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Vulnerable Agents: Ugandan Children's Experiences with HIV Rehabilitation and Reintegration

Colleen Walsh Lang
Washington University in St. Louis

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WASHINGTON UNIVERSITY IN ST. LOUIS

Department of Anthropology

Dissertation Examination Committee:
Bradley Stoner, Chair
Jean Hunleth
Lora Iannotti
Rebecca Lester
Shanti Parikh
William Powderly

Vulnerable Agents: Ugandan Children's Experiences with HIV Rehabilitation and Reintegration

by
Colleen Walsh Lang

A dissertation presented to
The Graduate School
of Washington University in
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requirements for the degree
of Doctor of Philosophy

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List of Abbreviations

ABC	Abstain, Be faithful, use Condoms – slogan adopted by national Uganda HIV prevention programming
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy, common term for HAART
ARV	Antiretroviral, refers to medicine or drug (often used in plural form ARVs)
CLHIV	Children Living with HIV
eMTCT	Elimination of Mother-to-Child Transmission (of HIV)
Global Fund	The Global Fund to Fight AIDS, Tuberculosis, and Malaria
HAART	High-Active Antiretroviral Therapy, commonly called ART
HC	Health Center (divided into 4 levels – HC-I, HC-II, HC-III, HC-IV)
HIV	Human Immunodeficiency Virus
HTLV-III	Human T-lymphotropic virus III (formerly the name for HIV)
IGA	Income Generating Activity
JCRC	Joint Clinical Research Center (see Primary Organizations)
MAM	Moderate Acute Malnutrition
MOH	Ministry of Health
MSF	Médecins Sans Frontières (Doctors Without Borders)
MTCT	Mother-to-Child Transmission (of HIV)
NGO	Non-Governmental Organization (includes community-based and faith-based organizations)
NRM	National Resistance Movement (led by Yoweri Museveni)
NSP	National Strategic Framework/Plan for HIV/AIDS
NSPPI	National Strategic Programme Plan of Intervention for Orphans and Other Vulnerable Children
OVC	Orphan and/or Vulnerable Child (often used in plural form OVCs)
PEPFAR	The US President’s Emergency Program for AIDS Relief
PLHIV	People Living with HIV
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission (of HIV)
RUTF	Ready-to-Use Therapeutic Food
SAM	Severe Acute Malnutrition

SCORE	Sustainable and Comprehensive Responses for Vulnerable Children and their Families
UAC	Uganda AIDS Commission
UDHS	Uganda Demographic Health Survey
UK	United Kingdom
UN	United Nations
UNAIDS	The Joint United Nations Program on HIV/AIDS
UNHS	Uganda National Household Survey
UNICEF	United Nations Children’s Fund
US(A)	United States (of America)
USAID	US Agency for International Development
VCT	Voluntary Counseling and Testing (for HIV)
VSLA	Village Savings and Loans Association
WFP	World Food Program
WHO	World Health Organization

Acknowledgements

It is with great gratitude that I first thank the children from Baaliro who let me into their lives. *Weebale nnyo, weebalile ddala!* Ethics boards are very concerned with protecting children from being unwillingly forced or coerced into participating in research. However, based on my experiences with the children at Baaliro,[1] at times I wonder if these ethics boards don't underestimate children's power to refuse – their ability to remain silent and/or not participate if they do not want to. Perhaps this is unique to Ugandan children, but I think it is more universal that we give children credit for. There is no doubt that if the children at Baaliro had not willingly participated in my research, I would have gotten nothing meaningful out of that research. With the power of their refusal in mind, I have tried to depict their agency and lack thereof in their complex life stories. They are first and foremost *children*, who happened to be infected with a virus. Many have experienced hardships, only some of which are related to HIV. More often their hardships were related to poverty – though the two, of course, are impossibly entangled. HIV always lingers in the background, but primarily these children are *living* their lives with resilience and hope for the future. I also thank the guardians of the children with whom I worked for allowing me access to their children, and for answering my questions as well. Thank you to Mutesa, who helped with transcriptions and translations.

Next, I thank the staff of Baaliro and Child Network for allowing me to interfere with their work. *Weebale okuddamu ebibuuzo bingi!* I felt as though I was constantly in the way, and constantly interrupting, but the staff, Sister Sally and Mary in particular, demonstrated amazing

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[1] I use the pseudonyms as assigned in this research for the children, caregivers, staff, and organizations in Uganda. However, I use real names for my host families, language instructors, and kayaking instructors in Uganda and for all American individuals and organizations.

patience in answering my endless stream of questions. I enjoyed my conversations with Sadat about his life, and life in general in Uganda. Julien granted me permission to study his organization fully aware of the critical eye anthropologists bring to everything they study, and Lucas set aside time to explain Child Network's organization, approach, and budget, even as he was busily attempting to coordinate three programs in two separate regions of the country, recover from a torn ACL, and keep up with his *futbol* schedule. I greatly valued the openness with which we discussed many of the topics that appear in this dissertation. I hope that my work can be of use to you all.

I thank the many staff at St. Damien's – from the hedge-cutter to the executive director – all of whom welcomed me with friendliness. I met many of the staff in 2006, when I first traveled to Uganda, and over the years our relationships have grown. Thierry has been my main connection to St. Damien's throughout this time as his organization has changed and grown. For several weeks in 2006 and again in 2012 Thierry and his family welcomed me into their home. Because they refused to accept compensation for their hospitality, I had to sneak a token of my appreciation into a thank-you note left on the table. Nurse Edith taught me how to cook when she lived with me during my first summer in Uganda, and years later I attended and participated in a *kwanjula* (introduction ceremony) for one of her relatives. Godfrey was always available to hear my concerns, and counsel me in difficult situations. I followed his example in my interactions with the children, because he was so well liked by them. He also taught me my first Luganda phrases, the all-important formal greetings. To the many individuals who I cannot call out by name – *Weebale emirimu!*

Whenever someone asks me how I learned Luganda, I often say that children taught me – for indeed it was through living with them that my language skills progressed from basic to conversational. Of course, the children taught me much more than language, including what Ugandan children want and what they hope for, how they (mis)behave, and how they both work and play. In truth, though, I credit my understanding of Luganda grammar, with its numerous noun classes and verb tenses, to the instructors at City Language Center in Bunamwaya, Kampala. I owe particular thanks to Baliruno Mpanga Simon for his instruction and for ensuring that the Luganda words and phrases I use throughout this dissertation are written correctly. Additionally, Simon clearly spelled out, by repeating them for several lessons until I was truly bored of the topic, the *obuvunanyizibwa* (responsibilities) of men, women, and children in Uganda. I did not know at the time how important the concept of responsibility would be for my work. *Weebale okunsomesa Luganda bulungi!*

To my host families – *Weebale okundabirira bulungi!* Musumba Evarist and his wife Martha are experts at welcoming guests into their home. It is often difficult to find host families who understand that the need to be alone at times is not a sign of distress or that eating smaller portions is not a sign of disliking the food; the Musumbas are well versed in the odd ways of *bazungu*. They have now hosted at least four anthropology graduate students, a lineage I am proud to be part of, and many more foreign visitors. Additionally, they always gave me a place to stay when I visited Kampala. Their children, especially Liz and Rose, had the difficult task of teaching me how to navigate Kampala by *matatu* and once even accompanied me as far as Mukono to make sure I would make it back safely. Wasswa Moses, Nakiyinga Ezeresi and their children allowed me to see family life from another perspective, and shared their most intimate family conversations with me. Their daughter, Peruth Babirye's work in transcribing and translating my difficult to hear field recordings was invaluable. Thank you all for welcoming me into your homes.

With a heavy heart, I send my gratitude to my research assistant, Joy. She not only served as a language translator, but also helped to translate many non-verbal and culturally nuanced interactions. She connected with children in a way that few adults in Uganda do, and countless times I gained insights that I simply would not have had without her. Unfortunately, through accompanying her during her numerous hospitalizations I also gained a better understanding of the health care system in Uganda than I would have wished. I bore witness to her suffering, and supported her in what ways I could, but in the end her struggle became too much – she stopped taking her medications, and passed away. I name her Joy in this work, because that is what she brought to the children with whom she interacted, as well as to me. Rest in peace my friend – O*mukama akuwe emirembe*.

Finally, among the people in Uganda who I want to thank are the staff at Kayak the Nile (headed by Sam and Emily Ward). The whitewater kayaking school gave me a respite from my, at times intense, work. I had never paddled a whitewater kayak before coming to Uganda, and facing the large volume rapids of the Nile was a challenge. Initially, paddling simply replaced the fears of and anxieties of fieldwork with another more immediate terror – the roar of the rapids. However, after many weeks of being sucked down, tossed around, and spit back to the surface gasping for air, I gradually gained competence and confidence. Kayaking, in a way, makes an apt metaphor for the experience of becoming an anthropologist. I especially thank David Egesa, my Ugandan instructor who taught me all of the skills to be a competent paddler. *Weebale okunsomesa okuvuga eryato bulungi*. I am thrilled that David and his Ugandan teammates could travel to Canada to compete in the 2015 ICF Freestyle World Championships in Ontario Canada but saddened to know that, by the time I am awarded my degrees, his river will be flooded… again, by yet another hydroelectric dam. Whether the whitewater industry in Uganda will survive this latest assault remains uncertain.

Here in America, I have had many supporters as well. First, I thank Brad Stoner, my advisor. Brad has been a wonderful support throughout the trials and tribulations of medical school, graduate school, and life. He has kept me on task, offering both encouragement and deadlines. Carolyn Sargent has been integral to my intellectual development, helping me to conceptualize and formulate my research as well as providing me with meaningful and timely feedback, which has greatly enhanced my written work. I also thank my committee members – Jean Hunleth, Lora Iannotti, Rebecca Lester, Shanti Parikh, and William (Bill) Powderly. In particular, Jean Hunleth's feedback and insights on methods and theories of childhood and agency have been indispensable.

Many others have contributed to my intellectual development and to this dissertation. Jean Allman helped me re-learn how to write during my first semester of graduate school (because after two years of only answering multiple choice test questions in medical school I had forgotten how). Carolyn Lesorogol gave me helpful revisions to my Fulbright application. Susan Reynolds Whyte introduced me to Phoebe Kajubi, whose insights on children's disclosure almost certainly prevented me from accidentally disclosing children's HIV status to them. Jill Korbin connected me with Eddy Walakira, senior lecturer in children and youth at Makerere University in Uganda, who served as my academic mentor while I was in Uganda. Julia Vorhoelter, with her insights from doing research in Uganda, provided helpful feedback as this dissertation was coming together. Aviva Sinervo, Kristen Cheney, and Charley Watters have all fostered meaningful discussion and feedback when I was presenting my work at conferences.

My path to pursuing both anthropology and medicine was certainly not a straight one, and I owe thanks to the many people who encouraged and supported my academic development along the way. I would never have found anthropology at all were it not for Jim McKenna (who taught my intro seminar at Notre Dame), and I may never have found my way to Uganda were it not for the support of Augustine Fuentes (my advisor at Notre Dame) who, through a fellow professor, introduced me to Father Tom McDermott who, in turn, introduced me to Thierry. I seriously doubt that I would have wanted to attend, let alone gotten into, an MD/PhD program without having had the opportunity to work for (and publish nine papers with) Lainie Friedman Ross. Lainie gave me the courage to pursue this crazy path as a physician scholar in the social sciences/humanities, and as a practicing pediatrician with a PhD in philosophy, provided a first-hand example of how to merge the two into a successful career. Not only professionally, but also personally Lainie has been a tremendous support through the ups and downs of life.

I owe a great thanks to Puneet Sahota who paved the way as the first student in the Medical Scientist Training Program (MSTP) in anthropology at Washington University in St. Louis (Wash U), as well as to Anita Chary. Being one step ahead of me throughout our time at Wash U, Anita was a constant source for advice, encouragement, and inspiration. I thank the staff at Wash U in the anthropology department, especially Kathleen Cook who welcomed me to the anthropology department with a key to the graduate lounge as soon as I arrived in St. Louis, and Kirsten Jacobsen who seamlessly took on Kathleen’s role when she retired. I also thank the staff of the MSTP, especially Brian Sullivan, Christy Durbin, Liz Bayer, and Linda Perniciaro. To all of the staff from both campuses: Thank you for helping me navigate the administrative challenges of doing a combined program in medicine and anthropology.

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To my family: I cannot thank you enough. Mom (Charleen Walsh), you have always wanted the best for me, and I’m glad that I was able to share my field site with you and Aunt Melanie. Catherine, you always will be my big sister, and not being able to just pick up the phone and call you was one of the hardest things about fieldwork. Dad (Tom Walsh), you were a kind and loving father, and I am deeply saddened that I never had the opportunity to show you Uganda – you would have loved it! Of course, this is only one of countless things that makes me miss you. My biggest sister Carey, you taught me to be more compassionate toward people who learn and behave differently, a lesson I did not learn easily as I was growing up. So much of your life was a struggle, but you enjoyed many adventures, could find joy in the simplest things, and had great empathy for others. Busia (the only grandmother I ever knew), I miss you more!

Last, but not least, thanks goes to my amazingly loving and supportive husband, Ed Lang. Since we met, you have always encouraged me to pursue my dreams, even when (more than once) that has meant living with an ocean between us. The absolute worst part of fieldwork was not being able to bring you with me. One of the best parts was when you came to visit and I was able to show you the many things and people you had heard so much about. You've listened to me talk about my research more than anyone else. You truly are the best! I love you.

Since starting the MSTP my father, eldest sister, and grandmother have died, I have been hit by a car, and I had to euthanize my dog. To say that the many people listed here have helped me through would be an understatement. Thank you to anyone I may have inadvertently forgotten. There are always more people to thank and I could not have gotten to where I am on my own.

Even as I acknowledge my many supporters and proclaim my interdependence as a person and a scholar, all errors remain my own.

