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Decision-Making Frameworks for HIV/AIDS Orphans
Case Study: A Growth Assessment of Nyumbani Village in Kitui, Kenya

By

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Master of Public Health

Global Health

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John Blevins, ThD
Committee Chair

# Abstract

Decision-Making Frameworks for HIV/AIDS Orphans
Case Study: A Growth Assessment of Nyumbani Village in Kitui, Kenya
By Andrea Fletcher

*This project consists of a case study discussion of ethical frameworks for decision-making of programs and institutions working with HIV/AIDS orphans. The three frameworks proposed and discussed include a human rights approach, a theological framework, and a public health/community engagement model. The case study is a growth assessment of Nyumbani Village, a project situated outside of Kitui, Kenya to provide holistic care to HIV/AIDS orphans and grandparents. The project consisted of gathering growth measurements of the children at Nyumbani Village and calculating their standardized z-scores to better understand the role of food distribution policies within the organization. Further monitoring of the growth of children at Nyumbani Village is necessary in order to fully understand the impact of the village on the nutritional status of the children that live there.*

# Decision-Making Frameworks for HIV/AIDS Orphans
## Case Study: A Growth Assessment of Nyumbani Village in Kitui, Kenya

By

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Washington & Jefferson College
2010

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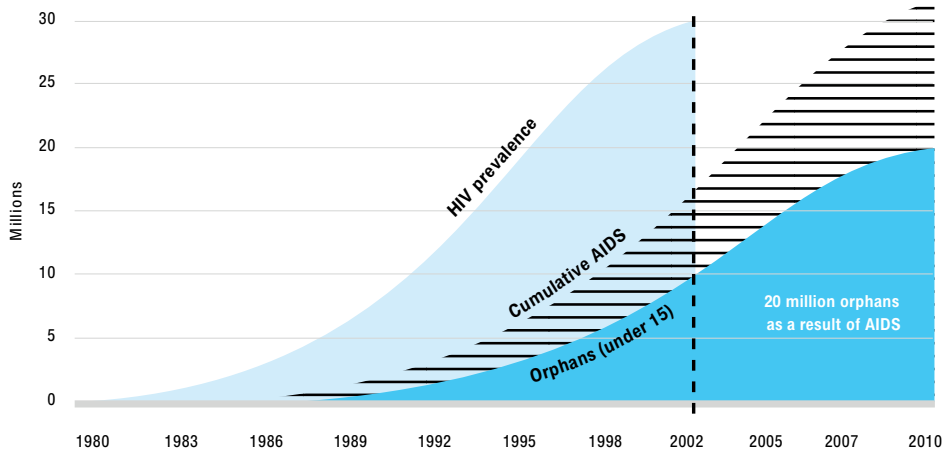
# Chapter 1: Introduction

In 2002 the United Nations General Assembly held a Special Session on Children. During his opening statement, then Secretary General Kofi Anan apologized to the children of the world saying *"We, the grown-ups, have failed you deplorably,..."* [1] Perhaps nowhere in the world is this statement more true than with the children who have been orphaned as a result of the HIV/AIDS epidemic in sub-Saharan Africa. An estimated 20 million children in the world have lost one or more parent due to HIV/AIDS, with 90% of these children residing in Sub-Saharan Africa.[2] As the number of children affected by HIV/AIDS continues to escalate throughout the world (Figure 1.1), the protection of orphans and vulnerable children affected HIV/AIDS has become a topic of critical importance.




***Source***: UNAIDS/UNICEF, 2003, adapted from Whiteside, A. and C. Sunter, 2000.

**Figure 1.1: The Worst Is Yet to Come: Epidemic Curves, HIV/AIDS and Orphans** [3]

These orphans are often called the "lost generation," or the "forgotten generation," but perhaps the "parentless generation" is more accurate. With the loss of parents there is often a loss of love, hope, and future. They are the first generation to be born into a world

with widespread HIV/AIDS, and as they move into adulthood their past is a lesson in the moral and ethical challenges that HIV/AIDS presents.

These challenges present critical questions for decision-makers on how to best provide for the health and well being of these children. With limited resources they must balance the fundamental rights and needs of children.

## *Purpose of the Study*

The aim of this paper is to better understand the application of ethical theory to evidence based strategic planning. Using Nyumbani Village in Kitui, Kenya as a case study, the paper looks at the complications of balancing resources when implementing programs for HIV/AIDS orphans. The case tackles the problem of nutritional status of the adolescents living at Nyumbani Village. By using BMI-for-age, height-for-age, and weight-for-age to determine growth differences between children, the discussion of the case focuses on the process of increasing food supplementation for the adolescents.

When there are limited resources we must not only decide *what* to do or *how* best to distribute them, but *why* we are making these decisions. This paper outlines some of those difficulties in decision-making through the application of ethical principles. Using one of the most difficult problems to solve in global health as an example, perhaps we can better understand the ethical frameworks that are necessary for public health practices in the future.

The case discussion applies three different ethical frameworks to approach how to best allocate resources and make difficult choices when addressing both the vast number of HIV/AIDS orphans, and also how and why nutrition and growth monitoring is important to better understanding the physical needs of these vulnerable children.

## *Research Questions*

- Which issues amongst HIV/AIDS orphans are the most critical to their health and wellbeing?
- How do we measure the overall health of children at Nyumbani Village?
- Are the policies on nutrition at Nyumbani Village adequate for addressing the current issues of the children?
- Which ethical frameworks are the most appropriate for decision-making at Nyumbani Village?
- What lessons learned from Nyumbani Village can be used in the care of HIV/AIDS orphans?
- Which frameworks for decision-making are the best future planning?

## *Research Objectives*

- To better understand the role of nutrition in the development of HIV/AIDS orphans
- To provide insight into different ethical frameworks for decision-making for organizations caring for HIV/AIDS orphans such as Nyumbani Village
- To develop a method for annually collecting the height and weight of the children at Nyumbani Village
- To analyze anthropomorphic measurements of the children at Nyumbani Village and determine the overall rates of undernourishment and malnourishment of the children
- To interpret the data from the nutritional assessment into meaningful policy changes within the village

# Chapter 2: Comprehensive Review of the Literature

## *The HIV/AIDS Epidemic*

The human immunodeficiency virus (HIV) is a retrovirus that infects the cells of the immune system. Infected cells have an impaired function, or are destroyed as a result of the virus. As the infection progresses, the individual's immune system becomes weaker making them more susceptible to infections. The most advanced stage of HIV infection is acquired immunodeficiency syndrome (AIDS). HIV is transmitted through unprotected sexual intercourse, sharing of contaminated needles, transfusion of contaminated blood, and between mothers and children during pregnancy, childbirth, and breastfeeding.[4]

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS) 2009 Global Reports an estimated 33.3 million adults and children are living with HIV, an increase from the 28.6 million in 2001, the number of newly infected adults and children decreased in 2009 to 2.6 million from the previous 3.1 million 2001. While the global prevalence of HIV remained the same from 2001 to 2009 holding steady and approximately 0.8% for adults 15-49 years of age. Correspondingly there were 1.8 million AIDS-related deaths amongst both children and adults.[5]

The majority of these people live in sub-Saharan Africa (22.5 million in 2009 and 20.3 million in 2001). 1.8 million new infections occurred in 2009 in sub-Saharan Africa, which is a decrease from the 2.2 million that occurred in 2001. The overall adult prevalence was 5.0% in 2009 and 5.9% in 2001, which resulted in 1.3 million AIDS-related deaths in 2009 and 1.4 million in 2001 respectively.[5] The global trends of

HIV/AIDS continue to fluctuate, but are hopefully beginning to hold steady. The same cannot be said for HIV/AIDS orphans as the number of children orphaned by HIV/AIDS continues to escalate (Figure 1.1).

**Orphans Affected By HIV/AIDS**

Although there has been a significant focus on HIV/AIDS as a public health issue, much of this focus has been on adults. In recent years great strides have been made in securing access to drugs for HIV positive children and providing care for HIV/AIDS orphans.[6] The United Nations Declaration of Commitment on HIV/AIDS calls for the development and implementation of national policies and strategic plans relative to children orphaned by HIV/AIDS.[7] The commitment (Article 65) includes providing a "*supportive environment for orphans and girls and boys infected and affected by HIV/AIDS*..."[7] This requires:

> *"Providing appropriate counseling and psycho-social support; ensuring their enrollment in school and access to shelter, good nutrition, health and social services on an equal basis with other children; to protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance…"*[7]

Although the commitment has been made, countries have been slow to mobilize resources to address children who are living with HIV, particularly on the topics of reproductive health and disclosure of status.[8] They have become the *"missing face of AIDS,"*[9] often left out of the conversation on how to best address the HIV/AIDS epidemic. The magnitude, complexity, and growth of the problem are overwhelming. There are no easy answers to addressing such a widespread issue, particularly when it is magnified by poverty, social injustice, and stigmatization.

In 1990 less than 1 million children in sub-Saharan Africa had lost one or both parents to HIV/AIDS. In 2001 the number had risen to close to 11 million, and by 2010 that number had reached somewhere near 18 million.[10] The outcomes of this are increase in orphans are catastrophic, and have yet to be fully realized in the long term. Although there are children in need throughout the world, sub-Saharan Africa carries the largest burden of children affected by HIV/AIDS. Almost 90% of children who have been orphaned by HIV/AIDS live in sub-Saharan Africa, with six countries combining for more than 9 million children: Kenya, Nigeria, South Africa, Uganda, United Republic of Tanzania, and Zimbabwe. Nigeria is in the lead with more than 2.5 children orphaned by HIV/AIDS.[2]

The HIV/AIDS orphan problem is an African problem. More specifically it is a problem for sub-Saharan Africa, and therefore ethical frameworks and decision-making must work within the cultural and societal context of Africa. There is an old saying that *"there are no orphans in Africa*"[11] because traditionally children who would typically be considered orphans are taken in by their extended family. This statement is no longer true, the HIV/AIDS epidemic has overburdened and stretched some of these extended families to their maximum extent and there is now a greater need for resources to care for these children.

