



CHILDREN'S RIGHT TO HEALTH IN THE CONTEXT OF THE HIV EPIDEMIC

A CASE STUDY OF RWANDA

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Dedication

To all those who have given their lives since the 19th century so that I, my parents, my children and grand-children can live in a free Rwanda, creating the basis for a state run by rules based on human rights.

"All human rights are universal, indivisible and interdependent and interrelated. The international community must treat human rights globally in a fair and equal manner, on the same footing, and with the same emphasis. While the significance of national and regional particularities and various historical, cultural and religious backgrounds must be borne in mind, it is the duty of states, regardless of their political, economic and cultural systems, to promote and protect all human rights and fundamental freedoms."

Vienna Declaration and Program of Action of the United Nations (UN) World Conference on Human Rights, 1993.

Abstract

Background: After the 1994 genocide, Rwanda based its development on pro-poor policies, promoting the equity and rights of children. The objective of this current research was to assess obstacles encountered by children living with human immunodeficiency virus (HIV) in exercising their rights to health.

Design: Mixed methods were used to respond to four main research questions on the right to information and participation, quality of prevention, physical and mental development, and financial management of the pediatric HIV response. Qualitative research and field assessment were applied to analyse access to primary prevention among marginalised groups. The quality of World Health Organization (WHO) and United Nations Children's Fund (UNICEF) policies, and the right to information and participation, were assessed by desk reviews. An assessment of non-governmental organization (NGO) reports and analysis of the cost-effectiveness of different prevention services - Prevention of Mother to Child Transmission (PMTCT) and male circumcision (MC) - were carried out. The validation of the Child Depression Index (CDI) was performed to assess its accuracy for the screening of depression in Rwandan HIV-positive children.

Results: Marginalised parents do not have their primary prevention needs granted at 100% due to law, stigmatization and criminalisation. The analysis of PMTCT regimens and the total cost calculation of lifelong care and treatment showed that Short-course Highly Active Antiretroviral Therapy (Sc-HAART), with 12 months breastfeeding, allows more children to be alive and HIV-negative at 18 months old. The neonatal MC is the most cost-effective, has a better potential to achieve universal coverage, and is associated with greater acceptability, safety, and feasibility. The rights of children to information and participation were not being fulfilled. The CDI cut-off is six – sensitivity 97%, specificity 72%; and 25% of children living with HIV in the study have depression. NGOs lack transparency in their financial management.

Conclusion: Legal framework improvement, better management by NGOs, timely scientific guidance from governing institutions coupled with primary prevention, and a cost-effective approach would have a higher financial return and lead to improved health outcomes.

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Acronyms

ACRWC:	African Charter on the Rights and Welfare of the Child
AFASS:	Acceptable, Feasible, Affordable, Sustainable, and Safe
AIDS:	Acquired Immunodeficiency Syndrome
ANC:	Antenatal Clinic
ARBEF:	Rwandan Association for the Promotion of Family Welfare
ARV:	Antiretroviral Therapy
AUC:	Area under the Curve
BF:	Breastfeeding
CAMERWA:	Central Purchasing of Essential Medicines in Rwanda
CBHI:	Community Based Health Insurance
CCHIP:	Comprehensive Community Health Initiatives & Programs
CD4:	Cluster of Differentiation 4
CDC:	United States Centers for Disease Control and Prevention
CDI:	Child Depression Inventory
CHAI:	Clinton Health Access Initiative
CHW:	Community Health Worker
CI:	Confidence Interval
CIDC:	Center for Infectious Disease Control
CNLS:	Commission Nationale de Lutte contre le SIDA
CRC:	Convention on the Rights of the Child
CTX:	Cotrimoxazole
DG:	Directorate General
DI:	Domestic Investment
DPT:	Diphtheria, Pertussis, Tetanus Vaccination
DSM IV:	American Psychiatric Association's Diagnostic and Statistical Manual (4 th Edition)
EAC:	East African Community
EALA:	East Africa Legislative Authority
EDPRS:	Economic Development and Poverty Reduction Strategy

EICV:	Enquête Intégrale sur les Conditions de Vie des ménages / Integrated Household Living Conditions Survey
EPP:	Estimation and Projection Package
FDI:	Foreign Direct Investment
FOSA:	Formation Sanitaire
FVA:	Faith Victory Association
FY:	Fiscal Year
GFATM:	Global Fund to Fight AIDS, Tuberculosis and Malaria
GDP:	Gross Domestic Product
GoR:	Government of Rwanda
HAART:	Highly Active Antiretroviral Therapy
HIV:	Human Immunodeficiency Virus
HMIS:	Health Management Information System
HOLN:	Health Organization of the League of Nations
HR:	Hazard Ratio
HRTT:	Health Resource Tracking Tool
ICD-10:	International Classification of Diseases (10 th Edition)
ICER:	Incremental Cost Effectiveness Ratio
IECBC:	Information, Education, and Communication for Behaviour Change
IHDPC:	Institute for HIV Disease Prevention and Control
IMCI:	Integrated Management of Childhood Illness
JLICA:	Joint Learning Initiative for Children and AIDS
KCUH:	Kigali Central University Hospital
Lc:	Long course
MC:	Male Circumcision
MDG:	Millennium Development Goals
MINALOC:	Ministry of Local Governance
MOH:	Ministry of Health
MSF:	Médecins sans Frontières
MTCT:	Mother to Child Transmission
NACC:	National AIDS Control Commission
NASA:	Mozambique National AIDS Spending Assessment
NCHS:	United States National Center for Health Statistics

NEPAD:	New Partnership for Africa's Development
NGO:	Non-governmental organization
NOVCSA:	National Orphans and Vulnerable Children Spending Assessment
NVP:	Nevirapine
ODA:	Official Development Assistance
OECD:	Organization for Economic Co-operation and Development
OI:	Opportunistic infections
OIHP:	Office International d'Hygiène Publique
OVC:	Orphans and Vulnerable Children
PACFA:	Prevention and Care for Females against AIDS
PEM:	Protein-energy malnutrition
PEV:	Program Elargi de Vaccination
PLHA:	People living with HIV/AIDS
PMTCT:	Prevention of Mother to Child Transmission
RBC:	Rwanda Biomedical Center
RDB:	Rwanda Development Board
RDHS:	Rwanda Demographic and Health Survey
RNIS:	Rwanda National Institute of Statistics
ROC:	Recipient Operating Characteristics
RR:	Relative Risk
RWF:	Rwandan Francs
Sc:	Short course
Sd:	Single dose
STI:	Sexually Transmitted Infections
TB:	Tuberculosis
TDF:	Tenofovir
TRAC Plus:	Treatment and Research AIDS Center Plus
TWG:	Technical Working Group on Nutrition
UDHR:	Universal Declaration of Human Rights
UN:	United Nations
UNAIDS:	The Joint United Nations Program on HIV and AIDS
CRC:	United Nations Convention on the Rights of the Child

UNDP:	United Nations Development Program
UNFPA:	United Nations Population Fund
UNICEF:	United Nations Children's Fund
US:	United States
USAID:	United States Agency for International Development
VCT:	Voluntary Testing and Counseling
WHO:	World Health Organization

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Disclaimer

The results, views and conclusions expressed in this Ph.D. research report are solely mine and do not represent the position of the Government of Rwanda or of the various institutions that supported the work.

Preface

Gabon, Belgium and France

In 1984 and 1985, I had my first experience of caring for persons infected by the human immunodeficiency virus (HIV) in Belgium, where I studied General and Tropical Medicine. I also lost several friends to Acquired Immunodeficiency Syndrome (AIDS) during those years. At that time we did not know that it was HIV – it was still a mystery, as HIV had not been discovered.

In 1985, I graduated as a Medical Doctor, and then worked in Gabon for four years. HIV was not, then, a “public health” issue in Gabon and I did not care for any people living with HIV/AIDS (PLHA) with AIDS in that country, probably because I was working in a very remote, rural area. In 1989, I moved to Brest, France where I pursued and received a diploma for completing a one-year medical course in the care and treatment of HIV-positive adults and children. My intention was to gain knowledge in HIV care because my family wanted to return to the East African Region where HIV was a recognized public health threat.

Returning to Rwanda

In 1996, my family and I returned to Rwanda, my homeland. I began work as a clinical pediatrician at the *Centre Hospitalier de Kigali* (CHK), now Kigali Central University Hospital (KCUH) (a pediatric ward in Rwanda concerns only children under 15 years old). It was, and still is, the biggest public referral teaching hospital in the country. I recall numerous case discussions concerning young children in our wards for whom the diagnosis of HIV infection was a death sentence rather than what it is in 2010 – a manageable chronic illness for which there is treatment, if not yet a cure.

The first case of HIV in Rwanda was diagnosed at KCUH in 1981. During the 1994 genocide against the Tutsi, approximately one million Tutsis and moderate Hutus were killed.¹ Among those one million persons were hundreds of thousands of children. During that period 250,000 to 500,000 women were raped, many purposely by HIV-positive men, and were infected. This denial of human rights to a significant percentage of the population, and the genocide against the Tutsis, took place after Rwanda had ratified the Universal Declaration on Human Rights, and other conventions. The outcome of these rapes was that these women gave birth to children living with HIV.

By the time I arrived in 1996, not only were there as many PLHA suffering from AIDS as there were in our neighboring countries, but many children were being born HIV-positive to mothers raped during the 1994 genocide and had very little access to treatment, given that the health system’s access to prevention and treatment services in Sub-Saharan Africa was limited at that time.

Since 1994, the Rwandan government has fought to make the use of rape as a weapon of war recognized as a crime against humanity and, over the past fifteen years, has promoted children’s rights through the implementation of a number of legal instruments, including the Rwandan Constitution and several child-specific laws and policies.²

My tenure as a clinical pediatrician in a public hospital in Rwanda continued until 2002. During those years, I cared for many children living with HIV. However, professional caregivers during those years were limited due to lack of resources – we were mostly only able to prescribe rest, adequate nutrition, vitamins, and immediate treatment for some opportunistic or concomitant infections when the drugs were on the list of essential medicines and available in the country. It was painful to see the suffering of our youngest citizens, especially because the antiretroviral treatment was available in many parts of the world, but not accessible in Rwanda and the rest of Africa due to financial barriers. It was rare that parents or friends of the family, or a charity, could afford long-term care and treatment for a child, though in such cases we were grateful.

By 1997 most countries around the world, including Rwanda, were building a response to HIV and AIDS. I began to take part in several technical groups on the Prevention of Mother to Child Transmission (PMTCT), and other prevention, care, and treatment of HIV, given my background in HIV case management. Such positions included advising the Rwandan Ministry of Health (MOH), United Nations Children’s Fund (UNICEF), World Health Organization (WHO), and UNAIDS, among other organizations both internal to Rwanda and international. Through this work, my commitment to reducing the spread of HIV infection became an immovable and major part of my life. I am dedicated to reducing the number of children affected by the disease and lessening its impact on families and society. I continue to exercise and improve my knowledge of HIV prevention, care and treatment, in addition to gaining a better understanding of health care delivery in low-income settings.

As result of my work I was selected to coordinate the launch and inaugural year (2001-2002) of the project of the First Lady of Rwanda, Her Excellency Madame Jeannette Kagame. This project was called the Prevention and Care for Families against HIV and AIDS (PACFA), which has since grown into a foundation, the “Imbuto Foundation,” and has extended its initial mission to now align itself with the overall economic development of Rwanda. I remain an active Board Member of the Imbuto Foundation. One year after coordinating PACFA, I was appointed to serve Rwanda as Executive Secretary of the National AIDS Control Commission and remained in this role until 2008. During these years, I contributed to the activities of several international organizations in HIV response, including the development of the Millennium Development Goals (MDGs) and I co-chaired the Joint Learning Initiative on Children and AIDS (JLICA).

Between 2001 and 2006, I co-chaired the Task Force for HIV and AIDS and Access to Essential Medicines, under the leadership of Professor Jeffrey Sachs, for the United Nations (UN) Secretary General, Kofi Annan. This task force was one of the ten thematically orientated task forces of the three-year Millennium Development Goal projects. The Task Force was comprised of representatives from academia, the public and private sectors, civil society organizations, and UN agencies. All members were selected on the basis of their technical expertise and practical experience and were global leaders in their fields. Together we performed research into the best strategies for achieving the MDGs targeting HIV and AIDS. We used this research to inform an implementation plan that would improve the human condition with respect to HIV and AIDS by 2015; the plan was proposed to UN Secretary-General, Kofi Annan.

For three years from 2006, alongside Peter Bell – the former President of CARE International – I co-chaired the JLICA, a global, independent network dedicated to improving the wellbeing of children affected by HIV by promoting evidence-based policies and actions.³ JLICA consisted of some 60 independent experts, researchers, policymakers, practitioners, community leaders,

and people living with HIV and AIDS (PLHA) from around the world, as well as 4,000 stakeholders, almost all of whom lived and worked in HIV high-burden countries. JLICA published its final recommendations in the first quarter of 2009. Governments, organizations, and institutions around the world currently use these recommendations as a basis for taking action.

During that period an NGO (non-governmental organization) called the Faith Victory Association (FVA) asked me to be the Principal Investigator on a study into the environment of children living with HIV. I agreed to do it for free, and coordinated and ran meetings during the weekend and holidays. I was eager to know more about the Rwandan reality of this matter. What I discovered while researching with FVA pushed me to engage in the research presented in this dissertation with even more energy.

In the last quarter of 2008, I was appointed to serve Rwanda as Permanent Secretary in the Ministry of Health and was subsequently appointed Minister of Health in May 2011. These two roles, as Permanent Secretary and now as Minister, meant many new responsibilities, overseeing diverse clinical and public health programmatic interventions, policies, strategies, plans, budgets, and monitoring and evaluation, among other tasks. One important part of my work in both roles has been to ensure that the right to health for all individuals in Rwanda is respected, including those who are living with HIV and AIDS. Responding to the needs of PLHA in Rwanda has brought to the fore an understanding of the need for equity across geographical, gender and age-based barriers to service delivery. Improving the lives of children in Rwanda who are living with HIV– as a result of being HIV-positive or of belonging to a family in which a member is HIV-positive – has remained central to my research interests and my capacity to respond has strengthened in parallel with my more frequent involvement in international initiatives.

Over the past sixteen years, throughout my domestic and international work, I have contributed to the fight to improve the human condition of children living with HIV and participated in the implementation of various solutions. Nevertheless, despite solidarity in our global efforts, there is a gulf between our potential capacity to solve problems for these children and the actual resources we have to mitigate the burden. Even in countries that are making great efforts to right the situation, including Rwanda – where the HIV program has been supported by strong political leadership, adherence to international and national standards and mobilisation by local leaders in communities – I had the feeling that the needs of children were not being met, even though the Government of Rwanda has a visionary integrated pediatric HIV program that is part of a holistic health and social protection framework.

For these reasons, among others, it became clear to me that I wanted to research those gaps between potential gains and real gains and use the findings to improve the condition of children living with HIV in Rwanda. As is the case in many parts of the world, our achievements in Rwanda, in the HIV and AIDS response, have favoured adults rather than children, but unlike many other parts of the world, in Rwanda – thanks to the commitment of our partners – we have the ability to treat 100% of children in need. There was thus a clear and necessary body of research that needed (and still needs) to be undertaken to help improve our service delivery methods, quality of care, and management efforts.

It is essential for policy-makers like me to understand the problems that prevent children's access to HIV services. The right to health is a fundamental human right, and identifying bottlenecks will help in amending and improving Rwanda's health care system. After reviewing current research, I decided to approach my own research and writing from a human rights

perspective, as there was a paucity of literature concerning the human rights framework in the context of children and HIV and AIDS. This approach, in my view, provided a solid argument for improving the lives of children who were growing up HIV-positive or affected by HIV.

I did this work in fulfilment of a Ph.D. at the University of Rwanda. In highlighting the gaps in our paediatric HIV program (which concerns children under 15 years old), my objective was to contribute to an improvement of the implementation of the government vision – a vision focused on the vulnerable. My aim is to accelerate Rwanda's progress toward achieving social justice and fulfilling human rights for all, which are at the heart of this vision.

Chapter 1: Introduction

1.1. Background

The following serves as background for this research that focuses on obstacles encountered by children living with HIV in exercising their rights to health.

Human immunodeficiency virus, global epidemic

Human immunodeficiency virus (HIV) belongs to the family of human retrovirus, and subfamily of lentiviruses, and causes AIDS in humans. AIDS was first recognized in 1981 in the United States (US), and Dr. Robert Gallo identified HIV in 1983 at the Pasteur Institute in Paris. Presently, there are two known viruses that cause AIDS: HIV-1 and HIV-2.⁴ The two types of virus possess similar clinical symptoms and may infect a person concurrently. HIV-1 remains the most virulent and the most predominant strain in the world.

Unprotected sexual intercourse with an infected person remains the main means of HIV transmission for adults, for children 90% of infections are due to mother to child transmission (MTCT).⁵ When infected the serologic test becomes positive after 3 months, followed by a long asymptomatic phase, during which there is no clinical manifestation of an HIV infection. HIV kills by destruction of the body's immunity system and the PLHA die of opportunistic infections, which is the stage of the disease named AIDS. Cotrimoxazole is systematically prescribed to reduce the opportunistic infections.

Currently, there are over 34 million HIV-positive people in the world. Data released in 2012 by the WHO and the Joint United Nations Program on HIV and AIDS (UNAIDS) confirm that Africa remains the most gravely affected region by far, and Sub-Saharan Africa accounts for 69% of all people living with HIV and AIDS (PLHA).⁶ Worldwide, between 2.2 million and 2.8 million people became newly infected with HIV in 2011. This shows that the fight against HIV infection did not meet expectations in Africa, as interventions for prevention, care, and treatment are being outpaced by the epidemic.⁵ Specifically, in 2010, more than 70% of new infections occurred in Africa.⁷ In Africa, AIDS remains one of the leading causes of death.⁸ Nearly half of all premature deaths due to HIV occurred in Africa in 2010.⁷

It should also be noted that the AIDS epidemic has an enormous impact on African children.⁶ In the world, in 2010, there were 3.3 million children living with HIV and more than 90% of them (3.1 million) were in Sub-Saharan Africa.⁶ This reflects a failure in program implementation, as 98% of perinatal HIV infections are through maternal to child transmission (MTCT) during pregnancy, labour, or breastfeeding and are preventable.⁹ However, globally, coverage of HIV prevention services for pregnant women only reached 35%, and only 48% of HIV-positive pregnant women received the most effective treatment for prevention of mother-to-child-transmission (PMTCT).⁷ Even if significant improvements have been made since the start of this doctoral research (2008), with a drop of 24% in new HIV infections among African children under 15 years between 2009 and 2011, a lot still needs to be done to improve the HIV pediatric response in Africa. This is urgent because in 2011 the unequal geographic distribution

of the burden of HIV infection on children persisted: globally, 330,000 children under the age of 15 were newly infected with HIV, and 300,000 of them were in Sub-Saharan Africa.

From the time that the first cases of HIV and AIDS were discovered until late 2013, neither a therapy capable of curing AIDS nor an effective vaccine against HIV has been produced. The drugs used in the HIV response (antiretroviral therapy (ARV)) reduce the viral load by combating replication of the virus but do not actually kill the virus. Although research into an HIV vaccine is in progress and has helped improve knowledge of human immunology, we are still far from discovering a vaccine capable of neutralising the virus and offering guaranteed protection against HIV infection.¹⁰

Faced with this reality, it is absolutely crucial to prevent infection by other means. There are some methods that can help to avoid infection, namely education, sexual abstinence, delaying first sex, having safer sex, faithfulness to your sexual partner, testing (knowing one's own status), post-exposure prophylaxis using ARV, and treatment of PLHA. The last two interventions are based on a reduction of the quantity of virus in the body (viral load) using ARV to avoid the reproduction of the virus. So in exposed persons, by decreasing the concentration of HIV to which they are exposed, the risk of the exposure turning into an HIV infection is also decreased. This principle explains the reduction of the risk provided by PMTCT in order for an HIV-positive mother to avoid infecting her baby.¹¹ It is also the cause of a 96% decrease in the risk of an infected partner transmitting the infection to HIV-negative sexual partners, using early treatment with ARV.¹¹

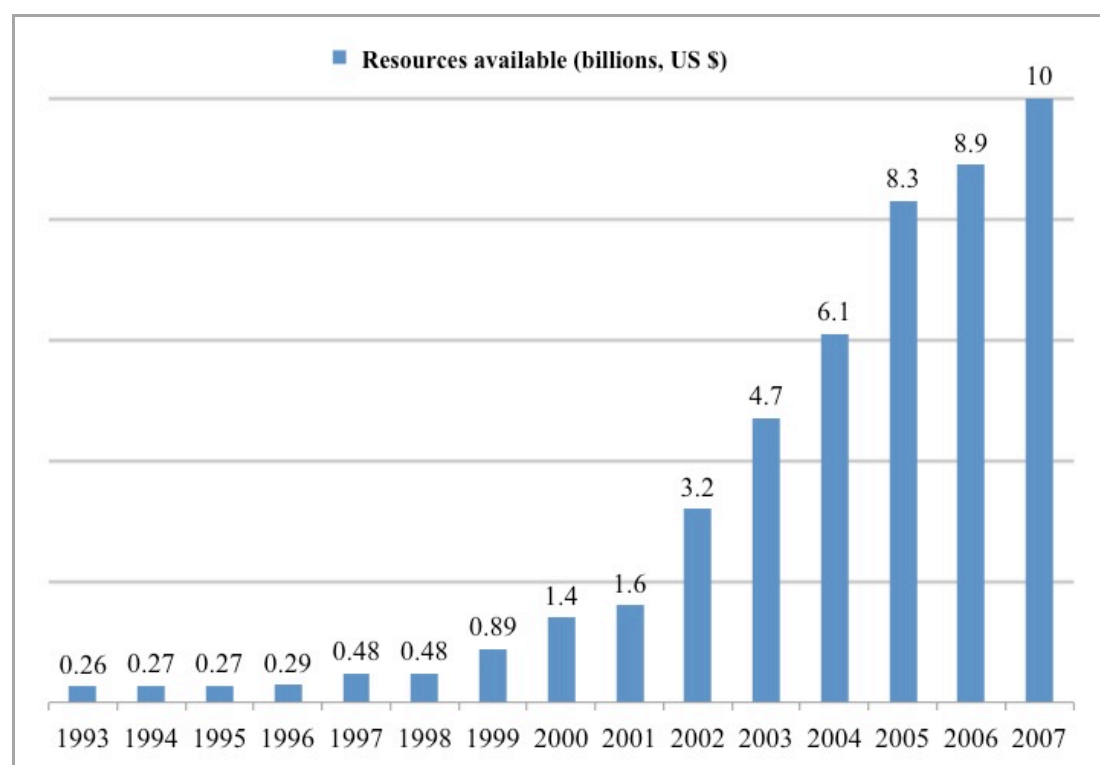
In 2006, the WHO protocol for PMTCT suggested that multiple ARV drug classes be used in combination to prevent vertical transmission of HIV, an improvement compared to the previous standard of care that offered only single dose Nevirapine (Sd-NVP).¹² Since 2010, the WHO recommendation is that all HIV-positive mothers, receive ARV, with two options: those with cluster of differentiation 4 (CD4) counts above 350 (not at AIDS stage) would receive NVP starting from 14 weeks of pregnancy, (referred to as Option A in the 2010 WHO guidelines),¹³ and all women with less than 350 CD4 would receive a combination of ARV and continue ARV for life (referred to as Option B in the 2010 guidelines).¹³ The WHO's latest guidelines, as of April 2012 are called Option B+, and recommend all women entering the PMTCT program to stay on combination ARV for life, with six months of exclusive breastfeeding and gradual weaning over a period of one month, with the introduction of balanced, and appropriate complementary food at six months while breastfeeding without exceeding the maximum recommended duration of 18 months.

Feeding methods are important for PMTCT, as breast milk is a source of MTCT. Until 2010, the WHO PMTCT guidelines on infant feeding suggested that using infant formula to prevent HIV in developing countries was untenable. The practice was discouraged in Sub-Saharan Africa, even where it was possible to implement it according to AFASS (acceptable, feasible, affordable, sustainable, and safe) criteria.¹⁴ Some nutritionists believed it was criminal to use feeding options other than breastfeeding in the developing world.¹⁵ Between 2006 and 2010, breastfeeding alone was recommended, followed by rapid weaning at 6 months.¹² Many countries still adhere to this advice without trying the other feeding options in AFASS conditions that can dramatically decrease the risk of MTCT through breast milk. Findings from Rwanda and the Côte d'Ivoire, show that there was no difference in the rates of morbidity and mortality between those infants who were breastfed or replacement fed.^{9, 16, 17} In the context of PMTCT, proposing breastfeeding only during the nutrition counseling of HIV+ parents, when other AFASS options were available, leads to unnecessary pediatric HIV infections.

Survival of people living with HIV/AIDS (PLHA) improved with the discovery of ARV. The goal of care and treatment for HIV is to halt disease progression through the management of opportunistic infections (OI), the reduction of viral load with ARV, and provision of palliative care when needed. In 1996, Highly Active Antiretroviral Therapy (HAART) was found to be an effective treatment for HIV-positive persons, which enabled long-term viral suppression with sufficient adherence.

HIV prevention, care and treatment need a great deal of funding to ensure the availability of drugs and technology. The World Health Organization's "3 by 5 campaign", initiated in 2003, aimed to mobilise resources and provide ARV to three million people living with HIV and AIDS (PLHA) in need of antiretroviral treatment by 2005; this target was met in December 2007, when an estimated 3 million people were receiving ARV in developing regions around the world.⁷ As of December 2012, the number of individuals on ARV globally increased to 8 million.⁶ Access to treatment in the poor countries was made possible because the price of ARV was reduced dramatically from US \$10,000 per person per year before 2000 to around US \$100 annually in 2007, and also because of the creation of The Global Fund to Fight AIDS, Tuberculosis and Malaria in 2001 and the President's Emergency Plan for AIDS Relief (PEPFAR) in 2003, which dramatically increased the volume of funds available for the fight against HIV and AIDS (Figure 1). These initiatives signaled the start of a massive scale-up of ARV in low- and middle-income countries where it had previously been unavailable to the vast majority of PLHA, who were unable to pay.¹⁸

Figure 1: Funds for the Fight against HIV from 1993 to 2007.



Source: Joint United Nations Program On HIV/AIDS: Financial resources required to achieve universal access to HIV prevention, treatment, care and support, September 2007. US Dollar (\$).

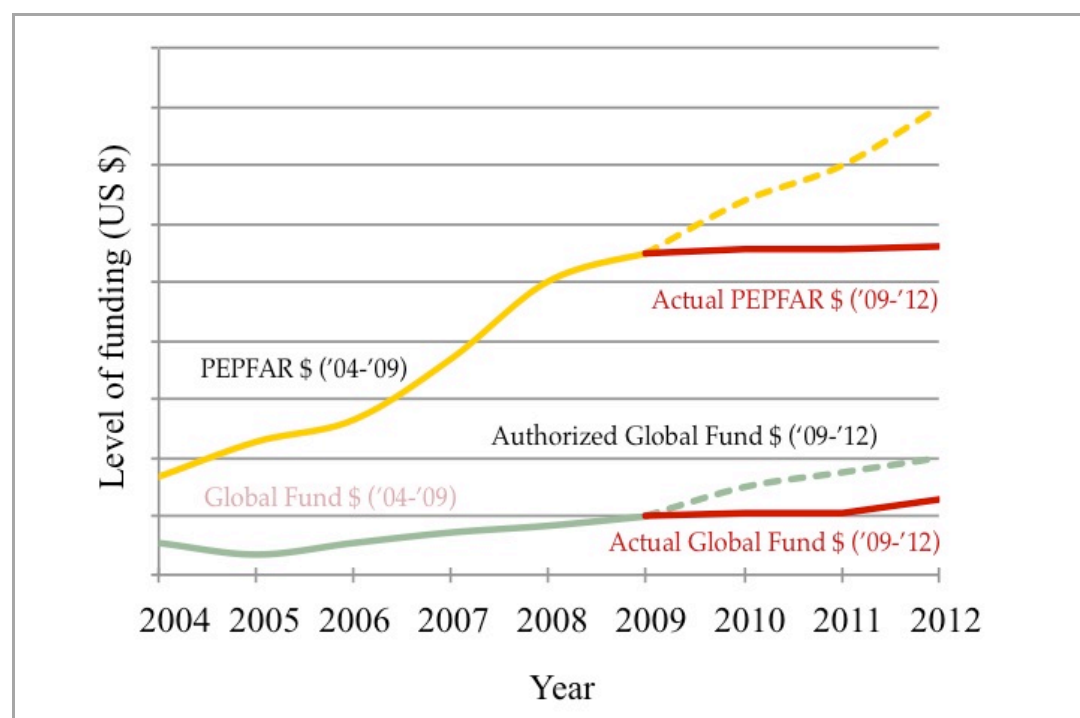
Since 1995, antiretroviral therapy has saved 14 million life years in low- and middle-income countries, including nine million in Sub-Saharan Africa. However, as of 2007, 7 million people eligible for HIV treatment still do not have access to it under the WHO's most recent treatment guidelines, recommending initiation of treatment at a CD4 count below 350 cells per cubic

millimeter.⁷

Among the excluded, according to UNAIDS, 72% of children living with HIV who are eligible for treatment do not have access.⁷ Without treatment, 50% of HIV-positive infants die before their second birthday.¹⁸

Figure 2 shows that since 2008 international funding for the fight against HIV and AIDS has remained flat. This is a problem if we are to cover all the needs of the HIV response as the world already faces a gap.⁵

Figure 2: Global AIDS Funding from 2004 to 2012.



Source: Office of the US Global AIDS Coordinator: *Funding Investments That Save Lives and Promote Security* (February 2011); Kaiser Family Foundation: *US Funding for the Global Health Initiative—The President's FY 2012 Budget Request* (March 2011).

Why a rights-based approach?

In a rights-based approach a duty-bearer is obligated to provide the rights to a claim-holder who is entitled to those rights for which the duty-bearer is accountable. A duty-bearer is required to deliver to a rights-bearer whether the rights-bearer makes a claim or not, even if the rights-bearer does not know their rights. A rights-based approach is especially appropriate in the case of children, as they rarely know that they have rights.

For the right to health, as for many other human rights under law, government is the primary duty-bearer; other duty-bearers include international institutions, donor communities, intergovernmental organizations, international and national non-governmental organizations (NGOs), and others whose actions have a bearing on the enjoyment of human rights in any country. However, there is a difference between a duty to deliver health care services and a duty to provide their norms and standards, as well as to monitor their implementation – for example, governments have a duty to provide appropriate norms and standards, health care services, to ensure the surveillance of their implementation, and to inform and teach the population about their rights and the need to use these services to maintain their good health. The World Health

Organization and sister agencies such as UNICEF and United Nations Population Fund (UNFPA) have a duty to provide health protocols, guidelines and surveillance.

The relationships between duty-bearers and claim-holders form a framework that connects individuals to all elements of society (Universal Declaration of Human Rights, 1948). One individual may have both claim-holder and duty-bearer roles, such as parents who are duty-bearers to their children and claim-holders *vis-a-vis* the government, which means that governments have to support parents/care-givers and step in when they fail to provide rights (Convention on the Rights of the Child, 1989).

Health is at the heart of the life of an individual, a family, a community, a country, a region and the world. It is a crucial basic commodity for every person. If a child's right to health is fulfilled, they will enjoy a better state of health and will have a better chance of becoming a healthy adult. Persons in poor health may have problems to earn an income and enjoy life fully. The determinants of health closely link the right to health to other fundamental human rights, most notably access to potable water, adequate hygiene, food, housing, freedom, education, employment, trade, peace and security. All are important and crucially linked to having sufficient resources to avoid living in poverty. Adequate financial resources in turn give people the ability to make choices and enjoy a way of life they value even in the health domain.

This research will not address the determinants of health *per se*, even if they are of vital importance, but will focus on the rights to that health.

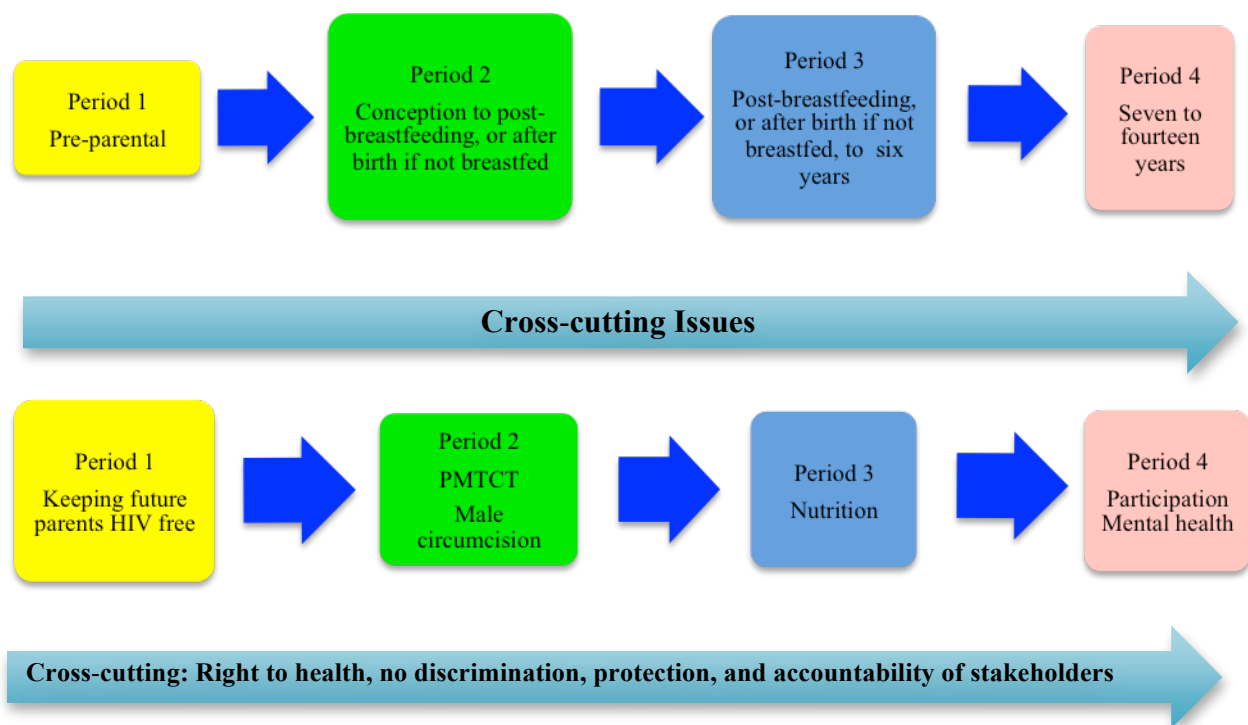
Why four periods of life?

In this thesis, a child is defined as an individual under fifteen years old, which is consistent with the UNAIDS definition of pediatric HIV infection. Additionally, in Rwanda, a child older than fifteen is no longer part of the pediatric HIV response.

In this research, children are considered affected by HIV if they are infected by HIV or if one of their parents is HIV-positive. *Vis-a-vis* the right to health, the vulnerability of children affected by HIV varies across their life. Events preceding a child's conception can have a later effect because more than 90% of HIV infections among children under the age of 15 have been acquired from their biological parents (the mother, and the father when he infects the mother).⁶ This implies that HIV prevention among future parents is a crucial component of the right of a child to be protected against HIV before birth, the period called Period One. The story line of this research thus starts with the right of a child to be born free of HIV. Another important period for a child born to an HIV-positive mother is Period Two, the time from their conception until the period of weaning, if breastfed, or immediately after their birth if exclusively bottle-fed. During this phase a child can be protected against the transmission of HIV from their mother through the use of antiretroviral therapy and the practice of safe nutrition.¹⁹ After breastfeeding, or after birth if not breastfed, the mother can no longer transmit HIV directly to her child. This part of the life of the child affected by HIV has been divided into two periods: Period Three and Period Four. Period Three is after breastfeeding, or after birth if not breastfed, to six years, and Period Four goes from seven to fourteen years. Seven years was the cut-off between Periods Three and Four, as it is considered by many to be the age of reasoning, the time by which a child is capable of making an independent choice and when the notion of morality begins. It is also the age when the majority of children have a social life independent of their parents.^{20, 21, 22}

The gaps and vulnerabilities along these four Periods have guided the story line for my thesis. Throughout this dissertation, the four Periods described above refer to the following: Period One, pre-conception; Period Two, from conception to post-breastfeeding or from birth if not breastfed; Period Three, from post-breastfeeding to six years; and Period Four, from seven to fourteen years (Figure 3). Finally, some elements of the thesis have addressed aspects that impact a child across more than one period and they have been grouped under the theme of ‘cross-cutting issues’.

Figure 3: The four periods of life in children under fifteen years old, in the context of HIV.



1.2. Research Problem

This research problem of interest is how to improve the HIV response aimed at improving the wellbeing of children affected by HIV in Rwanda and around the world. The right to health is at the core of the Convention on the Rights of the Child’s right to life, and this research will explore, in depth, existing gaps and challenges in each of the four periods of a child’s life.

1.3. Research Questions and Hypothesis

The research questions, which drive the thesis, address the critical gaps found in the literature review, according to the vulnerability of each of the four periods. There are two sub-questions for each of the four periods, plus one question to address cross-cutting issues identified in this research. They are summarized below in Table 1.

Table 1: Summary of Research Questions.

Research Questions	Period of Life	Sub-questions
<i>1. Are there barriers to prevention?</i>	Period 1 – Before conception	1. What are the barriers to sex workers and their children exercising their rights to health care?
		2. Are prisoners in Rwanda able to fulfil their rights to primary prevention of HIV?
	Period 2 – After conception to post-breastfeeding or after birth if not breast fed	3. What is the most cost effective PMTCT protocol for Rwanda?
		4. In the framework of HIV prevention what is the most cost effective male circumcision (MC) practice for Rwanda?
<i>2. Are there barriers affecting the physical and mental development of children affected by HIV?</i>	Period 3 – From after MTCT period and before seven years old	5. Are the nutritional protocols proposed by international regulatory bodies appropriate for Rwandan children?
		6. Are tools used to assess the nutritional status of malnourished children in Rwanda appropriate?
	Period 4 – From seven to fourteen years	7. Is the Children's Depression Inventory (CDI) tool appropriately adapted to assess the mental health of children in Rwanda?
<i>3. Are there barriers to health decisions for children affected by HIV, due to the non-respect of their rights to information and participation?</i>		8. Does the state and do parents fulfil their obligations to protect, inform, and involve children in the response to HIV?
<i>4. Are there barriers in financial management that inhibit the fulfilment of a child's right to health when affected by HIV?</i>	Cross-Cutting Issue	9. Did NGOs improve financial reporting after request by the Government of Rwanda (GoR)?

Although this research is approached openly, without preconceived ideas, I hypothesise that even though the Rwandan Government was committed to the promotion and protection of children's rights, the legal framework, policies and strategies did not always anticipate and meet the unique needs of children affected by HIV and AIDS. Consequently, the rights of children affected by HIV are not being fulfilled. This was not a financial problem but rather an issue of governance, and a structural and managerial problem. I approach this research with the full acceptance that the hypothesis put forward can be refuted.

1.4. Objectives

Primary objective

The objective of this research is to contribute to the improvement of the fulfilment of the Rights to Health for Rwandan children affected by HIV.

Secondary objective 1

To provide realistic solutions to bottlenecks and challenges evidenced through the literature review, in order to contribute to the improvement of access to prevention, care, and treatment services for Rwandan children affected by HIV, during four distinct periods, rooted in a comprehensive understanding of human rights.

Secondary objective 2

To provide national and international policy-makers, decision-makers, development partners, NGOs, and healthcare workers with recommendations on improvements to be made in the legal framework and in policies, strategies and programs for children affected by HIV, so that the children can better exercise their human rights to health, mental health and counseling services.

In exploring my hypothesis that children under fifteen years were not accessing their full rights to health in the context of HIV due to issues in management and governance, and in proposing realistic, cost-effective, ethical, and sustainable recommendations, I hope to be able to contribute to the better health of children in Rwanda. The solutions proposed are applicable to other vulnerable groups in Rwanda and to other countries with similar problems.

1.5. Motivation

Motivating this work is the great need to create evidence-based solutions for known gaps in care provision and to propose improvements in laws, policies, protocols and monitoring and evaluation for better protection of children affected by HIV. Moreover, the motivation for this work stems from a deep passion for social justice and belief that health is a human right. Further background regarding my personal and professional motivation for this research can be found in the Preface above.

1.6. Scope

This thesis employs an interdisciplinary approach, drawing from an array of fields including history, economics, statistics, international and national law, health policy, sociology of health and illness and health service delivery, to deeply explore the right to health of a child in the context of HIV beginning before conception up to 15 years of age.

1.7. Literature Review

In order to formulate the research questions of this thesis and develop the studies that could address them, I conducted an in-depth literature review that drew from a range of disciplines. The following summarizes the general approach and inclusion criteria that I adopted for completing this task, with specific detail provided for how this literature review informed the background, context and frameworks provided within Chapters 1 through 3. For Chapters 6 through 9, which include my findings, I also summarize the findings from my literature review

as it relates to each specific component of this dissertation at the beginning of each of those chapters.

During my search for relevant literature, I examined a range of sources, including peer-reviewed journals and books. To be included in the review, documents needed to relate to the questions that I explored and be published after 2005. However, in some areas, publications could go as far back as 2000 or potentially even earlier depending on when government and international documents are referenced (e.g. Declaration of Human Rights) as well as scientific studies that have informed them.

Beyond peer-reviewed journals and books, it was also important to include sources from the grey literature as these documents provide valuable information regarding the HIV-AIDS response across the world and thus greatly informed this research. The inclusion criteria that I applied for evaluating these items from the grey literature were: 1) the need to be referenced, and 2) written by credible authors or institutions.

In summary, the types of literature, in addition to peer-reviewed books and journals that I evaluated as part of the literature review, included:

- a. Grey literature
- b. Institutional reports and research
- c. Official reports on the Rwandan context, specifically on Rwanda's recent history, demographics, economics and financing, administration and systems, and stakeholder actions, plans, and reports
- d. Reports of, and research into, international governing institutions such as UNICEF and WHO, and into national governing institutions
- e. International and national legal, policy, protocol and guideline documents.

1.8. Difficulties and Mitigation Strategies

In general, the most challenging aspects of this research included the technical logistics of completing interviews among the vulnerable population and do so in such a way that they could benefit from it. For instance, finding a sampling strategy that would include a sufficient number of eligible participants while also ensuring that the appropriate precautions were taken to protect these vulnerable individuals was difficult. However, consulting experts in social science research in Rwanda and internationally have taught me about best practices, which proved very helpful in overcoming these challenges.

1.9. Scientific Publications

Given my position as a civil servant, many of these findings have already been disclosed through conferences, workshops, and research activities published in academic journals and grey literature, in order to advocate rapid implementation of the solutions that were informed through this research. Ethically, it did not feel appropriate to withhold this information until the presentation of my dissertation as the findings directly related to efforts that could improve the health of children in the context of HIV.

Below, I list the thirteen peer-reviewed, scientific publications that have arisen from the research undertaken for this dissertation thus far, organized by the aforementioned four periods of life. The research reported in these papers concerns children under the age of 15 years affected by HIV, and these papers, listed below, are part of this dissertation.

Period One: Pre-conception - keep future parents among key population free from HIV

1. Binagwaho A, Agbonyitor M, Mwanawasa A, Mugwaneza P, Irwin A, Karema C. (2011). Developing human rights-based strategies to improve health among female sex workers in Rwanda, Health and Human Rights An International Journal 12(2).
<http://www.hhrjournal.org/index.php/hhr/article/view/371/574>
2. Binagwaho A. HIV prevention in Rwandan prisons, Health and Human Rights: An International Journal 15(1).
<http://www.hhrjournal.org/2013/08/29/access-to-hiv-prevention-in-rwandan-prisons/>

Period Two: From conception to post-breastfeeding or from birth if not breastfed

3. Binagwaho A. (2008). The right of children in developing countries to be born and live HIV-free, Health and Human Rights: An International Journal 10(1)
<http://www.hhrjournal.org/index.php/hhr/article/view/28/91>
4. Binagwaho A, Pegurri E, Drobac PC, Stulac SN, Wagner CM, Karema C, Tsague L. Prevention of mother to child transmission of HIV: cost-effectiveness of antiretroviral regimens and feeding options in Rwanda, PLoS ONE 2013; 8(2): e54180
<http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0054180>
5. Binagwaho A, Fawzi MC, Drobac P, Franke M, Ivers L, Kim JY, Mukherjee J, Noguchi J, Rich M, Stulac S, Farmer P. (2009). HIV, infant feeding and implementation failure: advancing policies for women with HIV infection and attaining the Millennium Development Goals, Bulletin of the World Health Organization 87(8)
6. Binagwaho A, Ratnayake N, Mukherjee JS, Mugabo J, Karita E, Pegurri E. (2010). When one can infect two: A reflection on the impact of HIV discordance on child HIV infection, Pan African Medical Journal 2010; 5(10)
<http://www.panafrican-med-journal.com/content/article/5/10/full/>
7. Binagwaho A, Pegurri E, Muita J, Bertozzi S. Male circumcision at different ages in Rwanda: a cost-effectiveness study, (2009). PLoS Medicine 7: e1000211

Period Three: From post-breastfeeding or from birth if not breastfed to six years

8. Binagwaho A, Ratnayake N, Smith Fawzi MC. (2008). Holding multilateral organizations accountable: The failure of WHO in regards to childhood malnutrition. Health and Human Rights: An International Journal, Perspectives
<http://hhrjournal.org/blog/perspectives/holding-multilateral-orgs-accountable-the-failure-of-who/>
9. Binagwaho A, Agbonyitor M, Rukundo A, Ratnayake N, Ngabo F, Kayumba J, Dowdle B, Chopyak E and Smith Fawzi MC. (2011). Under-diagnosis of malnutrition in infants and young children in Rwanda: Implications for attainment of the Millennium

Period Four: From seven to fourteen years

10. Binagwaho A, Nsanzimana S, Remera E, Ruton Hinda, Nutt CT, Wagner CM, Karema C, Agbonyitor M, Yvonne Kayiteshonga, Smith Fawzi MC, Validation of the CDI in the context of Rwandan culture. (*ready for submission*)
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Cross-cutting issues

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1.10. Thesis Structure

This thesis, comprises a preface and ten chapters, examines gaps in content and implementation of laws, policies and care guidelines, and compared these to Rwanda's commitment regarding the right to health *vis-a-vis* prevention, care and treatment for children living with HIV. In the preface, I share with the reader how my professional life, the care I gave to children affected by HIV and the study of their situation had led me to question their access to prevention, care and treatment in Rwanda. In Chapter 1 – the introduction – I define the target group and present the hypothesis, which posits that children affected by HIV are unable to enjoy their right to health fully during the four periods of life - as defined for this research - because of management and governance issues rather than for financial reasons. The introduction also provides a summary of the scientific publications that have been published as part of this dissertation. In Chapter 2 – I provide a summary of the Rwandan context, which influences children's life in the context of HIV. In Chapter 3, I review both international and national legal frameworks governing the rights to health of a child affected by HIV in Rwanda. In Chapter 4, I provide a conceptual framework for this research and the methods that I employed to answer my research questions. In Chapters 5 through 9, I provide the results and discussion of each component of this dissertation research that relates to the four periods of life noted above. In Chapter 10, I provide a conclusion, series of policy implications, and a list of recommendations for the appropriate stakeholders to address the gaps and deficiencies found.

Chapter 2: Rwandan context

In this chapter, I provide a summary of the Rwandan context, including its HIV epidemic situation, geography, population, administration, infrastructure, resources and so forth. It was within this framework that children affected by HIV either gained access or encountered obstacles when trying to access preventive measures, care or treatment. Providing this context is critical to fully understanding Rwandan children's vulnerability to HIV infection over the course of the four distinct periods as well as the cross-cutting issues noted in this work. Given the subject of the present research, the contextualisation of Rwanda is described through the lens of the health sector.

2.1. Geography

The Republic of Rwanda is a landlocked, low-income country with a total area of 26,338 km², a member of the East Africa Community, bordered to the north by Uganda, to the south by Burundi, to the west by the Democratic Republic of Congo, and to the east by Tanzania. There are three natural borders: the Virunga Mountains in the north, the Akagera River in the east and Lake Kivu in the west. Only the southern border with Burundi has a conventional roadblock barrier. A lack of access to the sea and the long distance to the sea-ports of other countries drives up the cost of medicines and commodities in Rwanda. Through the East African Community (EAC) Parliament, new laws are currently under development to solve the taxation part of this issue.

Rwanda's topography is mountainous and the average altitude is 1,700 metres. Although located only two degrees south of the Equator, Rwanda's high elevation creates a temperate climate. The average daily temperature is (73° F) 23° C. There are two rainy seasons (February-May and September-December), marked with heavy downpours that occur almost daily.

2.2. Socio-economic context

Rwanda is the most densely populated country in Africa, home to approximately 10.5 million people, according to the 2012 Census, with a population density of 616 people per square kilometer.

Nearly half (43%) the Rwandan population are under sixteen years of age and 55% of the population are under twenty years.²³ According to the national definition, 29% of all children under eighteen years are vulnerable. According to the Enquête Intégrale sur les Conditions de Vie des ménages/Integrated Household Living Conditions Survey-3 (EICV3, 2010-2011) the proportion of female-headed households decreased from 29% to 27%. In contrast, disabled-headed households increased from 8 to 10%.

Financial Accessibility

Financial barriers to accessing health services have been reduced with Mutuelles de Santé (Mutuelles), a community health insurance program established by the Government of Rwanda as part of the national strategy to ensure universal basic health care. The *ubudehe* categories - the basis of the social and economic status of household - are used to determine the amount of the premium families pay for each of their members. The *ubudehe* categories are

determined by a participatory process in villages, whereby the community places all households in six socioeconomic categories, from destitute to rich, after having evaluated the assets of the households, with facilitation by trained volunteers.

Those in the bottom two categories, ($\pm 25\%$ of the population), are eligible for social protection programs and have free health care. Money mobilized by the government from domestic or development partners' funds cover their premiums. *Ubudehe* categories 3 and 4 pay 3000 Rwanda francs per capita and categories 5 and 6 pay 7000 per capita. Table 2 indicates the premium per category and the total amount of premium collected in the two last fiscal years.