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Colleen Walsh Lang

Washington University in St. Louis, May 2020

ABSTRACT OF THE DISSERTATION

Vulnerable Agents: Ugandan Children's Experiences with HIV-Rehabilitation and Reintegration

by

Colleen Walsh Lang

Doctor of Philosophy in Anthropology

Washington University in St. Louis, 2020

Professor Bradley Stoner, Chair

This dissertation explores the experiences of children living with HIV in Uganda. In contrast to the well-developed literature on the impact of the AIDS epidemic on children *affected* by HIV, there is relatively little written about the experiences of children *infected* with HIV. This research is timely because access to antiretroviral medications (ARVs or ART) among children is increasing. Globally in 2015, 1.8 million children under the age of 15 were living with HIV, but less than half of them (49%) had access to ARVs. Without ARVs, 30% of children born to infected mothers will become infected perinatally and nearly all perinatally infected children will die young, one in three before his/her second birthday. However, ARVs both prevent perinatal transmission and make it possible for infected children to live into adulthood. The experiences of children living with HIV, who represent simultaneously a failure of HIV prevention (by being infected) and a success of AIDS treatment (by being alive), are now more worthy of study than ever. Because of its reputation as a model country for its response to the HIV epidemic and its role in generalizing the concept of orphans and vulnerable children (OVCs), Uganda is an ideal site to explore the tensions between vulnerability and agency and the processes of responsibilization as they relate to children accessing HIV care.

The children in my study accessed HIV care via a nongovernmental organization (NGO) called Baaliro. Children normally presented to Baaliro with advanced HIV infection (stage III or IV) and then underwent 2-20 months of medical rehabilitations (ARVs, treatment for opportunistic infections, and nutritional rehabilitation), before being reintegrated into their home communities to be raised by family members. Baaliro employees continued to follow-up with reintegrated children, providing school fees and adherence support. Given both the long-term residential care and follow-up care they provide, Baaliro presented a unique opportunity to see how children's experiences with HIV/AIDS changed over time. I conducted 15 months of ethnographic fieldwork, living at Baaliro for ten of those months.

Through ethnographic "thick description" of the historical processes which have built the projectified landscape of HIV care generally (and pediatric HIV care in particular), and the physical and organizational structures within which Baaliro functions to provide HIV care to children, I have attempted to show the complexity of the context in which children living with HIV access care in Uganda. Within this context, the processes of medicalization and responsibilization interact in sometimes surprising ways. The tensions between children's vulnerability and children's (at times destructive) agency, between sustainable development paradigms which emphasize responsibility and patronage networks of interdependence, and between the biomedical and social meanings of food and health, are amplified when viewed through the lens of children's experiences. Overall, in sharing children's experiences living with HIV in Uganda, I seek to emphasize the complexity of their lives, to write against sustainable development rhetoric which privileges independence over interdependence, and to hold both children's vulnerability and their agency in frame simultaneously.

Introduction

A dozen children between the ages of six and fourteen swing their hips and stomp their feet while keeping their upper torso still as they dance into the center of the grassy field. Their movement is a little out of rhythm and their voices slightly off-key, but they oscillate their hips energetically and sing loudly like they have been instructed to do during their practice sessions in the weeks leading up to their performance. They open with traditional songs of greeting in Luganda and Lusoga (the languages of the two dominant ethnic groups in the region), kneeling as a sign of respect. Their performance concludes with a song of thanks:[1]

Twajja bubi nnyo nnyo	*We came [when we were] very, very badly off*
Kati tuwonye	*Now we are healed [made well]*
Baaliro[2] *weebale*	*Thank you Baaliro*
Okutujjanjaba[3]	*For rehabilitating us*

I look around and realize that hardly anyone, other than me, is watching the children's performance. Occasionally someone glances at the children and smiles. A few people comment afterwards that they were cute and that they danced well. But most are too busy eating from the sumptuous buffet (a hallmark of any Ugandan event) to pay them any attention. After waiting for hours while the adults occupied the microphones, the children finally have their opportunity to dance and sing – but no one listens.

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[1] The refrain, sang by all of the children, is printed here. For each of the three verses one child came to the front of the group to tell part of the story of his/her rehabilitation. The verses follow the pattern: look at me now [I look good], I came when I was not this way (I was sick/small/not studying), Baaliro gave me something to fix my problem (medicine/Plumpy'nut and food/school fees), and now I am better (healthy/big/studying).

[2] Unless otherwise noted, all names used in this dissertation are pseudonyms; however, individuals familiar with the subject matter and area will likely be able to identify organizations and even individuals.

[3] *Oku-jjajaba* literally means to treat [medically], to care for [medically], or to nurse, but in the context of Baaliro, it was used to mean "to rehabilitate."

Figure 0.1 Photograph of Children Singing
Photograph of children singing a song of thanks to Baaliro at St. Damien's Annual General Meeting. They placed their hands on their cheek and shook their heads as they sang the first line of the refrain: "Twajja bubi nnyo nnyo" [We came [when we were] very, very badly off]. Children's faces have been blurred to protect their identities, but as part of the choreography they also frowned sadly while making this gesture.

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This was the scene at the end of Annual General Meeting (AGM) of St. Damien's Health Care Services in East Central Uganda. The AGM was an opportunity for the locally-organized NGO's board members and the staff from its various HIV prevention and treatment programs to come together and congratulate one another on the past year's achievements. The AGM was also an opportunity for aid recipients (grandmothers, youth group members, and patients) to give testimonials about how they had been helped. The children performing on that day had been staying at Baaliro (a pediatric HIV-rehabilitation center) for 4-14 months. St. Damien's counted Baaliro among its programs,[4] and the vigor of the children's performance testified to their successful rehabilitation. But much more importantly, from the children's perspective, it was a big event, and there would be a party at the end – with loud music and good food. Also, though

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[4] As I discuss in Chapter 3, the actual organizational location of Baaliro with St. Damien's was more complex since Baaliro received nearly all of its funding from a Swiss-based NGO (Child Network).

they did not know it at the time, after the party, most were going to be reintegrated (returning to their communities to be raised by family members).

0.1 Children Infected with HIV

This dissertation explores the experiences of children living with HIV in Uganda. The children in my research accessed treatment and education via a locally-run foreign-funded NGO, which I call Baaliro. In studying their experiences, I pay special attention to and the ways in which the concept of responsibility shaped children's daily lives and long-term outcomes, as well as the active role children played both in contributing to their households and in shaping their futures. In contrast to the well-developed literature on the impact of the epidemic on children *affected* by HIV, there is relatively little written about the experiences of children *infected* with HIV, especially from an ethnographic perspective.[5] Most of the literature which does exist focuses on disclosure of HIV status and adherence to antiretroviral medications (ARVs), especially among adolescents. The anxiety surrounding HIV infected children approaching sexual maturity contrasts with the innocence and vulnerability typically associated with younger perinatally infected children. Like the children performing at the AGM, pre-pubescent children living with HIV are easily overlooked as subjects of research and their agency is even more rarely recognized. However, as I demonstrate throughout this dissertation, children infected with HIV are actively living their lives, and their agency and social roles warrant recognition.

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[5] I am aware of only two published books and one doctoral dissertation written by anthropologists about children's experiences growing up infected with HIV (Abadía-Barrero 2011; R. Parsons 2012; Szelag 2011). Abadía-Barrero's book pertains to institutionalized children in Brazil. Parsons' book gives a full picture of the lives and challenges of 13 children growing up with HIV in Zimbabwe. Szelag's dissertation focuses on personal, social, and structural factors influencing adolescents' adherence to ARVs.

This research takes place at a critical moment in the history of AIDS prevention and treatment, especially for children. Increased access to antiretroviral medications (ARVs) has greatly changed the likelihood of children becoming infected with HIV as well as the prognosis for infected children. Without treatment with ARVs, 30% of children born to infected mothers will themselves be infected (during pregnancy, delivery, or breastfeeding) and of those children born with HIV nearly all will die during childhood, with one in three dying before his/her second birthday (Preble 1990). However, with lifelong treatment on ARVs, more and more children infected with HIV are living into adulthood. Additionally, with maternal access to ARVs increasing, fewer children are becoming infected, and the projection of an "AIDS-Free Generation"[6] is beginning to seem possible. While it was once easy to overlook children infected with HIV because they would quickly die, now it is becoming easy to overlook children infected with HIV because the focus has shifted towards achieving an "AIDS-Free Generation," leaving out the experiences of those children already infected. However, despite these advances in treatment and prevention, globally in 2015, 1.8 million children under the age of 15 were living with HIV, and under half of them (49%) had access to ARVs (UNAIDS 2016a). The experiences of children living with HIV, who by the very nature of their existence represent simultaneously a failure of HIV prevention (by being infected) and a success of AIDS treatment (by being alive), are now more worthy of study than ever.

0.2 Research Approaches

Like many anthropologists, I had a difficult time deciding how to begin this dissertation. Describing her struggles in determining where to begin her ethnographic descriptions of Malay

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[6] Per UNICEF, "the vision of an AIDS-free generation is that all children and their families are protected from HIV infection and live free from AIDS" (UNICEF 2013, i).

homes – the ritual of site selection, the process of home construction, the houses themselves, the furnishing they contain, the people who inhabit them, or the kinship relationships and activities they indexed – Janet Carsten concludes, "All of these are different aspects of what makes houses house-like… they would all be legitimate beginnings to a story which – *like all anthropological stories – has no beginning because everything connects with everything else*" [emphasis added] (1997, 33).[7] I could not agree more and would additionally add that the layers of international discourse, national policy, and organizational relationships add to the difficulty of deciding where to start telling the story of children's experiences growing up infected with HIV.

My approach to avoid losing the richness of lived experience is to employ "thick description" – paying close attention to details as well as context (Geertz 1973). I provide detailed descriptions of people, places, and events, such as the history of national policies, the physical layout of the rehabilitation center, and the children themselves, in order to demonstrate the complexity and interrelatedness of the many actors and organizations involved in shaping the lives of children living with HIV. In addition to these more broadly applied anthropological principles of thick description and attention to complexity, I approach the study of children living with HIV by engaging with two prominent discourses within anthropology – critical medical anthropology and theories of agency.

0.2.1 Critical Medical Anthropology

Critical medical anthropology is attentive to structural inequalities and the political and economic contexts which produce health and illness (Farmer 1993; Morsy 1979; Singer and Baer 2011). In attending to the ground-level impacts of structural adjustment programs (SAPs), which

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[7] Warin's (2009, 15) quoting of Carsten inspired me to look up the original source.

have demonstrably restricted the access to healthcare for the poor in many countries, critical medical anthropologists generally reprove neoliberalism – an economic viewpoint based on the idea that economic growth will best occur via free markets, private sector competition, and minimal government involvement (Kim et al. 2000; Pfeiffer and Chapman 2010; Castro and Singer 2004; Whiteford 1998; also for history of neoliberalism - Harvey 2005). Critical medical anthropologists trace how neoliberal policies interact with local histories and realities producing suffering, especially among the poor and marginalized (Biehl and Petryna 2013).

Another aspect of neoliberal discourses is the emphasis on individual responsibility and rational choice theory. Through the process of responsibilization, citizens come to understand themselves as responsible and independent agents (Clarke 2005; Rose 1999). Most discussions of responsibilization have focused on the national level, but scholars are beginning to identify the processes responsibilizing NGOs and even individuals (Gray 2009; Shamir 2008). In this dissertation, I bring the perspective of critical medical anthropology to critique responsibilization as it occurs at the organizational and individual levels. While the focus of my research remains children's experiences, it was not possible to detach those experiences from the organizations through which children accessed life-saving treatment and care. In attempting to understand these organizational structures I gained an appreciation for the complexity of development hierarchies and organizational relationships. While remaining critical of processes of responsibilization, I also attend to the context of difficult circumstances and limited resources within which the staff of these organizations were operating.

Critical medical anthropology also provides a useful critique of how vertical health care programs create healthcare silos when programs target only specific diseases (Pfeiffer and Chapman 2010; Pfeiffer 2013). Similarly, they caution against too narrow of a focus on technological interventions (Farmer 2001, 2004; Farmer et al. 2013; Hahn and Inhorn 2008; Nichter and Kendall 1991; Nichter 2008; Rhodes et al. 2005; Singer and Baer 2011; Whyte et al. 2013). These scholars draw our attention to the ways in which the "magic bullets" of global health interventions offer quick fixes to complex problems and in doing so absolve governments and the world capitalist system from any responsibility for addressing the structural inequalities which promote and maintain poverty. Perhaps, then, it is not surprising that the actual impact of a magic bullet frequently falls short of its promised effect.

0.2.2 Vulnerability and Agency

The tensions between vulnerability and agency will be obvious to any scholar of childhood studies. Children, especially in Western society, are often constructed as completely vulnerable, innocent and un-agentic. The literature on the impact of the HIV/AIDS epidemic on children reflects this bias. Most of this research focuses on children *affected* by HIV, meaning children whose parents are infected with HIV, and is often done with the explicit purpose of advocacy (UNICEF 2006). These papers and reports tend to either focus on documenting stigma and discrimination resulting from parental HIV diagnosis (Deacon and Stephney 2007; Murphy, Roberts, and Hoffman 2002; Strode and Barrett Grant 2001; Surkan et al. 2010) or on documenting lower levels of education, mental health, physical health, and living conditions among children affected by HIV, especially AIDS-orphans[8] (Andrews, Skinner, and Zuma 2006; Atwine, Cantor-Graae, and Bajunirwe 2005; Boler and Carroll 2003; Daileader Ruland et al. 2005; Kaggwa and Hindin 2010; Monasch and Boerma 2004). This overwhelming emphasis on

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[8] In these papers, orphans are defined as individuals under the age of 18 (or in some cases 16) who have lost one or more parents. In the context of the impact of HIV/AIDS on children, this refers to children who have lost one or more parents due to death from AIDS.

children as vulnerable victims in need of saving is evident in the ubiquitous acronym OVCs – orphans and vulnerable children.[9] The innocence and vulnerability of OVCs is often emphasized in protectionist discourses (K. E. Cheney 2013). Vulnerable children may be portrayed as resilient, but they are rarely recognized as active participants in their world. Even a recent book, which based on its title (*The Children of Africa Confront AIDS: From Vulnerability to Possibility*) would suggest a recognition of children's active roles in confronting HIV, instead describes its topic as "the world's most marginalized population group, the children of Africa" (Singhal and Howard 2003). Additionally, the contributions to the edited volume focus overwhelmingly on the vulnerability of children, and the possibilities suggested by the authors rely on adults intervening on behalf of children, rather than on children's actions themselves. Not surprisingly then, children's roles as caregivers and heads of households have been a source of social anxiety (Mogotlane et al. 2010). The emphasis on children's vulnerability is even more extreme in children *infected with* HIV.