The term orphan means that the child has lost their mother (maternal orphan), father (paternal orphan), or both parents (double orphan) due to a particular incident. Although more children orphaned by HIV/AIDS are currently paternal orphans than maternal orphans, this may be changing due to the increased vulnerability of women to HIV/AIDS.[3] HIV/AIDS is exceptional in causing double orphans because if one parent is

infected, the probability of the other parent becoming infected is increased, therefore leaving children at a high risk for losing both parents, and often within a relatively short time of one another.[3]

If orphans are vulnerable, then double orphans fall into the *extremely* vulnerable population. As of 2005, there were 9.1 million double orphans, or children who have lost both parents, in sub-Saharan Africa.[3] Amongst orphans, double orphans are also most likely to live in the poorest wealth quintiles,[3] less likely to attend school,[12] are more susceptible to child labor,[10] and are at an increased vulnerability to exploitation.[13]

**Impact of HIV/AIDS on Growth and Nutrition**

Food and nutrition are intricately intertwined with the transmission of HIV and the progression of HIV to AIDS.[14] Nutrition remains a challenge for people living with HIV/AIDS despite advancements made in medical care and treatment. HIV infection has also been associated with extreme weight loss, chronic fatigue, nausea, and vomiting. These symptoms, coupled with an increased need for nutrition attributed to a decreased immune system and the need to fight off opportunistic infections, can have a serious effect on the health of an individual. Other symptoms of HIV that may contribute to a decrease in nutritional status are anorexia, loss of appetite, and odynophagia (painful swallowing). Deficiencies in micronutrients are also associated with HIV infection, although several different mechanisms may be responsible for this including a decrease in dietary intake, malabsorption, an impaired storage function, and altered metabolism of different micronutrients.[15 16] Another impact of HIV infection on nutrition is in the treatment. The number one complaint of people on Antiretroviral Therapies (ART) is hunger.[17]

HIV infection often occurs in the context of populations already struggling with poverty and hunger where chronic malnutrition is already a major problem.[18] Food

security is a fundamental pillar to combating HIV/AIDS.[14] The current political climate surrounding HIV/AIDS has been to make treatment available to those in need, but this is not without costs. One medical anthropological study in Mozambique found that many people on treatments were starving because as one participant stated, *"All I eat all day is ARVs."*[17] That is, drugs are available but food is scarce.

In Zambia a trial that investigated the determinants for survival amongst HIV positive children ages 1 to 14 being treated with cotrimoxazole concluded that, *"The relationships between weight-for-age and malnutrition are complex"* finding that prior malnutrition in combination with a current low weight-for-age was a predictor of mortality regardless of CD4 percentage.[19] HIV positive children who have chronic malnutrition are at a greater risk for complications, and may become more susceptible to deadly co-infections.

Another major issue in the development of HIV/AIDS orphans is access to healthcare. Since the HIV/AIDS epidemic has overwhelmed many sub-Saharan country's healthcare systems, programs targeting childhood diseases and illness have been weakened.[3 10] This is just one of the many issues that HIV/AIDS orphans face. There are multiple factors of parental HIV infection that may affect the development of their children, and losing their parents can be catastrophic.

Figure 1.2 demonstrates the complexity of the situation of HIV/AIDS orphans and the many other factors that influence their risk for other social and economic problems that may impact their development. As HIV progresses, children often become the primary caregivers for their ill parents. This may lead to psychosocial distress, lack of an adult care, and monetary insecurity. With the death of their parents, children (particularly

females) may experience even more economic distress with the loss of their inheritance, or the squandering of their inheritance by other family members and caregivers.

Lack of adult care may lead to discrimination and increased stigma as well as put orphans at high risk for child labor and sexual exploitation. As the child's economic problems become more severe this may put them at an increased risk for withdrawal or truancy from school, inadequate food supply, issues with material needs such as shelter, and reduced access to healthcare. All of these factors put HIV/AIDS orphans at an increased vulnerability to HIV and other infectious diseases.

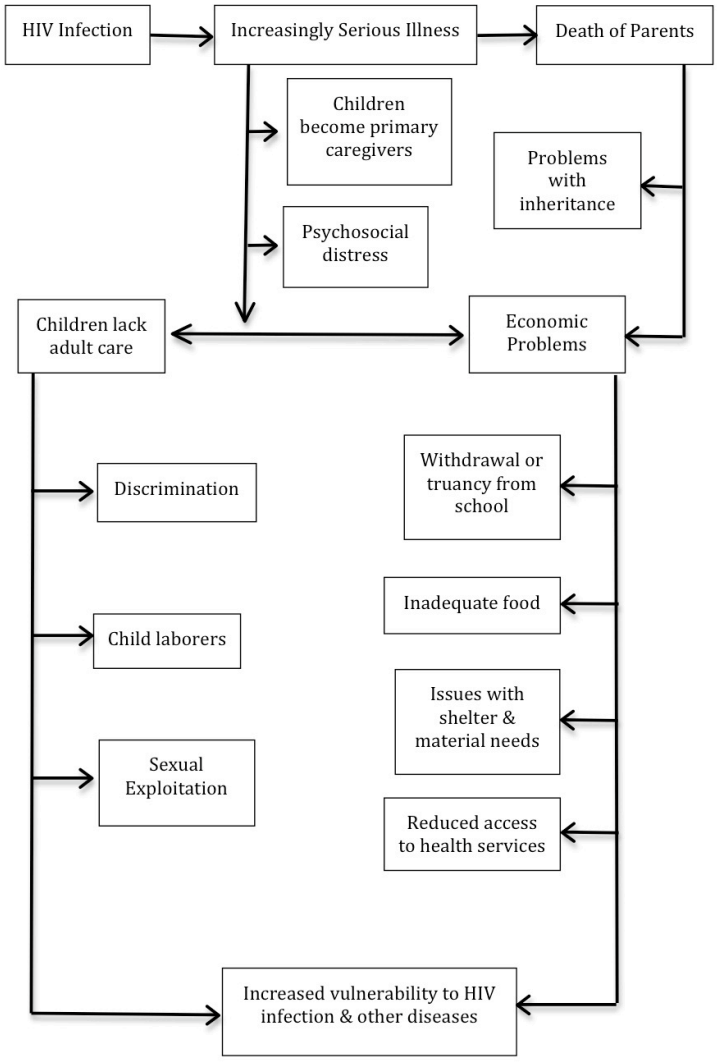



**Figure 1.2** Concept map of factors that affect HIV/AIDS orphans. *Adapted from Foster and Williamson, 2000*.[20]

## *HIV/AIDS Orphans in Kenya*

In 2001 Kenya declared a national emergency for HIV/AIDS, and by the end of 2003 the country had around 640,000 orphans from HIV/AIDS, representing 37% of the total orphan population.[12] There are currently an estimated 1.2 million orphans from HIV/AIDS living in Kenya.[2] Kenya's orphan population is different from most countries in sub-Saharan Africa because 20% more HIV/AIDS orphans live in rural areas compared

to urban areas.[12] This means that many of the resources available in urban settings are inaccessible to these vulnerable children.

In the wake of the 2008 post election violence, Kenya included social and economic rights as well as the rights of vulnerable populations in their new constitution. Article 43 of the 2010 constitution grants all citizens economic and social rights, including health, sanitation, housing, food, water, social security, and education.[21] The actual realization of these rights has proven to be particularly difficult due to the history of tribal tension and political corruption, and the full extent of the power of the new constitution has yet to be revealed.

In order to address *de facto* discrimination against orphans and vulnerable children in the education system Kenya introduced free primary education in 2003.[21] The cost of free education in Kenya is an estimated $97 million per year, most of which is being pledged by support from the World Bank, UNICEF, and donor countries.[10] This still left many orphans out of school because of the school fees required for uniforms and books. In response the government announced a program for families supporting orphans to have access to money for these fees in 2005, but the impact has yet to be measured in addressing these disparities.[12]

In the new constitution Kenya explicitly addressed the rights of children. Article 44 Section 2 of the new Kenyan constitution states "*A child's best interests are of paramount importance in every matter concerning the child*."[12] Article 53 explicitly outlines the rights of the child, including the right of every child to a nationality, basic education, nutrition, health care, protection from abuse and neglect, parental care, and not to be detained.[21] Kenya made a strong commitment to children's rights by signing the

United Nations Convention on the Rights of the Child on January 26th 1990, and ratified the Convention on the Rights of the Child on July 30th 1990. The inclusion of the child's best interests in the new constitution further establishes their commitment to the wellbeing of all children, including those who are most vulnerable.

Article 44 of the Kenyan constitution grants children the right to "*parental care and protection, which includes equal responsibility of the mother and father to provide for the child, whether they are married to each other or not;* "[21] This addresses many of the issues within the institution of marriage that have largely affected orphan's right to inheritance, family support, and social services. However, the constitution is still relatively young and the enforcement of these rights will have a crucial roll in whether or not they are realized.

Again, one of the unique features of the Kenyan orphan epidemic is that a large proportion of these children live in rural areas.[10] One study in Western Kenya (Kisumu) found that orphans experience higher death rates in rural areas as compared to urban areas.[22] Western Kenya (particularly the Nyanza region) generally has higher rates of HIV/AIDS and has been a larger focus of the research and prevention efforts.[23] [24]

Children's homes, institutions, and villages are not as cost-effective as children staying with kin-family and having community support.[25] Many orphans live with kin, but they often experience abuse, neglect, or have no real caregivers. Children who are HIV positive and orphans in Kenya have been known to stop treatment because of the stigma associated with HIV infection, because there is no one to take care of them, or because they are healthy looking and therefore their caregiver does not see a reason to continue.[26]

Proper education of caregivers and enforcements of the rights of children in Kenya are necessary in order to combat these problems.[26]

Grandparents serve as the largest group of caretakers and primary income for Kenyanorphans.[22] Children who have lost both parents usually live with older female relatives who have low levels of education and may not have a regular income, which puts the entire family at greater risk for poverty, as well as inadequate care and food.[27] A mixed method study in rural western Kenya found that 1 in 5 of caretakers of orphans were above the age of 55, and that there were major difficulties for these elderly caretakers in providing for the educational, nutritional, and medical needs of the orphans.[28] 51% of orphans in Kenya arenot living with a their single surviving parent are living with grandparents.[3] These stresses changed the traditional roles of the elderly and rather than being cared for by their children, they had subsequently "*lost their retirement*" and were serving as the primary source of income and care for their grandchildren.[28]

In one study conducted in western Kenya, 28% of the orphans were being cared for by "*culturally inappropriate*" caregivers such as *"matrilineal kinship or strangers."*[28] As one Kenyan widow in her early fifties phrased the problem :

"*In the past, people used to care for the orphans and loved them, but these days there are so many, and many people have died who could have assisted them, and therefore orphanhood is a common phenomenon, not strange. The few who are alive cannot support them."*[10]

AIDS kills the most productive members of society leaving in its wake those who are most vulnerable to defend for themselves.[14] This leads to an increase in dependency ratios, a decrease in household productivity, and ultimately an uncertainty in basic needs. As a vulnerable population HIV/AIDS orphans lack the social capital and economic means necessary to properly provide for themselves. School feeding programs to keep vulnerable

children in school have been successful in several sub-Saharan countries,[10] including Kenya,[12] but this may not be enough to provide adequate nutrition for these children.

