residency and have never ceased to challenge me to greater heights.

I wish to thank in a special way all my patients and their caregivers for contending with all the challenges of living with HIV/AIDS. They are truly heroes and champions. I doff my hat for them.

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Dr. Tochi Uchenwa, Dr. Obinabor, Dr. Uju Azubogu, Dr. Ezioma Alinor, Dr. Diamond, Dr. Adaku Nwosu, Dr. Anolue, Dr. Doris Ndefo, Dr. Ginika Udegbunam and all the Resident Doctors especially Dr. Chidinma Chukwumerije, Nurses, Pharmacists, Record Officers and other support staff. They have all been sources of motivation, inspiration, and assistance in my academic pursuit.

I appreciate my mother Bridget Nwolisa and my late father, Chief Dennis Nwolisa for guiding my footsteps and for giving me a good upbringing. I appreciate my supportive and nurturing siblings Ifeyinwa, Chinelo, Okwudili, Evan, Franca, Uju and Nkonyelu. I appreciate all my brothers and sisters-in-law for being there for me.

I wish to appreciate all the past and current Provosts and staff of the College of Health Sciences as well as the past and current Deans and staff of the Faculty of Clinical Sciences.

My special thanks to the past and current Chief Medical Directors and the past and current Chairman, Medical Advisory Committee of the University of Port Harcourt Teaching Hospital for creating a conducive environment for me to carry out my researches.

I remain very grateful to Prof. Hakeem Fawehmni, Prof. Ndubuisi Eke, Prof. Felicia Eke, Prof. Ihekweba, Prof. Christie Mato, Prof. Chioma Unachukwu, Prof. Ngozi Orazulike, Dr. and Prof. Fiebai, Prof. Eghwurudjakpor, and Dr. Dennis Okoye.

My thanks to all my colleagues and friends in Rivers State University Teaching Hospital (RSUTH) especially Prof. Assumpta Chapp-Jumbo, Dr. Ajibola Alabi, Dr. Boma West, and Dr. Uche Onubuogu.

My special thanks to IHVN staffs especially Mr. Godwin Ogbonna and all our community-based organisations (CBOs) (Lifetime Caring Foundation, Mankind, Rohi, Rivers of Hope, Tender Life Rescue, Perpetual Succour, Rhema Care and Rainbow watch) for being our implementing partners and providing care at community level.

My special thanks also to the state TB/Leprosy control program for providing us with a lot of logistics, and partnering with us to provide care to our patients. I am also very grateful to Rivers State Action Committee on AIDS (SACA) and Rivers State AIDS and STD Control Programme (SASCP) our vanguards, coordinating all our implementing partners and other stakeholders.

My sincere gratitude to all the Knights and Ladies of St. Mulumba especially in St. Francis Port Harcourt Sub-Council.

I will not fail to appreciate all my unique students who have continued to inspire and challenge me to be a better teacher.

I thank you all.

GLOSSARY

AIDS - Acquired Immunodeficiency Syndrome

ART - Antiretroviral Therapy

ARV – Antiretroviral

CLWHA - Children living with HIV/AIDS

EID - Early Infant Diagnosis

HIV - Human Immunodeficiency Virus

LTFU - Lost to follow-up

MTCT - Mother-to-child-transmission

OVC- Orphaned and Vulnerable Children

PABA - People affected by HIV/AIDS

PCR - Polymerase chain reaction

PITC - Provider initiated testing and counselling

PLWHA - Persons living with HIV/AIDS

PMTCT – Prevention of Mother-to-child-transmission

TB - Tuberculosis

WHO - World Health Organization

UNAIDS – The Joint United Nations Programme on HIV/AIDS

PREAMBLE

“LET THE CHILDREN COME TO ME. DON’T STOP THEM! FOR THE KINGDOM OF HEAVEN BELONGS TO SUCH AS THESE” Matthew 19:14

Vice Chancellor Sir, it is a great honour and privilege for me to stand here today to deliver the 177th Inaugural Lecture of this Unique University. I am grateful for this opportunity which is a once in a life time event for a Professor.

I started my career in the newborn unit and Pediatric Infectious Disease unit especially HIV and tuberculosis. At that time, I was interested in Dysmorphology/Congenital abnormality and Gene-environment interaction that results in birth defects in children delivered in the South-South zone. However, as the number of newborns and children infected with HIV increased, and also for expansion and growth of the Department, the need arose to expand the two subspecialties. I was then drafted to head the Paediatric Infectious Disease unit in 2012 where I have concentrated my researches till date.

Being informed of a diagnosis of HIV can make one feel the world has come to an end, especially as there is still no cure yet. The only time I have seen someone really happy about being diagnosed with HIV was during the Ebola virus era, when a father brought his very ill 4-year old child. The mother had just died from high fever and bleeding and the fear in him was palpable as no hospital was ready to treat the child for fear that it was Ebola. Results of investigation showed that the child had HIV and not Ebola and the father in great joy exclaimed “Thank God it is only HIV”

LECTURE OVERVIEW

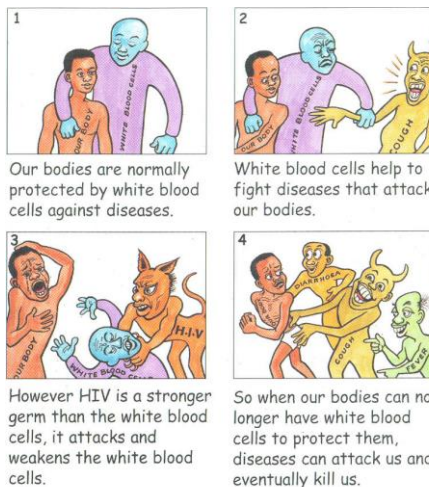
Vice Chancellor Sir, in this lecture, I shall:

1. Provide an overview of paediatric HIV
2. Briefly describe the life cycle of HIV
3. Discuss the various modes of transmission of HIV in children

4. Highlight some of the challenges in caring for an HIV-infected child
5. Suggest the way forward to preventing/eliminating paediatric HIV
6. Share information on what we are doing in the Paediatric Infectious Disease Unit
7. Conclude

1. OVERVIEW OF PAEDIATRIC HIV

HIV (Human Immunodeficiency Virus) is a virus that infects one and weakens the body's immune system. It is the virus that causes Acquired Immunodeficiency Syndrome (AIDS). AIDS is the collection of illnesses that occur following the eventual weakness of the immune system as a result of the HIV infection. Due to damage to the immune system, the body is no longer able to fight certain diseases and infections. This vulnerability to opportunistic infections marks the onset of AIDS (**Figure 1**). However, not everyone who is infected with HIV has AIDS. Anyone infected with HIV, though may be healthy, can still transmit the virus to another person.



HIV affects the immune system and allows other infections to attack

Fig 1. How HIV attacks the immune system

The epidemic of HIV and AIDS is a major problem in many countries. A very sad aspect of the epidemic is the number of young children who are infected. Until late 2019, before the emergence of COVID-19 pandemic, the HIV pandemic was one of the most devastating epidemics in recorded history. Although new HIV infections have fallen by 53% in children since 2010,¹ yet in 2017, according to the joint United Nations programme on HIV/AIDS (UNAIDS) estimates, 159,000 of the 180,000 new infections among children globally occurred in Sub-Saharan Africa, and Nigeria alone accounted for 23% of these new infections in the sub region.² Of the estimated 2.8 million children and adolescents aged 0–19 years living with HIV globally, 9 out of 10 of them (90%) live in Sub-Saharan Africa.³ In 2020, an average of 150,000 [range 100,000–240,000] children globally were newly infected with HIV, mainly through transmission of the virus from their mothers during pregnancy, delivery or while breastfeeding.¹ In Nigeria, about 22,000 new infections occurred in children aged 0-14 years in 2019.³ The high rate of HIV infection in children in Nigeria results directly from the high rate of HIV infection in women of childbearing age, the high fertility rate, and the ease of mother-to-child-transmission (MTCT). While there has been tremendous improvement in the management of HIV worldwide, lack of access to currently available and feasible interventions in Africa translates into a high burden of paediatric HIV disease. Annually, Nigeria is estimated to have 160,000 HIV-infected pregnant women, making it the second largest globally after South Africa.² As more women become infected, the numbers of HIV-infected children (and orphans) is expected to grow.

HIV/AIDS is a major cause of infant and childhood mortality and morbidity. In 2019, the total number of AIDS-related deaths of children and adolescents was 110,000 globally (79,000 in children aged 0-9 years and 31,000 in those aged 10-19 years). In Nigeria, the total number of AIDS-related deaths of children and adolescents was 16,200 (13,000 aged 0-9 years and 3,200 aged 10-19 years).³ Thus, almost 15 per cent of global AIDS-related deaths in children and adolescents occurred in Nigeria.

According to the National HIV/AIDS Indicator and Impact Survey (NAIIS) done in 2019, Nigeria's national HIV prevalence is 1.4% among adults aged 15–49 years, and 0.2% among children aged 0–14 years.⁴ Nigeria is one of the four countries in the world where annual infections among children are above 10,000, the others being Mozambique, South Africa and Tanzania. Although the HIV prevalence appears less than other Sub-Saharan African countries such as South Africa and Zambia, the sheer size of Nigeria's population (with children 0-14years constituting 43.49% of Nigeria's population of approximately 212 million as at 2021) means that a large number of children will become infected, and lack of progress here to curb the infection is of particular concern for Sub-Saharan Africa in particular with the potential to impact on the global burden of HIV.

AIDS has a devastating effect on children. With the prevailing poverty in Sub-Saharan Africa, children are the first to suffer. They suffer mental, psychological, social distress, and increasing material hardships. The older children may be the only caregivers for their sick or dying parents, and may drop out of / interrupt school, and are at risk of discrimination and abuse, both physical and sexual. As of 2020, an average of 15.4 million [range 10.6-20.9 million] children under the age of 18 years had lost one or both parents to AIDS-related causes.⁵ A lack of necessary investment in resources for adequate testing, paediatric antiretroviral (ARV) drugs and child-friendly prevention programmes mean children continue to suffer the consequences of the epidemic. Regular HIV testing, treatment, monitoring and care for children living with HIV can enable them to live long and fulfilling lives. HIV has now moved from being a life threatening illness to an ailment that can be adequately managed over an entire life.

What is special about HIV/AIDS in children?

1. HIV can progress very quickly in children due to their immunological immaturity, so early identification is critical.
2. Almost 90% of them acquired the infection from their parents.

3. HIV testing methods are different from that of adults.
4. Antiretroviral drug formulations are different from that of adults.
5. Children need special care to make sure they are growing and developing optimally.
6. Dependency on adult for decision making on their behalf for their care, including disclosure.

2. HIV BASIC STRUCTURE AND LIFE CYCLE ⁶

There are two types of HIV: HIV-1, which is found worldwide and is responsible for the worldwide pandemic, and HIV-2 which is found mainly in West Africa, Mozambique and Angola. HIV-2 is less virulent and infectious with slower progression and lower viral load. It makes little or no contribution to paediatric HIV.

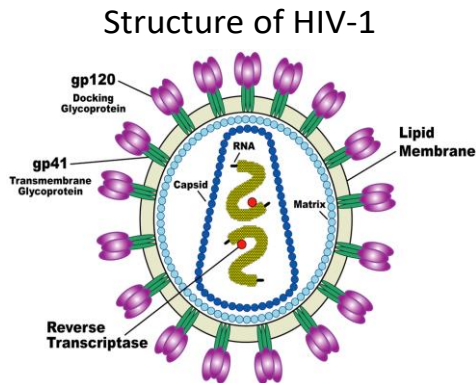


Figure 2: Schematic structure of HIV-1 (Source: ANECCA Handbook on Paediatric AIDS in Africa 2004)

The HIV particle has an outer double lipid (fat) layer derived from the host cell membrane. Within the lipid layer is the surface glycoprotein (gp120) and the trans-membrane protein (gp41), which facilitate entry of the virus into the host cell (**Figure 2**)

The core (capsid) is made of several proteins especially p24 (the main protein). Within this capsid are two single identical strands of ribonucleic acid (RNA), which are the genetic material of the virus (virion). The virion contains a number of enzymes, the most important of which are reverse transcriptase (RT), protease, and integrase.

The HIV life cycle in the host cell can be divided into several steps (**Figure 3**):

a. Binding: The HIV envelope glycoprotein (gp120) binds to the host cell receptors (CD4 molecule) and co-receptors (CCR5 and CXCR4) on the outside of the cell. These receptors and co-receptors determine which cells the HIV virus will infect.

b. Fusion: There is insertion of the trans-membrane glycoprotein (gp41) into the cell membrane of the host cell, with fusion of the two membranes.

c. Entry. The virus particle leaves its membrane behind (uncoating) and the core of the virus is released into the cytoplasm of the host cell. The host cell enzymes interact with the core of the virus, resulting in the release of viral enzymes.

d. Reverse transcription. For the virus to multiply, the viral single-stranded RNA is first converted into double-stranded DNA by the viral enzyme reverse transcriptase.

e. Integration and replication. The viral DNA is then able to enter the host nucleus and the viral enzyme integrase is used to insert the viral DNA into the host cell's DNA. This is called *integration*. Once a cell is infected, it remains infected for life because the viral genetic material is integrated into the host cell's DNA. The production machinery of the host cell produces viral proteins and RNA from which new, immature viral particles are formed in the cytoplasm of the CD4 cell (*replication*).

f. Budding. Newly formed immature viral particles gather at the membrane of the CD4 cells and push through the cell membrane by

budding, taking the lipid bilayer with them, ready to form new viral particles.

g. Maturation. The gp160, embedded in the cell membrane, is cleaved by the enzyme protease to produce functional gp41 and gp120 to form a mature virus, which is then ready to infect a new cell.

Knowledge of the structure and life cycle of HIV is important in understanding the basis for HIV diagnosis and the mechanism of action of antiretroviral (ARV) drugs. Current ARV drugs act mainly by antagonizing the various HIV enzymes necessary for viral replication.

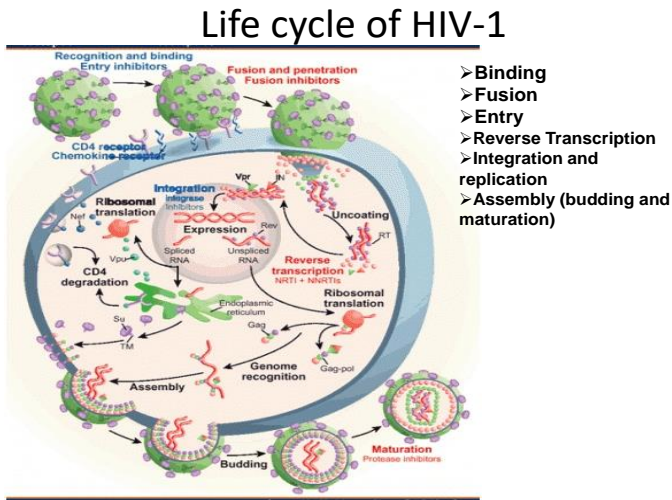


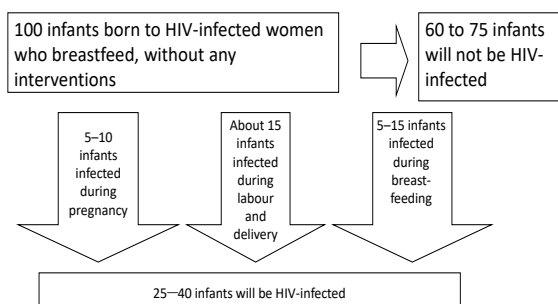
Fig 3. Life cycle of HIV-1(Source: ANECCA Handbook on Paediatric AIDS in Africa 2004)⁶

3. MODE OF TRANSMISSION

Majority (90%) infected children acquired the infection from their mothers – mother-to-child transmission (MTCT), also called vertical transmission. In the absence of any intervention, transmission occurs in 15 – 30% infants born to mothers with HIV infection in non-breast feeding populations, and 25-40% in the breastfeeding

population (**Figure 4**). This transmission occurred during pregnancy (5–10%), during labour and delivery (15%) and during breastfeeding (5 – 15%). With access to ART and other effective interventions for prevention of mother-to-child transmission (PMTCT) this risk can be reduced to <2% as is found in United States and Europe. Currently, Nigeria accounts for about 30% of the global MTCT.

Mother-to-Child Transmission



Overhead 1-9

Fig. 4: Modes of mother-to-child transmission of HIV

Factors facilitating mother-to-child transmission (MTCT)

During Pregnancy:

- High maternal viral load (new infection or advanced AIDS)
- Low CD4 count independent of viral load
- Viral, bacterial, or parasitic placental infections, such as malaria
- Vaginal bleeding (placenta praevia, abruptio)
- Sexually transmitted infections (STIs)
- History of current multiple sexual partners

During Labor/delivery:

- Rupture of membranes for more than 4 hours
- Invasive delivery procedures that increase contact with mother's infected blood or body fluids (episiotomy, artificial rupture of membranes)
- Prolonged obstructed labour
- Instrumental delivery
- Genital lacerations
- First infant in multiple birth
- Foetal genetic characteristics
- Preterm delivery
- Low birth weight

During Breastfeeding:

- Exposure to breast milk
- Prolonged duration of breastfeeding
- Mixed feeding (giving water, other liquids, or solid foods in addition to breastfeeding)
- Breast abscesses, nipple fissures, mastitis in the mother
- Oral disease in the baby (thrush or sores)

Other means of transmission accounting for 10% of HIV in children include:

- Blood transfusions, blood products and organ/tissue transplants. Children with severe anaemia following severe malaria and some children with blood diseases requiring repeated blood transfusions like sickle cell disease, haemophilia, leukaemia and other cancers are most at risk. This mode of transmission has been greatly reduced by national blood safety programmes and improved blood transfusion services.
- Use of contaminated sharp objects including needles, razor blades, clippers and tooth brushes. Scarification marks by traditional healers, communal traditional rituals and “therapeutic procedures” that involve bleeding are potential modes of transmission.