Table 2: Evolution of premium per category and the total amount of premium collected in the last two fiscal years.

<i>Ubudehe</i> categories	Premium	Percent of the Population (%)	Amount of premium collected (RWF)
2011-2012			
1&2	2,000	24.81	4,649,588,000
3&4	3,000	65.90	12,829,485,028
5&6	7,000	0.04	20,744,825
Total		90.75	17,499,817,853
2012-2013			
1&2	2,000	26.22	4,417,182,000
3&4	3,000	54.60	12,134,045,727
5&6	7,000	0.06	-
Total		80.88	16,551,227,727

Source: Community Based Health Insurance (CBHI) / Ministry of Health (MOH) Annual Reports 2011-12 and MOH Preliminary Estimations (awaiting the final CBHI Annual Report 2012-2013 validation of District Reports on CBHI Performance, which is still in process (<http://moh.gov.rw/index.php?id=17>); Rwandan Francs (RWF).

The Mutuelles policy is currently under revision to take into account the remaining financial barriers, as many Rwandans cannot afford the 10% co-payments for tertiary referral hospitals or cannot sustain paying them when they seek simple health services with laboratory examinations multiple times within a year, or for a number of family members within a year.

Antiretrovirals are free of charge for all in public health facilities, known as Formation Sanitaires (FOSA), but the co-payments for the consultations need to be paid.

There is a difference between being poor and being vulnerable. All the poor are vulnerable but some children who are not poor may have vulnerability. For example, the poor children from *ubudehe* 1 and 2 have their Mutuelles paid and receive free care, while some children from *ubudehe* 3 and 4 may be very vulnerable if they have parents who do not pay the health insurance premiums for their children, or who do pay the health services at each point when care is needed, if they have a number of children. Other children may live in wealthy families but may be vulnerable because they are HIV affected, or they have another chronic disease, live

with a disability, or live in a rural area (Orphans and Vulnerable Children (OVC) Policy, EICV2, EICV3; Rwanda Demographic and Health Survey (RDHS) 2005, 2010).

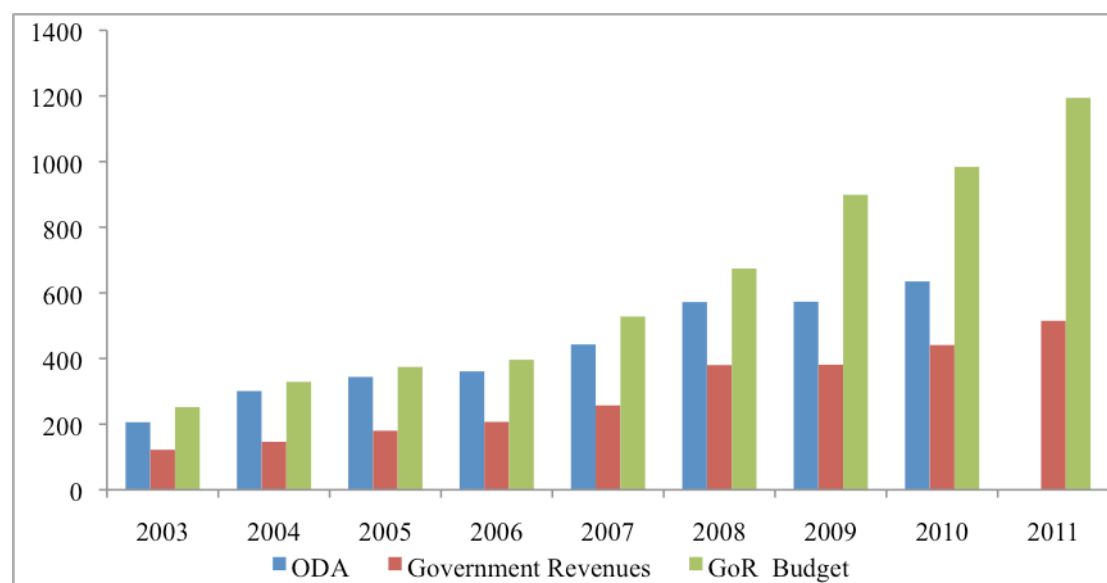
With improved services for orphans and vulnerable children (including reintegration and adoption into adult-headed households), the percentage of child-headed households has decreased since 2006, presumably also as children orphaned in the Genocide have become adults.

Women from the age of fifteen to forty-nine years are considered to be of reproductive age and comprise 23.5% of the population.²⁴ According to the RDHS2005, fertility rate in Rwanda was 6.1.²⁵ The RDHS2010 in Rwanda showed a 691% increase in uptake of family planning use (Table 4). Despite this dramatic decrease in the fertility rate, which can be attributed to extensive family planning campaigns and increased access to modern contraception, Rwanda still faces demographic pressure.

There is an increase among children aged 7 to 12 currently attending primary school [from 87% in EICV2 (2005-2006) up to 92% in EICV3 (2010-2011)] and, as far as children under 15 are concerned, access to nine years of free basic education is available for all children. Comparing EICV2 (2005-2006) and EICV3 (2010-2011), the gaps decreased between the poor and the wealthy for the majority of social indicators. This can be attributed to economic growth and social development based on equity. Between 2005 and 2010, economic growth reduced, in a significant manner, the percentage of people in poverty – 12 points decline [EICV2 (2005-2006), EICV3 (2010-2011)].

Rwanda's dependency on foreign aid for health in general, and the AIDS response in particular, is currently a major constraint and a financial challenge. Figure 4 shows that the government revenue, the government budget and the Official Development Assistance (ODA) have increased in Rwanda over the last 10 years, keeping the difference between government revenue and the ODA almost constant.

Figure 4: Official Development Assistance, Government of Rwanda revenues and budget: 2003-2011 (in billion RWF).



Source: Data Supplied by RDB, Rwanda Macroeconomic Variables Public Data Set 06/08/12 <http://www.minecofin.gov.rw/>; World Bank Data, Organization for Economic Co-operation and Development (OECD) data and MOH. (Note: investment is the amount promised for Foreign Direct Investment (FDI) and Domestic Investment (DI) – only Rwanda Development Board (RDB) keeps records of this).

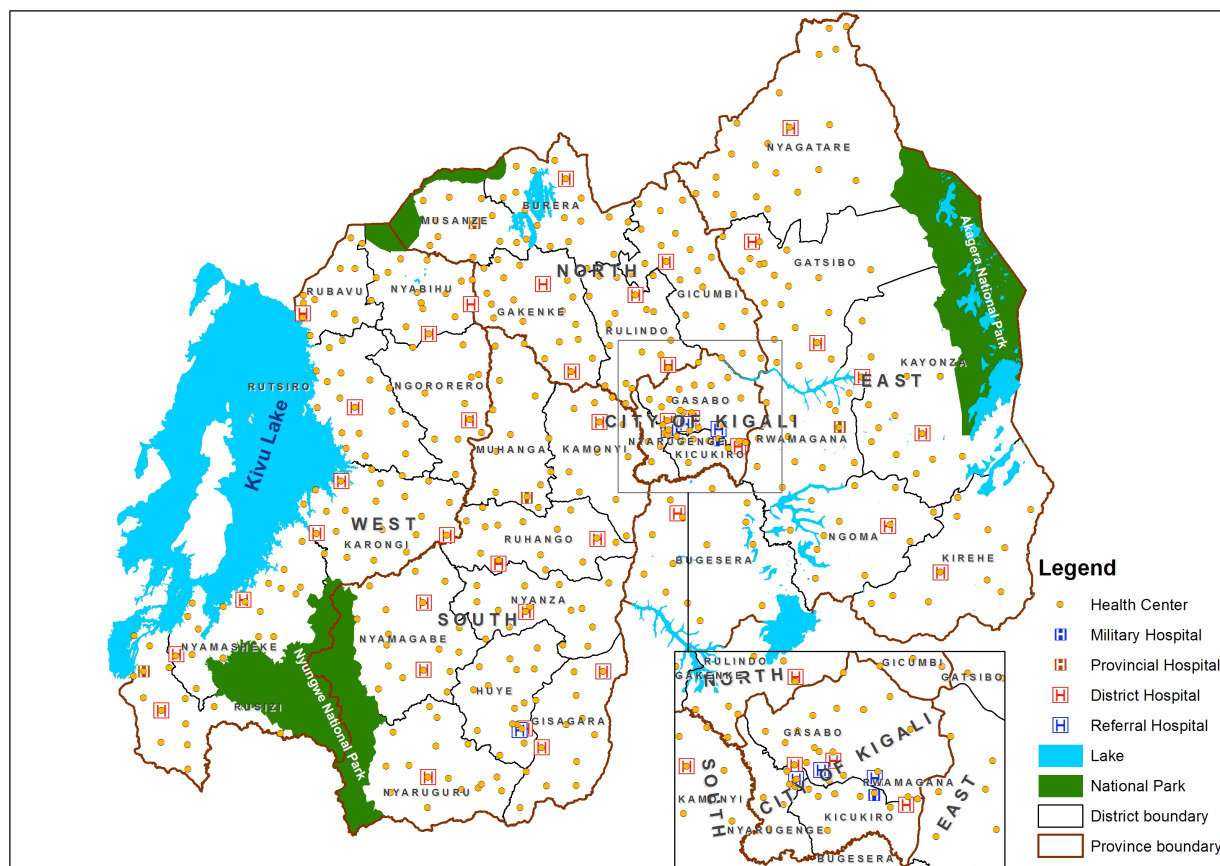
2.3. Health system

Rwanda's geography has a significant impact on health care delivery, as health facilities can be near as the crow flies but far or difficult to access by road or footpaths. Geographic equity in distribution of health services is critical in general, and certainly indispensable for addressing the needs of children across all the periods considered in this research. Transport to health facilities in rural areas is not always easy, given that many roads are not passable by car. The Ministry of Health in Rwanda has tried to improve this situation by bringing basic health services closer to the population, at the community level.

After the genocide of the Tutsi in 1994, one major challenge has been the creation of a health system with equitable distribution of health facilities in rural and urban areas according to population distribution, even though many of the government hospitals and health centers were badly damaged or destroyed by the violence during the Genocide.²⁶ It was in this spirit that the government began to construct health centers and hospitals, known as FOSA, aligned with administrative decentralization, to ensure the most balanced geographic distribution possible.

The country is divided into four provinces (East, West, North, and South) and Kigali City. The decentralized level consists of 30 administrative districts within the four provinces and Kigali City, 416 sectors, 2,148 cells, and 14,842 *imidugudu* (plural of *umudugudu*, "village"). There are three community health workers (CHWs) per village providing clinical services – about 45,000 in total. CHWs are not health professionals but are elected by the community, and once elected they are provided with the necessary training and tools by the Ministry of Health to provide basic services. For the same reason, there is a target for each cell, where there is no health center, to have a health post.²⁷ Currently, 200 have been created.²⁷ For equity, the plan is to have one health center per sector. In 2013 over 468 health centers exist across the country, and some sectors have several health centers.²⁷ We need to build 35 more health centers because 35 sectors do not have even one (HMIS June 2013). Health centers provide primary care. Figure 5 shows the distribution of health facilities in Rwanda as of December 2012.²⁵

Figure 5: Map of health facilities in Rwanda, December 2012.



Source: MOH/Health Management Information System (HMIS) June 2013 (Map made for this dissertation with data extracted from MOH/HMIS 2013 using Geographic Information System).

Comparing EICV2 (2005-2006) and EICV3 (2010-2011), the percentage of the population who reported an illness and/or accident and requested the services of a health professional increased by nine points (from 31% to 40%).

The proportion of this population visiting a health center increased from 49% in EICV2 (2005-2006) to 66% in EICV3 (2010-2011). This is due to several factors, among them an increase in satisfaction of the population with the services provided in health centers, from 64% in EICV2 (2005-2006) to 82% in EICV3 (2010-2011), and a reduction in the mean time needed to reach a health center from approximately 95 minutes in EICV2 (2005-2006) to 60 minutes in EICV3 (2010-2011).

This is progress, but in terms of access to emergency care, routine care and check-ups it is important to note that it takes half a day for a member of a household living an hour's walk from a FOSA to seek health services at that FOSA. It also takes a mother with young children longer than an hour to walk to a FOSA that is an hour's walk away as the bird flies. Each of the 30 districts have at least one district hospital, some have two. Table 3 shows the facilities by province and Kigali City. WHO recommends a walking distance of less than an hour to reach a health facility.

Table 3: Details of health facilities in Rwanda by province and Kigali city, 2010.

Province	Referral Hospitals	District Hospitals	Health Centers
City of Kigali	4*	4	35
Northern Province	0	7	85
Southern Province	1	11	115
Eastern Province	0	9	107
Western Province	0	12	109
TOTAL	5	42	451

Source: HMIS National Health Facility Database, 2012. Ministry of Health, *Annual Health Statistics Booklet 2012*. Note: *The 4 referral hospitals in Kigali are the Kigali University Teaching Hospital, King Faisal Hospital, Ndera Hospital, and Kigali Military Hospital.

Non-governmental organizations (NGOs), the majority of which are faith-based, own and operate approximately 40% of health facilities in Rwanda. We call their health facilities the “FOSA agréés” (Formations sanitaires agréés). They adhere to public sector regulations and guidelines codified through individual memoranda of understanding with the Ministry of Health, and they benefit from the Government of Rwanda's commitment to sharing a minimum of 50% of facility operating costs. All FOSA, both government-run and NGO-run, provide the same package of services and have the same protocols, rules, and responsibilities, and they are registered and receive the same advantages and support from the government.

The human resources available for health care were also greatly impacted by the Genocide, as many were killed or fled the country in the years before, and during, the Genocide. Efforts to rebuild the health infrastructure are therefore complemented by training and rebuilding its human resources for health.²⁸

2.4. Health improvements as of 2010

Key health indicators

The health sector in Rwanda has made tremendous leaps in improving health outcomes. Several of the advances in outcomes in the health sector will be mentioned briefly, to contextualise the disease burden and the country's achievements before presenting the research undertaken for this doctoral dissertation.

Contributions from community health workers in providing health services (such malaria diagnosis and treatment as well as gastroenteritis and pneumonia syndrome treatment) and in linking community members to care (including referral to services in health facilities such as antenatal clinics, routine immunisations and fighting malnutrition) have been part of the dramatic decrease in mortality over the past decade and have increased life expectancy, along with other achievements such as decreased morbidity and an increase in the uptake of contraception.²⁹

Rwanda has achieved steep reductions in mortality rates due to infectious diseases across all ages over the past decade, including those from HIV and AIDS, tuberculosis, malaria, pneumonia, and diarrhoea as well as in child and maternal mortality (Table 4 and Table 5). Life

expectancy has increased from thirty-three years in 1990 to over fifty-five years in 2010.^{30,31,32} However, malnutrition remains a serious public health issue, as shown in Table 4, for being underweight (moderate: between minus two and three standard deviations from median weight for age of reference population and severe: below minus three standard deviations from median weight for age of reference population) and for stunting growth (moderate: between minus two and three standard deviations from median height for age of reference population and severe: below minus three standard deviations from median height for age of reference population).³³

Table 4: Change in Key Health Indicators from 2000 to 2010.

Indicator	2000	2005	2007/08	2010
Total fertility rate	5.8	6.1	5.5	4.6
Married women (15-49 years) using any modern family planning method	4.3	10	27.4	45.1
Deliveries occurring at health facility	26.5	28.2	45.2	68.9
Infant mortality rate (deaths among 0-1 year old per 1,000 live births)	107	86	62	50
Child mortality rate (deaths among 1-4 year olds per 1,000 live births)	99	72	43	27
Under five mortality rate (deaths among 0-5 year olds per 1,000 live births)	196	152	103	76
Maternal mortality ratio (deaths per 100,000 live births)	1071	750	NA	476
Child malnutrition				
Stunting	43	45	NA	44
Wasting	7	4	NA	3
Underweight	24	23	NA	11

Source: National Institute of Statistics of Rwanda & Macro International, RDHS 2000, 2005, 2007/8 and 2010.

Table 5: The mortality reduction related to HIV, tuberculosis (TB) and malaria.

Indicator	Source	Timeframe	Estimates	Reduction
AIDS-related mortality rate (deaths per 100,000 population)	WHO 2012 ³⁴	2000-2009	190 (2000) 41 (2009)	78.4%
Tuberculosis mortality rate among HIV-negative people (deaths per 100,000 population)	WHO 2012 ³⁵	2000-2011	48 (2000) 11 (2011)	77.1%
Malaria deaths (total reported by Rwanda to WHO)	WHO 2012 ³⁶	2005-2011 (2005 was the height of an epidemic in Rwanda)	2,581 (2005) 380 (2011)	85.3%
Mortality rate from all causes (deaths per 100,000 population)	Institute for Health Metrics and Evaluation 2012 ³⁷	2000-2010	1,393.9 (2000) 697.5 (2010)	50.0%

Source: WHO (2012) and Institute for Health Metrics and Evaluation. (2012). *Global Burden of Disease Study 2010 (GBD 2010) Mortality Results 1970-2010*. Seattle, WA.^{34,35,36,37}

Specific advances have been made in bolstering maternal and child health. Rwanda's expanded program on immunisation has improved dramatically and remained robust over the past decade, recovering from the setbacks of 1994 when fewer than 25% of children received full courses of the measles and polio vaccines. The percentage of children aged 12-23 months who have been fully vaccinated has improved from 75.0% in 2005 to 90.1% in 2010.^{24,25}

In 2011, coverage rates for all WHO-recommended vaccines (BCG, three doses of diphtheria-tetanus-pertussis in pentavalent form, measles, and three doses of polio) exceeded 90%.³⁸ Between 2009 and 2013, four new vaccines were introduced nationwide: against pneumococcal pneumonia, bacterial meningitis, diarrhoea attributable to rotavirus, cervical cancer caused by human papillomavirus, and rubella (Table 6).

Table 6: Year of introduction and coverage of vaccine by 2011 in Rwanda.

Vaccine	Year Launched	Coverage by 2011
Bacilli Calmette Guerin	1970s	99%
Diphtheria-tetanus-pertussis	1970s	97%
Measles	1970s	95%
Polio	1970s	93%
Hepatitis B	2002	97%
Haemophilus influenzae B	2002	97%
Pneumococcal	2009	97%
Human papillomavirus	2011	93%
Rotavirus	2012	93%
Measles-rubella	March 2013	Evaluation to be made

Source: National Institute of Statistics of Rwanda & Macro International, Inc. (2012) RDHS2010. Calverton, MD; Program Elargi de Vaccination (PEV) Annual Report EPIDEMIOLOGY 2011 PEV Annual Report 2012; Ministry of Health/Rwanda Biomedical Center Vaccination Preventable Diseases Division Annual Report 2012-2013.^{24,39}

Between 2000 and 2010 the decline in pediatric mortality due to measles was 99.6%, to diarrhoea 63.1%, to HIV/AIDS 64.8%, to malaria 54.7%, and to pneumonia 42.2%. (Table 7)

Table 7: Estimated Reductions in Under Five Year Olds Mortality from Infectious Disease in Rwanda.

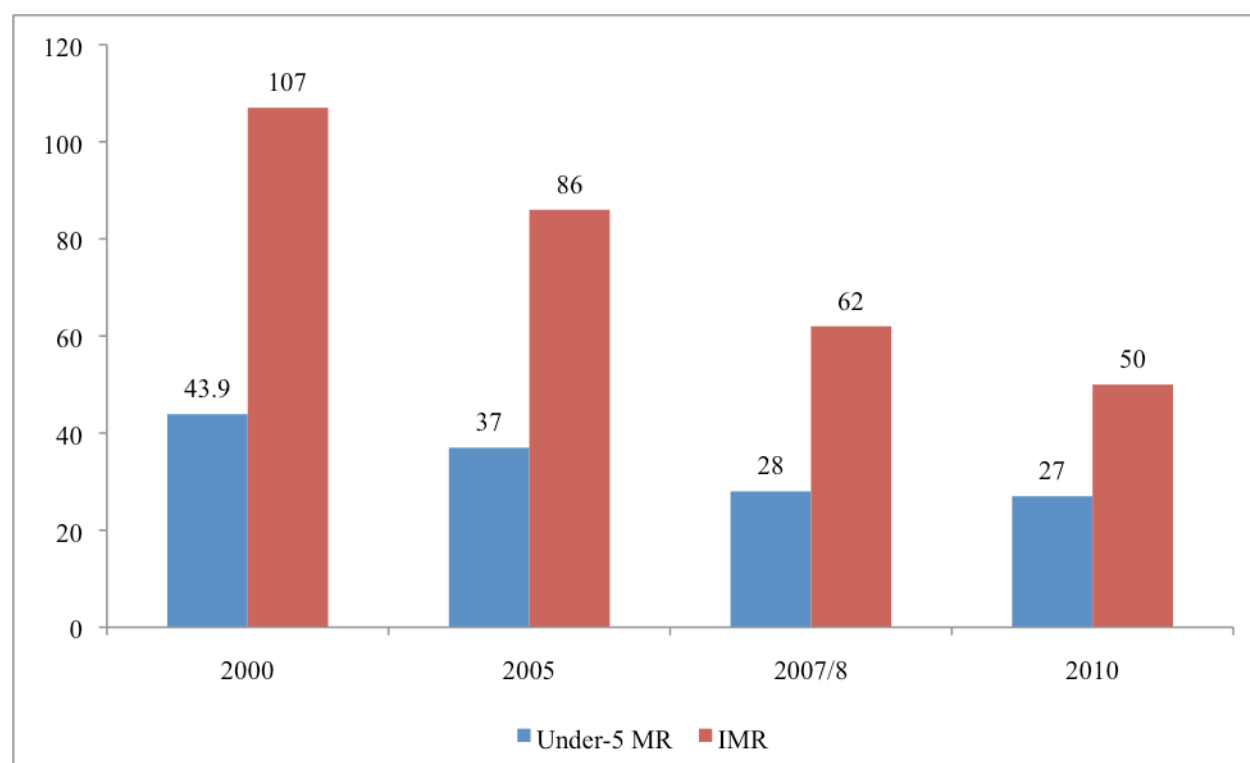
Cause	Estimates ²⁹	Reduction
Measles (deaths)	670 (2000) 3 (2010)	99.6%
Diarrhoea (deaths)	12,042 (2000) 4,447 (2010)	63.1%
HIV/AIDS (deaths)	2,176 (2000) 767 (2010)	64.8%
Malaria (deaths)	1,774 (2000) 804 (2010)	54.7%
Pneumonia (deaths)	13,493 (2000) 7,394 (2010)	45.2%

Note: Table 7 presents an original secondary analysis of raw data presented in the Online Appendix of Liu 2012.⁴⁰

According to the RDHS2005 and RDHS2010, Rwanda is on track to achieve the UN Millennium Development Goal for under-five mortality. Between 2005 and 2010 the decline in

the under-five mortality rate was 93%, in infant mortality 114%, and 63% for the neo-natal mortality rate decline (Figure 6).

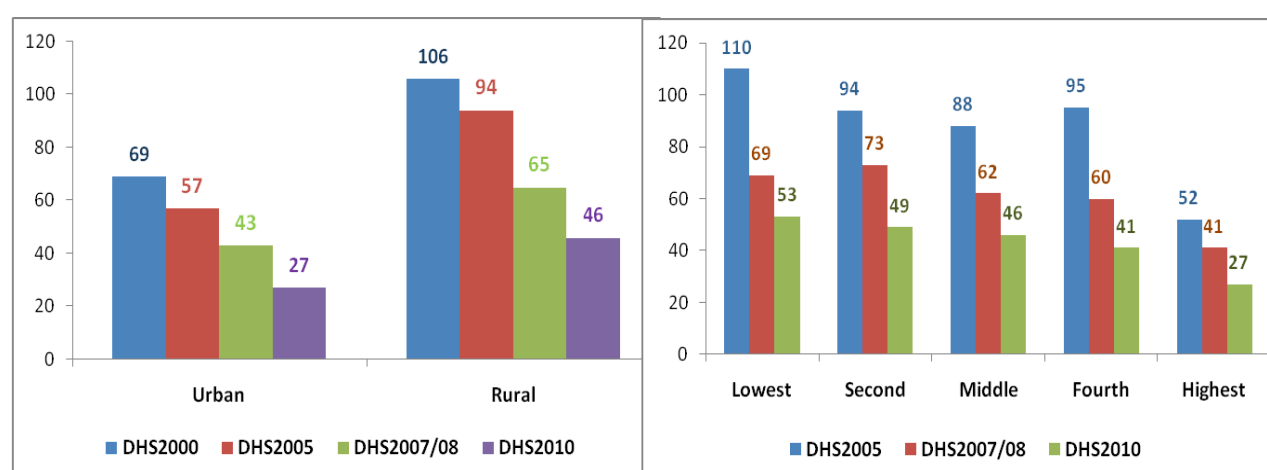
Figure 6: Infant and Under-Five Mortality Rates per 1000 Live Births in Rwanda from 2000 to 2010.



Source: RDHS2000, RDHS2005, RDHS2007/8 and RDHS2010.

The comparison of the decline in child mortality in higher and lower wealth quintiles and in urban and rural areas (Figure 7) shows an equitable distribution of progress, and that the poor are not left out of the service delivery platform.

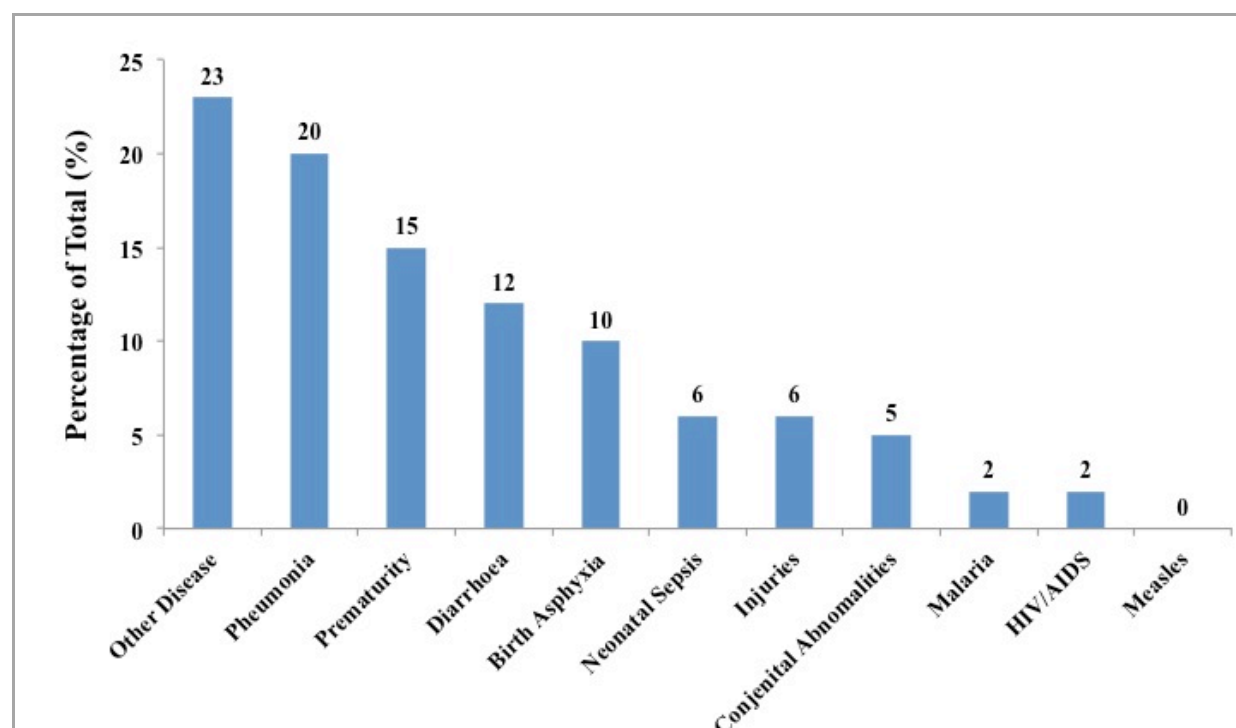
Figure 7: Decline in Child Mortality by Wealth Quintile and Residence from 2000 to 2010 in Rwanda.



Source: National Institute of Statistics of Rwanda & Macro International, RDHS2000, RDHS 2005, RDHS2007/08, and RDHS 2010. Calverton, MD.

Efforts have to be made to sustain these achievements in reducing child mortality from infectious diseases and infant illness and improve them, because children under five are still dying due to preventable diseases (Figure 8).⁴¹

Figure 8: Distribution of Deaths in Children Under Five in Rwanda, 2010 (by Percentage of Total and Cause in 2012).



Source: WHO 2010, 2012.

Health Financing

The above achievements cannot be attributed to one program or another. The equity approach, and the coordination of all stakeholders have certainly played a major role, and the creation of an alignment and synergism among partners has also contributed to the major progress in the health sector.⁴²

Coordination has allowed the integration of funds for different program interventions – infectious diseases, maternal health, child health and others - in the ordinary service delivery of FOSA and the systematic use of vertical funds (for example, funding designated for HIV, TB, malaria, vaccinations and family planning) to strengthen the overall health system. It has also allowed the health system to respond to the needs of other health services, for example improve services used in cases of malnutrition, surgery, and several others.

Health has a cost, and this progress has been made thanks to the efforts of the Government of Rwanda towards our own growing economy, and financial support from foreign assistance. Funding in the health sector comes from three major sources: the national budget, out of pocket/health insurance, and development partners. The reimbursement of services by health insurances has become an important source of revenue for the hospitals. In 2011-2012 health insurance companies have reimbursed 25,851,707, 360.70 RWF to health facilities for services given to the population.⁴³

The level of investment in the health sector from the government budget has also increased due to improved revenues from the collection of taxes and through growth in the economy in the informal sector (Figure 4). With all the funds mobilized through domestic taxes or Official Development Assistance, Rwanda exceeds the Maputo Agreement for the total proportion of

the budget spent on health, broadly defined by 16.05%, through funds disbursed for health in other sectors such as education, social affairs, decentralization and others.⁴⁴

From 2009 there was no further increase in the health sector in major funding for the HIV and AIDS response (Global Fund and PEPFAR - Figure 2, page 21) even though the enrolment of PLHA in treatment had increased. It is therefore crucial at the time when the availability of funds is diminishing for the AIDS response, to ensure effective coordination of all stakeholders, and the wise use of funds.

Table 8 shows the amounts of health sector spending from the government budget and from development partners as reported in the Health Resource Tracking Tool (HRTT) in the MOH. It has increased during the last three years from US \$419,636,013 in Fiscal Year (FY) 10/11 to US \$532,927,289 in FY 12/13.

Table 8 also shows the direct HIV spending contributed by GoR and the Development Partners, for HIV-related spending purposes only. These investments in the health sector are key to delivering quality and quantity in HIV services. The contribution of the government is small compared to external funding from the Development Partners but this does not take in account the government budget spent on general health system functioning that supported HIV services and infrastructure. There was an increase in funds allocated to direct HIV spending from GoR, from US \$294,401 in FY 10/11 to a budget of US \$1,128,107 in FY 12/13.

Also, Table 8 shows the total of both direct and indirect expenditures by the government on health and HIV over time, showing a decrease in external funding in the FY 12/13 compared to FY 11/12. ARV is a lifetime treatment financed by external funding. If external funding continues to decrease, and as the domestic budget cannot yet pay for the ARV, there is a risk the government will not be able to continue to provide ARV to all Rwandans who need it in the future.

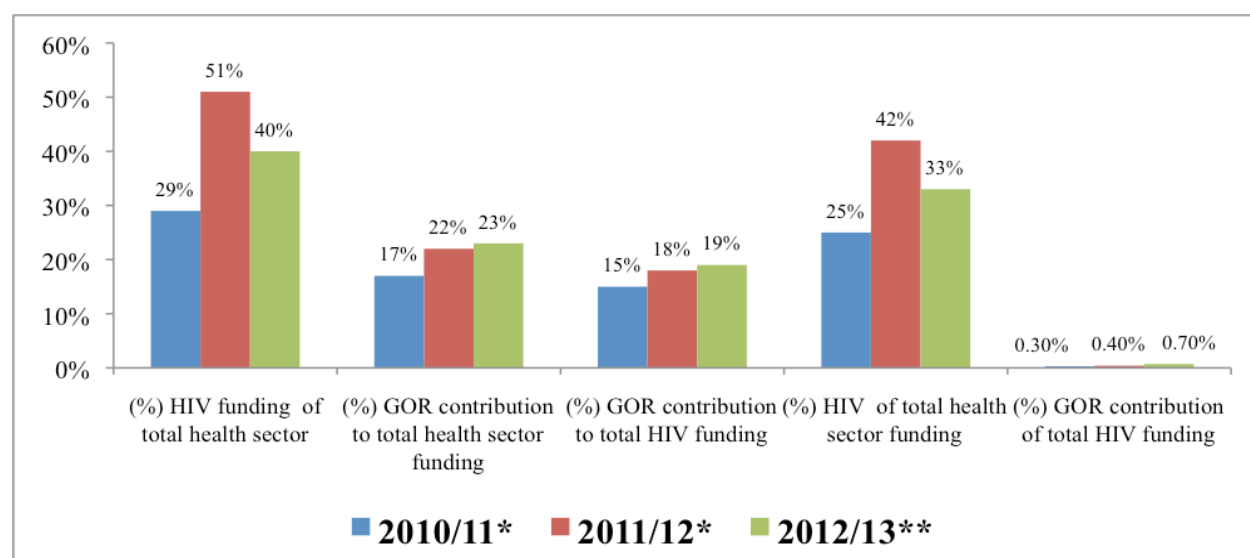
Figure 9 shows the proportion of HIV spending *vis-a-vis* the entire health sector spending. It also shows the contribution of the Rwandan government budget to health and to the HIV response. From FY 10/11 to FY 11/12, the proportion of HIV expenditure *vis-a-vis* the total health expenditure (but excluding private spending) increased from 25% to 42%, followed by a drop in FY 12/13 to 33%, which is an expression of the decrease in international funds for the HIV response (budget support). This international redrawing of funds partially explains the increase in the government contribution to the total HIV funding from 0.3% during FY 10/11 to 0.7% during the FY 11/12.

Table 8: Health sector spending (US \$) during the last three fiscal years.

Fiscal Year	2010/11*	2011/12*	2012/13**
Total health sector spending			
GoR	71,331,128	111,128,638	123,902,548
External	348,304,885	402,885,973	409,024,741
Direct HIV spending by source			
GoR	294,401	842,869	1,128,107
External	104,947,224	216,864,226	172,259,439
HIV expenditure (indirect +direct) by source			
GoR	17,841,028	47,710,130	39,619,671
External	104,947,224	216,864,226	172,259,439

Source: *MOH/HRTT Data Expenditures and Budget for the last three fiscal years: 2010/11, 2011/12 and 2012/13; ** MOH/HRTT Data Budget 2012/13

Figure 9: Health and HIV spending, Government of Rwanda contribution to health and HIV spending and proportion of HIV in health funding: 2010 – 2013.



Source: *MOH/HRTT Data Expenditures for the last three fiscal years: 2010/11, 2011/12 and 2012/13; **MOH/HRTT Data Budget 2012/13

Human immunodeficiency virus, epidemic in Rwanda

This section describes how Rwanda has mitigated the burden of HIV in relation to the four periods of a child's life in the context of HIV prevention, treatment and care. It also provides a summary of cross-cutting issues.

Prevalence

HIV is an issue concerning many sectors and the HIV response is a key part of Rwanda's development agenda.⁴⁵ Following the Genocide in Rwanda, there was no population-based HIV prevalence study until 2005 and prevalence estimates were based entirely on projections from UNAIDS spectrum tool. In 2002, statistics from UNAIDS suggested that Rwanda had a national seroprevalence rate of 8%, making it one of the ten most affected countries in Sub-Saharan Africa.⁴⁶ After 2005, Rwanda implemented its first population-based survey, the RDHS2005, showing 98% HIV test acceptance. The RDHS2005 and RDHS2010 sample in Rwanda is based on women aged 15-49 years and men aged 15-59 years. The prevalence rate does not include children under 15 years, women over 49 years or men over 59 years. With the first RDHS2005, the HIV prevalence estimates projected by UNAIDS were shown to be inaccurate, and in Rwanda the RDHS became the preferred reference for determining HIV prevalence. Since 2005, the Ministry of Health has undertaken a RDHS every five years, which includes a national estimate of HIV prevalence. The national RDHS2005 showed that Rwanda's HIV seroprevalence, among the general population aged 15-49 years, was 3%, with variability between the urban zones (7.3%) and the rural zones (2.2%) and the breakdown by gender showed a 3.6% prevalence for females and 2.8% for males. The national RDHS2010 had similar results, with Rwanda's HIV seroprevalence among the general population at 3%, with seroprevalence in urban areas more than three times higher than in the rural areas, and the breakdown by gender showing 4% seroprevalence for females and 2% for males. These data suggest that what was found for Africa is also true for Rwanda: the epidemic is having a disproportionate impact on women who may already be economically, socially, and sexually vulnerable. However, there is no evidence of gender inequality for HIV infection among children.⁴⁷ HIV prevalence among 15-24 year olds in RDHS2005 and RDHS2010 was stable at 1%. Data for prevalence in the most at-risk populations in Rwanda, including sex workers, is scarce. The HIV seroprevalence estimates for children is described in the next section with PMTCT, because more than 90% of HIV infection is acquired through MTCT.⁷

HIV health services

HIV testing, treatment, and prevention services are integrated into health centers and hospitals and have been progressively developed in urban and rural areas. In June 2013, 88% of all FOSA provided a full package of HIV services, up from 43% in 2008 (National Report HIV 2013).

Voluntary Counseling and Testing (VCT)

In 2008, the number of health facilities in Rwanda offering voluntary counseling and testing (VCT) services was 374 (75.4%). This number increased to 488 (98%) by the end of June 2013. Many efforts were made to mobilise the population to attend voluntary testing for HIV, accompanied by decentralization of services such as Mobile VCT, and the World AIDS Campaign. At the end of June 2013 a cumulative number of 13,760,891 HIV tests had been performed since 2003. The number of tests also increased by year from 2,633 per year in 2003, to 3,120,487 from July 2012 to June 2013. The seropositive rate has also decreased from 10.8 % in 2004 to 0.86% from July 2012 to June 2013.

Prevention Mother To Child Transmission of HIV/AIDS (PMTCT)

The Government of Rwanda is committed to the elimination of MTCT (National Strategic Plan 2009-2012) with a goal of reducing the MTCT to 2% by 2015 and to ensuring 90% of HIV-positive pregnant women receive a full PMTCT package.

In 2010 Rwanda did not implement the WHO proposed guidelines. All HIV-positive women with CD4 less than 500 were proposed to start HAART for life and women with CD4 above 500 were proposed ARV triple therapy for 18 months (Rwanda 2010 guidelines). However, we changed our guidelines in 2012 April, and all women who were supposed to stop ARV at 18 months continued treatment for life (option B+). The WHO's latest guidelines, as of April 2012, are called Option B+, and recommend all women entering in PMTCT program to stay on combination ARV for life, for all women entering the PMTCT program: six months of exclusive breastfeeding and gradual weaning over a period of one month, with the introduction of balanced, and appropriate complementary food at six months while breastfeeding without exceeding the maximum recommended duration of 18 months. Rwanda had already begun the Option B+ six months before WHO adopted it, after scientific consultation.⁴⁸

Among measures taken that facilitate access to PMTCT program is the reduction of the financial barriers. Antenatal care is free, delivery and pediatric care are covered by health insurance, but if women attend an antenatal clinic (ANC) in each of the three trimesters of the pregnancy then they are delivered in a health facility for free. In 2008 in Rwanda, 96% of all pregnant women attended at least one antenatal clinic.⁴⁹ In 2010, the proportion was 98% and among all the pregnant women, 35% attended four ANCs.²⁴ The poorest Rwandans, classified as *ubudehe* one and two, have all health services and care provided for free, and in public FOSA, HIV services are free for the entire population.

The government has also improved geographic access. By June 2013, 98% of FOSA provided PMTCT services – an increase from 382 FOSA in 2010 to 486 FOSA (RBC-Tracnet Report July 2013).

Community sensitization of families was also productive and increased the VCT of male partners of pregnant women attending ANCs, from 16% between July 2002 and June 2003 to 84% during the period July 2012 to June 2013. Currently, the rate of HIV among pregnant women attending sites for PMTCT has decreased, as shown in Figure 10.

Figure 10 shows that the uptake of PMTCT services increased, and the rate of seropositivity among the women enrolled in PMTCT decreased over the preceding seven years. Figure 10 also shows that male participation increased, and the rate of seropositivity in the partners of pregnant women decreased over the same period.

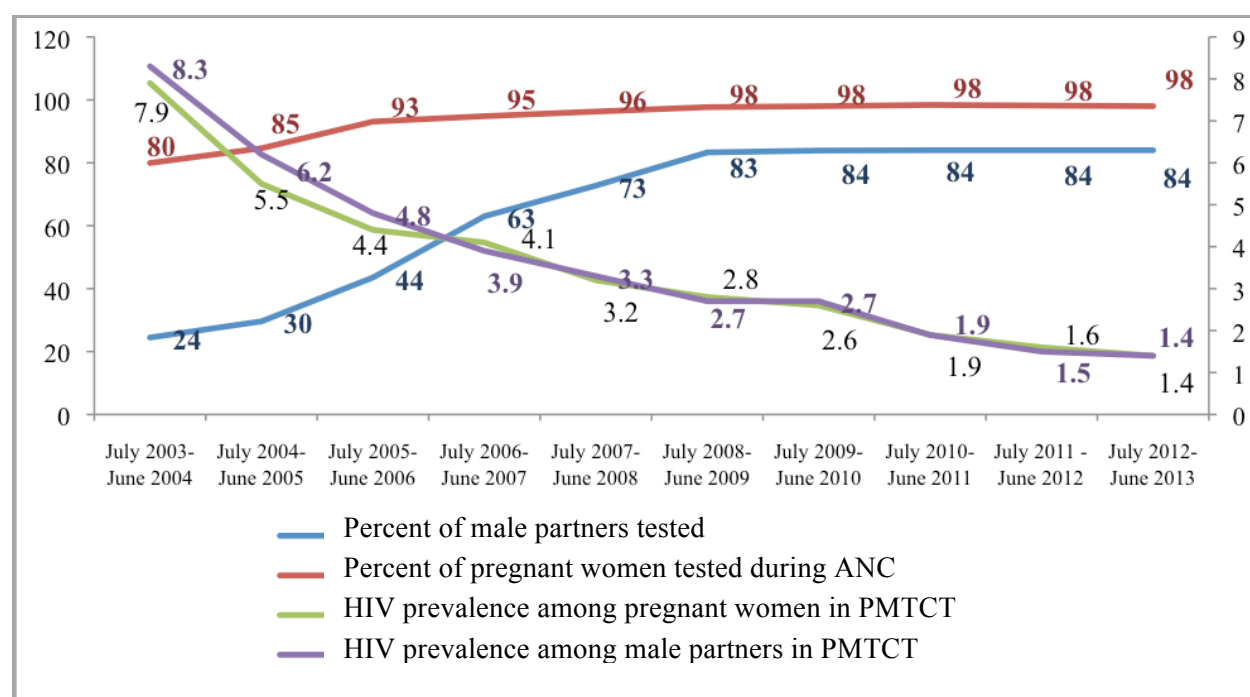
In 2010, 98% of HIV-positive pregnant women testing for HIV, reported in the Annual Report of the Ministry of Health, differs from the 68% estimated by the nationally validated 2010 HIV/AIDS Epidemiologic Update (using Estimation and Projection Package (EPP) Spectrum data from 2009) because the denominator of the National Annual Report of the Ministry of Health (MOH) is the number of women testing for HIV in PMTCT services compared to the number of projected pregnancies, and the denominator of the Epidemiologic Update is based on estimations derived from modelling population data. This UNAIDS model is based on the number of pregnancies projected according the fertility rate determined after the 2002 Census. The number of HIV tests to be performed was determined by UNAIDS according to the

projection of women expected to be pregnant without taking in account the high uptake of family planning that decreased the fertility rate.

The implementation of the new protocol across the country was gradual as it took time to procure the drugs for the new regimen and to train health professionals across the country.⁵⁰

In 2012, 90% of pregnant women were estimated to have taken ARV prophylaxis to reduce mother to child transmission.

Figure 10: Percentage of male partners tested in PMTCT, percentage of pregnant women tested during ANC, HIV prevalence among male partners tested in PMTCT, HIV prevalence among pregnant women tested during ANC in Rwanda PMTCT program: Rwanda 2003 - 2013.

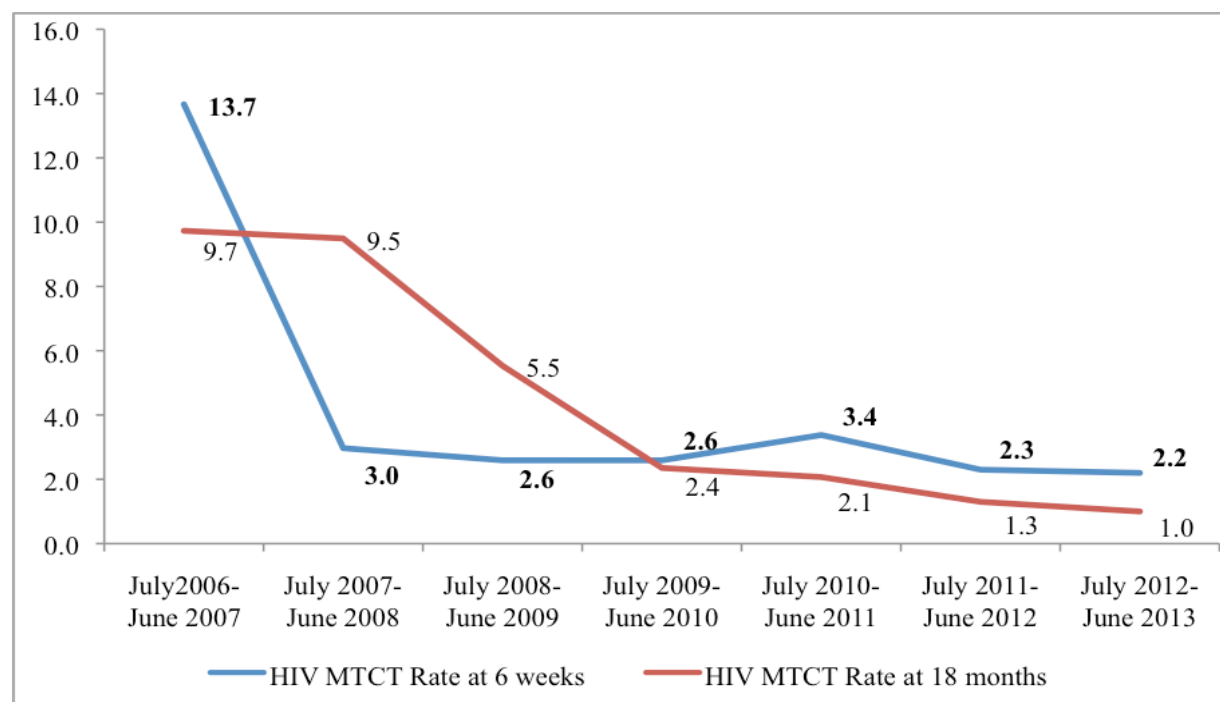


Source: MOH/RBC (2011). *National Annual Report on HIV & AIDS 2012-2013*. Kigali, Rwanda.

The new PMTCT Rwandan-adopted protocol decreases the risk of transmission to 2%, if women and their newborn babies are enrolled in the PMTCT program and adhere to it.⁵¹

The transmission rate among newborns decreased from 9.5 % for July 2007-June 2008, to 1.0 % for July 2012 – June 2013 among children tested at 6 weeks, and from 3.0% to 1.0% at 18 months, in the same timeframe (Figure 11).

Figure 11: HIV Mother To Child Transmission of HIV rate at 6 weeks and 18 months: Rwanda 2006 – 2013.



Source: MOH/RBC 2011 - Annual Report on HIV & AIDS 2012-2013, Kigali, Rwanda.⁵²

In 2011 UNAIDS estimated there were 27,000 Rwandan children under the age of 15 infected with HIV and 1,800 new infections among children under age 15. This showed progress, as according to UNAIDS it had decreased from an estimated 5,700 new pediatric HIV infections in 2000. However, the Rwandan government reports the number of new infections in 2011 to be 1,168 and the number of children living with HIV to be 23,064. The difference between the two reports is 3,936. This UNAIDS report is based on the number of newborns projected according to the fertility rate determined after the 2002 census. The number of expected HIV+ children is determined by the number of women expected to be pregnant, without taking in account the high uptake of family planning that has decreased the fertility rate.³¹

Antiretroviral Therapy (ARV)

Rwanda has been successful in providing ARV. In 2002 there were 870 PLHA on ARV. Since 2003, the mobilisation of funds from the global AIDS response - the World Bank, the Global Fund, PEPFAR and others - has allowed Rwanda's HIV/AIDS program to be funded and to expand ARV to universal access by 2013, for children and adults in need.¹⁸

By the end of June 2013, 122,972 PLHA were on ARV and 458 health facilities were offering care and treatment services.⁵²

In 2011 91% of HIV-positive individuals who were eligible for ARV in Rwanda were receiving it (90,460 out of 105,190).⁵² For a better understanding of where we stand, I will compare access to ARV for PLHA aged under 15 years and those aged above 15 years.