However, scholars have long called for recognition of children's agency, and offered nuanced understandings of it (Bluebond-Langner and Korbin 2007; James and Prout 1997; Schwartzman 2001). Central to these approaches is understanding children as strategic social actors – as "both constrained by structure and agents acting in and upon structures" (James and Prout 1997, 28). This theorization of agency resonates with Ortner's concept of practice theory according to which "culture constructs people as particular kinds of social actors, but social actors ... reproduce or transform ... the culture that made them" (Ortner 2006a, 129). Recognizing that agents act not in opposition to structures, but within "the multiplicity of social relationships in which they are enmeshed" facilitates understanding both children's vulnerability and agency

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[9] For more on concepts of orphanhood and vulnerability see Chapter 1.

simultaneously (Ortner 2006a, 130). In the context of children's experiences with HIV, an increasing number of scholars are recognizing the complexity of children's agency in their roles as caregivers (Hunleth 2017) and household heads (Ciganda, Gagnon, and Tenkorang 2012; Kendrick and Kakuru 2012; Richter and Desmond 2008).

Throughout this dissertation, I attempt to hold both children's vulnerability and their agency in the theoretical frame at the same time. I describe the cultural, social, and structural landscapes that alternately facilitate or inhibit children's access to care, as well as children's, caregivers', and NGO staff's attempts to navigate these landscapes in order to access and provide care. Henrik Vigh's (2009) concept of social navigation is especially helpful in describing children's attempts to plot their course to care as they react to changes in an ever shifting environment. Another way in which individuals enact their agency is by contesting their social roles. In my research this manifested in the ways that children and NGO staff alternately claimed, rejected, assigned, or denied the sick role to children (T. Parsons 1951). In recognizing children's agency it is important to acknowledge that agency is not always positive, but can also be destructive (Gigengack 2008; Wardlow 2006). Although I fear that the children's voices do not come through as strongly as I may have liked, I endeavor to at least represent children living with HIV as active participants in their rehabilitation and reintegration.

0.3 Model Country, Model Program

Uganda offers an especially appropriate location for this research. Uganda has always played a central role the AIDS pandemic. Even before HIV and AIDS were named, *siliimu* (slim disease) was documented by physicians in Uganda. Uganda's early national response to HIV and the subsequent reported drop in prevalence have earned Uganda an international reputation as an

HIV success story (I discuss whether this reputation is warranted in chapter 1). More recently, in 2015 Uganda reported mother-to-child-transmission rates below 3% and maternal coverage with ARVs of greater than 95%, placing it "on the fast track to an 'AIDS-Free Generation'" (UNAIDS 2016c). These successes, combined with the government's adoption of structural adjustment policies and privatization, have made the country an appealing recipient of international aid. The value of sustainable development and the dangers of "dependency syndrome" abound in national, popular, and NGO discourses about responsibility in Uganda. Additionally, as part of its response to HIV, Uganda played a major role in generalizing the concept of OVC, so much so that as of 2009, 96% of Ugandan children are defined as vulnerable (K. E. Cheney 2010b; Kalibala and Elson 2009). These factors combine to make Uganda an ideal site to explore the tensions between vulnerability and agency along with the processes of responsibilization.

Children in this study not only lived in Uganda, but also accessed life-saving treatment and long-term support via an NGO – Baaliro. I chose Baaliro not because I saw it as a problematic organization or approach, but in fact because its founders saw it as a "gold standard" model, and because Baaliro's approach to pediatric HIV treatment was unique. Baaliro did not function per most of the approaches to treating pediatric HIV. It was not an outpatient ARV clinic, nor an inpatient hospital, nor a permanent institution (or AIDS-home). Instead, Baaliro admitted children who were too ill to be treated in an outpatient clinic, provided residential treatment for children until they were medically stabilized, and then reintegrated children into their home communities to be raised by family members. What distinguished Baaliro from a typical hospital was that children spent between 2-20 months living at the center. What distinguished Baaliro from an AIDS-home was that children's stay at Baaliro was always temporary, and the goal was to return children home as quickly as their health and social situation allowed. Once reintegrated, children continued to receive ongoing medical and educational support from Baaliro (including follow up visits from staff, ARVs and other medications, and school fees and supplies). I know of no other program which uses this rehabilitation and reintegration model for treating children living with HIV in Uganda or elsewhere (though given the lack of any official registries it is certainly possible that one exists). Baaliro's founder and staff were highly committed to their model, and they had been highly successful in obtaining funding from international (mostly Swiss) donors to support the program. Overall, I was impressed by their attention to the immediate needs of child rescue (rehabilitation), their recognition of the benefits of having children grow-up under family care (reintegration), and their long-term commitment to children once they were sent home (follow-up). I emphasize my respect for Baaliro here, because throughout the remainder of the dissertation I am much more critical of the organization. I want to clarify that my critiques are not that Baaliro itself is a bad program, but rather that even a model program (in a model country) with staff who are genuinely committed to improving the welfare of children through a socially sensitive approach still fell prey to the dominant discourses of neoliberalism, biomedical reductionism, and responsibilization. Also, from a practical matter, given both the long-term residential care and follow-up care they provide, Baaliro presented a unique opportunity to see how children's experiences with HIV/AIDS changed over time.

0.4 Summary and Outline

In this introduction I have presented my theoretical approach to researching children's experiences living with HIV. This dissertation explores how globalized concepts of responsibility play out locally as they interact with local traditional concepts of interdependence and patronage, while paying special attention to the way children themselves respond to their situations and exercise their agency in ways that are simultaneously productive and detrimental, including in their attempts to mobilize others to meet their needs. Ultimately it highlights the complexity not only of children's lives and their responses, but also the complexity of providing medical treatment and social support to children living with HIV.

The next three chapters provide the background for understanding the analyses presented in the second half of the dissertation. In chapter 1, I explore the history of three key acronyms, including the policies and programs associated with them, and the ways in which this history affects children living with HIV in Uganda. I provide the historical background necessary to understand the importance of life-saving anti-retroviral medications (ARVs), the "crisis" of orphans and vulnerable children (OVCs), and the (over) abundance of non-governmental organizations (NGOs) in Uganda. I demonstrate how public sentiment, national policies, and international attitudes have interacted and changed over time and how this has created the background (the projectified landscape) in which Baaliro operated – as a foreign funded NGO providing ARVs to the country's most vulnerable OVCs.

In chapter 2, I describe my primary field site, Baaliro, and the other organizations with which it was enmeshed to provide care for children living with HIV. In describing this history of these organizations and their physical spaces, I show how Baaliro exists at the intersection of both a locally-organized NGO and a European-founded and funded NGO. Understanding these relationships are important because they form the immediate landscape of care through which the children in this study navigated. In the latter half of this chapter I provide a comparison of the demographics of children and caregivers who had ever been enrolled in Baaliro's program with Uganda national statistics and with other studies of children living with HIV in Uganda.

In chapter 3, I present my methods and, in particular, my approach to working with children living with HIV. I describe both successful and failed methods, as well as how my role at Baaliro shifted over time and how working with sick children affected the roles I could (and could not) take on.

In the first part of chapter 4, I describe the staff who worked and lived at Baaliro and the physical structures that made up Baaliro. In the second part, I describe the process of rehabilitation at Baaliro and the metrics staff both used and did not use in determining a child's readiness for reintegration. What links these two parts together is that they show the many ways that Baaliro defied easy categorization. In a sense, both the children at Baaliro and Baaliro itself occupied a liminal space – betwixt and between – between sickness and health, between hospital and home, and between rehabilitation and reintegration (Turner 1964).

The remaining chapters delve more deeply into analyses of responsibilization, social navigation, children's social roles, and children's agency. In chapter 5, I describe daily life for the children living at Baaliro. I discuss how Baaliro's emphasis on reintegration shaped children's daily practices at the center, and I utilize a Bourdieuan perspective to show how children's daily practices both reflected and shaped children's readiness for reintegration. Through participation in housework, children became responsible for exemplifying *empisa* ([good] manners/behavior) and "learning" about cleanliness and hygiene. Children at times embraced and at times rejected these lessons, which are neither new nor informative, yet which the staff, for good reason, felt were imperative for children's successful reintegration.

Chapters 6 and 7 both deal with food – as nutritional, emotional, and technological. In chapter 6, I discuss how food had different meanings for the staff (who used food-talk to discuss food's nutritional content and importance in rehabilitation) and the children (who used food-talk to reminisce about home and to create emotional bonds). I analyze several cases of children's refusal to eat and staff's reactions to them. Food refusal acted as a "weapon of the weak" for children, but with potentially detrimental consequences which cannot be ignored (Gigengack 2008; Scott 1985). Additionally, while staff were aware of the emotional needs of children, they had limited means to address them. Staff's continued emphasis on food's nutritional properties may have offered a way for them to cope with their inability to address children's larger social issues and emotional distress (Lester 2009). In either case, the agency enacted by both children and staff reflected the attempts of social actors (Ortner 2006a).

In chapter 7, I l look how a particular kind of food/medicine (ready to use therapeutic food – RUTF) originally developed as a "magic bullet" for famine related malnutrition was used by Baaliro for rehabilitation and was experienced by the children there. I look at the history of magic bullets in global health more broadly, and the processes by which their "magic" changes, especially by being extrapolated – or applied far beyond their original intent. I focus on the extrapolation of RUTF outside of its original use, and the paradoxical relationship of the children at Baaliro to RUTF: those who "needed" it most often refused to eat it, whereas those who were "healthy" requested and were usually denied it. In this way, I show how children remake the "magic" of RUTF for their own purposes.

In chapter 8, I utilize the concept of landscapes of need and responsibility to show how these landscapes can simultaneously flatten (in response to recognizing children in need) and steepen (as foreign NGOs' increasingly emphasize sustainability and responsibility), thus creating islands of care — alternately placing children on these islands, or leaving them stranded on the mainland with no way to access them. Utilizing China Scherz's concepts of the Kiganda ethics of interdependence offers an alternative way to consider dependence as mutually beneficial, rather than harmful to aid recipients, and utilizing Vigh's concept of social navigation facilitates understanding children (and caregivers) as constantly moving and reacting to and within an ever-changing landscape (Scherz 2014; Vigh 2009).

I conclude this dissertation by interrogating the concepts of responsibility (expressed throughout this dissertation) in the context of precarity which characterizes the lives of children growing up with HIV in Uganda. I show how difficult it was for Baaliro staff to predict which children would do well and which children would "rebound" to the treatment center – or die. Who is responsible when children do not do well? How are the concepts of responsibility, caregiving and love interconnected? How does this play out in a precarious context where children and caregivers may have little control over their circumstances, no matter how "responsible" they try to be?

Chapter 1: NGOs, ARVs, and OVCs: The Alphabet Soup Which Composes the "Projectified" Landscape of HIV Care

In this chapter I explore some of the history behind the alphabet soup which comes hand in hand with studying children living with HIV – namely non-governmental organizations (NGOs), antiretrovirals (ARVs), and orphans and vulnerable children (OVCs). Utilizing the lens of AIDS, I recount Uganda's history as a poster child for HIV prevention, the rise of NGOs for service delivery (especially for distributing ARVs and for meeting the needs of OVCs), and the growing emphasis on Ugandan children's "vulnerability." Building upon the work of previous scholars, I utilize reports generated by various Ugandan government ministries to track how national policy has changed over time (Bowen 2009; Foster, Levine, and Williamson 2005; McCulloch 2004; Mogalakwe 2009). While this history took place before most of my informants were born, it lays the important groundwork – or landscape – in which they found themselves growing up with, rather than dying from, HIV. Similarly, understanding the "projectified" landscape of HIV care in Uganda is important in order to situate Baaliro (a pediatric rehabilitation center) within this landscape (Whyte et al. 2013).

1.1 Uganda's AIDS (Success) Story

Though Uganda has never seen the extremely high prevalence of HIV that some of the most affected countries have,[1] early on in the epidemic Uganda was located squarely at the epicenter of what was then called the "AIDS Belt"[2] (Caldwell and Caldwell 1996). As of 2015,

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[1] By this I refer to historical or current national prevalence rates above 20% in Zimbabwe, South Africa, Botswana, Lesotho and Swaziland (AIDSinfo).

[2] The "main AIDS Belt" included "Uganda, Rwanda, Burundi, western Kenya, western Tanzania, parts of Eastern Zaire, Malawi, Zambia, Zimbabwe and Botswana (and probably southern Sudan)" (Caldwell 1995, 299). While half

Uganda remained in the top 10 for HIV prevalence worldwide (UNAIDS 2015b). Nearly a decade before physicians started to notice previously healthy young men in Los Angeles dying from a rare form of pneumonia,[3] locals in Uganda and Tanzania began noticing previously healthy men and women dying from weight loss and diarrhea, a condition they named *siliimu* (slim disease). *Siliimu* began to spread along the shores of Lake Victoria in Uganda during the late 1970s, and by 1982 Ugandan physicians and researchers in Rakai district identified it as being the same disease causing the deadly pneumonias in Los Angeles, the newly named AIDS (UAC and UNAIDS 2000; UAC 2007). Slim disease was officially linked to HIV (then called HTLV-III) in 1985 (Serwadda et al. 1985). The disease spread rapidly along highways, mirroring patterns of labor migration, and was further amplified by the political instability of the 1970's which was characterized by increased movement of government and rebel troops as well as intense smuggling along Lake Victoria (Kleinman et al. 2011; Morris and Ferguson 2006; Obbo 1993).

In 1986, Uganda was the first nation in the world to launch a dedicated AIDS program (the National Committee for the Prevention of AIDS) which was followed by an AIDS surveillance program (the AIDS Control Program) that same year, also one of the first of its kind (Parkhurst 2005). By 1989 Uganda reported 8,000 cases of AIDS – at the time the most reported by any African country (Goodgame 1990). In 1990, the first voluntary counselling and testing (VCT) program in Africa opened in Kampala, and was later named the AIDS Information Center (Hogle et al. 2002; Parkhurst 2001). In 1992, an antenatal clinic in Mbarara reported what would be the highest HIV prevalence ever reported in Uganda of 30.2%, and in 1995, at the IXth

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of the world's AIDS cases were found in the AIDS Belt, it accounted for only 2% of the world's population (Caldwell and Caldwell 1996).

[3] Then called *Pneumocystis carinii* pneumonia (PCP), PCP was renamed *Pneumocystis jirovecii* pneumonia in the early 2000s, but has retained the same acronym (CDC 2017).