- Sexual intercourse - The first case of AIDS in Nigeria was reported in 1986 in a 13-year old sexually active female. The rising incidences of child sexual abuse especially of young girls by older men, indulgence in high-risk sexual behavior by street children, sexual exploitation of children, and childhood prostitution are also causes of concern. Adolescent girls are particularly vulnerable to transactional sex – sex in exchange for goods, including petty items like cell phones. Peer pressure leading to sexual exploits as well as poverty which increases the vulnerability of young girls engaging in informal/forced sex all expose adolescents to HIV infection.

We carried out a study at University of Port Harcourt Teaching Hospital (UPTH) in 2007 to determine the mode of transmission among 384 HIV-infected children.⁷ Three hundred and forty-six (90.1%) of them acquired the infection vertically (MTCT), 24 (6.2%) were through blood transfusion, 6 (1.6%) were through sexual means, 5 (1.3%) were through contaminated sharp objects, whereas in 3 (0.8%), the source could not be determined. This means that in order to reduce HIV infection in children, emphasis should be on effective and readily available prevention of mother-to-child transmission (PMTCT) of HIV programme.

We also carried out another prospective study at UPTH in 2014 among 71 HIV-infected children who acquired their infection horizontally (non-vertical). The results showed that 47 (66.2%) were through blood transfusion, 13 (18.3%) were through use of contaminated sharp objects, 6 (8.5%) were through sexual route, and in 5 (7.0%) the mode of transmission could not be determined.⁸ All these routes are totally preventable. I also reported the unfortunate case of an HIV-exposed infant in whom mother-to-child transmission was successfully prevented but who acquired HIV infection horizontally after receiving a commercially donated blood (in a rural private hospital), and scarification marks (by a traditional healer) for a febrile illness with convulsion.⁹

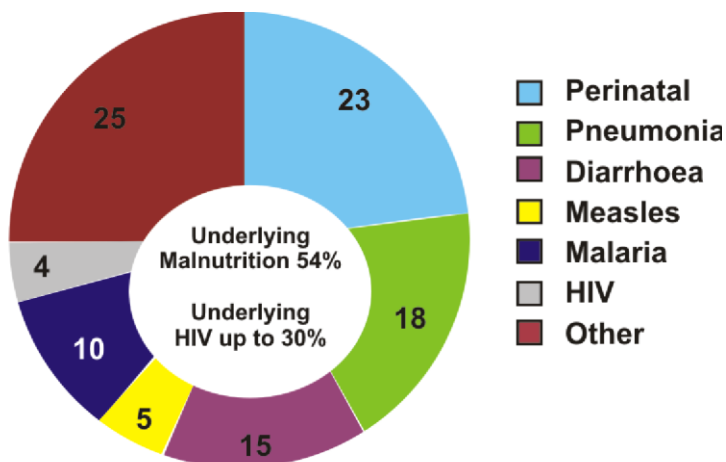
HIV is not transmitted through:

- Casual contact such as sharing food, shaking hands, hugging, or holding babies
- Eating from the plate of an HIV-infected person
- Toilet seat
- Sitting beside an infected person
- Playing together
- Airborne exposure via a person who is coughing or sneezing
- Mosquitoes or other Insect bites
- Witchcraft

The clinical course of HIV infection in children (with no interventions)

- Majority of perinatally HIV-infected children will develop HIV-related symptoms by six months of age
- 34% of infected infants die within the first year of life if not diagnosed and treated.
- Up to 50% of infected children will develop AIDS and die within the first two years of life.
- 75% will be dead by five years if there was no intervention.
- Children with HIV are more likely to die from common childhood illnesses (respiratory infections, diarrhoeal illnesses, tuberculosis (TB), malaria, undernutrition, etc.), including those who survive the first year of their life.

Contribution of HIV and AIDS to Child Mortality



30% of children admitted with malnutrition have HIV

Fig 5: Major causes of death among children under five in developing countries 2002 ^{10,11}

Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome (HIV and AIDS) have reversed many of the hard-won development gains in many Sub – Saharan countries including Nigeria thus increasing child mortality. Moreover, there is a correlation between child and maternal mortality in settings with high AIDS prevalence. Children whose mothers have died from HIV have higher probability of child mortality.

We carried out a study on the pattern of communicable diseases in patients admitted into children medical wards of UPTH between February 2004 and November 2005. Out of the 1,935 children with communicable diseases, HIV/AIDS was the 6th commonest cause of admission and the highest contributor of mortality. ¹² (**Table I**)

Table I: Pattern and outcome of the top communicable diseases in children admitted at the medical wards of the University of Port Harcourt Teaching Hospital

Disease	No. admitted	No.
Died	No (%)	No
(%)		
Malaria	741 (38.3)	4 (0.5)
Pneumonia	557 (28.8)	2 (0.7)
Diarrhoeal diseases	252 (13.0)	2 (0.8)
Septicemia	167 (8.6)	6 (3.6)
Meningitis	80 (4.1)	4 (5.0)
HIV/AIDS	49 (2.5)	10 (20.4)
Measles	37 (1.9)	1 (2.7)
Tuberculosis	33 (1.7)	2 (6.0)
Impetigo	9 (0.5)	0 (0)
Hepatitis	8 (0.5)	0 (0)
Conjunctivitis	1 (0.1)	0 (0)
Mumps	1 (0.1)	0 (0)

My contributions to Knowledge and Management of Paediatric HIV

Mr. Vice Chancellor Sir, Ladies and Gentlemen, since my employment in the University, I have been involved in training both undergraduate and postgraduate medical personnel on care of HIV-exposed and infected children. Paediatric HIV, being a rapidly evolving area with discoveries of new knowledge and insights, I have constantly had to update both the undergraduate and postgraduate medical personnel on new information and guidelines to help them keep abreast of current best practices.

In the area of research, I have contributed to knowledge with presentation of over 38 papers in local and international conferences. I have published 48 peer-reviewed journal articles and 10 chapters in medical text books. I am also a co-editor of the textbook “Pathophysiology of Clinical Symptoms, Signs and Laboratory Parameters which is geared towards increasing the thinking process and thereby greatly improve medical learning and practice. I have also successfully supervised 10 dissertations for senior residents

towards their Part II exams in the Postgraduate Medical Colleges (all of who have become consultants/senior lecturer and one of them a Professor).

I will like to use some of my contributions on research and clinical experiences to highlight the challenges encountered in managing HIV-infected children.

4. Challenges in managing HIV-infected children

With the availability of antiretroviral therapy (ART), HIV infection, which was once considered a progressively fatal illness, has now become a chronic treatable condition in children. However, the challenges these children are forced to face are very daunting. Every aspect of Paediatric HIV is a challenge. The issues usually start while they are still in the womb. There are challenges with clinical presentation and diagnosis, drug administration, dosing and monitoring. There are also issues with disclosure and adherence, stigma, and orphanhood, all having enormous psychosocial, mental and neuro-cognitive effect on child life. HIV does not even come alone and so is associated with many co-morbid conditions like malnutrition, major organ affectation and opportunistic infections, especially tuberculosis (TB). There is also a big issue on dependency on adults for their care. If the adult is not motivated, it will negatively affect their care. These unique challenges must be recognized and understood in order to provide appropriate holistic management to these children to enable them to become productive citizens of tomorrow.

i. Challenges right from the womb

The Human Immunodeficiency Virus is a known contributor to poor maternal and foetal outcome. Untreated maternal HIV infection is associated with adverse pregnancy outcome including preterm birth, low birth weight, intrauterine growth restriction, stillbirth and mother-to-child transmission, as well as maternal mortality with advanced disease.¹³ On the other hand, HIV-infected pregnant women who have received highly active antiretroviral therapy (HAART) before or early during pregnancy have experienced some

adverse outcomes like birth defects (Efavirenz, Dolutegravir),¹⁴ preterm births and low birth weight (protease inhibitor)¹⁵ and maternal anaemia (zidovudine).¹⁶ HIV-exposed infants even if uninfected have higher morbidity and mortality than unexposed infants despite safer breastfeeding and improved maternal health with maternal antiretroviral therapy. This is because, despite the avoidance of HIV acquisition, these children who are HIV-exposed uninfected (HEU) remain affected by HIV, since they are born to women with HIV and live in an HIV-affected household.

We carried out a cross-sectional study at the University of Port Harcourt Teaching Hospital between November 2007 and May 2017 on the pregnancy outcome of HAART-experienced and HAART-naïve HIV-infected women where we looked at 1,640 HIV-exposed infants. The mean birth weight of babies delivered by HIV-infected mothers who took HAART before or in pregnancy was lower than those delivered by treatment-naïve mothers [3.12±0.38Kg in HAART before pregnancy group; 3.13±0.53Kg in mothers who took HAART in pregnancy; and 3.18±0.74Kg in HAART-naïve mothers respectively). Prematurity and low birth weight were also seen more in mothers who had taken HAART. Fourteen (0.9%) babies had birth defects and all of them were in mothers that had taken HAART. The commonest birth defects were neural tube defect 7(50%) and congenital heart defect 4(28.8%). The overall transmission rate was 21.4% [12.5% in mothers that took HAART and 87.5% in HAART-naïve mothers which was seven times more than in mothers who received HAART].¹⁷

It is possible that these medications have some effects on the weight gain of these fetuses especially in late pregnancy, probably by limiting the transport or utilization of macro and micronutrients. We concluded that HAART was very beneficial in greatly reducing mother-to-child transmission although there are possible risks of lower birthweight, prematurity, and potential teratogenic effects of drug exposure on the foetus. So even though the problems start from the womb, our Creator has great plans for them: “For you created my inmost being; you knit me together in my mother’s womb. I

praise you because I am fearfully and wonderfully made.” [Psalm 139: 13]. “Before I formed you in the womb I knew you, before you were born I set you apart; I made you a prophet to the nations.” [Jeremiah 1:5]

ii. Challenges with Clinical presentation

Clinical signs and symptoms are usually useful in making a diagnosis. In children, the clinical features of HIV overlap with those of other childhood diseases thus making it difficult to suspect. The child may have subtle and non-specific ‘flu-like’ symptoms like fever, weakness, sore throat, swollen lymph nodes, and rash. HIV infection may present with conditions that also occur in children who are not HIV-infected such as recurrent ear discharge, persistent or recurrent diarrhea, severe pneumonia, tuberculosis, failure to thrive and severe acute malnutrition. This may lead to missed diagnosis if not actively looked for. HIV infection could also present with conditions that are common in HIV-infected children but less common in uninfected children (such as severe recurrent bacterial infection, persistent or recurrent oral thrush, bilateral painless parotid enlargement, generalized persistent non-inguinal lymph node swelling); as well as conditions that are only seen in immunocompromised children (like *pneumocystis carinii* (*jiroveci*) pneumonia, oesophageal candidiasis, herpes zoster (shingles) and invasive salmonella infection). These should increase the level of suspicion.

The clinical presentation also varies widely among infants, children and adolescents, and geographical location. At birth, most infants with maternally transmitted HIV infection appear perfectly normal on physical examination; however, there is rapid progression of the disease in children thereby resulting in severe immunodeficiency and clinical disease soon after birth.

Features commonly found more in children than adults are weight loss or failure to thrive, chronic diarrhea, chronic cough, prolonged fever, generalized lymph node swelling, enlarged liver (hepatomegaly), enlarged spleen (splenomegaly), oropharyngeal candidiasis, chronic ear discharge, recurrent pneumonia, and

recurrent skin infections. Because these symptoms/signs can also occur in many childhood illnesses, one needs a high index of suspicion. In the United States and Europe, systemic and pulmonary findings are common. In Africa, chronic diarrhea and severe malnutrition (wasting) are commoner.

In a study carried out by Eneh and Ugwu in UPTH between January 2003 and December 2007 ⁷ to determine the clinical presentation among 384 children with HIV infection, 336 (87.5%) children were symptomatic and the commonest symptoms were fever (75.3%), cough (64.9%), weight loss (41.1%) and diarrhea (40.8%). The commonest signs were lymphnode swelling (44%), pallor (39.3%), enlarged liver (38.1%), and oral thrush (23.8%) (**Table II**).

Table II: Symptoms and signs in the 336 symptomatic children

<i>Symptoms and Signs in the 336 Symptomatic Children[#]</i>			
<i>Symptoms</i>	<i>No=336 (%)</i>	<i>Signs</i>	<i>No=336 (%)</i>
Fever	253 (75.3)	Lymphadenopathy	148 (44.0)
Cough	218 (64.9)	Pallor	132 (39.3)
Weight loss	138 (41.1)	Hepatomegaly	128 (38.1)
Diarrhoea	137 (40.8)	Oral thrush	80 (23.8)
Rashes	118 (35.1)	Parotid swelling	23 (6.8)
DDMS	31 (9.2)	Splenomegaly	16 (5)
CSOM	29 (8.6)	Hypotonia	15 (4.5)
Seizures	20 (6)	Hypertonia	10 (3)
RDMS	14 (4.2)	Deep seated ulcers	4 (1.2)

Delayed developmental milestones
 CSOM – Chronic suppurative otitis media
 RDMS – Regression in developmental milestones
[#] Some patients had multiple symptoms/signs

All these features can also occur in other childhood illnesses and thus not specific to HIV infection. Most of the children in the study were already in the advanced disease stages, which indicated delayed diagnosis. This was despite numerous previous contacts with the health-care facilities where they were treated for other childhood illnesses without the suspicion of HIV infection. Persistence of these symptoms and signs however even after treating for common childhood illnesses should make one suspect HIV.

Diarrhoea is such a common feature of HIV infection that it is among the World Health Organization (WHO)'s major criteria for the case definition of paediatrics AIDS as it is experienced by over 50% of patients with HIV/AIDS at some time during their illness, and can be a major source of morbidity and mortality. So, we carried out a prospective study to determine the sero-prevalence of HIV in under-fives presenting to UPTH with diarrhea. We got a sero-prevalence of 9.6% with significantly more HIV-positive patients (75%) having chronic diarrhea. We therefore recommended that since diarrhoea is a common feature of HIV infection, all children with diarrhoea should be screened for HIV.¹⁸

iii. Challenges with Diagnosis

The diagnosis of HIV infection is a great challenge to paediatricians in resource-poor countries because the clinical presentations are similar to those of many other common childhood illnesses in developing countries, and so are not reliable and cannot be used alone for diagnosis. As such, laboratory tests are required for confirmation. When facilities for laboratory diagnosis were not readily available or affordable, the clinician often had to wait for the full-blown development of clinical signs and symptoms of the disease before diagnosis can be made.

Laboratory diagnosis of HIV in children is not straight forward like in adults. For adults, whereas HIV antibody test (which is cheaper and faster and does not require sophisticated laboratory or professional) is diagnostic, this is only so for children older than 18 months of age. This is because all infants born to HIV-infected

mothers are antibody- positive at birth (due to passive transfer of maternal HIV antibody across placenta). Most uninfected children lose maternal antibody between 6-12 months of age (**Figure 6**). Only a small proportion continue to have antibodies up to 18 months of age. Hence, positive IgG antibody tests in infants younger than 18 months cannot be used to make definitive diagnosis.

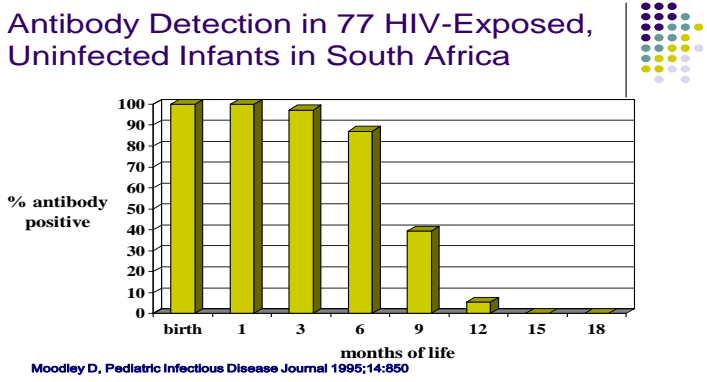


Fig. 6: Antibody detection in 77 uninfected infants from South Africa, tested with Abbott ELISA in a non-breast feeding population. Antibody titers declined gradually during first 3 months, then rapidly thereafter with 94.5% being HIV antibody negative at 12 months and 100% being HIV antibody negative at 15 months.¹⁹

Early infant diagnosis (EID) by virological (antigen) testing is thus essential for young infants less than 18 months born to HIV-infected mothers. The tests include HIV DNA/RNA PCR (polymerase chain reaction), HIV culture and HIV p24 antigen. These tests are very expensive, not routinely available and can only be performed by highly specialized personnel in sophisticated laboratory making it difficult to provide consistent and timely results for caregivers especially in rural areas. Even when children and infants are tested, results can take a long time to come back, which means that families do not always return for the results and never learn of a child’s HIV status. Prolonged turnaround times between

blood sample collection and the return of test results to healthcare providers and parents are critical bottlenecks to early initiation of treatment. Without knowing the HIV status of a child it is impossible to access life-saving treatment, and without treatment, half of all children born with HIV will die by the age of two years. Breast feeding infants remain at risk for acquiring HIV infection. For infants who are still breastfeeding, a negative virologic test cannot reliably exclude HIV. Such Infants must always be tested again 6 weeks after complete cessation of breast feeding.

Point-of-care early infant diagnosis (POC EID) provides the opportunity to reduce test turnaround times, limit patient loss along the HIV testing cascade, reduce infant mortality and facilitate task shifting to lower cadres of health workers at health-care facilities with decentralized services. Adding nucleic acid test (NAT) at birth to the existing national infant testing schedule may result in earlier identification of HIV-infected newborns and consequently lead to earlier treatment initiation and lower mortality among infants.