For people aged 15 years and older, the midterm review of the 2002-2006 National Multi-Sectorial Plan showed that 8,815 were on ARV (Commission Nationale de Lutte contre le SIDA - CNLS 2004). In June 2011, 98% of people aged 15 years or older and in need of ARV were receiving them (88,526 out of 90 460).⁵² There are more females receiving ARV (55,036)

than males (33,490), which is a sign of equity, as according the RDHS2010, the number of women infected by HIV is higher than the number of men.⁵²

The midterm review of the 2002-2006 National Multi-Sectorial Plan reported 468 HIV-positive children less than 15 years old on ARV (CNLS 2004). In June 2011, 7,597 out of 14,730 children under 15 years old in need of that treatment (according to the HIV and AIDS in Rwanda 2010 Epidemiologic Update) were receiving ARV.⁵² There was no significant gender imbalance, as 3840 were female, and 3757 male. The number of children treated with ARV showed that only 52% of PLHA under 15 years old and in need received the right treatment, which is evidence of a lack of access to health for children living with HIV aged 0-14, when 98% of the people in need aged above 14 receive ARV.⁵²

There is a disagreement between the government of Rwanda and UNAIDS over the ARV coverage of children aged 0-14 years. UNAIDS, like the MOH, reported that 7,597 children under age 15 were on treatment in 2011, and that ARV coverage in children was 46% of those in need, much higher coverage than the estimated 23% of eligible children accessing treatment worldwide in 2010.⁷ However, the 46% coverage estimate is subject to debate for the government, as there is no consensus over the denominator. The MOH's estimate of coverage is higher than that given by UNAIDS because, as explained before, the MOH believes the estimated new infections and the total number of HIV-positive children cited by UNAIDS is too high, given the general decline in fertility.⁵³

In 2009, the Ministry of Health adopted a new protocol for the early ARV of children under 18 months, based on recently published peer-reviewed studies showing that early initiation of treatment can reduce pediatric mortality by up to 76%.⁵⁴ This new Rwandan national pediatric treatment protocol concerns the treatment of children less than 18 months old and has decreased the mortality rate of children living with HIV.⁵⁵

After explaining to the reader the motivation for this research, the hypothesis, and the four periods of life considered, Chapter 3, introduces the national context in which the children living with HIV receive health services. It details the Rwandan geographic and administrative environment and also describes the health sector and its achievements, as well as the situation of the HIV epidemic in Rwanda. This chapter also indicates the improvements in access to HIV services needed for children, as it is necessary to have a proper understanding of it, in order to envisage improvement of the rights to health for children living with HIV. The next chapter will summarise the international and national legal and policy framework governing the right to health of children living with HIV in Rwanda.

Chapter 3: Legal framework and policies governing the health of children living with HIV

It is important to start by describing the legal framework governing the four periods of life before attaining the age of 15 years, because this thesis is grounded in human rights principles. In these four periods, every step corresponds to physical and mental stages of development and to different health risks for children that need a specific approach.

The accepted definition of human rights explains that rights are regarded as belonging to all human beings.⁵⁶ A rights-based approach demands that children living with HIV be treated as human beings in the here and now, with the same fundamental rights appropriate to age, as all other human beings. It means governments and others have a responsibility to ensure that all children are able to enjoy their human rights. Children living with HIV require extra attention in order to enjoy the best possible health outcomes. This requires that an equal rights approach for children living with HIV be promoted, as they may need special services – such as those that can mitigate the burden of their health condition – in order to experience the same outcomes as children who are not affected by HIV.

A countrywide implementation of a legal framework based on human rights, specific to the rights of children, is vital to assure equitable children's fully access the right to health, especially to prevention, care, and treatment of HIV infection.

3.1. International human rights framework for health

Human rights are described in several documents. The Universal Declaration of Human Rights (a non-binding document, adopted by the United Nations General Assembly in 1948) (UDHR) is the foundation of two binding covenants.⁵⁶ The two binding UN human rights covenants have been ratified by Rwanda: The International Covenant on Economic, Social, and Cultural Rights, and the International Covenant on Civil and Political Rights (both adopted by the United Nations General Assembly in 1966 and ratified by Rwanda in 1975). It is important to note that these international documents were conceived in the wake of the Second World War and the political independence of most African, Asian, South American, and Latin American nations.

Rwanda's own (and Africa's own) legal framework on children's rights is supported by the power of international laws. These international laws include the Convention on the Rights of the Child (CRC) adopted by the United Nations General Assembly 1989 and ratified by Rwanda on September 19, 1991 (Presidential Order n°773/16 of September 19, 1991) and the African Charter on the Rights and Welfare of the Child (ACRWC) adopted by the African Union Assembly of Head of States and Governments in 1999 and ratified by Rwanda (Presidential Order n°11/01 of May 30, 2001).^{57,58} CRC constitutes the standard in the promotion and protection of the rights of the child and defines a child as a human being that has rights equal to

all other human beings. This international framework recognizes that every human being below the age of eighteen years is a child, unless majority has been attained earlier under the law applicable to the child.

There are four pillars of children's rights in the CRC: rights of survival, development rights, protection rights, and participation rights. Many of these rights are directly linked to the right to health: nutrition, hygienic sanitation, clean water, and access to health care; development rights and access to information about their rights; protection rights from all forms of neglect, exploitation and cruelty; and participation rights – having a say in matters affecting their social, economic situation, freedom of association and participation and access to suitable information (Articles 17, 18, 20).

By ratifying these documents, the Rwandan government's obligation to human rights was no longer optional. True compliance with the documents requires the respect of rights, the protection of rights, and the fulfilment of rights. Firstly, the concept of respecting rights indicates that the government will not violate laws supporting human rights issues. Secondly, protection of rights involves governmental prevention of rights violations by the State and others, as well as the provision of redress when rights are violated. Thirdly, fulfilment of rights entails the government's active mobilisation to realise human rights.⁵⁹

Once ratified these international legal documents were incorporated into the 2003 *Constitution* and into other national laws. The national legal framework that domesticates the provisions of the international documents includes regulations concerning children that are specific to each of the four periods of the life of a child under 15. These specifications include children's rights existing under four pillars of the CRC: issues related to health; the right to life, social protection, participation in health decisions, and expression of their own view. As part of this research I undertook a desk review to assess whether the *CRC* was fully incorporated into Rwandan law in a binding manner and whether the policy framework for implementation is in place to promote children's rights, so that children are able to exercise those rights. This has enabled me to identify key barriers and bottlenecks in the fulfilment of the children's rights to health, due to a lack of legal rights, a failure of policy or a failure of policy implementation.

3.2. International regulatory institutions for health and HIV

International organizations play a significant role in global health policy. This section considers the two major international organizations that are important for this research - the World Health Organization and the United Nations Children's Fund (UNICEF) – which were founded immediately following World War II.

The WHO was preceded by, and attempted to assume the functions of, several fragmented organizations including the *Office International d'Hygiène Publique* (OIHP), and the Health Organization of the League of Nations (HOLN). In addition to being a regulatory body for epidemiology, and the standardisation of disease classification and biology, the WHO added several responsibilities that are a reflection of the present-day UN Millennium Development Goals.⁶⁰ In its mission statement, the WHO holds itself to be: “*the directing and coordinating authority for health within the UN system. It is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries and monitoring and assessing health trends*”.⁶¹

UNICEF was founded specifically in response to emergency situations involving children after the Second World War. Although originally targeted towards European children, in the days

when its name was the ‘United Nations International Children’s Emergency Fund’, it immediately assumed a global role, and six years later had activities in Asia, the Middle East, Latin America, and Africa. In 2013, UNICEF (United Nations Children’s Fund) declared that it *“believes that nurturing and caring for children are the cornerstones of human progress. UNICEF was created with this purpose in mind – to work with others to overcome the obstacles that poverty, violence, disease and discrimination place in a child’s path. We believe that we can, together, advance the cause of humanity”*.⁶²

In the present work, I have studied and analysed whether WHO and UNICEF have each served the right to health of the children affected by HIV in Rwanda.

3.3. Rwandan legal framework for health

The Rwandan hierarchy of laws

The ultimate law is the Constitution, followed by Organic Laws, Ordinary Laws, Presidential Decrees, Prime Ministerial Decrees, Ministerial Decrees, and so forth.⁶³ As regarding international treaties, the Constitution of the Republic of Rwanda of 04 June 2003, as amended to date, states in its Article 190 that *“Upon their publication in the official gazette, international treaties and agreements which have been conclusively adopted in accordance with the provisions of law shall be more binding than organic laws and ordinary laws except in the case of non-compliance by one of parties.”*⁶³ The Constitution of Rwanda subordinates the applicability of ratified treaties to their publication in the Official Gazette. Once gazetted in Rwanda, any international treaties shall supersede Organic Laws and thus be just below the Constitution in terms of their judiciary power. Thus, the UN Convention on the Rights of the Child of 1989, which is an international treaty duly ratified and gazetted by Rwanda takes precedence over any conflicting provisions in the Law N°54/2011 of 14/12/2011 relating to the rights and the protection of the child, the Family Law (an Ordinary Law) and the Penal Code (an Organic Law).^{65,66,67}

The East African Community (EAC) treaty provides that the *“Community laws shall take precedence over similar national ones on matters pertaining to the implementation of this Treaty”*. To date there are no laws or policies concerning health in the EAC and the international policy for health is the Covenant on Economic, Social and Cultural Rights, the CRC and the ACRWC.⁶⁸

Constitution

A Constitution defines the fundamental political principles of a country. It establishes the structure, procedures, powers, duties and limits of the government and guarantees certain rights to the people. On May 26, 2003, Rwanda adopted a new Constitution by referendum that was then promulgated on June 4, 2003. This Constitution references the international human rights legal framework and guarantees human rights for all citizens, as stated in its Preamble: *“... Faithful to democratic principles and concerned about ensuring the protection of human rights and promoting respect for fundamental freedoms, in accordance with the 'Universal Declaration of Human Rights' and the 'African Charter of Rights of ... Convinced of the necessity to achieve effectively national unity, peace, social justice, and respect for human rights based on liberty, equality, and fraternity for all members of the Rwandan community...”*. The Constitution of Rwanda defines a citizen’s right and entitlement to measures that ensure the highest attainable standard of health.⁶³

International treaties ratified and published in the *Official Gazette* are part of the National Law and preceded any Acts of Parliament before the courts of law as stated in Article 109 of the constitution. The national sovereignty assumed in the constitution is thus limited by binding international treaties and conventions that Rwanda has ratified, such as the Universal Declaration of Human Rights (1948), the UN Convention on the Rights of the Child (1989) (CRC) and the African Charter on the Rights and Welfare of the Child (1990) (ACRWC).^{58,69}

The Constitution states that the family is the natural foundation of Rwandan society (Article 27), that parents have the right and obligation to raise their children (Article 27), and that the state shall put in place appropriate legislation and institutions for the protection of the family with particular attention to the mother and child in order to ensure that the family flourishes (Article 27). The Rwandan Constitution recognizes the child's rights to protection (Article 28) as well as the right and obligation to health for all citizens (Article 41).⁶³ However, the Constitution is mostly based on faith in the family to protect and nurture a child rather than on the recognition of the need to protect a child adequately against possible negligence by that family.

Rwanda's 2003 Constitution eliminated references to ethnicity and stands clearly against any type of discrimination (Article 11 and 16). Though it does not make specific references to HIV, discrimination against people based on their HIV status, is included under the general prohibition of discrimination of any kind.

The next section will set out the domestic laws that promote and protect children within the context of Rwanda's ratification of international legal documents.

Laws governing child protection in Rwanda

Rwanda has incorporated UDHR's articles into its domestic legal framework, in addition to the CRC and the ACRWC.⁵⁸ In reviewing the Rwandan legal framework, it became clear that the laws regulating health need to be better aligned to the international commitment as stated in the Rwanda's Constitution.

Table 9 provides a summary of my analysis of how key Rwandan laws governing the protection of the child conform to the CRC.

Table 9: Conformity of the major Rwandan laws governing the protection of the child to the Convention on the Rights of the Child (CRC).

Year Law Enacted	Law	Comments	Conformity to the CRC
2012	Law No. 54/2011 of 14/12/2011, gazetted 25/06/2012	Related to the rights and protection of the Child. It replaced and updated Law No. 27/2001 on the Rights and Protection of the Child Against Violence Provides legislation concerning the health and welfare of the child 1. Introduces the principle of ‘in the best interest of the child’. 2. Protects child rights to equal treatment, citizenship, family life, health insurance, preventive and curative health care, and protection against malnutrition, education and fair treatment before the law. 3. Protects children with special needs e.g. children with disabilities, living with HIV, street children 4. Protects children from exposure to alcohol or other harmful drugs. 5. Protects from sexual exploitation through trafficking, prostitution and pornography.	Yes
2012	Organic Law No. 01/20/2012, Instituting the Penal Code, gazetted 02/05/2012	It sets 1. The penalties for crimes committed against children. 2. The minimum age of legal responsibility at 14 years. 3. Protected from sexual exploitation through trafficking, prostitution and pornography.	Yes
2008	Law No. 59/2008 gazetted 10/09/2008 On the Prevention and punishment of gender based violence.	Protect children from gender-based violence. It is important for the child to be born, that expectant mothers can use HIV services without fear of gender discrimination from the community or violence from their partners. As shown in the 2004 Rwandan report on the CRC, the Committee recognized the need to give more support to PMTCT services. Rwanda is aligned to the CRC these recommendations and has integrated PMTCT services with other services aimed at reducing maternal mortality.⁵⁸	Yes
2008	Law No. 65/2007 Creation, Organization and Management of the Mutual Health Insurance Scheme	Makes health insurance mandatory. Has the provision of coverage for children improve the scheme and ensure universal coverage.	Yes
2007	Law No. 30/2007 established the Observatory for Children's Rights	Within the National Human Rights Commission. Responsible for the independent monitoring of children's rights and ensures that abuses of child rights are identified at community level and reported.	Yes

Laws governing the right to health of children affected by HIV in Rwanda

The following section includes details of national laws related to each of the four periods of life and highlights gaps in their content, implementation or enforcement in relation to the rights to health in the context of HIV.

Period One: Pre-conception

During this period the right to health analysed in this research is the right of the child to life and to be born free from HIV, and therefore the right of children to be protected from HIV transmission from their parents.

Legal context of condoms in prison

There is no law prohibiting prisoners from having sex, but Law No. 34 2010 published in the Official Gazette No. 04 of 24/01/11 does not allow privacy in prison. As in our culture, sex cannot be had in public, the rule of no privacy means for many that there is no possibility of having sex in prison - but we know that it is not the case as prisoners do have sexual intercourse.⁷⁰ There is a need to protect the prisoners against the risk of HIV transmission while having sexual intercourse during their prison sentences.

Sex Work

According to the articles related to prostitution in Section 4 of the Penal Code, sex work is a criminal activity that is punished with imprisonment. This risks creating an environment that unwittingly decreases sex workers' access to social protection opportunities and health, including ARV and PMTCT services for those HIV-positive.

It is important to note that penalties are increased for any person who commits a prostitution offence involving a child.⁶⁷

Period Two: from conception to post-breastfeeding or from birth if not breastfed

Rights of the Unborn Child to Antenatal Care

In a human rights framework, the duty of the government is to provide accessible and affordable services and to create demand for them by raising awareness through health education and promotion. In the context of HIV, the health of pregnant women has traditionally received less attention than the health of children.⁷¹ In Rwanda, government policy recommends four antenatal care visits (ANC). According to the RDHS2010, 98% of women attend one ANC from a skilled health provider and 35% per cent attend the four ANCs recommended by national policy. As per national policy, PMTCT is integrated with antenatal care. The rights-based approach to testing within the context of PMTCT requires a woman to take an HIV test and seek HIV preventive services to protect her exposed child if she tests positive for HIV. After birth, as per national protocol, she is advised to bring the child to a health facility, within the first 72 hours of life, for HIV prevention services. This is an issue of both children's rights and women's rights – both mother and child are rights-holders. In this case, the mother also bears the child's rights, and she has the right to choose to take the HIV test or not, and if she is HIV-positive she has right to choose to take ARV for PMTCT or not. General Comment 3 analyses the scope of the problem, including the duty of states to avail

services to parents, develop guidelines for PMTCT and ensure mothers and fathers are aware of the services and the reasons they should use them. General Comment 3 highlights the need for respect of two potential conflicting rights - the rights of the child to be born free of HIV, and also respect for “voluntary, confidential HIV counseling and testing” and for parents having a right to decide which services to use or not.⁷² For instance, in a country where HIV is a public health issue (prevalence more than 1%), UNAIDS guidelines advise for an expectant mother and father to undergo voluntary counseling and testing for HIV, which is done in Rwanda.⁷³ This should be seen as in the best interest of the child.

The term "best interests of the child" is meant to describe the set of principles or factors that guide a court's deliberation when assessing what decisions would keep a child safe and how best to meet a child's needs, including the health and safety of a child. According to the UN Committee on the Rights of the Child (2009) typical administrative proceedings include, for example, decisions about children's education, health, environment, living conditions, and protection.

In the Rwandan legal framework, Article 11 of Law No. 54/2011 of 14/12/2011 relating to the Rights and the Protection of the Child published in the Official Gazette No. 26 of 25/06/2012 states that, *“The child shall enjoy his/her rights from conception and he/she is reputed born whenever his/her interests are concerned”*. This statement indicates that a child-to-be, as a rights-holder, is a person who has the right to be protected against HIV infection.

HIV is a public health issue in Rwanda, (prevalence more than 1%), and the majority of pediatric HIV infections are acquired through parental transmission during pregnancy, delivery or breastfeeding. Thus, children are legally entitled before birth, in delivery and during breastfeeding to have their mother, as a duty-bearer, if HIV-positive, to adhere fully to a PMTCT program, according the national protocol. Parents also have to ensure that their child is ARV compliant if the child needs ARV.⁷³

HIV is a chronic disease with high risk of MTCT to a child if an HIV-positive pregnant woman refuses ARV as one of the components of PMTCT. The right to health of the foetus is recognized in Rwandan law, but there is no enforcement based on the articles of the Penal Code, against those that do not protect a foetus against HIV so that a child has the maximum chance of being born HIV free. For example, Article 256 of the Rwandan Penal Code penalises those who do not rescue or help a person in danger, but it makes no special provisions in the case of children-to-be who might be infected through parental transmission of HIV, especially when mothers refuse PMTCT, even though ARV are not dangerous for pregnant women. The Rwandan Penal Code explains in Article 570 that *“Any person who neglects to assist a person in great danger when there is no risk for him/her or others while in a position to do so or to seek assistance... shall be liable to a term of imprisonment of two (2) years to five (5) years and a fine of one hundred thousand (100,000) to one million (1,000,000) Rwandan francs”*.⁶⁷ This stipulation in the Penal Code is clear even if it does not explicitly refer to health or HIV infection. Simply because there is no explicit provision in the law dictating that an HIV-positive mother must enrol in the PMTCT program to avoid infecting her child-to-be, does not mean that a pregnant woman does not have to enroll in a PMTCT program. It is important to note that there is also no clear provision in law for the case where a pregnant HIV-positive woman refuses to take the drugs needed to protect her child from HIV infection. There also is no provision in the law stating that HIV-positive fathers must protect their partners and children-to-be from HIV infection (by using condoms with an HIV negative partner and taking ARV if necessary). Finally, there is no legal obligation requiring that men tell their partners who is or could be pregnant, that they are HIV-positive or use protective measures so as not to infect a

pregnant or lactating mother. This raises issues of the rights of mothers, as they are also claim-holders.

It is clear that punishment alone will not necessarily bring the desired results, as this will not guarantee the protection of the child-to-be. Progress could be made if health professionals sensitize parents who do not seek PMTCT services for their child to the reasons why it is necessary, while assuring them of appropriate psychosocial support so that children-to-be can be given the necessary care. However, in cases where the parents refuse, the best interests of the child should prevail.

From the portion of Period Two starting after birth, to end of Period Four (fourteen years old)

Right to HIV Diagnosis and Treatment

These rights start after birth and continue throughout the life of a child affected by HIV.

Responsibility of parents and caregivers

HIV is a chronic disease for which drugs have to be taken for a lifetime in order to remain healthy with a high risk of death for children without treatment or those who are not able to adhere to treatment. The parent or caregiver who, after proper explanation, sensitization and support does not enable an exposed child to access testing or treatment services, or any adult who blocks HIV-positive children from accessing care and treatment, should face the penalties provided in Article 256 of the Rwandan Penal Code concerning those who do not rescue or help a person in danger, even if it does not mention HIV infection.⁶⁷

Article 570 of the Rwandan Penal Code should apply, where parents know that being HIV-positive without ARV is a death sentence for a large number of children, even if it does not mention HIV infection.

Responsibility of health professionals and teachers

Health personnel have two contradictory legal obligations, both to protect the confidentiality of PLHA and families and to actively assist a child who needs an HIV diagnosis and treatment, in cases of known exposure, or when clinical signs or medical history indicate a child is at risk of being infected by HIV. For example, when a child has an unexplained decline in physical development, it can be the sign of any severe disease, however in a country where HIV is a public health issue it may be a sign of an acquired immune deficiency.⁷³ Health professionals should therefore propose to care givers that they authorise an HIV test, because it is known that if the child is HIV-positive then lack of treatment carries a high risk of death. Currently health professionals need specific permission from parents to perform an HIV test on a child under 12 years old, and Law No. 54/2011 of 14/12/2011 is not clear for children older than 12 years. To align to CRC at all ages, a child, who is appropriately counseled, should be able to undergo an HIV test without parental permission, if mature enough, i.e. with an understanding of the implications of the test and capable of making informed choices on the basis of the results of the test.

A professional who reveals confidential information is punishable by law according to Article 283 of the Rwandan Penal Code: *“Any person serving as a keeper who reveals a professional secret entrusted to him/her by virtue of function, occupation or religious authority shall be liable to a term of imprisonment of six (6) months to two (2) years and a fine of one million*

(1,000,000) to seven million (7,000,000) RWF or one of these penalties”. Article 284, makes an exception to this code for “a person who informs the judicial or medical authorities of mistreatment or deprivation of what is essential to the health of a child or a person unable to protect him/herself because of physical or mental state”. According to the latter Article, parents who are well informed and sensitized, and who refuse to allow an HIV test for a child exposed to HIV or with clinical signs of possible HIV infection, should be reported to the appropriate judicial authorities, particularly as HIV treatment is available and free for all in public health facilities. Health professionals have no excuse for not reporting these cases and they should connect children at risk of being HIV-positive, or suffering from HIV or AIDS, to an HIV diagnostic, care and treatment program. Rwandan law protects against any form of physical and psychological abuse and neglect of children, but without the reinforcement that protects children affected by HIV against any health professional’s negligence in diagnosing, preventing, or treating HIV.

Given that the only way to put a child onto treatment is through testing and that half of all HIV-positive untested children will die before they reach two years old, teachers, leaders and community members should also be trained to advise parents or caregivers to test the child if they are informed of any risk, or if they witness a physical decline.^{74,75} The current legal system in Rwanda does not enforce this. Without enforcement, many children may go untested.

Right to Primary Care

Rwanda has several legal frameworks in place, as of 2012, to protect the right to primary health care. In Article 44, relating to the rights and protection of the child, in Rwanda’s Official Gazette No. 26 of 25/06/2012, it is stated that: “*The Government takes all necessary measures to ensure that the child enjoys his/her right to good health, with emphasis on the development of the primary health care. The Government ensures the availability of preventive and curative care, the effective implementation of national immunization systems for children, to combat malnutrition by all means and takes appropriate measures for controlling the quality of children nutrition and providing clean water to children*”.

Article 45 states “*Every child who is on the Rwandan territory must be affiliated to a medical insurance in accordance with relevant law*”. This is not achieved, as according to recent surveys only around 70% of the population are covered by health insurance.⁷⁶ Thirty percent of the Rwandan population lack access to care because they do not have health insurance, so there is a high risk for the children from these families to be excluded from accessing care. Finally, in Article 46, it is stated “*Follow-up of the child with specific diseases after being treated in specialized center. An Order of the Minister in charge of children determines the rehabilitation and social reintegration mechanisms at the end of the health care of the child*”. This has not yet been achieved.

Period Four: From seven to fourteen years old

Right to Express Views and to Participate in Health Decisions

The CRC recommends that: “*State parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child*”.

In a human rights based approach, children’s health programs should be based on a participatory approach, from design to implementation, and in monitoring and evaluation, so as to ensure the fulfilment of human rights, as participation is part of the right to health. Children –

unlike adults – are limited in their legal capacity and this makes the interconnectedness of human rights and health more complex for children than it is for adults.

This right to participation in decisions is especially important when ensuring the fulfilment of human rights for children living with HIV and AIDS. Children affected by HIV and AIDS must be included in the development of laws, policies and strategies, and programs relating to pediatric HIV and AIDS. According to Article 12 in the Convention on the Rights of the Child, the government, the community, school, and the family should guarantee to listen to and incorporate HIV-affected children's viewpoints.⁷⁷

Interventions for HIV-affected children that are made with their participation are more useful, more appropriate and more accurately grounded in human rights.^{72,78} Many multilateral organizations and UN agencies are pushing governments across the world to take the opinions of HIV-affected children and communities into account when designing, implementing and evaluating HIV laws, policies, strategies, and programs.⁷⁹ The Rwandan Committee Periodic Report on the CRC of July 2004 and June 2013 shows progress made by the State in its legal framework and programs relating to children but recognizes that children's participation and the acceptance of their viewpoint still needs to be reinforced in Rwanda.⁸⁰

Since 2006, Rwanda has succeeded in strengthening its incorporation of children's viewpoints on HIV through the Annual Pediatric HIV Conference, where children, aged seven to seventeen, have a parallel session on the same topics as adults. Children's views are taken into account in the recommendations, and their feedback is taken into careful consideration.⁸¹ The participation of children in the Economic and Poverty Reduction Strategy (EDPRS) and in the Annual Youth Forum have also improved the incorporation of children's viewpoints, but much needs to be done to make children more skilled in being able to give opinions about their own care and treatment.

In order to be able to participate in decisions concerning their health, persons living with HIV must first be aware of their serostatus and be able to access uncensored and age-appropriate information promoting health. The right to know your HIV serostatus should be guaranteed.

The Right to Seek Testing and Treatment

Since 2012 there has been a new provision in the Law (Official Gazette No. 26 of 25/06/2012) in Article 55 titled "Children HIV-positive or affected by HIV," which allows children at the age of 12 to have some rights concerning HIV. However, there is a discrepancy between the provisions in Rwanda's three official languages (French, English, and Kinyarwanda). In French, it is stated, "*L'enfant âgé de plus de 12 ans peut se faire examiner ou consulter par un médecin agréé ou infirmier(e) attitré nonobstant l'opposition ou l'interdiction de ses parents ou de toute autre personne qui lui assure la garde*". In English, the document states, "*A child above the age of twelve years has the right to consult an authorized professional medical doctor or a nurse and to go through medical examination notwithstanding the opposition or prohibition of his/her parents or guardian*". And finally, in Kinyarwanda, the Gazette states, "*Umwana urengeje imyaka cumi n'ibiri (12) y'amavuko, afite uburenganzira bwo kwisuzumisha cyangwa kwivuka ku muganga cyangwa umuforomo w'umwuga wa Leta nubwo ababyeyi be cyangwa undi wese umurera baba batabishaka cyangwa babimubujije*".

To summarise the differences, in the French version it is stated that children at twelve years and up can undergo clinical examination and consultation with a health professional. The English language has the same indication as the French version. However, in the Kinyarwanda language

it states that, children are permitted explicitly to seek testing *and treatment*. This discrepancy indicates a serious shortfall in the French and English versions, which can be used against the rights of the child if a health provider so chooses. Even if, as stated in Article 68, the law was drafted in French, and even when conflicts arose, the language in which the law was debated in Parliament – Kinyarwanda – prevailed, we need to acknowledge that many health professionals, some of whom may not speak Kinyarwanda, and others may be disturbed by this discrepancy, giving them a window to not fulfil the right of the child. Thus, in this dissertation I will consider that only the right to HIV testing and consultation exist, rather than the right to treatment, given the absence of any mention of treatment in the French version. (The right to HIV testing can be argued, as the word “examine” in the French version can be understood as “examine blood” and indicate testing; whereas there is clearly no provision for treatment.) This ambiguity is a limitation that constrains children’s legal autonomy in accessing comprehensive HIV services. Given this legal context, parental authority must therefore be sought for the majority of medical decisions and care-seeking activities.

Article 6 of Law No. 54/2011 of 14/12/2011, relating to the rights and the protection of the child, stipulates: *“In all judicial and administrative proceedings related to the child, the primary consideration shall be in the best interests of the child”*. All in all, the Children’s Act needs to be reviewed as regards the opinion of the child. The CRC, recommends as follows: *“States parties need to introduce legislation or regulations to ensure that children have access to confidential medical counseling and advice without parental consent, irrespective of the child’s age, where this is needed for the child’s safety or wellbeing. Children may need such access, for example, where they are experiencing violence or abuse at home, or in need of reproductive health education or services, or in case of conflicts between parents and the child over access to health services. The right to counseling and advice is distinct from the right to give medical consent and should not be subject to any age limit”*.⁶⁵ This is highlighted by the CRC, and there are other rights relevant to this section, including the right to privacy (Article 16), which protects the confidentiality of the child’s health status.

Rights concerning all four periods

Right to Health

Complex relationships exist between the domains of human rights and health. The right to health, as also cited in the Constitution of the World Health Organization (WHO) – elaborated on further in the International Covenant on Economic, Social, and Cultural Rights and other international and regional human rights treaties such as the CRC or ACRWC – is the *“right to the enjoyment of the highest attainable standard of health”*. It is the right to a set of arrangements – norms, institutions, laws, and an enabling environment – that can best secure the enjoyment of health. As the former UN High Commissioner for Human Rights, Mary Robinson stated: *“The right to health does not mean the right to be healthy, nor does it mean that poor governments must put in place expensive health services for which they have no resources. But it does require governments and public authorities to put in place policies and action plans which will lead to available and accessible health care for all in the shortest possible time. To ensure that this happens is the challenge facing both the human rights community and public health professionals”*.⁸² The right to health does not mean the right to good health, absence of illness or disease, but the right for every child to enjoy the best possible state of health at all stages of their mental and physical development.

Article 24 of the Convention on the Rights of the Child discusses more specifically a child’s right to health.⁶⁵ This right to health not only encompasses a child’s right to health care, treatment, and prevention of malnutrition and disease, but also includes governmental

responsibility to decrease infant mortality, encourage pre-natal and post-natal care, provide accurate health information, support preventative health care services, and eliminate all traditional practices that are harmful to children's health. Similarly, Article 14 of the ACRWC also declares "...every child shall have the right to enjoy the best attainable state of physical, mental and spiritual health".⁵⁸ It urges States to give children the right to all of the services and care described in the CRC. Further, the ACRWC adds that basic health service programs should be integrated into national development plans; states should guarantee the participation of NGOs, communities, and beneficiaries in the planning and management of children's health programs; and community resources should be mobilized for the development of primary health care for children. This is done through professional associations and civil society organizations.

A child's right to health is highlighted by the CRC, and there are other rights connected to the right to health, in addition to those cited earlier and that are relevant to this research, including:

- Seeking and receiving information and access to material and information promoting their wellbeing and health (Article 13 and 17) These two Articles allow the child to be informed about prevention so as to protect themselves from HIV, to request information on their HIV status and if infected to be given an explanation of where and how they can access care and treatment.
- Protection from physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse and neglect in the care of parent(s), legal guardian(s) or any other person (Article 19). This provision protects against infection through sexual abuse and protects the child in need of care and treatment from being denied it. CRC in its Article 34 recommends that States Parties undertake to protect the child from all forms of sexual exploitation and sexual abuse. It is known that more than 90% of pediatric HIV infections are acquired through MTCT but the risk of a child being infected during sexual violence needs to be prevented.⁵ The Committee on the Rights of the Child, analysing the Third and Fourth Periodic Reports of Rwanda adopted by the Committee at its sixty- third session (27 May–14 June 2013), pointed out the high prevalence of sexual violence against children, including in schools and in the community. It also recognized the effort of the State in establishing of the "Isange One Stop Center" at the National Police Hospital and thirteen districts, and of the Gender-Based Violence Technical Working Committee under the Ministry of Gender and Family Promotion co-chaired by the Ministry of Health, responsible for the implementation of the National Policy to Fight Gender-Based Violence (2011- 2016) and, to prevent and respond to the needs of child survivors of domestic and gender based violence
- Survival, and development (Article 6). This concerns the right to be HIV free and to access care and treatment if HIV-positive.

Right to Protection

The General Comment 3 specified that the provisions of the CRC apply to the treatment and prevention of HIV. However, General Comments are not binding *per se* even if they do provide further clarification of the original document. CRC General Comment 3 makes clear that children have the right to protection from HIV and AIDS. To make this protection a reality, we need to identify all the parties responsible for the rights of the child, and not just the State. Legal guardians, educators, health professionals, and community members all have responsibilities, and States must facilitate these responsibilities.

The Convention on the Rights of the Child not only stipulates all of the rights that children are inherently afforded but also recognizes the importance of children being aware and knowledgeable about these rights, as stated in Article 42: “*States parties [should] undertake to make the principles and provisions of the Convention widely known, by appropriate and active means, to adults and children alike*”.

All the rights and obligations listed above provide a solid foundation for the establishment and advancement of successful rights-based HIV prevention, treatment, and care programs for children. Given the complexity of the realities of children’s rights, the government must also educate parents on the rights of children, encourage inter-generational dialogue, and protect the rights of children against violations or negligence.

This framework is not yet universally embraced, nor do those who accept it uniformly implement it. The coming section will compare the CRC with Rwandan domestic laws. It will identify the gaps in the national laws (having a legal right), the gaps in policies (policies to implement legal rights), and the gaps in policy implementation where laws and policies are in place but the children affected by HIV are not able to exercise their rights, because they are unaware of their rights, parents refuse to let them access their rights, the government did not create the services, or for other reasons.

Articles 18 and 27 of the CRC state that these legal protections and safeguards for children are the joint responsibilities of states and parents.⁸³ Article 18 states that parents have primary responsibility for the “*upbringing and development of the child. The best interests of the child will be their basic concern*”. States have to “*render appropriate assistance to parents*” as they carry out their duties.⁸⁴ Article 27 concerns the child’s right to an adequate standard of living, stating that “*the parent(s) or others responsible for the child have the primary responsibility*” for fulfilling this right, while the State should “*take appropriate measures to assist parents and other responsible for the child*”.⁸⁵ To ensure, when possible, the appropriate and necessary medical care for children affected by HIV, the CRC should be more specific *vis-a-vis* protection of the child where parents neglect the health of their children, and *vis-a-vis* the State’s assistance to parents.

Rwanda has a new legal framework in place, as of 2012, (Law No. 54/2011 Relating to the Rights and Protection of the Child in Rwanda’s Official Gazette No. 26 of 25/06/2012), which is better aligned to the CRC than the previous law.

Right to Freedom from Discrimination

In the international legal documents – UDHR, CRC, ACRWC – there are limited legal documents or no specific legal documents on discrimination of PLHA, even though many rights concern the livelihoods of HIV affected persons. For example, the documents deem discrimination unethical, which would include discrimination against people living with HIV and AIDS (PLHA).⁸⁶ Non-discrimination (CRC, Article 2), is the root of equity. The fulfilment of the right to health for everybody, in full equity, needs to prohibit all distinction, exclusion, restriction and differentiation of treatment within a community, and between communities.

Health programs should thus promote a non-discriminatory rights-based approach through their design and implementation, so as to ensure the fulfilment of human rights. If children affected by HIV are discriminated against and face social exclusion, they will not enjoy human rights in general and the right to health in particular.

Article 1 of Law No. 47/2001 of 18/12/2001 prohibits discrimination as “any speech, writing, or actions based on ethnicity, region or country of origin, the colour of the skin, physical features, sex, language, religion or ideas aimed at depriving a person or group of persons of their rights as provided by Rwandan law and by International Conventions to which Rwanda is part”.⁸⁷ The Committee on the Rights of the Child, analysing the Third and Fourth periodic reports of Rwanda, at its sixty-third session (27 May–14 June 2013), expressed concern about the stigma and discrimination faced by children affected by HIV. The Constitution of the Republic of Rwanda protects all citizens against inequities and discrimination with Articles 16 and 11, applicable to persons living with HIV/AIDS (PLHA). However, the “anti-discrimination” laws need elaboration and reinforcement, as there is discrimination against PLHA and vulnerable groups even if it remains rare.^{69, 88}

In Article 4 of Law No. 54/2011 relating to the rights and protection of the child in Rwanda’s Official Gazette No. 26 of 25/06/2012, it is stated that: “Children are born equal [under] ... the law and are provided with the protections which are required by their childhood condition without any discrimination. However, the adoption of positive measures in favour of groups of disadvantaged children, in order to mitigate or to eliminate conditions which cause or contribute to perpetuate discrimination, shall not be considered as a form of discrimination”.

In Article 10 of Rwanda’s Official Gazette No. 26 of 25/06/2012, it is stated that: “Every child shall have the right to be provided with special protection by his/her family, the Rwandan community and the Government for his/her physical, mental, spiritual, moral, psychological and social growth according to the human dignity”. This applies to parents and caregivers. This research assesses the missed opportunities in physical and mental health development.

3.4. Rwandan health laws, policies and strategies important for children affected by HIV

Gaps related to the right to health and protection of children in the Rwandan legal framework

Children's access to health services has made progress but there are still several gaps remaining. Table 10 provides a summary of the gaps between the CRC and Law No. 54/2011 of 14/12/2011 in relation to access to health and the protection of the child.

Table 10: Gaps between the access to health and protection provided by Rwanda's Law No. 54/2011 of 14/12/2011 relating to the rights and protection of child and the CRC.

CRC	LAW No. 54/2011 of 14/12/2011 Relating to the Rights and Protection of Children	Gaps in National Legal Framework and Policies
Period 1		
Article 6: State parties recognize that every child has the inherent right to life.	Article 8: Right to life The child has a right to life and they shall not be deprived. Notwithstanding the provisions provided by the Penal Code, deliberate abortion is prohibited and punished by the law.	No gaps as abortion is regulated and accepted only in case of rape, incest, endangering the health of a mother or non-viable pregnancy.
Periods 2 to 4		
Articles on the right to be born healthy Article 2: State parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination.	Article 4: Equality of the children Children are born equal and entitled to the enjoyment of rights and freedoms recognized and guaranteed by the law and are provided with the protection required by their childhood condition without any discrimination.	There are no gaps concerning these articles. In addition, Rwanda's Constitution and Law No. 47/2001 of 18/12/2001 provides for these rights. There is a need for enforcement ^{69,89}
Article 6: State parties recognize that every child has the inherent right to life.	Rwandan Constitution Article 12⁸⁹	No reinforcement for HIV treatment when it is known to be a death sentence for 50% of the HIV-positive children at two years if no access to treatment. ¹⁸ This should be considered the same for any other life threatening situation.

Table 10 continued

CRC	LAW No. 54/2011 of 14/12/2011 Relating to the Rights and Protection of Children	Gaps in National Legal Framework and Policies
Periods 2 to 4 (cont.)		
Article 19 (2): State parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child. Article 9: ... in a particular case such as one involving abuse or neglect of the child by the parents...	The Law No. 54/2011 of 14/12/2011 relating to the rights and the protection of the child is aligned to this article. Article 28: Obligation to denounce violence and mistreatments against the child A child victim of the facts mentioned in points 1, 2, 3 of paragraph 2 of Article 27 of this law, has the right to denounce them to the authority in charge of placement. Members of the family or any other person knowing that the child is a victim of violence or mistreatment shall have the obligation to denounce them to the authority in charge of placement or to the nearest organ of Rwanda National Police. Article 27: Reasons for placement of the child No child shall be arbitrarily separated from their family, however, in the best interest of the child, parents, guardians or any other person legally responsible for the child may be denied the right to keep the child and such right be transferred to a third party due to the following reasons: 1. violence; 2. mistreatment; 3. Incapacity to provide them with care following mental disability; 4. Being stripped of parental authority.	There is no provision in the law covering a mother who does not participate in PMTCT services without knowing her status and infects the child if she is HIV+, nor is there a provision in the law dealing with pregnant HIV+ woman refusing to take drugs to protect the child against HIV. There is no provision in the law that handles a father who, without knowing his status, refuses to be part of PMTCT services and is HIV+ and infects his pregnant wife and subsequently their children to be. If an HIV+ man does not tell his wife his status, does not protect her and refuses to practice safer sex himself and infects the wife and subsequently infects their children to be, it should be considered as negligence, possibly contributing to a fatal outcome. No access to care and treatment other than care in case of mental disability is mentioned and when such negligence happens to a child it is not reinforced by sanction despite the fact that denying ARV has drastic consequences for the health of HIV-positive children. Article 11 of Law No. 54/2011 of 14/12/2011 gives provision for the protection of a child born to parents who are HIV-positive, through PMTCT; this should be considered as a right at the foetus stage.

Table 10 continued

CRC	LAW No. 54/2011 of 14/12/2011 Relating to the Rights and Protection of Children	Gaps in National Legal Framework and Policies
Periods 2 to 4 (cont.)		
Article 24 (1): State parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. State parties shall strive to ensure that no child is deprived of their right of access to such health care services. Article 24 (2) (c): To combat disease and malnutrition.	Article 42-46 on child's health and welfare This article covers not only right to health but also the social determinants of the right to health: education, nutrition, housing, etc. Article 55: Children infected or affected by HIV /AIDS An Order of the Minister of Health shall determine programs and strategies to ensure protection and assistance to those children.	There is no law governing the PMTCT and related information. There is no reinforcement in the Rwandan laws in cases where a parent or a health professional refuses HIV treatment. As of 30th September 2013, a draft Ministerial Order from the Minister of Health is on the desk of the Prime Minister.
Article: 18 (2) State parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children.	Article 26: Government obligation of assistance to indigent parents or guardians The Government shall, depending on its means, establish a mechanism to assist indigent persons who assume parental responsibility to the child, in order to allow them to meet their obligations of providing the child with what they need in terms of their nutrition, health care, education, clothing and housing.	Through <i>ubudehe</i> all the poor – <i>ubudehe</i> 1 and 2 - as well as child heads of household, are enrolled in “Mutuelles de Santé” by the government. No gaps within the law but there are some in the implementation process, as only 70% of the population benefit from health insurance.^{24, 67}
Article 26: State parties shall recognize for every child the right to benefit from social security.	Article 41: Taking care of orphans and other vulnerable children This article covers the government responsibility for the costs of affiliation to the “mutual health insurance” for orphans and other vulnerable children. Local authorities certify the vulnerability of children. An Order of the Minister in charge of Gender and Family Promotion should determine modalities for the implementation of this article.	The Order of the Minister of Gender and Family Promotion determining the modalities for implementation has not yet been made.

Table 10 continued

CRC	LAW No. 54/2011 of 14/12/2011 Relating to the Rights and Protection of Children	Gaps in National Legal Framework and Policies
Period 4		
Article 6: State parties recognize that every child has the inherent right to life. State parties shall ensure to the maximum extent possible the survival and development of the child.	Article 55 of the Rwanda Child Act Official Gazette No. 26 of 25/06/2012 in titled “Children HIV-positive or affected by HIV.” “A child above the age of twelve years has the right to consult an authorized professional medical doctor or a nurse and to go through medical examination notwithstanding the opposition or prohibition of their parents or guardian.” Treatment is clearly stated only in the Kinyarwanda version, not in the French or English versions, and the law was not drafted in Kinyarwanda. This may render its interpretation difficult by health professionals.	There is no clear age to be followed for the child to be allowed to decide on HIV treatment. This can be problematic and confusing, especially where we have different translations of the same law. Should health professionals consider the age of 12 as stipulated in the Rwanda Child Act, Article 55, and paragraph 2 in Kinyarwanda when this is not included in the French and English versions?⁹² This Ministerial Order is needed in order to give a full description of the procedures in place, and is, as of 30th September 2013, on the desk of the Prime Minister. This article gives the right to a child older than 12 years to be tested, examined, and seek treatment (in the Kinyarwanda version only) but it does not provide protection in any language for children younger than 12 who may want to be tested and treated if parents refuse. Furthermore, it provides no protection to children unaware of their need for testing and medical treatment.
Article 12: State parties shall assure a child who is capable of forming their own views the right to express those views freely. Article 13 (1): The child shall have the right to freedom of expression.	Article 7: Opinion of the child The child’s opinion is given due consideration in accordance with their age and maturity in regard to the subject in which they are heard. But this article only concerns judicial or administrative procedure.	This right to participate in health decisions is not mentioned in any law except for seeking HIV testing and clinical examination as per Article 55 law on protection (Official Gazette No. 26 of 25/06/2012) but with the mistranslation as stated earlier.

Table 10 continued

CRC	LAW No. 54/2011 of 14/12/2011 Relating to the Rights and Protection of Children	Gaps in National Legal Framework and Policies
Period 4 (cont.)		
Article 13 (1): ... this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.	Article 20: Right to access information and right to rest and leisure A child has the right to access suitable information and the right to rest and leisure. A Prime Minister's Order shall determine appropriate modalities for different institutions to ensure the child's rights as to accessing appropriate information and communication, books according to their age, recreational facilities and the means of enjoying rest for social and cultural purposes.	There is no specific mention of health and there is no reinforcement, as there are no legal consequences when children are not informed that they are HIV- positive.

Even where the laws for the protection of children and their access to health exist there is a lack of implementation and enforcement, as shown in Table 11.

Table 11: Sanctions for non-compliance with laws governing child protection and access to health.

LAW AND ARTICLE	PROVISION	COMMENT
LAW N°54/2011 OF 14/12/2011 RELATING TO THE RIGHTS AND THE PROTECTION OF THE CHILD		
Article 41: Taking care of orphans and other vulnerable children	The Government is responsible for the costs of affiliation to the “mutual health insurance” for orphans and other vulnerable children. Local authorities certify the vulnerability of children.	HIV is a disability. ⁹³ No sanction no reinforcement
Article 42: Child with special disability	A child with a special physical or mental disability shall be placed in special institution for care and treatment.	No sanction Still waiting for the implementation guidelines. Important to note that mental illness may confer a vulnerability <i>vis-a-vis</i> sexual abuse

Table 11 continued

LAW AND ARTICLE	PROVISION	COMMENT
LAW N°54/2011 OF 14/12/2011 RELATING TO THE RIGHTS AND THE PROTECTION OF THE CHILD		
Article 44: Protection measures for the health of the child	The Government takes all necessary measures to ensure that children enjoy their right to good health, with emphasis on the development of primary health care. The Government ensures the availability of preventive and curative care, the effective implementation of national immunisation systems for children, to combat malnutrition by all means and takes appropriate measures for controlling the quality of children's nutrition and providing clean water to children. An Order of the Minister in charge of children shall determine modalities for the implementation of provisions of this article.	No reinforcement if legal guardian refuses
Article 45: Medical insurance	Every child who is on Rwandan territory must be affiliated to a medical insurance scheme in accordance with relevant law.	No reinforcement. 10% of <i>ubudehe</i> 1 and 2 do not benefit of a health insurance
Article 46: Follow-up of a child with specific diseases after being treated in a specialised center	An Order of the Minister in charge of children determines the rehabilitation and social reintegration mechanisms at the end of the health care of the child.	No reinforcement, and HIV causes impairments.

Table 11 continued

LAW AND ARTICLE	PROVISION	COMMENT
LAW N°54/2011 OF 14/12/2011 RELATING TO THE RIGHTS AND THE PROTECTION OF THE CHILD		
Article 54: Handicapped children	Children with physical or mental disability shall be entitled to a special protection from the Government and enjoy all the rights recognized by a child without any form of discrimination related to their state or any other situation which would result from it. An Order of the Minister in charge of education shall determine programs and strategies to ensure special education meant for children with disability. An Order of the Minister in charge of children shall determine modalities of assistance to children with disability for their welfare.	Not universally done in Rwanda. No reinforcement of the Article.
Article 55: Children infected or affected by HIV /AIDS	Children infected or affected by HIV/AIDS shall benefit from a special protection and assistance of the Government, depending on its means. A child above the age of 12 years has the right to consult an authorised professional medical doctor or a nurse and to go through medical examination notwithstanding the opposition or prohibition of their parents or guardian.	The ministerial instruction is not yet endorsed by the Cabinet. No sanction. The Article is not reinforced.
Organic Law N° 01/2012/OL of 02/05/2012 Instituting the Penal Code		Penalties and sanctions. Any person, who commits what is forbidden by this law, shall be prosecuted and punished in accordance with the Penal Code.
Article 188: Defines any sexual act performed on a child as rape.		
Article 189: Makes it criminal to know of a rape or indecent assault on a child and not report it.	When the victim is a child under 14 years, the perpetrator is liable for life imprisonment.	

Table 11 continued

LAW AND ARTICLE	PROVISION	COMMENT
Organic Law N° 01/2012/OL of 02/05/2012 Instituting the Penal Code		Penalties and sanctions. Any person, who commits what is forbidden by this law, shall be prosecuted and punished in accordance with the Penal Code.
Article 190: Having sexual relations with a child of the same sex.	Sentence up to 25 years	
Article 191: Raping a child and causing the death of the child or the child becoming infected by an incurable disease.	Sentence up to life imprisonment	
Article 192: The rape of a child is committed by a guardian, government official, religious leader, security officer, medical officer, an educational officer, a trainee or any person using their professional power over the child.	Sentence up to life imprisonment	
Article 201: If the perpetrator is a relative of the victim, or has authority over them, is their teacher, or if the crime has been committed by a public servant, religious representative, medical doctor, surgeon or others with authority or care duties towards the child.	Double the sentence for sexual crimes against children.	
Article 212: Makes it a crime to share income from a child in prostitution or to advertise prostitution or pornography.		
Article 206: Makes it a crime to incite a minor to prostitution and provides heavier sentences than for a non-minor. Funding a brothel is punished much more severely if it involves children.	The sentence doubles if the child is taken into prostitution abroad.	

Table 11 continued

LAW AND ARTICLE	PROVISION	COMMENT
Organic Law N° 01/2012/OL of 02/05/2012 Instituting the Penal Code		Penalties and sanctions. Any person, who commits what is forbidden by this law, shall be prosecuted and punished in accordance with the Penal Code.
Article 221: Makes it illegal, with heavy sentence, to offer alcohol or stimulants to a child under 18.		
Article 222: Heavy sentences for offering drugs to a child or involving them in the drugs or arms trade.		
Article 157: Penalty for involuntary manslaughter.	Causing death of a person without intention.	Six (6) months to two (2) years and a fine of five hundred thousand (500, 000) to two million (2,000,000) Rwandan francs or one of these. Could be used for children infected by HIV who died because of lack of drugs but is not so applied.
Article 159: Causing illness to another person.	Involuntarily (no intention) causes illness or permanent incapacity or disability to a person, by administering a substance likely to cause death or seriously endanger health.	Imprisonment of six (6) months to one (1) year and a fine of five hundred thousand (500,000) to one million (1,000,000) Rwandan francs or one of these penalties. Could be applied to health professionals if they did not counsel expecting parents to follow PMTCT, but is not so applied. Could apply to HIV-positive expecting parents, knowing their status or not, who refuse to follow PMTCT after proper information sensitization and counseling.
Article 226: Refusal to provide care to a child.	Any person with legal responsibility for a child who refuses them medical treatment	
Article 229: states that it is a criminal offence to deprive a child of medical care, food or other required care.		