International Conference on AIDS and STD in Africa, a report declared that Uganda had the highest proportion of HIV/AIDS cases of any country in Africa (Parkhurst 2001). Since 1993, HIV/AIDS has been the leading cause of death in Uganda, and it remained so as of 2015 (IHME Viz Hub and UW 2017; Kleinman et al. 2011). But, by 1998 the Mbarara center reported that prevalence rates had dropped to 10.9% among its population, and by 2005 prevalence had fallen to 6.4% nationally (Kleinman et al. 2011; Parkhurst 2001). The often cited (though decontextualized and epidemiologically problematic)[4] 20% drop in prevalence at the Mbarara clinic earned Uganda its reputation as a model country for its early response to AIDS (Parkhurst 2001, 2002). However, it is likely that the peak national HIV prevalence in Uganda was closer to 12-13% in the early 1990s and that Uganda never reached a national prevalence of 20%,[5] let alone the 30% reported at the sentinel site in Mbarara. Nonetheless, Uganda was the first African country – if not the first country worldwide – to claim a decline in adult HIV-prevalence[6] and its national response to HIV has been more successful than many African nations whose governments responded to AIDS with denial or ambivalence (UNAIDS 2015b; T. Allen and Heald 2004; Kleinman et al. 2011). As a result, in these countries, HIV-prevalence rates continued to climb into the 2000s and many remain above 10% today, in contrast to the rates below 7.3% since 2001 in Uganda.[7]

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[4] Although the prevalence rates from the Mbarara center only represent the prevalence at that one surveillance site, they have been widely and inappropriately cited as representing the nationwide prevalence during that time.

[5] Although even these estimates are points of contention, all Uganda AIDS Commission reports continue to claim that Uganda had a national prevalence of 18% in the early 1990's (UAC 2007, 2012a, 2015a).

[6] Current estimates report that prevalence first began to decrease from 13.3% in 1991 to 13.1% in 1992 (UNAIDS 2015b).

[7] Uganda's prevalence was reported as 7.1% in 2015, and it ranked 10th in prevalence rates globally. Uganda reported its lowest prevalence of 6.5% in 2004-2005, and has had prevalence rates at or below 7.3% since 2001 (UNAIDS 2015b).

Much of Uganda's early success has been attributed to the openness of the National Resistance Movement (NRM), led by Yoweri Museveni, to confronting AIDS (Parkhurst 2005; Schoepf 2003; Whyte 2014). As early as 1986, the same year he came to power, President Museveni gained international acclaim by being the first African president to declare his government's commitment to fighting HIV/AIDS and, as previously mentioned, launched the AIDS Control Program. Museveni went on to establish the Joint Clinical Research Center (JCRC) in 1990 as a collaboration between the Ministries of Health and Defense and Makerere University. Early on the JCRC housed some of the first clinical trials of ARVs and it would later be the first site where patients could access ARVs in Uganda.[8] In 1992, the Uganda AIDS Commission (UAC) officially formed, with the mission of coordinating the "multisectorial approach to AIDS control," and the following year the *National Operational Plan* and *HIV/AIDS Policy Guidelines* were published (UAC 1993, 2007). Starting in 1997, the UAC has published a 5-year *National Strategic Framework/Plan for HIV/AIDS*, or an update to that plan, every 3 to 4 years (2000; 2004, 2007, 2012a, 2015a).

Although Uganda became internationally famous for its ABC (abstain, be faithful, use a condom) messaging, whether this campaign actually originated in Uganda, whether sustained population-wide behavior change actually occurred, and especially whether condoms played a role in reducing infection rates have been hotly debated (T. Allen and Heald 2004; D. A. Feldman 2003; E. C. Green 2003; E. C. Green et al. 2006; Hogle et al. 2002; Schoepf 2003). Most scholars, however, agree that the unique role that Museveni's government played in its

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[8] According to a report given by Peter Mugyenyi, the director of the JCRC, to the CDC in Atlanta in 2002, clinical trials of antiretroviral medications began as early as 1991 with a single-drug study of ZDV at the JCRC, followed by a two-drug study in 1993, and a triple therapy study in 1996 (Mugyenyi 2002b). The JCRC sites remain the premier HIV treatment centers in Uganda, where patients can access not only second line, but also third line ARVs as well as drug resistance testing and HIV genotyping.

response to HIV was key to Uganda's success (T. Allen and Heald 2004; D. A. Feldman 2003; Parkhurst 2002, 2004; Pillsbury 2003). This role included a strong political commitment to opening up conversations around HIV/AIDS, a decentralized government which empowered local councils, cooperation between the government and NGOs, and successfully soliciting aid from international donors. Interestingly, despite theories that dependency delegitimizes national governance, the Ugandan government's acceptance of international aid for AIDS and its use of NGOs to deliver HIV/AIDS services, may have actually bolstered Museveni's legitimacy among Ugandans (Parkhurst 2005).[9] Regardless of why they occurred, Museveni's vociferous call for a response to HIV combined with Uganda's early successes in reporting decreasing HIV prevalence as early as the 1990s made Uganda a model for HIV/AIDS interventions, attracted funding from international donors and ultimately laid the groundwork for building its "projectified landscape" of HIV/AIDS care (Whyte et al. 2013).

1.2 NGOs – Building the Projectified Landscape

Just as Museveni's government gained international praise for its approach to HIV/AIDS, so it did for its approach to the role of government in development. Since at least 1987, the Ugandan government has embraced a neoliberal framework for poverty reduction which has focused on privatization and dismantling the public sector (Muhumuza 2005; Reid 2017; Tumukwasibwe 2010). Robert Tumukwasibwe describes the "continuation of the World Bank['s] and the IMF['s] ruthless structural adjustment programs in Uganda" (2010, 59). However, based on Tumukwasibwe's direct quotation of President Museveni's autobiography (*Sowing the Mustard Seed: The Struggle for Freedom and Democracy in Uganda*), Museveni

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[9] I will return to this point when discussing the rhetoric of sustainability vs. dependency in Chapter 8.

himself was less critical of neoliberal approaches and rejected the notion that his government was coerced into neoliberal governance by outside political forces:

> NRM government inherited in 1986 an extremely difficult economic situation. We needed some outside help, … I think where IMF helped us was in making us realize the importance of macro-economic tools, such as letting prices find their own level. … We were able to show that it was actually more patriotic to privatize the economy than to leave large chunks of it in the hands of the public sector… we did not adopt market economics as a consequence of pressure, but because we were convinced that it was the correct thing to do for our country. (Museveni (1997) cited in Tumukwasibwe 2010, 59)

Regardless of whether the embrace of neoliberal reforms was coerced or voluntary, it combined with the relatively weak and young private sector to create the conditions for the growth of NGOs:

> It is within this neoliberal context the NRM regime was required to undertake policy reforms as a condition for development aid. The reforms called for institutional alternatives that mostly focused on privatizing development… but the embryonic nature of the private sector in Africa led donors to explore alternatives of working through NGOs." (Muhumuza 2005, 393)

Put another way, Uganda's reputation as a "structural adjustment success story" bolstered its position both with aid agencies and enhanced its attractiveness as a recipient for funding (Parkhurst 2005, 577). By 2004, a national paper reported that there were at least 4,250 registered NGOs in Uganda, with many more unregistered also in operation (Muhumuza 2005, 393).

While the embrace of neoliberal development strategies and the growth of NGOs occurred in Uganda generally, it is also accurate to say that Uganda became a nexus of global *HIV/AIDS* intervention specifically.[10] In the 1990s, Uganda received more funding for HIV/AIDS from international donors than any other country in sub-Saharan Africa, yet the

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[10] I am not claiming that Uganda's explosion of NGOs was tied to AIDS alone. Indeed, NGOs are involved in many aspects of life including education, infrastructure, health care, agriculture, and economic activities. However, many of these programs in some way relate back to HIV, which perhaps is not surprising given the priorities of donors.

country received around 30% less total aid per capita than the average sub-Saharan nation (Parkhurst 2005). Starting in the late 1980s and early 1990s a multitude of AIDS projects and mass information campaigns popped up throughout the country. The AIDS Support Organization (TASO), one such "grassroots" organization, grew out of the first AIDS clinic which opened in Mulago Hospital in 1987 and would become one of the best-known patient organizations in Africa, if not worldwide (Kleinman et al. 2011; Whyte 2014). Over the next two decades, community based Voluntary Counseling and Testing (VCT), Awareness and Sensitization, and Post-Test Clubs abounded as the "multi-sector approach" endorsed by the government but funded by foreign do-gooders[11] wove HIV prevention messages into all areas of public life and attempted to convince people to "live positively." While it is difficult to get a count of the number of AIDS-related organizations in Uganda, according to some estimates by 1997 there were already more than 600 organizations in Uganda involved in AIDS activities, a number which grew to at least 700 by 2001, 1,000 by 2003, and 2,000 by 2006 (Hogle et al. 2002; Kleinman et al. 2011; Schoepf 2003). As of 2014, the Uganda AIDS Commission e-mapping and monitoring system lists 6,331 organizations carrying out HIV/AIDS activities in Uganda, only 26 of which were listed as government organizations (UAC 2014a).[12]

The vast majority of these organizations are non-governmental, community-based, and/or faith-based and most rely on foreign funding. The 2007 *National HIV & AIDS Strategic Plan* contains a graph (reproduced as Figure 1.1) which depicts a four-year period from 2003-2007 in which the amount of HIV-related aid directed toward Uganda quadrupled (UAC 2007). This rapid increase was driven by foreign, especially US, sources while funding from the Ugandan

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[11] For example, in 2003 TASO received 95% of its budget from international donors (Coutinho et al. 2006, 138).

[12] Baaliro was not included on this database, however St. Damien's was. This is not surprising, since, as will be discussed in Chapter 2, St. Damien's counted Baaliro as one of its programs.

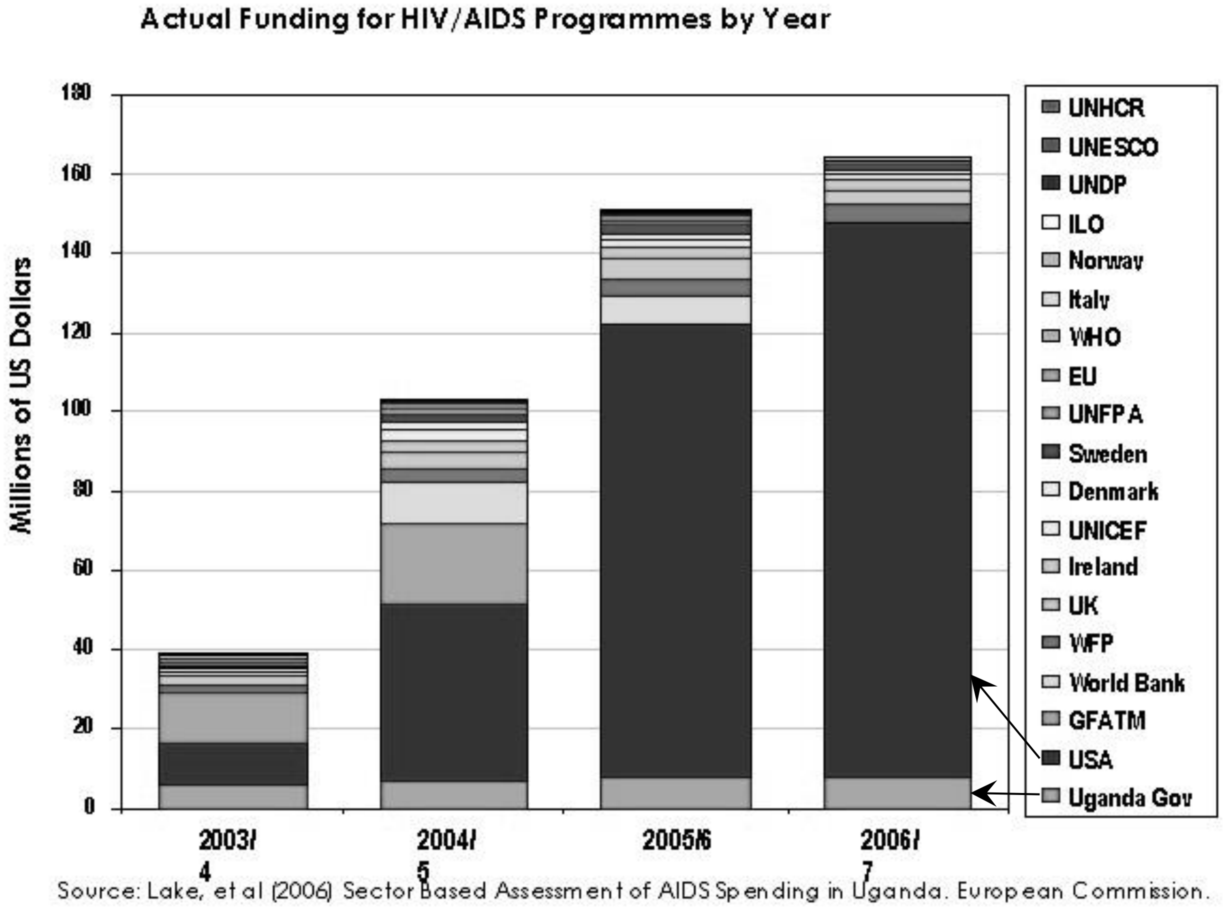

Figure 1.1 Actual Funding of HIV/AIDS Programs in Uganda 2003/4-2006/7
Published in Moving Toward Universal Access: National HIV & AIDS Strategic Plan 2007/8 – 2011/12 *(UAC 2007). Uganda AIDS Commission, Republic of Uganda. I was unable to locate the original source cited in the figure. UAC publication was in color and has been modified to black and white for this document. Arrows added.*

government remained almost stagnant. In 2007/2008 the government of Uganda provided only 5% of funding for the national HIV/AIDS response, and that number only increased to 11% in 2009/2010, with "external funding" still accounting for nearly 90% of funds (UAC 2012a).