Provider initiated testing and counselling (PITC) or “opt out” strategy refers to a routine offer of HIV testing and counselling for all patients who visit a health facility by a health professional (particularly in HIV endemic communities), irrespective of the presenting symptoms, and without a separate written consent. So, in order to increase HIV detection in our hospital, we carried out a study to assess the uptake of PITC and its usefulness in case detection at the University of Port Harcourt Teaching Hospital (UPTH). The study revealed that testing was highly acceptable (80%) and has a good case finding rate (6.65%). This facilitated early identification, early referral and early linkage to care and treatment of all those children found to be positive.²⁰ We therefore recommended that such public health strategy that facilitate early detection of HIV and referral for early treatment should be encouraged for wider HIV control and prevention in Nigerian communities.

Where age-appropriate HIV tests are unavailable, WHO recommends that a presumptive diagnosis of HIV (using clinical signs) can be made in infants younger than 18 months if the infant is confirmed to be antibody positive and is symptomatic with 2 or more of the following: severe oral thrush, severe pneumonia, severe wasting /malnutrition and severe sepsis.^{21, 22} We reported six cases in special care baby unit (SCBU) of UPTH in 2009 of neonates (children <28 days of age) who fulfilled the WHO criteria of presumptive diagnosis of severe HIV disease based on the presence of some clinical and immunological criteria.²³

Cases 1 and 6 had severe wasting and severe sepsis, case 2 had severe wasting, oral thrush and severe sepsis, case 3 had severe pneumonia, oral thrush and severe sepsis, case 4 had severe pneumonia and severe wasting while the 5th case had severe wasting and oropharyngeal candidiasis. All the babies and their mothers tested seropositive to HIV-1 antibody.

At the time of this study, DNA PCR was not readily available in this region. When DNA PCR became available in 2007, cases 5 and 6 were tested and confirmed positive. Cases 3, 4 and 6 died at four and half months, 25 days and 42 days respectively. This further buttresses the urgent importance of universal HIV screening for all pregnant women in pregnancy and ARV in pregnancy to reduce their viral load and thus prevent transmission to these innocent babies. The DNA PCR results of two of the cases that were positive further lends support that these clinical signs and symptoms may assist in early diagnosis of HIV infection in young infants. We therefore concluded that where HIV virologic studies are largely unavailable, clinical and immunologic criteria can be used for a presumptive diagnosis of severe HIV infection in children younger than 18 months and may guide the decision to initiate antiretroviral drugs early.

iv. Challenges with Treatment

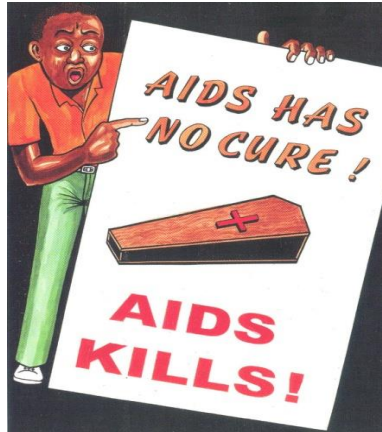


Fig 7: AIDS has no cure

There is no cure yet for HIV which means that once treatment is started with antiretroviral drugs, the child takes the medication for life. This means that these growing children are left with unavoidable challenges of dealing with lifelong adherence with complex treatment regimens. Conveying the importance of HIV treatment to a young child or adolescent can be difficult. Antiretroviral therapy (ART) cannot cure HIV infection or eliminate it from the body. Instead, it stops HIV from replicating, allowing the immune system to recover. If ART is stopped, HIV disease progression resumes. Increasing access to ARV therapy has transformed the prognosis for children and adolescents living with HIV and they are now growing up into adulthood, getting married and, thanks to ARVs, having HIV-negative children of their own.

The goals of treatment with ARVs include:

- To prolong survival
- To promote growth and development
- To reduce HIV-related illnesses and improve quality of life
- To prevent HIV disease progression (by reducing virus growth to undetectable levels)
- To preserve/restore the immune function of the child
- To reduce the risk of (but not prevent) transmission of HIV

Treating an HIV-infected child goes way beyond merely providing antiretroviral drugs.

Ten Point Package For Paediatric HIV Care

- Confirm HIV status as early as possible, conduct disease staging and initiate antiretroviral therapy.
- Early identification and treatment of acute bacterial infections
- Prophylaxis and treatment of opportunistic infections (HIV infection is associated with an increased frequency of common childhood infections which are usually persistent/recurrent, severe, life threatening and responds poorly to treatment)
- Maintenance of good nutrition
- Monitoring of growth and development
- Immunization against vaccine preventable diseases.
- Management of AIDS- defining illnesses
- Psychological support or other social or community based support programs for the family
- Palliative care for the terminally ill child
- HIV status disclosure and planned transition to adult care

Initially, several criteria exist for initiating ARV drugs based on clinical staging and CD4 cell count/percentage, however in 2016, WHO rolled out a new guideline of “Test and Treat”, which recommended that antiretroviral therapy (ART) should be initiated in everyone living with HIV irrespective of the clinical stage/CD4 cell count because of new evidence from clinical trials and observational studies showing that earlier use of ART results in better clinical outcomes for people living with HIV compared with delayed treatment, and that reduction of viral load to undetectable levels will dramatically reduce HIV transmission rate.²⁴

HIV treatments with antiretroviral (ARV) drugs for children work, however it may be harder to achieve virologic suppression in children than in adults. Initially, not much child-friendly ARV formulations were available and the syrups were single drugs,

voluminous, requiring multiple dosing, unpalatable and unpleasant tasting which makes treatment even more challenging. Some of these medicines need to be kept cool in a refrigerator, which can be an issue in some countries like ours with very poor electricity. Unlike in adults also, a child's body is constantly changing and they have a high rate of metabolism, so dosages for infants and children will change as the child grows until the child attains a weight of 25kg when he/she can take adult formulations. This makes the dosing of HIV medicines particularly difficult as pharmacists and paediatricians treating children growing up with HIV need to be aware of special dosage instructions and communicate changes in dosages to the caregivers.

However, there has been major breakthroughs with improved paediatric formulations in the form of small oral pellets (that is easily opened and sprinkled over a child's food, including expressed breast milk) and fixed drug combinations (FDCs) in tablet forms (that are scored and are easily splittable and dispersible). FDCs especially Dolutegravir (DTG) (an integrase inhibitor) based combinations has contributed to more children being virally suppressed. We carried out a prospective cross-sectional study among HIV-infected children and adolescents who were on treatment (with reverse transcriptase inhibitors) at the Paediatric HIV clinic of the UPTH in 2020 to compare the HIV viral suppression rate at baseline and after 6 months of transition to a dolutegravir-based regimen.²⁵ At baseline, 45.3% were virally suppressed (viral load < 1000 copies/ml with 23.6% having undetectable viral load of <20 copies/ml), however after 6 months, 91.5% became virally suppressed with 57.5% having undetectable viral load. Also, 80.6% of those who were initially thought to have treatment failure (because of their persistently high viral load) became virally suppressed. This study thus showed that DTG-based FDC is efficacious in the treatment of eligible children and adolescents with HIV/AIDS with significant viral load suppression.

Broad Spectrum of Needs of HIV-infected children

As HIV is a chronic disease (one that lasts a lifetime), children living with HIV/AIDS (CLWHA) have many needs beyond medical care with antiretroviral drugs. These needs will vary with the individual patient, family and circumstances they are experiencing at the time.

a. Physical Needs - Clinical care, clothing, housing, education for children, toilet needs, care of wounds, personal and oral hygiene, affordable and locally available balanced diet and safe water.

b. Psychosocial Needs - Association with peers without experiencing stigma and discrimination, Confidentiality regarding their HIV status by all who know about it, Love and acceptance from others, Right to live, Visits with friends and family members, Security, Play, Dealing with the child's questions.

c. Spiritual Needs - Access to worship with others, Reassurance that God loves and accepts them, Visitation and support from religious groups, Prayers.

d. Economic and Social Needs - Financial support and Income-generating activities for parents/caregivers, Vocational training, Legal protection against discrimination based on HIV status, Care for Orphaned and Vulnerable Children (OVC).

e. Needs of PABHA - People affected by HIV/AIDS (PABHA) include parents, siblings and other close associates. PABHA need to be taught facts about HIV/AIDS, how to adequately care for infected child, how to prevent being infected while providing care. PABHA need understanding and support from members of the community.

Any hope for a cure for HIV and AIDS in sight?

Although the cure for HIV has been a priority since the virus' discovery, it remains elusive. The Food and Drug Agency (FDA) defines HIV cure as "any therapeutic intervention or approach that controls or eliminates HIV infection to the point where no further medical interventions are needed to maintain health".²⁶ Despite the widespread implementation of highly effective antiretroviral therapy (ART) and subsequent validation of the "undetectable equals

untransmittable,” or U=U concept, millions of new cases and AIDS-related deaths continue to occur annually. However, treatment can control HIV and enable people to attain an undetectable viral load and live a long and healthy life. Scientists are researching two types of cure: a functional cure and a sterilising cure (there is no 'natural cure' or 'herbal cure') for HIV. (There will never be an “AIDS cure” because AIDS is a defining set of symptoms rather than a virus, like HIV).

The types of “cure”

A functional cure (HIV remission) – This is something that suppresses the virus without the need for ongoing antiretroviral treatment. Some people think that antiretroviral treatment is effectively a functional cure as it is capable of suppressing the amount of HIV virus in the body to such low levels that it cannot be detected, or make one ill – but it would still be present. The goal is not to clear the viral reservoir from the human host but rather to reach sustainable infection control in the absence of ART. This is typified in the “Mississippi Baby” and other children, but in all these cases the virus has re-emerged. Most of these children received antiretroviral therapy at birth or very early after infection.²⁷

A sterilising cure (Eradication) – This is one where the HIV virus is eradicated from the body completely, including from hidden reservoirs. This implies that HIV has been removed completely from the human host. There are only two known adults who have been cured in this way: Timothy Ray Brown, also known as the “Berlin Patient” and Adam Castillejo the “London Patient”. Both received chemotherapy and bone marrow transplants as part of a treatment for cancers.^{28, 29} Their transplants came from persons with a natural genetic resistance to HIV. In addition to the CD4 receptor, HIV requires a second co-receptor CCR5 to infect a cell. This co-receptor is congenitally absent in 2.3% of individuals which confers a natural resistance to HIV infection. Both Brown and Castillejo have been deemed cured (no HIV viremia, off ART). The transplants cleared their infections and gave them new immune systems that resist infection with the virus, however, bone marrow transplants are

expensive, dangerous and complicated interventions that can have serious side effects, making them an impractical cure for the millions of people now living with HIV and so are not practical as a wider HIV cure. However, this process has given researchers important information that they are using to work towards a cure.

Researching an HIV cure: the main approaches ³⁰

- 'Activate and eradicate' (sometimes known as 'Shock and kill') which aims to flush the virus out of its reservoirs and then kill the infected cells.
- The 'Lock and Block' technique takes the opposite approach to 'Shock and Kill'. This method aims to trap HIV in its reservoir cell so that it can never be reactivated. Whilst the virus is still present in the body, it is trapped away so that it cannot escape its host cell and cannot replicate.
- Gene editing which aims to change immune cells so they cannot be infected by HIV.
- 'Immune modulation' which is looking for ways to permanently change the immune system to fight HIV more effectively.
- Stem cell transplants which aim to completely eliminate a person's infected immune system and replace it with a donor immune system. This is the most complex and risky approach.
- HIV vaccine? A number of HIV vaccine trials show encouraging results. However, so far, a vaccine would only offer partial protection and would need to be given in several doses and be used in combination with other prevention and treatment options.

So, while there is promising research being carried out in these areas, there is no cure on the horizon yet.

v. Challenges with Loss to follow up and Retention in care

HIV is a lifelong illness. This means that children in care and treatment have to visit health facilities frequently. Despite improved and highly successful programmatic coverage with ART, significant

numbers of children drop out of care at various points along the treatment pathway, and treatment gains fail to reach sufficient numbers of children and adolescents. Children who are lost to follow-up (LTFU) while on treatment compromise their own health and the long-term success of ART program. Loss to follow-up (LTFU) negatively impacts on the immunological benefit of ART and increases AIDS-related morbidity, mortality, and hospitalizations. A child is considered LTFU if he/she has failed to return to clinic ≥ 3 months after the last scheduled clinic appointment and is not known to be dead or transferred out of the facility. In resource-limited settings, patient retention poses a serious challenge to effective treatment of HIV-infected children. Even where treatment is available and accessed, retention in care (i.e. remaining alive and receiving highly active ART at the paediatric infectious disease clinic using clinic visit dates) is a key issue in our setting. Children are more vulnerable to being lost to follow-up than adults because they cannot come on their own for their treatment but rely on their parents/caregivers to bring them for healthcare services.³¹

Given the difficulty in identifying HIV-infected children and linking them to care, we cannot afford to lose them again once engaged in care. More attention needs to be given to finding the patients who miss scheduled clinic visit (using the most cost-effective methods) before they become LTFU with the aim of reengagement in care. This is because children who are LTFU are at a great risk of discontinuation of ART. Retention in care is thus critical in order to prevent medication interruptions, maintain immunologic benefits, prevent HIV drug resistance, viral rebound and treatment failure, monitor drug toxicity and clinical HIV disease progression as well as to identify and treat any new opportunistic infections that may occur.³²

Some of the reasons children are lost to follow up include distance to healthcare facilities, primary caregiver also HIV-infected and too sick to bring child to clinic, a fee-for-service programme, low caregiver level of education, stigma, transportation cost, the burden of frequent hospital visits, resort to alternative treatment and advice,

reliance on spiritual and cultural beliefs for cure, tight work schedules of caregivers and weak follow-up within clinics. Apart from these, an unfriendly clinic environment and unfriendly attitude of care providers and supporting services with consequent negative clinic experience can pose a great challenge to retaining children in care.³³ With this in mind, I carried out a study at UPTH in 2017 to assess the impact of a child-friendly clinic on clinic experience, retention in care and loss-to-follow up of HIV-infected children.

It was an interventional study carried out in three phases. Phase one was a satisfaction survey to find out the patient/caregivers' satisfaction of the clinic environment and services provided, using a self-administered questionnaire. Phase two was the creation of the child-friendly environment, and phase three was a post-provision of child-friendly clinic satisfaction survey.³⁴ There was also active patient tracking done by either the expert clients (volunteer mothers of HIV-infected children) through home visitation or the doctors, through phone communication. The results from this study showed that LTFU significantly dropped from 27.7% to 7.0% and the retention rate significantly improved from 62.5% to 82.5%. From this finding, it was obvious that making the clinic child-friendly can impact greatly on HIV care by improving patient satisfaction and retention of HIV-infected children in care and reducing loss-to-follow up. Identifying and locating children living with HIV (CLHIV) who have missed appointments through regular tracking and tracing are important interventions to ensure all CLHIV are retained in care and receiving regular treatment. However, given the large numbers of patients and the limited resources facing health services, developing strategies that prevent patients from missing appointments may be more cost-effective than tracking those who do not return.

Patient satisfaction is an indicator used to measure and evaluate the quality of healthcare as it assists healthcare providers in identifying patients likely to dis-enroll from care. We carried out a cross-sectional study from September 2018 to May 2019 at the Paediatric HIV clinic of the UPTH to assess patients'/caregivers' perception

and satisfaction with outpatient HIV services with the hope that findings from our study will provide useful information to assist the clinical and non-clinical staff as well as the management of the hospital to develop quality enhancement strategies and interventions that will improve the quality of healthcare and patient satisfaction in the hospital, thus ensuring patient retention in care.³⁵ Our findings showed that majority of the patients (85.53%) were satisfied with the provider interpersonal skills followed by the physical environment at the outpatient department (OPD) (77.63%). However, only 53.29% were satisfied with the waiting and consulting time. The overall satisfaction rate was 73.68% based on the three domains measured. The level of satisfaction with outpatient HIV services at the UPTH is high. Program managers' review of patients' appointment time and use of electronic consultation tool will reduce the consulting and waiting time and further improve patient's satisfaction and retention in care.

vi. Challenges with Adherence

With no cure yet for HIV, the ultimate goal of antiretroviral therapy is to achieve maximal and durable suppression of virus replication. This will in turn reduce the destruction of CD4 cells, reduce immune suppression and slow disease progression.³⁶ These benefits however can only be achieved through consistent adherence to antiretroviral drugs in order to maintain adequate drug levels in the body. Antiretroviral therapy (ART) success therefore hinges on a near-perfect level of adherence in order to achieve a reliable viral suppression. On average, children who are perinatally infected will have to take ARVs 20 years longer than people who acquired HIV as adults, which heightens the complexity of adhering to treatment for children as they become adolescents, coupled with confusion around ARV regimen as they transition between child and adult treatment regimen.

What is Adherence? It is the extent to which a client's behavior (like taking medication, following a diet, and/or executing lifestyle changes) corresponds with the agreed recommendations from a healthcare provider in terms of care (correct date and time for clinic

appointment) and treatment (correct drug, timing, dosing, compliance to food restrictions and no missed doses). This is determined through a **shared decision making process** between the client and health care provider. Unlike drugs for other chronic illnesses where adherence levels of 70-80% are considered adequate to achieve treatment goals, in the case of antiretroviral therapy, adherence levels greater than 95% is required to obtain a successful treatment outcome.^{37, 38} An adherence rate below 95% is associated with increasing levels of virologic failure.³⁷ **Adherence is different from compliance!!!!**

Compliance is a passive behavior in which a patient is following a list of instructions from the doctor. Compliance implies the patient does what he or she has been told to do by the health care provider. Focusing on compliance ignores the importance of the relationship between the health care provider and the child and family. Adherence on the other is a more positive, proactive behavior, which results in a **lifestyle change** by the patient, who must follow a daily regimen.