Previous studies have shown that the overall health of orphans and nutritional status of orphans is worse than non-orphans in Kenya.[22] Although little is known about the effects of being both HIV positive and an orphan, overall children who have a clinical history of malnutrition and are HIV positive are at a higher risk for death when compared to HIV positive children who do not have a history of prior malnutrion.[19 24]

There are few studies that document the energy and food requirements of children who are HIV positive.[18 19] Of what is known, children who are HIV positive and asymptomatic have an energy requirement increase by 10% just to maintain normal body weight. If experiencing weight loss their energy requirements may increase by 50%-100%.[18]

In a population study conducted in Western Kenya on the health status of HIV/AIDS, orphans were compared with non-orphans by collecting general health indicators.[29] This study used children <6 years old comparing orphans and non-orphans, as well as the loss of one parent with the loss of both. The study found a significant difference when the children had lost their parent >1 year prior, and with paternal loss compared with maternal loss.[29] Without intervention this disparity could increase throughout childhood as the child grows.

Nationally, 35% of Kenyan children under the age of five are stunted, with a higher proportion (37%) of males being stunted than females (33%).[24] The mean z-score for children in Kenya based on height-for-age is-1.4 and for weight-for age is -0.9. On a provincial level, the Eastern province has the highest proportion of children under five

who are stunted (47%).[24] Factors that may play a significant role in the stunting of children include gender, maternal education, and wealth quintile. Although children who are under five may have a high prevalence of stunting, in Western Kenya the prevalence of stunting has been shown to decrease with age and the onset of puberty.[30]

## *Case Study: Nyumbani Village*

The Children of God Relief Institute (COGRI) is a faith-based organization with the mission "*to provide quality comprehensive care and support to HIV infected and affected children, their families and communities in a sustainable manner,"* and a vision of *"sustainable communities affected by the HIV pandemic, inspired by Christian compassion*." [31] COGRI consists of three different major programs; a children's home in Nairobi, an HIV primary care program in informal settlements, and a village for orphans and grandparents.

Nyumbani Village, situated outside of the small town of Kwa Vonza is on 1,000 acres of land donated by the Kitui District County Council and is a "*self-sustaining community to serve orphans and elders who have been left behind by the HIV pandemic*."[31] The village was created thanks to 2.4 million dollars from USAID, along with other outside donations, and will be funded in the future through sustainable farming initiatives. In the most basic sense Nyumbani Village is an orphanage combined with a nursing home, but in reality it is much more complex. The village consists of twenty clusters of houses, each cluster containing four houses, and each house containing one grandparent and ten to twelve children. The village also has a primary school, secondary school, polytechnique institute, administration building, and organic farm.

The village provides basic amenities for both the aging population and the children that are residents such as food, clothing, housing, water, sanitation, and health care. Additionally it provides a support system in psychosocial counseling and social groups for both the children and the elderly. Since all of the children who reside in the village are orphans, they are able to adapt to fit the special needs of these children. All of the village residents are from the same tribe, the Kamba, and therefore are share linguistic, cultural, and religious traditions.

According to the 2010 Kenya DHS survey 4.1% of Kamba people are HIV positive. The Eastern district, where the village is located, has an HIV prevalence of 3.5% amongst both genders Nyumbani Village. The village is predominately Catholic, and throughout Kenya there is a 5.9% prevalence of HIV amongst Roman Catholics.[24]

COGRI has been influential in the care for HIV/AIDS orphans since early on in the epidemic. In 2003, Nyumbani Home in Nairobi filed a suit against Kenya's Ministry of Education for discrimination. The children had been refused admittance to schools because there was no room for them and they did not have birth certificates.[13] In January of 2004, the Kenyan High Court approved an agreement between Nyumbani Children's Home and the Ministry of Education that permits children who are HIV positive to attend government schools. It was a landmark decision because it not only confirmed the principle of nondiscrimination in Kenya including HIV status, but it also referenced international agreements such as the Convention on the Rights of the Child and the Universal Declaration of Human Rights.[13]

While there are a few other examples of functioning models for children's villages many of these have received criticism for introducing a standard of living that is much

higher than the surrounding community resulting in difficulties for when children reintegrate back into the community after they leave the isolation of the village. [25] These villages can only continue if they have the resources, children are raised in a similar environment to the one of their original family, children are part of the neighboring community, trained social workers are available for the supervision of the village, and the neighboring community shares in the cost of running the village.[25]

## *Ethical Frameworks*

In the application of public health ethics there are many different theories and frameworks that can be used to approach ethical dilemmas. For the case study of Nyumbani Village three different frameworks will be used to discuss the issues that play out in resource allocation. Due to it's international donor relations and strong ties to human rights the first approach is based in human rights in the context of orphans and vulnerable children. The second framework incorporates the strong background of both the organization and the people of the village in Christianity. This involves a theological framework centering on the dignity of a person and their duty to their community. The third framework is a public health model focused on community engagement. This model is based on a set of principles developed and for best practices used in public health.

This is by no means an exhaustive list of ethical frameworks. It is an introduction to begin the discussion amongst stakeholders and identify common themes between different approaches. It is important to consider different because although communities have cared for orphans and vulnerable children forever, never has such a large scale intervention been necessary in the lives of so many children.

**A Human Rights Based Approach**

How do we raise an entire generation of children? This is one of the main questions that is presented by of the case study of Nyumbani Village. International documents are a universally accepted framework for the recognition and understanding of the basic rights of children, particularly those that are most vulnerable such as HIV/AIDS orphans. One of the strengths of a human rights based approach is that it can be applied to any Member State and can cross cultural boundaries.

The basic rights and dignity of the child are paramount to consider when tackling HIV/AIDS, and they provide a foundation for one possible framework for ethical decision-making. The integration of human rights with public health is a widely accepted framework for addressing large-scale interventions that require a global response.

In order to better understand the epidemiology of the epidemic, we must also understand the capacity of human rights to impact the disease.[32] The UNICEF report titled "*A Call to Action: Children, the missing face of AIDS*" put the intricate relationship between HIV/AIDS orphans and human rights best when they said:

> *"AIDS is redefining the very meaning of childhood for millions, depriving children of many of their human rights - of the care, love and affection of their parents; of their teachers and other role models; of education and options for the future; of protection against exploitation and abuse. The world must act now, urgently and decisively, to ensure that the next generation of children is AIDS- free."*[9]

The protection of the rights of orphans and vulnerable children in the HIV/AIDS epidemic is vital to the protection of *all* children. HIV/AIDS can be used as a springboard for the discussion and implementation of the rights of children and the need for human rights in public health frameworks. It can also be influential in understanding the relationship between human rights and HIV/AIDS. Addressing human rights issues

surrounding orphans and vulnerable children requires countries to also address issues such as gender equality, health disparities, educational needs, and development.

States Parties must ensure "*to the maximum extent possible*"[33] the rights of the child, but the question I pose is what if this is not enough? There is an obligation on the international community through the Convention on the Rights of the Child and the Universal Declaration of Human Rights to intervene in times of crisis such as the HIV/AIDS epidemic in sub-Saharan Africa. If the international community does not intervene in places where the government's "*maximum extent*" is inadequate, then the future of these children is jeopardized. If we do not address the rights of orphans and vulnerable children in the HIV/AIDS epidemic we will have to apologize to another generation of children for, in the words of former U.S Secretary General Kofi Anan, "*failing them deplorably*."[1]

The international community has set forth goals for international aid and development, particularly through the Millennium Development Goals (MDG). MDG six is to "*Combat HIV/AIDS, malaria, and other diseases*" with the aim of reducing the spread of HIV/AIDS by 2015, and achieving universal access to HIV/AIDS treatment by 2010.[34] If we are to reach these goals, it is paramount to incorporate human rights into HIV/AIDS prevention, as well as public health infrastructure and guidelines. Without addressing these critical issues in human rights, the HIV/AIDS epidemic cannot be fully addressed, nor will the most vulnerable populations be protected from violations against their most basic rights.

The 2005 World Summit Outcome reaffirmed rights of the child specifically in the context of HIV/AIDS in Article II on Development:

*"We acknowledge the substantial efforts and financial contributions made by the international community while recognizing that these diseases (HIV/AIDS, malaria, tuberculosis and other infectious diseases) and other emerging health challenges require a sustained international response."*[35]

The 2005 World Summit Outcome also developed the goal of reducing vulnerability, stigma, and discrimination "*in particular orphaned and vulnerable children and older persons…"*[35] Yet, in the year 2012 we are still not close to achieving these goals. While we may be able to draw a consensus on the rights of children, action on the protection of these rights is often slow and the most vulnerable children may reach adulthood before anything is achieved.

The Convention on the Rights of the Child (CRC) follows four guiding principles, which are fundamental to the rights of all children. These four principles are[25 33]:

- *Nondiscrimination* (Article 2)
- *Best interest of the child* (Article 3)
- *Survival and development* (Article 6)
- *Participation* (Article 12)

These guiding principles recognize the rights of all children to civil and political rights, as wells as economic, social, and cultural rights. These principles are further applied in an ethical framework through a seven-step process developed by UNICEF. The Human Rights Approach (HRA) for programming and planning interventions for children process includes:[25 36]

1. Identification of children's rights: what would be the minimum standards?
2. Assessment: what is the situation of children?
3. Identification of rights gaps: what are the rights violated or at risk?

4. Causality analysis: what are the causes at all levels of the rights violated?
5. Duty bearers: who are they, what are their roles and obligations?
6. Capacity and resource analysis of the duty bearer
7. Define goals, strategy and actions: what action must be undertake, by whom and how?

These steps require institutions to think deeply about the applications of the rights of children and to develop a strong understanding and appreciation for the role of these guiding principles in decision-making.

**A Theological Framework**

Kenya and Nyumbani Village are both predominately Christian[24] and so for the context of this case study a faith-based framework that is rooted in Christianity will be presented. While the foundation of this framework is Christianity, the Bible, Quran, and Vedas (primary Hindu texts) all instruct followers to protect and care for orphans.[37] Thus, it is reasonable to conclude that other religiously grounded frameworks could be applied in the discussion of the care for orphans. This is just a outline for one of the many options that could be adapted to fit the circumstances.

As a Faith Based Organization, Nyumbani has a strong reference for their ethical decision-making in the history of the organization and Catholic tradition. With it's Catholic roots faith is deeply ingrained in its structure, culture, and history of the organization. Father D'Agostino, the founder of Nyumbani was a Catholic Priest, and Sister Mary Owens, a catholic nun, currently serves as the Executive Director. Catholicism is a major part of the daily activities in the village including holding religious services regularly.