According to the most recent *National AIDS Spending Assessment*, "in comparison with other countries in the region Uganda registered higher total levels of funding for the HIV/AIDS response than the other countries, except South Africa" (UAC 2012c, 11). Regionally, Uganda had the highest proportion of funds managed by private agencies, the lowest proportion funds managed by public agents, by far the highest percentage of funds spent by private providers, and lowest percentage of funds spent by public providers (see Appendix D for graphs of comparisons with other countries in the region) (UAC 2012c). In 2010, Uganda's HIV/AIDS funds flowed primarily from international and private donors (67% and 22% respectively) were managed by external and private financing agencies (51% and 30% respectively) and were ultimately spent by private providers (69%), with NGOs making up at least 75% of private providers (UAC 2012c). More recent reports show that in 2014-2015, the government of Uganda provided only $50.5 million out of a total $486.8 million in funding provided for HIV/AIDS in Ugand; bilateral partnerships made up $346.5 million (with PEPFAR being the largest bilateral partnership at $323.4 million); and multi-lateral partnerships made up $89.8 (with the Global Fund being the largest multilateral partnership at $70.2 million) (UAC 2015a, 50). Put another way, government contributions continue to make up little more than 10% of the country's HIV/AIDS budget (10.4%), with funding from PEPFAR (by far the single largest donor) making up nearly two thirds of the budget (66.4%).

The fact that countries with high proportions of international contributions have higher proportions of resources managed by external (international) and private agencies and utilized by private providers, whereas countries with high proportions of contributions from public sources have higher proportions of resources managed by public financing agencies and utilized by public providers is not entirely unique to HIV/AIDS care globally nor to Uganda. The rise of neoliberal economic theory in general, and structural adjustment programs in particular, have resulted in the weakening of government services – notably health care (Farmer et al. 2013; Pfeiffer and Chapman 2010). As neoliberal economic theory has come to dominate development policies globally, NGOs have often filled the gap left by weakened national governments, especially in providing services for the poor (Makoba 2002). Meanwhile, the rise of transnational (for-profit) corporations (including pharmaceutical, biotechnology, private health care, and insurance companies) has “played an enormous role in the corporatization and commodification of health… shift[ing] focus away from public and community health to emphasize private and individual health with a strong reliance on medical technology” (Millen and Holtz 2000, 220). The lack of public health systems combined with the influx of international donors’ support funneled to NGOs has resulted, unsurprisingly, in a fractured and uneven health (lack-of) system focused on vertical disease (namely, though not exclusively, HIV) (Pfeiffer 2013). The subsequent inequalities in services are not lost on Ugandan officials. As the *National AIDS Spending Assessment* further points out: “When International Sources provide funds, mostly managed by External and Private FAs [financing agencies]…, for specific parts of the country and particular activities/interventions, this promotes inequity. This is likely to lead to *islands of excellence* on one hand and *grossly underserved areas* on the other” [emphasis added] (UAC 2012c, 14). Furthermore, many of the NGOs providing services operate within time-limited and donor-specified projects. It is in this context, which Whyte aptly refers to as the “projectified landscape” of HIV care, that the roll-out of ARVs took place (Whyte et al. 2013; Whyte 2014).[13]

1.3 ARVs – ART Roll-Out: Dramatic, Rapid, and Unequal

Whyte calls us to understand the roll-out of ARVs as a historic event, which, from the perspective of people infected and affected by HIV living in Uganda, was both dramatic and rapid (Whyte 2014). The dramatic nature of ART comes from the so called “Lazarus effect,” or its ability to restore health for people on the brink of death. In 2010, (RED) and HBO produced a

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[13] In the context of health care delivery in Guatemala, Chary and Rohloff (2015) similarly refer to a “patchwork” of NGOs, aid organizations, and civil society.

documentary titled *The Lazarus Effect* featuring the experiences of Zambian patients and health workers with ARVs. Similar to images of malnourished children who transition from skeletal to plump with the consumption of RUTF, the before and after pictures of HIV-positive individuals who receive ARVs are certainly dramatic, if not miraculous.[14] Lucas, the coordinator of Child Network, frequently referred to this documentary in discussions with both staff and visitors at Baaliro.

For a sense of scale of the rapidity of the roll-out we can look how at the number of people accessing ART and the number of places providing ARVs increased over time (see Figure 1.2). While technically available since 1996 from the JCRC, only 450 people in Uganda were known to have access to ART by 1997 (Park 2012). The number accessing treatment grew to roughly 5,000-10,000 by 2002, but even as of 2003 only a handful of clinics, mostly located in urban Kampala, provided ARVs, and the medications were only available to patients enrolled in research studies or those who could afford the prohibitively expensive treatment (Park 2012; Martínez-Jones and Anyama 2002). 2004 marked the roll-out of "free ART" in Uganda, and treatment numbers jumped to 45,000 (still only 12% of the eligible population)[15] with 175 ART treatment centers by the following year (Park 2012; Whyte 2014). Since the free ART roll-out, the number of people on treatment, the coverage-rates, and the number of programs providing ART have continued to grow rapidly. By 2013, the country reported nearly 1,500 ART treatment centers, and by 2015 they were treating 775,000 adults (still only 57% of the eligible adult population) (UNAIDS 2015b; Park 2012; UAC 2014b, 2015b; Whyte 2014).

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[14] RUTF is ready-to-use therapeutic food (which commonly goes by the brand name Plumpy'nut) used to treat severe acute malnutrition in children. For further discussion of the power of before and after photos and the "magic" of biomedical interventions see Chapter 7.

[15] Eligibility criteria for ARVs have been based primarily on CD4 count and/or WHO clinical staging. Eligibility criteria have shifted over time and will be discussed more in the next section.

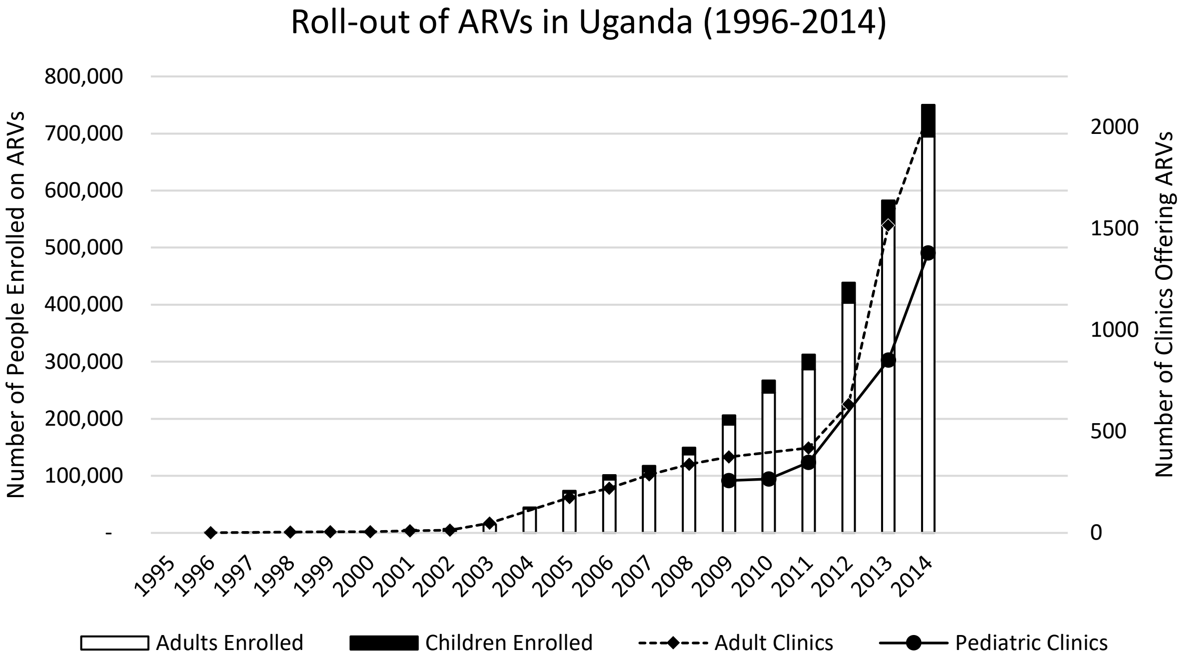

Figure 1.2 Roll-out of ARVs in Uganda (1996-2014)
Data were compiled from the sources cited below and included the following reports from Ugandan Governmental Ministries: HIV/AIDS Country Progress Reports (2008, 2010, 2012, and 2015), the National Strategic Plan for HIV/AIDS (2007-2012, 2011-2015, and 2015-2020), National Strategic Programme Plan of Interventions for Orphans and Other Vulnerable Children (2005-2010, 2011-2016), and the Pediatric HIV Communication Campaign Strategy, as well as reports by WHO, PEPFAR, JCRC and independent researchers. When more than one value was provided for a given year, the values from all reports which provided a value for that year were averaged. Values for the number of adult centers were unavailable for 1997, 2004, and 2010. Values for the number of children on treatment were unavailable before 2004, and values for the number of pediatric centers were unavailable prior to 2009 and in 2012.
Data Sources: (Martínez-Jones and Anyama 2002; MGLSD 2004, 2011; MOH 2010a; Mugyenyi 2002a; Okero et al. 2003; Park 2012; PEPFAR 2005; UAC 2007, 2008, 2010, 2012a, 2012b, 2015a, 2015b; UNAIDS 2015b)

In addition to the availability of generic drugs and the dropping cost of ARVs, the rapid roll-out of ARVs was made possible by two key factors: funding from international donors (in particular PEPFAR and the Global Fund) and the existence of AIDS care organizations (i.e. NGOs) which were able to add ART to their existing services (Whyte 2014). While acknowledging that many of the “first generation”[16] experienced access to ART as a dramatic, life-saving and rapidly occurring event, Whyte also describes how access to ART also further segmented the already complex and projectified landscape of care in Uganda, separating those organizations which provided ARVs from those which did not and enhancing HIV care disparities based on tiered clinical care, socioeconomic status, and “eligibility” criteria. Those who could land on the resulting “islands of excellence” (those clinics which offered ART) gained a second chance at life, but those trapped on other islands (at clinics which did not offer ART) or in the vast sea of grossly underserved areas (unable to connect with a HIV clinic at all), continued to die.

1.3.1 Where ARVs Fit in Uganda’s Health Care System

To get a sense of where access to ARVs fits within Uganda’s projectified health care system, I will first provide an overview of the Ugandan healthcare system which is officially divided into tiers (MOH 2000). At the top are hospitals, which themselves are divided into district-level general hospitals, regional referral hospitals (which offer specialized services, such as pediatrics), and the two national referral hospitals – Butabika (for mental health) and Mulago (for all other issues), both in Kampala. Ranking below hospitals are four levels of health centers (HC). The lowest, HC-I, have no physical structure, but are village health teams who focus on prevention and health promotion. Every village is supposed to have a village health team composed of community volunteers who can refer patients to health care facilities and distribute medications (such as malaria treatment). HC-II are nurse-staffed parish-level facilities which offer only the most basic level of outpatient care. Every parish is supposed to have an HC-II to

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[16] Whyte and colleagues (2014) explain how, the “generation” of patients who received access to ARVs during the roll-out shared the experience of being brought back from the dead and being granted a second chance at life.

treat common diseases and offer antenatal care. HC-III are sub-county level facilities staffed by at least one senior clinical officer and have a maternity ward and laboratory services. Every sub-county in the country is supposed to have an HC-III. HC-IV are county-level facilities staffed by at least one senior medical officer and a doctor. These mini-hospitals have all the services of an HC-III and, additionally, are supposed to have inpatient wards and an operating theater so they can admit patients and provide emergency surgeries and blood transfusions. St. Damien's is a registered HC-III. Baaliro, where I conducted my field research, is not itself registered as a health center, but rather counts as a program under St. Damien's.

Medical services at all levels of Uganda's healthcare system are frequently lower than their ranking may suggest as a result of insufficient or unqualified staff (such as a HC-IV being run by clinical officers rather than physicians), non-existent or non-functioning laboratory services, broken equipment, and/or a lack of medication (Kavuma 2009). In particular, HC-1 and HC-II services may be completely missing in a given area. Larger infrastructure issues, such as power and water outages also affect the ability of existing centers to deliver quality medical care. Additionally, higher level health facilities are located in more populated areas, thus one's ease of access a higher tiered facility is largely dependent on where one lives, especially the distance from an urban center.

In addition to these official tier levels, health services are also generally divided among private, public, and NGO providers. Different kinds of clients frequent different tiers of service offered from different providers. Overall, Uganda's government health care system can be described as "functioning and heavily used" (Whyte 2014, 9). Public services are generally "free," though they often suffer from long wait times, staffing strikes, supply and medication stock-outs, and overcrowding. Although Uganda abolished user fees in 2001 at all government health facilities, nationally families still meet 61% of healthcare costs out of pocket (MGLSD and UNICEF 2015).[17] Private services are generally the highest quality, though they often demand payment before providing care, and only the wealthiest patients can afford treatment in private clinics. NGO services vary greatly, but most require at least a minimum user fee and have a mixture of free and for-fee services.[18] Thus, how much one can pay for treatment generally determines where one can go for healthcare.

In the case of the ART roll-out, AIDS care was divided into three categories which combine aspects of both the official and provider-type systems. Park describes how ARVs and NGOs entered into the tiered public health system in Uganda:

> A main hospital and the district health office can be found in the district capital, which is surrounded by a number of NGOs, with names and acronyms like TASO, CRS, Family Hope, JCRC, Mildmay, and many more. Farther away are several smaller government health units. In addition, NGOs run outreach services to bring treatment and care closer to the villages in order to reduce patient transport expenditures. (Park 2012, 192)

Initially, during the roll-out of free ARVs, the medications were only available at the highest category of treatment centers (HC-IV) and hospitals, such as the Infectious Disease Institute at Mulago Hospital, and the JCRC (Whyte 2014). Clients either paid out of pocket for medication (and were wealthy), or were enrolled in research studies (and considered themselves very lucky). These institutes provided high quality anonymous care with short waiting times, but generally were expensive and did not provide any extra services. In contrast, the second category of treatment sites, NGOs, provided personal care, often assigning clients a counselor and conducting home-visits. ARVs were always free (though some NGOs charged a “client registration fee” to start treatment) and medications for opportunistic infections and tests were

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[17] This report did not distinguish the source of out-of-pocket expenses from among private clinics, pharmacies (especially frequented when government facilities are out of stock for a needed medication), or other sources.