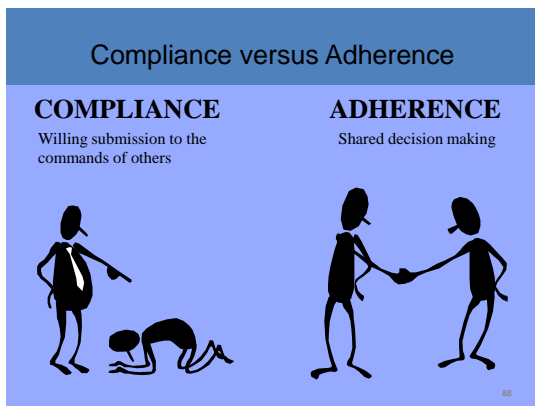


Fig. 8: Comparison of adherence and compliance

Unfortunately, maintaining adequate levels of adherence to antiretroviral medications has proved challenging not only for children and their caregivers living with HIV, but also for healthcare providers because a failing regimen as a result of poor adherence

will lead to treatment failure, increased opportunistic infections, increased hospitalization and outpatient visits and thus increased work load. Non-adherence may eventually mar the dramatic improvements in HIV-related health parameters. Suboptimal adherence may include missed or late doses, treatment interruptions and discontinuations, as well as sub-therapeutic or partial dosing. Taking a pill/pills (no matter how sweet) every single day at specified time/times is not an easy task at all, neither for the child nor for the caregiver!!!! Furthermore, adherence is not static and can vary with time on treatment, thus underscoring the need for continuous adherence education, support, and assessment as integral components of care.

Antiretroviral adherence in young children and adolescents pose unique and formidable challenges. Many of them are still largely dependent on a caregiver to take their medications. Young children and adolescents may refuse to take medication especially as the reason for such medication may not have been disclosed to them. Most paediatric formulations are unpalatable, and taking ARVs with some other drugs for opportunistic infections can greatly add to the pill burden. Understanding the factors that influence adherence is therefore very crucial in order for the health care provider to develop measures to support and sustain patient's adherence in the clinical care of HIV-infected children. This informed us to carry out a study to determine the adherence level and factors influencing adherence among HIV-infected children and adolescents in UPTH in 2013.³⁹

In that cross-sectional survey a total of 213 caregivers and their children were interviewed. A hundred and sixty-two (76.1%) had adherence rates $\geq 95\%$. Only 126 (59.2%) were completely (100%) adherent. The commonest caregiver-related factors for missing doses were forgetfulness 48(55.2%), travelled 22(25.3%) and drugs finished 16(18.4%), while the child-related factors were refused drugs 10(11.5%), slept 8(9.2%), and vomited 8(9.2%). Predictors of poor adherence include mother as the primary caregiver (OR 3.32; 95%CI, 1.33-8.67), younger than 5years (OR 2.62; 95%CI, 1.30-5.31) and presence of a co-morbidity (OR 3.97; 95%CI, 1.92-8.33).

Having a medication reminder strategy (OR 6.34; 95%CI, 3.04-13.31), regular clinic visits (OR 8.55; 95%CI 4.01-18.45) and status disclosure ($p=0.008$) predicted a better adherence. From this study, it showed that adherence was still suboptimal and that barriers to Paediatric ART adherence are largely caregiver-dependent. Thus identifying and addressing these barriers in each caregiver-child pair will improve adherence and patient outcome. With the finding that non-disclosure of HIV status was a big barrier to adherence, we further studied the various aspects of disclosure of HIV status in children.

vii. Disclosure - “breaking the conspiracy of silence”

As more children with HIV survive into adolescence and adulthood as a result of improved access to highly active antiretroviral drugs, one of the most difficult issues that families with HIV-infected children face is disclosure of their children’s HIV status to them. Disclosure of an HIV diagnosis to a child is a controversial and emotionally laden issue. HIV disclosure entails communication about a potentially life threatening, stigmatizing, and transmissible illness, and many caregivers fear that such communications may create distress for the child.

What is HIV disclosure in children? Disclosure in a child refers to a state in which an HIV-infected child or an adolescent gains knowledge of his/her HIV status. Optimal disclosure is disclosure that is age-appropriate, timely (starting as early as possible), prepared, and not accidental. It should be health-promoting (with the child/adolescent made fully aware of his or her own illness and its consequences), family centered, takes place within a supportive and enabling environment and is linked to appropriate support. Such disclosure tends to increase a child’s understanding about his/her condition and facilitate active participation in care and treatment.

Children whose status was disclosed to them took charge of their healthcare, visiting a health facility unaccompanied, ensuring adherence to their antiretroviral drugs and communicated better with their caregivers. Disclosure of HIV status to children is essential for

disease management. For these children, learning about their HIV diagnosis is necessary to building trusting family relationships and an important step towards long-term disease management and transition from pediatric/ adolescent care into adult care settings. As children on antiretroviral therapy (ART) become older, issues of treatment adherence, sexual health, bereavement and transition to adult care cannot be adequately addressed without disclosure.⁴⁰

The American Academy of Pediatrics⁴¹ and the World Health Organisation (WHO)⁴² strongly encourage disclosure of HIV-positive status to start at school-age between 5 and 7 years (incrementally according to their understanding/cognitive development) and that **all** adolescents should also know their HIV status. That way they will be fully informed of their health status and can make informed decisions regarding their actions and life choices.

My colleagues and I carried out a study in 2008 where we interviewed mothers of HIV-infected children attending the paediatric infectious disease clinic at the UPTH in order to explore the mothers' opinion on disclosing their children's HIV status to them.⁴³ The study revealed that although most mothers (84.7%) would want to disclose the HIV status to their children, majority (50.3%) would want to disclose between 15 – 18 years. From a follow-up study we conducted, only 26% have actually disclosed.⁴⁴ Many parents/caregivers delay telling the child about their HIV positive status for a number of reasons. They fear that the child is too young to comprehend and might disclose to other people. They fear that their (parent's) status will be disclosed (since majority of HIV infection in children is vertically acquired from parents to the child). They may be anxious about stigma and discrimination from the community, guilt regarding transmission, uncertainty on how and when to disclose, and fears of negative emotional reactions on the child or how to respond to the difficult questions from the child.

In that same study we explored the reasons for HIV status disclosure or none disclosure among caregivers of HIV-infected children and adolescents. The reasons given for non-disclosure included fear of

disclosure to others (100%), child too young to understand (94.5%) and fear of impact on child's emotional health (56.7%). Among caregivers that have disclosed, the commonest reasons given were child asking why he/she is taking drugs (57.7%) and child refusing to take drugs (57.7%). One of the most difficult questions usually asked by the children during disclosure was: "How did I get the HIV" ⁴⁴

A child is never "not ready" for some level of disclosure even if it means just starting with learning something about his/her body and health. Any child seeing a doctor often and taking medicine every day knows that something is wrong. Children who ask direct questions are ready to hear about their diagnosis and will seek that information elsewhere if the caregivers are not forthcoming in providing it. If children find out their infection status from someone other than a parent, they may feel unable to confide in their parent thus putting a lot of strain and mistrust on family relationship. It is best to start talking with the child early and as honestly as possible, bringing up a little at a time, such as why they are visiting the doctor or taking medicine.

Disclosure can be beneficial for both the caregiver and the child.

Benefits of Disclosure

- Empowers the child to participate in care and treatment
- Enables household members to support treatment adherence
- Disclosure helps child, family and community adopt positive attitude
- Knowledge of status improves self-esteem.
- Have better coping skills and fewer psychosocial problems
- Parents who have disclosed the status to their children experience less depression/stress than those who have not.

In that same study, we also sought to find out whether disclosure was beneficial or not and found that majority of the care givers felt relieved after disclosure (76.9%). Among the children whose status has been disclosed, the caregivers felt there was a positive impact as 92.3% had excellent/good adherence to ARVs following disclosure

while 84.6% reported that the child was more motivated to take ARVs, was more determined to survive (84.6%), had improved social interaction (84.6%), had improved general health (77%) and better self-esteem (69.2%). The major negative impact on the child reported by the care givers were depression (38.5%) and child being scared and cried the whole day (34.6%).⁴⁴

Children react to HIV disclosure in different ways depending on the child's cognitive development, family background and how the disclosure was done (planned or accidental). Disclosure can be a traumatic event for many children (especially for those who learnt of it inadvertently in an unsupportive manner) and can be accompanied by feelings of anger, hopelessness and rebellion. Most accidental disclosure occurs through healthcare providers and other family members and increased inquisitiveness of the child surfing the websites to know what the drugs are used for (a fact that most adults tend to overlook). Disclosure must therefore be gentle and adjusted to the child's age and level of understanding.

Many studies on disclosure in children have largely described it from either the health provider's perspective or caregivers' perspective. We undertook another cross-sectional study on HIV-infected children and adolescents aged 8–18 years who are aware of their status (with child specifically mentioning that he/she has been told they have HIV) attending Paediatric HIV clinic UPTH from April 2015 to March 2016.⁴⁵ We interviewed these children using an open-ended interviewer-administered questionnaire in order to explore the actual impact of disclosure on them as reported by the children themselves, how they have coped and suggestions on how they think it could be done better.

The commonest immediate reactions these children felt were depression (61.5%), sadness (41.0%) and shock (28.2%), however 82.1% stated that immediate reactions had decreased over time as they have come to accept their situation. Coping strategies include becoming more prayerful (61.5%), being closer to parents (46.2%) and making friends with other HIV positive children (23.1%). All

the adolescents (100%) agreed that disclosure has positively impacted on their taking their ARV drugs and clinic attendance and have developed strategies to conceal their status from persons whom they felt should not know about it. This implies that despite initial distress, they had resilience to accept and live with the HIV diagnosis.

The commonest questions they would love to ask were “How did I get it?” (79.5%), “Will the drug cure me?” (67.9%), “How long will I take the drugs?” (56.4%), “Will I die from it? (53.8%) Their major concerns about being HIV infected were the fact that they will take drugs for life (76.9%), may not get married (53.8%) and that they may be rejected by friends if they got to know (46.2%).⁴⁵

One of the things the children did not like about how they were told was that they will die if they do not take their drugs (78.2%). Reminder that they will die and be separated from family and friends especially if they have experienced the death of a family member can be a source of great anxiety, hopelessness and fear. Battling with a stigmatizing illness, taking pills daily and being reminded that they will die can be quite daunting.

The children suggested better ways of disclosing to them like “Don’t tell them they will die if they don’t take their drugs” (79.5%); “Explain to the child how he got it and don’t hide it” (76.9%), “Always answer their questions truthfully and not evade the questions” (65.4%), and “Discuss HIV with child first to prepare his mind” (53.8%).⁴⁵

Another reason why the child’s/adolescent’s HIV status should be disclosed to them is a sure upcoming onset of sexual activity and the need for sexual and reproductive health education to curb transmission of the virus. Although 18 of our adolescents were in a relationship, 12 (66.7%) have not disclosed to their partners, the reason being that they may be abandoned.⁴⁵

viii. Co-morbidities in HIV-infected children

HIV-infected children may present with co-morbidities in form of co-infections, non-infectious conditions and side effects associated with antiretroviral therapy. Co-morbidities in HIV-infected children are other conditions existing simultaneously and usually independent of HIV. Babies are usually born with an immature and naïve immune system, predisposing them to an increased frequency of bacterial infections. When the immunosuppressive effects of HIV are added to this underlying immature immune system, the ability to respond to pathogens and other antigens and the ability of immune systems to recall the memory of past exposure is diminished. This places HIV-infected infants at particularly high risk of invasive bacterial infections. Therefore, the common conditions associated with HIV are frequently infections. There is also impaired response after immunizations so that HIV-infected children are not optimally protected from vaccine preventable diseases like measles and tuberculosis. Common co-infections seen in HIV-infected children include tuberculosis, pneumonia, and diarrhoeal illnesses. Non-infectious HIV-related co-morbidities include malnutrition, HIV encephalopathy, HIV cardiomyopathy, HIV associated nephropathy, and certain cancers. These co-morbidities also have implications for the treatment and care of HIV-infected children, including the timing and choice of antiretroviral drugs. The co-morbidities that confront these children are overwhelming. They constitute the greatest contributors to case fatality and may have a prolonged effect on their health outcomes and survival. In a prospective study we carried out on Paediatric HIV among 384 HIV-infected children at the UPTH between 2003 and 2007, the commonest co-morbidities were tuberculosis 91 (23.7%), pneumonia 59 (15.4%), HIV encephalopathy 45 (11.7%) and malnutrition 42 (10.9%), with the commonest contributors to case fatality being pneumonia (44.4%) and malnutrition (33.3%).⁷ Some of these children had more than one co-morbidity.

In another prospective pilot study we carried out among HIV-infected children at the paediatric infectious disease clinic to determine the prevalence of microalbuminuria (which is one of the

early manifestation of HIV-associated nephropathy (HIVAN), microalbuminuria occurred in 12% of the children. Eighty-three percent of them already had clinical AIDS.⁴⁶

a. Common childhood infections and Opportunistic infections

The T-cell or a CD4 cell is the most important cell of a healthy immune system and this is the cell affected by HIV. As the virus multiplies, it destroys the T-cells. The immune system is very weak without its T-cells, and cannot fight off infections. As such, HIV-infected children get infections that those with strong immune systems do not usually get. They may also get the same infections as those with healthy immune systems — but they may become more sick or fall sick more often. The fewer the number of CD4 T-cells, the sicker the person. Respiratory infections and diarrhoeal illnesses are the most common causes of morbidity and hospital admissions in children with HIV. Diarrhoea is often complicated with malnutrition.

Characteristics of infections in HIV-infected Children

- Mostly caused by the same pathogens causing infections in HIV-uninfected children as well as organisms that are rare in HIV-negative children
- Frequent/Recurrent
- More severe
- Last longer
- Not as responsive to treatment
- Have high mortality

Opportunistic Infections (OIs)

These are infections caused by organisms that would not cause disease in a person with a well-functioning immune system. In other words, infections take the opportunity of the weak immune system. They occur more commonly with advancing immune compromise. Children with HIV/AIDS are especially susceptible to OIs due to suppression of their immune system, and indirectly, due to presence of certain conditions that influence the immune system like psychological stress and poor nutritional status. The OIs are often occult, with unusual clinical presentation and involves unusual

organisms. They are often difficult and expensive to treat. This is why prevention of infections with chemoprophylaxis, especially with cotrimoxazole is a crucial component of care of HIV-infected children as it reduces morbidity and mortality. Enrolling into care and initiating ARVs as early as possible before destruction of CD4 cells can also forestall getting an OI.

Common opportunistic infections associated with HIV include:

- Tuberculosis (a bacteria)
- Cryptococcosis meningitis (a fungus).
- Toxoplasmosis (a parasite).
- Pneumocystic jiroveci pneumonia (PJP) (a fungus)
- Candidiasis (a fungus).
- Cryptosporidiosis (a protozoan parasite)
- Cytomegalovirus diseases (a virus)
- Herpes simplex virus (HSV) (a virus)
- Isosporiasis (a parasite)
- Histoplasmosis (a fungus)
- Salmonella (a bacteria)
- Certain cancers, including Kaposi's sarcoma.

b. TB/HIV co-infection – “a deadly duo”

Worldwide, tuberculosis (TB) is the most common co-infection among people living with HIV. It can be very serious and if it is not treated, it can kill. HIV infection is one of the reasons for the resurgence of TB infection and progression to active disease as well as increased risk of reactivation of latent TB.⁴⁷ Children with HIV infection are between 5-10 times more likely to develop TB, and children with dual infection of TB and HIV are 4 times more likely to die than those with TB alone. HIV and TB pathogens thus interact, acting in synergy and resulting in profound immunosuppression, an accelerated clinical course and premature death if not treated.

Clinical features of TB like a persistent cough, fever, unintended weight loss, poor appetite, enlarged lymphnodes and night sweats are also found in HIV infection making it difficult to differentiate

between the two. Diagnosis of TB in children is difficult as the commonest form is smear negative TB. Children less than 8 years rarely cough up sputum and the bacillary load is usually small which may not be detected by the standard GeneXpert and unless gastric aspirate or stool sample GeneXpert is done, bacteriological diagnosis is often not possible. Mantoux test is often negative as most of these children are also severely malnourished which interferes with delayed hypersensitivity response. Most children will however be diagnosed clinically with radiological support.

Treatment of TB in HIV-infected children is also a challenge because of drug-drug interactions of anti-tuberculous drugs (Rifampicin) and ARVs (non-nucleoside reverse transcriptase inhibitors like nevirapine and protease inhibitors like lopinavir and ritonavir) which may require dose adjustment or outright switch of drugs. There is also synergistically increased toxicity in co-ingestion of some ARVs and anti-tuberculous drugs (hepatotoxicity: nevirapine, isoniazid, stavudine); optic neuritis (ethambutol); Nephrotoxicity and ototoxicity (Streptomycin, tenofovir).

We carried out a retrospective study in UPTH from 1st January 2011 to 31st December 2014 to find out the prevalence of HIV infection among children 0-5 years with tuberculosis. Of the 179 under-5 children with TB, 72 (40.2%) of them were HIV positive. Although majority of the children had BCG vaccine in early infancy, they were not optimally protected.⁴⁸

We carried out another study among school age children aged 6-18 years which showed that of the one hundred and forty children in that age group that were treated for tuberculosis in our facility, 41 (35%) of them were HIV positive.⁴⁹ We therefore recommended that an effective school health services should be established in all our primary and secondary schools in Port Harcourt to aid early detection of these infectious diseases and prompt commencement of treatment. Pre-school entry medical exams should be made compulsory in all the primary and secondary schools in Port Harcourt. Following these findings, we carried out public

enlightenment campaigns in some primary and secondary schools in Port Harcourt to increase awareness. We also commenced universal TB screening in our outpatient clinics for all patients, irrespective of the presenting complaints, in order to improve case finding.