The East African Legislative Assembly (EALA) debated and passed the HIV Prevention and Management Bill in 2012, with very clear paragraphs 4 and 6.⁹⁵ This Bill 23(6) states: A child may be tested for HIV in terms of subsection (4) if the person testing is satisfied for reasons to be stated in writing that:

- There are reasonable and sufficient grounds for the test to be undertaken;
- The child is old enough to understand the implications of the test and is capable of making informed choices on matters relating to the results of the test;
- The child has been appropriately counseled in accordance with this act;
- The child has voluntarily consented to undergo the test; and
- It is in the best interests of the child over 12 years to undergo the test without parents being an obstacle.

The Bill stipulates in Article 5(d): The Government shall take appropriate measures to: *"provide, in relation to HIV and AIDS, equitable access to relevant information, goods and services including essential medicines without discrimination"*. As of 30th September 2013, the Bill is still waiting assent by the EAC Heads of State before it can become an Act of the EAC. The EAC treaty provides that the *"Community laws shall take precedence over similar national ones on matters pertaining to the implementation of this Treaty"*.

Thus in Rwanda it will fill the current vacuum due to the wrong translation of the Law No. 54/2011 of 14/12/2011 and the right of children older than 12 years to seek all HIV services and HIV/AIDS information.⁹⁶ However, it does not provide protection for children younger than 12 years who are mature and capable of giving their consent.

When the EAC HIV/AIDS Bill is ratified by all Heads of State, and comes into force, a Prime Ministerial Order will promulgate the contents of the EAC HIV Prevention and Management Bill for national implementation.

Gaps related to health in the Rwandan policies and strategies

Table 12 presents a summary of the gaps existing in the national policies and strategies guiding the right to health for people affected by HIV. It shows that even if policies have provision for children's rights to HIV services, many policies were approved more than five years ago and the rights are only partially covered.

Table 12: Gaps in policies compared to Convention on the Rights of the Child.

NATIONAL POLICIES	COMMENT/OBSERVATION
Politique Nationale de Santé de la Reproduction, 2003	Gaps remain in prevention of mother-to-child-transmission (PMTCT) services and for the survival rates of children born to HIV+ parents because there is no obligation for parents who are HIV+ to join the program
Child Health Policy, 2005	Partially, as no obligation to join PMTCT or Integrated Management for Childhood Infection
Health Sector Policy, 2005	Provision for PMTCT services and access to treatment but no obligation
Politique Nationale de Lutte Contre le VIH/SIDA, 2005	Gaps remain for the right to support for Orphans and Vulnerable Children (OVC) and PMTCT services
National Nutrition Policy, 2007	No gaps
National Community Health Policy, 2008	No specific action for the right of a child to be protected against HIV
National Strategic Plan on HIV/AIDS, 2009-2012	Gaps remain for PMTCT and treatment but no obligation to follow the program if parents HIV-positive or to treat a child who is HIV-positive
Rwanda Community Based Health Insurance, 2010	No gaps
National Policy for Orphans and Vulnerable Children (OVC), 2011	Children affected/infected by HIV/AIDS are recognized vulnerable children. - Specific objectives of the policy (Category No. 10 of OVC: children infected and affected by HIV). - To integrate assistance for children affected / infected by HIV AIDS in OVC program to avoid stigmatization - To ensure a nutritional and health assistance for children infected / affected by HIV/AIDS - To ensure psycho-social support for children and their families - To ensure inheritance rights of children in affected households
The National Integrated Child Rights Policy 2011	Under Ministry of Local Governance (MINALOC), there is a need to coordinate a comprehensive multi-sectoral implementation of children's rights comprising of seven themes, including survival and health
Adolescent, Sexual and Reproductive Health & Rights, 2011-2015	No gaps

3.5. Health services for children affected by HIV

At a community level, the role of CHWs is to sensitize people about HIV prevention and compliance with HIV care and treatment, but not provide other HIV services.

In health centers and hospitals, in order to address the problem of a countrywide lack of qualified human resources, some HIV service tasks have been shifted from medical doctors, of whom there are too few, to trained and experienced nurses. A Ministerial Instruction determining the conditions and modalities of therapeutic care for people living with HIV and AIDS (PLHA) under the shift of tasks has been approved and signed in September 2009 but it does not concern initiation of pediatric treatment, and it is still only a doctor who can provide that service. However, the Basic Package of Health Services does not mention pediatric HIV care and treatment even if the majority of treatment for HIV-related conditions takes place in health centers.

In all FOSA - health posts, health centers, and hospitals - trained nurses with 4 years' experience in HIV treatment are allowed to perform HIV counseling and testing and to follow-up the pediatric treatments initiated by a doctor. Mutuelles de Santé does not play a direct role in HIV treatment and care but by increasing health utilisation creates more opportunities for entry points to HIV diagnosis and treatment. HIV services, ARV, and treatment of opportunistic infection are free for all in the public sector.

3.6. Rwandan regulatory institutions for health

The health sector in Rwanda is regulated by a series of laws, which I summarize in Table 13.

Table 13: Laws regulating the health sector.

Year Law Enacted	Law	Conformity with the CRC
1999	Law No. 12/99 On pharmaceutical product	Yes, no conflict and not specific
2001	Law No. 30/2001 Establishing the medical council	Yes, no conflict and not specific
2006	Law No. 08/2006 Determining the organization and functioning of the district	Yes, no conflict and not specific
2007	Law No. 62/2007 On Mutual Health Insurance scheme	Yes, no conflicting and not specific
2009	Ministerial instruction on task-shifting	Yes, follow-up but not initiation of the treatment for children
2012	Ministerial Order No. 20/31 Determining the modalities for the deployment of medical staff in health sector	Yes, no conflict and not specific

The conception as well as the monitoring and evaluation of the implementation of laws, policies, strategies, and programs, derive from the central government. The coordination of monitoring the performance of health centers, and district, referral and private hospitals is, as per law, the responsibility of the district authorities. Program implementation occurs in close collaboration between the central level and leadership in districts, sectors, and villages (*imidugudu*). More information on health sector coordination can be found on the Ministry of Health of Rwanda website.⁹⁷ For the purposes of this dissertation, I will focus on several areas relevant to the present research and have included key institutions in the health sector which directly manage the coordination of planning, and the monitoring and evaluation of the prevention, care, and treatment of children affected by HIV and AIDS in Rwanda.

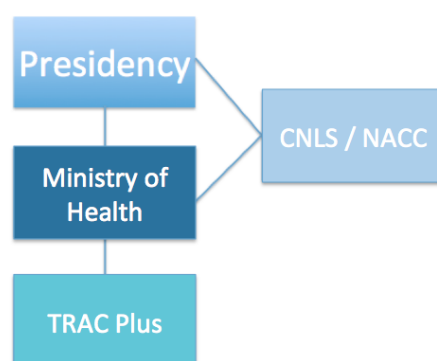
This research endeavour began in 2008. There was an institutional reform of the health sector in 2011, two and a half years after this research had started. It is therefore important to describe the institutions in charge of the AIDS response before and after 2011.

Before 2011, two laws governed the public sector organizational structure responsible for the fight against HIV:

1. Organic Law No. 32/2008 of 28 July 2008 establishing the Commission Nationale de Lutte contre le SIDA/National Aids Control Commission (CNLS/NACC) and determining its organization, functioning and competence.
2. Law No. 28/2007 of 27/06/2007 establishing the Center for Treatment and Research on AIDS, Malaria, Tuberculosis and other Epidemics (TRAC-Plus), and determining its responsibilities, organization and functioning.

The Office of the President served as the ultimate authority for the HIV response (Figure 12 shows the key institutions). The Ministry of Health was the institution responsible for implementation and for reporting to the President and Parliament. The CNLS was the institution in charge of the development of policies related to fight against HIV and AIDS and the coordination, monitoring and evaluation of the non-clinical part that fight. CNLS also managed public funds, out of the national budget, for the national AIDS response and was in charge of the monitoring and evaluation of the non-clinical aspects of it. TRAC-Plus was the entity in charge of research, care, and clinical monitoring and evaluation for the HIV and AIDS program (including protocols and guidelines for care and treatment for HIV-positive persons). TRAC-Plus was also responsible for the monitoring and evaluation for malaria, tuberculosis, emerging infectious and neglected tropical diseases.

Figure 12: Public Sector Organizational Structure of the fight against HIV/AIDS, in Rwanda before July 2011.



**Note: CNLS = Commission Nationale de Lutte contre le SIDA, NACC = National AIDS Control Commission, and TRAC Plus = Treatment and Research AIDS Center Plus.*

In 2011 Organic Law No. 32/2008 of 28 July 2008 creating the CNLS and Law No. 28/2007 of 27/06/2007 creating TRAC-Plus were repealed and Law No. 54/2010 of 25/01/2011, establishing Rwanda Biomedical Center (RBC) and determining its mission, organization and functioning, was gazetted. Within RBC, the HIV, Sexually Transmitted Infections (STI) and Blood Borne Infections Division of the Institute for HIV Disease Prevention and Control (IHDPC) is coordinating and reporting to the Ministry of Health (Table 14) through the Directorate General (DG) of RBC. In 2013, Law No. 48/2012 of 14/01/2013 modified and complemented Law No. 54/2010 of 25/01/2011, with no changes in the management of the fight against HIV. The current relationships and role of each entity involved in the coordination of the fight against HIV is described below. (Table 14)

Table 14: Public sector organizations responsible for the HIV and AIDS response in Rwanda.

Roles and Responsibilities of Actors After 2011	
Ministry of Health (MOH)	Responsible for and represents all public institutions involved in fight against HIV and AIDS in front of Cabinet, Parliament and development partners. Monitors and evaluates policy implementation. Direct coordinator of maternal and child health program and community health. The MOH reports to the Office of the Right Honourable Prime Minister.
Rwanda Biomedical Center (RBC)	Responsible for the coordination, as well as the monitoring and evaluation, of the implementation of clinical services for infectious and non-infectious diseases, procurement of goods, procurement of goods, and equipment, and production of drugs. The RBC Board reports to the MOH.
Institute for HIV Disease Prevention and Control (IHDPC)	Institution in RBC in charge of implementing the coordination, monitoring, and evaluation of clinical and health-related matters for infectious and non-infectious diseases. It reports to the DG of RBC.
HIV, STI and Blood Borne infections Division in the Institute for HIV Disease Prevention and Control (IHDPC)	Division in IHDPC in charge of implementation of the coordination, monitoring and evaluation, of clinical services in the HIV and AIDS response and related matters. This division is in charge of proposing HIV policies and strategies, clinical guidelines, protocols and training, taking into account the latest development of science and social knowledge. It reports to the Head of IHDPC.

3.7. Other Rwandan regulatory institutions important for the children's rights to health

National Commission for Children

Law N°22/2011 of 28/06/2011 established the National Commission for Children; its responsibility is to promote and protect the rights of children in Rwanda. The National Commission for Children is an independent organ established to monitor the effective implementation of the rights of children, and accountable for the implementation of national laws, police and programs for children. It reports to the Minister of Gender and Family Promotion.

Child's Rights Observatory

Law No. 30/2007 established the Child Rights Observatory. It is based within the National Commission for Human Rights and is responsible for protecting and monitoring Rwandan children's rights.

So far the motivation that led to this doctoral research, the specific population it targeted, and the periods of life with which this research is concerned were explained. The Rwandan socio-economic, health and HIV context influencing the situation of children affected by HIV were

presented. The reasons why the international, global, and regional human rights frameworks are important in creating an enabling national environment for children affected by HIV were exposed. The national and international legal framework governing the right to health for children infected by HIV were also presented. Chapter 3 explored the gaps in the international and national legal frameworks, and national policies guidelines and protocols that prevent children affected by HIV from fulfilling their right to health. This shows that there is many ways in which the Rwandan legal system can be improved to benefit the rights to health of the child, affected by HIV, especially where the national laws are inconsistent and not aligned to the CRC.

In the following section, I will summarize the background of the methodology, review the research questions that I later answer with the hope of bringing new knowledge to improve the pediatric AIDS response.

Chapter 4: Methods and ethical considerations

This research was grounded in an understanding of human rights, and intended to contribute to bridging the gap between what we know about providing prevention, care, treatment, protection and support to children affected with HIV and what we actually do provide.

The literature review, that evidences what is known, and what is not yet examined or implemented in Rwanda, supported the planning process of the research.

4.1. Key findings from the literature review

A. This study is concerned with six major human rights

1. Knowing one's rights = K
2. Education = E
3. Express opinion and Participation = P
4. Health = H
5. Non discrimination = D
6. Social support = S

B. There are four periods in life

1. Before pregnancy: primary prevention.
2. MTCT period: pregnancy, delivery and breastfeeding.
3. After MTCT period to six years: before the age of reasoning.
4. Seven years to fourteen years: age of reasoning.

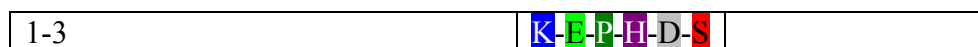
C. There are four areas of study

1. International and national legal framework and institution for human rights.
2. Funding of the pediatric fight against HIV/AIDS not reaching targeted children due to inappropriate transparency and accountability mechanisms.
3. Primary prevention, PMTCT and male circumcision.
4. Physical and mental development.

D. The missed opportunities in the four periods of life of a child: time frame including human rights (represented below by letters in colour) concerned and the area of research (represented below by numbers)

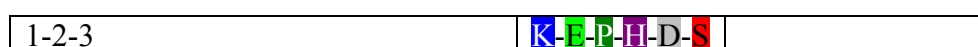
Period One

1. Primary prevention: Before pregnancy.



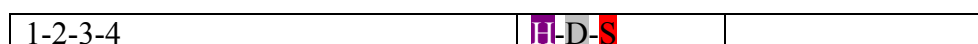
Period Two

2. MTCT period: during pregnancy, delivery, and breastfeeding.



Period Three

3. From after MTCT to six years: after MTCT and before the Age of Reason.



Period Four

4. From seven to fourteen years: Age of Reason before 15 years.



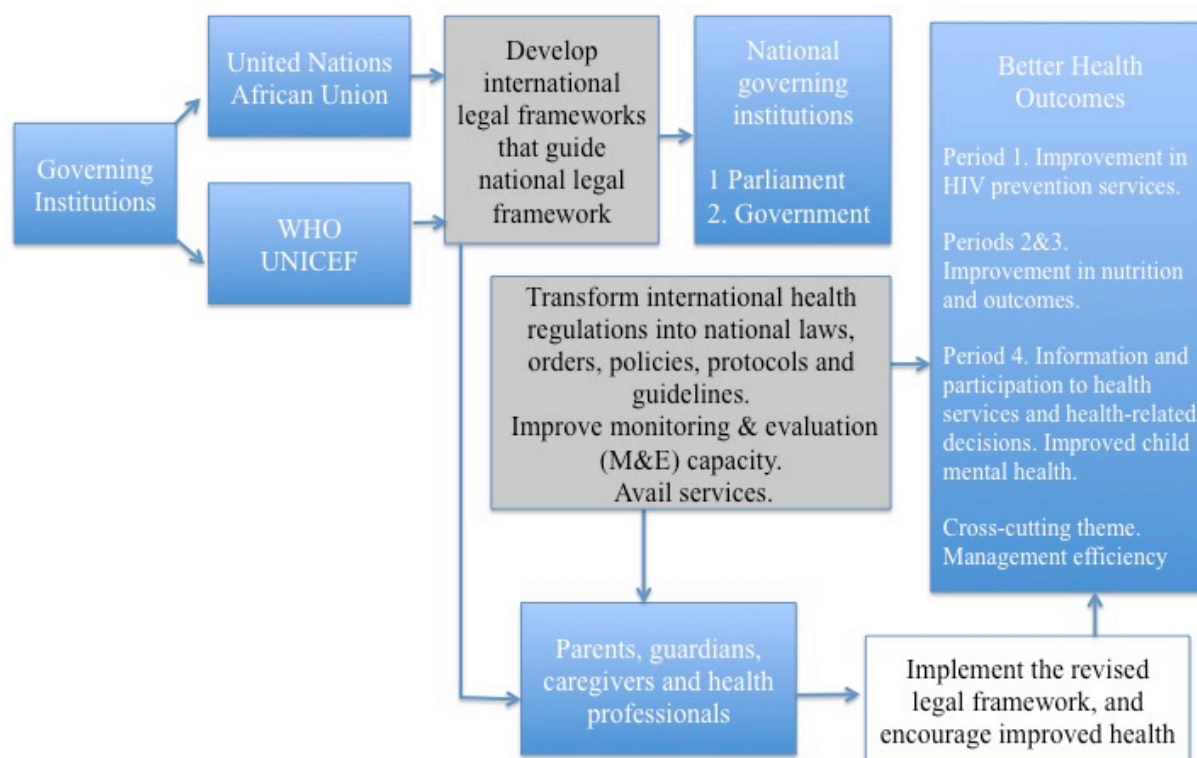
Additional detail regarding the literature review for each specific component of this dissertation is provided within each specific segment of the thesis.

4.2. Conceptual framework

While conducting the literature review, I uncovered several key relationships between the institutions in charge of children's rights to health, the legal framework, policies and their implementation.

The conceptual framework summarises the relationships between institutions, laws, policies and strategies at an international and national level that govern the child's right to health (Figure 13). The supranational agencies and institutions create the international legal framework and the national legal framework has to be aligned when the country has ratified the international legal documents. International organizations such as WHO and UNICEF set the norms in the health sector. The Parliament votes on laws, and the Government ensures their implementation through accurate policies, strategies, protocols, guidelines and access to health services for children affected by HIV and their monitoring and evaluation. Parents and caregivers are rights holders for children for the prevention of disease, their care, treatment and wellbeing.

Figure 13: Conceptual frameworks (relationships between institutions, laws, policies and strategies at an international and national level).



4.3. Research questions

The literature review related to the fulfilment of the right to health of children affected by HIV helped me to conceive four periods of life, and to identify critical gaps in the access to HIV prevention, to physical and mental development, and in financial transparency and accountability. Of the six human rights related to health, in the desk review, the two most important are the right to information and the right to participation.

The research questions, which drove the thesis, have addressed the critical gaps found in the literature review, according to the vulnerability of each of the four periods. The research questions aim to contribute to solutions for identified gaps and to propose improvements in laws, policies, protocols, and monitoring and evaluation for better protection of children affected by HIV and for a better pediatric HIV response. This led to four main research questions drawn around the four important periods of life for children to exercise their rights to health in relation to HIV infection.

There are two sub-questions for each of the four periods, plus one cross-cutting question.

Question 1: Are there barriers to prevention?

Period One

Before conception

Sub-question 1: What are the barriers to sex workers and their children exercising their rights to health care?

Sub-question 2: Are prisoners in Rwanda able to fulfil their rights to primary prevention of HIV?

Period Two

After conception to post-breastfeeding or after birth if not breast fed

Sub-question 3: What is the most cost effective PMTCT protocol for Rwanda?

Sub-question 4: In the framework of HIV prevention what is the most cost effective male circumcision practice for Rwanda?

Question 2: Are there barriers affecting the physical and mental development of children affected by HIV?

Period Three

From after MTCT period and before seven years old

Sub-question 5: Are the nutritional protocols proposed by international regulatory bodies appropriate for Rwandan children?

Sub-question 6: Are tools used to assess the nutritional status of malnourished children in Rwanda appropriate?

Period Four

From seven to fourteen years

Sub-question 7: Is the CDI appropriately adapted to assess the mental health of children in Rwanda?

Question 3: Are there barriers to health decisions for children affected by HIV, due to the non-respect of their rights to information and participation?

Sub-question 8: Does the state and do parents fulfil their obligations to protect, inform, and involve children in the response to HIV?

Cross-cutting theme

Question 4: Are there barriers in financial management that inhibit the fulfilment of a child's right to health when affected by HIV?

Sub-question 9: Did NGOs improve financial reporting after request by the GoR?

4.4. Overview of methods

Mixed methods were used to address the four main research questions and the eight sub-questions on the right to information and participation, quality of prevention, physical and mental development and the financial management of the pediatric HIV response. The research included quantitative and qualitative components, combining the reliability and statistical power of standardised surveys with the insight and understanding that can be gained from qualitative case studies. A detailed methodology for each paper is included below in relation to the sub-question that it answers.

Table 15: Overview of Research Methods.

Specific Research Questions	Overview of Method
1. What are the barriers to sex workers and their children exercising their rights to health care?	Mixed methods including 1) literature review, 2) desk review of national reports on sex worker policies, 3) qualitative interviews with n=6 former or current female sex workers between the ages of 21-40 with children in school in rural Rwanda, and 4) an analysis of 2006 and 2008 Rwandan Behavioral Surveillance Surveys. <i>(See Annex for additional interviewee characteristics)</i>
2. Are prisoners in Rwanda able to fulfil their rights to primary prevention of HIV?	Desk review of availability of HIV services and prevalence of education materials in Rwanda's 16 prisons.
3. What is the most cost effective PMTCT protocol for Rwanda?	Cost-effectiveness analysis.
4. In the framework of HIV prevention what is the most cost effective male circumcision practice for Rwanda?	Cost-effectiveness analysis.
5. Are the nutritional protocols proposed by international regulatory bodies appropriate for Rwandan children?	Desk review from September 2008 to January 2009 of charts used prior to 2009 in Rwanda and analyses of reports and policies related to child malnutrition.
6. Are tools used to assess the nutritional status of malnourished children in Rwanda appropriate?	
7. Is the Children's Depression Inventory (CDI) tool appropriately adapted to assess the mental health of children in Rwanda?	Validation study of international CDI among n=87 Rwandan children (ages 7-14 years of age, aware of their HIV status, receiving ARV for at least 6 months, and enrolled in school) who were identified via stratified sampling procedure of n=100 children from 10 health facilities across the 5 provinces in Rwanda. <i>(See Table 30 for sample characteristics)</i>
8. Does the state and do parents fulfil their obligations to protect, inform, and involve children in the response to HIV?	Content analysis of Rwandan policies for HIV-AIDS services and comparative review of other policies in sub-Saharan Africa.
9. Did NGOs improve financial reporting after request by the Government of Rwanda (GoR)?	Survey of n=6 (4 international and 2 national) NGOs using the National Orphan and Vulnerable Children Spending Assessment (NOVCSA) at two separate time points (2008 and 2009) to compare reported spending for fiscal year 2007.

Note: See the Annex for copies of questionnaires, data collection tools, and further details regarding cost-effectiveness assumptions and calculations.

Qualitative research and field assessment methods were used to analyse access to primary prevention among marginalised groups. The quality of WHO and UNICEF policies, and the

rights of children affected by HIV to information and participation, were assessed by desk reviews. The value for money of pediatric programs to fight HIV, and financial reports of NGOs were assessed to verify their accuracy and the cost-effectiveness of PMTCT and MC. The validation, in the Rwandan context, of the CDI was performed to assess its accuracy for the screening and depression management needs, for Rwandan HIV-positive children.

The results were published in peer-reviewed journals and the methods from each paper are included below. For each paper, the background, results and discussion are presented together in sections of Chapters 5 through 9. It is noted in the text whether the methods and findings are a reprinted version of text that has been published as a journal article of which I am first author.

4.5. Ethical considerations

Each individual component of this thesis has adhered to the highest ethical and academic standards. Data were collected only after the study designs had been approved by the relevant authorities and ethics committee (National Ethics Committee and the Ethics Committee of the University of Rwanda). Ethical approval was obtained for primary data collection. For all additions and changes in the survey, ethical approval was requested and received from either the National Ethics Committee or from the University of Rwanda Ethics Committee, depending on the study.

The following sections describe the ethical issues taken into consideration at the time of research design and implementation, including details of ethical approval. Various methods were used to keep the HIV status of participants confidential in order to minimise any reluctance among parents, and above all to protect children and their families.

Given that some information was sensitive, only participant identification codes were recorded on research materials, to maintain confidentiality. All completed data collection tools (questionnaires and audio files) and files linking participant names and identification codes were kept in a secure location. Data were entered into electronic files, which were protected by a password to restrict access. Trained interviewers collected all data on the participants; these interviewers were chosen based on their professional categories (such as doctors or nurses). Data collectors were bound by professional secrecy and this assessment was regarded as part of their patient service agreement. At no time were names entered into the database and all information retrieved from the files ensured strict confidentiality of the data.

The objectives of the studies were explained to potential participants. The voluntariness of their participation in the research and the fact that the information was strictly confidential and anonymous was emphasised. The collected data were used by the Principal Investigator (myself) and researchers colleagues, solely for the work authorized by the Ethics Committee for this thesis and for no other purpose, other than using the outcomes for advocacy purposes.

Informed written consent in Kinyarwanda was obtained in advance of each interview from all adults involved in the survey, as well as the consent of the parents or guardians of participating children. We also obtained the oral consent of children in the presence of their parents.

Interviews were conducted only with children who were older than seven years and with adults. This presented a difficult ethical problem because some of the children and adults could not read the form and thus could not consent in writing to participate in the study. Verbal assent was obtained from all illiterate adult respondents, after a comprehensive explanation of the study aims, methodologies, and data usage in Kinyarwanda.

Health care professionals at the selected health facilities identified the children who knew their status, and only children who knew their status were interviewed. Each HIV-positive respondent participated in individual interviews in a quiet, private office. Respondents were clearly informed of their right to withdraw from the study or not respond to a question at any point in time.

In addition to the ethical approval, the National AIDS Control Commission and/or TRAC-Plus approved the research with the sex workers, and Rwanda's Psychosocial Center gave approval for the assessment of the mental health status of children who were HIV-positive.

4.6. Interview considerations

To ensure the scientific quality and proper representation of participants in the research, all material and sampling strategies were validated in collaboration with quantitative and qualitative experts. The proposals and questionnaires were submitted for review to the appropriate ethical committees.

The interviewees for all the qualitative sections, involved children affected by HIV, selected purposefully to ensure proper representation of the participants by taking into account geography, age, and sex.

Because the target population speaks mostly Kinyarwanda, and the interviewers and supervisors speak French or English (in addition to Kinyarwanda), all questionnaires, which included structured and open-ended questions, were created in French and translated into English and Kinyarwanda by a team of professionals in the field. There was a systematic back translation in French by another professional team to ensure accuracy of the translation.

Only trained interviewers administered the questionnaires. For each question, to ensure standard procedures during interviews, each investigator received and was trained on an *aide-memoir* (a questionnaire with instructions), specifying the procedures to prepare and conduct the interview, data security, and protecting participant ethical rights. A pilot of the questionnaires was carried out in advance of the study to test the questionnaires, and the questionnaires were adjusted based on results from the pilot.

All qualitative data (from focus groups and individual interviews) were recorded and transcribed in English or French by the interviewers themselves, according to the language they preferred, after which they were analysed thematically.

These processes minimised the potential risks linked to non-representativeness and non-replicability of the interviews, the subjectivity of the interviewers and errors of transcription and translation, and they protected the rights of participants in the studies.

4.7. Detailed methodology for each component of the research

Methods for Research Question 1

The methodology for answering Question 1 (Are there barriers to prevention?) is provided below for each sub-question within Periods 1 and 2.

Period 1. Sub-question 1. What are the barriers to sex workers and their children exercising their rights to health care?

To answer this question, I employed the following methods that have been published in a peer-reviewed article for which I am first-author, titled: "Developing human rights-based strategies to improve health among female sex workers in Rwanda". Permission has been granted from the Health and Human Rights Journal for the reprinted text.

This research uses a multi-pronged approach to analyse the social background and health impacts of female sex work in Rwanda. Four sources of information serve as the primary evidence base for the research. The first is a review of the academic literature relating to the causes and effects of sex work, with a primary focus on Sub-Saharan Africa. The second consists of national and international reports and policies on sex work. Thirdly, we drew from qualitative analysis of semi-structured interviews with six (n=6) representatives chosen by their associations of female former sex workers from rural Rwanda (see Annex for questionnaire). The questions focused on the following themes: social economic profile, level of education, interactions with police, interactions with health system with respect to themselves and their children, interactions of children in the school environment, and aptitude for leaving prostitution. Criteria included that the woman needed to have been in prostitution, had at least one child in school, and that this child had required health services. The interviews were conducted under the auspices of the Treatment and Research AIDS Center Plus (TRAC-Plus) and non-governmental partners. The respondents all came from rural Rwanda, were between the ages of 21 and 40, had at least one child in school, and had no secondary education. Interviewee codes for the six female respondents were applied by generating a two-letter and two-digit code using a mix of letters from their first name and their district in which they reside in Rwanda along with their year of birth.

The research also supported an effort to design rights-based interventions to fight HIV/AIDS among sex workers, while sensitizing leaders and parliamentarians at a time when Rwanda was debating legislation that would reinforce criminal sanctions against prostitution. The fourth source of information consisted of an analysis of the 2006 and 2008 Rwandan National Behavioural Surveillance Surveys.⁹⁸

Rigorous social scientific study of sex work in Rwanda is in its early stages. This research that underlies it does not attempt to present a comprehensive analysis of this complex social reality. The intention is to reflect, in an illustrative and exploratory way, experiences, views, and concerns expressed by some sex workers, in order to inform an on-going political debate and stimulate additional research. Both additional scientific study and greater social mobilisation among sex workers are needed urgently. Meanwhile, we believe it is already possible to point to suggested convergences between some sex workers' expressed needs and the promise of an integrated, rights-based policy approach.

Period 1. Sub-question 2. Are prisoners in Rwanda fulfilling their rights to primary prevention of HIV?

To answer this question, I employed the following methods that have been published in a peer-reviewed perspective for which I am first-author, titled: "HIV Prevention in Rwandan Prisons". Permission has been granted from the Health and Human Rights Journal for the reprinted text published. The entire chapter is what was submitted to the Journal.

This study used a desk review to determine the availability of HIV prevention services in prisons. Members of the HIV Prevention Unit in RBC were consulted. Public data were gathered for secondary analysis of whether or not prevention programs such as information education communication for behaviour change campaigns and distribution of condoms for free or for purchase exist within 16 of Rwanda's prisons.

Period 2. Sub-question 3. What is the most cost effective PMTCT protocol for Rwanda?

To answer this question, I employed the following methods that have been published in a peer-reviewed perspective for which I am first-author, titled: "Prevention of mother to child transmission of HIV: cost-effectiveness of antiretroviral regimens and feeding options in Rwanda"; permission has been granted from PLoS ONE for the reprinted text.

In 2010, the authors calculated the cost and effects of different PMTCT scenarios for a cohort comprising the estimated 10,300 HIV-infected pregnant women needing PMTCT in Rwanda in 2009 and adopted the perspective of the Government of Rwanda as a health care payer.⁹⁹

We compared PMTCT regimen options (see Table 16) for HIV-positive pregnant women not eligible for lifelong HAART (Highly Active Antiretroviral Therapy) and HIV-exposed infants, as per 2010 WHO PMTCT guidelines¹³ and 2010 Rwanda PMTCT guidelines:¹⁰⁰ Dual ARV prophylaxis and short course HAART (Sc-HAART) prophylaxis extended throughout breastfeeding.

Table 16: PMTCT antiretroviral regimen options for HIV-positive pregnant women not eligible for lifelong HAART and HIV-exposed infants considered for the modelling, Rwanda 2010.

ARV regimen and infant feeding options	Mother ARV regimen	Infant ARV regimen
Dual ARV prophylaxis and breastfeeding (WHO – Option A)	Twice daily AZT from 14 weeks gestation or as soon thereafter as possible; AZT+3TC during labour and delivery; 7 days AZT+3TC post-partum	Sd-NVP at birth, then once daily NVP for the first six weeks of life ¹⁰⁰
Dual ARV prophylaxis and replacement feeding	Twice daily AZT from 14 weeks gestation or as soon thereafter as possible; AZT+3TC during labour and delivery; 7 days AZT+3TC post-partum	Sd-NVP at birth, then once daily NVP for the first six weeks of life ¹⁰⁰
Short course (Sc)-HAART prophylaxis and 6, 12 or 18 months breastfeeding (WHO-Option B)	Short-course (Sc) HAART prophylaxis from 14 weeks gestation throughout the duration of breastfeeding period. First-line regimen is TDF+3TC+NVP.	Sd-NVP at birth, then once daily NVP for 6 weeks
Short course (Sc)-HAART prophylaxis and replacement feeding	Short-course (Sc) HAART prophylaxis from 14 weeks gestation until 1 week post-partum. First-line regimen is TDF+3TC+NVP.	Sd-NVP at birth, then once daily NVP for 6 weeks

For Dual ARV prophylaxis, two infant feeding options were considered: 1) exclusive breastfeeding (BF) for six months and continuation of BF for the first twelve months (Option-A), and 2) replacement feeding from birth. For Sc-HAART, the infant feeding options were: 1) breastfeeding for six, twelve, or eighteen months (Option-B), and 2) replacement feeding from

birth. While six months of exclusive breastfeeding is currently recommended in Rwanda, recent data suggests that the rate of exclusive breastfeeding in the general population is only 38%.¹⁰¹ In 2005, the average duration of breastfeeding in Rwanda in all women was 24.9 months.¹⁰¹

Replacement feeding was modelled on the Partners In Health delivery model, which has operated in two rural districts in Rwanda since 2005. The model includes provision of nine months of formula and related supplies, community health workers conducting home visits for directly observed ARV, social worker home visits, regular support for formula preparation and active follow-up of defaulters.¹⁰²

Under each scenario, all HIV-positive pregnant women eligible (CD4 count <500) for HAART treatment receive long course (Lc) HAART, initiated at time of diagnosis, for life. First-line regimen is tenofovir, lamivudine, and nevirapine (TDF+3TC+NVP). If CD4 is above 350, NVP is replaced by EFV after the first trimester. The infant ARV regimen includes Sd-NVP at birth, followed by once daily NVP for six weeks. In the absence of data for Rwanda, we considered 73% of HIV-infected pregnant women in PMTCT programs to be eligible for ARV – as reported in the scientific literature.¹⁰³

For the purposes of modelling and comparison across options, we included a scenario in which the mother-baby pair receive no intervention and assumed that in each scenario all women not eligible for Lc-HAART were covered with the chosen option (while all eligible women received Lc-HAART under each scenario). We also assumed that the entire cohort of HIV-infected pregnant women discovered their HIV status when tested during antenatal care visits. Pregnant women who did not come for antenatal visits, who came late, who were identified during labour, or who had suboptimal regimens for any other reason, such as low adherence, were not considered in the base case model. Also, in Rwanda, where there is very high coverage of HIV counseling and testing services and of ARV programs, some HIV-infected pregnant women are already aware of their HIV status when initiating PMTCT services and are enrolled in ARV programs. Given that these women were eligible for treatment and were already receiving lifelong ARV prior to ANC and PMTCT, we did not attribute additional ARV costs to the PMTCT program for the purposes of the cost-effectiveness calculations (the daily NVP to baby that would be added to the mothers' existing regimen is only a small cost).

Table 17 provides details of how ARV regimens and feeding practices were distributed in the cohort of pregnant women for each study base case scenario.

Table 17: Antiretroviral regimen options and feeding practices distribution in each study scenario based case (for non-eligible women).

Study scenarios	No intervention	Dual ARV breastfeeding	Dual ARV replacement feeding	Sc-HAART 6 mo. Breastfeeding	Sc-HAART 12 mo. Breastfeeding	Sc-HAART 18 mo. breastfeeding	Sc-HAART replacement feeding
No prophylaxis, %	100						
Dual ARV, %		100	100				
Sc-HAART Prophylaxis, %				100	100	100	100
Mixed feeding first 6 months, %	60 ¹⁰⁵	60	-	60	60	60	-
Exclusive breastfeeding first 6 months, %	38 ¹⁰⁵	38	-	38	38	38	-
Mean duration of breastfeeding, months	24.9 ²⁵	6 ²⁵	-	6	12	18	-
Replacement feeding, %	2 ⁴⁹	2	100	2	2	2	100

One-way sensitivity analysis was performed for the main inputs of the model: breastfeeding practices; cost of ARV, laboratory tests, and replacement feeding; the proportion of eligible women; HIV transmission rates and HIV-free survival rates.

Costs

Direct costs were modelled based on all inputs in each PMTCT option (including staff time and consumables) and related cost components. Since PMTCT in Rwanda is horizontally integrated with other services, we included only the extra cost of adding PMTCT services to existing activities and attributed a percentage of the indirect costs (capital and recurrent). We assumed that if PMTCT services were to be established in new sites, infrastructure and other capital costs would be similar across PMTCT treatment options and, therefore, the ranking across options would not change. Using an exchange rate of 570 Rwandan Francs per US dollar (\$),¹⁰⁴ the list of inputs and data sources for each of the costed items is summarised in Table 18.

Table 18: Inputs, assumptions and data sources for costs of PMTCT interventions, Rwanda.

ITEMS	COMMENT AND SOURCE
ARV medications	Protocols were taken from WHO 2010 guidelines adapted to the Rwanda context^{100, 105} Prices of drugs were from Clinton Health Access Initiative (CHAI) price list, April 2010¹⁰⁶ In addition to the price of drugs, were included: - Freight cost: 20% for syrups, 12% for pills - Central Purchasing of Essential Medicines in Rwanda (CAMERWA) management costs: 9%
Cotrimoxazole (CTX)	2010 Protocols from the Center for Treatment and Research on AIDS, Malaria, Tuberculosis and Other Epidemics (TRAC-Plus) ARV guidelines.¹⁰⁰ CTX 25/5 mg/kg once daily for each child born to an HIV-infected mother in whom the diagnosis of HIV is not yet formally excluded. - CTX 960 mg once daily for mothers during pregnancy and for 6, 12 or 18 months under Sc-HAART options CTX price was from CAMERWA, plus freight and management costs as per ARV medications.
Laboratory	Quantities of exams varied according to PMTCT protocols. The following exams were included¹⁰⁷: HIV Polymerase Chain Reaction (PCR) for early infant diagnosis (one to three times per child, US \$30 per exam); HIV rapid antibody tests (one to two times per child plus for pregnant women, US \$1.59 per test); CD4 cell counts (every 6 months per child, US \$20.7 per exam); haematology (two to four times per child, US \$4.9 each time); biochemistry (two to four times per child, US \$8.3 each time); viral load (one time per child under Sc-HAART 12 and 18 months, US \$50.5 each time). Prices were provided by the 2007 quantification exercise from TRAC-Plus and CAMERWA and adjusted to 2009 US \$ equivalents.¹⁰⁸
Staff time (personnel direct services)	The following actions were costed: administer or dispense ARV; administer CTX; blood draw; charting on PMTCT; counseling about ARV; counseling for infant feeding; family planning services; lab test for adult women and infants; offer or register for HIV testing; pre-test and post-test counseling (VCT); pre- and post-test counseling for patient and partner; administer ARV. The frequency of each action for each of the scenarios was determined by consensus of the authors involved in PMTCT at the health centers. The cost of each action was taken as the average cost (type of staff, staff time and average salary cost including social security and taxes) in all Rwanda PMTCT facilities in 2009 as reported in the Pediatric HIV/AIDS Care Costing Study in Rwanda, 2010 Intermediate Report.¹⁰⁹ The referenced study recorded the type of staff and staff time for each action by repeated observation in a representative sample of health centers in the country.

Table 18 continued

ITEMS	COMMENT AND SOURCE
Staff training	The need for staff training was assumed to be 3 to 5 days per PMTCT site, 4 staff trained for each site (consensus of authors). The expected useful life of training (rate of refresher training) was estimated at two years. The cost of staff training was as per the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) National Strategy Application budget, US \$67 per day per person all included.¹⁰⁹
Promotion/ mass media IECBC campaign	The cost of a national promotion Information, Education, and Communication for Behaviour Change (IECBC) campaign: US \$190,000 was taken from the GFATM National Strategy Application budget. ¹⁰⁹
Contribution to the capital and running costs (overhead/administration) of a health center	The financial analysis of 2 average health centers in Musanze District by CCHIPs (Comprehensive Community Health Initiatives & Programs) and CHAI in FY 2009 estimated US \$24,971 for logistics, utilities, material goods, maintenance and renovation, medical equipment and support staff. Since in an average health center in Rwanda, 5% to 10% of overall staff time is attributable to PMTCT activities (Rwanda MOH key informants): 2 days a week dedicated to PMTCT activities (2 full-time nurses out of 15 nurses, 10% of doctors' time), we attributed 10% of the overhead to PMTCT (the same amount across PMTCT options). We also added 10% of the annual amortization cost for a health center building. ¹¹⁰

For HIV-positive pregnant women (identified through PMTCT) eligible for ARV, we calculated the cost of treatment for 18 months only, as this would contribute to 18 months of HIV-free survival in breastfed children.

The replacement feeding component includes counseling for replacement feeding in the maternity ward after delivery (staff time of feeding assistants and midwives); follow-up home visits by community midwives with related staff time and transport costs (1 visit per week during first 2 months of enrolment and 1 visit per month during months 3-18); education at health centers by social workers (including time of staff, demonstration kits and transportation reimbursement for each participant); time spent by health staff in administrative issues and meetings related to milk distribution; material provided to mothers (small stove, thermos, jerry cans, baby bottles, pot); the cost of formula from birth until 9 months of age, using the least expensive bulk formula pricing available in Rwanda (6 tins per month for babies aged 0-2 months; 8 tins per month for babies aged 3-5 months; 4 tins per month for babies aged 6-8 months) and the cost of training staff (5 days on average per staff member).

Effectiveness

Two outcomes of interest were considered to evaluate PMTCT regimen effectiveness: the number of childhood HIV infections prevented against “no intervention”, and 18-month HIV-free survival (number of children uninfected with HIV and alive at 18 months). The transmission probabilities used to estimate the number of HIV infections in children born to HIV-positive mothers and the relative risk of mortality for HIV-exposed uninfected children used to calculate 18-month HIV-free survival rates were extracted from the literature, including from two large reviews,^{111,112} and are reported in Table 19. The widest ranges reported in the literature were used in sensitivity analysis to best account for uncertainty around the base case values.

Table 19: Transmission probability for each PMTCT protocol and feeding option and mortality rates at 18 months (data refer to 12-24 months) for HIV exposed uninfected children used to calculate HIV-free survival.

Transmission probability percentage at birth (replacement feeding)	Base Case	Low range	High range
No intervention	20% ¹¹³	13% ¹¹⁴	30% ¹⁹
Dual ARV (Option A, WHO)	4% ¹¹³	2% ^{115,116}	6% ^{115,116}
Sc-HAART prophylaxis (Option B, WHO)	1.2% ¹¹⁷	0% ¹¹⁷	2.5% ¹¹⁷
Breastfeeding transmission probability per month	Base Case	Low range	High range
1-6 months, exclusive breastfeeding	0.5% ¹¹³	0% ^{118,119}	3.3% ^{118,119}
1-6 months, mixed breastfeeding	1% ¹¹³	0% ^{118,119}	6.6% ^{118,119}
With Sc-HAART	0.33% (first 6 months mixed feeding) 0.17% (first 6 months excl. breastfeeding and additional months) ¹²⁰	0.08% ¹²⁰	0.4% ¹²⁰
With infant daily NVP during 6 months breastfeeding (Option A)	1.7% at 6 months ¹²¹	0% ^{121, 118, 119}	2.9% ¹²¹
7+ months - mixed feeding	0.75% ¹¹³	0.65% ¹²²	0.85% ¹²²
Values used to calculate survival at 18 months for HIV exposed uninfected children	Base Case	Low range	High range
Breastfeeding for 12 months or more, mortality rate	5.3%, estimate at 18 months ¹²³	--	--
Estimate of Relative Risk (RR) of mortality if breastfeeding for 6 months versus breastfeeding for 12 months or more	RR= 1.5* *Assumption in the absence of published data (middle point)	RR= ^{17,124}	RR=3 ^{111**} **RR 3 refers to 24 months HIV-free survival if early weaning at 4 months
Estimate of RR if formula feeding versus breastfeeding for 12 months or more	RR = 2 ^{112***} ***reported data from Pakistan and Senegal, with consideration that survival rates with national scale up may be worse than reported in the PIH program (used in low range)	RR=1 ^{9, 111, 125,126, 127}	RR=6 ¹²⁸ or higher ^{112****} ****data from Ghana, as an example of RR higher than 6

Savings

Savings correspond to the lifetime costs of HIV treatment and care (HAART, OI, laboratory tests, care program) for HIV infections averted among children or the average number of years of survival under treatment multiplied by the annual cost of treatment and care, adjusted for the rate of access to treatment and adherence. Costs were discounted using a 3% rate, as per common practice in cost-effectiveness analysis.¹²⁹ Costs of treatment for AIDS include antiretroviral treatment (first- and second-line drugs), laboratory tests and home-based care. Research has shown that OIs are exceedingly rare among HIV-positive infants who had been immediately initiated on HAART.⁵⁴ The incidence of OI is expected to be low given Rwanda's early adoption (in 2009) of immediate initiation of HAART for HIV-positive infants. Thus, OI treatment costs were not included in inputs. Specific survival information for HIV-infected children in Rwanda is not currently available, however, studies on the impact of HAART on the survival of children infected prenatally are available for some other developing countries.^{130,131} Based on results from Banerjee et al., which reported the longest follow-up period, a survival rate of 15.1 years from the date of diagnosis was assumed.¹³⁰ A death rate of 6% and 6.9% at one and two years of HAART was used, respectively, as per a multicounty report in Sub-Saharan Africa.¹³¹ Assumptions and data sources for each of the costed items are summarised in Table 20. More detail and actual quantifications are available from the authors upon request.

Table 20: Inputs costed in the model and related sources for prices for treatment of HIV-infected children.

Items	Source
ARV drugs	Protocols are as per TRAC-Plus 2010 ARV guidelines.¹⁰⁰ First-line: ABC+3TC+NVP, ABC+3TC+EFV, AZT+3TC+NVP, AZT+3TC+EFV (61% of children). Second-line: AZT+3TC+LPV/r, ABC+3TC+LPV/r, AZT+ABC+3TC+LPV/r (39% of children). Distribution of children less than fifteen years old across the protocols (according to age/weight) was provided by the TRAC-Plus ARV quantification team, part of the CPDS (Coordinated Procurement and Distribution System). CHAI price list, April 2010 was used for prices of ARV medications.¹⁰⁰ CAMERWA management cost and freight costs were added to price of drugs.
Laboratory	The following were considered: CD4 cell counts tests; biochemistry tests; haematology tests; viral load tests; other tests; consumables. Quantification and costs were provided by CPDS as per 2009 patient needs, prices and budget.
Care	Care for children on ARV (staff time) included: medical visits, social work consultations, monthly counseling groups, nutritionist time, home visits. Direct patient visits by doctors, nurses, social workers, CHWs are included. Other staff (clerks etc.), are not included. No other costs (non-personnel operational costs such as vehicles, equipment, and infrastructure) were included. Costing reflects different ages: infancy (age 0-1) and young childhood (age 1-10), when more frequent doctor visits are required for dosage changes; and adolescents (age 11-15). Gross monthly salaries, according to Rwanda MOH base salary norms, were used. Current TRAC-Plus guidelines were used whenever possible. In other cases, PIH local experience in pediatric HIV care was used to estimate visit length, frequency, and staffing.
CTX	Dosage of Cotrimoxazole (CTX) as per Rwanda ARV guidelines¹⁰⁶ and WHO 2006.¹² Changes from Syrup to pills was taken at 6 kg or 7 months.¹⁰⁰ Prices for CTX were provided by CAMERWA, including freight and management costs.

Children's antiretroviral treatment costs apply to 90% of the cohort of HIV-infected children. This percentage was obtained assuming 95% access to ARV (a realistic assumption for Rwanda given an estimated coverage rate of 77% in 2009⁹⁹ and the ambitious targets for scaling up¹³²) and considering the current high level of adherence to treatment and low losses to follow-up.^{133,134,135,136} The cost for the cohort of HIV-infected children was additionally adjusted for the mortality rate as per Rwandan preliminary findings of RDHS2010 at different ages.

Period 2. Sub-question 4. In the framework of HIV prevention what is the most cost effective male circumcision practice for Rwanda?

To answer this question, I employed the following methods that have been published in a peer-reviewed perspective for which I am first-author, titled: "Male circumcision at different ages in Rwanda: a cost-effectiveness study"; permission has been granted from the PLoS Medicine for the reprinted text.

The analysis adopts the perspective of the Government of Rwanda as a health care payer. In the absence of available tools to evaluate the impact of neonatal, adolescent, and adult MC, a basic cost-effectiveness model was developed. Calculations refer to an average Rwandan adolescent or adult male, and reflect risk factors for HIV, such as age at first intercourse and presence of STI, as well as sexual behaviours such as condom use, number and concurrency of partners.

Effectiveness, defined as the number of HIV infections averted, was calculated by projecting the reduction in HIV incidence over time. Costs included the materials necessary for performing circumcisions, staff time, associated staff training, patient counseling, the treatment of adverse events, and related IECBC campaigns. These were conservatively adjusted for the averted lifetime cost of health care (ARV, OI, laboratory tests), considering only averted HIV treatment costs, not those of other STI.

One-way sensitivity analysis was performed by varying the main inputs of the model, and the thresholds at which each intervention (a) is no longer cost-saving, and (b) costs more than one GDP (Gross Domestic Product) per capita per life-year gained, were calculated for the following variables: discount rate, HIV incidence, protection rate of MC, the cost of MC, the cost of health care averted, and adherence to ARV.

The model was applied to three hypothetical male cohorts in Rwanda in 2008: newborns, adolescents, and adult men. The number of male infants born in Rwanda in 2008 is estimated to be approximately 210,000 (Rwanda National Institute of Statistics (RNIS), 2009). Although only 38% of births occur in health facilities,²⁵ 97% of newborns receive BCG vaccination in a health facility within 1 month of birth (Vaccination program Rwanda/PEV, December 2007). This visit to a health facility provides an opportunity to circumcise the infant, thus making it feasible to offer circumcision to nearly all infants, of which we estimate at least 70% are likely to undergo the procedure. Acceptance of MC in Rwanda is expected to be high since there are no cultural barriers, demand is already on the rise (MOH, Rwanda), and the intervention is expected to be accompanied by an intense national IECBC campaign. The number of circumcisions would be about 150,000 children annually. To facilitate comparisons for this exercise, we considered a similarly sized cohort of adolescents and of adults (there are 2,140,000 males older than 15 years in the country, Rwanda National Institute of Statistics (RNIS), although optimal implementation strategies should probably aim for higher annual coverage of adolescents and adults during the initial years of the program.