There are numerous scripture writings that point to helping vulnerable populations. Two that explicitly state the duty of followers to help orphans include:

*"God defends the cause of the fatherless and the widow, and loves the alien, giving him food and clothing." (Deuteronomy 10:17-18)*

*"Religion that God our Father accepts as pure and faultless is this: to visit and look after orphans and widows in their distress." (James 1:27)*

There is a longstanding tradition in Christianity of caring for the poor and vulnerable and special attention is granted to widows and orphans. This tradition, or narrative can be used not just to inspire a social ethic, but as a social ethic.[38]

One of the many theological frameworks of thinking is to understand the narrative of the story of religion and its role in caring for HIV/AIDS orphans as the ethics. For example the tradition of social justice in the narrative of Christianity goes as far back as the gospel of Matthew and St. Francis of Assisi.[39] Social justice involves an understanding of the solidarity and equality of humankind. It is a central theme in Catholic ethics, and is derived from a foundation in basic human rights and the inherent dignity in all people.

In his encyclical on capital and labor in 1891 titled *Rerum Novarum*, Pope Leo XIII established a tradition for the "preferential option for the poor" and that society has a duty to protect the poor and vulnerable.[40] This is one of the many indications of social justice being a driving force in Catholic ethics. *Rerum Novarum* calls for the interpretation of the bible to be based around the principal of preferential for the poor and equality amongst people. This interpretation of social just can provide guidance for where to start with ethical decision-making at Nyumbani Village.

There are some concerns about the implications of using the Christian story as an ethical framework[39], primarily that there are many different ways to interpret the same story. The best way to get around a problem such as this is to *base* a framework on biblical text rather than using the actual the bible itself as a tool for decision-making. A second concern is that the bible is a largely male dominated text, and the overwhelming majority of caretakers/grandparents at Nyumbani Village are women.

Religion plays a central role in the everyday decision-making of faith-based organizations such as Nyumbani Village, and as a part of its heritage and current ethos it offers a meaningful framework to turn to for applied ethics. A framework such as "Theology-in-action"[39] uses theological reflection as a way of engaging *orthodoxy* (right belief) and focusing primarily on *orthopraxy* (right action). This model of theoretical reflection places a strong emphasis on the final action and utilizes the practice of theological reflection to determine and understand ethical norms. That is to say that what matters is not only the reflection on these decisions, but also translating those reflections into meaningful actions within the community.

Religious institutions have always played a central role in public health and the protection of vulnerable populations. To leave them out of the ethical debate is to leave them out of the story,[39] and the story of places like Nyumbani Village and it's interpretation of the bible may provide a powerful insight into how decision-making has occurred in the past and on what principles it should follow in the future. The story of Jesus shapes community practices that can inform decision-making in difficult times. It can instill a sense of also resiliency that is important in any place, yet alone one working through challenges.

**Public Health/ Community Engaged Model**

Public health ethics differs from medical and research ethics in that the latter are both much more concerned with individual autonomy.[41] By its name, public health is concerned with the collective whole of a community rather than an individual. It is incompatible then to attempt to place medical and research frameworks into a public health setting, and therefore separate principles and ethical frameworks have been developed that differ from medicine and bioethics. In 2002 The Public Health Leadership Society developed twelve principles for public health ethics. These twelve principles are as follows[42]:

> ***1.*** *Public health should address principally the fundamental causes of disease and requirements for health, aiming to prevent health outcomes.*
>
> ***2.*** *Public health should achieve community health in a way that respects the rights of individuals in the community.*
>
> ***3.*** *Public health policies, programs, and priorities should be developed and evaluated through processes that ensure an opportunity for input from community members.*
>
> ***4.*** *Public health should advocate and work for the empowerment of the disenfranchised community members, aiming to ensure that the basic resource and conditions necessary for health are accessible to all.*
>
> ***5.*** *Public health should seek the information needed to implement effective policies and programs that protect and promote health.*
>
> ***6.*** *Public health institutions should provide communities with the information they have that is needed for decisions on policies or programs and should obtain the community's consent for their implementation.*
>
> ***7.*** *Public health institutions should act in a timely manner on the information they have within the resources and mandate given to them by the public.*
>
> ***8.*** *Public health programs and policies should incorporate a variety of approaches that anticipate and respect diverse values, beliefs, and cultures in the community.*

> ***9.*** *Public health programs and policies should be implemented in a manner that most enhances the physical and social environment.*
>
> ***10.*** *Public health institutions should protect the confidentiality of information that can bring harm to an individual or community if made public. Exceptions must be justified on the basis of the high likelihood of significant harm to the individual or others.*
>
> ***11.*** *Public health institutions should ensure the professional competence of their employees.*
>
> ***12.*** *Public health institutions and their employees should engage in collaborations and affiliations in ways that build the public's trust and the institution's effectiveness.*

One of the major differences between these principles and those set for the by medical ethics and bioethics is the inclusion of the use and dissemination of information. In public health it is important to think critically and "*use data rather than speculation*"[43] in decision-making. It is not simply enough to say that a problem exists or that a policy is a good idea, it must be evidence based.

There is a major shift in bioethics and public health ethics to the focus on social justice and inequalities *globally*.[44] This brings into question *who* should be making public health decisions and policies surrounding the care of vulnerable populations such as HIV/AIDS orphans. Should it be donors, local government, institutions, relatives, caregivers, or the children? There are many different partnerships and collaborations that go into organizing these decisions, however, this may lead to conflicting priorities amongst stakeholders.

Engaging communities in public health policy is important in establishing trust and integrity in public health policy.[43] It is also outlined in several of the previously stated principles, particularly number six,[42] which calls for institutions to disseminate the

information to the community and obtain their consent before implementation and help in decision-making for policies and programs.

While the international community has been slower to address the problems presented by such a large number of HIV/AIDS orphans, local communities have been addressing the issues from the beginning. It is important to recognize and respect their role and autonomy as a community in addressing their health issues.[45] Previous experiences tell us that community based programs can be very effective and supporting local responses may be not only more appropriate, but also a more ethical.

# Chapter 3: Project Content

## *Methodology*

**Introduction**

In the case study of Nyumbani Village, growth measurements need to be systematically collected and recorded in a way that accounts for staff and children turnover, as well as basic analysis. In order to begin an annual system of growth and nutritional analysis of the children in the village data was collected from the village clinic. The purpose of this was to better understand the nutritional needs of the children there, and if the policies in place were adequately addressing the malnutrition of the children living in the village. Annual height and weight were collected and an analysis of the information was conducted to better understand the development of the children in the village.

A comparison of children by age, sex, and HIV status was completed using World Health Organization (WHO) international anthropomorphic standardized z-scores for weight-for-age, height-for-age, and BMI-for-age. The data were then further analyzed to

determine the appropriate places for intervention in the nutritional needs of the children at Nyumbani Village.

**Population and sample**

Nyumbani Village consists of twenty clusters of houses with each cluster containing four houses. Eight to twelve children and one grandparent who serve as the primary caregiver for the children occupy each house. The children may or may not be related to the grandparent in charge, but most children have at least one biological sibling in their home and are from the same clan or home village as the others in their house.

All of the houses are built from the same local brick materials and each cluster shares a common water source. Each house is also equipped with an ecological toilet from which the waste is collected weekly. There are several public deep pit latrines located throughout the village. Many houses have small gardens, chickens, and banana tree circles that serve as additional supplementation to their diet, although data was not collected on the exact diet of the children. Income is generated for the village through sustainable farming initiatives that hires local workers to farm the surrounding semi-arid land. Much of this food is sold at local markets, and is also disturbed to the families in the village as part of the village programming. The children and grandparents are given food through a centralized distribution system within the village administration; however, the children eat both breakfast and lunch at school whenever they are in session.

Children who are HIV positive are also given supplements to their diets such as milk, eggs, liver, and sometimes meat on a rotational basis through the village administration and clinic. Information and analysis on how the families supplement their diets was not collected, nor was evaluation of the HIV positive children food

consumption. Overall he height and weight of 667 children were, 325 males and 342 females. Of the data collected 91 children ages 5-10 were able to be calculated for z-score analysis using weight-for-age, 516 children ages 5-19 were able to be calculated for z-score analysis for both height-for age and BMI-for age.

**Research design**

A quantitative study was conducted using a cross-sectional design using data collected for the village clinic as annual height and weight checkups of the children living in the village was used in order to determine the developmental needs of the children in the village for future programming and food distribution. Permission was granted from the Executive Director of COGRI, the Nyumbani Village Director, as well as the Nyumbani Village Clinical Officer. Since the project was conducted at the request of Nyumbani Village as part of an ongoing relationship between COGRI and Emory University, no IRB approval was sought. Rather this project was considered a preliminary data collection as part of an ongoing relationship between Nyumbani Village and Emory University.

**Procedures**

The list of children within the village was obtained from Hotcourses Primary School, Lawson Secondary School, and the village's homecare department. The lists were cross-referenced and double-checked with students to assure that the correct birth year, standard in school, cluster, and house number were obtained. The HIV status of each child was obtained from the clinic, as well as the antiretroviral therapies of each child who was HIV positive. Basic measurements of height and weight were used to calculate anthropomorphic measurements for children at Nyumbani Village. These include weight-

for-age, height-for-age, and BMI-for-age. The term "Adolescents" generally refers to children ages 5-19. What constitutes a "child" may vary between organizations and countries with some recognizing adulthood at 15, and others at 18. The standard international definition defined in the United Nations Convention on the Rights of the Child is any persons under the age of 18.[33] For the sake of this case study the investigation was limited to adolescents, or children 5-19.

**Instruments**

All height and weight measurements were obtained using the World Health Organization standard protocol for nutritional analysis. Heights were measured in centimeters using a chart drawn on the wall with a standardized ruler. Weight measurements were obtained in kilograms using a calibrated scale. HIV status from the clinic health records determined by a rapid test during the admission process of the children.

House and cluster numbers, birth year, and standard or class in school were verified by the school administration and home care department in the village. Birth months for most of the children were either unknown or estimated, and so only birth years were recorded as the most accurate calculation for age.

**Data analysis**

Data analysis was conducted using the World Health Organization Anthropomorphic calculator for children ages 5-19; the SAS macro for Anthro Plus and SAS software were used to determine the international standardized z-scores for each child as well as specific demographic groups such as sex and HIV status. The WHO Multicentre Growth Reference Study Group Standards for Methods and development[46] was used to determine the standardized z-score for each child.