Of a greater concern is the development of multidrug resistant TB (MDR-TB). MDR-TB presents with similar features and is transmitted in the same way as drug-sensitive TB, but its progression is rapid and its treatment, associated drug toxicity, and monitoring constitute a heavy burden to the patients in particular and the health system in general. In our study on Multidrug Resistant Tuberculosis in Children in Port Harcourt over an 18-month period from January 2018 – June 2019, one (25%) out of the 4 children diagnosed with MDR-TB was also HIV-infected.⁵⁰ The pill burden of taking anti-TB drugs and ARVs can be enormous as both drugs are taken at different times of the day and involves multiple pills.

c. Immune reconstitution inflammatory syndrome (IRIS)

In HIV infection, an exaggerated inflammatory reaction to a disease-causing microorganism (especially mycobacteria tuberculosis, varicella zoster, herpesviruses, and cytomegalovirus (CMV)) sometimes occurs when the immune system begins to recover rapidly (immune restoration) following treatment with antiretroviral (ARV) drugs. This is known as Immune reconstitution inflammatory syndrome (IRIS). It occurs in two forms: "unmasking" IRIS refers to the flare-up of an underlying, previously undiagnosed infection soon after antiretroviral therapy (ART) is started; "paradoxical" IRIS refers to the worsening of a previously recognized infection after ART is started. IRIS can present with mild or life-threatening symptoms and signs which are diverse depending on the infectious or noninfectious agent involved. In these patients, clinical deterioration occurs despite increased CD4⁺ T-lymphocyte counts and decreased plasma HIV-1 viral loads. Because of wide variation in clinical presentation and the spectrum of symptoms and etiologies, diagnosis remains problematic. Furthermore, no test is currently available to establish an IRIS diagnosis. Low CD4⁺ cell count or CD4⁺ percentage, higher HIV RNA at ART initiation and

the type of opportunistic infection especially tuberculosis at antiretroviral therapy initiation, has been found consistently to be a risk factor for IRIS. In patients with TB, the rate of paradoxical IRIS could be as high as 30% to 43% after antiretroviral treatment initiation^{51, 52} In such situations, sequential treatment for TB and HIV is recommended, starting with anti-TB drugs for at least 2 weeks before initiating ART. The risk of increased rates of IRIS following early antiretroviral therapy in tuberculosis has to be weighed against the benefit from early antiretroviral therapy. In severe cases where the discontinuation of ART is a possibility, the potential disadvantages of therapy cessation, such as the development of viral resistance or AIDS progression, should be considered.

d. Malnutrition (Micro and Macronutrient deficiency) and HIV (another deadly duo)

Malnutrition can be defined as “the cellular imbalance between supply of nutrients and energy and the body’s demand for them to ensure growth.”⁵³ Malnutrition and HIV are strongly related and complement each other. There is a vicious circle between HIV infection and malnutrition. This vicious circle contributes in depressing the child's immune system. On the one hand, malnutrition damages the lymphoid tissues, decreases the concentration of CD4 T-cell, elicits dysfunctions in the immune system, promotes increased vulnerability of the host to infections, increases oxidative stress, which can accelerate immune cell death.⁵⁴ These immune dysfunctions are referred to as nutritional-acquired immune deficiency syndrome (NAIDS).⁵⁵ This ultimately leads to an increased HIV replication with rapid progression of HIV infection to AIDS. On the other hand, HIV infection increases catabolism, HIV-related opportunistic infections such as persistent diarrhoea or oral and oesophageal candidiasis which have a negative impact on nutritional status among children. HIV/AIDS and malnutrition thus form a **deadly duo** with each one fueling the other. Use of antiretroviral therapy (ART) without nutritional support, or nutritional support without ART, will often result in poor treatment

responses and outcomes. Thus, nutritional care is fully part of the paediatric HIV healthcare package.

Malnutrition is so common and a major problem in HIV-infected children that it is one of the major criteria for WHO clinical case definition of Paediatric HIV/AIDS.⁵⁶ HIV wasting was included as an AIDS-defining condition (ADC) in 1987 by the Centre for Disease Control (CDC) and Prevention and is defined as an involuntary weight loss of >10% from the baseline.⁵⁷ The risk of death is three times higher in malnourished children who are HIV-infected (even when patient is on effective ART) compared to those who are not infected.

All forms of malnutrition - Acute malnutrition (wasted), Chronic malnutrition (stunted) or mixed malnutrition (wasted and stunted) can be found in HIV-infected children living in resource-limited settings. HIV can cause malnutrition through a number of ways including inadequate calorie intake from poor appetite, mouth ulcers, increased nutritional needs and higher requirement for micronutrients, persistent/chronic diarrhea from infections as well as side effects of certain ARVs (ART-induced diarrhea); HIV enteropathy from direct HIV-mediated and indirect cytokine-mediated damage to the gastrointestinal mucosa in the absence of pathogens, with resultant malabsorption and micronutrient deficiency.

Micronutrient (vitamins and trace elements) deficiencies often coexist with macronutrient (protein and carbohydrates) deficiencies and can produce dysfunctions in the immune system and other host defensive mechanisms. Clinically, the most important of the single nutrient deficiencies, in terms of their immunological effects in malnourished children, are the vitamins A and C, and the trace metals, iron and zinc.

We carried out a case control study of 70 HIV sero-positive (subjects) and 70 age and sex matched HIV sero-negative children as controls at the University of Port Harcourt Teaching Hospital in

2014 to determine their nutritional status and their serum zinc levels.⁵⁸ The results showed that among the subjects, 57.1% were underweight as against 4.3% of the controls. Forty-five (64.3%) of the subjects were stunted with 22.9% being moderately or severely stunted. This is in sharp contrast to the control group, where only 14.3% were stunted, and they were all in the mild category. Twenty-nine (41.4%) of subjects were wasted and of these 21.4% had moderate to severe wasting. Only six (8.6%) of the controls had mild wasting.

Forty-two (60%) of the subjects were zinc deficient as against 29 (41.4%) of the controls ($p=0.028$). Zinc deficiency was associated with advanced HIV disease ($p=0.003$), children younger than 60 months, lower socio-economic classes, stunting, wasting and underweight and also manifested clinically with increased severity and duration of diarrhoea and pneumonia. We concluded that there is a high prevalence of zinc deficiency in HIV-infected children and based on this, we now place them on routine zinc supplementation as part of their management to improve their immunity. We also provide them with nutritional supplements and counselling.

ix. Impact of HIV on Psychosocial/psychological well-being of children

HIV is a social disease and its management requires all aspects of physical, psychological, spiritual and social support along with community mobilization and participation.⁵⁹ Psychological well-being is one of the important elements of children's health and development. Psychosocial wellbeing is when individuals, families, or communities have cognitive, emotional, and spiritual strengths combined with positive social relationships. It is a combination of feeling good, feeling happy, well-supported, satisfied with life, capable and functioning effectively. Psychosocial well-being increases resilience to stress and encourages one to learn, grow, and bond with others thus enabling them to successfully overcome difficulties and achieve what they want out of life. Important components of psychological well-being (like autonomy, competence, healthy relationships, self-acceptance and purpose and

meaning of life) are all affected in HIV-infected children. ⁶⁰ Psychological well-being is only attained by achieving a state of balance affected by both challenging and rewarding life events.

Children infected with HIV face social, emotional and psychological hardships beyond their capacity. Several stages can be sources of great stress for both parents and the child, including the initial diagnosis, dealing with a lifelong illness that has no cure yet, disclosure of disease status to the child, difficulties resulting from long-term care, including financial and emotional strain, limitation of developmentally appropriate functioning, dependency on medication, need for frequent hospital visitation for medical care than is normal for their age, disfigurement resulting from certain opportunistic infections or severe wasting accompanying progressive disease, dealing with stigma, discrimination and social isolation, and preparation for and acceptance of the patient's eventual death or bereavement. To mitigate these events, it is important to encourage children to have a positive outlook on life.

The various psycho-social implications on children include anger, pain, fear, anxiety, depression, loneliness, grief, guilt and shame, lack of interest in surrounding, loss of confidence, feeling unloved, feeling worthless or inferior to others, blaming self for the sufferings the family is going through, feelings of isolation, suicidal tendencies, lower cognitive abilities and other behavioural problems. Many psychosocial problems are rooted in stigmatization, lost hope, chronic poverty, inability to meet basic needs, and inability to fill normal social roles such as that of parent/child relationship.

For HIV-infected children who live to adolescence, the normal stressful developmental challenges of this stage, including puberty, sexuality and the desire to "fit in" with peers are seriously compounded by being HIV- infected. The realization that living daily with the virus will mould the decisions that they make in their social lives like who to hang out with, disclosing to friends especially sexual partners, and adaptations to the demands of self-management of their health care can be overpowering. The

detrimental effects of HIV on growth and pubertal development pose significant challenges and additional psychosocial stress for the infected teenager. Unidentified and untreated pubertal abnormalities in HIV-infected children may result in adverse psychosocial consequences and reduced final adult height.

We carried out a cross-sectional comparative study among HIV-infected adolescents aged 10-18 years and age and sex matched HIV-uninfected adolescents attending University of Port Harcourt Teaching Hospital (UPTH) and Braithwaite Memorial Specialist Hospital (BMSH) to determine their pattern of pubertal development.⁶¹ The findings showed that the proportion of HIV-infected adolescents with pubertal delay was 4.7% compared to 0.6% in non-HIV-infected adolescents. HIV-infected adolescents attained puberty at significantly later ages than non-HIV-infected adolescents with pubertal delay being significantly more common in adolescents in late WHO clinical stages.

The family having children with HIV/AIDS is generally a family dealing with crisis, illnesses, lack of resources, social isolation, and in need of medical, psychological and social services. It is important to assist these children and their families through inter-disciplinary interventions oriented to improving the quality of life. Given the myriad psychosocial stressors and issues encountered by HIV infected children and youth, comprehensive mental health care services remain crucial.

x. Quality of life (QoL)

HIV infection in children is a chronic illness with effect on physical, emotional and social well-being which will thus affect their quality of life when compared to uninfected children, or even children with other chronic diseases. So as the focus shifts away from just survival, the next challenge is to optimize the health of these children in order to improve their quality of life. Health-related QoL measures provide a more comprehensive assessment of the physical, psychological, and social functioning of children since health outcome measures focused on CD4⁺ cell percentage or viral load

might not provide a complete information about the overall impact of the illness and the treatment. The QoL can be affected by the treatment regimen, side effects of the drug, need to adhere to life-long ART, frequent illnesses and hospitalizations, poor body image and low self esteem, activity restrictions, stigma and discrimination, regular clinic visits, and frequent school interruptions. All these issues can affect functional, physical, psychological and social performance, leading to a significant impact on health related quality of life of HIV-infected children. Supporting a family holistically can be the best way to ensure a good quality of life for the child. This should include social protection schemes that provide external assistance to poorer families in areas where HIV prevalence is high. Such schemes are now seen as a valuable part of improving the quality of life of children affected by HIV.

xi. Stigma and discrimination

Vice Chancellor Sir, the epidemic of HIV brought up other epidemics – fear, ignorance, denial, stigma and discrimination. Early description of stigma can be found in the Holy Bible where lepers are required to ring a bell and announce “Unclean!, Unclean!!, Unclean!!!” to warn any person that they are around.

Leviticus 13:45-46 45 “Anyone with such a defiling disease must wear torn clothes, let their hair be unkempt, cover the lower part of their face and cry out, ‘Unclean! Unclean!’

46 As long as they have the disease they remain unclean. They must live alone; they must live outside the camp”.

While leprosy in the Bible symbolizes the defilement of sin which results in separation from God and the community, a report in the National Press, Kiev Culture, Ukraine in 1986 states that “AIDS is not just a disease, it is a sanitary inspector which helps rid society of people who have led an immoral way of life.”⁶²

A religious leader in Zambia who discussed HIV-positive patients in a local clinic said, “Those patients are promiscuous . . . careless with themselves. God is punishing them for disobedience . . . the diseases

are not traditional in nature and those affected are examples of what God can do to those who disobey His commandments.”⁶³

It must be clearly stated however that all these assertions are wrong as being HIV-infected is not a punishment from God for disobedience or any wrong doing. Also, HIV is not always as a result of immoral behaviour especially in children as 90% are from mother-to-child transmission which is of no fault of theirs. Even for adults some are not from immoral behaviours as they may have acquired it from infected blood transfusion or inadvertent sharing of contaminated sharp objects.

What is Stigma? Stigma has been defined as a perception of “differentness” and occurs when society labels someone as tainted or less desirable. Merriam-Webster dictionary defines stigma as a set of negative and often unfair beliefs that a society or group of people have about something or somebody. HIV/AIDS-related stigma contributes to the “hidden burden of disease” and has contributed immensely to the poor access to services for HIV-affected families. What is HIV discrimination? Discrimination is the practice of unfairly and unjustly treating a person or group of people differently from other people or groups of people based on their real or perceived HIV status.

HIV-related stigma and discrimination thus refers to prejudice, negative attitudes and abuse directed at people living with (or affected by) HIV/AIDS which has created and perpetuated social inequalities. It is the greatest challenge to slowing the spread of the disease. Fear of stigmatisation has pushed the epidemic underground in some places. The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) cites fear of stigma and discrimination as the main reason why people are reluctant to get tested, disclose their HIV status and take antiretroviral (ARV) drugs.⁶⁴ It has been estimated that over 50% of vertical HIV transmissions globally can be attributed to the cumulative effect of stigma because it affects a pregnant woman's decision to enroll on PMTCT programmes and interrupt adherence

to treatment and retention in care.⁶² Many women were afraid to tell their husbands and other family members of their HIV status, leading them to stop treatment because they felt unable to explain why they were on medication.

As a matter of fact, the terminology alone – ‘mother-to-child transmission’ to some extent portrays some level of stigmatization on the women, since it implies that the woman is solely to blame for the infection of the child. Some persons have therefore adopted an alternative terminology, ‘parent-to-child transmission’ (PTCT), as a way of shifting the emphasis away from women alone, and portraying the role of fathers and thus encouraging fuller participation and inclusion of men in the range of prevention, diagnosis, treatment and support services.

A significant milestone in most children’s long-term disease management is learning their HIV status. Caregivers often cite fears about the child telling others and subsequent stigma and discrimination of the child and family as a major barrier to disclosure. For them, not disclosing their own or their child’s HIV status was an important protective strategy to avoid stigma and discrimination. Efforts to promote disclosure and adherence will need to consider and confront challenges related to stigma and discrimination.

Children living with HIV are more vulnerable to experiencing stigma and discrimination. Myths and misinformation increase the stigma and discrimination surrounding HIV and AIDS. In 2011, the United Nations General Assembly Political Declaration on HIV/AIDS made “eliminating stigma and discrimination” one of its 10 targets for ending HIV/AIDS.⁶⁵ Without addressing HIV-related stigma and discrimination, the world will not achieve the goal of ending AIDS as a public health threat by 2030. As millions of children gain access to lifesaving treatment and transit into adolescence and adulthood, emphasis is now moving from merely survival to interventions to address the significant impacts of stigma on long-term outcomes.

From early in the AIDS epidemic, a series of metaphors have been used to describe HIV. These include HIV/AIDS as the “**Grim Reaper**”, “**punishment**” for immoral behavior, “**crime**” in relation to innocent and guilty victims, as “**war**” in relation to a virus which needs to be fought, and as “**horror**” in which infected people are demonized and feared. The fear surrounding the emerging HIV epidemic in the 1980s largely persists today. At that time, very little was known about how HIV was transmitted, which made people scared of those infected due to fear of contacting the incurable and deadly virus. This fear, coupled with many other reasons, means that lots of people **falsely** believe that:

- HIV and AIDS are always associated with death
- HIV is associated with behaviours that some people disapprove of (such as homosexuality, drug use, commercial sex or infidelity)
- HIV infection is the result of personal irresponsibility or moral fault (such as infidelity) that deserves to be punished
- HIV is only transmitted through sex, which is a taboo subject in some cultures

Boma (15years female) has this to say....“Because we were taught in school that you get AIDS if you sleep around, some of my friends already think I am messing around with boys”

Shirley (13years female) “Once they know...they isolate you. You will be eating alone on your plate, using your own cup and spoon, and if anyone accidentally touches your cup or spoon, they will run and scrub their hands thoroughly with a disinfectant. Sometimes they may abandon their things to you if you have touched it!”

For children who have been diagnosed with HIV/AIDS, the stigma, discrimination and abuse that may happen is often silent but deep.

Furo (17years male orphan) "Imagine how it feels when people run away from you. I had so many questions to ask like “how and why did I get it?”, “why am I stunted?”, “what sin did I commit that God is punishing me for?” I only found out about my condition after mum and dad died, so no one could answer my questions. Because

people around me wanted nothing to do with me, I have withdrawn myself too from the world around me and hope that one day, this terrible disease will all go away and I will be OK. But there is little hope of that – they say there is no cure yet for this disease. I am still alive now only because I am taking my drugs (antiretrovirals) regularly, but inside I feel like I am dying because of the way people think, feel and behave towards those of us living with HIV".

Although there has been a tremendous advance in people's understanding and awareness of HIV and the call for "zero stigma and discrimination" is being hailed globally, it continues to impact on the lives of children at many different levels. For HIV infected children, stigma and discrimination is experienced in many settings (individual, household, community, school, playgrounds, healthcare and worship places).

***At Individual level** – They have low self-esteem and feel dejected and abandoned. This will force HIV-infected children to withdraw into themselves and avoid contact with other children for fear of a negative reaction.