For purposes of modelling, it is assumed that infants were circumcised at birth, adolescents at age 15 years, and adults at age 30 years. The model projects HIV infections averted until death. The average life expectancy in Rwanda is 52 years at birth, 62 years at age 15, and 64 years at age 30.¹³⁷

Effectiveness

Effectiveness is the product of the number of people susceptible to HIV infection in the cohort, the HIV incidence rate at different ages, and the protective effect of MC, discounted back to the year of circumcision and summed over the life expectancy of the circumcised man.

People susceptible to HIV infection in the cohort

The analysis of effectiveness is limited to those adolescents and adults who are HIV negative. The model includes the cost of voluntary HIV counseling and testing (VCT) for all adolescents and adults. In keeping with current UNAIDS recommendations,¹³⁸ MC will be offered

regardless of HIV status and whether a client accepts VCT. MC would only be withheld if it is medically contraindicated. HIV prevalence rate reported in the 2005 RDHS (0.4% for 15 year olds and 4.2% for 30 year old men) was used in the analysis.²⁵ Given the high coverage of PMTCT programs in Rwanda (72% of pregnant women in need of PMTCT services have access to them and more than 60% of all health facilities in the country provided PMTCT services in 2008) and the Universal Access targets the country has set for the next few years (90% coverage by 2012),^{25,139} it is expected that the proportion of children born HIV-positive will become negligible over time. Therefore, the effectiveness of MC for children is extended to the entire cohort.

Estimation of age-specific incidence rates

In 2008, HIV incidence in Rwanda per 5-year age groups (15–19, 20–24, 25–29, 30–34, 35–39, 40–44, 45–49) was estimated using the EPP and Spectrum software developed by UNAIDS and the Futures Group, under the United States Agency for International Development (USAID) Health Policy Initiative. EPP and Spectrum are a suite of mathematical models based on demographic (RNIS), epidemiological (RDHS 2005, sentinel surveillance), and programmatic (ARV and PMTCT, MOH) data that are used for official HIV estimates in Rwanda. Within the age groups, incidence was assumed as equal at each age point. For instance, HIV incidence at 30 years of age was calculated as total incidence for the 30–34 age group divided by 5. Total incidence among men over the age of 15 years is assumed to be due to sexual intercourse. The infections averted for infants are conservatively estimated because they do not include any infections averted prior to age 15 years, as no data is available regarding sexually acquired infections prior to age 15 years.

Calculation of cumulative incidence

The future age-specific annual HIV incidence was assumed to remain constant at the 2008 rate. To account for the uncertainty related to this assumption the HIV incidence rate was varied during sensitivity analysis. For each age cohort the probability of becoming infected with HIV over the remaining years of life (cumulative incidence) was calculated as the probability of getting infected in year x_0 added to the probability of getting infected in year $x_0+1 = x_1$ if not already infected in year x_0 and so on.

Discounting health effects

Since health effects occur several years in the future, common practice in cost- effectiveness analysis involves applying an annual discount rate of 3%.¹²⁹ Incidence discounted to 2008 was calculated as: incidence at age $x/(1+3\%)^{\text{age } x}$, and summed over each of the 5-year age periods. Since a 3% discount rate may be low for Rwanda, higher discount rates were used in the sensitivity analysis.

Efficacy of Male Circumcision

In accordance with the randomised control trials for MC and HIV prevention previously cited, an average value of 55% for the protective effect of MC was used and it was assumed that it was constant over the lifetime of the individual.

Calculation of infections averted

Infections averted were calculated as HIV incidence over the 5-year age groups multiplied per the size of the cohort and per the efficacy of MC (55%). People already HIV-positive at age 15 years and at age 30 years received HIV testing and counseling, but were not circumcised (150,000[1-HIV prevalence at age 15 or 30 years]). The future stream of infections averted was discounted back to 2008.

Calculation of years of life saved

On average, the time between HIV infection and the need for treatment is 8 years.¹⁴⁰ For per-person years of survival under treatment the average life expectancy under care as reported by the US-based Walensky study was used. This corresponds to a time in the US before treatment of patients with multidrug resistance was available (and approximating the situation in Rwanda as of 2008).⁶⁴ This number corresponds to a life expectancy of 14.9 years without discounting (in the absence of treatment, it would only be 1.6 years from AIDS diagnosis). In order to account for conditions in Rwanda, which are less favourable than they were in the US (such as lower access to second-line therapies and higher rates of competing mortality from other causes, among others), we decreased life expectancy to 14 years on average for the base case analysis. The uncertainty of this value is accounted for during sensitivity analysis. Thus, life years saved are those that are lost from $8+14 = 22$ years following infection, until that person's life expectancy at the age of infection.

Table 21 summarizes the variables used to calculate the effectiveness of MC in Rwanda and shows incidence (new infections) among men per age group.

Table 21: Effectiveness of neonatal, adolescent, and adult MC in Rwanda, 2008.

Subgroup	Variables	Values							Total
	Age groups (y)	15–19	20–24	25–29	30–34	35–39	40–44	45–49	—
	Incidence rate (cumulative over the age group) (Spectrum)	0.04%	0.08%	0.36%	0.37%	0.27%	0.33%	0.12%	1.56%
	Projection period	2023–27	2028–32	2033–37	2038–42	2043–47	2048–52	2053–57	—
Infants (born in 2008)	Averted infections in the cohort ^a	31	66	294	307	222	271	97	1,288
	Discounted averted infections	19	35	132	119	74	78	24	482
	Projection period	2008–12	2013–17	2018–22	2023–27	2028–32	2033–37	2038–42	—
Adolescents	Averted infections	31	66	293	305	221	270	97	1,283
	Discounted averted infections	29	54	205	185	115	122	38	748
	Projection period	—	—	—	2008–12	2013–17	2018–22	2023–27	—
Adults	Averted infections	—	—	—	294	213	260	93	859
	Discounted averted infections	—	—	—	277	173	182	56	689
	Projection period	—	—	—	2008–12	2013–17	2018–22	2023–27	—

^aThe incidence rates are multiplied by cohorts of 150,000, minus the number of infections that occurred previously.
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Costs

Direct costs were modelled on the basis of interviews with experienced health care providers and MOH officials in Kigali to determine all inputs involved in a procedure (from staff time to

consumables) and related prices. Health care providers were asked to base their estimates on actual cases in which they participated. The validity of the costing model was counterchecked with recently published World Health Organization (WHO) and UNAIDS guidelines/protocols.¹⁴¹

For infants, the cost of circumcision employing the Mogen Clamp method was estimated. The Mogen Clamp method was chosen because it is a simple procedure which requires only one reusable piece, does not require suturing, and causes less pain and complications than other methods, though there is a risk of injury if not applied carefully.¹⁴¹ This method appears suitable for national roll-out, even in remote areas.

Since the national HIV policy in Rwanda discourages vertical programs and strongly promotes integration into existing services, infant MC would be integrated into existing neonatal and vaccination services and there is therefore no expected cost for infrastructure development. Although the procedure would be integrated into the existing services of health facilities, the complexity, time, and space involved in adult MC will require infrastructure investment. Hence, to circumcise 150,000 adults we accounted for 94 additional small surgical rooms (eight procedures/day/room per 200 days/year) with a 10-year useful life. The Central Purchasing of Essential Medicines in Rwanda (CAMERWA) and private pharmacies in Kigali provided wholesale price quotations for consumables.

Unit costs from a recent costing exercise carried out in Rwanda were used for non-medical inputs such as the implementation of a nationwide IECBC campaign.¹⁴¹ Additional budgeting information from current practice in the health system was used for calculating the cost of training staff and counseling patients.

Costs of complications were based on calculations from a recent publication on the cost-effectiveness of adult MC in South Africa¹⁴² using findings from the Orange Farm MC Trial. The overall cost of adverse events standardised to one person is US \$1.03. For children, half this amount (US \$0.50 per MC) was used. Given that the frequency of side effects in children is less than half the adult rate, and the average complication less severe, this is a conservative estimate.

In the case of adolescents and adults the incremental cost of testing and counseling for HIV (US \$0.29)¹⁴³ was summated. This value compares well with average costs in other African countries¹⁰⁸ and does not include the fixed costs of installing new VCT centers. This last assumption is based on the fact that HIV tests are already offered as an integrated service in Rwanda and are widely available in existing health centers.

The higher cost of MC in adolescents and adults is due to several reasons, including the higher cost of imported consumables involved in this more complex surgical procedure (the single most expensive item being local anaesthetic), laboratory tests, amortization costs for the surgical kits, the cost of HIV testing and counseling, the increased staff and staff time necessary, and the need for infrastructure scale-up. As expected, for both children, adolescents and adults, the costs of performing MC are less than the prices currently charged by private practitioners.

These cost estimates do not include the possibility of large economies of scale, for instance those resulting from large orders of supplies and equipment, or cost reduction through the judicious use of task shifting to nurses and other health workers. Since it is not known at what level economies of scale might be attained, we account for the possibility of lower unit costs in the context of a large-scale MC program in the sensitivity analysis.

Savings

Savings correspond to the lifetime costs of HIV treatment for the HIV infections averted (average number of years of survival under treatment multiplied by the annual cost of treatment and care), adjusted for the rate of access to treatment and adherence.

Cost of treatment

Costs of AIDS treatment and care include ARV (first and second line), treatment for major OIs, laboratory tests, and home-based care. Average unit costs from a recent costing exercise carried out in Rwanda¹⁰⁸ were used. Primary sources for this compilation exercise included the MOH, TRAC-Plus Center for Infectious Disease Control (CIDC), CAMERWA, National Reference Laboratory, Agence Européenne pour le Développement et la Santé, WHO, the Clinton Foundation, and health services providers such as the Rwandan Association for the Promotion of Family Welfare (ARBEF).

Cohort to which apply savings

AIDS treatment costs apply to 90% of the sub-cohort of people living with HIV and AIDS (PLHA). This percentage was obtained assuming 95% access to ARV - a realistic assumption for Rwanda given an estimated coverage rate of 80% in 2008 and the ambitious targets for scale-up - and considering the current high level of adherence to treatment and low losses to follow-up.^{139,141} Given the inevitable uncertainty related to assumptions about future care, overall cost (depending on coverage and cost of treatment) was varied during sensitivity analysis. Furthermore, the values of adherence to treatment were also varied.

Discounted savings

To calculate discounted savings, treatment costs were multiplied by the number of discounted infections averted and then discounted for the delay from infection averted to averted treatment costs (8 years plus two-thirds of 14 year average survival on treatment). Since HIV infections averted were already discounted back to the time of circumcision, treatment costs were discounted only back to the time of the infections averted to avoid double discounting. Treatment costs were discounted using the same rate as for effects, and as if they happened at two-thirds of the way between the average age at which treatment starts and death. This assumption takes into account that ARV costs are back-loaded and most OI-related costs and home-based care occurs in the years prior to death.

Methods for Research Question 2

The methodology for answering Question 2 (Are there barriers affecting the physical and mental development of children affected by HIV?) is provided below for Periods 3 and 4.

Period 3. Sub-question 5. Are the nutritional protocols proposed by international regulatory bodies appropriate for Rwandan children?

Period 3. Sub-question 6. Are tools used to assess the nutritional status of malnourished children in Rwanda appropriate?

To answer these questions, I employed the following methods that have been published in a peer-reviewed perspective for which I am first-author, titled: “Under-diagnosis of Malnutrition

in Infants and Young Children in Rwanda: Implications for Attainment of the Millennium Development Goal to End Poverty and Hunger”; permission has been granted from the International Journal for Equity in Health for the reprinted text.

Due to the lack of response to treatment of malnutrition among malnourished children in general and children affected by HIV in particular, for this research a desk review of charts, used, prior to 2009 in Rwanda, for growth measurement to assess the nutritional status of children under the age of five was performed. The growth references used in Rwanda before May 2009 were compared with the international standards developed by WHO in 2006.¹⁴⁴

Between September 2008 and January 2009 a comprehensive the desk review was conducted with analyses of reports and policies, and interviews with professionals in the Rwandan health sector.

Period 4. Sub-question 7. Is the CDI appropriately adapted to assess the mental health of children in Rwanda?

To answer this question, I employed the following methods that are included in a paper that is being prepared for peer-reviewed publication (submission to the British Medical Journal – Pediatrics), titled: “Validation of the CDI in the Rwandan context”.

Study design and sampling: A validation study was implemented comparing the CDI with depression as determined by professional psychologists trained in the use of a structured instrument based on the criteria for major depression in the American Psychiatric Association’s Diagnostic and Statistical Manual (4th Edition) (DSM-IV) and International Classification of Diseases (10th Edition) (ICD-10).^{145,146,147} The structured clinical assessment served as the gold standard. Study participants were Rwandan children living with HIV from seven to fourteen years of age aware of their HIV status and receiving antiretroviral treatment for at least six months. All children were enrolled and attending school in Rwanda. Participants were invited to be part of the study when they attended appointments at the health facilities to receive treatment.

As this study was part of a larger study that explored barriers to ARV adherence at school, children who were HIV-negative were excluded and children not attending school were also excluded because the larger study also examined the impact of schooling on adherence.¹⁴⁷ Finally, children outside the age range of seven to fourteen were excluded because the study consisted of an interview which may have been challenging for children younger than age seven. In addition, this study concerned children under fifteen years old, to correspond with the age range for pediatric services in Rwanda. The child enrollment age was seven years as it is considered the age of reasoning (age at which a child is capable of acting responsibly).²²

Study participants were selected from ten health facilities. Facilities supporting ten or fewer pediatric patients on ARV were excluded from the study. Two health facilities providing ARV to children in each of the country’s five provinces were identified, using the list of all health facilities available in January 2010 at the Rwanda Biomedical Center Institute of HIV/AIDS and Disease Prevention and Control (RBC/IHDPC). Of the two facilities selected in each province, one was randomly selected among those offering support groups for children living with HIV, and the other was randomly selected among those that did not provide these services. This sampling strategy reflected the broader study that was assessing the impact on adherence of support groups.¹⁴⁸ Support groups are composed exclusively of HIV-positive children and were created to help children socially and psychologically by mentorship from specialised

health professionals. The decision to take health facilities with and without support groups was made because the larger study assessed the impact of the support group on adherence. It is estimated that the ten sites were selected adequately and reflect the spectrum of ARV care being provided to children in Rwanda.

From a total of 150 children who were recruited for the parent study on barriers to ARV adherence among children under fifteen years old, a subset of 100 children completed the CDI. At each of the ten sites, five children were identified per age group: seven to nine years of age, 10-12 years, and 13-14 years, resulting in a total of 15 children chosen per site, and creating a total study population of 150 children. These children were identified by random selection from a list stratified by age of all children between seven to fourteen years old on ARV for at least six months at each selected site. Out of the 100 children selected, 87 were successfully recruited to be part of the study. Given the small sample size, 13 additional children were randomly selected among the remaining 50 enrolled in the adherence study to achieve the targeted sample size for the validation study.

Measures and assessment

The Children's Depression Inventory (CDI) was selected as the tool to be validated in Rwanda given its simplicity and brevity of administration. The CDI can be used by health workers at all levels of training and in clinical as well as non-clinical settings to detect children with elevated depressive symptoms comparable with major depression.¹⁵⁰ The CDI is a self-report questionnaire that assesses cognitive, affective, and behavioural signs of depression in children aged seven and above. The Short-Form of the CDI was included in this study, consisting of ten items, each based on three statements from which the respondent chooses the one that best reflects his/her feelings in the past two weeks. Each item is scored 0, 1, or 2, with 2 representing the most severe symptoms. The CDI was administered orally by experienced psychologists and not by self-report to ensure comprehension of the survey.

The tool was initially developed and tested among a sample of over one thousand children in grades two through eight in the U.S.¹⁴⁹ Although the CDI has been used in several studies in Sub-Saharan Africa, it has not yet been validated in these settings, particularly with regard to identifying appropriate cut-off scores.^{151, 152, 153, 154} Given that the presentation of symptoms and interpretation of severity may vary across cultures, it is important to validate measures of psychological symptoms in different contexts, to ensure that the measure is identifying children with elevated symptoms comparable with major depression with a fair degree of accuracy. For example, studies among adolescents from China and Puerto Rico reflected the need for different cut-off scores for a level of symptoms comparable with major depression in different cultural contexts.^{155,156}

A structured clinical assessment was used as the gold standard to evaluate the validity of the CDI and identify appropriate cut-off scores for children in Rwanda. The instrument was a checklist based on the criteria for major depression in the DSM-IV and the ICD-10. Following administration of the CDI, the clinical assessments were performed by experienced psychologists from the National Psychosocial Center who had prior experience in pediatric mental health.

Parents of children diagnosed with depression during the study were offered enrolment for their child in a mental health treatment program in the same health facility where the interview was conducted, or in the nearest health facility offering mental health services. The Ethics Committee of the University of Rwanda, which is recognized by the Rwandan National Ethics

Committee, provided ethical approval.

Statistical analysis

Descriptive statistics were calculated for socio-demographic characteristics of study participants, including frequencies for urban/rural residence, province, sex, age, education, and orphan status. In addition, these frequencies were compared for children who were diagnosed by study psychologists as having depression or not. Sensitivity and specificity estimates were calculated at varying cut-off scores for the CDI, using the structured clinical interview by the psychologists as the gold standard. Receiver Operating Characteristic (ROC) analysis was performed to evaluate the overall validity of the CDI as compared to clinical assessment in the Rwandan context.

Methods for Research Question 3

The methodology for answering Question 3 (Are there barriers to health decisions for children affected by HIV, due to the non-respect of their rights to information and participation?) is provided below.

To answer this broader research question, I employed the following methods that have been published in a peer-reviewed perspective for which I am first-author, titled: “Adolescents and the Right to Health: Eliminating Age-Related Barriers to HIV/AIDS Services in Rwanda”; permission has been granted from AIDS Care for the reprinted text.

The authors conducted an in-depth analysis of Rwanda’s health policies for adolescents to determine the inconsistencies and gaps in policy, which make them vulnerable to HIV outcomes. A detailed literature review of Rwanda’s children-focused HIV/AIDS services and health policy framework was conducted, as well as a search of similar policies in Sub-Saharan Africa, including South Africa, Botswana, Namibia, Lesotho, Malawi, Kenya, Tanzania, and Ethiopia. Using desk review and the literature from other countries, and the author’s personal experiences for insight and perspective, a series of recommendations for Rwanda were developed.

Methods for Research Question 4

The methodology for answering Question 4 (Are there barriers in financial management that inhibit the fulfilment of a child’s right to health when affected by HIV?) is provided below.

Sub-question 8. Does the state and do parents fulfil their obligations to protect, inform, and involve children in the response to HIV?

To answer this research question, I employed the following methods that have not been published elsewhere.

Using the NOVCSA questionnaire, data on OVC spending were re-collected; from NGOs found by CNLS to have discrepancies of over 30% in their 2008 report on spending (fiscal year 2007). The same questionnaire as the one used by CNLS for NOVCSA in 2008 (Fiscal year 2007) was used to ensure good comprehension and comparison of data reported. Six NGOs were selected according this criterion: four international NGOs - Care International, FXB, Hope and Homes for Children and World Vision, World Relief International – and two national NGOs – SOS Village d’Enfants, and Rwanda Network of People living with HIV/AIDS (RRP+).

In the first quarter of 2009, the NGOs were given the same questionnaire they had been given in 2008. They responded on the same 2007 fiscal year spending period to evaluate the consistency of their reporting. The goal of the research was to evaluate the transparency and consistency of reporting. This research does not evaluate the quality of the work reported.

4.8. Chapter Summary

Previous chapters, defined why this research was undertaken, the children involved in this research and their periods of life, health system, the HIV epidemic, and the legal context, as well as the international and national backgrounds of this research. Chapter 4 provided the research questions to be answered and summarised the methodology and the ethical considerations of the research. The results of each component of the thesis are presented in Chapters 5 to 9.

Chapter 5: Results from Period One - primary prevention before parenting

As explained earlier, prevention efforts can be life-saving and need to start well before a child is born, given that 90% of pediatric HIV infections are due to MTCT.^{5,157} During Period One, primary prevention involves averting infections in mothers and fathers in order to protect their future children. Not all future parents are at the same level of risk of being infected by HIV. Those particularly vulnerable to HIV infection are called - after UNAIDS - the “Key population at higher risk to HIV exposure”⁶ Key populations are groups which represent the largest percentage of people newly infected globally, generally during unprotected sexual intercourse with an HIV- positive partner.¹⁵⁸

Primary prevention among key populations is very important for preventing pediatric HIV infection, as they are at high risk of exposure to HIV and may have children. This section includes details of two key populations present in Rwanda - sex workers and prisoners.

5.1. Sex workers

HIV prevalence among sex workers in Rwanda is 51% compared to 5% for females of reproductive age from the general population.^{123, 159} This ten-fold increase in HIV prevalence is likely to lead to a higher risk of infection for a child born to a sex worker than a child born to a non-sex worker.

The future children of sex workers (men or women) who accept sexual intercourse without protection for money are at higher risk of being HIV-affected than the general population because primary prevention was not followed in Period One.¹⁶⁰ As a result of the high risk for sex workers being HIV-positive, it is important to know if stigmatization and socio-economic factors prevent their access to HIV prevention and treatment services.

**The following chapter is reprinted from an article of which I am first author: “Developing human rights-based strategies to improve health among female sex workers in Rwanda”. Permission has been granted from the Health and Human Rights Journal for the reprinted text.*

I conceived the original idea and study design, provided direction on the research question and context of the health sector in Rwanda, did the literature review, developed the methodology led the interviews, contributed to data analysis, did the interpretation of results and wrote the manuscript.

Introduction

Globally, sex workers are highly affected by HIV and other STI.¹⁶¹ In 2009, UNAIDS reported that HIV prevalence among sex workers in some countries in the world has approached 90%, but evidence suggests that in an enabling environment with the correct and appropriate HIV prevention interventions, the epidemic can decline drastically.^{162, 163}

In many settings, key drivers of prostitution include gender and economic factors in which poverty social, financial, or family crises play a major role.^{164,165,166} In some instances, women who enter sex work may also have endured childhood trauma, including physical or psychological abuse.^{167,168}

Sex workers are not only often poor but also under the legal age to work in formal employment.¹⁶⁹ Unable to work legally, they are therefore forced to seek informal and illegal work. This population often has poor levels of education and skills and frequently lacks family support. Sex workers are even more vulnerable because they often do not have the power to negotiate safer sex, can face violence from clients if they refuse sex without condoms, and can receive more money by having unprotected sex.¹⁷⁰ Discrimination against sex workers decreases their access to health and increases their vulnerability and that of their children to HIV.^{161,171,172,173}

Sex work is not limited to one gender; there are men and boy prostitutes whose clients are women or men who have sex with men. However, the majority of sex workers are female.¹⁷⁴ This pattern is linked to gender discrimination, which reduces many girls' access to education and training and thus their later opportunities in the formal economy.

Nonetheless, targeting interventions toward prevention of HIV transmission among sex workers (and empowering them to make different choices) is absolutely essential. Successful IECBC campaigns and specific programs targeting sex workers and their clients who promoted condom use, along with regular testing for STI, were carried out in Kenya, Botswana, Cote d'Ivoire, and other countries.^{162,171,175} These IECBC campaigns have reduced HIV prevalence among sex workers, and in some countries they have even decreased the national prevalence. Kenya saw a reduction in HIV incidence among sex workers, from 25-50% to 4%.¹⁶² The government IECBC campaign in Thailand led to a general reduction in the national HIV prevalence.¹⁷² In India, the 'three R's' of the Sonagachi program: 'respect' for sex work; 'reliance' on sex workers; and 'recognition' of sex workers' rights, improved condom use amongst sex workers from 27% to 86% and decreased HIV prevalence among them.^{173,176}

In Rwanda, 80% of sex workers give "survival" as their reason for engaging in sex work.¹⁷⁷ The majority of sex workers began engaging in sex work by having occasional exchanges of sex for money to provide them with temporary income.¹⁷⁷ In time, women are often unable to escape this lifestyle and sex work becomes their permanent source of income.¹⁷⁷ Sex workers often begin sex work during adolescence.¹⁶⁸ At this age, they may face a lack of social support and financial destitution that pushes them into this risky work environment.¹⁶⁸ Programmatic data from the Rwanda Biomedical Center found a remarkably high HIV rate of 51% among sex workers.¹⁵⁹ We know that being uneducated and poor are two barriers to access to care, what remains unknown for sex workers in Rwanda is whether the stigma they face in society, due to their sex work, has an impact on their access to PMTCT services when pregnant, and access to health care for their children even if there are examples of programs that have managed to enable former sex workers to gain employability skills and give up sex work.¹⁷⁸

Methodology

Please refer to Chapter 4 for the methodology.

Findings

In Rwanda, the majority of sex workers interviewed for the TRAC-Plus sponsored study entered sex work during adolescence, mainly between the ages of 17 and 22. For all the female sex workers who shared their stories, the lack of social or familial support increased the financial pressures that precipitated their entry into sex work.¹⁷⁹ In this research, one informant described her experience:

I started prostitution when I was seventeen years old. I had a husband, but we didn't stay together. We divorced on grounds of prostitution and infidelity. I went back to my family, but they rejected me. My family kept telling me to give my child back to his father. In this situation, I started renting my own house, where I received men. They paid me RWF 200 or RWF 300. [This income] enabled me to raise my child. . –CM70, female, rural Rwanda

The socio-demographic profile of young prostitutes in Butare, Rwanda's second largest city, may be representative of the wider sex worker population in the country.^{98,180} According to a study sponsored by the National AIDS Control Commission/Commission Nationale de Lutte Contre le SIDA (CNLS) and conducted by PSI Rwanda, sex workers in Butare generally went into sex work for economic survival in the face of events such as unexpected pregnancy, often exacerbated by a withdrawal of support by family and community.⁹⁸ In Rwanda, as in other societies, premarital sex and pregnancy bring shame to a whole family.¹⁸¹ When caught in such situations, some girls may be excluded from their families and previous social networks. In this research, one informant recalled:

I fell in love with a young man and during our relationship, he got me pregnant. He refused to marry me. After learning that my family was beating and mistreating me, demanding to know who impregnated me, he ran away. I gave birth to a baby girl. Afterwards, I had many problems that forced me into prostitution, due to the fact that the person who was supposed to assist me had run away, and my family had abandoned me. –AR73, female, rural Rwanda

The social vulnerability that can force women into sex work is compounded by patterns of gender bias in access to formal education. Before the national program of nine years basic education these patterns leave many young women with poor levels of education and skills, making it harder for them to find legal employment.¹⁶⁹ Girls' exclusion from education is often traceable to family poverty, which made it difficult in the past for families to pay school fees or buy uniforms and other materials. Currently the twelve year basic education means that education is now free but there are still costs in sending children to school.

In this research, a former sex worker who grew up in a rural area explained:

Before going into prostitution, I went to [primary] school and passed exams for high studies. After Senior One, I couldn't pay the school fees. Since my family was poor, I was forced to stay at home. When I saw how other girls were living, and considering the fact that I was suffering a lot, I started having sex with anyone who gave me some money to buy beauty lotions. I got used to this

lifestyle, and when my family and people around started criticising and isolating me, I decided to move away to town. –JM78, female, rural Rwanda

Such narratives confirm how participation in sex work, which may initially be catalysed in part by poverty and inadequate social support, further reinforces social marginalisation and uprooting for many of the women involved.

This cyclical deepening of social exclusion has intergenerational effects. The intergenerational transmission of risks is shown, for example, through the problems that children of sex workers face in succeeding at school, due to issues of discrimination on the part of teachers and classmates.¹⁶⁹ Rigorous studies on the educational success of the children of sex workers have not yet been undertaken in Rwanda. However, sex workers interviewed for TRAC-Plus repeatedly drew attention to this issue. In this research one said,

Sometimes, my child comes back from school being very sad because of how he has been treated by the other pupils. I don't have enough to give him all he needs, so that he could be like the other children, who have fathers who can provide for them. All this affects our children . . . –CM70, female, rural Rwanda

Compromised educational success is especially dangerous for the female children of sex workers, as it may continue the cycle of poor, uneducated women who join the underground work of prostitution to survive.

Many sex workers and former sex workers interviewed for the TRAC-Plus study described suffering discrimination on the part of public authorities, including the police and judicial system. Such discrimination emerged, for example, when sex workers tried to obtain police and legal support to confront client violence. In this research one interviewee noted:

What I can add is that authorities reject us just because we're prostitutes. Even when you're right in your complaint, they don't consider it; they're more likely to stick you in prison. –AR73, female, rural Rwanda

Health impacts of sex work in Rwanda

It is widely recognized that sex workers face social stigmatization. However, the health consequences of this pattern are too rarely acknowledged in public debates in Rwanda or elsewhere. Neither the health impacts of sex work on individual women nor the wider public health implications receive adequate attention. It is argued that these health dimensions must be made central to any responsible discussion of how to address sex work through public policy.

Extreme poverty itself is associated with numerous negative health impacts, as a large body of literature has made clear.¹⁸³ In addition, sex workers face specific forms of social exclusion and specific work-related exposures that greatly heighten their health risks, beyond those common to most members of low-income communities. Sex workers face underlying structural vulnerabilities due to their social and economic position, coupled with additional risks at the level of what some analysts have called “intermediate” health determinants, that is, more proximal factors that grow out of structural socioeconomic roots. One such intermediate health determinant is the health care system itself, and the differential access and quality of care it provides to people, based on their social, economic, and gender status.^{183,184}

Sex workers are frequently the direct victims of inequitable treatment within the health system. After repeated experiences of discrimination, they may become reticent to seek assistance from the formal health system at all, no matter how desperate their need.¹⁸⁵ Many TRAC-Plus interviewees cited personal experiences in this regard. Health workers, if they know a sex worker's profession, often refuse to treat them in an appropriate manner. In this research one informant noted:

I live in the center of town, where most health workers live, and I run into them all the time. [At the clinic,] if they know you haven't given up prostitution, they can refuse to serve you, because they suspect you've been with their husbands. They keep grabbing other people's files and passing you over, because you're a prostitute. –AR73, female, rural Rwanda

Such systematic discrimination has a destructive public health impact, denying women access to information and family planning services, as well as prevention, care, and treatment for HIV and other STI.

For many female sex workers, social exclusion and health risk converge in HIV infection. In some settings, HIV prevalence among sex workers can reach 60-90%.¹⁶³ The health consequences for individual women are devastating, while at the population level; these trends constitute a critical public health concern.¹⁸⁶

In Rwanda, another study revealed that some 95% of Rwandan sex workers surveyed fully understood their risk of HIV infection.¹⁸⁷ Despite knowing the dangers, the sex workers questioned did not feel they could leave sex work. While HIV might kill them slowly, they explained, without an income they and their children would immediately face starvation and homelessness.¹⁸⁷ One informant summarised the situation starkly:

When you [are] in prostitution, the only thing that matters is money. You act like a businessman . . . So when you get one client with a condom and another client without, you welcome them all. You don't care about HIV/AIDS . . . When you're poor and can't buy food or pay your rent, you never care about HIV/AIDS. The only thing you care about is getting money. –JM78, female, rural Rwanda

If sex workers do become infected with HIV, compounded discrimination based on their profession and HIV status can make it hard for them to adhere to treatment. This is especially so when HIV-positive sex workers are jailed. As one interviewee stated:

When you're arrested, they just throw you in prison. Sometimes you're not able to talk to a policeman and tell him that you'll miss your doses. The worst thing is when you are arrested at the beginning of the weekend. Then you spend the whole weekend without seeing any policeman till Monday. –AR73, female, rural Rwanda

Informants emphasised that, even when they had a chance to talk to policemen about their medication needs while in detention, their requests were often ignored, putting the continued efficacy of their treatment at risk.

The same social and economic pressures that often push women into sex work later make it hard for them to exit this form of employment, even if they want to do so. In many countries,

the traditional response to prostitution is almost wholly punitive, involving arrest and incarceration.¹⁸⁷ This strategy is based on the assumption that if women are punished harshly enough for participation in sex work, they will be persuaded to leave it and adopt alternative ways of providing for themselves and their children. Interviews with sex workers and former sex workers in Rwanda point to the fundamental flaws in this strategy, which ignore the economic and social constraints that determine many poor women's "choices" about sex work.

In general, temporary detention only interrupts sex work activities for a short time, without providing sex workers with sustainable solutions to leave prostitution. Once out of prison, women may have to pay back the debts accrued while incarcerated, such as those involving the needs of their children. Ironically, then, instead of facilitating women's departure from sex work, repressive incarceration policies may actually lock women more rigidly into the cycle of selling sex for economic survival. One interviewee recalled,

One day, they put me in jail, and my child ended up sleeping outside. He wasn't able to open the door of our house by himself ... so he slept on the doorstep. That's where they found him the next morning. In jail, I spent the whole night crying. I swore I would quit prostitution. I said, "I'll look for a job in construction or agriculture." . . . So when I was released from jail, I was determined to quit. But when I got home, my children and I didn't have anything to eat. That same evening I got a call from a client. We were hungry, so I had no choice. I accepted and ended up resuming prostitution. –CM70, female, rural Rwanda

Concern for their children's welfare may prompt women to seek escape routes from sex work. But in the absence of viable economic alternatives, the very same pressure pushes many women right back into selling sex. The experiences narrated by Rwandan sex workers confirm reports from women in other settings that the stigma surrounding social identification as a prostitute makes it harder for sex workers to obtain more socially acceptable jobs.^{169,187}

Discussion

The study was part of an effort to design rights-based interventions to HIV response for sex workers, while sensitizing leaders and parliamentarians at a time when Rwanda was debating legislation that would reinforce criminal sanctions against sex workers.¹⁸⁸

The sex workers interviewed in this study are young women and girls who started sex work because of a lack of social support from their family and community, or economic constraints. This was found also in other studies in Rwanda and other countries, as sex workers often begin sex work during adolescence and often have poor levels of education and skills, and lack family support.^{168,180} Treatment and Research AIDS Center Plus (TRAC Plus) found an HIV rate of 51% among sex workers.¹⁵⁹ HIV prevalence is found in many countries to be 60-90%, creating a high risk that sex workers will transmit HIV to their own children and to clients, who may then infect their other partners and future children.¹⁶²

Yet MTCT is not the only risk children born to sex workers face *vis-a-vis* HIV infection. Children of sex workers are often doubly vulnerable in that they may have to drop out of school due to stigma, and female drop-outs may also enter sex work. This may result in a continuation of the cycle of poor, uneducated women who become sex workers to survive.

The research presented also illustrated the stigmatization of sex workers. In most countries, including Rwanda, sex work is illegal and has a serious impact on the health of those involved.¹⁸⁹ One study found that the illegality of sex work forced them to work secretly and seek help less frequently from social services since they were worried about being arrested by the police. Many sex workers operated in the most secretive and violent parts of cities or towns, and constantly had to worry about survival with little means to protect their health, thereby increasing their risk of HIV infection.¹⁹⁰ Solutions are needed because sex workers who are forced to work secretly are not protected and can face serious violence.¹⁷⁰

Furthermore, although sex workers know their risk of HIV infection (one study in Rwanda showed 95% knew their risk), many did not want to leave their work, declaring that HIV does not kill them rapidly, while the impact of the socioeconomic problems that they and their children face are immediate.^{170,177,187} The infrequent use of condoms among Rwandan sex workers exacerbates their risk of HIV infection and transmission, but many clients refuse condoms and sex workers lack the power to negotiate safer sex. Thus, many sex workers have unprotected sex, since the client may become violent if they refuse, or because they can receive more money.^{170,180} The majority of young women surveyed in the study noted a lack of social support. In Rwanda, having premarital children can bring shame to the whole family. In such situations, a girl may be excluded from her family and left without any community support. There is also serious gender discrimination in these situations, whereby girls and women suffer the social consequences more than their male partners. When a woman is over eighteen years old, society requests nothing of the boy or man with whom she had the premarital child. If the girl was under eighteen years of age when the incident occurred, the family can go to justice for rape if the father was an adult.

In the context of key populations at high risk of becoming HIV-positive, all states that have ratified UDHR and General Comment No. 14 (2000), have violated their obligation to respect, protect, and fulfil rights to non-discrimination and to health, because sex workers are precluded from exercising their right to health, and are thus putting their lives and the lives of their children danger.^{161,171,172,175,176,186}

So far there is no movement in Rwanda to promote the regulation and legalisation of sex work, as there has been in some countries, such as Mexico.¹⁹¹ Since many sex workers start sex work for economic reasons, the issues surrounding sex work can only be solved by giving sex workers opportunities for an economically viable life, with access to health care as a fundamental human right as ratified in the Universal Declaration of Human Rights.⁵⁹

For many female sex workers, social exclusion and health risk converge in the risk of HIV infection. In some settings, HIV prevalence among sex workers can reach 60-90%.¹⁶³ The health consequences for individual women and their future children are devastating, while at the population level these trends constitute a critical public health concern.¹⁶³

5.2. Prisoners and HIV prevention

**Part of the following chapter is reprinted from a perspective I authored, published in a peer review journal: "HIV Prevention in Rwandan Prisons". Permission has been granted from the Health and Human Rights Journal for the reprinted text published. The entire chapter is what was submitted to the Journal.*

Introduction

The prison population is another key population at higher risk of HIV exposure, because they may have increased vulnerability to HIV infection that can endanger their future children.

In every society, vulnerable persons can be disproportionately marginalized, unable to reap the benefits of services that are theoretically provided to the general public. Just as marginalization begets vulnerability, so vulnerability begets poor health. In most instances, there is a responsibility to develop a package of policies and social services specifically targeting vulnerable populations. In Rwanda, post-1994 genocide policymaking called for a complete overhaul to create, widen, and strengthen safety nets for the poorest and most vulnerable.

Further, given that the genocide was precipitated by internationally imported and inserted division and social marginalization, it was more important than ever for the post-1994 government to place a political premium on policies and plans that ensured equity in access to education, health care, business development, and so forth. The present research concerns the context in which a specific population vulnerable to HIV - prisoners - is able to fulfil their full right to health.

The right to health was written into the 2003 Constitution in Rwanda.⁹⁰ In this framework, the Ministry of Health understands the right to health to mean that all opportunities for health and well-being are shared among the entire population, and that there is no geographic, gender, age, or other disparities in accessing health care. In Rwanda, efforts to buoy the health and well-being of all people, including those across categorizations associated with vulnerability, have borne fruit. A community-based health insurance scheme, called *Mutuelles de Santé*, covers 92% of the entire population; the poorest 25% of Rwandans pay no health care co-payments or premiums.²⁹ Recent analyses show that Rwanda is on track to achieve the health-related United Nations Millennium Development Goals.²⁹

With respect to HIV/AIDS, Rwanda, like many countries in Africa and elsewhere, capitalized on the upsurge in global funding for health that began in 2002. Funding institutions such as the President's Emergency Plan for AIDS Relief (PEPFAR), and The Global Fund to Fight HIV/AIDS, Tuberculosis, and Malaria (Global Fund) made it possible—for the first time in the history of the fight against HIV/AIDS in Africa—for Rwanda to systematically establish a system of care that would target those most vulnerable to HIV infection; provide the full package of preventive, diagnostic, and treatment services countrywide; and strengthen the entire health system as a result.¹⁹² As a result of these financial inputs, Rwanda has achieved universal access to ARV, with 78.4% reduction in mortality associated with HIV/AIDS, and a low 2% HIV transmission rate from mother to child.^{52, 193} The disease is now considered and approached as a chronic illness, as it is in many Western countries, rather than an unnecessary death sentence.

The UN Human Rights Committee declared that prisoners should receive the same opportunities for medical care as they would were they not in prison, and yet prisoners in Sub-Saharan Africa generally do not have adequate access to HIV prevention, care, and treatment.^{194,195,196,197} There is a real dearth of literature on HIV transmission in African prisons.¹⁹⁸ We can expect that men and women both face serious health risks in prisons, as described in the Zambian prison system.¹⁹⁷ Furthermore, HIV infection prevalence in some African prisons is reported to be up to 50 times higher than reported among non-incarcerated populations.¹⁹⁸

The current state of HIV in Rwandan prisons is unknown, therefore future research for an

understanding of how prisoners are protected is important. Sexual activities are known to occur within Rwandan prisons, as they occur globally, but sexual activities also occur outside Rwandan prisons when prisoners convicted during genocide trials are doing community work which may reduce their sentences.¹⁹⁹

As a result of this situation Rwanda should be exploring whether HIV prevention programs are working among prisoners to protect them and their family members (spouse and future children) in the period when they will be released of the prison.

Methodology

Please refer to Chapter 4 for the methodology.

Findings

Sensitization campaigns and knowledge-building activities are offered in each prison around Rwanda to promote awareness around HIV transmission, opportunities for care and treatment, and general precautions regarding sexually transmitted infections.²⁰⁰

As mentioned above, certain categories of incarcerated persons may regularly go outside of the prison grounds to engage in paid community work as part of their sentence. Some prisoners who do community work reported that on these occasions they have sex with their wives, community members, fiancées, girlfriends or sex workers – all without condoms, as these are not available – and some prisoners even father children and have expressed that this boosts morale and improves their perspective on life outside of prison.²⁰¹

Some prison inmates admitted having sex with other men, although this is strictly taboo and men who have sex with men may be heavily stigmatized and discriminated against if discovered.⁷⁰ They have sex for pleasure with the ‘active’ and ‘passive’ roles alternating in a form of ‘paying back’ the other partner. Homosexual relationships with both a physical and emotional dimension also exist.²⁰¹

Discussion

TRAC-Plus (note: RBC since 2011) and its partners provide VCT, prevention services and ARV services in prisons even though prisoners in Rwanda still do not have access to condoms. However, knowledge and information cannot fully protect prisoners against sexually transmitted infections including HIV. Thus, we should consider what kinds of tools are available to the general public that could be provided to prisoners to stop the spread of HIV.

Despite the wide recognition that prisoners leave the prison grounds to engage in work, there is minimal acknowledgment of the types of sexual activities that may be taking place en route to the workplace, at the workplace, or en route back to the prison. It is documented that sexual activity with community members, prostitutes, spouses, fiancées, or friends does occur during these transition and work times. Given that HIV infection among prostitutes in Rwanda is 51%, according to a Serological Behavioural Study conducted by TRAC-Plus in 2010, prisoners may often be highly exposed to HIV infection, as they cannot access condoms.²⁰²

The absence of condom availability is based on the fact the Law No. 34 2010, published in the Official Gazette No. 04 of 24/01/11, disallows privacy in prisons even during visitation (except for a visit with a lawyer, all visits must be in the presence of a guard or other competent prison

staff) and in our culture there is no sexual intercourse in public. Prisoners, therefore, have little chance to have safer sex because condoms are not available.

Inside the prisons, even though men having sex with other men is highly stigmatized, prisoners report having sexual relationships without protection. Sex in prisons is a global reality - not just in Rwanda.

Finally, male prostitution has been evidenced to occur in Rwanda, as it occurs elsewhere around the world. If male prostitutes were in prison, this type of sexual activity would likely not cease just because of imprisonment.

Reform should be considered to allow the distribution of condoms in prison, and in the area surrounding where prisoners do community work, as in the general public to stop the spread of HIV. This will protect prisoners as well as their sexual partners and future children from HIV infection and other sexually transmitted infections.

Chapter 5 presented results involving Period One, when protecting the right to health of children-to-be who could potentially be affected by HIV means keeping future mothers and fathers free from HIV since the majority of pediatric infections are acquired from MCT. It was illustrated with two groups from those among the most at risk of being exposed to HIV, and who are potential parents. The results for Period One demonstrates that far more could be done to protect children-to-be. The next chapter will discuss protection *vis-a-vis* MTCT as well as procedures that can be undertaken at that period of life - starting from conception to the end of any possible infection of a child through MTCT i.e. birth if bottle-fed' or to the end of breastfeeding.

Chapter 6: Results from Period Two - from conception to post-breastfeeding or from birth if not breastfed.

During this period, to be protected against HIV infection, in countries where this pandemic is a public health issue, children should benefit from a set of life-saving health interventions, because allowing children to start life HIV-free, or with an early treatment if HIV-positive, fulfils their rights to health and a healthy life.⁷³ Neonates and children exposed to MTCT should be directly protected by ARV and safe exclusive breastfeeding or bottle-feeding, and their mother provided with ARV, and conditions for safe delivery. Children born to HIV-positive mothers should also benefit from early testing and appropriate follow up, when possible, so as to be diagnosed and put on treatment in a timely manner if found to be HIV-positive. For neonates it is also critical to consider other methods of prevention such as MC. MC is an important service to offer, because when performed on neonates it can contribute to a long-term solution to HIV prevention for male adolescents, adults and even future parents.

Due to decreased funding for the fight against HIV, it is important to be sure that we do as much as possible with the funds available. All intervention should follow the most accurate protocols, based on evidence generated by science and cost-effectiveness analysis, to fulfil the right of the greatest number of children in need. This is why this research undertook to study the cost-effectiveness of the two major prevention programs for this age, PMTCT and MC, because it is important to know if what we were doing, and whether for example, following the international guidelines, is the best in terms of value for money.

6.1. PMTCT cost effectiveness

**The following chapter is reprinted from an article on which I am first author: “Prevention of mother to child transmission of HIV: cost-effectiveness of antiretroviral regimens and feeding options in Rwanda”; permission has been granted from PLoS ONE for the reprinted text.*

I conceived the original idea and the research questions, participated in conception and study design, provided direction on the research question and context of the health sector in Rwanda, contribute to the literature review, organized the data collection, contributed to data analysis, interpretation of results and drafting manuscript discussion and conclusion and contributed to writing the other sections.

Introduction

A wide body of rigorous scientific research has demonstrated the increased benefits of triple ARV compared with previous regimens, including clinical trials from Botswana and Malawi.^{120,121} These studies supported the WHO's 2010 guidelines. The PMTCT guidelines issued by WHO in 2010 offered great improvements, but no formal cost-effectiveness analysis was performed and the cost of providing the appropriate treatment for HIV-positive children for life and good follow-up was not considered.¹³ Previous literature on cost-effectiveness of PMTCT interventions did not take triple ARV into consideration, and for the most part did not take into account the lifetime costs for treating a child as a result of failing to avert pediatric HIV infections.^{203,204,205,206,207,208} There is a need for context-specific research that explores the cost-effectiveness of the different PMTCT regimens. This would provide Rwanda with more evidence for advocacy purposes by demonstrating value achieved for money spent.

Methodology

Please refer to Chapter 4 for the methodology.

Findings

Average cost

Table 22 outlines the average cost per HIV-infected mother and HIV exposed infant (mother-infant pair) under each PMTCT regimen. Dual ARV prophylaxis with breastfeeding (WHO-Option A) was the least expensive option at US \$738 per mother-infant pair, followed by Sc-HAART with 6 months breastfeeding (US \$801). The higher average cost per HIV-infected mother-infant pair is with Sc-HAART and 18 months breastfeeding (US \$1,024). Details of cost components are available from the author upon request.

Table 22: Average cost per HIV-infected pregnant women-infant pair, US \$.

Costing data	Dual ARV Breastfeed ing	Dual ARV replaceme nt feeding	Sc- HAART 6 mo. Breastfeed ing	Sc- HAART 12 mo. breastfeed ing	Sc- HAART 18 mo. breastfeed ing	Sc- HAART Replacem ent Feeding
Prophylaxis						
ARV costs	420.96	409.84	485.09	530.28	575.46	439.90
CTX	15.75	5.80	18.66	23.20	28.16	5.80
Lab costs	165.57	138.63	160.88	247.38	281.81	138.03
Other (workers cost)	4.27	3.86	4.97	5.89	6.78	4.29
Training	28.14	28.14	28.14	28.14	28.14	28.14
PMTCT promotion	18.45	18.45	18.45	18.45	18.45	18.45
Capital and running costs	84.85	84.85	84.85	84.85	84.85	84.85
Replacement Feeding						
Counseling in maternity ward post- delivery		0.16				0.16
Home visits		4.74				4.74
Education at health center		8.64				8.64
Indirect costs staff		3.31				3.31
Material		29.12				29.12
Milk		242.53				242.53
Additional capacity (training)		3.35				3.35
Total	\$737.98	\$981.41	\$801.03	\$938.19	\$1,023.65	\$1,011.31

Effectiveness

The findings from the analysis in Rwanda show that the fewest new HIV infections in children occur when HIV-positive pregnant women receive Sc-HAART coupled with replacement feeding for infants (124 versus 3,987 in the no intervention scenario). The highest number of new HIV infections in children occurs when mothers receive Dual ARV and breastfeed for 12 months (865 new infections).

Across all Sc-HAART options throughout the breastfeeding period, the shortest breastfeeding period (six months) averted the most HIV infections (286 new infections versus 488 in the case of 18 months breastfeeding). Dual therapy with replacement feeding is associated with 76 fewer vertical HIV infections than Sc-HAART during 18 months of breastfeeding (412 versus 488), but remains inferior to Sc-HAART during 12 months breastfeeding (387 new infections). Infections through long-term breastfeeding overcome the effects of a more effective regime of ARV prophylaxis.

Analysis of HIV-free survival, within the assumptions of the base case, changes the ranking across options. The highest numbers of HIV-uninfected children still alive at 18 months are found for Sc-HAART with 12 months breastfeeding (9,387 children) followed by Sc-HAART with 18 months breastfeeding (9,292). The other Sc-HAART scenarios (Sc-HAART with six months breastfeeding and with replacement feeding) still rank higher than Option A.

Net costs (Cost-Savings)

The annual cost of treatment and care per child, according to age range, is provided in Table 23. When looking at net costs (savings on future treatment and care from HIV infections averted after subtracting the cost of providing PMTCT services), all options appear as cost-savings at different degrees. The highest net costs are reached with Sc-HAART with six months breastfeeding (US -\$ 13,912,837) followed by Sc-HAART and replacement feeding (US -\$12,721,758). The least net costs are reached with Sc-HAART and 18 months breastfeeding (US -\$10,410,727). Since all scenarios are cost-saving, the cost effectiveness ratios of net cost over infections averted are not reported.