Standard z-scores were determined to designate children who are obese, overweight, average, undernourished, and malnourished. Since few children in the village were under age 5 or over age 19 the standard measurements include:

- Weight-for-age (for children ages 5 to 10)
- Height-for-age (for adolescents ages 5 to 19)
- BMI-for-age (for adolescents ages 5 to 19)

**Limitations and delimitations**

At the initial onset of the study it was clear that there was a lack of communication within the different organizations working within the village. For example the primary and secondary schools are separate administratively from the social workers and clinic. Although each has their own set of records, there was no central database of information on people living in the village. Some of the children had different dates of birth, housing numbers, and names when the lists were compiled. Verification of children's names, ages, etc., was difficult due to this lack of inter-organizational communication.

One of the major limitations in the data was the accuracy of birth years obtained. This was due to the fact that many of the children's birth dates were unknown and the best available record of their birth was by year. This limited the analysis because the children's age could only be calculated to the nearest year rather than month. Birth registration is a common problem amongst HIV/AIDS orphans,[27] and creates serious issues when attempting to determine how many children are affected and where to allocate resources to address their specific needs.

Another limitation of the data was verification of HIV status. Children are tested for HIV upon admittance to the village but are not tested again unless there is an indication that they may have had a false positive test or they ask to be retested. This is an issue

because many of the children who are sexually active may have become positive and are not re-retested. There are legal and ethical issues with requiring the mandatory re-testing of the children, and so the HIV status of the adolescents may not be accurate.

# *Results*

**Introduction**

The distribution of the children's gender and their HIV status were determined using SAS software (n=667) (Table 3.1). The mean age of the children was 13.17 years (SD= 3.67) and standard school grades of 5, 6, and 7 had the largest cohorts of children in them. There are slightly more female children living in the village, with 51.27% of the children being female and 48.73% being male, although this was not statistically significant. Neither sex was found to be at a higher risk for HIV infection with 94.77% of males being negative and 94.74% of females being negative (Table 3.1).

A cut off z-scores of <-2 SD was established to determine whether or not children were undernourished or malnourished. Children with a <-2 SD were considered to be thin or undernourished. Children with a ≥ -2SD were considered to be normal or sufficient in their growth. Males were 36.7% more likely than females to have z-scores of <-2 SD based on weight-for-age and 78.88% more likely to have z-scores <-2 SD based on BMI-for-age.

However, females were 44.02% more likely to be <-2SD when considering height-for-age. (Table 3.1). Although these were the only statistically significant results (95% CI = 0.3199 – 0.964), it does not diminish that there are some interesting trends in the growth of the children at Nyumbani Village.

Neither sex was more likely than the other to be HIV positive HIV positive (Table 3.2). Children who were HIV positive were nearly three times as likely to be at risk for thinness (OR= 2.07 95% CI = 0.3732-17.52), although these children were younger (ages 5-10) then the average age of all of the children which was 13.17 (SD = 3.67). When comparing HIV status for height-for-age, HIV positive children were 55.6% more likely to have a score <-2 SD (Table 3.2).

**Table 3.1** HIV status and z-scores stratified by Sex for children living at Nyumbani Village in Kitui Kenya, June-July 2011.

| | **Males** | | **Females** | | | |
|---|---|---|---|---|---|---|
| **Variable** | **n** | **(%)** | **n** | **(%)** | **OR** | **95% CI** |
| Sex | | | | | | |
| *HIV Positive* | 17 | (5.23%) | 18 | (5.26%) | | |
| *HIV Negative* | 308 | (94.77%) | 324 | (94.74%) | 1.007 | (0.5049-2.013) |
| *Status combined* | 325 | (48.32%) | 342 | (51.27%) | | |
| Weight-for-age | | | | | | |
| *<-2 z-score* | 4 | (7.69%) | 4 | (10.26%) | | |
| *≥-2 z-score* | 48 | (92.31%) | 35 | (89.74%) | 1.367 | (0.2899-6.444) |
| Height-for-age | | | | | | |
| *<-2 z-score* | 36 | (14.75%) | 24 | (8.82%) | | |
| *≥-2 z-score* | 208 | (85.25%) | 248 | (91.18%) | 0.5598 | **(0.3199-0.9674)** |
| BMI-for-age | | | | | | |
| *<-2 z-score* | 23 | (9.43%) | 14 | (5.15%) | | |
| *≥-2 z-score* | 221 | (90.57%) | 258 | (94.85%) | 1.788 | (0.9114-3.585) |

**Table 3.2** Sex and z-scores stratified by HIV status for children living at Nyumbani Village in Kitui Kenya, June-July 2011.

| | HIV Positive | | HIV Negative | | | |
|---|---|---|---|---|---|---|
| **Variables** | **n** | **(%)** | **n** | **(%)** | **OR** | **CI (95%)** |
| Sex | | | | | | |
| *Males* | 17 | (48.51%) | 308 | (48.73%) | | |
| *Females* | 18 | (51.43%) | 324 | (51.27%) | 0.9935 | (0.4968-1.981) |
| *Sexes combined* | 35 | (5.25%) | 632 | (94.75%) | | |
| Weight-for-age | | | | | | |
| *<-2 z-score* | 2 | (20.00%) | 6 | (7.41%) | | |
| *≥-2 z score* | 8 | (80.00%) | 75 | (92.59%) | 3.07 | (0.3732-17.52) |
| Height-for-age | | | | | | |
| *<-2 z-score* | 4 | (16.67%) | 56 | (11.38%) | | |
| *≥-2 z-score* | 20 | (83.33%) | 436 | (88.62%) | 1.556 | (0.4412-4.46) |
| BMI-for-age | | | | | | |
| *<-2 z-score* | 1 | (4.17%) | 36 | (7.32%) | | |
| *≥-2 z-score* | 23 | (95.83%) | 456 | (92.68%) | 0.5507 | (0.02577-3.1) |

## Weight-for-age

The weight-for-age z-scores were obtained for all children ages 5-10 years (n= 91). The overall mean z-score was -0.46 (SD= 1.08) regardless of gender or HIV status. When broken down by status the mean z-score for HIV positive children were -1.25 (SD= 1.2) and the mean z-score for HIV negative children was -0.36 (SD = 1.03). A box plot with the distribution of means and standard deviations by age in years (Figure 3.1) shows how the average mean z-score for weight-for-age of the children changes by age in years.

Males recorded an overall mean of -0.51 (SD = 1.03) with HIV positive males having a mean z-score of -0.83 (SD = 1.17) and HIV negative male having a mean z-score of -0.47 (SD = 1.01). Females had an overall mean of -0.4 (SD = 1.15) with HIV positive females having a mean z-score of -1.9 (SD = 1.05) and HIV negative females having an overall mean of -0.23 (SD = 1.04). Figure 3.2 demonstrates the differences between HIV status and sex amongst children at Nyumbani Village.

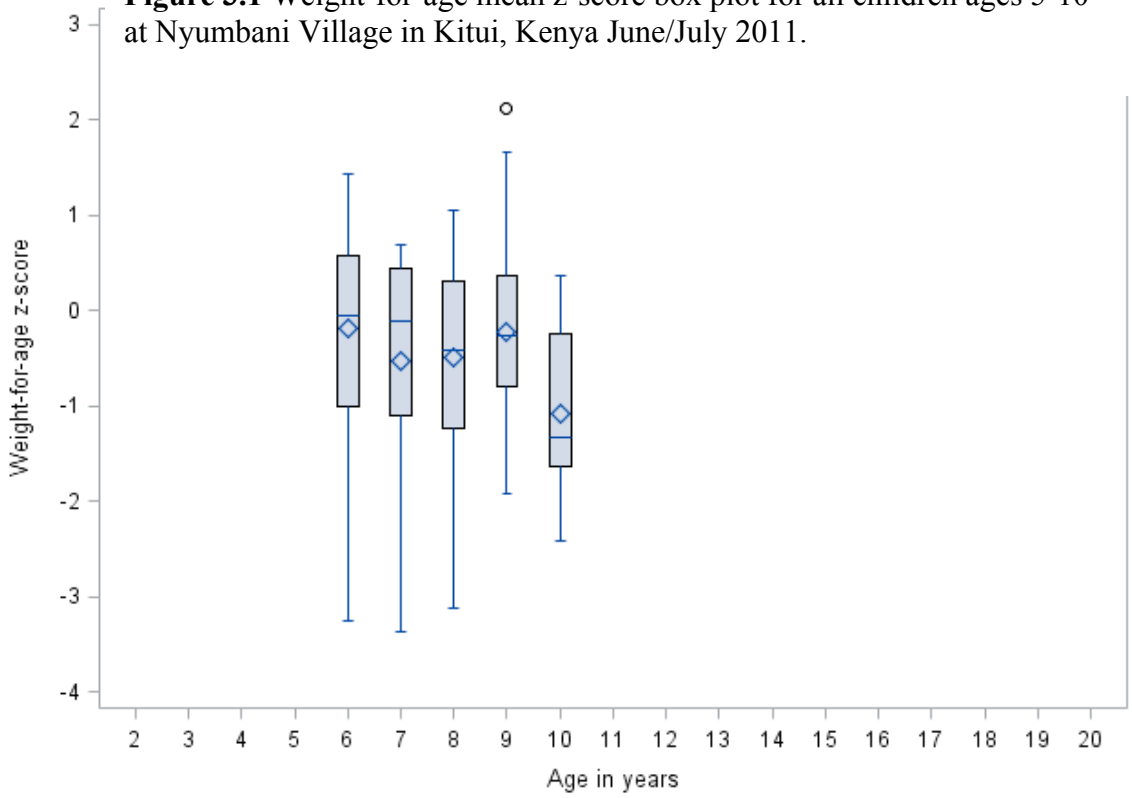
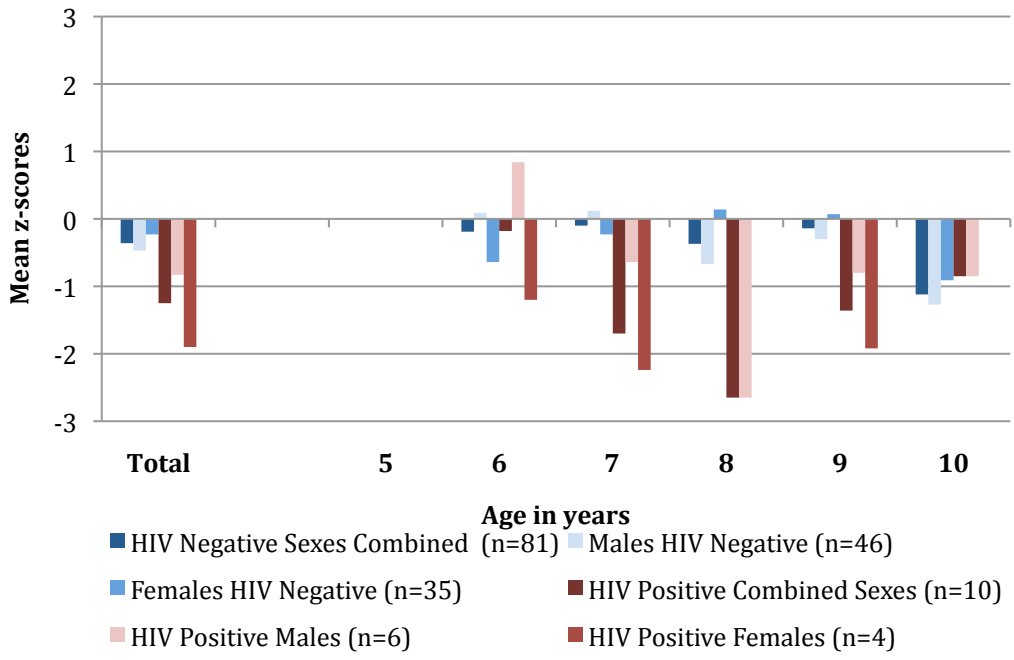



**Figure 3.1** Weight-for-age mean z-score box plot for all children ages 5-10 at Nyumbani Village in Kitui, Kenya June/July 2011.