***In the household setting**, stigma is manifested in the form of verbal abuse, rejection, eviction and imposed restrictions on the child, blame, anger, denial, and withdrawal of treatment and care, sometimes leading to blatant neglect. Many HIV-infected children and adolescents are orphans with many being cared for by uninfected relatives and extended family members. The discrimination experienced at the caregiver level including delays in giving children medicines or taking them to clinic negatively impact on these HIV-infected children. Some adolescents have to hide the fact they are on a medication, and take the medication in secret. Some caregivers delayed disclosure of their HIV status or the child's HIV status to spouses (or sexual partners) and children because of fears about stigma. Many of our children and their mothers have been abandoned by their father/spouse because of their HIV status.

***In the community settings** – especially amongst discordant couples (where mother is infected and the father is not), many HIV-infected

women (and their infected children) have been forced to leave the house and are abandoned. HIV-infected persons are ostracized and not allowed access to communal things like fetching water, attending meetings or other social gatherings. There is shunning and avoidance of everyday contact, verbal harassment, physical violence, verbal discrediting and blaming, gossip, and denial of certain traditional rights and privileges. Many have been evicted from their houses or forced to relocate somewhere else. Most parents have also lost their jobs which will throw the family into poverty.

**In schools*, HIV-infected youths experience stigma from peers in the form of taunting, gossiping, or bullying which may lead to problems in school attendance and performance. In the classroom, children are often subjected to isolation, name calling and jeering due to the disfiguring skin conditions, stunting and pubertal delay that may result from HIV and which leads others to make assumptions about the child's HIV status. Children often miss school to attend clinic and to collect their ARV drugs and such regular absenteeism will lead to questions being asked about their condition and some punitive measures meted against them by the teachers. The children thus face the dilemma of missing school (and being punished) or missing clinic appointments and drug pickup (and get sick from not taking drugs).

Children go to considerable lengths to conceal their ARV drugs from fellow classmates, so that their HIV status is not revealed. This commonly results in drug doses being missed or taken late. Whilst they are fully aware that poor adherence will result in treatment failure and the deterioration of their own health, these children are driven by fear of the way others will treat them if their HIV status is revealed, to take the risk associated with concealment. However, despite the alarming rate of stigmatization, it is encouraging that most school-aged children could still attend school. As a consequence of stigma, some HIV-infected children still face restricted access to school while the majority face some type of exclusion including remaining day students. Fear of transmission, and misconceptions of the disease are major reasons for

stigmatization at school. Increasing children's knowledge and dispelling myths about HIV/AIDS may reduce stigma and discrimination at school.

In the cross-sectional study we carried out at UPTH in 2020 on adolescents who are aware of their status, they reported that as a form of stigma management, and to protect themselves against negative reactions and social isolation, they are often selective about who they hang out with and whom they tell. None of the children agreed to tell the school authorities or classmates while 14.1% felt stigmatized (treated differently by peers and teachers).⁴⁵

****In places of worship*** – In many places of worship, HIV-infection is still preached as a punishment from God for living immoral lives. Such persons are therefore avoided. Furthermore, the practice of faith healing in various churches has led some children to stop their ARV treatment as they pray for healing from HIV, resulting in poor adherence, virologic failure, frequent opportunistic infections and a greater likelihood of AIDS-related death.

****In healthcare facilities*** - HIV-related discrimination in healthcare can take many forms, including minimizing contact with/or care of children living with HIV, negative attitudes and degrading practices by health-care workers, delaying or denying treatment (including absence of dedicated equipments for HIV-infected children) and isolation of children living with HIV from other patients. Healthcare workers may violate a child's privacy and confidentiality, including disclosure of a child's HIV status to family members or hospital employees without authorization. In some health care settings, services are segregated based on HIV status. HIV-infected children are kept apart from other children who are not infected and some clinics are clearly labeled "HIV clinic" so that as soon as one emerges from there, people will just say, "that one is HIV-infected." Even when the services are made free, fear of stigma will not allow them to utilize such services. Most of them mixed with only HIV-positive people or health care professionals managing HIV-infected children. They experience constant fear of being discovered and

enduring further isolation, remorse and guilt. They go through self-imposed isolation and social exclusion. Caregivers often travel long distances to attend clinics far from home to avoid recognition either by healthcare staff or by other clinic attendees. We have so many clients from cities in neighboring states – Yenagoa, Aba, Owerri, Benin, Asaba, Onitsha, Abakaliki, Enugu, Bonny, Calabar- not because there are no centres that offer HIV services in these areas, but these parents are forced to make these tortuous journeys with their children to avoid stigma. Some caregivers who are not HIV-infected are reluctant to take the children to a clinic because they are afraid that they would be seen at the HIV clinic and others would assume they were infected.

Stigma and discrimination not only impact on children’s psychological well-being and mental health but also on their adherence to ARVs. Stigma-related experiences of HIV-infected children and adolescents like social isolation and rejection, discrimination, denial of human dignity, physical violence, lack of self esteem, anxiety, hopelessness and depression will all impact on their development, decrease their quality of life and hamper treatment behaviors.

“Whenever AIDS has won, stigma, shame, distrust, discrimination and apathy was on its side. Every time AIDS has been defeated, it has been because of trust, openness, dialogue between individuals and communities, family support, human solidarity, and the human perseverance to find new paths and solutions.”

- Michel Sidibé, Executive Director of UNAIDS ⁶⁶

Five forms of stigma have been identified - Perceived, Enacted, Internalized, Anticipated and Associative stigma. ^{67- 70}

Perceived Stigma (Felt Stigma)- This refers to the individual's subjective belief or personal awareness about the attitudes or behaviors of others towards them. Children fear losing friends or not being able to share food or sleep in the same room as other children

because they feel that they will be rejected or treated differently. Adolescents fear social isolation/rejection, losing friends, being hated, chased away from peers, diminished social interactions, and loss of respect among peers. They feel that some people perceive them as less competent than usual, that others are concerned that they could “catch” their illness through contact like a handshake or eating food they prepared, that others may feel awkward and tense when they are around them, and fear that someone may tell others about their illness without their permission. Perceived stigma may be underestimated as asking caregivers about the children’s feelings can only be approximate and not completely reflecting the opinion of the children. However, the actual stigma experienced might be quite different from the perceived stigma.

Enacted (Lived experiences) - Enacted stigma refers to the real life experience of discrimination and prejudice experienced by HIV-infected children. It involves the behaviors, attitudes, hostility, overt acts of humiliation directed by others towards HIV-infected persons. Discrimination can be described as the enactment of stigma. Even if others were not aware of the child’s status, some caregivers still prevented their HIV-infected child from playing and sharing toys with other children for fear that HIV could be transmitted or that others would discover the child’s status. In this manner, caregivers enacted the social isolation presumptively based on their fears. Other forms of enacted stigma include loss of community due to neighbors moving away after knowing one’s HIV status, loss of employment or loss of customers by HIV-infected business owners, family members and friends refusing to share food or utensils, and a general loss of respect in the community.

Internalized (Self-stigma) - Internalized stigma involves thoughts and behavior stemming from a person’s own negative perceptions about himself/herself because of their HIV status. It describes the process in which an individual accepts society’s negative evaluation and incorporates it into personal value and sense of self. The stigmatized person adopts the negative societal beliefs and feelings, as well as the social devaluation. Internalized stigma was often

experienced as feelings of shame of being infected, or for mothers, shame from infecting their child. A common manifestation of internalized stigma was having low self-esteem, feelings of “hating themselves” and “insulting themselves in their hearts,” shame, loss of self-efficacy, low self-confidence and hopelessness, feeling unworthy of the very social interactions with family and friends that they so feared losing due to their HIV status. Internalized HIV stigma encompasses feelings of being “less than” others, dirty or unclean, and/or deserving of negative outcomes due to having HIV. Self-stigma and fear of a negative community reaction can hinder efforts to address the HIV epidemic by continuing the wall of silence and shame surrounding the virus. Negative self-judgement resulting in shame, worthlessness and blame represents an important but neglected aspect of living with HIV. Self-stigma affected a person's ability to live positively, limits quality of life, adherence to treatment and access to health services. Internalized stigma has a particularly deleterious effect on psychosocial and behavioral health among people living with HIV and is associated with greater risk of depression, substance use and suicide.

Anticipated stigma involves the expectation of bias, discrimination, stereotyping, and/or prejudice from others to occur in the future due to one's HIV status. Anticipated HIV stigma may shape the behaviors of the HIV-infected person. They may expect poor health care, social rejection, job loss, physical violence, and other forms of poor or unfair treatment regardless of whether they have had these experiences in the past or not. These expectations can shape how they interact with others. For example, those who anticipate greater stigma from healthcare providers are less likely to access care, they may avoid certain interactions wherein they expect to be treated poorly due to their HIV status. These expectations may also take a physical toll on them, overburden physical functioning to the extent that it acts as a chronic stressor which impacts negatively on the physical health of persons living with HIV/AIDS (PLWHA).

Associative stigma (secondary stigma) is stigma that results from a person's association with PLWHA. It refers to the experience of stigma by family or friends of members of stigmatized groups or among healthcare providers who provide care to members of stigmatized groups. Children and youth living with HIV may have at least one family member who is not infected. These un-infected children and youths may therefore experience associative stigma, which includes experiences of internalized, experienced, and anticipated stigma due to having a family member living with HIV.

EXAMPLES OF STIGMATIZING AND DISCRIMINATORY STATEMENTS SOME OF OUR PATIENTS HAVE EXPERIENCED

- *MY AUNT WHOM I LIVE WITH AFTER THE DEATH OF MY MUM TOLD ME "I DON'T WANT TO SEE YOU PLAYING WITH MY CHILDREN OR SHARING PERSONAL THINGS"*
- *"MY AUNT TOLD HER CHILDREN THAT I WILL SOON DIE SO THEY SHOULD STOP ASSOCIATING WITH ME"*
- *"FRIENDS IN SCHOOL STARTED TAUNTING ME AND STOPPED PLAYING WITH ME, I HAD TO CHANGE SCHOOL. I FELT VERY SAD LOSING MY FRIENDS BECAUSE I REALLY LIKE THEM"*
- *"WE HAD TO RELOCATE TO ANOTHER PLACE BECAUSE NEIGHBOURS AND THEIR CHILDREN WERE AVOIDING US. I LOST CONTACT WITH ALL MY FRIENDS"*
- *"DAD LEFT US BECAUSE MUM AND I WERE HIV-INFECTED"*
- *"IF YOUR PARENTS DIED, RELATIONS WILL NOT WANT TO TAKE YOU IN IF THEY FOUND OUT THAT THEY DIED FROM HIV"*
- *"CAREGIVERS WHO ARE NEGATIVE MAY NOT WANT TO BRING THE CHILD TO CLINIC BECAUSE THEY FEAR THAT PEOPLE MAY THINK THAT THEY ARE ALSO HIV-INFECTED"*

Healthcare providers are also not spared, since the assumption is that if you take care of HIV-infected persons, then you must be HIV-infected yourself!!! Once when I entered the ward to review my patients, most of the mothers grabbed their children and one shouted to the neighbour *"CARRY YOUR CHILD, THOSE HIV DOCTORS ARE COMING"*

Many also had internalized the stigma – “My HIV status was continually thrown in my face by my uncle and in the end I believed I had no place on this earth, no reason to be alive and I seriously contemplated killing myself. I had no reason to believe I was worth anything. I had lost all my confidence, I was empty”.

- *“ I FEEL ASHAMED OF BEING HIV-INFECTED ”*
- *“I CURSE MY SELF FOR BEING INFECTED ”*
- *“I HAVE STARTED AVOIDING FRIENDS OR PLAYING WITH THEM”*
- *“I PREFER TO STAY ALONE ”*
- *“I CHOSE TO BECOME A DAY STUDENT AS I DON’T WANT MY FRIENDS TO SEE ME TAKING DRUGS AND ASK ME WHY”*
- *“I STOPPED TAKING MY DRUGS BECAUSE I NO LONGER WANT TO LIVE”*
- *“I FEEL I AM A BURDEN TO THE FAMILY AND WANT TO DIE”*
- *“I AVOID MY SIBLINGS FOR FEAR OF GIVING IT TO THEM”*

Some of our clients are students of this great unique institution pursuing various careers. Am happy they were not discriminated in the admission process and HIV (a mere virus) will not determine what great heights they will attain.

As children with HIV continue to benefit from increased access to ARVs, there is an urgent need to create safer, more supportive environments for them so that they do not just live longer but that they may enjoy happy, fulfilled childhoods in which they feel protected, confident (to challenge those who stigmatize them), safe (especially from stigma), valued and loved. These children need help to develop the confidence, obtain support and life skills to cope with stigma, so that it does not negatively impact on their lives. There is need for stigma-free environments for children. We need to listen and acknowledge the experiences of children and how stigma impacts on their lives. We then need to celebrate the courage and determination of HIV-infected young people who are living

positively and choose to bravely speak out about their experiences because they are the fearless youth, shaping the way society understands and responds to HIV.

The Declaration of Commitment adopted by the United Nations General Assembly Special Session on HIV/AIDS in June 2001 states that confronting stigma and discrimination is a prerequisite for effective prevention and care, and reaffirms that stigma and discrimination on the grounds of one's HIV status is a violation of human rights and needs to be addressed in order to achieve public health goals and overcome the epidemic.⁷¹

xii. Orphans and vulnerable children (OVC)

One of the most devastating impacts of HIV is the loss of whole generations of people in communities hardest hit by the epidemic. In this regard, it is often children who feel the greatest impact via the loss of parents or older relatives. Some are being orphaned without knowing why their parents died and some of them find out their HIV status after the death of the parent, leaving them with a very big psychological burden to carry. So not only are the most productive populations being decimated, but also the future of these children is at risk.

Who is an HIV orphan? An HIV orphan is a child under 18 years who has lost either the mother (maternal orphan) or father (paternal orphan), or both (double orphan).⁷² A vulnerable child (in the context of HIV) is one who is aged 0-18 years who is affected by HIV/AIDS through illness of one or both parents or a principal caretaker, or one whose wellbeing is threatened by HIV/AIDS. The term "HIV orphan and vulnerable child (OVC)" is defined as a child, 0-18 years old, who is either orphaned or affected or made more vulnerable because of HIV and AIDS by virtue of, among others, living in a household where one or more persons are ill, dying, or deceased, or which fosters orphans, and children whose caregivers are too ill or old to continue to care for them.⁷³ They often have more health needs than their peers.⁷⁴

An estimated 13.4 million children and adolescents (0-19 years) worldwide had lost one or both parents to AIDS as of 2015. More than 80% of these children (10.9 million) live in Sub-Saharan Africa. ⁷⁵ In some countries which are badly affected by the epidemic, a large percentage of all orphaned children are orphaned due to AIDS. ⁷⁶

Children orphaned by AIDS, or who are living with sick caregivers, continue to face an increased risk of physical and emotional abuse as compared with other children in Sub-Saharan Africa, including other orphans. This increases these children's vulnerability to HIV. ⁷⁵ The numerous challenges facing OVC include lack of education, shelter, health, protection and nutrition. These children are more prone to ill health than children in more secure circumstances, have less access to health care and miss meals more frequently, and are more likely to skip school, or not go to school at all. ⁷⁴ Parental death can affect various aspects of a growing child's development. The loss of a father or mother can result in loss of shelter, school drop-out or non-enrolment in school, poor health outcomes, malnutrition, abuse and stigmatization. When a parent dies, older children may be expected to skip school and take up paid employment and care for younger siblings. The ability of bereaved children to continue in school depends on households' resources and the public support for education. The preoccupation with the illness or death of their parents, the isolation due to the loss of friends, and the undertaking of additional work that comes with caring for ill parents or supporting oneself after one's parents have died often make it difficult for orphaned children to concentrate in school. Without education and skills training, children orphaned and made vulnerable by HIV/AIDS are more likely to fall deeper into the cycle of poverty and engage in high-risk behavior, which perpetuates the cycle of HIV transmission.

Extended families (often grandparents) and communities are forced to absorb these orphans affected by HIV and AIDS to protect, care for and support them even though some households are having an especially difficult time coping. The feeling of isolation experienced

by these children can be heightened if the orphaned children are separated from their siblings, as often occurs when family members split up the child rearing duties. Sibling separation can be difficult for children as they often rely on each other to cope with the loss of their parents. Sexual abuse by male relatives also remains a significant challenge for orphaned and vulnerable girls.

Efforts to care, support and protect vulnerable children should not only focus on their immediate survival needs such as food, education, water, shelter and clothing, but also on long-term developmental needs that reduce children's vulnerability such as life skills, child protection, vocational training, food security, and household economic strengthening. To care properly for orphans and vulnerable children, a minimum package of support is needed and includes access to services such as education, health care, social welfare and protection. However, without laws, policies and services that assist families and communities in caring for children at risk, such support tends to remain low.

xiii. Challenges of COVID-19

Late 2019 saw the whole world being devastated by the corona virus (COVID-19) pandemic which has been spreading and ravaging the whole world, snuffing life out of people and spreading fear everywhere. Although children are not the face of this pandemic, but because HIV-infected children are immunocompromised and commonly have underlying lung disease, they are at a high risk of not only contracting it, but of becoming very ill. Again, because they are poor, and may not have regular water supply, they are not able to abide with the hygiene of regular hand washing. Of course it is difficult to practice physical distancing between child and mother. Symptoms of COVID-19 like fever, cough, difficulty with breathing overlap with tuberculosis (TB) which is a common co-infection in HIV-infected children and so either can be missed. In the panic to urgently find a cure for this novel virus, some scientists reported a possible efficacy of an antiviral drug lopinavir/ritonavir (LPV/r). This drug coincidentally is a very vital drug in paediatric ART regimen and so when it was diverted to “treat” corona virus, this led

to stock out of the drug thereby leaving millions of children without it. In an effort to curb the spread of the virus, the government rolled out certain mitigation measures like total lockdown and travel restrictions. This meant that many children were deprived from picking up their drugs which will greatly impart on adherence and viral suppression. Some children who travelled out of the state before the lockdown, were caught up in other states making it extremely difficult to access health care. Most ARVs are produced outside this country, and as the pandemic spread, lockdown meant most factories were shut down. Even drugs that were already being transported were caught up in the international /interstate travel restrictions which all affected the supply chain. A pandemic of fear, anxiety and depression was also going hand in hand with COVID-19 contagion in these children who are already extra-sensitive to emotional stress.