Table 23: Cost of treatment and care components per child per year, US \$.

Cost per year	Children 0-1 year old	Children 1-10 years old	Children 11-15 years old
ARV	374.66	374.66	374.66
Laboratory	87.17	87.17	87.17
Other care	84.16	63.23	56.41
CTX	12.33	2.45	3.27
Total	558.32	527.52	521.52

Figure 14 shows the number of HIV infections occurring in children together with the net total cost for each of the PMTCT scenarios.

Figure 14: Number of new HIV infections occurring in children and net total cost, US \$.

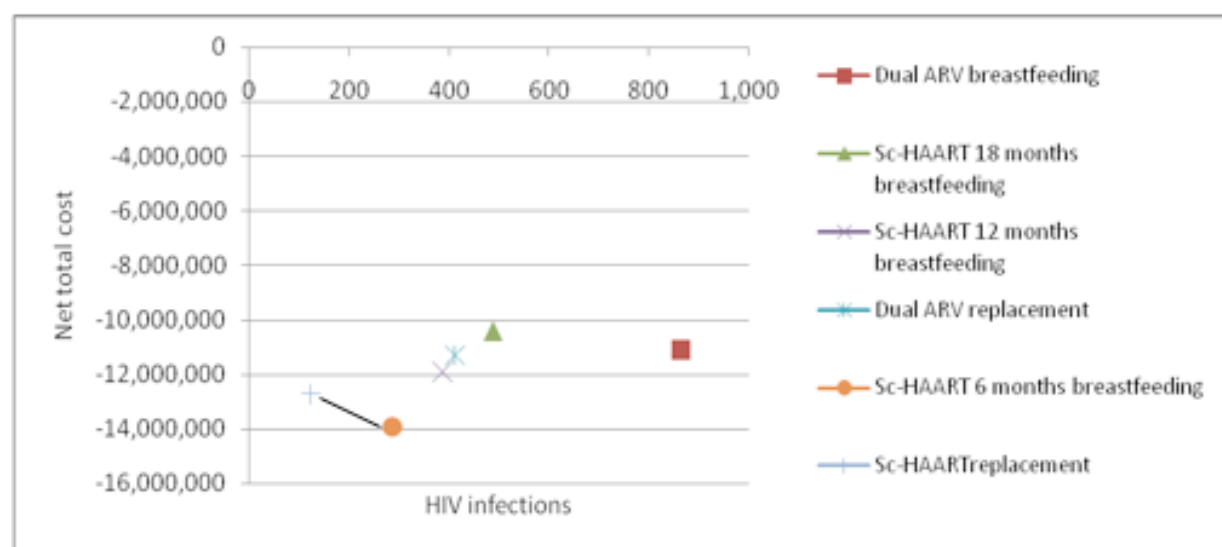
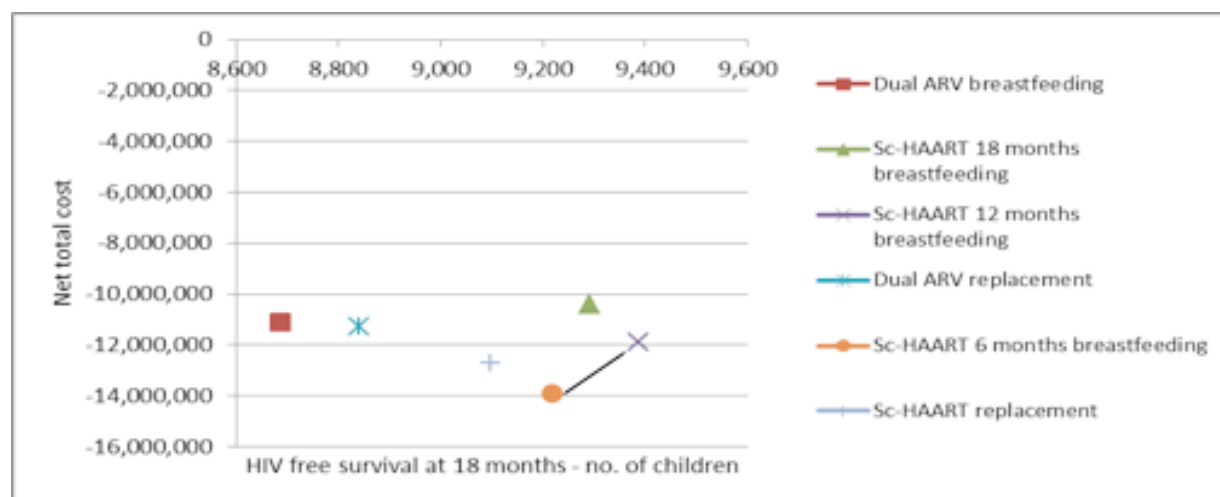


Figure 15 shows the number of children uninfected with HIV and alive at 18 months together with the net total cost for each of the PMTCT scenarios.

Figure 15: HIV-free survival (at least 18 months) and net total cost, US \$.



Note: Sensitivity analysis-low range, Relative Risk (RR)=1.

Incremental cost-effectiveness analysis

When ranking scenarios based on the number of HIV infections, the analysis showed two alternatives, averting more HIV infections and saving more money than all the other scenarios – see (Figure 14): Sc-HAART with 6 months breastfeeding and Sc-HAART with replacement feeding. Sc-HAART with replacement feeding averted 163 additional HIV infections than Sc-HAART with 6 months breastfeeding for an incremental cost of US \$1,191,079 and Incremental Cost Effectiveness Ratio (ICER) of US \$7,319.

When ordering scenarios based on the number of children alive and uninfected, ICER analysis shows that there are only two alternatives that are not dominated (Figure 15): Sc-HAART with 6 months breastfeeding and Sc-HAART with 12 months breastfeeding. Sc-HAART with 12 months breastfeeding allows 170 additional children alive and HIV-uninfected at 18 months for an incremental cost of the program of US \$2,017,310. ICER equals to US \$11,882.

Sensitivity Analysis

Given the uncertainty embedded in the input values of the base case scenario, we conducted a one-way sensitivity analysis for key variables of the model.

Breastfeeding practices

To investigate the sensitivity of findings to breastfeeding practices, ranges were used for both breastfeeding duration and for the percentage of exclusive breastfeeding. As per recommendations, the base case uses 6 months as the actual duration of breastfeeding (for options other than Sc-HAART for 12 and 18 months). However, anecdotal reports from health providers in Rwanda suggest that the duration of breastfeeding for HIV-infected women may be higher than the recommended 6 months due to lack of financial means. We therefore took 18 months as the low range (or worst case scenario) in terms of actual breastfeeding duration in cases when health providers recommend 6 months to the mothers. For the percentage of women practicing exclusive breastfeeding during the first 6 months, the base case uses 38% as per the rate in the general population.¹⁸² In reality this percentage could be lower (this analysis used a token 50% decrease from the base case, or 19%, in the absence of data) or higher. The proportion of mothers who practice exclusive breastfeeding may be higher since HIV-infected women are more aware of the HIV transmission risk. A recent study from Uganda shows that

up to 92% of women on ARV exclusively breastfed their infants for a median duration of 4.0 months and stopped breastfeeding at a median age of 5.0 months.²⁰⁹

Even in the most favourable of the breastfeeding scenarios (with 92% of mothers exclusively breastfeeding for the recommended 6 months), the highest number of HIV infections is averted by Sc-HAART with replacement feeding. The second best option in terms of number of infections averted remains Sc-HAART with 6 months breastfeeding. As expected, the extra infection averted through Sc-HAART with replacement feeding, compared to Sc-HAART with 6 months' breastfeeding, would cost more (an extra US \$14,229 versus US \$7,319 in the base case). In the worst case scenario for breastfeeding practices, when the percentage of mixed feeding and the actual breastfeeding duration increased to 18 months (independently of the duration of HAART), the number of HIV infections averted with the breastfeeding options (other than Sc-HAART for 18 months) decreases substantially. Therefore, Sc-HAART with replacement feeding becomes even more favourable and this scenario dominates all the others (the highest number of HIV infections averted for saving additional money).

When looking at HIV-free survival as an outcome of interest, we find that across the range of values for breastfeeding practices, Sc-HAART with 12 months breastfeeding still allows more HIV uninfected children alive at 18 months than Sc-HAART with 6 months breastfeeding and all other scenarios are dominated. The extra cost per child alive and uninfected is US \$11,780 in the worst case scenario for breastfeeding practices, and US \$10,774 in the most favourable breastfeeding scenario.

We conclude that our ranking across PMTCT scenarios is robust, or not sensitive, to breastfeeding practices.

Costs of anti-retrovirals, replacement feeding, and laboratory tests

Acknowledging that the cost of inputs may vary over time, the analysis explored potential 50% cost increases or decreases in the inputs that account for the highest proportion of cost, namely: ARV cost, laboratory costs and the cost of replacement feeding. As expected, if prices of ARV and laboratory tests increase, the replacement feeding options become more favourable. If prices of ARV and laboratory tests decrease, Sc-HAART scenarios become more cost-effective since they become cheaper. The opposite occurs when the cost of replacement feeding increases. When ARV costs increase, savings also increase.

When looking at HIV infections averted, it is found that even with varying input costs, Sc-HAART with replacement feeding and Sc-HAART with 6 months breastfeeding remain highest in the ranking across PMTCT options. When all costs increase by 50%, Sc-HAART with 6 months breastfeeding still dominates all scenarios, with the exception of Sc-HAART and replacement feeding, which allows more HIV infections to be averted for an extra cost of US \$11,643 per extra HIV infection averted. When all costs decrease by 50%, the same is true, and the extra cost per extra HIV infection averted becomes as low as US \$2,995.

When looking at HIV-free survival as an outcome of interest, Sc-HAART with 12 months breastfeeding and Sc-HAART with 6 months breastfeeding remain the dominant scenarios across the range of cost variations (+/- 50%). The ICER for Sc-HAART with 12 months breastfeeding versus Sc-HAART with 6 months breastfeeding increases to US \$16,590 when costs increase, and it decreases to US \$7,175 when costs decrease.

The findings are not sensitive to potential variations (estimated at a maximum of $\pm 50\%$) in input costs.

Proportion of women eligible for anti-retrovirals

With respect to the new eligibility criteria of a CD4 threshold of 500, data concerning the proportion of eligible women in Rwanda was not available. Thus we assumed that 73% of women in PMTCT programs may be eligible for ARV, as reported in the literature.¹⁰³ Given the uncertainty of this value in the Rwandan context, the analysis explored the effect on the results if only 36% of women were eligible for ARV (CD4 less than 500). This is a 50% decrease compared to the base case value.

With 36% of women eligible for ARV it is found that when looking at HIV infections averted as an outcome of interest, Sc-HAART with 6 months breastfeeding still dominates all scenarios, with the exception of Sc-HAART and replacement feeding, which allows more HIV infections averted for an extra cost of US \$3,415 per extra HIV infection averted. When looking at HIV-free survival as an outcome of interest, Sc-HAART with 12 months breastfeeding and Sc-HAART with 6 months breastfeeding remain the dominant scenarios. Sc-HAART with 12 months breastfeeding allows more HIV uninfected children alive at 18 months for an increased extra cost of US \$15,639 per child. Thus the results are not sensitive to plausible changes in the proportion of eligible women in the cohort of HIV-positive pregnant women.

HIV transmission rates for each PMTCT option

Ranges for the HIV transmission rates, as per the most recent data available in the literature, are provided in Table 19. The highest and lowest values were used. Analysis for the lower boundary is most important considering that 500 CD4 was used as a cut-off for ARV eligibility in this study (as per Rwanda guidelines) and this may reduce the estimates of transmission as reported in the literature for a 350 CD4 cut-off. As expected, there is a higher number of new HIV infections in situations with a higher HIV transmission probability. However, the overall ranking across scenarios does not change.

For HIV infections averted as an outcome of interest, when the low transmission rates are used, Sc-HAART with 6 months breastfeeding dominates all options with the exception of Sc-HAART with replacement feeding. However, the extra cost for an extra infection averted with Sc-HAART and replacement feeding versus Sc-HAART with 6 months breastfeeding increases to US \$38,712. When the higher transmission rates are used, the extra cost for an extra infection averted with Sc-HAART with replacement feeding versus Sc-HAART with 6 months breastfeeding decreases to US \$2,951.

For HIV-free survival as an outcome of interest, Sc-HAART with 12 months breastfeeding and Sc-HAART with 6 months breastfeeding still dominate all other scenarios across the range of HIV transmission rates. The ICER for Sc-HAART with 12 months breastfeeding versus 6 months breastfeeding decreases to US \$7,542, when low HIV transmission rates are used and it increases to US \$94,544 when high transmission rates are used.

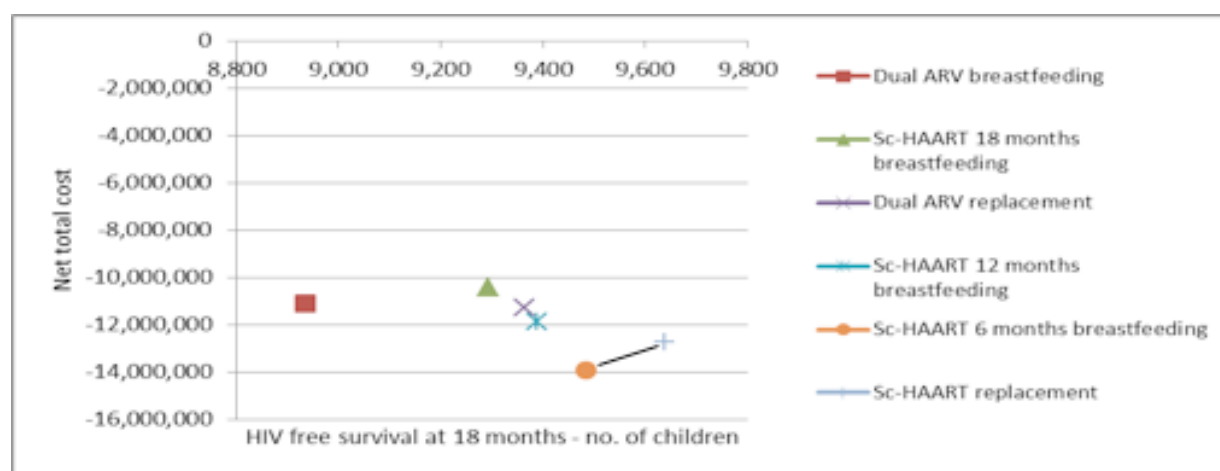
Mortality rates at 18 months for HIV exposed uninfected children

In the absence of national data for Rwanda, the Relative Risk (RR) of mortality rates for children breastfeeding for only 6 months, or being formula fed, were drawn from the literature (Table 19). However, several assumptions had to be made. For example, as no study was found

on the RR for mortality for 6 months breastfeeding versus 12 months or more, an RR of 1.5 was taken as the mid-point between the worst case of an RR of 3 (when weaning at 4 months) and the best scenario in which there would be no difference in survival outcomes.¹¹¹ In the case of survival rates for replacement feeding, we took a conservative approach for the best case. Rather than using an RR of 0.5 (as reported in the Partners In Health program⁹) it is assumed that survival rates for such a program may be less optimal in the context of a national scale up, and therefore selected a best case, low scenario, RR equal to 1.

When re-doing the analysis with this lower range (RR=1), Sc-HAART with replacement feeding allows the highest number of children alive and uninfected at 18 months, for an extra cost per child of US \$7,745 compared to Sc-HAART with 6 months breastfeeding. All other options are dominated. (Figure 16)

Figure 16: HIV-free survival (at 18 months) and net total cost, US \$.



Note: Sensitivity analysis-low range, Relative Risk (RR)=1.

When looking at the threshold at which the rankings of scenarios change, it is found that Sc-HAART with replacement feeding becomes the scenario with the highest HIV-free survival attainment, if RR is 1.4 or lower. This would require a setting where replacement feeding with an available, nutritionally adequate and safe diet could be provided, such as in the model described in our study. For Sc-HAART with 6 months breastfeeding to become the favourite option in terms of HIV-free survival attainments, RR should be 1.1 or below. This RR of mortality rate at 18 months might be the actual rate in some contexts, depending on the conditions of mothers and infants (and the support provided to them) during the weaning period and in the months that follow. When the analysis is re-done using the higher RR ranges (Table 19), Sc-HAART with 12 months breastfeeding results in the highest number of children alive and HIV uninfected at 18 months, for an extra cost per child of US \$2,089 compared to Sc-HAART with 6 months breastfeeding, dominating all other options.

It is concluded that when using HIV-free survival as an outcome of interest, the results are sensitive to the assumptions used for the mortality rates among HIV exposed uninfected children, and therefore to the conditions (adequacy, safety) in which early weaning (after 6 months breastfeeding) or replacement feeding will take place.

Discussion

Both the Convention on the Rights of the Child and the African Charter note proper pre-natal

and post-natal care as being vital for ensuring that children exercise their right to health.^{58,210} In terms of HIV, such services should specifically include the PMTCT because when HIV prevalence is over 1% it is a public health issue.⁷³ Every child deserves the chance to start life with optimal health, it is important that PMTCT services are encouraged, accessible, affordable and acceptable to pregnant women and their partners, and provided to all who require and accept treatment. There is almost universal access to PMTCT services but not everyone uses the services. For the maximum protection of children against HIV infection all pregnant women and expectant fathers, in Rwanda should follow the PMTCT.

This study modelled cost-effectiveness of various PMTCT ARV regimens and infant feeding options in the Rwandan context to inform policy dialogue at a time of increasing need for more value for money in global health interventions, and a global commitment to the elimination of MTCT by 2015.²¹¹ This is the first cost-effectiveness analysis of PMTCT regimen options that covers most of the regimen options available in 2010 in resource-limited settings, and uses HIV-free survival as the outcome of interest. Policy analysis of PMTCT regimens should prioritize child and maternal survival. Therefore, decision-making regarding solely HIV infections averted should be avoided.

This study shows that all MTCT regimens under analysis are cost saving compared to ‘no intervention’. This indicates that investing in PMTCT services does bring future savings when taking into account the reduced needs for treatment and care services for children in whom infection is averted. As such, it is a moral and practical imperative for governments to aim for the highest number of children alive and HIV-uninfected (HIV-free survival) within an affordable PMTCT program.

Sc-HAART with 12 months breastfeeding and Sc-HAART with 6 months breastfeeding dominate all other scenarios when considering 18-months HIV-free survival. Sc-HAART with 12 months breastfeeding allows the highest number of children alive and HIV uninfected at 18 months, for an incremental cost per extra child of US \$11,882. However, this finding is very sensitive to the values used for the relative risk of mortality comparing children who are breastfed for 12 months or longer to exposed but HIV-uninfected children who are breastfed for 6 months or those who are formula fed from birth. Given the uncertainty embedded in these mortality assumptions, it is difficult to draw unidirectional conclusions. Cost-effectiveness findings for HIV-free survival are sensitive to the actual feasibility of providing nutritionally adequate and safe replacement feeding. WHO has recently issued program guidance supporting the non-discontinuation of HAART after initiation among all HIV-positive pregnant women (Option B+).⁴⁸ Although the analysis was not designed to specifically model this scenario, one could anticipate that the outcomes of interest in the study (children HIV infections averted and 18-months HIV-free survival) would not change significantly for Option B+ compared to Sc-HAART when measured at the end of the breastfeeding period. If the cost is higher under Option B+, this could be offset by the additional health benefits to women from earlier initiation of treatment and non-discontinuation. Other benefits include reduced heterosexual transmission risk to male partners. We highly recommend further analysis on the cost-effectiveness of Option B+.

When considering HIV infections averted, the most cost-effective PMTCT regimens are Sc-HAART for 6 months post-partum with exclusive breastfeeding and Sc-HAART with replacement feeding. A recent analysis from Malawi also suggested that Sc-HAART with 6 months breastfeeding was cost-effective for PMTCT.⁹⁴ Yet this study did not look at HIV-free survival.¹²⁵ The sensitivity analysis presented here shows that the ranking across PMTCT options is robust to plausible changes in values of key inputs parameters. Sc-HAART with

replacement feeding prevents more infections than Sc-HAART with 6 months breastfeeding for an incremental cost of US \$7,319 per incremental HIV infection averted. When a mother can afford or be provided an adequate, safe, sustainable, and culturally acceptable substitute of breast milk, Sc-HAART with replacement feeding can be recommended. However, at the population level, the benefit of replacement feeding should be balanced with the increased child morbidity and mortality risks associated with abstaining from breastfeeding or early cessation of breastfeeding, particularly in resource-limited settings. There is evidence suggesting an increased risk of mortality, morbidity and slower early growth among HIV-exposed children than their HIV-unexposed counterparts.^{17,126} Recent studies have nevertheless reported no significant increased risk of child mortality however, this is only possible when individualized community-based follow-up systems are implemented and direct support (milk, safe water, cooking equipment) is provided to mothers.^{9,17,126}

An important limitation of this study is that the theoretical model excludes the possible impact of suboptimal treatment delivery resulting from poor adherence rates, losses to follow up, and suboptimal timing of ARV initiation. In addition, non-adherence to the different interventions considered would each have distinct impacts on our study's endpoints. Results are based on the ideal manifestation of the data, without taking into account possible deviations, for the main purpose of ranking options for decision making. Since fewer than 100% of women enrol and completely adhere to PMTCT the real number of infections averted would be less than anticipated by this model.

In Rwanda, the national ARV policy states that all persons living with HIV should have universal access to care and treatment for HIV. Therefore, the additional cost for each child who becomes infected is an increased – and lifelong – cost for the Government of Rwanda as the health care payer. Although the model uses the longest surviving pediatric cohort currently available in the literature, AIDS is a chronic illness and it is clear that care and treatment costs would continue to accumulate as children enter adulthood.¹³⁰ As HIV care and treatment advances continue, improved survival in children with HIV would also be expected to increase. As such, the more efficacious PMTCT options would become increasingly cost-effective. Therefore, this model is somewhat conservative when estimating the potential savings from PMTCT options.

6.2 When One Infects Two

**The following section is reprinted from an article of which I am first author: “When one can infect two: A reflection on the impact of HIV discordance on child HIV infection”; permission has been granted from the Pan African Medical Journal for the reprinted text.*

I conceived the original idea and the research question, provided direction on the research question and context of the health sector in Rwanda, conducted the literature review, led the desk review, led the analysis, interpreted of the results and I was the lead in writing the manuscript.

A number of studies have looked at the prevalence of HIV discordant couples in Africa.^{212,213,214,215} An article recently published in the Lancet estimated that up to 94% of new heterosexually acquired HIV infections occur within marital or cohabiting relationships in urban areas of Rwanda and Zambia.²¹² In Kigali, the capital city of Rwanda, it is estimated that up to 12% of cohabiting couples seeking voluntary counseling and testing services are HIV discordant. The proportion of discordant couples with an HIV-positive man is almost the same as that of discordant couples with an HIV-positive woman.²¹²

There is a need to better analyse the impact of HIV sero-discordance in the context of pregnancy and PMTCT. In general, PMTCT programs in the African context tend to offer one HIV testing and counseling session only to women and little follow-up is planned for women who test negative to HIV during pregnancy.

In Rwanda, where HIV prevalence among pregnant women was 4.3% in 2007, about 73% of pregnant women attending antenatal clinics agreed to undergo HIV testing and 84% had partners who agreed to undergo testing in 2009.¹³³ This means that more than 27% of pregnant Rwandan women still do not know their HIV status. Although there are great efforts to encourage the partners of pregnant women to be tested for HIV through couple counseling and testing, among women who do know their serostatus, 16% do not know the status of the father of the child. Both of these issues place the child of an HIV negative mother at risk.

The risk of HIV acquisition by pregnant women in very high prevalence settings may reach up to 10.7/100 woman years as recently shown in a study conducted in South Africa.²¹⁶ It is also known that primary infection of women around pregnancy or lactation is more likely to result in HIV transmission to the child due to high viral load.^{216, 217, 218}

This reality suggests the need for specific guidelines regarding HIV testing of pregnant women and their partners, with repeat testing of HIV negative pregnant women, particularly in an HIV discordant relationship. Education about risk of acquiring new infections and the distribution of condoms should also occur at each antenatal, post natal, newborn and child visit.

In Rwanda nearly all pregnant women come for at least one antenatal care (ANC) visit. The percentage of pregnant women attending ANC, who were tested for HIV, increased from 10.5% in 2002 to more than 70% in 2009 (about 295,000 pregnant women).²¹⁶ The high acceptance rate of the first test makes us expect similarly high acceptance of a second test among HIV negative pregnant women. Special emphasis on counseling may be given to those women who did not accept HIV testing in the first place.

A study into the adequacy and feasibility of a second HIV test during pregnancy at a referral Hospital in Kigali, Rwanda, confirmed that a second test should be recommended for HIV negative women. In fact, among 1,342 HIV negative pregnant women at first test, 3 cases of HIV sero-conversion were found (107 days on average between the first and second test for the three cases) for a cumulative incidence over 9 months of 2.1%. The partners of two of the three women tested negative at the first test and one was of unknown HIV status. Overall, 3.28% of partners of the HIV negative pregnant women tested HIV-positive at first test, and 13.34% of HIV negative women did not know the HIV status of their partners.²¹⁹

A cost-effectiveness study of HIV re-screening during late pregnancy to prevent perinatal transmission in South Africa, a country with an overall national HIV prevalence among antenatal women aged fifteen to fifty years of 29.3% in 2008, found that re-screening would prevent additional infant infections and result in net savings.^{220,221} The minimum time interval between the initial and repeat screens would be from 3 to 18 weeks, depending on prophylactic and treatment regimens, in order for HIV rescreening to be cost-saving. Overall, HIV rescreening late in pregnancy in very high-prevalence, resource-limited settings such as South Africa would be a cost-effective strategy for reducing MTCT.²²¹

Every country should define its protocol according to knowledge of HIV prevalence and the risk of vertical infection during pregnancy and lactation. Moreover, if the male partner is found to be positive and the woman is negative, intensive counseling on the use of condoms and the

need for repeat testing throughout the gestation period and during lactation should be given. Rwanda's model of couple HIV counseling and testing, which promotes male involvement and ensures HIV disclosure, provides a positive support environment that facilitates the management of sero-discordant results, particularly during pregnancy. HIV testing becomes an entry point for prevention of heterosexual transmission during pregnancy, including systematic condom use, and antiretroviral therapy if eligible for HIV-positive male partners.²²²

There is the potential to save the lives of women, but also their children, through repeated HIV testing and counseling in the context of PMTCT; morally, this cannot be ignored.

6.3 Right of a Child to be Born HIV Free

**The following section is reprinted from an article of which I am first author: "The right of children in developing countries to be born and live HIV-free"; permission has been granted from the Health and Human Rights Journal for the reprinted text.*

I conceived the original idea and the argument, provided direction on the research question and context of the health sector in Rwanda, led the literature review, led the desk review, did the analysis, led the interpretation of the results and I was the lead in writing the manuscript.

Ten years ago, in international public health circles, it was common to suppose that people with HIV in developing countries had no right to life — although health experts avoided stating the point quite so bluntly. The problem was that survival for those in advanced stages of AIDS depended on their receiving triple therapy with ARV — a treatment judged too costly for poor people in low-income countries and too complex for them to manage. As a clinician, I remember clearly that, at the time, ARV were in effect considered so mysterious and sophisticated that it was assumed one had to be an extraordinary specialist to prescribe the drugs and care for the PLHA taking them. To understand the multiple permutations and interactions of the different classes of ARV, along with their possible side effects, seemed to constitute a distinct science reserved for very knowledgeable people. The patients, too, were thought to need unusual discipline — and an arsenal of timers, watches, and other tools — to adhere to the complex ARV regimens, which required ingesting a battery of different pills at precisely regulated time intervals. For the therapy to succeed, patients had to be knowledgeable and determined enough to apply their wise doctors' instructions unfailingly — a condition that many people imagined most poor Africans would be unable to fulfil.

Attitudes about AIDS therapy in developing countries have changed dramatically in the decade since, as have the realities of AIDS treatment provision in these regions. Between 2001 and 2006, the number of people on antiretroviral therapy in low- and middle-income countries increased almost sevenfold — from 240,000 to about 2 million. In 2003, only 100,000 Africans — a mere 2% of those in need of life-saving antiretroviral treatment — were receiving it. By 2007, this figure had multiplied a dozen times. Sub-Saharan Africa was estimated to have more than 1.3 million people on ARV, approximately 28% of those in need.²²³

These gains have come, above all, thanks to the activists who struggled resolutely to expand access to ARV. Activists and their allies have battled on all fronts, from drug prices and intellectual property rights regimes, to the design and financing of ARV programs, to the training of health workers, to treatment education among people living with HIV and AIDS (PLHA), to action for overall health system strengthening.²²⁴ The struggle is not over. Much still remains to be achieved on the way to truly get universal access to HIV/AIDS prevention, treatment, care, and support. But, thanks to the efforts of activists, especially people living with HIV and AIDS (PLHA), we are no longer arguing about *whether* poor African patients should

have access to life-saving antiretrovirals, but about *how* best to implement AIDS treatment in African settings, building on the successful programs already firmly established in many countries.

Antiretroviral treatment programs in Sub-Saharan Africa and other low-income regions have been difficult and time-consuming to build. However, their progress has proven to the world the profound error in thinking of those who, a decade ago, assumed that poor people living with HIV and AIDS (PLHA) in the global South would have to be sacrificed in order to protect people in the North. Their argument was based on the fear that drug-resistant HIV strains would proliferate if ARV were widely distributed in developing countries, where providers or patients could be trusted to handle these precious drugs properly.

However, five years of large-scale treatment programs in both urban and rural settings in the developing world have demonstrated unequivocally that to explain to poor, illiterate people how to follow an antiretroviral triple therapy regimen is not an impossible challenge for African, Asian, or Latin American health care providers. At the same time, these programs have confirmed that poor HIV-positive people who lack education by northern standards are able to understand and follow instructions on how to use these medicines.

The people living with HIV and AIDS (PLHA), social workers, nurses, physicians, and patients who together have led these ARV programs, are true pioneers. They have advanced the struggle for the right to health as a fundamental right for all people, of all social conditions, in all regions, and concerning all forms of illness for which effective treatments exist. They give us an example to follow in resisting the fatalism of those who insinuate that poverty and illiteracy make it impossible, in practice, to realise people's right to life and health.

This example must strengthen our resolve on the question of breastfeeding versus replacement feeding for the children of HIV-positive mothers.^{182,225} The history of expanding access to ARV encourages us to challenge those who now argue that safe replacement feeding is beyond the capacity of poor, illiterate, HIV-positive mothers. This is an area of great controversy, and experts deeply committed to children's wellbeing find themselves on different sides of the question. Some construe the existing evidence as showing that, in low-income African settings, replacement feeding will inevitably cause greater harm to children than other available alternatives (e.g. exclusive breastfeeding to six months, with maternal ARV), because of the excessive demands that replacement feeding imposes on mothers.^{17,226,227,228,229} For replacement feeding to work, mothers must, day after day, secure uncontaminated water to mix infant formula and ensure the cleanliness of feeding implements — a challenge some critics maintain is insuperable. However, the historical lessons learned from the treatment access movement caution us against portraying as an inherent and unchangeable incapacity of poor African people or beleaguered African health systems, what is in reality an implementation failure that can be remedied through effective delivery strategies.

In Rwanda, a recent study conducted in 2008 in the rural areas of Kayonza and Kirehe shows a reduced mortality rate for children born to HIV-positive mothers and fed with breast milk replacements, compared with the mortality rate for the rest of the population in the same age range.²³⁰ This outcome provides evidence that, when properly conducted, the fight against AIDS can be an opportunity to improve general survival rates for children under 12 months. For 198 children enrolled at birth in this study, the mortality rate was 26 per 1000 live births, compared to 125 per 1000 live births for the general population.²⁵ These findings contrast sharply with the negative outcomes reported in other studies in which HIV-positive mothers

used replacement feeding.²²⁶ These results ought to make us consider carefully before decreeing that such mothers are not capable of preparing a bottle for feeding correctly.

Universality is the very essence of human rights. It is therefore unacceptable to promote a two-tiered approach to AIDS treatment or to replacement feeding, because doing so implies that some people have more human rights than others. It suggests that wealthy women's rights include being able to feed their children safely, while poor women's do not. This contradicts the most basic principles of human rights theory. Moreover, on the level of practical implementation, health care providers and people living with HIV and AIDS (PLHA) in developing regions have shown that effective training combined with the appropriate technical and financial resources can ensure excellent delivery and follow-up of ARV treatment. Why then, should this not also be the case for infant feeding with breast milk substitutes? The study conducted in Kayonza and Kirehe proves that it is possible. The results of the study show a rate of vertical transmission of HIV reduced to about 2%. Meanwhile, the rates of diarrhoea and acute malnutrition among children fed with breast milk substitutes in the program are not higher than those in the general population, as reflected in a baseline study conducted by UNICEF in Kayonza and Kirehe districts in 2006.²³²

The right to choose is a fundamental human right. It should be up to a mother and her family to choose the way they want to feed their child, from a range of different means available to them. In the Kayonza and Kirehe study, fewer than 1% of women who received information, and were given the option of providing replacement feeding, chose to nurse their babies.²³¹ This result challenges the notion that women will refuse to bottle-feed in a culture where breastfeeding is the norm, out of fear of the stigma that might come with being seen to bottle-feed their children.

All this is not to minimise the obstacles that confront efforts to expand replacement feeding in low-income communities, the lack of infrastructure, unreliable access to water, lack of information, and many other factors. These problems are real and serious but this should not prevent us from setting, for our people in the global South, the same objectives that exist in the North. When the means are available, it is criminal to mismanage those means, to fail to use them judiciously for the good of the community, by failing to provide people where possible with the knowledge and tools they need to care for their children and themselves properly.

The low mortality rates for infants of HIV-positive mothers in the Kayonza and Kirehe program show that the fight against HIV and AIDS, including replacement feeding programs linked to PMTCT, can be opportunities for public health — even though we know too well that these programs, when mismanaged, can be dangerous. Let us never again mistake a contingent and correctable implementation shortfall for an eternal verdict on the capacities of Africans, decreeing that African health care providers can never deliver this type of service effectively to African patients. That some programs have failed to meet appropriate performance standards is undeniable and bitterly disappointing but let us place the responsibility for this bad management where it belongs — with the bad managers. Let us not ascribe the failure to the incorrigible ignorance of African communities and poor African women— and then make them pay for their supposed failure with the health and lives of their children.

We must not repeat now with replacement feeding the same tragic error that was made ten years ago with antiretroviral medicines. Mothers living with HIV have the will to survive and to raise healthy children. Let us offer them the choice and provide them with the means to carry it through. Let us stop deciding who has the right to life and who does not. Let us respect human rights and seek together the way to realise them in practice.

6.4. Nutritional Rights of the Infant

**The following section is reprinted from a paper of which I am first author: "HIV, infant feeding and implementation failure: advancing policies for women with HIV infection and attaining the Millennium Development Goals"; permission has been granted from the Bulletin of the World Health Organization for the reprinted text.*

I conceived the original idea and the argument, provided direction on the research question, led the desk review, led the analysis and interpretation of results and I was the lead in writing the manuscript.

Coutsoudis et al. offer a viewpoint on the WHO guidelines on HIV and infant feeding, which suggests that the use of infant formula among HIV-positive women in the developing world is, to a large extent, currently untenable.¹⁸² The article has many valid arguments and it is well known that promotion of formula feeding among HIV-positive women within the context of inadequate community support, unreliable formula supply and contaminated drinking water can result in excess infant mortality.²³³ However, empirical data exists that counters some of the authors' views. It has been demonstrated that formula feeding among HIV-positive women in a context with counseling support and education, access to clean water and uninterrupted availability of breast-milk substitutes can offset the risk of infant mortality. In Côte d'Ivoire, there were no differences in risks of diarrhoea, respiratory infection, malnutrition, hospitalisation or death in breastfed versus formula-fed infants of HIV-positive women. The authors of this study suggest that offering safer conditions (clean water, free formula) and a more supportive environment (replacement feeding, counseling and education) were elements that reduced the potential threat of mortality among formula-fed infants. These findings were sustained after a two-year follow-up period.¹⁷

With safe formula feeding, the vertical HIV transmission rate can be reduced to less than 2% and this is an attainable goal in a resource-limited setting, as indicated by results from a preliminary study in Rwanda.²³⁴ In addition to a low transmission rate, the mortality rate reported was modest (21 per 1000 person-years) among those infants enrolled at birth in the Inshuti Mu Buzima PMTCT program in rural Rwanda who were offered free formula, materials, education and support through community health workers.

Evidence from South Africa offers a more complex picture of infant feeding outcomes in the context of HIV. There, formula feeding demonstrated a protective effect on HIV transmission per death among those living in households with piped water (hazard ratio, HR: 0.51; 95% confidence interval, CI: 0.31–0.84). Among those who had piped water and fuel, and who disclosed their HIV status, the protective effect of formula was greater (HR: 0.32; 95% CI: 0.16–0.62). However, among women who did not have piped water or fuel and did not disclose their HIV status, formula feeding conferred an increased risk of HIV transmission per death by 3.5 fold (HR: 3.45; 95% CI: 1.89–6.32).²³⁵ These findings suggest that contextual factors are critical when considering the appropriate feeding options for HIV-positive women in resource-poor settings, indicating that in some settings the provision of formula would result in increased child mortality, as Coutsooudis et al. argue.¹⁸²

However, these findings also suggest that aggressive measures to improve water quality and access to other resources may reduce the risk of child mortality associated with provision of infant formula. In fact, improving access to potable water may be the most critical element in offering safe feeding alternatives to HIV-positive women with infants in developing countries, and should not be considered an unattainable goal. One of the eight Millennium Development

Goals (MDGs) is to “ensure environmental sustainability” (Goal 7) and one of the targets is to “reduce by half the proportion of people without sustainable access to safe drinking water”.

Although addressing the global water crisis may not be immediate, as indicated by the MDGs, targets for improving access to potable water must be set and attained for the near future. One should not lose sight of the fact that progress has been made in the past twenty years and since 1990 approximately 1.6 billion people have gained access to safe drinking water. During this period, the child mortality rate for developing countries declined from 103 to 80 per 1000 live births, suggesting improvement with respect to MDG Goal 4 of reducing child mortality.²³⁶ Therefore, despite the suggestion that “poverty is not easily or quickly reversed” a positive, goal-directed outlook can offer results more quickly.¹⁷

If programs reducing MTCT through formula feeding are deemed not feasible in a large majority of settings throughout the developing world, thousands of infants will continue to die due to the presumed inability to offer access to clean drinking water and a safe environment for formula feeding. However, in settings where women are offered a safe and supportive environment, the potential for child mortality can be offset and the risk of HIV transmission can be dramatically reduced. The fight against HIV/AIDS can serve as an entry point to demonstrate to families in remote areas that access to clean water and reduction in HIV transmission, as well as child mortality, are attainable goals as we work collectively towards reaching the MDGs.

6.5. Cost Effectiveness of Male Circumcision

**The following chapter is reprinted from an article on which I am first author: “Male circumcision at different ages in Rwanda: a cost-effectiveness study”; permission has been granted from the PLoS Medicine for the reprinted text.*

I conceived the original idea and the concept, led the design of the study, provided direction on the research question and context of the health sector in Rwanda, led the data collection, contributed to the literature review and to data analysis, the interpretation of results and the drafting of the manuscript

Introduction

Male circumcision in neonates offers an opportunity to avert future infections the child may acquire once sexually active. However, again, the cost-effectiveness of circumcision in neonates, compared to adolescents or adults, has not been explored.

Male circumcision is one of the oldest and most common surgical procedures in human history.²³⁷ MC is extremely important to consider as a preventive tool, as it significantly decreases the risk of sexual infection by HIV. Three randomised control clinical trials in Africa have shown that MC reduces risks for HIV transmission from women to men by 51%-55% in Uganda, 53% in Kenya and 60% in South Africa.^{238, 239, 240, 241} These striking statistics suggest that MC is currently more protective against HIV transmission than the most promising vaccines and topical microbicides.

In places where MC is not a cultural practice, neonatal MC as a public health measure may face religious and cultural resistance.²⁴² Neonatal MC could also be rejected where MC is a traditional adolescent ritual as is the case in some countries in Africa.²⁴³ Some groups who have gone so far as to deny the existence of AIDS or denounce “science” or “medicine” as a whole,

have also campaigned against MC.²⁴² In Rwanda, MC is not currently a common practice. When this research began in 2008, 21% of health facilities in Rwanda had staff trained to perform male circumcision. Only 13% of males aged fifteen to fifty nine years in Rwanda were circumcised.⁸⁰ In 2011, a national plan for scaling up MC to decrease HIV transmission began gradual implementation for adults.²⁴⁴ However, there is currently no systematic program for male circumcision among neonates and adolescents.

There have been cost-effectiveness studies for male circumcision in adults, but there are few studies in Sub-Saharan Africa that concern adolescent male circumcision, and no study that examines circumcision for newborn boys. The cost-effectiveness studies on adult MC scale-up showed positive results in Uganda, as well as in other neighboring countries including Lesotho, South Africa, and Swaziland where the prevalence is higher.^{142,237,245} This would make MC efficient in the prevention of HIV. One study in Uganda showed that, for cost-effectiveness, MC should target men over thirty years old, as at that age there is a rapid return on investment in MC *vis-a-vis* infection averted.²⁴⁶ However, there are no studies analysing the cost effectiveness of neonatal male circumcision, which could provide direct protection for future adolescents.

Methodology

Please refer to Chapter 4 for the methodology.

Findings

Table 24 provides a summary of costs. Details of unit costs are available from the authors upon request.

Table 24: Costs standardised to one Male Circumcision procedure for a cohort of 150,000 adults and 150,000 newborns in Rwanda, 2008.

Costs (Direct Costs of Procedure)	Unit Cost Infant MC (US\$)	Unit Cost Adolescent/ Adult MC (US\$)
Mogen Clamp (reusable 1,000 times)	0.3	NA
Infant consumables: 1 g EMLA cream; two impregnated gauze; one absorbable suture; 100 ml antiseptic; 1 ml glucose solution; two pairs gloves)	6.5	NA
Adolescent/adult consumables: lidocaine anaesthetic, 15 ml; suture material, three; gauze, 15; sticking plaster; anti-inflammatory; two syringes and needles; antiseptic; gloves masks; caps and aprons; condoms	NA	21
Surgery kit, including sterilization costs and amortization	0.6	8
Laboratory exams (bleeding time, full blood count)	—	6
Staff time infant: nurse A1 level (30 min plus counselling), public system	2.5	NA
Staff time adolescent/adult: surgeon and nurse (1 h plus counselling), public system plus 15 min bandage three times every 5 d	NA	6
Programme costs		
Promotion campaign (over a cohort of 150 000 people) ^a	3.5	3.5
Training of health professionals, including counselling and supervision	0.8	1.3
Infrastructure costs		
94 small surgical rooms (adolescent/adult)	NA	2.8
Side effects	0.5	1
Subtotal	15	50
Cost of HIV testing and counselling	—	9.2
TOTAL (rounded amounts)	15	59
Prices paid by clients, Kigali		
Health centre	starting 13 ^b (MOH standard)	—
Private sector	45 ^b	87

Base case year, 2008.

^aThe costs of a promotion campaign for a circumcision program that targeted infants, adolescent, and adults would be less than the sum of the individual campaigns, which would increase the cost-effectiveness of each if implemented jointly.

^bDorsal slit method (reflecting current practice in Kigali) in hospital.

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Tables 25 and 26 present savings and discounted savings for the three cohorts in Rwanda.

Table 25: Lifetime savings per each HIV infection averted.

Category of Savings per Each HIV Infection Averted	Input Values and Assumptions	Life-Time Costs per Person/ Amounts over 14 y (US\$ 2008)
Home-based care	US\$40 per year for counselling, medical care, clothes, nutrition, etc.). 10% of symptomatic PLHIV receive home-based care in Rwanda. ⁹	56
Prophylaxis and treatment of major OIs	Average 3 y per person. US\$160 is the WHO average treatment cost for sub-Saharan Africa. Cost of generic for co-trimoxazole, fluconazol, anti-TB drugs is US\$122 (CAMERWA).	846
Laboratory tests including supplies	70% of patients. Average cost is US\$73 per year per person (CD4, US\$8; viral load, US\$25; DNA PCR US\$15; hematology, US\$6; biochemistry, US\$20, including reagents and all supplies plus annualized cost of equipment), National Laboratory.	715
ART	ART per person per year first line is \$710 (80% of patients). TB per year is \$201 (8%), TB costs over 2 y. Cost of therapy given for toxicity (to treat secondary effects, pregnancy, etc.) is \$402 (15% patients per 1 y). Cost of second-line therapy is \$1,726 (20% of patients). Palliative care is \$267 per life-time (10% of patients).	12,890
Total	Rounded amounts	14,500
	90% of the cohort (to account for losses to follow-up)	13,050

⁹Coverage assumptions come from published literature (WHO) and routine data/consensus discussions among HIV service providers in Rwanda. PLHIV, people living with HIV/AIDS; TB, tuberculosis.
doi:10.1371/journal.pmed.1000211.t003

Table 26: Savings for neonatal, adolescent, and adult MC in Rwanda, 2008.

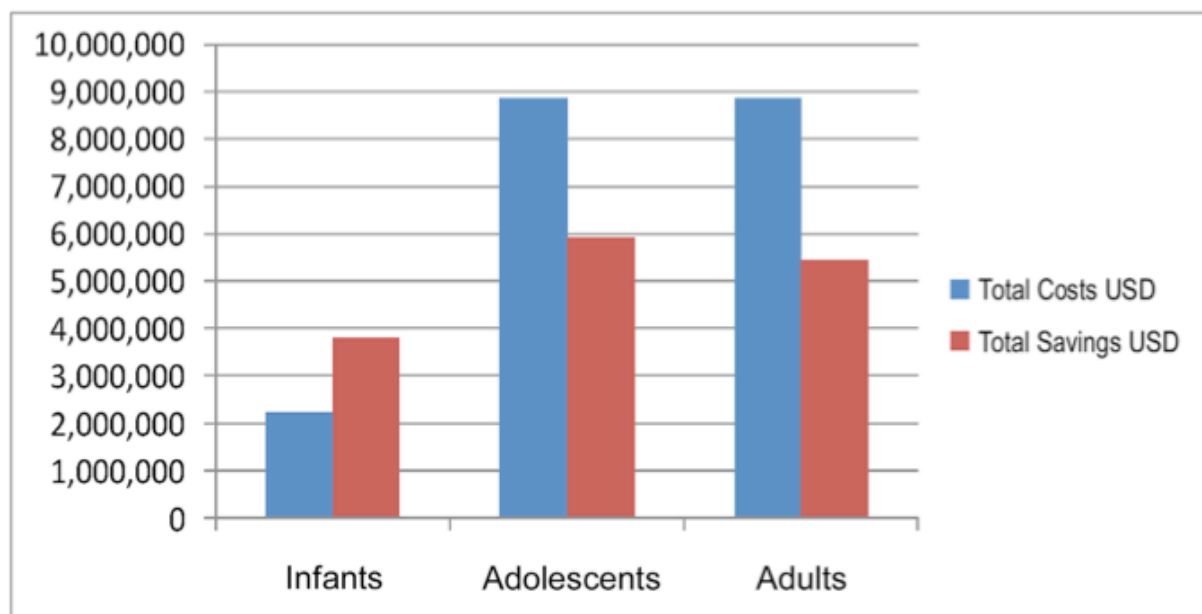
Subgroup	Variables	Values							Total
	Age groups	15–19	20–24	25–29	30–34	35–39	40–44	45–49	—
Infants	Projection period	2023–27	2028–32	2033–37	2038–42	2043–47	2048–52	2053–57	—
	Averted infections in the cohort	31	66	294	307	222	271	97	1,288
	Savings in US\$ = lifetime cost of treatment per person × 90% adherence × averted infections	404,550	861,300	3,836,700	4,006,350	2,897,100	3,536,550	1,265,850	16,808,400
	Discounted averted infections	19	35	132	119	74	78	24	482
	Discounted savings US\$ = (lifetime cost of treatment per person × 90% adherence × discounted averted infections)/[(1 + 3%) ^{delay}], Delay = (8 + 2/3 × [14])	149,898	273,167	1,045,253	941,477	587,539	619,189	192,000	3,808,523
Adolescents	Projection period	2008–12	2013–17	2018–22	2023–27	2028–32	2033–37	2038–42	—
	Averted infections	31	66	293	305	221	270	97	1,283
	Savings US\$	404,550	861,300	3,823,650	3,980,250	2,884,050	3,523,500	1,265,850	16,743,150
	Discounted averted infections	29	54	205	185	115	122	38	748
	Discounted savings US\$	232,602	423,883	1,621,957	1,460,924	911,705	960,818	297,933	5,909,820
Adults	Projection period	—	—	—	2008–12	2013–17	2018–22	2023–27	—
	Averted infections	—	—	—	294	213	260	93	859
	Savings US\$	—	—	—	3,836,700	2,779,650	3,393,000	1,213,650	11,209,950
	Discounted averted infections	—	—	—	277	173	182	56	689
	Discounted savings US\$	—	—	—	2,189,564	1,366,214	1,439,811	446,460	5,442,049

doi:10.1371/journal.pmed.1000211.t004

Cost-effectiveness results for infants, adolescents, and adult MC

Figure 17 provides total costs (unit cost of MC and HIV testing and counseling US \$6,150,000) and discounted savings for the Government of Rwanda if a cohort of 150,000 males were to be tested for HIV and circumcised in 2008.

Figure 17: Total costs and savings for neonatal, adolescent, and adult MC (cohort 150,000 males), Rwanda, 2008.



For infant MC, total costs (US \$2,250,000) are lower than discounted total savings (US \$3,808,523). Therefore, the intervention is cost-saving. For adolescents and adults, total costs (US \$8,850,000) are higher than total savings, with net costs of US \$2,940,180 and US \$3,407,951, respectively. The cost-effectiveness ratio (net cost per infection averted) is US \$3,932 and US \$4,949 for adolescents and adults, respectively.