**Figure 3.2** Mean z-scores of weight-for-age of children ages 5-10 stratified by HIV status and sex at Nyumbani Village in Kitui, Kenya June/July 2011.




**Height-for-age**

The mean height-for-age z-score regardless of sex or status was -0.82 (SD = 1.16) (n = 516). When broken down by HIV status, HIV positive children had a mean z-score of -1.1 (SD = 1.51) and children who were negative had a mean z-score of -0.81 (SD = 1.14). A box plot with the distribution of means and standard deviations by age in years (Figure 3.3) shows how the average mean z-score of the children's height-for-age changes by age group.

The mean z-score for males regardless of HIV status was -0.92 (SD -1.23). HIV positive males had a mean z-score of -0.69 (SD = 1.27), and HIV negative males had a mean z-score of -0.94 (SD =1.22). The mean z-score for females was -0.73 (SD = 1.09) regardless of HIV status. HIV positive females had a mean z-score of -1.45 (SD = 1.59) and HIV negative females had a mean z-score of -0.69 (SD =1.05). Figure 3.4

demonstrates the differences between HIV status and sex amongst children at Nyumbani Village based on the standard measurements of height-for-age.

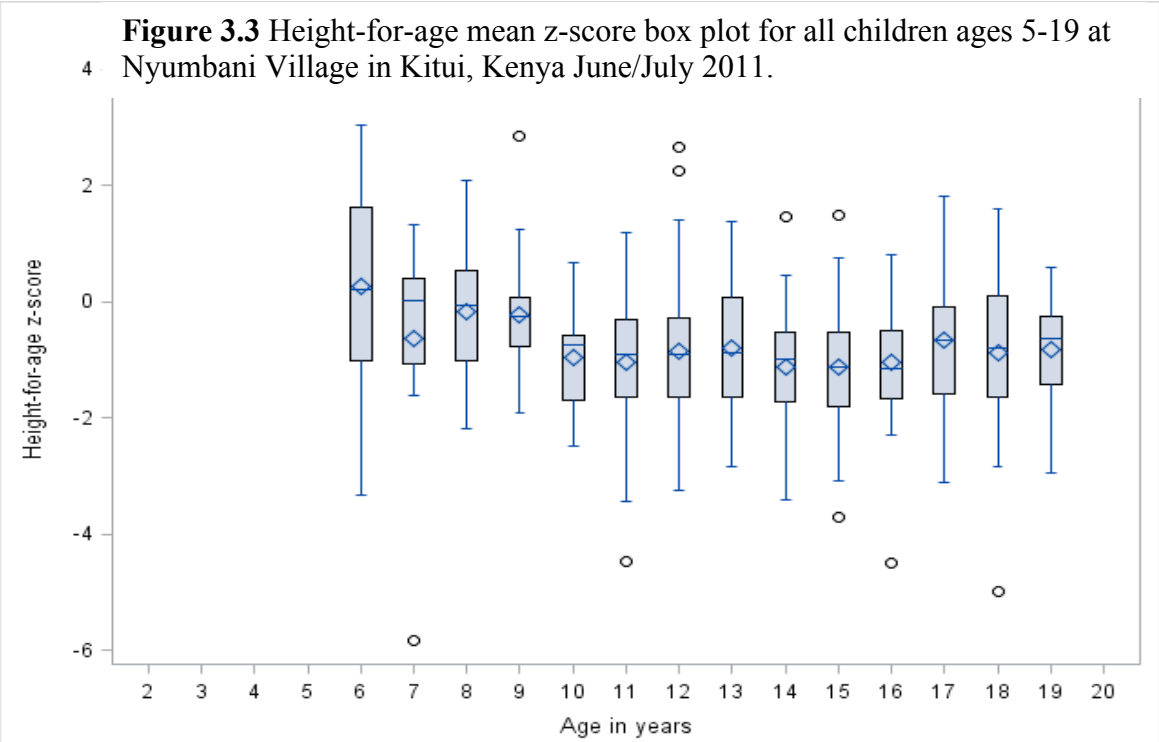



**Figure 3.3** Height-for-age mean z-score box plot for all children ages 5-19 at Nyumbani Village in Kitui, Kenya June/July 2011.

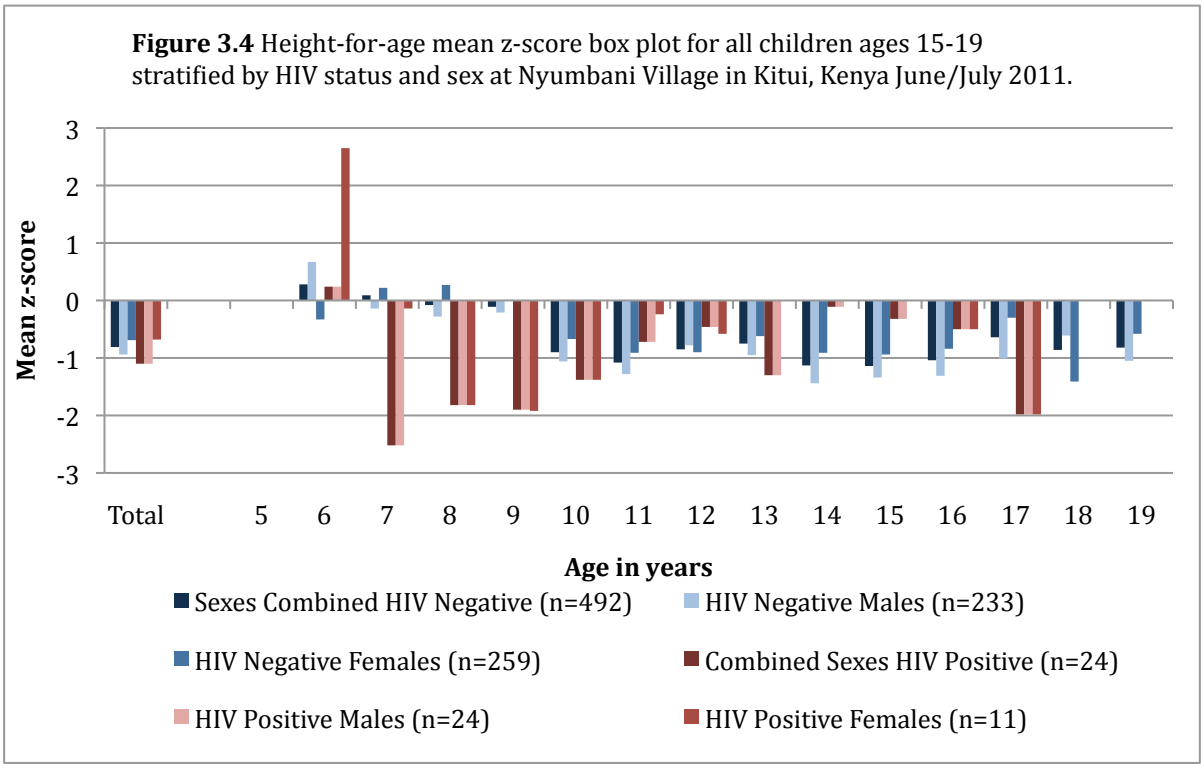



**Figure 3.4** Height-for-age mean z-score box plot for all children ages 15-19 stratified by HIV status and sex at Nyumbani Village in Kitui, Kenya June/July 2011.

**BMI-for-age**

The mean z-score for children at Nyumbani Village regardless of sex or HIV status was -0.60 (SD = 0.94) (n = 516). For both sexes children who were HIV negative had a mean z-score of -0.60 (SD = 0.94), and HIV positive children had a mean z-score of -0.42 (SD = 0.92). A box plot with the distribution of means and standard deviations by age in years (Figure 3.5) demonstrates how the average mean z-score of the children's BMI-for-age changes by age in years.

The mean z-score for males regardless of status was -0.80 (SD = 0.90). HIV positive males had a mean z-score of -0.68 (SD -0.84), and HIV negative males had a mean z-score of -0.80 (SD = 0.9). The mean z-score for females regardless of HIV status was -0.41 (SD = 0.94). HIV positive females had a mean z-score of -0.23 (SD = 1.0) and HIV negative females had a BMI-for-age mean z-score of -0.42 (SD = 0.94). Figure 3.6

demonstrates the differences between HIV status and sex amongst children at Nyumbani Village based on the standard measurements of BMI-for-age.