The effects of the pandemic are not limited to health (including mental health) but extend to many dimensions of children's lives: their education, safety and food security and increasing poverty in many families that lost their means of livelihood. These effects are largely attributable not to the virus but to the mitigation measures governments have taken, which in some settings, may have inadvertently done more harm than good. For some children, the impact will be lifelong. Moreover, there is currently limited data available to determine the course of COVID-19 in people living with HIV (PLHIV).

Bearing in mind their immunocompromised status, we had to reschedule their appointments to limit the number of contact and duration of time they need to have with the health facility.

We had to resort to multi-month dispensing of 4-6 months which although feasible in adults may not be so suitable for young children whose doses can change with weight gain. We had to resort to differentiated service delivery for delivery of medications where a community based organization (CBO) comes to the facility and

picks up antiretroviral drugs for clients within their area of coverage and delivers same to the homes of the children.

We had to make a lot of phone calls to monitor adherence and adverse effect and opportunistic infections. All these were geared towards minimizing their exposure to COVID-19 at healthcare facilities. During the lockdown, some doctors and other health workers were harassed by security personnel on their way to work to provide care to those children that managed to reach the health facility.

Vice Chancellor Sir, we have seen the enormous challenges faced by HIV-infected children. Although the life of an HIV-infected child is riddled with a lot of challenges, however, they are still children with dreams, hopes, aspirations and desires for the future that need to be fulfilled. The good news is that HIV (with all its challenges) can be totally eliminated in children. HOW!!!!!!!

Preventing HIV infection in infants and children

Despite significant advances in HIV treatment and care, children continue to be born with HIV infection due to the low coverage of antenatal care and prevention of parent-to-child transmission (PPTCT) services in Nigeria. The most significant shortcoming in the response to paediatric HIV remains the woefully inadequate prevention of mother-to-child transmission (PMTCT) strategies, allowing a large number of children to be born with HIV in the first place, in spite of it being largely preventable. In developed countries, mother-to-child transmission has been virtually eliminated. However, in resource-limited countries where >95 per cent of all vertical transmissions take place, infected infants still continue to be born. It is impossible to discuss care for HIV-infected children without focusing on PMTCT because pediatric HIV infection is a preventable condition. This will require a more determined intervention in the teenage and child bearing populations. While we are still at PMTCT in developing countries, developed countries are talking about elimination of mother-child transmission (EMTCT). MTCT of HIV can be stopped, provided

that expectant mothers have access to services to prevent mother-to-child transmission (PMTCT) during pregnancy, delivery and breastfeeding.

Despite the fact that the National PMTCT program in Nigeria started since 2001, limited coverage of services (which should be offered before conception, and throughout pregnancy, labour and breastfeeding) has continued to affect the country's performance in reducing new infections among children. In June 2011 UNAIDS and the United States President's Emergency Plan for AIDS Relief (PEPFAR) launched the Global Plan towards the elimination of new HIV infections among children by 2015, and keeping their mothers alive.⁷⁷ Among the 22 priority countries that were targeted by the UNAIDS global plan of eliminating new HIV infections among children by 2015, Nigeria's performance was the poorest, a mere 21% reduction in new infections among children from 2009–2015.⁷⁸ The 'Start Free, Stay Free, AIDS Free' initiative, was launched in 2016 led by UNAIDS and PEPFAR and aims at building on the progress achieved under the Global Plan to scale up HIV prevention, by reaching and sustaining 95% of pregnant women living with HIV with lifelong HIV treatment in order to reduce the risk of a mother living with HIV passing the virus to her child (Start Free); ensuring that children with an HIV-free start are empowered to stay HIV-free throughout their childhood (Stay Free); and providing children and adolescents living with HIV with antiretroviral therapy (ART) to prevent disease progression (AIDS Free)

“No child should be born with HIV; no child should be an orphan because of HIV; no child should die due to lack of access to treatment.”

*Ebube Sylvia Taylor, an 11-year-old Nigerian, born free of HIV, speaking to world leaders who gathered in New York in 2010 to share progress made towards achieving the Millennium Development Goals by 2015.*⁷⁷

The United Nations four-pronged approach remains the most effective way to prevent HIV infection in infants and young children.⁷⁹

- **Prong 1: Prevention of HIV infection in women (and men) of reproductive age**

If all men and women of reproductive age were HIV negative, the rate of MTCT would be zero!!!! To achieve this Prong 1, there should be:

- i. Behavioural change in both boys and girls, men and women
- ii. Create health education in public awareness campaigns to increase knowledge on HIV, including its routes of transmission, the personal, family, and community consequences of its acquisition, and the methods of prevention
- iii. Pre/Post exposure prophylaxis
- iv. Structural-level efforts to reduce gender inequalities and support income-generating activities for women

- **Prong 2: Preventing unintended pregnancy among HIV-infected women**

- i. Universal access to testing and counseling, leading to individual HIV status identification. Where only the male partner is infected with HIV, various assisted reproduction techniques are now available to achieve pregnancy without infecting the woman, and hence vertical transmission to the infant can be avoided.
- ii. Provision of good quality, user friendly, easily accessible family planning services to prevent unplanned pregnancy. Family planning is one of the most important PMTCT measures. When women living with HIV are supported to plan when to have or not have children, the number of children being born with HIV reduces.
- iii. Initiating antiretroviral drugs as soon as possible in order to reduce the viral load. Infected women can thus plan their pregnancy at an optimal time when their viral load is undetectable (and thus less transmissible) and the CD4 count is high.

- **Prong 3: Prevention of transmission from HIV-infected pregnant women to their infants during pregnancy, delivery, and breastfeeding**
 - i. HIV testing and counseling during antenatal clinic visits to identify pregnant HIV-infected women and provide them with access to PMTCT services as well as follow up their exposed infants.
 - ii. Modification of obstetric practices - Discourage invasive obstetric procedures such as external cephalic version, artificial rupture of membranes, vacuum extraction, and episiotomy. Minimize cervical examinations, and do not perform unless absolutely necessary. Avoid prolonged obstructed labor. Remove any remaining maternal blood and amniotic fluid from the infant promptly after delivery and avoid suctioning the infant's mouth and pharynx unless absolutely necessary
 - iii. Administration of antiretroviral (ARV) therapy to mother and ARV prophylaxis to the infant. The infant's prophylaxis and duration is based on risk assessment (irrespective of feeding method). For low risk, baby receives daily nevirapine from birth to 6 weeks of life. For high risk, baby receives daily nevirapine and zidovudine from birth to 12 weeks of life.
 - iv. Safe infant feeding: The 2010 recommended infant feeding in the context of HIV are:
 - a. Exclusive Breastfeeding for 6 months with introduction of nutritionally/locally adequate complimentary feeds, continued breastfeeding for at least 12months of life.
 - b. Replacement feeding (**if AFASS - acceptable, feasible, affordable, sustainable and safe**) taking into account the risks posed by using replacement feeding, including infections other than HIV and malnutrition.
Breast milk is the best nutrition source for both HIV-exposed and unexposed infants. In Nigeria, although 97% of infants are breastfed, according to the National Demographic and Health Survey 2018, only 29% are exclusively breastfed for the first 6 months.⁸⁰ Although breastfeeding accounts for one third (1/3) of MTCT, however, in many resource-limited settings, infants

who do not breastfeed are up to six to ten times more likely to die from malnutrition, pneumonia and diarrhoeal disease.^{81, 82} The dilemma then in our setting where child mortality due to these conditions is relatively commonplace, is to balance the risk of infants being infected with HIV through breastfeeding, with the risk of death from other causes due to lack of breastfeeding. This is to ensure HIV-free survival (i.e. survival of infants while remaining HIV-uninfected).

In developing countries where breastfeeding is the norm, the risk of HIV transmission to the newborn child can be more than halved by consistent adherence to antiretroviral drug regimens in order to reduce the viral load in the breast milk. Even shorter durations of breastfeeding of less than 12 months are better than never initiating breastfeeding at all. With ARV support and adherence for the mothers, breastfeeding is increasingly becoming safer with fewer MTCT (1-2%) so that it is now possible for infants to continue breastfeeding for up to 12 months or longer, with little risk of the infant acquiring HIV, while also being protected from other major causes of child mortality.

The evidence for the long-term benefits of longer duration of breastfeeding for both maternal and child health outcomes, including child development and prevention of non-communicable diseases (like obesity and diabetes), highlights the relevance of supporting breastfeeding in high and low income settings alike. The superiority of breastfeeding over artificial feeding is well documented and exclusive breastfeeding remains one of the most valuable interventions for improving child survival, especially in resource poor settings.

We carried out a retrospective-prospective study in UPTH in 2015 to determine if there was any change in the infant feeding methods before and after the 2010 WHO guidelines and to compare the mother-to-child transmission rates by

various modes of infant feeding before and after the 2010 guidelines (2007-2010 and 2011-2014 periods). The results showed that the overall risk of mother-to-child transmission of HIV was reduced to 4.3% in the breastfeeding populations (from a background risk of 25.6%; $p=0.000$), whereas there was no significant change in the risk of transmission among formula-fed babies ($p=0.29$) and in those that were mix-fed ($p=0.24$) in the two periods. Exclusive breastfeeding for the first six months was associated with a 5.3 times lower risk of HIV transmission when compared to mixed feeding (OR 11.14 (95%CI 7.2-17.21; $p=0.000$). We concluded that with antiretroviral drug intervention, **breastfeeding has become safer** and have the potential to significantly improve child survival while remaining HIV-uninfected and the "balance of risks" between breastfeeding and replacement feeding has fundamentally changed.⁸³

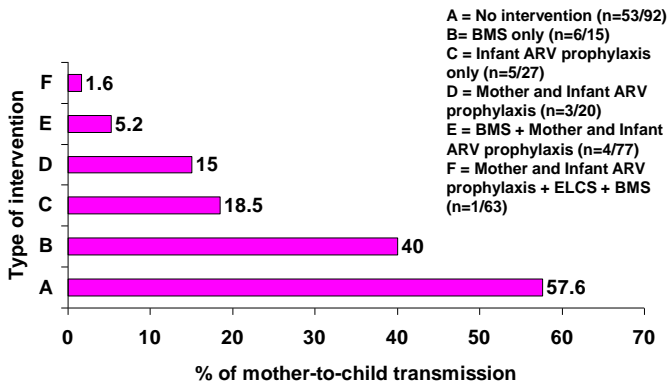
- **Prong 4: Providing care and support to HIV-infected women and affected members of the families.**

Care and support for HIV infected women address concerns about: their health and future, the health and nutrition of their children, and the welfare of their families. Promoting maternal health among women living with HIV is central to keeping them alive and at the center of the agenda to eliminate pediatric HIV. It is important to develop and reinforce linkages with other relevant services for referral to access any further treatment, care and support. This also includes sexual and reproductive health interventions for HIV-infected women as well as ART, OVC, Psychosocial care for the HIV-infected children. Immunization schedule of the HIV-exposed infant is the same as for the non-exposed infants except that live vaccines especially BCG and yellow fever are avoided in the HIV-exposed infants who have HIV-related symptoms.

With these interventions, it is possible to prevent transmission from HIV-infected pregnant women to their infants. Unfortunately, most women in Nigeria who need these interventions are still not

accessing them. In the developed countries, antiretroviral prophylaxis in combination with other interventions such as elective caesarean section before onset of labour and rupture of membranes, and refraining from breastfeeding, have now almost entirely eliminated HIV infection in infants, with transmission rates below 2%. This can also be achieved here in our setting.

My colleague and I evaluated the effectiveness of the prevention of mother-to-child transmission (PMTCT) interventions in HIV-exposed infants presenting at the University of Port Harcourt Teaching Hospital between November 2007 to June 2008 and found that among mothers who had full PMTCT intervention, the transmission rate was 1.6% as against 57.6% in mothers who had no PMTCT intervention. **(Figure 9).**⁸⁴ We concluded that PMTCT interventions are highly effective in preventing HIV infection in exposed infants.



{ARV=antiretroviral; BMS=breast milk substitute; ELCS=elective caesarean section}

Fig 9: Type of intervention and the mother-to-child transmission rate of HIV

With scaling up of PMTCT services in our hospital, we carried out another study on the Outcome of PMTCT services at UPTH between January 2016 and December 2018. ⁸⁵ Among the mothers that had the complete PMTCT intervention, the mother-to-child transmission (MTCT) rate of 1.1% was observed, while it was 28.6% among mothers who had no form of PMTCT. So again PMTCT interventions in the control of MTCT of HIV was found to be very effective. Identified statistically significant risk factors to MTCT include: lack of use of HAART by the mother; No infant ARV prophylaxis; Mixed feeding; Prolonged breast feeding; and delivery in the traditional birth attendant home. To eliminate MTCT of HIV therefore, PMTCT services must be encouraged and promoted.

5. Way forward in preventing Paediatric HIV/AIDS

Children are disproportionately affected by the HIV epidemic, and continue to be left behind in the provision of life saving treatment. Combinations of efforts are needed to prevent new HIV infections among children, ensure that their mothers remain healthy, and improve the diagnosis and treatment of children already infected. To address the multi-factorial issues that revolve around HIV/AIDS in children, there is an urgent need for a concerted, sustainable and multi-pronged individual, community, national and global response. Each infection can and should be prevented and for those already infected, early diagnosis is of utmost importance prior to disease progression. As of now, most HIV programmes in Nigeria are donor dependent with less encouraging moves towards sustainability and ownership by the local health authorities. The following are suggestions on the way forward:

At Individual/Family level

1. Behavioural change/Adopt a positive lifestyle: Abstinence, being faithful to one sexual partner, reduction of multiple concurrent sexual partners, avoid sharing sharp objects (beauty salons, razor blades, clippers, pedicure, manicure, beauty tattoos) including tooth brushes, avoid intravenous substance abuse, avoid injections from chemist shops, delay sexual debut in youths empowering them to make safer choices, correct and consistent use of condom with HIV-

infected partners and persons of unknown HIV status, avoid pre-mastication (i.e. chewing foods or medicines before feeding to a child) by an HIV-infected person, avoid cult activities that may involve blood oath, prevention of child sexual abuse, and give post-exposure prophylaxis (PEP) for HIV with triple ARVs to victims of sexual abuse.

2. Health Education - Create public awareness through campaigns to increase knowledge on HIV, including its routes of transmission, the personal, family, and community consequences of its acquisition, and methods of prevention.

3. Encourage regular HIV testing and counseling so that each person will know their HIV status. There should also be more emphasis on promoting and facilitating couples testing and male involvement in PMTCT programmes in general.

4. Initiating antiretroviral drugs as soon as possible in order to reduce the viral load. Infected women can thus plan their pregnancy at an optimal time when their viral load is undetectable (and thus less transmissible). This is also known as “treatment as prevention” or TasP.

5. Exclusive breastfeeding for the first 6 months of life and continued breastfeeding up to 12 months of life while ensuring breast milk is safer by adherence to antiretroviral therapy (ART) by the mother, and extended antiretroviral (ARV) prophylaxis for the infant during the period of breastfeeding.

At Community Level

1. Avoid traditional/cultural/communal practices that involve cutting with shared unsterilized instruments, scarification, passage rites, blood oath for filial love or cultism, “wife gifts”.
2. Strengthening community support systems to allow them to effectively support children and caregivers to keep them healthy and ensure that they have access to the HIV services they require without stigmatization.

3. Enhance community capacity to provide care and support to HIV-infected children and their families, accelerate case-finding through integration into community-health programmes as well as improve case follow-up and essential care for HIV-exposed newborns and their families.
4. Greater community education and engagement. Involvement of people living with HIV (PLWH) in HIV programmes cannot be overemphasized.
5. Structural approaches: addressing the social, economic, political, environmental and legal factors directly affecting HIV risk and vulnerability of women and children and to increase economic opportunities for young people, particularly young women. The combination of dependence and subordination can make it very difficult for girls and women to demand safer sex (even from their husbands) or to end relationships that carry the risk of HIV infection. Lower access to education, lower levels of economic independence and intimate partner violence erode the ability of women to negotiate safer sex and retain control of their bodies.

At Health Facility Level

1. Making HIV testing / counseling widely available leading to individual HIV status identification. Routine provider initiated testing and counseling (PITC) should be offered to all children and women seen in health facilities for any services including emergency units, out-patient clinics, inpatient admissions, antenatal care, PMTCT clinics, family planning clinics, adolescent clinics, immunization centres, tuberculosis treatment centres, nutrition centres, and indeed within any programme for vulnerable children and women so that women and children will know their status.
2. Provision of good quality, user friendly, easily accessible family planning services to prevent unplanned pregnancy. When women living with HIV are supported to plan when they want or do not want to have children, the number of children being born with HIV reduces.

3. Improved antenatal care (ANC) coverage for all pregnant women especially those at risk and underserved so that they can have access to be tested. Low uptake of ANC results in missed opportunities for HIV testing and subsequent enrolment in care.
4. Training and retraining of healthcare workers particularly with child-counselling skills on how to provide effective HIV services devoid of stigma and discrimination for children living with HIV.
5. Mentoring some health facilities to scale up paediatric HIV services (diagnosis and treatment) in the communities to bring it closer to where the children most affected live.
6. Development of adolescent-focused services, with adolescents participating in planning for their services as well as having a transition plan and support for the transfer of the adolescents to adult care.
7. Integration of HIV diagnosis, care, treatment, and support for children with existing HIV care and treatment services, and existing maternal, newborn and child health programmes.
8. Periodic RNA-PCR assay (viral load) in children on ART for early diagnosis of failing regimen and initiation of 2nd line ART.