[18] Recall that St. Damien’s is an NGO service provider. Some of its services are free, but others have a fee.

sometimes free/subsidized, but wait times were often very long. Additionally, NGOs often had other programming for clients – such as home visits, supplementary food programs, post-test clubs, and income-generating activities. Clients were encouraged to become involved in NGO activities, especially advocacy, and participation could increase one's access to services. However, involvement in advocacy activities could also expose a client's HIV status to the community, making him/her susceptible to stigma and discrimination. Clients receiving ARVs from NGOs were generally poor. The final category, rural government health units, have come about more recently as, in an effort to increase access to ARVs, the government began pushing for the decentralization of ART to lower level facilities and pushing to accredit more health facilities to deliver ART, even expanding down to the HC-II level (UAC 2012a, 2015a). However, this raises concerns of exacerbating health care inequalities. As the most recent *National HIV and AIDS Strategic Plan* explains:

> Though accelerated decentralization of services has brought services closer to the community, less trained staff and facilities with less capacity will have rapidly increasing patient loads. This *magnifies existing health system gaps* that have to be tackled to ensure effective and quality care and treatment." [emphasis added] (UAC 2015a, 25)

With a history of drug stock-outs as well as reports of understaffing and unmotivated staff at government facilities, these concerns are well founded (Park 2012; UAC 2010, 2015b). Additionally, rural health centers are often staffed by community members, so confidentiality is nearly impossible. Rural government health centers, thus, generally have offered the lowest quality of care and minimal if any additional services. In summary, "the projectified landscape of AIDS care means that much depends on who is your service provider (patron)" (Whyte et al. 2013, 159). However, who one's service provider is also depended greatly on one's socio-economic status.

A further layer of complexity in this landscape is that service providers get their ARVs from a variety of sources. Sung-Joon Park attempted to map out links between funders, suppliers, and treatment providers for ARVs. The resulting diagram[19] is a convoluted tree with a handful of funding/donation sources which branch and coalesce into supply organizations and warehouses, ultimately branching proliferously to over a dozen treatment providers (the majority of which have 10 or more sites). Some treatment providers receive ARVs from more than one warehouse/supply organization, adding to the complexity of the relationships.

1.3.2 Eligibility Criteria for ARVs

Lastly, eligibility criteria determined who could qualify to start on ARVs.[20] When ARVs were first becoming available, the number of patients who needed the medications far exceeded the drug supply (and available health care budgets), and thus defining eligibility criteria based on CD4 count[21] and/or WHO clinical staging assisted with triage and rationing (Bennett and Chanfreau 2005; Nguyen 2010; Rosen et al. 2005a, 2005b). Eligibility criteria were cloaked in science, with recommendations weighted based on the strength of research studies supporting them. However, the rationale behind the eligibility criteria (especially CD4 count cut-offs), also

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[19] Reproduced in (Whyte et al. 2013, 160)

[20] Eligibility criteria were the official criteria used to determine which patients would receive (free) ARVs. However, not surprisingly, other factors such as personal networks and social class also greatly influenced one's access to treatment (Whyte 2014). Additionally, as I discuss in the next section, eligibility criteria have been different for pregnant women (for the prevention of mother to child transmission) and in children, making gender and age also important factors.

[21] A CD4 count is a lab test that measures the number of CD4 T-lymphocytes (CD4 cells) in a sample of blood. In people with HIV, it is the most important laboratory indicator of how well the patient's immune system is working and the strongest predictor of HIV progression (aids.gov 2016).

reflected the need to prioritize treatment for the sickest patients, to prevent the development of resistance (noting concerns of adherence to treatment),[22] and to minimize drug toxicity and cost.

Eligibility criteria have shifted over time, making “coverage” percentages difficult to compare. As eligibility criteria are loosened and more people qualify for initiating ART, the coverage percentage may appear to drop, even if more people are actually being treated. For instance, in 2013 Uganda could report coverage rates of 69% or 40% depending on whether it applied 2010 or 2013 guidelines respectively (UAC 2014b). Uganda has based its national AIDS policy on the internationally defined guidelines and, not surprisingly, has adopted new guidelines into its official policies. Initially, in 2002, the WHO set a CD4 count of <200 cell/mm^3 (also the level which defines AIDS) for patients to start on ART (WHO 2004). However, when ARVs were first being rolled-out, it was not uncommon for individual organizations to have eligibility criteria which were more stringent than the national guidelines required, such as being within the organization’s “catchment area,” having a lower CD4 count, and/or fulfilling additional behavioral requirements (which were intended to index a recipient’s moral worthiness). For example, in one program “the eligibility criteria were a CD4 count of less than 150 [cells]/mm^3, having a demonstrable family unit, absence of a history of alcohol or drug abuse, and absence of psychotic behavior” (Okero et al. 2003, 10). When Uganda published its first *National Guidelines for the Implementation of Antiretroviral Therapy* in 2003 it did not set a threshold for CD4 count, but left it up to physicians at accredited facilities to decide (MOH 2003b). In 2009, the updated national guidelines set the eligibility criteria at a CD4 count of <250 cell/mm^3 (slightly higher than the international standards at the time) (MOH 2008).

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[22] The assumption was that less sick patients would have poorer adherence because they would not be as motivated to take their medications (since they did not feel sick) and would therefore be more likely to develop resistance.

In 2010, the WHO raised the CD4 count limit to <350 cell/mm^3 citing several studies which indicated that earlier initiation of ART reduced HIV-related mortality, and this change was adopted in Uganda the same year (UAC 2012a; WHO 2010a). However, the WHO warned that raising the CD4 count eligibility criteria could displace patients who urgently needed therapy and could be prohibitively expensive for some countries. They also cited concerns of ART-related side effects and toxicity and the development of drug resistance predicated by poor adherence among asymptomatic patients.

In 2013, the WHO further broadened eligibility criteria to include a CD4 count <500 cell/mm^3 and all individuals suffering from TB or hepatitis B and sero-discordant couples regardless of CD4 count citing a continued shift in the “risk-benefit ratio towards initiating ART earlier” (WHO 2013, 95). Evidence was mounting that, left untreated, HIV not only compromised the immune system, but also contributed to multiple non-HIV defining health issues (including cardiovascular, kidney, and liver disease, cancer, and neurocognitive conditions). Studies showed that ART also had the potential to reduce sexual transmission, and there were fewer concerns about accessibility and cost. In fact, some argued that the cost of earlier initiation of ART could be offset by increased patient productivity if patients could initiate treatment before becoming sick. The remaining concerns focused on drug resistance and potential toxicity. Also in 2013, Uganda updated its guidelines to meet the new WHO standards and additionally included lifelong treatment for all pregnant women and anyone who was a member of one of the “most-at-risk-populations” (MARPs), defined as drug users, sex workers and their clients, men who have sex with men, and prisoners (UAC 2014b). Most recently, in 2016, the WHO guidelines changed to recommend immediate and lifelong initiation of ART for all individuals (regardless of age or CD4 count), citing evidence of improved clinical outcomes, the development of safer, more efficacious, and more affordable drugs, and the efficacy of early treatment initiation in preventing HIV transmission as their rational (WHO 2016a). Meanwhile, in the US, the Department of Health and Human Services *Panel on Antiretroviral Guidelines for Adults and Adolescents* (2016) has recommended initiating ART in *all* infected individuals regardless of CD4 count since 2012.[23]

Thus, in summary, eligibility criteria initially played an important role in limiting the number of patients who qualified for ART and attempting to ensure that the sickest patients received access to the limited resources first. Additionally, eligibility criteria reflected the policymakers' concerns that early initiation of treatment would contribute to the development of resistance, that the risks of ARV toxicity would be greater than the benefits of treatment, and that the cost of treatment would simply be too high for low and middle-income countries to afford. As the cost of ARVs has decreased, the drugs have become more widely available and accessible (Hoen et al. 2011). Additionally, the drugs themselves have become less toxic, and clinicians have learned that the benefits of starting ARVs sooner far outweigh the risks (Calmy et al. 2009). All of these factors have contributed to the shifting guidelines and decreased health-based inequalities for accessing ARVs.

In addition to the geographical, socioeconomic and health based inequalities during the roll-out of free ARVs, two "life-stage" based populations experienced the roll-out differently from adults as a whole. The first were pregnant women and the second were children. Despite early concern and research on mother-to-child-transmission (MTCT), the actual roll-out of ARVs

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[23] Between 2012 and 2016, the panel gave varying strength to its recommendation to initiate ART based on CD4 count (strongly recommending initiation for patients with CD4 count <500 cells/mm^3 and moderately for CD4 counts >500 cells/mm^3); however, it nonetheless recommended initiation of ARVs for all HIV patients since 2012. In 2016 the panel updated its recommendations based on evidence from clinical trials to *strongly* recommend initiating ART for all patients regardless of CD4 count in order to reduce HIV related morbidity and mortality and to prevent HIV transmission (Panel on Antiretroviral Guidelines for Adults and Adolescents 2016).

for pregnant women lagged behind that of the general population initially. Coverage for pregnant women, however, quickly caught up to and exceeded that of adults in general. The roll-out for children, however, lagged even farther behind, and has only begun to catch up in recent years. In the next section I will explore the history of the roll-out in these populations and offer some of the reasons behind the unevenness and discrepancies. I have constructed a graph depicting treatment coverage among adults, pregnant women and children from the early 1990's to 2015 (see Figure 1.3). Given the ever-shifting definition of who is eligible to start treatment on ARVs,

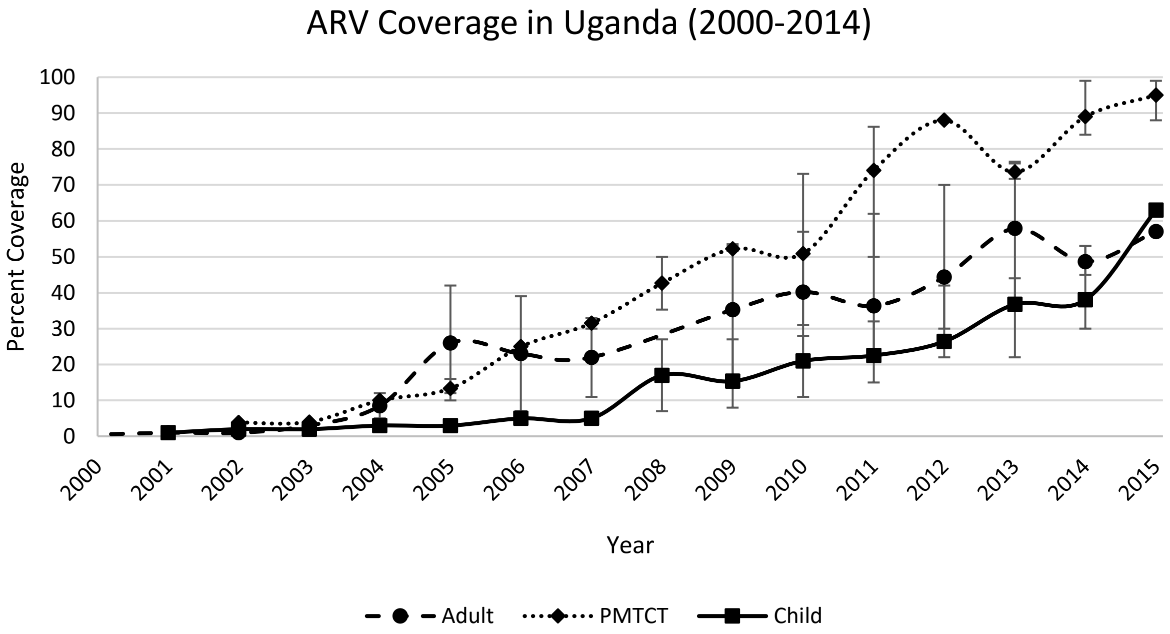

Figure 1.3 ART Coverage in Uganda 2000-2015
Data were compiled from the sources cited below and included the following reports from Ugandan Governmental Ministries: HIV/AIDS Country Progress Reports (2008, 2010, 2012, 2014, and 2015), the National Strategic Plan for HIV/AIDS (2003-2006, 2007-2012, 2011-2015, and 2015-2020), as well as reports by UNAIDS and UNICEF. When more than one value was provided for a given year, the values from all reports which provided a value for that year were averaged. The error bars represent high and low estimates for the year. Coverage estimates were unavailable prior to 2000 and for the following years: children prior to 2001, PMTCT prior to 2002, adults in 2008.
Data sources: (UAC 2004, 2007, 2008, 2010, 2012a, 2012b, 2014b, 2015a, 2015b, UNAIDS 2013, 2014b, 2014a, 2015b; UNICEF 2010).

the wide variability in coverage estimated for any given year, and the variability in coverage in different regions,24 this figure should be interpreted with caution. However, I believe it depicts the history of the uneven topography of ART coverage in Uganda.

1.3.3 Pregnant Women's Access to ARVs

Today HIV-infected pregnant women are targeted to receive ARVs regardless of their CD4 count for the prevention of mother-to-child transmission (PMTCT) of HIV worldwide. Without treatment, the WHO estimates between 15% and 45% of children born to infected mothers will themselves be infected with HIV; however, with treatment the rate drops to below 5% (WHO 2017b). Mother-to-child transmission (MTCT) of HIV can occur during pregnancy, labor and delivery, or breastfeeding. PMTCT efforts are also relevant for children living with HIV for several reasons. Foremost, and most obviously, since mother-to-child transmission is a primary way by which children are infected, as PMTCT efforts become more successful fewer children are infected with HIV, and PMTCT was therefore considered integral to "moving towards the elimination of paediatric HIV" (WHO 2010c, i).

Initially PMTCT targeted only the perinatal period, but in 2011 UNAIDS introduced the *Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive* which focuses on eliminating new infections among children and reducing AIDS-related maternal death (Chi, Stringer, and Moodley 2013; UNAIDS 2011). While not utilized in this initial document, the approach would eventually be shortened to the acronym eMTCT (*elimination* of mother-to-child transmission). In 2014, the Uganda AIDS Commission

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[24] For example, while in 2009 national coverage rates were ~35% for adults and ~13.5% for children, that same year a study in Iganga district (one of the districts within Baaliro's catchment area) documented considerable lower coverage rates of 10.3% of adults and only 1.9% for children (Scheibe et al. 2013).

proudly proclaimed that since enacting eMTCT “a remarkable reduction in new infections among children was achieved; from 27,660 in 2011; 15,411 in 2012, and 9,629 in 2013” (UAC 2014b, viii,7). Reducing the number of new infections in children is overwhelmingly a positive thing, but having elimination as the goal makes those children who are infected into signs of failure. The failure is multi-tiered, at the level of mothers, health care workers, the community and even the nation as a whole, but mothers bear the brunt of the stigma and shame. Several studies looking at barriers to getting children enrolled in ART and to disclosure of a child’s HIV status have shown that stigma and shame often delay both the initiation of pediatric treatment and disclosure (Abadía-Barrero and LaRusso 2006; Boender et al. 2012; Cree et al. 2004; Kajubi, Whyte, et al. 2014; Lowenthal, Jibril, et al. 2014; Ostrom et al. 2006; Schenk et al. 2014; Vreeman et al. 2013). This burden can be especially strong in communities where PMTCT messaging is widespread, and mothers feel more responsible for having not protected their children from infection (Class 2014). With this in mind, I review the history of PMTCT efforts in Uganda.