The findings from the analysis in Rwanda show that neonatal MC is less expensive than adolescent and adult MC (US \$15 instead of US \$59 per procedure) and is cost-saving, even though savings from infant circumcision will be realised later in time. The fact that MC of infants in Rwanda is a cost-saving intervention means that for each MC performed, the Government of Rwanda will save money. Still, the costs per infection averted for adolescent and adult MC compete with other HIV prevention interventions. Net costs for adolescents are lower than for adults since circumcising adolescents will avert a greater number of infections than circumcising older men (protection from MC applying to a greater number of years of exposure to HIV). Circumcising adolescents also has the potential to avert the highest number of discounted HIV infections, because the delay from birth to initiation of sexual activity devalues the infections prevented from infant MC more than those prevented by adolescent MC.

The discounted cost per life year gained for adolescents and adults is US \$334 and US \$613, respectively. To calculate the number of life years gained, this analysis multiplied the discounted HIV infection averted at different ages by the life expectancy at that age group²⁴⁷ less the years of survival that would in any case have occurred with HIV and treatment availability (8 years plus 14 = 22 years).

According to the WHO, the per-capita GDP, adjusted for the purchase power parity of the country, can be used for setting thresholds for cost-effectiveness. Thus, interventions for which the additional cost incurred to gain one quality-adjusted life year is less than the country's per-capita GDP are considered to be very cost-effective. Considering that GDP per capita in Rwanda (based on 2007 estimates) is US \$355,²⁴⁸ MC for adolescents is slightly less than one GDP/per capita/life year gained and therefore highly cost-effective, while MC for adults is less than two GDP/per capita/life years gained and therefore potentially cost-effective (WHO

criteria). The WHO criteria were designed to be used with disability adjusted life years, which would increase the cost- effectiveness ratios of adolescent and adult MC estimates here somewhat, were that adjustment to be made.

Although the extent of monetary savings is not comparable to those associated with preventing HIV, we estimated that for each year-cohort (150,000 males) there will be 5,000 fewer cases of syphilis and virtually no cases of penile cancer (1-2 cases fewer). For male children, there will be at least 2,500 fewer urinary tract infections. These findings further suggest that the figures presented here underestimate the cost-effectiveness of the procedure.

Sensitivity and Thresholds Analysis

Given the uncertainty embedded in the input values of the base case scenario, we conducted a one-way sensitivity analysis and explored a wide range of values in order to identify thresholds (Table 27). This analysis reports the threshold at which the procedure costs more than one GDP/capita/life year gained (WHO criteria for cost-effectiveness). For infant MC we also reported the threshold at which the intervention is no longer cost-saving.

Table 27: Threshold analysis.

Variable	Base Case	Cost-Saving Threshold (Infants)	Highly Cost-effective Threshold (<1GDP/Capita/Life Year Gained) GDP per Capita = US\$355 (2007 Estimate) (Infants)	Highly Cost-effective Threshold (<1GDP/Capita/Life Year Gained) (Adolescents)
Discount rate	3%	4.1%	5.4%	3.1%
HIV incidence	Stable at 2008 values	40% decrease	61% decrease	2% decrease
Protective effect of MC	55%	33%	22%	54%
Cost of MC procedure	US\$15 infant; US\$59 adult/adolescent	US\$25	US\$38.50	US\$60
Cost of treatment and care	US\$14,500 per person lifetime	US\$8,600	US\$900	US\$14,100
Adherence to treatment	90%	54%	6%	88%

doi:10.1371/journal.pmed.1000211.t005

Overall, results for infant MC appear robust. However, MC for infants is no longer cost-saving for a small increase of the discount rate. Infant MC remains highly cost-effective across a reasonable range of changes in the base case scenario.

To take into account the positive effects of the numerous HIV prevention interventions ongoing in the country, a sensitivity analysis reducing the annual rate of HIV incidence from the 2008 base case (without changing other values) was performed. It is found that the cost-effectiveness of neonatal MC is not very sensitive to a decrease in HIV incidence, and that neonatal MC remains cost-saving until incidence decreases 40% from the base case value, suggesting its suitability for countries with lower HIV incidence and prevalence.

Circumcision, and in particular adult MC, carries the potential for risk compensation through an increase in risky sexual behaviour. Although a study published in 2007 does not support this theory,²³⁷ we tested our results by reducing the net protective effect of MC. Neonatal MC is cost saving until a protective effect of MC of 33%, and overall results for neonatal MC are relatively insensitive to a decrease in the protective effect of MC.

Neonatal MC is cost-saving up to a cost per procedure of US \$25. Understandably, since benefits will happen later in life, for neonatal MC to remain cost-saving the maximum cost per procedure has to be lower than the cost per adolescent and adult MC. Neonatal MC would still be highly cost-effective if the lifetime cost of treatment and care (savings per infection averted)

fell to US \$900. Since costs per MC are lower in infants, cost-effectiveness of neonatal MC is expected to be relatively insensitive to a reduction in savings from averted treatment and care. The sensitivity to decreases in the adherence rate to ARV (or to increased losses to follow-up) mirrors that for cost of treatment and care. Adolescent MC is highly cost-effective for the base case scenario but no longer so for very small changes in the input variables. Adult MC is neither cost-saving nor highly cost-effective in Rwanda when considering only the direct benefit of reduced health care costs in the circumcised man.

Discussion

Infant MC can lower health system costs because of moderate implementation costs, high and durable protective effects, and the averted HIV-care costs. As the sensitivity analysis shows, these findings are robust across a wide range of input values for Rwanda. The study shows that adolescent MC may be a highly cost-effective intervention. MC for adults is the least cost-effective of the three procedures.

Findings are generally consistent with results from other costing studies on adult MC in Lesotho, Swaziland, and with cost-effectiveness analysis of adult MC in Kenya, Uganda and South Africa, even though in these countries HIV incidence, and consequently the number of potentially averted HIV infections, is much higher.^{142,237,245,249} In Uganda, with an annual HIV incidence of 1.25% and a cost per adult MC of US \$69, the cost of MC (not adjusted for savings on treatment) per HIV infection averted was estimated at US \$1,485 (including the indirect effect on women). The study in South Africa shows that MC generates large net savings after adjustment for averted HIV medical costs. With an annual HIV incidence of 3.8% and a cost per adult MC of US \$55.7, the cost of MC (unadjusted for averted medical care costs) per HIV infection averted was estimated at US \$181 (including the indirect effect on women) while for 1,000 circumcisions net savings (adjusted for averted medical care cost) were US \$2.4 million.

A recent study by White et al. also found that MC is a cost-saving intervention in a wide range of scenarios of HIV and baseline circumcision prevalence.²⁴⁶ The authors predict that circumcising neonates, although cheaper, would only become cost saving after around 30 years (within the time horizon of this study). These findings are consistent with the analysis presented here because this model considers the net present value of the interventions, extended to the entire life of the circumcised individuals. The absolute cost per infection averted is significantly lower in the White paper than in this present analysis, but this is to be expected given that they estimated benefits of reduced secondary infections among the sexual partners of the circumcised men, while this present analysis did not. The White paper also concludes that as neonate and adult programs are likely to be relatively noncompetitive for staff, facilities, and training, an optimal strategy may be to scale up both simultaneously, which is also consistent with the present findings, albeit for a setting with much lower incidence and prevalence.

Neonatal circumcision is a less expensive procedure (faster, less complicated, and with fewer side effects) than adolescent and adult circumcisions and can also be cost saving (even when considering the discounting effect). Most importantly, male infant circumcision can be easily integrated into existing health services (such as neonatal visits and vaccination sessions) and where health workers are well trained, it does not require skilled surgeons and infrastructure that could drain an already weak system. Moreover, neonatal MC may carry less risk of a compensatory increase in risky sexual behavior and it is likely to be more protective than adolescent or adult circumcision because there is no possibility of sexual activity during healing. Finally, circumcision among children does not carry the same implications as those for adolescents and adult MC, such as discomfort, stigma, and days out of

school and work (with their associated opportunity costs).

It is therefore deduced that infant circumcision has a better potential to achieve the very high coverage over time of the population required to achieve maximal reduction on HIV incidence than adolescent and adult circumcision.

This model assumes similar sized cohorts for adolescents and adults as for infants, and one might wonder why, given that the population in need of circumcision is so much larger than a single birth cohort. This was done for several reasons. First, the government policy question that prompted the study was whether infant circumcision should be added as a strategy to that already proposed for adolescents and adults. Thus, by using the size of the Rwandan birth cohort, the per-person costs could be compared with MC at other ages and the total costs and affordability of infant MC could also be assessed. Since the model does not attempt to estimate secondary benefits (e.g. to the female partners of circumcised men) or the herd effect of high levels of MC, the relative results will be the same regardless of whether the model is run with a cohort of one or 150,000. However, while 150,000 children represent a high level of annual coverage of the birth cohort, a realistic strategy for adolescent or adult catch-up should probably aim for higher annual coverage. A realistic assessment of what coverage levels could be attained, and at what cost (especially one that considered effects of scale on program costs) goes beyond the purpose of this study.

Given that this study does not quantify the indirect benefits of MC, the cost-effectiveness estimates are conservative. This is likely to be even truer for infants than for adolescents and adults for two reasons, MC coverage of infants is likely to be much higher, potentiating the herd effect, and, behavioural compensation is less likely to occur with infants.

The present study shows that systematic availability of MC services for all newborns helps to prevent vulnerable populations from being left out of services and this increases program efficiency in the long-term, through access to prevention interventions. As described earlier, neonatal MC is associated with better acceptability, safety, and feasibility than MC among adolescents or adults.^{250,251} It also results in major cost-savings even when HIV prevalence is low. However, several studies have recommended targeting men above age 30 for optimal cost-effectiveness.²⁵²

As described earlier, resistance to male circumcision is common across contexts.^{242,243} Although MC is not a traditional practice in Rwanda (12% of the population is circumcised), uptake of adult MC in Rwanda shows that resistance to MC is not a threat.^{253,254} In Rwanda, voluntary adult and adolescent MC is associated with counseling for behaviour change communication strategies. Thus, in addition to the clinical advantages of neonatal MC, adolescent and adult MC also give another entry point to sensitization about the consequences of risky sexual behaviour. Adults and adolescents choosing voluntary MC as a protective measure against HIV infection also need to be sensitized to continue using protective measures (i.e. condoms) and not to have a false sense of security.²⁵⁵

Neonatal MC also does not take time away from being in the workforce, as is the case for adult males who undergo MC. Performed by trained professionals during the neonatal period, MC heals during the same period as the umbilical cord (when the mother is on maternity leave). Moreover even if neonatal MC cost saving is only realised later, in around thirty years, as is seen in some studies, savings in productivity and health care over the lifetime of sexually active men is higher.^{252,256} It is important to perform the MC before initiation of sexual activity as the healing from MC takes 6 to 8 weeks and the deep healing takes 6 months to be completed.²⁵⁷ As

such, another advantage of neonatal MC is the fact that it is not impacted by sexual activity. Rwanda is acting on its plan to offer voluntary male circumcision to 2,000,000 youths and adults, in order to significantly reduce HIV transmission.²⁴⁴ The program is moving gradually toward this goal. Although the study showed that neonatal MC was cheaper, Rwanda's national HIV prevention program decided to address the HIV transmission risk of those who are at high risk now - youths and adults.

It is necessary to recognize that any modeling exercise is at best an approximation of reality. Studies that model the future, like this one, approximate a reality that does not yet exist, and this requires making a number of assumptions about the future (for instance on what will happen to HIV incidence rates, on the effectiveness of large-scale circumcision, and on the costs of HIV treatment in the future). Thus, these results, like those of similar exercises, must be seen as valuable inputs into decision-making because they identify likely impacts of different courses of action. They cannot pretend to eliminate the uncertainty that underlies such decisions, just to reduce it. As mentioned above, this model also has limitations related to what it does and does not include. The most important of these limitations is the fact that the model only takes the prevention benefit for the circumcised individual into consideration, and not for his sexual partners and offspring.

Chapter 6 presented the results from Period Two, from conception to the end of breastfeeding for breastfed children or from birth for a child not breastfed. This time is of particular concern as it is the period of MTCT. The results indicate that for PMTCT and MC, more should be done to increase value for money. The next chapter gives results for the period starting at the end of MTC risks and before the age of reasoning and will discuss the role of international organizations in protocols and guidelines to monitor nutritional status.

Chapter 7: Results from Period Three - from after breastfeeding, or after birth if not breastfed, to six years old

WHO and UNICEF have in their responsibility the production of international guidelines and protocols related to the diagnosis and treatment of malnutrition. Within countries these two institutions also have a mandate to advise governments on their accuracy in implementing these international guidelines. Their roles are crucial because monitoring nutritional status is important for all children, but particularly important for HIV-positive children, as it is a sign of the disease not responding to the treatment.

This chapter comprises a desk review on how these two organizations have accomplished their responsibilities *vis-a-vis* the care, treatment and monitoring of the nutritional status of Rwandan children, as a proxy for children affected by HIV, as even asymptomatic HIV-positive children have a fragile nutritional status. Their resting metabolic rates are 10% higher on average than HIV-negative individuals.²⁵⁸

7.1. Holding multilateral organizations accountable: the failure of WHO with regards to childhood malnutrition

**The following chapter is reprinted from an article on which I am first author: “Holding multilateral organizations accountable: the failure of WHO in regards to childhood malnutrition”; permission has been granted from the Health and Human Rights Journal for the reprinted text.*

I conceived the original idea and the research question, provided direction on the research question and the context of the health sector in Rwanda, conducted a literature review, led the desk review, carried out the analysis and interpretation of results and I was the lead in writing the manuscript.

At a time when accountability is a key message for countries, constituencies, and organizations, it is important that major multilateral agencies such as the WHO are also held accountable for actions taken or not taken. This section first reviews the methods of monitoring growth and development among children under five years of age by the WHO. It then addresses the fact that the WHO delayed disseminating new Child Growth Standards. In addition, more technical support for managing chronic malnutrition in young children is needed from the WHO. This delay of distributing accurate standards had cost the lives of malnourished children around the world.

Malnutrition can account for up to 50% of deaths among children under the age of five since it is a significant underlying factor of child mortality. In developing countries, approximately 25%

of children in this age range are moderately or severely malnourished (underweight and/or stunted).²⁵⁹ With over 9.2 million deaths of children under-five in 2007 worldwide, malnutrition accounts for a significant degree of this burden of childhood mortality.²⁶⁰ Since this is such a prevalent condition causing great devastation, it is essential that physicians and other health care providers be given the best tools to properly assess malnutrition in hospitals, clinics, and community-based settings. This section discusses the standards used to assess childhood malnutrition in the international community over the last 30 years and implications for their dissemination and use.

In 1977, the United States National Center for Health Statistics (NCHS) produced growth references to assess proper physical development.²⁶¹ The growth references used the weight-for-age, height-for-age, and weight-for-height distributions from studies conducted in the United States to identify underweight, stunted, wasted, and obese children. These references were used by hospitals and clinics throughout the United States and were immediately adopted by the World Health Organization. As a result of the WHO adoption of these standards, the US-based growth references for children were widely disseminated and used in countries around the world.

However, a number of studies subsequently showed that the 1977 NCHS/WHO growth reference standards were not appropriate for all infants and children. In particular, the 1977 NCHS/WHO standards tended to underestimate levels of low weight-for-age (underweight) for breastfed infants.^{262,263,264} As early as 1995, the WHO documented recognition of the problem, particularly in the use of the 1977 NCHS/WHO standards for infants.²⁶⁵ The reference data was based on information collected from infants in the Fels Longitudinal Study from 1929 to 1975 in Yellow Springs, Ohio. The limitations noted by the WHO working group at the time included that: 1) the sample was limited to Caucasian infants from mostly middle-income families; 2) data was collected every three months rather than monthly, which limited the accuracy of developing the growth curve, particularly from 0–6 months of age; and 3) the majority of the infants in the sample were bottle-fed, and if they were breastfed it was only for a short duration (typically less than three months).²⁶⁵

A study examining the 1977 NCHS/WHO standards in a developed area of Brazil provided empirical evidence for the limitations of using the 1977 NCHS/WHO growth references for infants in other settings. This data demonstrated that infants in their sample grew faster than the 1977 NCHS/WHO reference in the first six months of life with a relative decline thereafter. Among the sub-sample of infants that were either exclusively or primarily breastfed from 4–6 months of age, the average decline occurred earlier, usually after three months of age. As a result, breastfed infants were falsely perceived as not getting adequate nutrition through breast milk. Concerns arose that the perceived faltering may cause unnecessary early introduction of non-human milk.²⁶⁶

As a result of empirical data demonstrating limitations in the use of the 1977 NCHS/WHO standards, in 2000 the US Centers for Disease Control and Prevention (CDC) published a set of growth charts meant to replace the NCHS growth reference.²⁶⁶ These charts were based on national data from the US for infants and children from birth to 20 years of age from five national health examination surveys and supplemental data. The study sought to be more ethnically diverse and to better represent breastfed and bottle-fed infants. Studies comparing CDC growth charts to the 1977 NCHS/WHO references resulted in mixed views. Similar to findings described above, there were notable differences, particularly among breastfed infants under six months of age. The WHO found that *'breastfed infants grow more rapidly in the first 2 months of life and less rapidly from 3 to 12 months in relation to the CDC curves'*.²⁶⁷ The

overall consensus, however, was that the CDC growth charts more closely matched the population in the US, particularly since the majority of infants in the US are at least partially bottle-fed. A study comparing the 1977 NCHS/WHO growth references and CDC growth charts showed that CDC charts were superior in accurately representing the United States population.²⁶⁸

In 2006, after 11 years of debate, and 29 years following the original publication of the NCHS Chart, the WHO released new growth charts based on primary data collected from 1997 to 2003 in Brazil, Ghana, India, Norway, Oman, and the US. The WHO sample population only included breastfed infants and measured infant weight and length every two weeks for the first two months and monthly thereafter. Similar to previous findings, a comparison of the 2006 WHO Child Growth Standards to the 1977 NCHS/WHO international growth reference showed significant differences in infants. The mean weight-for-age z-scores of infants in the first six months were higher for the 2006 WHO standards compared to the 1977 NCHS/WHO growth reference. After six months the 2006 WHO standards fell below the 1977 NCHS/WHO values. One significant limitation of the 1977 NCHS/WHO standards was the finding that prevalence of low height-for-age was higher for all age groups using the 2006 WHO standards, particularly for early infancy.²⁶⁹ More recent data indicates significant limitations in the 1977 NCHS/WHO standards. Among children screened for severe malnutrition in a Médecins sans Frontières (MSF) program in Niger, the 2006 WHO standards identified more than eight times the number of severely malnourished children compared with the 1977 NCHS/WHO standards (25,754 versus 2,989 children). The implications are significant. Children identified as severely malnourished according to the 1977 NCHS/WHO standards were less likely to recover and more likely to be lost to follow-up compared to those identified by the 2006 WHO standards. In addition, there was a greater likelihood of hospitalisation and death among those children identified by the 1977 NCHS/WHO standards compared to the 2006 WHO standards.²⁷⁰

Based on this data, it is clear that the new (2006) WHO standards more accurately assess childhood malnutrition in developing countries, particularly in settings where the large majority of infants are breastfed. However, many settings in the field still use the old (1977) NCHS/WHO standards due to poor technical assistance and capacity building in countries with a high burden of malnutrition. The WHO delayed the creation of these charts and has also failed to update its own manual regarding the management of severe malnutrition.²⁷¹ In addition, only in 2008 has the WHO updated the Integrated Management of Childhood Illness (IMCI) training booklet and the Manual for the Health Care of Children in Humanitarian Emergencies with the new WHO nutrition standards.^{272,273}

There was documented recognition of problems with the 1977 NCHS/WHO references by the WHO as early as 1995, but no efforts were made to change the standards until 1997, and new standards were finally published 11 years after acknowledgement of the problem. While 20 million children suffered from malnutrition yearly, health care workers often continued to use charts that were inaccurate. The delay in acting to change these charts in a more expeditious manner was at the expense of children's lives. More than two years after the introduction of their new growth charts, the WHO has still not updated some of its manuals for health care workers, meaning many continue to use references published nearly 30 years ago. This is evidenced by UNICEF's recent State of the World's Children 2009 report, which provides prevalence estimates of being underweight using the 2006 WHO standards; however, prevalence rates of wasting and stunting are still provided using the 1977 NCHS/WHO standards.²⁶⁰ UNICEF states in the 2009 report that '*the WHO Child Growth Standards are gradually replacing the widely used NCHS/WHO reference population [standards]*'.²⁶⁰ This suggests that many countries have not changed their growth reference standards and continue to

under-diagnose children who are malnourished. It is concerning that it took more than a decade to develop growth standards appropriate for developing countries. Offering technical assistance and capacity building for these countries falls within the WHO's mandate, but over the past three years the WHO has demonstrated significant delay and has failed to adequately support the dissemination and appropriate use of these standards in countries with a high burden of malnutrition.

The WHO has been tasked with setting international standards for health. As a multilateral agency it has the responsibility of not delaying progress towards developing more accurate nutrition standards and for finding gaps in the uptake and implementation of the revised standards. Children have unnecessarily suffered the consequences of ignoring recognized problems in nutrition standards for years. The same problem has extended to the WHO malnutrition guidelines, which have fallen short in the management of chronic malnutrition. The WHO website for publications offers no standards for care or management of children with chronic malnutrition, despite their own acknowledgement that this condition causes poor growth which can result in delayed brain development and a reduced capacity to learn.²⁷⁴

At a time where there is consensus about accountability, Rwanda, among other countries, has agreed to be part of the NEPAD (New Partnership for Africa's Development) Peer Review for Joint Assessment of the Government. There is agreement that accountability is necessary not only for the Government, but also developing partners and civil society, but people have been silent about the accountability of multilateral organizations like the World Health Organization. Many developing countries depend on the WHO to provide them with accurate information. Since they often do not have the resources themselves to remain up-to-date, it is vital that they can rely on the WHO to quickly make available and widely disseminate the standards that reflect the highest standard of care. The question remains: if we know the right thing to do, and we know the consequences it may bring, why do we continue to do wrong?

7.2. Under-diagnosis of Malnutrition in Infants and Young Children in Rwanda

**The following chapter is a partial reprint from an article on which I am first author: "Under-diagnosis of Malnutrition in Infants and Young Children in Rwanda: Implications for Attainment of the Millennium Development Goal to End Poverty and Hunger"; permission has been granted from the International Journal for Equity in Health for the reprinted text.*

I conceived the original idea and the research question, provided direction on the research implementation and the context of the health sector in Rwanda, led a literature review, led the data collection, performed the data analysis and interpretation of results. I was the lead in writing the manuscript.

Introduction

Over three million deaths occur from protein-energy malnutrition (PEM) in children under five worldwide annually.²⁷⁵ The burden of malnutrition in the developing world accounts for a large majority of these deaths, where one in four children under five are underweight. Based on this level of malnutrition it is unlikely that the MDG1 goal of eradicating extreme poverty and hunger will be attained by the year 2015.²⁵ In Rwanda, an estimated 44% of children under five suffer from chronic malnutrition.²⁷⁶ The Ministry of Health estimates malnutrition as one of the ten leading causes of death for children under age five. Hidden or unreported malnutrition contributed to more than half of child deaths.²⁷⁷ The substantial burden of infectious disease contributes to the high rate of malnutrition among children, leading to negative effects on

growth, as well as increased vulnerability to future occurrences of infection. Improved nutrition can reduce child morbidity and mortality related to infectious disease, as adequately nourished children are more likely to fight and recover from an infection, to avoid the negative effects of infection on growth, and to resist the repeated occurrence of infection.²⁶²

Malnutrition is not only seen in adults and children in the later stages of HIV infection. Signs of nutritional and metabolic imbalances, including wasting and stunting, may exist in the early stages of HIV infection.^{278,279} In asymptomatic adults and children who are HIV-positive, basal metabolic rates are 10% higher on average than an HIV-negative person of the same age, height, and weight. Furthermore, the basal metabolic rate increases 20-30% more during episodes of OI.²⁵⁸ Increases in basal metabolic rate occur at the same time as a decrease in physical activity.²⁸⁰ Given the new difference in energy expenditure, it is not surprising that malnutrition is a common presentation among people living with HIV and AIDS (PLHA).

Changes in metabolism and energy intake are also highly important. Protein wasting alters protein turnover, which may be responsible for the decreased muscle mass associated with HIV status.²⁸¹ The change in body composition may also be linked to nutrition. Serum lipid and protein levels are depressed in HIV-positive individuals, but normal food intake which regularly includes animal protein, is less frequently accompanied by anomalies in serum macronutrient levels.²⁸² Unfortunately, many families in Rwanda and Africa cannot afford to eat adequate portions and varieties of protein.

Even with good nutrition, however, gastrointestinal dysfunction caused by inflammation, infection, diarrhoea, and other problems can lead to dehydration and severely decrease macronutrient and micronutrient absorption capacities.²⁸³ For children in developing countries in particular, chronic diarrhoea and microbial infection can lead to problems in absorption that persist even in the absence of acute disease.²⁸⁴ Intestinal derangement may also exist as a primary HIV-associated syndrome, but the mechanism is not well understood.²⁸⁵ Overall, such gastrointestinal dysfunctions may cause micronutrient deficiencies, wasting, stunting, further immune impairment, and death.^{286,287} Moreover, there are other mechanisms that cause hypophagia associated with HIV, including loss of appetite and nausea related to HIV-associated illness or medications, trouble swallowing or other oral problems, psychological factors, stigma, and poor access to food.^{288,289,290}

Unfortunately, children appear most vulnerable to HIV-associated changes in metabolism, as they are growing and have more energy needs per kilogram of body weight compared to adults because of the additional energy requirement in their stage of development.²⁹¹ Children have fewer energy reserves in the form of body fat and have lower muscle mass than adults, so any changes in nutrition and metabolism have a more direct impact on protein synthesis, basic physiologic function, growth, and immune responses.²⁹² The high levels of malnutrition in the general population in Rwanda mean that it is imperative to know whether our understanding of malnutrition among children affected by or infected with HIV is a major shortcoming of the national HIV response in Rwanda.

Due to the high prevalence of malnutrition in children under five and the implications for morbidity and mortality, it is essential that health professionals and paraprofessionals have access to the best tools possible for determining a child's general nutritional status in community, health center and hospital settings.

This section examines the growth references used prior to 2009 in Rwanda to assess the nutritional status of children under the age of five, and outlines the problem of the limited

capacity to identify malnourished children due to inadequate technical input from national and multinational experts. In addition, the section describes the process in which the growth references used in Rwanda were updated to correspond with the international standards developed by WHO in 2006.²⁶⁴

Before May 2009, health facilities in Rwanda used graphs in a booklet with a growth chart of children's health published by the MOH with the support of Development partners, and entitled *Ifishi Y'Ubuzima Bw'umwana (Child Health Card)* for children less than 1 year, and for children greater than 1 year and less than 5 years as the growth references for measuring malnutrition. The graphs, were used to track children's growth based on weight-for-age. The growth charts were used for the purpose of detecting and monitoring malnutrition in all Rwandan children under five years of age in Rwanda. The booklet was given to all caregivers of children in Rwanda at the time of the first diphtheria, pertussis, tetanus (DPT) vaccination (DPT1) of the child in governmental, as well as non-government, clinics throughout the country (prior to the development of the new guidelines coverage for the DPT1 was 96% in 2007).²⁹³ Parents were instructed to bring the booklet to subsequent vaccination appointments so that weight-for-age could be measured regularly and malnutrition could be readily identified and treated.

Design

Please refer to Chapter 4 for the methodology.

Findings

Comparing the Growth Charts

As evidenced in Table 28, children below one year, fall under two different categories, indicating that the *Ifishi Y'Ubuzima Bw'umwana* for infants the less than 1year chart does not follow the most current international standards for malnutrition growth monitoring. As a result, some children who are severely malnourished will be sent home with no nutritious or therapeutic food or hospitalisation care when it needed. For example, a six-month-old boy weighing 4 kilogrammes would be classified as severely malnourished under the 2006 WHO growth standards and require hospital admission given the high risk of mortality. Using *Ifishi Y'Ubuzima Bw'umwana*, this same child would be classified as being of normal weight and would therefore be sent home without further assessment or treatment.

Table 28: Weight-for-age charts of WHO compared to Ifishi Y'Ubuzima Bw'umwana for infants <1year.

Age of male infant (months)	Weight (kg)	2006 WHO growth chart classification	IFIHI Y'UBUZIMA BW'UMWANA classification < 1 year (2009 Rwandan Growth Chart)
1	2.9	Severely malnourished	Normal /healthy
2	3.7	Severely malnourished	Normal /healthy
3	4.4	Severely malnourished	Normal /healthy
4	4.9	Severely malnourished	Normal /healthy
5	5.3	Severely malnourished	Normal /healthy
6	5.7	Severely malnourished	Normal /healthy
7	5.9	Severely malnourished	Normal /healthy
8	6.2	Severely malnourished	Normal /healthy
9	6.4	Severely malnourished	Normal /healthy
10	6.6	Severely malnourished	Normal /healthy
11	6.7	Severely malnourished	Normal /healthy
12	6.9	Severely malnourished	Normal /healthy

Figure 18 below shows how *Ifishi y'ubzima* for children <1 year used before 2009 is under standard compare to WHO 2006 and to *Ifishi y'ubzima* for children <1 year used after 2009.

Figure 18: Comparing measurements of severe malnutrition: child's age in months.

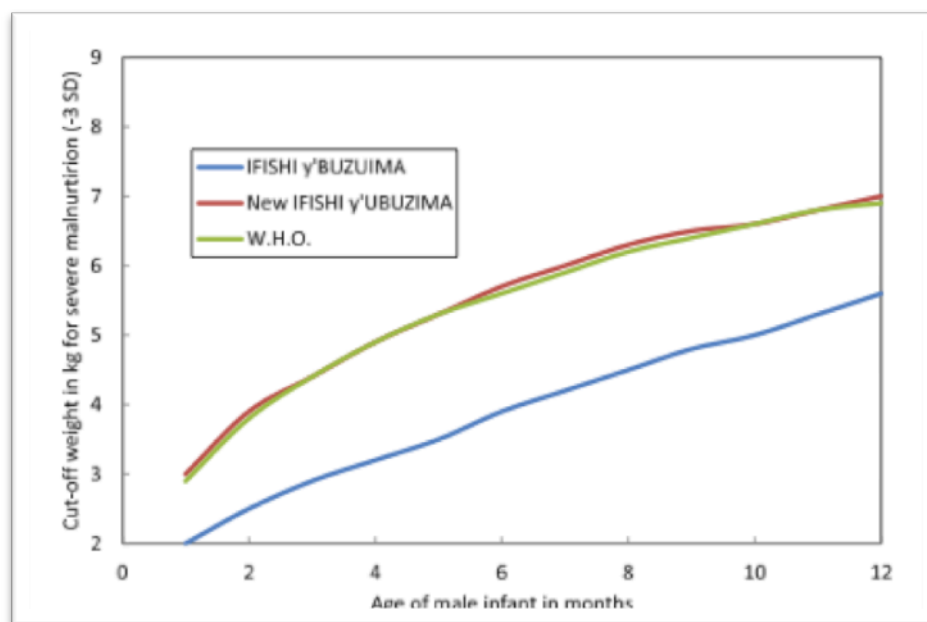
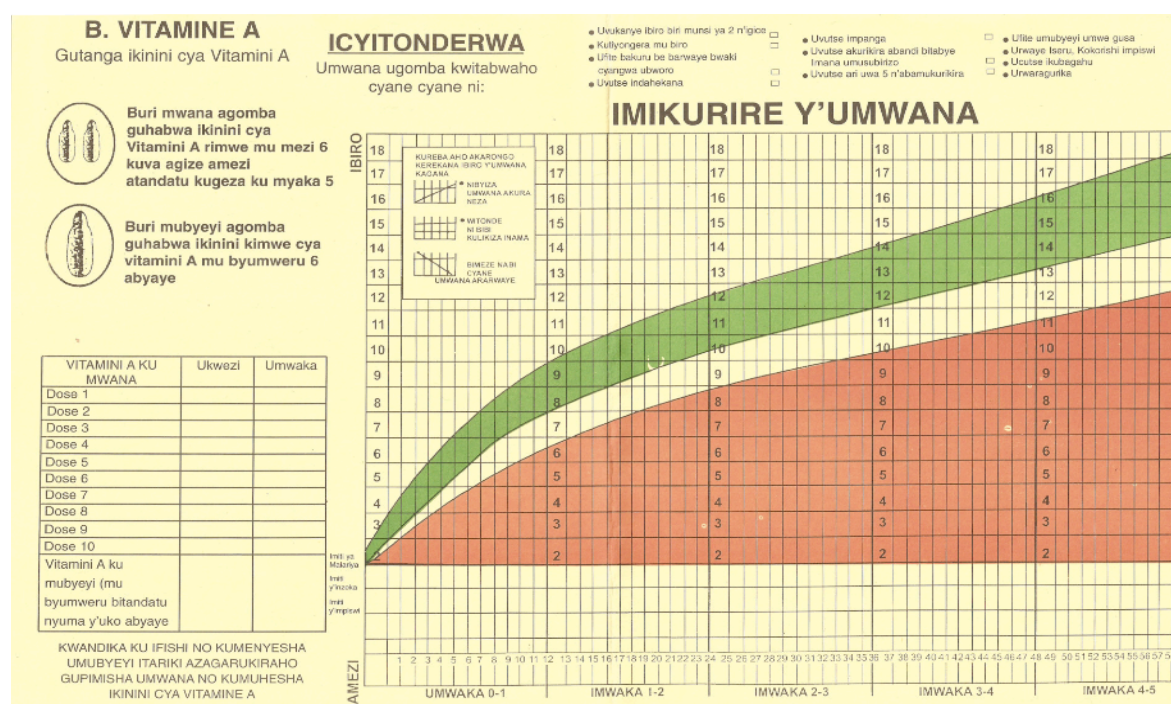


Table 29: Weight-for-age charts of WHO compared to Ifishi Y'Ubuzima Bw'umwana for children >1year.

Age of male infant (years)	Weight (kg)	2006 WHO growth chart classification	IFIHI Y'UBUZIMA BW'UMWANA classification (2009 Rwandan Growth Chart)
1 year (12 months)	6.9	Severely malnourished	Normal/healthy
2 years (24 months)	8.6	Severely malnourished	Moderately malnourished
3 years (36 months)	10.0	Severely malnourished	Moderately malnourished
4 years (48 months)	11.1	Severely malnourished	Moderately malnourished
5 years (60 months)	12.2	Severely malnourished	Moderately malnourished

Table 29 shows that children between the ages of one year and five years, fall under two different categories, indicating that the Ifishi Y'Ubuzima Bw'umwana for infants >1year, the >5years chart does not follow the most current international standards for malnutrition growth monitoring. As a result, some children who are severely malnourished were sent home without nutritious or therapeutic food, or hospitalization when it is needed.

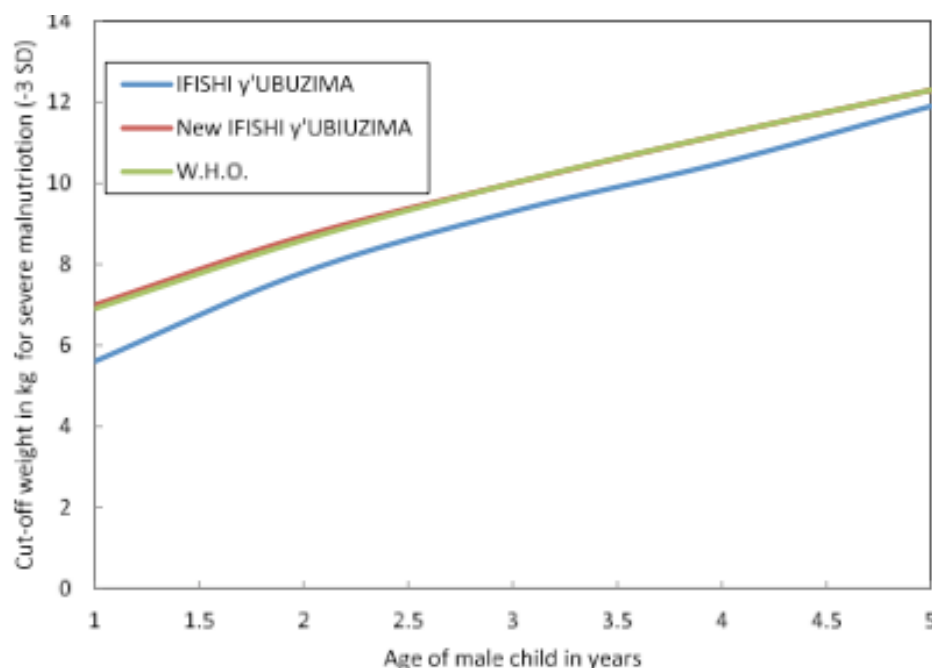
Figure 19: imikuririe y'umwana, (Ifishi Y'Ubuzima Bw'umwana for infants >1year) old growth chart used before 2009.



When comparing the old growth charts, below, *imikurire y'umwana* (*Ifishi Y'Ubuzima Bw'umwana* for children <1year) (Figure 19) used before 2009, in Rwanda by all health centers, with the 2006 WHO growth chart, the difference in diagnosis is stark.

Figure 20 below show how *Ifishi y'ubuzima* for children > 1 year and < 5 years used before 2009 is under standard compare to WHO 2006 and to *Ifishi y'ubuzima* for children >1 year and < 5 years used after 2009.

Figure 20: Comparing measurements of severe malnutrition: child's age in years.



We interviewed health professionals at all levels of the health sectors and reviewed reports and policies but we did not find the origin of the design of the two *Ifishi y'ubuzima* for children <1 year and children >1 year and < 5 years, used before 2009.

Between 2006 and 2009, following the release of the new WHO standards, UN agencies in Rwanda continued to advise on, have provided fund for the printing, for the facilitation, for the dissemination and training on the use of the *Ifishi Y'Ubuzima Bw'umwana* for children <1 year and the *Ifishi Y'Ubuzima Bw'umwana* for children >1 year and < 5 years, two inaccurate growth monitoring charts. This occurred despite representation in the Ministry of Health's Technical Working Group on Nutrition (TWG) of the UN agencies. The TWG was created to advise the Ministry of Health and had full access to all information related to the 'rolling out' of the new 2006 WHO growth standards.

Discussion

UNICEF and WHO are international normative institutions for health and wellbeing. In Rwanda, UNICEF and WHO country experts were the members of the Technical Working Group on Nutrition important group for advising on monitoring and care given around malnutrition. They did not perform their role in advising the Government, that the care being provided was not based on accurate diagnostic tools. The tools recommended were found to be sub-standard.

The example from Rwanda is not isolated, and may be indicative of similar evaluation problems in other countries. Through a study conducted in a malnutrition treatment program in Maradi, Niger, it was demonstrated that the revised growth standards and cut-off points for malnutrition under the updated 2006 WHO guidelines offered more sensitive and accurate assessment, which were related to shorter durations of treatment and lower mortality rates for malnourished children.²⁷¹

In order to ensure accuracy, particularly when new international guidelines and protocols are brought forward for national adoption, the technical agenda of international organizations (WHO, UNICEF, and the United Nations Population Fund (UNFPA)) should prioritize an annual review of the accuracy of tools and guidelines in high burden countries.

Utilising accurate and updated measurement standards can have far-reaching effects that transcend the immediate indicators observed. As nutrition is linked to physical and cognitive growth, as well as to the management and progression of some infectious diseases such as TB and HIV, the updated standards have the potential to increase the identification of children suffering from infection. This may lead to earlier detection of TB and/or HIV and better survival rates and outcomes, particularly for children who are found to be acutely malnourished, since TB is difficult to diagnose in children.²⁹⁴ As higher numbers of children in Rwanda are now more likely to be treated for malnutrition, those also suffering from TB and HIV will also benefit, therefore promoting better health overall. Malnutrition and infectious disease in a child under five years of age can have a negative lifetime effect on their emotional and intellectual development.²⁹⁵ At the societal level, malnutrition can inhibit a country's long-term economic development, since economic growth is contingent upon a healthy and productive workforce.²⁹⁶

What has been done to address the situation

This situation was documented for this research and the discrepancies that existed between the 2006 WHO standard growth chart and the *Ifishi Y'Ubuzima Bw'umwana* for children <1 year and

the *Ifishi Y'Ubuzima Bw'umwana* for children > 1year and <5 growth charts were reported to the authorities of the MOH at the end of 2008. In response, the movement to correct the tools and guidelines started in the MOH with the support of the TWG and the Rwandan Pediatric Society.

The new national growth charts (Figures 21 and 22) were finalised in early April 2009, then produced and distributed in May 2009. The new charts are used in all health facilities in Rwanda and are available on the Internet, and in hard copy form at 426 health centers and 42 district hospitals.²⁹⁷

Figure 21: *Ibiro By'Umwana W'Umukobwa Ukurikue Imyaka (Ifishi Y'Ubuzima Bw'umwana for children > 1year, <5) - The new and correct growth chart for girls currently used to monitor malnutrition in Rwanda.*

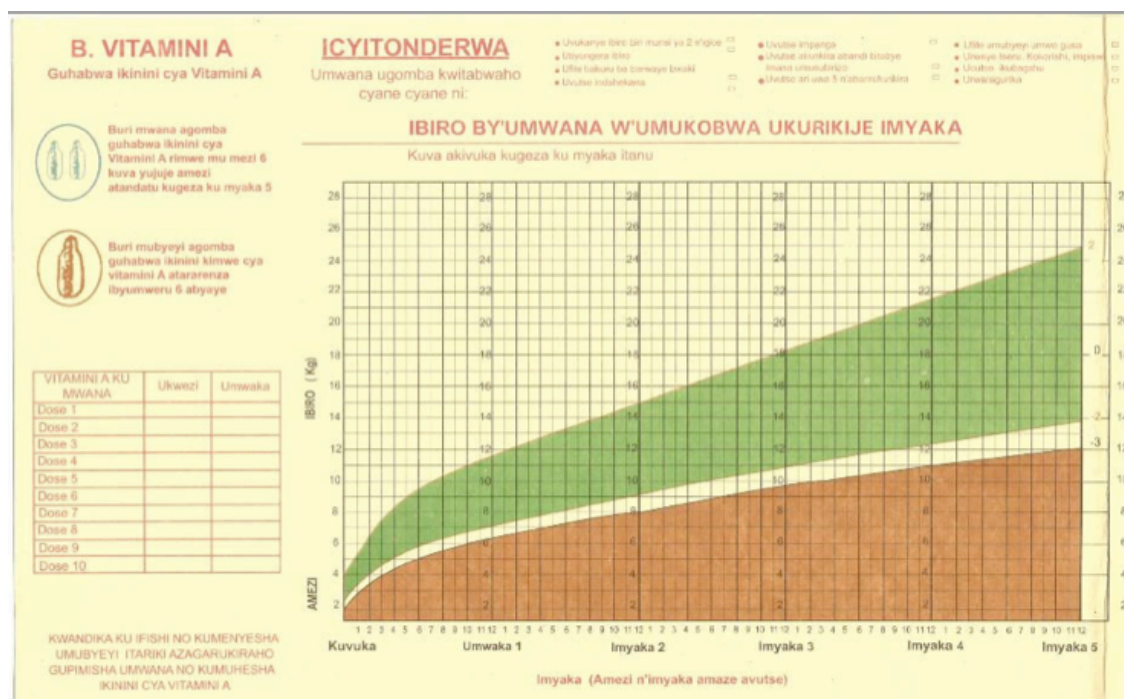
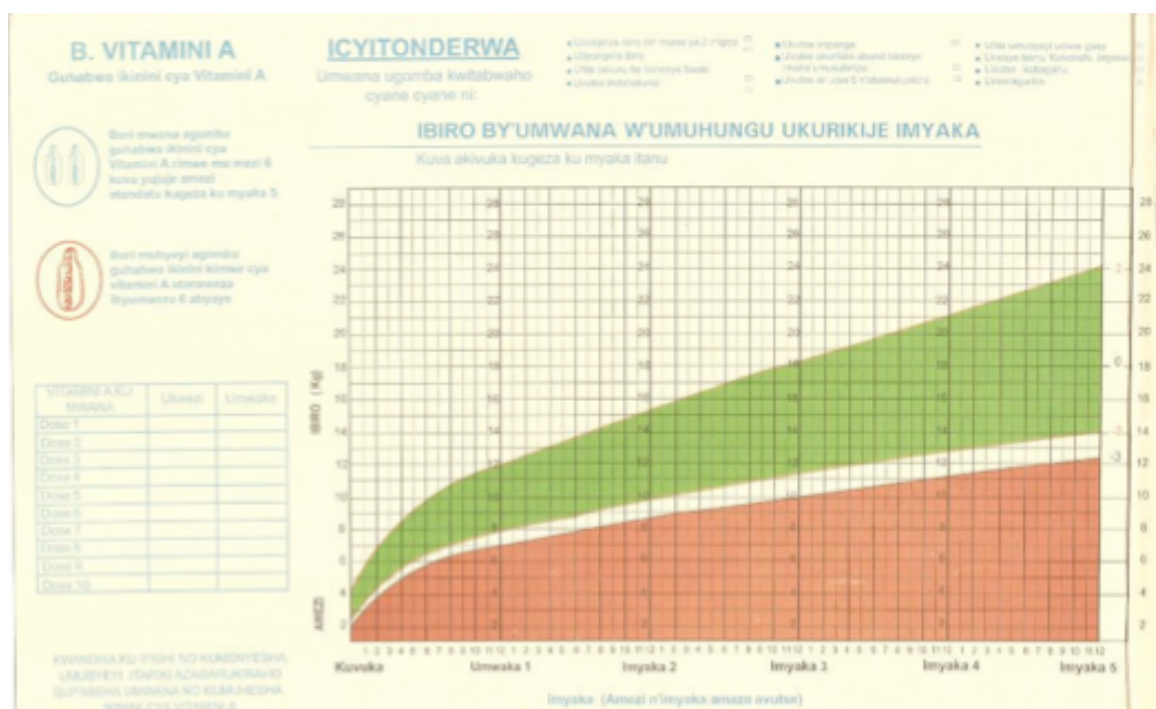


Figure 22: Ibiro By'Umwana W'Umukobwa Ukurikue Imyaka (Ifishi Y'Ubuzima Bw'umwana for children > 1year, <5) - The new and correct growth chart for boys currently used to monitor malnutrition in Rwanda.



Chapter 7 presented results about Period Three of life, the period between the end of any possibility of MTCT to that of the age of reasoning. It has showed that the inappropriate growth monitoring and nutritional frameworks were threats to the health of children affected by HIV. The delay in producing proper guidelines and protocols to diagnose and treat malnutrition, as well as not providing context-appropriate advice to the Government, has denied malnourished children their right to health. The next chapter will show the results of the period when a child can participate in the exercise of their right to health.

Chapter 8: Results of Period Four – from seven to fourteen years old

This period, when a child is between seven and fourteen years old, contrasts with the other periods because in this age-range, children can better understand their situation and express themselves. Depression is often co-morbid with chronic illnesses and can negatively impact the health outcomes of other diseases.²⁹⁸ HIV infection can now be considered a chronic disease when the person who is HIV-positive is on ARV.¹³⁰ We should assess children affected by HIV to ensure they have access to mental health care and treatment if needed. In the Rwanda context this is important due to the 1994 violence during the genocide against the Tutsi.

No tool has been validated for quick assessment of child depression in Rwanda, which is an obstacle to providing mental health care to children affected by HIV in need. This research validated a tool to ensure that depression can be easily diagnosed in children affected by HIV.

8.1. Validating the Childhood Depression Inventory

The following text is part of a paper ready for publication (submission to the Journal of Pediatrics): “Validation of the CDI in the Rwandan context”.

I conceived the original idea and the research question, provided direction on the implementation of the research and the context of the health sector in Rwanda, conducted a literature review, led the data collection, performed the data analysis and interpretation of results and I was the lead in writing the manuscript.

Introduction

Depression has been a significant burden on people living with HIV and AIDS (PLHA) and can result in an increased risk of opportunistic infection and mortality.³⁰⁰ In Rwanda, antiretroviral medications are available throughout the country and increased survival has resulted in HIV becoming a chronic illness in this context. However, prior research has demonstrated that those with chronic conditions are at a higher risk of depression. Depression among HIV-positive people has been extensively documented in various studies, with depression noted to be the most common psychiatric illness that affects people living with HIV and AIDS (PLHA) depressive symptoms.²⁹⁹ Within the context of HIV, depression has been associated with reduced adherence to ARV and poorer quality of life. Depression is also associated with a lowered health status, increasing viral load, decline in CD4 count and decreased quality of life amongst people with a positive HIV status.^{300,301} Depression is also linked to decreased adherence to antiretroviral treatments.³⁰²

Among children living with HIV, depression has also been documented as being co-morbid, similar to other chronic diseases that require life-long treatment.²⁹⁶ Therefore, it is vital that the mental health needs of children living with HIV are prioritized in national health programs, but

thus far, the mental health care in this high risk population has been neglected, particularly in settings with limited resources.³⁰³

The mental health needs of children are likely to be greater in Rwanda given the history of trauma. It has been shown that when a community experiences widespread trauma which massively affects social and cultural units, children of the following generations often continue to display symptoms of psychological trauma.^{304,305} Depression among children has been evidenced in Rwanda and mental health care should be a high priority, in part due to the legacy of genocide and the impact on the next generations.^{305, 306}

Given the history of trauma coupled with the impact of HIV on children, there is an urgent need to identify those suffering from depression to increase access to treatment and also improve HIV-related outcomes. Therefore, screening for depression needs to be integrated into treatment for children living with HIV in this setting. In Rwanda when a child is confirmed to be seropositive, there is systematic – though basic – psychological support intervention consisting of counseling at the health facility. Rwandan children with depression are not treated in health centers, they are treated at district hospitals and receive psychotherapy and, if needed, medication is provided by nurses and medical doctors trained in mental health care.³⁰⁷ They also have access to psychiatrists in referral hospitals if needed. However, there are only seven psychiatrists in Rwanda. Therefore, providing mental health care at the district level in correspondence with HIV treatment is important for improving access to care and may also result in secondary prevention whereby children living with HIV who present with depression may not need treatment that would be typically offered at referral hospitals.