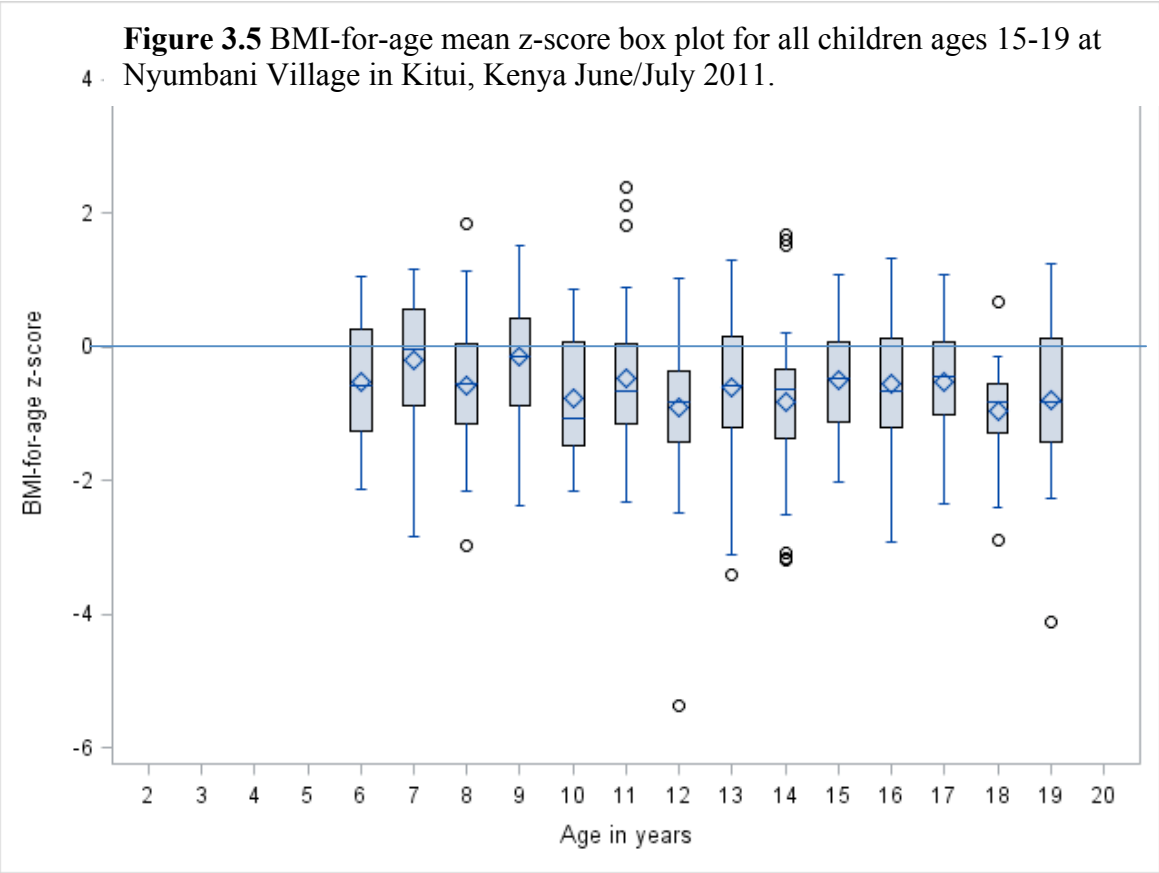
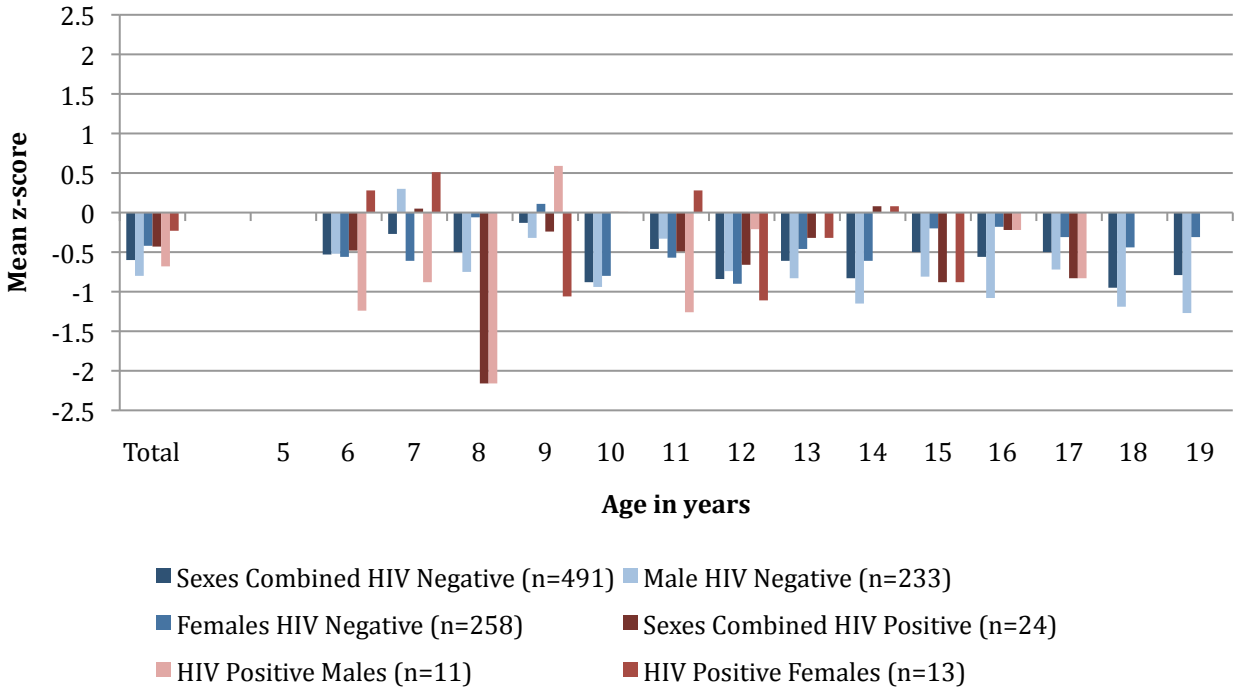



**Figure 3.5** BMI-for-age mean z-score box plot for all children ages 15-19 at Nyumbani Village in Kitui, Kenya June/July 2011.

**Figure 3.6** BMI-for-age mean z-score box plot for all children ages 15-19 stratified by HIV status and sex at Nyumbani Village in Kitui, Kenya June/ July 2011

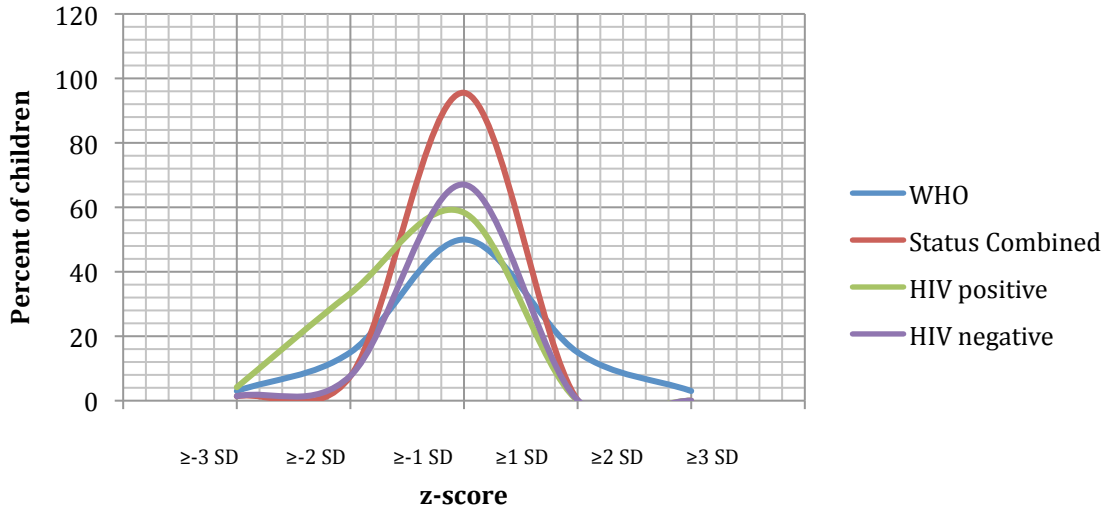



**Major Findings**

On all three measurements males had lower mean z-scores than their female counterparts. Although HIV positive females had a much lower mean z-score in weight-for-age and height-for-age. HIV positive children had lower mean z-scores in weight-for-age and height-for-age, but when broken down by HIV status and gender, HIV positive children had lower mean z-scores than their negative peers.

When comparing the percent of children who fell within each z-score range for BMI-for-age to the WHO percentages (Figure 3.7) the children at Nyumbani were skewed to the left, regardless of HIV status.

**Figure 3.7** Z-score distribution of BMI-for-age for all children at Nyumbani Village compared to WHO standard percentiles stratified by HIV status Kitui, Kenya Jue/July 2011.




The Eastern province of Kenya has the highest rate of stunting amongst children under five years of age, with 42% of children being stunted.[24]

Table 3.3 compares Kenya and Eastern providence percentages for z-scores of weight-for-age and height-for-age of children under five years old from the 2008 DHS Survey[24] with the data for all children gathered at Nyumbani Village. The major difference between these two data sets is that the children in the village are adolescents (5-19) whereas the children in the DHS dataset are under 5. However, it does show an important comparison that the children in the village have higher overall mean z-scores and a much smaller percentage are stunted and thinness. While stunting decreases as children grow older[30], the village is a substantial improvement in the basic living conditions for the children and further investigation into the overall health of the children within the village compared to those in the surrounding area is necessary to further understand the impact of the village on the health of the children there.

**Table 3.3** Comparison of mean z-scores and percentiles of the 2008 Kenyan DHS survey to children living at Nyumbani Village in Kitui Kenya, June-July 2011

| Variable | All of Kenya* | Eastern Providence* | Nyumbani Village |
|---|---|---|---|
| Weight-for-age** | | | |
| *% Below -3 SD* | 3.6% | 19.8% | 3.29% (n=3) |
| *% Below -2SD* | 16.1% | 0.7% | (n=8) |
| *Mean z-score (SD)* | -0.9 | -1.0 | -0.46 (1.08) |
| Height-for-age*** | | | |
| *% Below -3 SD* | 14.2% | 17.1% | 2.71% (n=14) |
| *% Below -2 SD* | 35.3% | 41.9% | 11.63% (n =60) |
| *Mean z-score (SD)* | -1.4 | -1.7 | -0.82 (1.16) |

* All children in the 2008 Kenya DHS survey were under five years of age
**Age range of children at Nyumbani for WAZ was 5-10 year
*** Age range of children at Nyumbani Village for HAZ was 5-19 years

Further investigation into the long-term effects of ART and HIV on the growth of adolescents is also necessary in order to better inform food distribution policy at places such as Nyumbani Village. A WHO meeting in Durban, South Africa on Nutrition and HIV infection they concluded that HIV seems to have a greater association with wasting in children rather than stunting. They also stated that much of the effects on the growth of children is determined by which ART they are on, how long they have been on the drugs, and their viral load. Little is known about low resource settings, and the longer-term effects of ART therapy on growth.[47]

The information on growth at Nyumbani Village raises important questions that were outside of the scope of this project. Further investigations need to be conducted in order to better understand the differentiation of children based on length of time in the village (i.e. does a longer duration in the village have a higher or lower comparative z-

score) as well as the impact on z-scores of HIV progression (i.e. do children the impact of viral load and CD4 counts on z-scores).

The data does not provide a clear path forward in making decision. However, it does show a need for stronger collection, analysis, and dissemination of information for evidence-based strategic planning. It also demonstrates the importance of routine health screening and surveillance of the children at Nyumbani Village to help guide policy and practices.