Pregnant women were among the earliest targets for ARVs in Uganda once they became available, but even prior to the use of ARVs, PMTCT was a primary concern in Uganda. This is hardly surprising considering that the earliest surveillance sites were antenatal clinics, thus pregnant women had always been at the center of the AIDS epidemic. Additionally, the problem of mother-to-child-transmission was quickly recognized as the second leading cause of HIV infection in Uganda, next to heterosexual transmission, and prevention of vertical transmission (from mother to child) appeared among the earliest goals in national efforts to address HIV/AIDS (UAC 1993; UAC and UNAIDS 2000). Without intervention, researchers estimated that 30% of children born to infected mothers in Uganda would be born with HIV, and that all children born with HIV would die – one third before their second birthday (MOH 2003a; Preble 1990). As late as 2003, one report succinctly stated:

> It is also known that even with standard care, HIV-1 infection in children is fatal because antiretroviral therapy is not yet widely accessible. The majority of these infected children usually die by their second birthday. This therefore makes the prevention of vertical transmission of HIV extremely important, especially since it is the main route by which children get infected. (MOH 2003a, 10)

Seen as innocent victims, doomed to death, preventing children from being infected was obviously the best strategy.

Initial efforts in PMTCT, prior to the development of ARVs, controversially focused on reducing vertical transmission through preventing pregnancies in HIV-positive women, reducing transmission during deliveries, and modifying breastfeeding practices (UAC and UNAIDS 2000). Preventing pregnancies was controversial because, due to social pressures and cultural norms, many women desired to continue having children. Modifying, in reality reducing, breastfeeding was controversial because of the well documented risks of formula feeding and benefits of breastfeeding in resource poor areas where access to clean water, hygiene, and sanitation are major concerns and formula is prohibitively expensive (Coutsoudis, Coovadia, and Wilfert 2009).

In 1994, clinical trials in the US and France demonstrated the efficacy of perinatal AZT (one of the first ARVs) combined with formula feeding for the duration of infancy in reducing rates of MTCT from 25% to 8% (MOH 2003a). Unfortunately, with a price tag of $1,000 for a perinatal course of AZT and an additional $600-$1000 for formula (necessary to prevent transmission during breastfeeding), each course of treatment cost approximately $1,800. Given the cost of treatment and the reduction of transmission rates from 25% to 8%, it would cost an estimated $10,588 to prevent a child from becoming infected with HIV. [25] Consequently, PMTCT was deemed “far too expensive” for use in low and middle income countries, but the fact that a child’s life was valued at less than $11,000 warrants somber reflection.

In 1997, multiple trials of ARVs for PMTCT began in Kampala and several other sites across East and Southern Africa funded by UNAIDS and the US National Institutes of Health (MOH 2003a). Results became available in 1999, revealing that the “nevirapine short-course” regimen (a single dose of nevirapine for mothers at the onset of labor and for babies within 72 hours of birth) cost only $4 and reduced transmission to below 14%. Between 2000-2002 the UN supported a pilot program for PMTCT among pregnant women at 6 sites in Uganda, but only provided ARVs to approximately 1000 women per site and only from the 36th week of pregnancy to the first week after the birth their child (MOH 2003a). Women in the study were also provided with information regarding the dangers of transmitting HIV via breastfeeding, but given little support beyond this information. It is worth noting that although ARVs decrease HIV transmission, since the study stopped providing ARVs soon after birth and did not provide formula, some women were likely transmitting HIV to their babies by breastfeeding. Although they were “informed” about the dangers of breastfeeding, they had little alternative.

In 2003, the national strategy for PMTCT called for routinely testing and treating pregnant women and, recognizing that the health of the mother impacted the health of the child, recommended that ARVs to be provided for the mother long-term (MOH 2003a). However, as of 2003 the national PMTCT guidelines had still only been implemented in 35 districts (62.5% of

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[25] In order to calculate the cost of preventing HIV transmission to one child, I calculated the number-needed-to-treat (NNT), which is a measure of the number pregnancies needed to be treated in order to prevent one child from becoming infected. NNT=1/(control event rate – experimental event rate) = 1/(0.25-0.08) = 5.88 (Kane 2017). I then multiplied the NNT by the total cost of a course of treatment for one infant (including the cost of formula estimated at $800) ($1,800).

districts)[26] and even in these districts coverage and accessibility was poor and pregnant women only received ARVs for PMTCT during the month surrounding delivery, allowing for transmission during breastfeeding and doing little to improve the long-term health of the mother (UAC 2004). Despite the national roll-out of ARVs in 2004, in 2005, Uganda was identified as one of 10 countries contributing to two thirds of mother-to-child transmission worldwide, and only an estimated 11% of HIV-positive pregnant women in Uganda were receiving ARVs for PMTCT (with even fewer receiving them long-term for their own health) (IATT 2007). Meanwhile, 2005 estimates reported that up to 42% of eligible adults living with HIV had regular access to ARVs (UAC 2007).

In 2005, Uganda revised its policy guidelines to focus on PMTCT holistically – providing "primary prevention; prevention of unintended pregnancies among PLWHA;[27] reduction of mother to child HIV transmission and provision of comprehensive HIV care for the mother and her family" (UAC 2008, 22). However, under these guidelines, pregnant women still only received ARVs in the perinatal period, and "exclusive breastfeeding" was the only recommendation for PMTCT during breastfeeding. From 2005-2007 PMTCT, coverage rose from 12% to 30%, but even as of 2009, only 53% of HIV-positive pregnant women received any ARVs for PMTCT (limited to the perinatal period), and only 17% of them were on ART long-term (UAC 2007, 2010; UNICEF 2010). In 2010, the revised national guidelines finally allowed women (and/or their babies) to continue taking ARVs until they finished breastfeeding, but despite nearly half a decade of calls to get pregnant women on ART long-term, still only those

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[26] Uganda currently has 111 districts and 1 city (or 112 districts). In 2002 there were only 56 districts. Since 2005 the Ugandan government has been increasing the number of districts as part of its policy of decentralization.
[27] PLWHA = People living with HIV/AIDS

who met the eligibility criteria used for all adults (CD4<350 cells/mm^3) could continue on ART after they had finished breastfeeding (UAC 2010).

The biggest change in Uganda's approach to PMTCT came in 2011 with the roll-out of "Option B+" under which *all* HIV-positive pregnant women were to receive ART "for life," regardless of CD4 count, in order to not only reduce the risk of transmission but also to improve maternal health (UAC 2012a, 8). Under Option B+, Uganda strove for "virtual elimination of MTCT" and within a few years the new framework of eMTCT[28] (*elimination* of mother to child transmission) with lifelong ART fully replaced PMTCT which had limited maternal access to ARVs to the perinatal period (UAC 2012a, 23, 2014b). Embracing the concept of treatment as prevention,[29] eMTCT used mother-to-child transmission as a platform to scale up earlier initiation of adults on ART and granted lifelong access to treatment. Unfortunately, for several years uptake remained variable, with between 50-86% of women accessing PMTCT, but less than one in five of them remaining on lifelong ART as of 2011 (UNAIDS 2015b; UAC 2012b). However, in 2013, spearheaded by first lady Janet Museveni, facilities offering eMTCT services were present in over 2,000 health centers and in all 112 districts, and by 2015 Uganda reported >95% maternal coverage for PMTCT, and vertical transmission rates of 2.9% (UAC 2012b, 2014b; UNAIDS 2016b). As of 2016, Uganda reported the third lowest MTCT rates in Sub-Saharan Africa and was one of only two countries to report PMTCT coverage as >95%

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[28] The *HIV and AIDS Uganda Country Progress Report - 2013* appears to be the Uganda AIDS Commission's first use of eMTCT as an acronym in an official report (UAC 2014b).

[29] This concept came from several studies which demonstrated that early initiation of ART not only improved morbidity and mortality rates of infected individuals, but also decreased transmission (Eaton et al. 2012; Granich et al. 2010; Quinn et al. 2000; S. J. Reynolds et al. 2011). Granich et al. (2010) offers a particularly effective review of the topic. Additionally, the *National HIV and AIDS Strategic Plan 2015/2016-2019/2020* cites Spectrum Modeling System estimates of AID-deaths and new HIV infections averted with increased access to ART (UAC 2015a).

(UNAIDS 2016b).[30] These achievements have earned Uganda international praise for making the "greatest progress, reducing new infections [in children]" and placing it "on the fast track to an AIDS-free generation" (UNAIDS 2016b, 4).[31]

In summary, even before ARVs effectively prevented mother-to-child-transmission, concern regarding vertical transmission was high, and the Uganda AIDS Commission listed prevention of vertical transmission as a key concern. Initial concerns focused on the inevitable mortality of infants infected with HIV at or soon after birth, and seemed to be primarily focused on preventing children's suffering rather than addressing maternal health (UAC and UNAIDS 2000). As ARVs became more widely available, PMTCT, originally considered too costly, became widely touted for its cost effectiveness (UAC 2007). Obviously, it was more effective to give a mother ARVs and prevent a child from becoming infected, than for a child to take ARVs for his/her whole life. Additionally, PMTCT was cheaper and easier than starting adults on ART since PMTCT only required the use of ARVs for a few weeks, whereas ART was for a lifetime. PMTCT also allowed policymakers to focus on infants as innocent victims allowing them to sidestep the moral issues of how mothers became infected and mothers' lack of access to ARVs. The latest push toward eMTCT maintains focus on protecting children, but also extends coverage to all pregnant mothers to remain on lifelong ART, addressing the fact that maternal and child health are inextricably linked. Since ramping up eMTCT, Uganda is now on the "fast track to an

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[30] South Africa at 2% and Botswana at 2.6% have lower rates of MTCT. The Global Plan's MTCT target is below 5%. However, Botswana is classified as a "non-breastfeeding country" per the Global Plan, and therefore it's MTCT target is below 2%. South Africa is also the only other sub-Saharan African country to claim PMTCT rates of >95%, though Swaziland, Mozambique and Namibia also claim PMTCT rates of 95%.

[31] In 2011, then Secretary Clinton defined an AIDS-free generation as one where "virtually no children are born with the virus. As these children become teenagers and adults, they are at far lower risk of becoming infected than they would be today thanks to a wide range of prevention tools, and if they do acquire HIV, they have access to treatment that helps prevent them from developing AIDS and passing the virus on to others" (PEPFAR 2012, 4). Per UNICEF, "the vision of an AIDS-free generation is that all children and their families are protected from HIV infection and live free from AIDS" (UNICEF 2013, i).

AIDS-free generation," but one wonders what this means for those children who have already been born infected.

1.3.4 Children's Access to ARVs

One might think that since maternal access to ARVs was so strongly motivated by concern for the health of Uganda's children, therefore pediatric access to ARVs must also have been a national priority. However, while Museveni's government proclaimed a national response to AIDS as early as 1986, and AIDS-orphans[32] rapidly attracted national and international attention, HIV *infected* children were not included in the Uganda's national response to HIV for more than two decades, and expanding pediatric treatment came fully eight years after the initial roll-out of ARVs for adults. Additionally, even today the linkage between eMTCT services for mothers and their potentially exposed infants remains weak. Though 95% of pregnant women in Uganda are reportedly on lifelong ARVs, only 33% of HIV-exposed infants receive virologic testing within two months, and only 25% of exposed infants receive ARV prophylaxis within the first six weeks (UAC 2015b; UNAIDS 2016b).[33] Overall, as of 2015, at best 63% of infected children in Uganda (age 0-14 years) receive ARVs (UNAIDS 2016b). I will first review the history of pediatric ARVs in Uganda, and then explore some of the reasons why pediatric care has historically lagged behind that of adults.

By 1995, HIV/AIDS was already the second leading cause of death after malaria for children 5-14 years old in Uganda, and since 2005 it has been the leading cause of death (IHME Viz Hub and UW 2017). However, children were left out of Uganda's *National Strategic Plans*

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[32] I discuss the construction of orphanhood, and AIDS-orphans in particular, more in the section on OVCs.

[33] Both of these interventions are part of the PMTCT cascade, because early virologic testing and initiation of ARV prophylaxis (especially for breastfeeding infants) can prevent vertical transmission.

for HIV/AIDS (NSPs)[34] until 2000, and even then were initially only mentioned in reference to orphans and vulnerable children (OVCs) – i.e. those children made vulnerable by their *parent's* infection, not as infected individuals *themselves*. The treatment of children infected with HIV was listed as a goal in the 2003 and 2007 NSPs, but only a few thousand children, less than 10% of those in need, accessed ART for the first five years (UAC 2004, 2007). In 2009, the national guidelines used the same eligibility criteria for children over the age of five as for adults (CD4 count <250 cells/mm^3) and only children under a year of age were started on ART immediately regardless of their CD4 count or clinical staging (MOH 2008).[35] Also, the 2010 *UNGASS Country Progress Report* focused almost entirely on PMTCT, including starting exposed children on ARV prophylaxis, neither of which addressed the treatment of already infected children (UAC 2010). It was not until 2012 that addressing pediatric AIDS was listed as a specific goal in the NSP (UAC 2012a). Even then, expanding pediatric ART to HC-IIIs was viewed in conjunction with eMTCT and improving early infant diagnosis and prophylaxis. The same plan also revealed huge gaps, with only one in four children living with HIV accessing ARVs, and only 7% of exposed infants being followed-up with post-exposure prophylactic ARVs. In 2012, the UAC recommended a new family-centered approach to improving pediatric adherence, using children as an "index" case to access families, and treatment guidelines were revised to be less restrictive, allowing for ART initiation for any child under the age of two who tested positive as well as shifting CD4 count cut-offs for older children (UAC 2012b; MOH

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[34] The exact name of this document changes with nearly every publication. In 2000 and 2003 this document was called the *National Strategic Framework for HIV/AIDS Activities in Uganda*. In 2007 it was renamed the *National HIV & AIDS Strategic Plan*. In 2011 the order of worse was switched to *National Strategic Plan for HIV & AIDS*, but in 2015 it switched back to *National HIV & AIDS Strategic Plan*. I will refer to all of these documents collectively as the *National Strategic Plans* (NSPs).