Despite this critical need for care, there is currently no screening instrument for depression that has been validated among children living with HIV in Rwanda. It has been demonstrated that mental health assessments developed in the U.S. or Europe cannot be used in other countries unless there is local adaptation and validation of the instrument for that setting. Given that care is provided at the district level, a simple screening tool for depression at this point of care would greatly increase access to mental health services for this at risk population. Therefore, the primary aim of this study was to examine the reliability and validity of a commonly used measure of depression, the Children's Depression Inventory (CDI), among a group of children living with HIV receiving antiretroviral treatment. The CDI has never been validated in an African setting, even though many studies have used it in other African countries to evaluate rates of depression amongst children.^{308, 309} It is crucial that such a screening tool be evaluated as appropriate to the Rwandan environment, as mental health disorders can often manifest in different ways depending on the cultural context.

Validating the CDI for the Rwandan context raises methodological challenges. The process must be rigorous in order to ensure standardised results across different groups who are interviewed by different health professionals in order that the tool be universally trusted by health professionals, institutions, and the end users and their families.^{310, 311}

Methods

Please refer to Chapter 4 for the methodology.

Findings

Table 30 presents the socio-demographic characteristics of study participants. Fifty-seven percent of the participants were female and 93% were currently enrolled in primary school.

Thirty-three percent of the participants were from urban settings and 20% were from each of the five provinces, in correspondence with the sampling strategy for the study. Supported and non-supported sites were equally represented (50% for each group).

Table 30: Characteristics of respondents in the CDI validation (N=100).

	N
Residence	
Urban	33
Rural	67
Province	
East	20
Kigali City	20
North	20
South	20
West	20
Does the health facility have a support group?	
Non-supported	50
Supported	50
Sex	
Male	43
Female	57
Education level	
Primary	93
Secondary	6
Vocational	1
Are parents alive?	
Both alive	35
One dead	46
Both dead	19

Table 31 demonstrates the distribution of socio-demographic characteristics by children who were depressed versus not depressed according to the structured clinical assessment. A statistically significant finding was observed for province, whereby 75% of the children in the Western Province were depressed, as compared to five percent in Kigali City ($p < 0.001$). Other differences were observed, although given limited statistical power the findings were not significant. A trend was observed whereby over 28% of participants residing in rural areas were depressed versus 18% in urban areas ($p = 0.331$). Nearly 30% of girls were depressed versus 19% for boys, although this finding was not statistically significant ($p = 0.247$).

Table 31: Characteristics of respondents by presence or absence of clinical depression in CDI validation (N=100).

	Depressed N=25	%	Not Depressed N=75	%	Total N=100	P- Value
Residence						
Urban	6	18.2	27	81.8	33	0.331
Rural	19	28.4	48	71.6	67	
Province						
East	2	10	18	90	20	0.000
Kigali City	1	5	19	95	20	
North	2	10	18	90	20	
South	5	25	15	75	20	
West	15	75	5	25	20	
Is the health facility supported?						
Non-supported	11	22	39	78	50	0.645
Supported	14	28	36	72	50	
Sex						
Male	8	18.6	35	81.4	43	0.247
Female	17	29.8	40	70.2	57	
Education level						
Primary	24	25.8	69	74.2	93	0.108
Secondary	0	0	6	100	6	
Vocational	1	100	0	0	1	
Are parents alive?						
Both alive	10	28.6	25	71.4	35	0.790
One dead	10	21.7	36	78.3	46	
Both dead	5	26.3	14	73.7	19	

Table 32 provides estimates of sensitivity and specificity at varying cut-off scores of the CDI using the clinical assessment as the gold standard. The sensitivity ranged from 72% to 44% for cut-off scores of six and nine, respectively. For specificity, estimates were from 97% to 100% for the same cut-off scores.

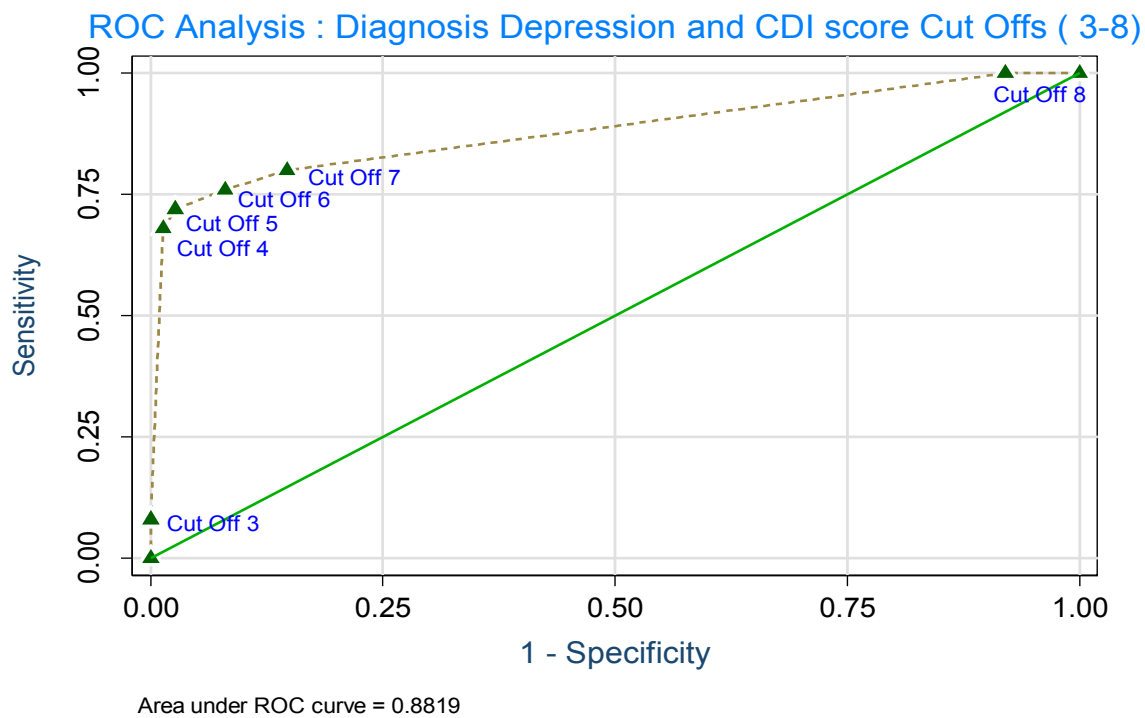
Table 32: Correlation between CDI Scores and Diagnosis of Depression.

		CDI score				
		>6	<=6		Sensitivity:	0.72
Depressed	Yes	18	7		Specificity:	0.97
	No	2	73			
		CDI score				
		>7	<=7		Sensitivity:	0.64
Depressed	Yes	16	9		Specificity:	0.97
	No	2	73			
		CDI score				
		>8	<=8		Sensitivity:	0.60
Depressed	Yes	15	10		Specificity:	0.99
	No	1	74			
		CDI score				
		>9	<=9		Sensitivity:	0.44
Depressed	Yes	11	14		Specificity:	1.0
	No	0	75			

Note: Due to the small sample the Fisher Exact test was used

Based on Recipient Operating Characteristics (ROC) analysis, the area under the curve (AUC) was 0.88, demonstrating a fair degree of accuracy of the CDI as compared to a structured diagnostic interview as the gold standard (see Figure 23).

Figure 23: ROC Analysis: Diagnosis of Depression and CDI Score Cut-offs (3-8).



A CDI cut-off score of 6 demonstrated a high area under the curve, estimated at 0.88. The CDI cut-off score of 6 has a sensitivity of 72% and a high specificity of 97 %.

Discussion

Children living with HIV are at risk of major depression, due in part to the social isolation and stigma that may accompany the disease as well as uncertainty about their future. In Rwanda, since treatment for HIV is more widely available for children living with HIV, the disease has become a chronic condition. Depression is often co-morbid with chronic illness, and as HIV-related survival has improved substantially it is important to consider strategies for identifying and treating major depression among children living with HIV.

Results demonstrate the feasibility of administering a screening measure for depressive symptoms among children receiving HIV treatment in Rwanda. Based on ROC analysis, the overall accuracy of the CDI was good (AUC = 0.88). A cut-off score of six demonstrated reasonable sensitivity (72%) and excellent specificity (97%). This is in contrast to the cut-off score of 7 used with American pediatric populations, suggesting that a lower threshold of symptoms may reflect a need for mental health care in this context.¹⁵⁰

Findings from this study indicated that socio-demographic factors such as urban or rural residence, sex, and educational level were not statistically significantly associated with depression in this population. This may be due to limited sample size, given that expected trends were observed for some variables. For example girls had a higher prevalence of depression as compared to boys (30% versus 19%) this is a difference that has been noted in other studies.³¹²

Those with a secondary level of education demonstrated a protective effect as compared with those at a primary or vocational level of education (0% versus 27%) although these differences were not statistically significant. However, children receiving ARV in the Western Province were at the highest risk of depression. Consideration of geographical variation in the burden of depression in this population may be necessary in planning the roll out of services that accompany screening activities. Research is underway to better understand why the level of depression is higher in that area, examining risk factors such as history (impact of genocide) and other health risks (malnutrition). Poverty may also play a role, since children receiving ARV in rural areas were at higher risk of depression (28%) as compared with those in urban settings (18%), although this finding was not statistically significant. Therefore, broader initiatives in poverty reduction in Rwanda, a key priority of the government, may in the long-term have an effect on the burden of depression among children living with HIV.

There are some limitations to the study. One is the small sample size - a greater number of study participants would improve statistical power. Some of the null findings outlined above may be due to limited statistical power. However, since the research also involved in-depth clinical evaluations, logistically it would not have been feasible to recruit a large number of children in our study population. In addition, due to the random selection process among children living with HIV receiving treatment there was not an equal number of depressed and non-depressed participants which also limits the statistical power of the study. One other limitation is that the clinical evaluations took place over the course of one day. It often takes many sessions for a child to open up to a mental health provider, and interviews with the child's caregivers and school teachers are frequently held to provide a more in-depth assessment of the child's mood and other depressive symptoms as they relate to a level of severity comparable with major depression. Finally, since this validation study was conducted with children living with HIV receiving care, the findings may be limited in terms of generalizability to children by age group, and the age groups were not evenly divided by sex.

Although the CDI demonstrated a very good specificity in this population (97%), the sensitivity (72%) was fair at this level of specificity. This is to ensure that false-positives are minimized given limited resources for mental health care in Rwanda. However, the lower sensitivity can result in not detecting over 25% of children who may need care for depression. Future studies should examine inclusion of symptoms locally derived so that sensitivity in identifying depression using a screening tool can be increased.

A highly sensitive screening tool would be needed among children living with HIV, as demonstrated by results from the structured clinical interview that demonstrated a prevalence of depression of 25%. There is a need to develop Rwandan policy to address routine screening for depression among children living with HIV. Given the expansion of access to HIV treatment, an initial target population can be among children receiving care. Caring for the mental health of this population may result in improved adherence and survival. It has also been documented living with HIV can have a negative impact on one's quality of life. Mental health care may also provide them with more hope and aspiration for the future – a feeling that often is associated with depression. Increased hope may also translate into children living with HIV to take better care of their own health as adolescents, and as adults in the future.

An additional consideration is that depression is associated with high risk behavior and substance abuse, which can increase the risk of re-infection with HIV and further transmission of the virus.³¹³ This is relevant because the RDHS surveys have shown that children under 15 are having sex. Within pediatric populations, such actions are of particular concern among adolescents; having a policy of routine screening, treatment, and follow-up for depression

among children living with HIV could help to keep prevalence rates low among Rwandan adolescents and young adults.

The increased health benefits of treating depression can be seen with other chronic conditions. In patients with diabetes, for example, a number of studies have linked depression to poor glucose control, increased hypo- and hyperglycemic symptoms, increased rates of diabetes complications, and higher glycosylated hemoglobin values.²⁹⁹ For patients with asthma, one study found a possible association between depression and asthma morbidity and mortality. These results show that it is important to screen for depression in children suffering from all chronic diseases, not only HIV. There is no statistically significant finding in the difference between depression among the orphan and the non-orphan. This is contrary to other studies, which have found AIDS-orphans to have higher rates of depression and other mental health issues compared to non-orphans.^{314,315,316,153,154,317} Such a result may be explained by the small sample size of the study as such the rate of depression within different demographic groups should not be generalised to the greater Rwandan pediatric population.

By using a quick, easy to interpret screening tool for depression, the goal of increasing access to necessary mental health services among this age group is achievable for Rwandan national health policy. Such a screening tool is crucial, as depressed children often do not report their symptoms to their parents, teachers or school workers.³¹⁸ Moreover, such a goal is revolutionary, as no African government has yet dedicated resources to routine screening of children at risk for depression, nor has a policy been put in place that will systematically provide treatment to those in need.

8.2. The Child's Rights to Health Information and to Participate in Health Decisions

The following section is a partial reprint from an article on which I am first author: "Adolescents and the Right to Health: Eliminating Age-Related Barriers to HIV/AIDS Services in Rwanda"; permission has been granted from AIDS Care for the reprinted text.

I conceived the original idea and the research question, provided direction on context of the health sector in Rwanda, conducted a literature review, led the desk review, performed the analysis and interpretation of results and I drafted the manuscript.

Introduction

Adolescents have been identified as a priority target group in the national Rwandan AIDS policy.³¹⁹ Forty-two per cent of Rwanda's population is currently fifteen years of age or below.³²⁰ However, the needs of adolescents are often lost in the larger discussion about people living with HIV/AIDS (PLHA).³²¹ Despite robust programming at national and local levels, inadequate data and coordination have led to adolescents being underrepresented in many countries' prevention, testing, treatment, and support programs - Rwanda is no exception.³²¹

For Rwanda, this contradiction highlights a serious shortcoming in the country's legal and policy framework for providing adolescents with HIV/AIDS services. Under international, regional, and domestic law, all adolescents are entitled to measures ensuring the highest attainable standard of health.^{322,323,324} However the legal provision that addresses the age of consent to medical treatment in Rwanda still needs more clarity.

Despite the gains, HIV remains a threat. It has major implications for individual, family, social, and economic stability. PLHA are a vulnerable population, and adolescents especially so because they lack many social and economic protections to mitigate the effects of the

disease.^{325,326} Rwanda is among several countries working to reconcile inconsistent medical and legal standards for providing adolescents with HIV/AIDS services. This section identifies gaps, policy barriers, and inconsistencies in legal protection in Rwanda that may create age-related barriers to HIV/AIDS services and care. The following section occasionally draws comparisons with existing and proposed laws in other African countries.³²⁷

Methods

Please refer to Chapter 4 for the methodology.

Findings

Existing legal framework

The definition of a child varies from country to country and from one international body to another.

According to the Convention on the Rights of the Child (CRC), majority is attained at the age of 18 except where national law specifies an earlier age.²¹⁰ UNAIDS defines children as individuals aged zero to fourteen years.³²⁸ However, the World Health Organization's definition of an adolescent is all persons between ten and nineteen years of age, a definition, which straddles the period between childhood and adulthood. In Rwanda, the definition is similarly ill-defined. Persons are considered criminally responsible for their actions at the age of fourteen. They may work³²⁹ and register for identity cards at the age of 16.³⁴⁹ Rwandans may claim citizenship, vote, and serve in the military at the age of 18.^{330,331,332} Finally, by the age of twenty one, individuals reach full legal capacity for all civil matters, including marriage.³³³

The question of age has troubled the Rwandan legal framework for HIV. Over the past decade, Rwanda has instituted progressive policies to help stem the spread of HIV, promote the wellbeing of PLHA, and coordinate a multi-sector response to the disease.³³⁴ Such efforts have reinforced Rwanda's commitment to the rights of children, encouraging them to adopt a number of legal instruments, including the CRC, the ACRWC, and write similar commitments into Rwanda's own Constitution. Nevertheless, Rwanda's legal and policy framework does not fully appreciate the unique needs of adolescents affected by HIV/AIDS. In addition, adolescents have so far have no completed legal provision to participate in decisions concerning their own health.

Rectifying access to HIV care for adolescents is a novel area for intervention concerning the adolescent's right to health. A review of current policy inconsistencies has helped identify areas for intervention to improve care for adolescents.

Age and barriers to prevention

Laws in Rwanda regulating sexual activity and protecting adolescents' rights to reproductive health services do not reflect the average age of sexual debut. Interviews with adolescent girls indicate that protection is needed as, according the RDHS 2005, most girls disclose that they have engaged in sexual relations from the age of fifteen.²⁵ However, health care providers have the right to refuse to provide contraceptives to a minor, or to perform an HIV test for a minor, and there is no legal provision for minors to exercise these rights. Similarly, adolescents' inability to control the disclosure of their test results can violate their privacy and subject them to discrimination from their family and community. In addition, because treatment decisions are

mediated through adult caregivers, adolescents may not always receive the services and support they need if their caregivers are unwilling to give them.

Ensuring legal and independent access to contraceptives such as condoms is a critical component of preventing HIV infection among adolescents.³²¹ The National Policy on Condoms, for example, provides only general guidance that condoms should be available to all segments of society ‘without restriction or exclusion’ and it is silent on the issue of age.³³⁴

Other Sub-Saharan African countries offer innovative reforms for contraceptives. Though relatively new, their proactive approach is promising. Prior to 2007, the age for obtaining contraceptives in South Africa was fourteen years.³³⁵ The new South African child protection laws³³⁶ led to the Children’s Act No. 38 of 2005, which permits adolescents to obtain contraceptives at the age of twelve years and guarantees confidential access.³³⁶ Since these provisions have only been implemented in the last few years, it is still too early to gauge the overall impact of the Children’s Act in South Africa. However, opinions on the potential for Children’s Act to improve access to all aspects of HIV-related services have been quite positive.³³⁷

Rwanda will need a more open and clarified mandate for condom access to ensure adolescents have knowledge of, and access to, condoms. In Rwanda, access to contraceptives must be available at a younger age than it is now, and provided without the need for parental consent so as to target a higher proportion of the sexually active population and those most at risk. Lowering the age would also align with the reality of adolescent culture and sexual behaviour in Rwanda. Additionally, adolescents should be given legal access to and information concerning appropriate, age related, modern family planning methods. Education for family planning and contraception must also be encouraged to eliminate social barriers to utilising preventive services.

Access to male circumcision

Male circumcision is another highly cost effective method of HIV prevention, which reduces male risk of infection up to 60%²³⁸ and would save millions of dollars each year in averted treatment costs.³³⁸ Despite data suggesting its benefits, Sub-Saharan African countries have divergently adopted MC. In South Africa, for example, access to MC is restricted in order to protect boys from potentially harmful traditional practices²⁵⁶ and laws specify that boys under sixteen years may not be circumcised except for religious purposes or for medical reasons on referral³³⁹ and boys between sixteen and eighteen years of age must have their parents’ consent.²⁶⁰ By contrast, Botswana has considered offering MC as a routine part of care at all health facilities.³⁴⁰

In Rwanda, only 12% of males are currently circumcised. Although UNAIDS urges countries to allow adolescents capable of understanding its benefits and risks to undergo MC without parental consent¹³⁸ Rwandan law still requires them to ask their parents for permission for the procedure. The current legal framework has an opportunity for reform because there is no law that is tackling MC services. MC savings (see methodology in Chapter 4 for additional detail) in Rwanda, even with its lower relative HIV incidence, correlate with cost-effectiveness analyses from other countries. Rwanda will need to eliminate age-related barriers to MC or allow adolescents to access the procedure with an adult of their choosing. Alternatively, in keeping with the CRC, adolescents could be permitted to consent independently to the procedure upon a finding that they were sufficiently mature.³²⁶ Change is possible. Younger

participants at the 2010 Pediatric AIDS Conference in Rwanda identified the procedure as a top priority.³²¹

Barriers to testing and disclosure

The CRC recommends that adolescents have access to confidential voluntary counseling and testing (VCT) and strongly discourages disclosure of results to third parties, including parents, without the consent of the adolescent.⁶⁵ The Rwandan legal framework is incomplete. Rwanda's Law No. 54/2011 of 14/12/2011 relating to rights and protection provides for children age 12 to access VCT without parental consent, but Cabinet still have to approve the Ministerial instruction to implement the law. This law however remains silent for adolescents on the right to VCT before the age of twelve and the right to control the disclosure of their test results at any age.

We need to also consider children's right to disclosure. In fact, despite 63% of Rwandan children who are exposed perinatally being tested at 6 weeks⁴⁷ only 12% of children tested actually receive their results.³⁴¹ Failure to disclose HIV status has an impact on treatment for this population. A recent study discovered that 40% of ten to nineteen year-olds started anti-retrovirals after their CD4 count had fallen below 200 cells/mm³³⁴² despite the WHO recommendations at that time, for initiation at 350 cells/mm³.³⁴³ This poor implementation of the laws protecting children rights to testing and disclosure creates a barrier to VCT.

In a recent survey of Rwandan children some only learned of their positive status after receiving stigmatizing treatment from family members or neighbors.³⁴⁴ Additional barriers to VCT exist. According to caregivers, they include distance to testing facilities, lack of transportation, multiple children, and a lack of specialists to perform tests.³⁴⁴ Providers argue that parental ignorance is also a problem.³⁴⁴

Existing legislation throughout Sub-Saharan Africa provides a variety of solutions to the question of age, voluntary testing, and disclosure of results. Some laws impose strict parental consent.^{345,346} At the opposite end of the spectrum, countries such as Ethiopia and Namibia are more permissive and recognize an adolescent's capacity to consent to testing; the former requires the age of fifteen years, while the latter accepts the age of fourteen years.³⁴⁷ South Africa has enacted strong adolescent empowerment laws, recognizing that adolescents become sexually active before the legal age of consent of sixteen years old.³⁴⁸ The country thus permits adolescents access to counseling and services through its 2007 South African Children's Act and permits consent to testing at the age of twelve years, or even younger, if they possess 'sufficient maturity to understand the benefits, risks and social implications of such a test'.³³⁶ Additionally, the South African Children's Act guarantees children the right to pre- and post-test counseling and provides that no one may disclose a child's test results unless required to do so by law.

While the Rwandan context is different from the aforementioned countries, with its lower rate of childhood HIV infection and a later average age of sexual debut, it should consider implementing Rwanda's Law No. 54/2011 of 14/12/2011 and lower its minimum age for independent access to testing and disclosure. Rwanda should also change the legal framework to make MC, HIV testing and disclosure of results available to adolescents under 12 years who demonstrate the appropriate level of maturity to consent, and such maturity could be assessed using a psychological evaluation made by a specialist.

Concerning the access to VCT of children under 12 years, an option, which would balance the competing interests of increased access to testing and ensuring that proper support is in place, would be to permit adolescents to select an adult of their choosing to accompany them for testing and disclosure if they express the worry that their own caregivers are a barrier.

Barriers to treatment

While 56% of all individuals under 15 years old in Rwanda in need of treatment are on highly active ARV, the target was 100%.^{47,52} Rwandan law is a current barrier to meeting this goal. Despite the unequivocal statement of the UN Committee on the Rights of the Child that adolescents should be able to obtain treatment without parental consent,³²⁶ and the CRC provision for an adolescent's right to medical treatment, there are still no such guarantees under Rwandan law. Rwanda's Law No. 54/2011 of 14/12/2011 relating to rights and protection is unclear about it in two out of the three languages. The decision to obtain treatment is often out of an adolescent's hands. In addition to a weak legal framework, other barriers include lack of education regarding the importance of treatment, lack of follow-up by health providers, and poor roads and infrastructure preventing travel to clinics.³⁴⁵

To address these barriers, Rwanda must lower its age for consent to medical treatment to below majority. Rwanda and other countries must also ensure more child-friendly services and health centers.³²¹ In a novel approach to increasing access to treatment, at the 2008 Pediatric Conference on AIDS, organised by the Ministry of Health of Rwanda, children participants recommended mobilising fellow school children to help identify the children in need of treatment.³⁴⁹ This creative approach would rely on increasing education to eliminate stigma and to promote awareness. In summary, adolescents must be allowed to participate in decisions regarding their treatment so as to empower them to engage in their health and wellbeing.

Barriers to support

In Rwanda, in the legal protection for adolescents' right to HIV/AIDS services may have significant consequences for OVC living in households headed by children. Adolescent heads of households and their dependents face particular vulnerabilities as Rwandan law in English, French and Kinyarwanda is still not clear on authorisation to take medical decisions without the permission of an adult. The Government does pay for health and fees for OVCs but this is still insufficient; and does not confirm the ability of heads of households to act legally on their own behalf and still permits potential denial of access.

In other countries, including South Africa, responses to similar concerns have focused on recognizing child-headed households as legally autonomous entities. Although South Africa is the only country to have done so in law, other countries are developing legislation, including Malawi and Lesotho.³²⁵ In recognition of its particular history and demographics, Rwanda must also create a legal and administrative framework to emancipate child heads of household at the age of sixteen years, to allow them legally to make health decisions for themselves and those in their direct care.

In Chapter 8, I have demonstrated how the absence of a validated screening tool to assess the risk of depression means that children affected by HIV are not permitted to fulfil their right to health. I also provided evidence that much improvement is needed to allow children affected by HIV to fulfil their right to participate in decisions concerning their health. The next chapter will discuss transparency and accountability in the use of the funds dedicated to the pediatric HIV response by NGOs.

Chapter 9: Results from across the 4 periods

Policies that promote the prevention, care and treatment of children affected by HIV require sizeable financial investments. It is important to properly use funds that have been dedicated to that purpose. If it is not done, children will not receive adequate care, prevention and treatment in return for the funds invested. This is important now because, as said before, there has been a decrease in funding for the HIV and AIDS response in Rwanda. This is the case in many other countries for which development partners are the major players in financing the fight against HIV. This is why it is crucial to ensure that these funds (PEPFAR and Global Fund) are paying for the things and activities for which they are intended, transparently. The study did not assess the public institutions as they have regular audits that are performed by the Office of the Auditor General, whose professionalism has been internationally acknowledged.

9.1. Financial accountability for NGOs and support for orphan and vulnerable children (OVC)

The following text has not been published elsewhere.

Introduction

Every child has a right to care and a supportive environment as they grow. Due to vulnerability linked to HIV infection, it is essential to explore the environment in which a child affected by HIV grows up and how the funds dedicated to their support and care are spent. For children who are orphans, or otherwise vulnerable, national and international organizations play a significant role in ensuring that their rights are fulfilled. Such organizations implement major programs in support of orphans and vulnerable children (OVC). In Rwanda, OVCs are considered to be those who are HIV-positive, or those who have lost one or both parents, those who have a parent who has a chronic illness, and those who are otherwise home-insecure, very poor or have an unstable family environment.

There are often inconsistencies in the amount of funding directed toward OVC programs and the amount that is actually delivered by way of services and support systems. In 2007, a NOVCSA tracked money spent on OVC.³⁵⁰ It led CNLS to develop data collection tools that assess expenditure for OVC by categories in the OVC ‘minimum package’ as instructed in the national policy, that includes spending on nutrition, health, education, security, and psychosocial support. NOVCSA is used with a similar methodology to that of the National Health Account (NHA), run by Ministries of Health across the world (NHA follow WHO guidelines and are published every two to three years depending on the country).³⁵⁰ The objective of NOVCSA was to understand where the money dedicated to OVC was going and to verify that it was being used effectively for services to OVC. This concerned all the money given for HIV programs targeting OVC, and compares the expenditures for OVC declared by donors and the real amount of money spent on OVC services. CNLS obtained the first and unique results of NOVCSA in 2008, which showed a lack of transparency in financial management of international NGOs working for OVCs.³⁵⁰

The question of accountability concerns multiple stakeholders in the pediatric fight against HIV. All stakeholders are important and governments need to lead and coordinate them while ensuring effectiveness or sustainability. Highlighting the primary responsibility of governments does not undermine accountability of other stakeholders, especially that of non-governmental organizations that are needed to complement the government's role.

Methods

Please refer to Chapter 4 for the methodology.

Findings

Some organizations reported inconsistent expenditures in the 2007 reporting period. In the second questionnaire, Care International gave different data. By their own records, they received US \$724,972.20 for OVC, but only spent US \$223,080.53 on OVC services, leaving 69% (US \$501,891.54) of their funding not used for OVC support. In 2008 they reported not spending 83% on OVC services in fiscal year 2007. Hope and Homes for Children is another international organization that reported in 2009 having spent 35% of its 2007 funding on the OVC support package, using 65% of the US \$911,543.25 that it received for OVC on other activities that were not OVC-related, compared to the 57% reported as not used on OVC in 2008, in the NOVCSA.

Discussion

NGOs are needed since the public sector in many countries does not provide a direct service for children affected by AIDS. Governments have the duty to mobilise money for children affected by HIV and AIDS, as many countries do not have a sufficient budget for programs to respond to the effects of HIV on OVC. Actions to improve the lives of children affected by AIDS require resources and there are not enough resources to cover all the needs.

The other role of Government is to ensure proper allocation of available funds. Funding for children in the overall AIDS response shows inequity in the allocation of funds and the utilisation of funds. Vulnerable children receive little of the allocated funds or services, despite comprising a sizeable portion of the affected population.³⁵¹ However, at the very least human rights and health equity should dictate how money is allocated. This should define who the beneficiaries are, their needs, and our attention to their vulnerabilities.

In 2008 when this began research, over half of Rwanda's 11 million people were children, 220,000 of whom were AIDS orphans.³⁵² Despite this staggering figure, no systematic tracking of outcomes from funding efforts for OVC existed, as there were no systematic data quantifying all of the private, public, and development partner spending on OVC. As such, it is difficult to coordinate fund allocation for activities and to track OVC expenditures. This lack of control has led to a lack of transparency and financial accountability. This problem exists elsewhere for example, when reporting on health issues, such as the number of individuals on ARV, children are often lumped in with adults, as in the Mozambique National AIDS Spending Assessment (NASA).³⁵³

The lack of clarity in reporting is part of the reason why there is a lack of accountability. As a result, when one looks at the OVC spending data, it appears to be fairly low. Many African countries spend less than 10% of their total finances for HIV response on OVC issues, according to National AIDS Spending Assessment Reports. For example, Ghana's spending on

OVC was 1.08% in 2006³⁵⁴ and 0.29% in 2007, and 1.10% of total spending on HIV/AIDS was spent on OVC (US \$425,999), and 0.42% of total spending on HIV/AIDS was spent on OVC (US \$261,175) in 2010.^{355,356,357} Zambia's 2006 funding amount for OVC was only 4.4% of the HIV response budget and supported 15% of the total number of OVC.^{358,359} For the 2013 and 2014 fiscal years, Rwanda has budgeted 18% of its HIV money for OVC.³⁶⁰

In 2007, only 70% of the overall amount of money received for OVC reported in the NOVCSA could actually be accounted for as being used to provide elements of the minimum package of services as per policy. Such a large discrepancy may be a result of incomplete answers due to a blatant disregard of the request for financial report by the Government of Rwanda through CNLS, or because of a refusal to disclose the large amount used for overheads.

When asked to provide a breakdown of their overheads, World Vision stated that they were only allowed to disclose their international overhead status, not the national amount. This problem exists not only within international NGOs, it extends as well to national NGOs. Eight national NGOs receiving money from the World Bank, the Global Fund, and the United Nations Development Program (UNDP), among others, could not account for part of the money given to them for OVC support. Alternatively, the incomplete answers may be due to poor bookkeeping by organizations, whether they are multilateral, national or international NGOs. Either way, the fact that organizations are unable to give an accurate breakdown and account for how their money is being used to provide services for OVC, means that there is a risk that the money may not be used wisely, and children are under-served as a result. Proper financial records are necessary for accurate monitoring of the provision and use of services. The absence of accurate and detailed records blocks precise analyses of the cost-effectiveness of services.

A year after the initial data collection on OVC spending, I asked the 10 NGOs with the worst records, as reported in NOVCSA, to break down their 2007 OVC funding using the same questionnaire on OVC expenditure. The 10 organizations had discrepancies for over 30% of their funding for OVC. This trend has been found in other countries as well.³⁶¹

NOVCSA funding results showed international organizations to be more likely to use money for overheads than national organizations, since Rwandan organizations such as Rwanda RRP+ and SOS Village d'Enfants reported using a higher proportion of their funds on OVC versus overheads. Such findings may be logical since support programs initiated locally would be more in tune to the needs of OVC in Rwanda, and may have already been providing some support for them without donor finances. In national organizations, adequate salaries would also be given based on national norms instead of American or European norms, and money would not need to be spent on sponsoring regular round-trips (often business class) flights home for expatriate employees. Thus, the costs to provide services would be lower in national organizations, allowing more OVC to benefit from the same amount of money. Despite this, international NGOs are systematically chosen over national NGOs to receive funds for OVC. For example, 70% of PEPFAR money goes to international NGOs and only 30% goes to locally based groups.³⁶²

The pretext given for funding international organizations is their managerial capacity, even if they are not better at providing services for OVC, and are not cost-effective.³⁶¹ For example, a group of researchers found that local projects provided OVC support at a fraction of the monetary cost used by international projects - sometimes for an amount 10 times lower.³⁶¹

Instead of giving the money to intermediaries, donor organizations should consider giving funding to local organizations in conjunction with capacity building tools so that national NGOs

can strengthen their financial accounting, administrative procedures and managerial skills.^{363,364} If handled in this way, administrative costs would be reduced and local capacity would be improved and could then be passed on to smaller community-based organizations. This is a core principle of sustainable development.³⁶⁵

Although some donor organizations claim to provide capacity building tools to local organizations, this has not yet been done well, as competition for international funds relies on an NGO's administrative, financial and programmatic capacities. In reality, however, there are very few examples of local NGOs becoming direct recipients of funding after receiving capacity building support.³⁶⁴ Thus money earmarked for children often remains in donor countries as overhead to support an organization's headquarters instead of supporting OVC. This is shown in a study where it was noted that less than 30% of American funding for foreign assistance was spent outside the United States. Only a fraction of this money was actually spent on providing support to local communities.³⁶¹ A recent RAND Health Corporation study estimated the trade-off between overhead and administrative costs and direct services of PEPFAR funding, reporting that if such transaction costs were reduced by 50%, approximately 700,000 more individuals could have received ARV worldwide in 2010.³⁶⁶ This is a huge missed opportunity, because it is a tremendous amount of taxpayer-generated money from other countries that could have been used to provide welfare to more children affected by HIV.

On the other hand, donor organizations have started to realise the merits of partnering directly with community organizations, and have announced projects to increase the amount of money given directly to grassroots NGOs.³⁶³ Except for a few beneficiary countries with donors such as PEPFAR, most direct recipient organizations are not local but rather international NGOs that take the same overhead (30-60%), and the money for children affected by HIV goes directly to their headquarters in the US.³⁶³

NOVCSA was performed once only, but to prevent misuse and misreporting, an exhaustive investigation of organizations' activities and expenditures on OVC in Rwanda should continue to be done on an annual basis. The lack of transparency makes analysis of funds virtually impossible. The results should be publicised for transparency purposes in Rwanda and in the country where the international NGO is based. Analysis should be done concerning funds classified as 'overheads' to determine what that money was used for. Once results are available, cost-effectiveness studies should gauge the most cost-effective way to provide services to OVCs. A comprehensive breakdown of money spent on children will promote efficiency by allowing countries to actually allocate funds according to evidence. All along the financial chain in the HIV response, money dedicated for children is not yielding the expected results. Governments as well as development partners have a clear responsibility for financial losses resulting from transaction and overhead costs.³⁶⁵

Chapter 9 has demonstrated how the lack of protection and of efficiency in the use of the funds dedicated to the health of children affected by HIV are barriers to fulfilling the right to health across the four periods of life in young people under 15 years. The next chapter summarises the conclusions of the research.

Chapter 10: Conclusions and recommendations

In the previous chapters, the key findings identified in the course of this research were analysed, summarised, and discussed, concerning missed opportunities and bottlenecks in Rwanda in fulfilment of the Rights to Health by children affected by HIV during four distinct periods of the first fifteen years of life. This chapter draws conclusions based on these findings.

It was hypothesised that the primary barriers for children affected by HIV to fulfilling their right to health were related to management and governance issues rather than financial constraints. The findings of this research confirmed this hypothesis.

The four periods chosen according to the vulnerability faced by children affected by HIV *vis-a-vis* access to health services, have facilitated the understanding of children's needs and rights. The research has analysed the management responsibilities of key players, including international and national regulatory authorities, national and international NGOs, professionals in the health sector and parents or care-givers.

Below is a summary of the key areas of concern in each of the four periods identified by this research:

For Period One:	Non-protection of marginalised future parents
For Period Two:	Delays by WHO and UNICEF in adjustment of protocols according to scientific knowledge, the lack of follow-up in the implementation of new protocols, and the use of approaches that are not the most cost effective
For Period Three:	Delays in producing appropriate guidelines and protocols to diagnose and treat malnutrition and not fulfilling one's duty as an advisor to countries on nutritional status measurement
For Period Four:	Poor access to mental health care, failure to enforce and respect the right to information and the right of participation, a lack of enforcement of the parents' or care-givers' responsibilities, and lack of transparency and accountability of NGOs in OVC funds management

10.1. Conclusions

The world has failed to address pediatric prevention of HIV adequately, although UNAIDS and WHO have demonstrated that pediatric HIV infection could be eliminated.⁴¹⁰ This research confirms it for Rwanda and demonstrates that from pre-conception up to the parental stage, that the Rwandan people are concerned about the theme of this thesis, either because they belong to the populations discussed in Periods Two to Four – the children concerned by HIV prevention care and treatment - or because they are concerned about Period One and they need to benefit from primary prevention to fulfil the Right to Health by future generations of children. More

children will survive into adulthood if these needs are satisfied, as they will be less and less likely to be infected with HIV.

Rwanda adopted evidence-based policymaking to ensure that the rights of PLHA are fulfilled, but children living with HIV were left behind not only in access to prevention, care, and treatment, but also because their plight was not in the central purview of policymaking. Many policies were made without children's needs specifically in mind. This has also been the case globally, and too often it fragmented the pediatric HIV response during the first two decades, making it incomplete with, as a consequence, a long and fatal silence. Proper HIV prevention, treatment and care programs for children can be fully successful only if they are grounded within children's rights in combination with scientific knowledge within the pediatric services. A countrywide legal framework is vital for the creation of rights-based public health laws and policies.

These rights include, but are not limited to: the right to health; the right to non-discrimination; the right for children to have their interests treated as the primary consideration; the right to life, survival, and development; the right to participate in decisions concerning their health; the right to mental health services; and the right to access age-appropriate information. All the aforementioned rights are among many others covered in the UDHR, the CRC and the two key international treaties: the International Covenant on Economic, Social, and Cultural Rights (1966), and the International Covenant on Civil and Political Rights (1966) and are endorsed by the WHO Constitution as well as by most governments around the world. None of these documents directly identify HIV and AIDS, but their regulations apply to HIV and AIDS issues. Since the Government of Rwanda has signed and ratified these international legal instruments, it must respond to HIV and AIDS with rights-based laws, policies and strategies.⁸³ The documents on the international human rights framework articulate the principles that were used in this research to analyse access to rights to health for Rwandan children affected by HIV.

This research shows that Rwanda has not realised the national commitments made to fulfil the rights of HIV-affected children; many of these gaps are not necessarily due to financial issues, as we could be doing far more with what is available, and Rwanda has many opportunities for improvement.

Since the international human rights framework constitutes legally binding obligations, superseding national laws of states that have signed and ratified them, this research has been concerned with barriers in accessing the rights to health for children in the context of HIV; legal violations demand accountability.

In Period One, a critical area to address with a view to making improvements is the stigmatization of, and discrimination against, vulnerable groups. When HIV infects them, such stigmatization and discrimination can increase. As a result the chance of getting tested for HIV decreases, as does the use of appropriate health care, and can thus result in unintentional transmission of the virus to others, including their children. It is therefore crucial to address gaps in care faced by the most vulnerable individuals in society, who are of reproductive age or below and run a higher risk of being HIV-positive, including professional sex workers, and prisoners. Many professional sex workers suffer from having too few economic opportunities, and it is thus necessary to propose an integrated, rights-based policy approach by providing opportunities for appropriate income-generating activities so that they do not have to act in a risky manner. Knowledge and sensitization are important, but are not enough to stop the spread of HIV. As of September 2013, none of the prisons in Rwanda had condoms available, as prisoners are not supposed to have sexual intercourse during their sentence. They are, however,

finding ways to engage sexually during their terms—either in prison, at worksites, or while travelling between locations. Such sexual activity is a risk not only to the prisoners but, if the inmates become infected by HIV, also to their sexual partners and any child who will be conceived, while in prison or after the release. Rwanda should seriously consider whether it would be a smart decision to provide all the tools for HIV/AIDS prevention in prisons - without restriction - in order to advance our fight against HIV/AIDS. This fight is a global one. If we continue to ignore prison populations as a major risk group for HIV transmission, we will also continue to place intense pressure on national health systems because such prevention could also lower the costs associated with care and treatment.

As duty-bearers to their children, parents have a primary responsibility to those children to ensure that their rights are met. In the context of HIV prevention, parents need to avoid the transmission of HIV from the mother to child. However, when parents are unable to fulfil these obligations, the State's duties begin. States also have independent obligations as duty-bearers to ensure that appropriate measures are in place to fulfil these rights. A rights-based approach to health in the context of HIV therefore requires emphasis on State capacity in addition to parental obligation.

During Period Two, in the context of PMTCT, parents should have the obligation to seek testing to know their status and seek care. The lives of women, but also their children, have the potential to be saved with repeated HIV testing and counseling in the context of PMTCT. This work advocates routine, provider-initiated testing to increase access and reduce stigma, and advocates increased links between HIV/AIDS services and primary care, including antenatal care. By creating a more supportive environment for women to be tested, women can be empowered to protect their health while also securing the health of their child. Each country should define its protocol according to their knowledge of HIV prevalence combined with the risk of vertical infection during pregnancy and lactation. Moreover, if the male partner is found to be positive and the woman is negative, intensive counseling on the use of condoms and the need for repeat testing throughout the gestation period and during lactation should be given. Rwanda should apply a model of couple counseling and testing for all parents-to-be that promotes male involvement, ensures HIV disclosure, and provides a positive and supportive environment that facilitates the management of sero-discordant results. HIV testing becomes an entry point for combination prevention of heterosexual transmission during pregnancy including systematic condom use, and ARV if eligible, for HIV-positive male partners.

A problem of international organizations such as WHO and UNICEF is the length of time it takes to develop international guidelines that are appropriate (or can be adapted) to different country contexts. This impacts children affected by HIV and does not allow them to fully enjoy their rights to health care. These international organizations must be held responsible for their inefficiencies, their mission failures to change as the science changes, as they do not review technical standards and guidelines in a timely fashion. For infants born to HIV-positive mothers, the feeding options proposed and implemented are crucial for their right to health.

WHO and UNICEF must also take responsibility for advising countries of cost-effective approaches so as to ensure value for money, taking in account the socioeconomic environment of families, communities and countries. The use of cost-effective prevention programs is important for lowering mortality rates for more children with the same amount of money.

This study shows that in Period Two, MC for infants is cost-effective. Although the benefits of MC performed during Period Two will be gained later in life, if the procedure is cost-effective

at all ages, the positive results are stronger for MC of male newborns than for adolescents and adults.

Given the low cost and long-term benefits, this study suggests that countries with moderate HIV epidemics should offer routine infant MC, integrated into existing health services. In addition, adolescents and adults should be offered MC until the aging of circumcised infants renders it out of date. Due to the increased complexity of the latter, each country will need to consider a variety of options for achieving high levels of coverage of adolescent and adult MC. Options may include specialised centers, mobile surgery units, and specialised surgery teams that move from clinic to clinic. MC should be offered as part of an integrated HIV prevention package that includes promotion of safer sex (delayed initiation, reduction in multiple/concurrent partners, and access to condoms).

African leaders and development partners should stop managing the HIV response as an emergency issue and release themselves from a one-year or even a five-year planning perspective to focus on sustainable long-term choices for countries. From a development perspective, since infant MC is proven to be an effective means of HIV prevention, we cannot keep waiting without action simply because gains will only be achieved far into the future. We must plan accordingly, based on the best information available, knowing that currently there is neither vaccine nor cure for AIDS in sight, while remaining open and flexible to adaptation if better solutions become available. In the presence of infant MC, adolescent and adult MC would become a sort of 'catch up' campaign that would be needed at the start of the program but would then become superfluous upon attainment of high levels of infant coverage. Infant MC is likely to be highly cost-effective even in countries with a lower incidence than Rwanda. In Rwanda, if the dynamic benefits of MC are considered in addition to the health benefits for the circumcised man, even adult MC is likely to be close to or below the highly cost-effective threshold. This suggests that Rwanda should simultaneously scale up MC across a broad range of age groups, including an appropriate mass media IECBC campaign to promote neo-natal MC, as this is not a cultural norm. A pilot implementation exercise in one district, accompanied by close monitoring and operational research on key variables, should be followed by a scale-up of the program countrywide.

During Period Four the child has reached the age of reasoning. At the age of seven years children affected by HIV should benefit from quick, routine mental health assessments to detect depression, because identifying depressed children is a first step that allows access to comprehensive health care that comprises mental health care when needed. This assessment should be made by one of the health professionals following the child at the point of primary care. This study has found 25% of children are depressed. This is especially important in countries affected by war or any form of violence such as that experienced in Rwanda, where the impact of the Genocide has left many of its citizens traumatized and suffering in silence, with impacts on the next generation.

In Rwanda it is not only children born to sex workers that experience rights violations. Some children living with HIV are still suffering from rights violations through discrimination, lack of information, lack of psychological and social support. Rwanda has the resources to overcome these violations, and this is required to achieve the best clinical outcomes possible. It is also important for all children at all ages to access HIV prevention services such as VCT and male circumcision as it is cost effective, cost-saving and efficient.

Rwanda must review its legal and policy frameworks for provisions that impede children's abilities to access their right to health. This is especially the case in Period Four, for adolescents

in need of HIV/AIDS services. Rwanda does not provide any legal or policy mechanisms to allow mature children below the age of 12, to access HIV services without parental consent. Rwandan policymakers could re-evaluate the laws regarding the age of the right to seek HIV testing, care and treatment case by case and with context-specific exceptions it can improve the right to health for adolescents. This will improve children's right to participation in decisions concerning their own health, and clarify the age from which a minor should have the capacity to exercise personal autonomy in making medical treatment decisions free of parental control. This is, of course, linked to the right to be appropriately informed about their HIV status.

There is also a need to review the inconsistencies in legal documentation regulating the ages at which children can access HIV prevention, care and treatment services. As presented this research review simply consists of examining the translation of a law between different official languages. The ambiguity created by the inaccurate translation of a law in French and English may allow health care providers to refuse some health services to children. Of course Rwanda's social and economic context should be taken into account and the legal changes must be made after national consultation, education and sensitization which not only focuses on the law, but also on the elimination of other barriers, such as socio-cultural ones. This constitutes a comprehensive approach, which is pivotal to the HIV response.

Other legal provisions concern the four periods and have to be changed and a consistent legal framework applied to protect children against the negligence of parents and health workers when the denial of prevention, care and/or treatment occur. Some of the changes that need to be made concern the health providers and parents, and start during pregnancy. The legal framework should be changed to make it clearer how States facilitate legal guardians, educators, health professionals, and community members, and the responsibilities of each of them in helping a child to obtain their rights in full.

With regard to all periods for children affected by HIV to exercise their right to health, Governments have a duty to perform better monitoring, evaluation and resource tracking by using tools such as the NOVCSA; this was done only once in Rwanda. NGOs use millions of dollars provided by taxpayers or donations dedicated to OVC to other activities not related to them. At a time when there is a consensus about government and public institutional accountability, it is necessary to create a framework of accountability for all stakeholders in the HIV response for children. This includes international institutions, multilateral organizations (e.g. the World Health Organization, UNICEF, UNAIDS) and bilateral organizations as well. In this manner, national ownership of, and responsibility for, programs will increase and will be respected, and children will be better served.

10.2. Recommendations

To overcome or mitigate the gaps found during the course of this research, here are key recommendations proposed to stakeholders at different levels, to develop an enabling environment for a human rights-based approach for access to prevention, care, and treatment for children affected by HIV in Rwanda.

For international governing institutions

1. Ensure that the Committee on the Rights of the Child building upon the CRC produce legal documents more specific *vis-a-vis* the responsibility of both parents and of the State. The new legal framework should address the lack of specific concerning the responsibility of parents *vis-a-vis* their children and the responsibility of the States.

2. WHO and UNICEF to follow scientific changes more quickly so as to adapt the protocols for pediatric prevention, care and treatment of HIV infection, and use a cost effectiveness and value for money approach when advising countries about children's programs.
3. National offices of WHO, UNICEF to advise in an accurate and timely manner on implementation of new pediatric guidelines and protocols for HIV infection services for example, neonatal MC.

For national governing institutions

4. Create a proper Rwandan legal framework for the implementation of human rights, stating clearly what the State should provide to different stakeholders and the responsibilities of each stakeholder for children to fulfil their rights to health.
5. Amend the existing legal framework to change the legal 'age of seeking HIV services' to allow any minor, evaluated by a clinical psychologist as mature enough, to have the capacity to exercise different steps in making medical treatment decisions, in autonomy, free of parental authority, even if they are less than 12 years old.
6. Advocate the signature of EAC HIV AIDS Bill Part VI, 34-36 by the five EAC Heads of State.
7. Train health care providers and leaders in the health sector in human rights and health, so that all could have the chance to access health services without discrimination and stigmatization and for the professional to contribute to avoid societal marginalisation, especially for potential parents.
8. Review the laws governing the right to protection to assure their correct translation in all the three official languages.
9. Ensure regular and independent audits on results and efficiency of NGOs giving support to children affected by HIV.

For the Ministry of Health

10. Provide appropriate HIV care and treatment guidelines.
11. Provide HIV prevention services to all citizens without restriction and educate them in how to use them and where to find them.
12. Ensure, when possible, an efficient HIV service, the appropriate and necessary medical care for children affected by HIV.
13. Promote neonate MC.
14. Develop standard tools for psychological maturity measurement, appropriate for Rwanda and create a tool to gauge a child's maturity and ability to participate in their health decisions. Train health professionals to use the tool, to be skilled enough to decide whether a child is mature enough to participate in decisions concerning their health.
15. Create a national tool for rapid screening of depression in children for early referral to mental health services when needed.
16. Improve resource tracking of funds for the pediatric fight against HIV and hold NGOs and all service providers accountable.

For Non-Governmental Organizations (NGOs)

17. Report in a timely fashion, with transparency on program implementation and use of funds for children affected by HIV.

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