# Chapter 4: Discussion, Conclusion, and Recommendations

## *Introduction*

There are larger questions and issues that play into the nutritional needs of the children at Nyumbani Village, and for HIV/AIDS orphans as vulnerable population subgroup. There is need for a cohesive framework for making these decisions that can be applied to other organizations working with orphans and vulnerable children, particularly in the HIV/AIDS epidemic.

In this discussion I outline the strengths and weaknesses of three different ethical frameworks for public health decision-making in the case study of Nyumbani Village. The first framework is a Human Rights Based Approach that considers the United Nations Convention on the Rights of the Child and other international body documentaiton. The second framework is a theological framework rooted in Nyumbani and COGRI's religious ties to Catholicism. The final framework is based on a public health and community engagement model using public health ethics as a foundation for decision-making.

# *Ethical Frameworks*

**A Human Rights Based Approach**

In the case of Nyumbani Village a Human Rights Approach (HRA) helps us to understand the duty of the international community to support HIV/AIDS orphans and the justification for a program that takes into account the holistic needs of the children. It provides insight into the existence of the village, and why it is an intervention in the lives of these children is an obligation to humanity.

If we look at Nyumbani Village through the human rights approach seven- step process,[25 36] one concern might be in defining goals, strategy and actions (*number 7: what action must be undertaken, by whom, and how*) with much of the concern lying in *by whom?* We must carefully consider the role of the local community and the children, but also the role of international partnerships, local governments, and implementing organizations.

The dilemma of resource allocation amongst the different rights of the child also becomes a problem with the HRA. While a HRA might tell us which rights to protect and promote, it does not tell us what to do when we may only be able to choose a handful of rights. What do we do when we can't do it all? In the context of HIV/AIDS orphans, we must ask if it justifiable for them to give up their rights to a culture, language, and tribe if it means that they will be given food, medicine, and clean water?

The HRA also does not address issues that may be important to a particular organization's history and mission. For example the argument can be made to consider *love* as one of the basic rights of children at Nyumbani Village.[48] In providing basic rights such as proper nutrition, housing, and education, Nyumbani village provides love to the children who live there. If it is the duty of institutions caring for orphans and vulnerable

children to provide love[48], then perhaps the best way to go about doing so is care for their other rights as well.

While a human rights approach may justify the existence of a place such as Nyubmani Village, what it lacks is the ability to make practical decision in application, particularly in emergency settings. To go back to our case example if we were to approach the nutritional needs of the children in the village from a human rights based approach we might say that the children have a right to proper nutrition as stated in the Convention on the Rights of the Child[33], but that they have equal rights to education, housing, health, freedom from exploitation, culture, language, and religion. However, if we only have limited funds per child it is just not possible to provide everything in an equal manner. Also, some children, such as those who are HIV positive, may have different needs such as requiring a more robust diet. While a human rights approach gives us guidance for decision-making at higher levels such as donor agencies and international collaborations it may be inadequate for addressing day-to-day decision making of an organization like Nyumbani Village.

The Human Rights Approach is child-centered, without disregarding the role of a child's environment. It recognizes that children's rights require obligations from families, communities, society, the state, and the international community. It requires action at various levels and a longstanding commitment amongst partners both locally and internationally.[25 36]

**A Theological Framework**

A faith-based framework in the case of Nyumbani Village may allow for a greater respect for the community involved and the role of the history of the organization. Theological reflection and precedence in ethical principals is more of a process than a set

of guidelines, but nonetheless it offers a viable alternative to some of the difficulties with the HRA. A theological framework would include the community in decision-making. This involvement in some way would serve as a form of liberation from vulnerability and empower both the individuals and community to be resilient in times of difficulty.

One question that arises within a theological framework that is also reflected in the human rights based approach is: *who determines the narrative?* That is, who should be involved in the decision-making? As Nyumbani moves forward this may very well be a deciding factor in its success. There must be a balance between external partners and community engagement. This is where the public health model may be able to help provide insight the roles of multiple stakeholders.

**A Public Health/Community Engaged Model**

The linkage between the public health model and a theological framework lies in social justice. Social justices is the moral foundation for public health.[49] and is ultimately routed in the longstanding history between public health and religious institutions. In the case of Nyumbani Village, the children are minors and they are technically the ward of the village, meaning that the village staff both legally and ethically have the responsibility of decision-making for the children. However, in their daily lives the grandparents are the main caregivers of the children and should play an integral in the decision-making process of the health and wellbeing of the children in their care.

The protection of children affected by HIV/AIDS requires the strengthening of community-level interventions.[27] We should not only question the existence of Nyumbani Village since it removes the children from their base community, but also the lack of involvement of community members in decision-making on policies and programs such as

nutrition and growth. Although there are many local and national officials involved in the decision-making process of Nyumbani Village, if we were to use a public health model, more input from the children and grandparents is necessary in the process.

A community-engaged model would require the inclusion of members of the community in developing a framework. For example, the grandparents who serve as the primary caregivers at Nyumbani Village would be given a greater role in determining how to best address the nutritional needs of the children. They would be engaged more in determining how best to fairly distribute food and how to allocate resources, albeit under the guidance of a framework and in collaboration with other stakeholders.

One of the fundamental questions that any public health program must ask itself is *"How effective is it in achieving its stated goals?"*[43] In the case study of Nyumbani Village their mission statement that they aim to:

> *"…ensure that the children receive love, sustenance, health-care, holistic education and culture transfer, aiming at their physical, psychosocial and spiritual development, and, at the same time, providing holistic care and support for the grandparents in their later years…"*[31]

This leaves the discretion of the measurement of these goals to the organization and donors. In a public health framework education and physical development have measureable standards, it might not be considered ethical to include programming for the "holistic care" or "love" of the children because we cannot properly measure whether or not this has occurred. This is where a theological perspective may offer the ability to better understand the role of compassion and love in the lives of the children at Nyumbani Village.

Too often public health resource allocation falls victim to the "socioeconomic status fallacy." In the principles set for the by the public health framework practitioners must "*address principally the fundamental causes of disease and the requirements for health.*"[42] However, this may include extremely complex underlying causes such as poverty, lack of education, geography, and the all encompassing "socioeconomic status." It is simply impossible to address the fundamental cause of a disease that has many complex factors that play fundamental roles in the "*cause of disease and the requirements for health*." It would not be easy to determine the fundamental cause of nutritional deficiencies for HIV/AIDS orphans.

A public health framework addresses the need for decision-making at a community level and the role of partnerships in decision-making. It also provides us with a solid foundation of principles for which to begin developing principles for Nyumbani Village and other organizations working with HIV/AIDS orphans. In combination with the HRA and theological framework it provides an important perspective beyond the individual at the community level.

## *Recommendations*

The main recommendation for Nyumbani Village based is to look further into monitoring the growth of the children and consider thoghtfully the involvement of the community in decision-making surrounding food supplementation. More systematic information is needed about what the children in the village are eating and whether or not the HIV positive children are in fact the ones receiving the distributed diet supplementation. Through conversations with the grandparents and clinical officer it was apparent that many of the grandparents were concerned about the fairness of giving one

child more food than the others in a situation where food was sometimes scarce. There were also concerns about singling out the children based on their HIV status and reinforcing stigmatization by treating the children differently on basic needs. However, further understanding of these issues would be extremely helpful in determining future policies and programs.

Although the aim of this project was to centralize some of the information on the children such as height and weight within the clinic, for further monitoring and evaluation purposes a more complete gathering of data is necessary. Including but not limited to age at entry, birth place, year of parental death, siblings within the village, family outside of the village, relation to primary caregiver, and illness within the past year. Yearly evaluation and monitoring of children's weight and height using WHO Anthroplus is critical to monitoring the overall health and wellbeing of the children and identifying those who may need more food assistance in their homes.

Nyumbani Village demonstrates the need for a long-term holistic commitment to the wellbeing of HIV/AIDS orphans. As part of the response to the volume of HIV/AIDS orphans, donors must give communities a safety net over a long period of time, rather than short-term grants for specific projects.[45] There must be a commitment to the development of children in a setting that respects their rights and needs. It cannot simply be a one time intervention, but must include a sustained commitment to impacting their lives.

One of the most interesting and alarming results of the data is that as the children at Nyumbani grow older there seems to be a more long-term effect on their growth (Figure 3.2, 3.4, and 3.6). This may be because the older children in the village have had the majority of the damage done before coming there (the village has only been around since

2005). For example a child who is 15 may have spent the first 10 years of their life outside of Nyumbani Village, and thus their growth may be outside of the village's control. The village offers an opportunity to gather valuable information on what happens when there is an intervention in the lives of HIV/AIDS orphans. While there may be ethical concerns involving orphans in research, there are also ethical concerns about *not* having information from which to make decisions.

Although many of the necessary interventions required in preventing children from being malnourished must occur before they even enter the village, efforts must be made to reach children who are not able to come to the village, and collaborations are necessary in order to further identify children who are at risk and need additional aid. When children are admitted to the village nutrition needs to be made a major priority in influencing their overall health. Ensuring that all children have equal access to proper nutrition is vital to their growth, as well as improving their overall health.

Further research is needed in order to better understand how families in the village are supplementing their diets, how food is distributed within the homes, and where gaps in access to food may be occurring. For example many families have chickens and gardens but little information was available on how much they sell to the local community, and how much of the food they actually eat themselves. It is also important to better understand what happens in homes when their rations begin to run out, or food becomes scarce. Is this food going to the younger children first? Do the children who are HIV positive take precedence over those who are negative? Answers to these questions could provide valuable insight into the distribution of food and programming surrounding nutrition in the future.

## *Conclusion*

Nyumbani Village is an innovative solution to raising the vast number of children who have been orphaned by the HIV/AIDS epidemic. If we do not act soon in helping these children we may very well disappoint an entire generation who have lost their parents. These decisions should not be made lightly but rather should consider an ethical framework, and evidence based planning to tackle the difficult day-to-day decision making of how to care for these children.

Each of the three frameworks proposed, the human rights based approach, theological framework, and a public health/community engaged model, each have strengths and weaknesses in providing insight into ethical decision-making. The answer is not simply that one of these frameworks is the best for providing ethical principles for the case of Nyumbani Village or HIV/AIDS orphans as a whole. Rather, the best approach may be to combine elements of each framework to create a set of guiding principles for the village, and the care of HIV/AIDS internationally.

There are similarities between the three frameworks and common principles such as equality, protection of vulnerable populations, and providing basic needs that can be further tailored to the village's needs. Perhaps the most important aspect of the ethical framework used for making decisions at places such as Nyumbani, is we actually use some common foundation for our decision-making. Organizations working with HIV/AIDS orphans in must put considerable thought *why* and *how* they will make decisions, and *who* will be involved in this process

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