At Government/Non-governmental Level

1. Strengthening and scaling up of the PMTCT to primary health care centres that provide services in the community in order to ensure decentralization and wider PMTCT coverage to the places where a lot of women may go for delivery services. In most parts of the country, PMTCT programmes mainly exist in tertiary and few secondary health facilities, whilst a good percentage of deliveries take place in the periphery (at home with traditional birth attendants, in churches and private health facilities).
2. Strengthening of laboratory capacity for early infant diagnosis (EID) to improve turnaround time leading to early initiation of ART in children <18 months of age. Many studies have

confirmed that when infants are diagnosed and managed early, the survival rate is dramatically improved and the mortality reduced.⁸⁶

3. We need to have a reliable procurement and supply management in order to ensure availability of ARVs both for infant prophylaxis and treatment for the infected child and mother as well as improve availability and accessibility of 2nd line ART for those failing 1st line drugs.
4. Update and implement policies and legal documents pertaining to confidentiality, consent, stigma, discrimination and status disclosure in children and adolescents and among spouses.
5. Development of child-friendly fixed-dose combinations with the three drugs (as is seen in the adult fixed dose combinations) to ensure that simple and effective affordable treatment becomes widely available and accessible for all children in need. To achieve this requires political will and investment by industry.
6. Enhance government investment, ownership and accountability and non-dependence on donor agents.
7. Decentralize interventions to lower-level health systems where applicable and utilize communities for early identification and provision of care. Use of simplified approaches to dosing and simplified formulations such as FDCs also help to decentralize pediatric care
8. Strengthening of monitoring and evaluation systems (include core indicators of PMTCT and HIV care and treatment services for children in national monitoring and evaluation frameworks and expansion of efforts to monitor programme effectiveness and quality).
9. Support researches in pediatric AIDS in order to identify areas of need and improvement.

6. What have we been doing in the Paediatric ART clinic?

Vice Chancellor Sir, realizing that HIV has moved from being a life threatening illness to a chronic illness like hypertension, diabetes and cancers, so the way to go is to “Offer care beyond illness, care beyond ART and care beyond childhood and adolescence”

I must say that as a healthcare provider, providing health care for this group of children is emotionally challenging. However, the passion we have for them and the joy of seeing them navigate successfully through all the challenges that confront them has been the sustaining factor, otherwise it can drain one emotionally and financially. Apart from providing medical care we had to provide financial and emotional support, because a lot of the children and mothers have been abandoned by husbands and relatives and some had lost their jobs and had no source of income even for transportation to hospital or to feed. Many of the children are orphans being looked after by aged grandmothers with very meager resources.

Advocacy

Initially, while so many facilities especially up North had many implementing partners competing to provide support for HIV programme, we in Port Harcourt had none for years. We were given reasons of security concerns because of the militancy and kidnapping. It was really very difficult and we felt like “orphans” and had to make do with whatever the hospital management had to provide. After several advocacy visits, Clinton Health Access Initiative (CHAI) formerly known as Clinton Foundation came to the rescue.

With the signing of an MoU with UPTH on Paediatric HIV care in 2007, CHAI started supplying us with fixed drug combination (FDC) ARVs, nutritional support with Plumpy nut, Dry blood Spot DNA PCR kit for early infant diagnosis so that as early as 6 weeks of life, the HIV status of the child will be known. Before this time, we had to wait until 18months of age before determining if a child is infected or not. This was quite tiresome and frustrating for both

parents and health care providers. They also provided HIV Rapid diagnostic test kits as well as supported us to train health care providers on how to use them. With this we commenced provider initiated testing and counselling (PITC) a form of opt out testing of HIV for all children that came to paediatric department irrespective of the presenting complaints.

Later with further advocacy, other implementing partners like Institute of Human Virology, Nigeria (IHVN) and FHI 360 also came in at different points to continue to provide support for HIV care and management.

When we discovered that consultation fees posed a great barrier for our children to attend clinic even for drug pick-up, we commenced another advocacy to UPTH Management and Rivers State Government. Today, we are very happy to announce that consultation fee has been waived and chest radiograph for clinical diagnosis of tuberculosis is now done free, thus reducing the cost of care. We are grateful to UPTH management, Rivers State Government and our implementing partners.

We are actively promoting linkage and collaboration with our colleagues in the Obstetrics & Gynaecology department so that all HIV-exposed infants of HIV-positive mothers are referred to paediatrics ART clinic for continuum of care, early infant diagnosis (EID) and early initiation of ART if unfortunately infected.

Mentoring

With the collaboration of CHAI, we were able to carry out HIV ARV Scale up programme in Rivers State, mentoring 6 hospitals - Pope John Paul Hospital Eeken, General Hospital Omoku, Primary Health Center Aluu, Churchill Primary Health Centre Port Harcourt, General Hospital Emohua and Cottage Hospital Obio. This greatly increased the number of centres offering comprehensive paediatric HIV care and management (in terms of early infant diagnosis, treatment and support) In an effort to improve Paediatric HIV patient care, and reduce loss to follow-up, still in collaboration with Clinton

Foundation, we formed and inaugurated a support group for Paediatric HIV. We also trained 10 expert clients (volunteer mothers of HIV-infected children) to assist in patient tracking as a way of reducing loss-to-follow up and improving retention in care. They were also trained on how to provide basic home-based care for the children.

Last Mondays of every month has been dedicated to our adolescents because we realize they have special needs as they are coming to terms with puberty, disclosure, peer pressure etc. With the support of our partners, we have trained some adolescents who are living positively with HIV and called themselves the Determined Adolescent Treatment Supporter (DATS) team. They enroll their fellow adolescents and interact with them, monitor their adherence and have monthly meetings to discuss issues that affect them. From 15 years of age, we start to give them transition counselling on how to take charge of their health in preparation to final transfer to adult centered care at 18 years escorted by a support staff.

Clinical care

Realizing that HIV is a lifelong illness which means that children in care and treatment have to access health facilities frequently, this therefore implies that they may miss some school days, explorative and play activities which are necessary for their intellectual and cognitive development, I secured a grant from Clinton Health Access with which we created a child/adolescent friendly clinic fully equipped with recreational and educational toys for children in the clinic in order to make clinic experience pleasurable. This play pen area has gone a long way towards improving HIV patient satisfaction and retention in care and treatment and reducing loss-to-follow up.

With availability of viral load testing which started in 2015, we are now able to monitor the viral load of our children and detect at an early stage, those who are virally unsuppressed and possibly have virological failure which will warrant switching to second line drugs. ARVs are more regular and we now have more child-friendly

formulations that are easier to administer. With our enhanced adherence counselors, the level of adherence has greatly increased. We are partnering with some Community based organisations (CBOs) who support children with drug pick-ups, escort them to hospital to ease transport fares, do home visits, ensure adherence to drugs and clinic visits, pay their hospital bills, support them during admission, monitor their growth and give nutrition support, place the out of school back to school, ensure that the child's environment is safe and the child free from any form of abuse or neglect. During the COVID-19 pandemic, we had to send drugs to the homes of children that have been locked down and had to link up care and treatment to those who travelled out of the state and were caught up in other states due to the lock down and travel restrictions.

Recently, there has been greater attention on reducing LTFU rates to ensure patients are retained in care, maintain adherence and achieve better long term outcomes. We use phone calls, text messages and sometimes home visits and clinic escorts to remind patients of scheduled clinic appointments. Our CBOs have been very useful in providing care to our orphan and vulnerable children (OVC), ensuring that they are healthy, safe, in school, stable as well as empower the caregivers by providing them with small scale businesses.

A lot of our clients have transited to adult care. Some have married and have uninfected children. It is a wonderful feeling to care for a child from infancy and watch him/her grow into an adolescent and adult. Some of them are students of this great unique institution pursuing various careers. Am happy they made it through all the challenges. They are truly heroes.

Research

In the area of research, my colleagues and I have carried out a lot of researches in various aspects of HIV in children as already highlighted in this lecture. Results from these researches have not only contributed to the National data, but have greatly enhanced the care we provide to these children. We also carry out regular

satisfaction surveys because patient perception and satisfaction is an indicator used to evaluate the quality of healthcare as well as to compare different healthcare programmes or systems, identify which aspects of a service need to be changed, improve patient satisfaction and assist health care providers identify clients that are likely to disenroll.

7. Conclusion

Vice Chancellor Sir, we have seen that paediatric HIV infection is contributing increasingly to childhood morbidity and mortality. Majority of the cases result from MTCT. There are certainly many challenges, but there are also several actions we all can take to help mitigate some of these barriers! Efforts should be made to prevent MTCT and a holistic care provided for infected children and their families. Improving coverage of PMTCT services is a fundamental necessity if optimal prevention of new infections in babies and appropriate treatment of infected women is to occur. HIV free survival of children depends on successful reduction or even elimination of MTCT and survival of their HIV infected mothers. Scientific and programmatic evidence from Africa has demonstrated that complete elimination of HIV in children is possible and the international community has committed itself to achieving this goal. When children living with HIV have access to treatment they do well and can live normal, healthy and happy lives, just like any other child. We should stop stigmatizing and discriminating against them.

You are all part of the solution!

I ask all of us seated here, “CAN WE TOTALLY ELIMINATE NEW HIV INFECTION IN NIGERIAN CHILDREN”? And I answer borrowing from a famous election slogan from the former American President, Barack Obama, “YES WE CAN”!!!!

Yes, we can totally eliminate paediatric HIV.

Yes, we can address the needs of already infected children adequately.

Yes, we can support these children to live healthy and productive lives.

Yes, we can protect them from becoming the next wave of the pandemic.

I hope you will all become front-line advocates and be a part of the journey to help these children to achieve their full potentials in life. Children are so precious and fragile, we should protect and defend them in every way we can.

Matthew 18:10 *“See that you do not despise one of these little ones. For I tell you that their angels in heaven always see the face of my Father in heaven.”*

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CITATION



PROFESSOR ROSEMARY O. UGWU

MBBS (UNN) FWACP

Department of Paediatrics and Child Health

Faculty of Clinical Sciences, College of Health Sciences

Professor Rosemary Ogochukwu Ugwu (nee Nwolisa) was born into the family of late Chief Dennis Nwolisa and Mrs. Bridget Nwolisa of Alor in Idemili South Local Government Area, Anambra State. She is the 6th child and the 5th daughter in a family of 8 children (seven females and one male). She was named Ogochukwu meaning “God’s blessings” being born at the time her late father graduated from the University of Nigeria, Nsukka with a BSc. Economics.

EDUCATION

Her late father knowing that education is power, strived to educate all her daughters to higher institution before giving them out in marriage, especially at a time when educating the girl child was considered a waste of money. Rosemary received her primary education at Zik’s Avenue Primary School, (formerly Santa Maria Primary School) in Enugu. She proceeded with her secondary

education in 1977 at the Girl's Secondary School, Awkunanaw, Enugu where she finished as the overall best graduating student and won the awards as the best in Mathematics, Additional Mathematics, Chemistry, and Physics. It was not surprising that she was science inclined and with her love for caring for sick people even from a tender age of 7 years, it was an actualization of her dreams when she went ahead to University of Nigeria to pursue a course in Medicine and Surgery from where she graduated with Bachelor of Medicine; Bachelor of Surgery (MBBS) in 1989. Being one of the best graduating students, she was taken on merit to do the one-year internship at the University of Nigeria Teaching Hospital, Enugu.

PROFESSIONAL CAREER/ACTIVITIES

After her National Youth Service at Industrial Clinic of the Nigerian Railway Corporation Enugu in 1992, she worked as a medical officer in private hospitals including Tin Can Island Hospital, Lagos. Still yearning for more knowledge, she took the Primaries examination and had the best results in the Primaries of the National Postgraduate Medical College. This encouraged her to start her residency programme in Paediatrics in 1997 at University of Port Harcourt Teaching Hospital and completed the programme in October 2004 after obtaining the Fellowship of the West African College of Physicians (FWACP). She was awarded with the "Best Resident Award 2004" by Association of Resident Doctors, Rivers State Branch and "Award of Recognition" by the Nigerian Medical Association, Rivers State Branch in 2004.

Professor Rosemary Ugwu was employed as a Lecturer 1 by the University of Port Harcourt in May 2005 and appointed an Honorary Consultant at the University of Port Harcourt Teaching hospital in September 2005. Her quest for knowledge spurred her into research which saw her rise to the posts of Senior Lecturer in 2008, Reader in 2011 and a Professor of Paediatrics and Paediatric Infectious disease in 2015.

She has served as Examiner in the Part I (Membership) and Part II (Fellowship) examination of the West African College of Physicians (WACP) from October 2011 till date and an External examiner for

the Part III MBBS in some Nigerian Universities. She has been involved in WACP accreditation visits to tertiary health facilities in Nigeria.

She is the Paediatric Association of Nigeria (PAN) representative in the National Intermittent Preventive Treatment (IPTi) Research and Policy Uptake Task Team. This is an operational research by the Malaria Consortium supported by the National Malaria Elimination Programme (NMEP) and funded by the Bill and Melinda Gates Foundation with the main goal of reducing infant morbidity and mortality from malaria.

She is a member of many professional bodies including Nigerian Medical Association (NMA), Medical and Dental Consultants Association of Nigeria (MDCAN), Nigerian Society of Paediatric Infectious Diseases (NISPID) and Paediatric Association of Nigeria (PAN)

ADMINISTRATIVE SERVICES

Professor Ugwu has served the University, the hospital and Rivers State in various capacities. In the University, she served as the Secretary, Faculty of Clinical Sciences Research committee 2006-2008, Coordinator, Introduction to Clinical Medicine Course from 2012 to 2016, Treasurer, Welfare Committee of Faculty of Clinical Science since 2015 till date and Acting Head of Department, Paediatrics and Child Health 2016 to 2018. She has also served as Panelist in the professorial assessment interview.

In the University of Port Harcourt Teaching Hospital, she was the Head of Department and Project Manager, Department of Paediatrics from 2016 to 2018. She was the Treasurer, Medical and Dental Consultants Association of Nigeria UPTH from 2011 to 2013. She has headed the Paediatric Infectious Disease Unit from February 2012 till date. She founded the Support Group for Paediatric HIV, UPTH and with a small grant secured from Clinton Health Access Initiative, she provided a child-friendly environment for the care of HIV-infected children. She has served in many

committees (including UPTH Medical Board) and panels of investigations. She is the focal Paediatrician, Smile Train Team, UPTH which provides free and holistic care to children with cleft lip/palate and a member of a multinational study on management of malaria in African countries being conducted by Novartis, of which UPTH is one of the two facilities representing Nigeria.

In the state, she co-mentored 6 hospitals for Paediatric antiretroviral drug (ARV) Scale-up programme in Rivers State in collaboration with Bill Clinton Foundation from 2007 to 2012 and currently, she is the Chairman, Rivers State Childhood Tuberculosis Control Team and the Chairman, Paediatric and Adolescent ART technical working group, Rivers State, and Paediatric HIV Coordinator, University of Port Harcourt Teaching Hospital, PH.

She has also delivered several health talks in churches, to women groups and primary and secondary schools in Port Harcourt and was a Guest Lecturer on several occasions in radio and television programmes in African Independent Television (AIT) and Rivers State Television (RSTV).

RESEARCH AND PUBLICATIONS

Professor Ugwu is an avid researcher and has over 45 publications in reputable local and foreign journals, as well as over 35 paper presentations in local and international conferences. She has also contributed 11 chapters in four books used nationally and internationally. She co-authored the textbook “Pathophysiology of Clinical Symptoms, Signs and Laboratory Parameters which is geared towards increasing the thinking process and thereby greatly improve medical learning and practice. She has also successfully supervised the Part II dissertations of 10 senior residents towards their Part II exams in the Postgraduate Medical Colleges, all of whom have become consultants/Senior Lecturers, and one a Professor.

She is a reviewer for many journals including Port Harcourt Medical Journal, African Journal of Paediatric Nephrology, Nigerian Journal

of Paediatrics, Indian Journal of Paediatrics, The Nigerian Health Journal and the Clinical Case Reports in Medicine.

She has attended several courses, workshops both local and international where she made oral and poster presentations and was the facilitator/resource person in many of them.

AWARDS:

As a sports loving person and a strong advocate for lifestyle medicine she has participated in sporting activities where she excelled as: (1) Silver Medalist, volley ball team of the University of Nigeria to Nigerian Medical Student Association (NIMSA) games at Ife, 1987; (2) Silver Medalist, 800metres NIMSA Games Ife (1987); (3) Bronze medalist 100metres NIMSA Games Ife (1987); (4) Bronze medalist 1,500metres NIMSA Games Ife (1987) and (5) Blue belt Martial Arts.

FAMILY AND CHRISTIAN LIFE

Professor Ugwu is a devoted Christian of the Catholic denomination. At St. Francis Catholic Church, Rumuokwuta, she has served as member, Parish Pastoral Council and is a member, Medical Sub-Committee of Catholic Women Organization at both Parish and Diocesan levels. She is also a Lady of the Order of Knights of St. Mulumba, St. Francis Port Harcourt Sub-council, and the Chairperson, Obukpa Women Association, Port Harcourt Branch.

She is happily married to Engr. Ikechukwu Raymond Ugwu (KSM) (Chief Nwachinemere of Obige Obukpa) and the marriage is blessed with 4 children, a female and 3 males (a medical doctor, a computer scientist, an electrical engineer and a mechanical engineer level 4 undergraduate). Her hobbies include research, reading novels, travelling and watching sports on TV.

Thank you.

Professor Owunari A. Georgewill
Vice-Chancellor