[35] Using the same eligibility criteria for children over the age of 5, and starting children under a year of age on ART immediately regardless of CD4 count was in keeping with WHO standards at the time.

2011). In 2013, Uganda further revised its ART guidelines to state that all children under the age of 15 should be started on ART regardless of CD4 count or WHO clinical staging (MOH 2013). Despite these ambitious guidelines, in 2014 UAC estimates reported that treatment of children lagged significantly behind that of adults (31% vs. 48%). The report concluded that overall, "the increase in paediatric ART has been slow, in the range of 10,000 children enrolled per year, instead of the projected 35,000 children per year" (UAC 2015b, 27). Other statistical estimates suggest that Uganda is making better progress increasing pediatric coverage, with aidsinfo.com estimating pediatric coverage at 53% in 2014 and 63% in 2015 (UNAIDS 2015b). However, even at its best, this means that less than two out of every three children in need of ARVs are receiving them. I should note that while I focus on Uganda, access to ARVs for children has generally lagged behind that of adults globally (UNAIDS 2014a).

There are several reasons for this gap in children's access to ARVs. First, in some of the earliest reports on HIV in Uganda, children were completely excluded with the succinct phrase, "the problems of pediatric AIDS are not discussed here" (Goodgame 1990, 383). There was a tendency to focus on the impact of HIV on the nation's "productive population." While children could represent future productivity, they were conceptualized as dependents rather than as productive in their own rights. For example, when explaining its rationale for focusing on HIV-positive children, the Uganda Ministry of Health focused on children's future "growing up to be a productive member of society" (MOH 2010a, 5). This tendency to overlook children's issues and to focus on children's future productivity, rather than acknowledging their current contributions is hardly unique to Uganda or to HIV (Hardman 2001; Hirschfeld 2002; James, Jenks, and Prout 1998; La Fontaine 1986; Lancy 2008, 2015; LeVine 2007; LeVine and New 2008; Montgomery 2008; Schwartzman 2001; van der Geest 1996).

Second, from a sheer numerical perspective, many more children have been *affected* by HIV than *infected* with the virus. Estimates vary wildly, but according to UNAIDS, since 1990 at least 2.6 to 8.5 times as many children were orphaned by HIV as were infected with HIV, and 2015 estimates report 660,000 AIDS-orphans and 96,000 children living with HIV in Uganda (UNAIDS 2015b).[36] According to 2000 estimates, the discrepancy was even more exaggerated with only 4,000 cases of children living with AIDS having been reported, but an estimated 1.9 million AIDS-orphans living in Uganda (UAC and UNAIDS 2000). Estimates of non-orphans affected by HIV are harder to come by, but given Uganda's average household size of 4.7 persons and the prolonged course of HIV, it is fair to assume that many more children were living in households with one or more infected adults, and thus affected by HIV (UBOS 2016).[37]

Third, historically it was easy to overlook children living with HIV because, quite simply, most did not live very long. It was (and largely still is) assumed that *virtually all* pediatric HIV cases are from mother-to-child transmission. Without treatment, the mean age of death for children born with HIV is 2.2 years, with 66% of children dying before their third birthday and 75% before their 5th birthday (MOH 2010a; UAC and UNAIDS 2000). Although with access to ARVs, HIV-infected children can live full productive lives, the legacy of such dismal survival statistics remains and "some caretakers as well as healthcare providers… [still] assume that all children infected with HIV will die early" (MOH 2010a, 1).

Because of this assumption, certain age groups of children living with HIV have received more attention than others. Initially programs overlooked children ages 5-9 years, because they were presumed to be "relatively free of HIV infection" since those infected in pregnancy/infancy

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[36] These reports define an AIDS-orphan as a child (under the age of 18) who has lost one or both parents to AIDS. Children who have lost one parents are called single orphans, those who are lost both are called double orphans.

[37] The idea that not (yet) orphaned children are *affected* by HIV has contributed to the expanding concepts of vulnerability discussed later in this chapter.

would have already died (UAC and UNAIDS 2000, 11). Many healthcare workers continue to assume that children above the ages of 3-5 years must be HIV-negative, thus missing those HIV infected children who do survive early childhood (Schenk et al. 2014). Even as efforts to target pregnant mothers and infants have ramped up, services geared towards 5-9 year olds remain weak. Most pediatric HIV programming today focuses on early infant diagnosis and initiation of treatment or on providing treatment options for notoriously difficult to treat adolescents. According to its most recent *Situational Analysis of Children in Uganda*, “the number of AIDS-related deaths in children aged 0-4 years decreased by more than 50% from 100,000 between 2000 and 2012, while the number of [AIDS-related] deaths in adolescents[38] increased from less than 50,000 to over 100,000 [from] 2000-12” (MGLSD and UNICEF 2015, 5)(MGLSD and UNICEF 2015). The report does not provide any information about AIDS-related deaths among children age 5-9 years. The report attributed the “unprecedented HIV/AIDS burden among the adolescent age group” to “the recorded successes in the eMTCT and ART programmes, … as a significant proportion of vertically infected children survive and graduate into teenage years” (MGLSD and UNICEF 2015, 36). However, the same report also mentions that adolescent girls make up 2/3 of new infections, therefore, the survival of children born with HIV may actually not be the greatest contributor to the rising rate of HIV among Uganda’s adolescents. Regardless of whether children infected as infants are living into adolescence or adolescents are being newly infected, internationally, health care providers and researchers are increasing their attention to the growing population of infected adolescents (Busza et al. 2014; Fournier et al. 2014; Lowenthal, Bakeera-Kitaka, et al. 2014; Mavhu et al. 2013; Mburu et al. 2014; Mupambireyi et al. 2014; Snyder et al. 2014; Vujovic et al. 2014; Willis et al. 2014). Children age 5-9 years

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[38] In keeping with international definitions, in official reports in Uganda an adolescent is defined as someone aged 10-19 years old. Youth refers to those 15-24 years old, and young people are ages 10-24 years old.

continue to be overlooked, perhaps because they are generally considered easier to handle than adolescents, and caregivers report less difficulty with adherence. However, because this age group is largely ignored, most clinics miss the opportunity to educate children about their HIV status prior to adolescence, which almost certainly contributes to the difficulty with adherence that family and medical providers then face when children reach adolescence (Abadía-Barrero and LaRusso 2006; Kajubi, Whyte, et al. 2014; Lowenthal, Jibril, et al. 2014; Mburu et al. 2014; Menon et al. 2007; Midtbø et al. 2012; Vreeman et al. 2013).

Fourth, one of the factors contributing the most to children's delayed access to ART is simply a lack of services. Various reports cite the limited number of facilities offering pediatric ART, let alone actually offering child-friendly services (MGLSD 2011; MOH 2010a; UAC 2015b). While the number of facilities continues to increase, and Uganda is making a concerted effort to decentralize access to pediatric ARVs and increase the number of pediatric ART facilities, additional factors such as frequent stock-outs (running out of medications), inadequate training for healthcare workers (both in terms of community-level workers referring children to HIV centers for testing and treatment, and inadequate training in pediatrics at HIV centers), and poor linkages between PMTCT and pediatric HIV treatment services remain (Boender et al. 2012). Regarding drug stock-outs, pediatric formulations of medications can be especially difficult to acquire, although since 2005 funding from the Clinton Health Access Initiative has largely overcome this particular barrier in Uganda (CHAI 2016; UAC 2015b).

Finally, even when treatment is readily available, a number of social and economic factors contribute to low levels of treatment among children living with HIV. Denial, stigma, lack of awareness, misinformation, and the burden of care can all delay or prevent caregivers from bringing children for treatment (Boender et al. 2012; MGLSD 2011; MOH 2010a; R.

Parsons 2012; Schenk et al. 2014). Despite Uganda's status as a model country for its commitment to fighting AIDS, stigma and misinformation remain persistent problems. As stated in the UAC's latest report, "There are still several socio-cultural factors that are *increasing* HIV stigmatization" [emphasis added] (UAC 2015b, 50).[39] While children themselves may be pitied rather than blamed for being infected, they and their caregivers (especially if the mother is surviving) can experience "cascade stigma" if the child's status is revealed (Deacon and Stephney 2007; Murphy, Roberts, and Hoffman 2002; Schenk et al. 2014). In Mozambique, Deena Class (2014) found that HIV-prevention messages which focus on sexual fidelity and PMTCT enhance the stigma of mothers who have HIV-positive children by implying that they must be promiscuous (to have been infected in the first place) and irresponsible (because responsible mothers can prevent their children from becoming infected), regardless of the fact that numerous researchers have demonstrated that monogamy and marriage are risk factors for HIV (Hirsch et al. 2010; Mkandawire-Valhmu et al. 2013; Tolan 2005).[40] Didier Fassin (2013) takes this analysis one step farther arguing that the construction of children as innocent victims worthy of assistance actually hinges upon the portrayal of others (adults) as negligent and unworthy. In Uganda, the desire to protect children from stigma is frequently cited as a reason to delay disclosure, which itself leads to problems with adherence (Fallon 2014; Kajubi, Whyte, et al. 2014). Even simply attending a known HIV clinic can lead to disclosure of a child's HIV

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[39] Unfortunately, the report does not elaborate on what those socio-cultural factors are, nor provide a way to access the mid-term review from which this claim was made.

[40] Class additionally has called into question the assumption that virtually all children infected with HIV are infected via mother-to-child transmission (Class 2014). She argues there are "strong empirical indicators of horizontal transmission" raising the possibilities of transmission via sharp implements, medical treatment, and sexual assault. While I question the generalizability of her evidence, she does raise an interesting argument regarding the unintended consequences of prevention messaging, along with evidence that subsequent stigma leads to difficulties with disclosure, delayed treatment initiation, and poor adherence.

status, thus making caregivers reluctant to initiate treatment for HIV infected children (Schenk et al. 2014).

Lack of awareness, both in terms of recognizing the signs and symptoms of pediatric HIV and knowing whether/where treatment is available, as well as misinformation about ARVs additionally contribute to the underutilization of available pediatric HIV services. Delayed initiation of treatment can lead to the perception that, at best, ARVs will not make a difference or, at worse, ARVs actually weaken children and cause death (MOH 2010a; Schenk et al. 2014).[41] Additionally, the burden of care can be too great for caregivers (MGLSD 2011; MOH 2010a; R. Parsons 2012; Schenk et al. 2014). While ARVs are free, caregivers are still burdened by not only the responsibility of monitoring daily treatment,[42] but also the costs of transportation and lost time from work when bringing children to regular clinic appointments,[43] the costs of lab tests, and the costs of medications to treat opportunistic infections.[44] The nutritional needs of

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[41] I witnessed a similar perception toward both nasogastric tubes (NG-tubes) and lumbar punctures during my fieldwork. NG-tubes were used only in the most wasted patients (most of those I saw were severely malnourished children) and lumbar punctures were used to treat cryptococcal meningitis – a deadly fungal infection which occurs only in severely immunocompromised patients. In both cases, patients frequently died shortly after the medical interventions. From a strictly biomedical perspective, their deaths were not because of the interventions themselves, but because the patients were so sick. However, families who had heard stories about (or themselves experienced) people dying after receiving NG-tubes or lumbar punctures were often reluctant to accept either intervention for fear that it would hasten their loved one's death.

[42] Although only briefly mentioned in the literature, the burden of overseeing daily medication administration should not be underestimated. I frequently interacted with caregivers whose work responsibilities (often in agriculture) required that they leave home before sunrise and did not allow them to prepare an evening meal until after dark. Thus, being home to watch a child take his/her medication twice a day (at 12 hour intervals) was at best challenging and often impossible. The burden was even greater if the child had difficulty swallowing the medications because of over-sized pills (common when pediatric formulations are unavailable) or bitter syrups.

[43] Again, the burden of regular clinic visits should not be underestimated. Many programs for ART initiation in children require weekly clinic visits for at least the first month, followed by bi-monthly visits for another month or two, and then monthly visits thereafter. Only children who have been on treatment for a year or more and who are doing especially well clinically are supposed to be permitted to have clinic visits any less frequently, and even they must come in at least four times per year.

[44] Parsons (2012) describes the struggles of children to afford treatment for non-life-threatening infections and the negative consequences on their quality of life.

children living with HIV may also be greater than those of uninfected children and, at the very least, caregivers are advised to give children food when they take their ARVs.[45] Caregivers, may already be overburdened by caring for many children and lack the financial and emotional reserves to support a child living with HIV.

In summary, pediatric care of HIV has long lagged behind care for adults. Children are assumed to be infected primarily through mother-to-child transmission and infected children are often pitied, because without treatment the vast majority will die early in life. However, with treatment, infected children have lifespans comparable to uninfected children and can be productive members of society, both during childhood and into adulthood. In recent years, both the Ugandan government and international organizations have been making concerted efforts to close the pediatric treatment gap, and have been somewhat successful in doing so. However, the moral economy of childhood innocence hinders (ir)responsible adults from accessing care for their charges. Additionally, the socio-economic factors which contribute the most to limiting children's access to care are among the most challenging to address.

1.3.5 AIDS in Uganda Today

Despite the previously mentioned successes in reducing HIV prevalence in Uganda, AIDS remains a prominent issue in the country. Uganda has a national HIV prevalence of 7.1% among adults (ranking 10th globally, and the highest in East Africa), 1.5 million people infected (tying for first globally with Kenya and Mozambique), and 96,000 children (ages 0-14 years) living with HIV (ranking second globally) (UNAIDS 2015b). During the period of my research

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[45] I discuss children's nutrition in more detail in Chapter 8. Additionally, the requirement that ARVs should be taken with some kind of food, is not always so simple when there is no refrigerator and food must be prepared over a wood/charcoal stove.

(2014-2015) the Uganda AIDS Commission was drafting the latest NSP which would be in effect between 2015-2020. According to this latest NSP, Uganda is one of ten countries accounting for 81% of HIV in Sub-Saharan Africa, a region which itself contains 71% of people worldwide living with HIV, and one of only two African countries to see the number of HIV infections *increase* between 2005-2013 (UAC 2015a). Despite this, the NSP is, overall, optimistic. Uganda prides itself on having a declining number of *new* infections, especially among children. In 2013 Uganda reached a “tipping point” when the number of people starting on ART outpaced the number of new infections. Additionally, “there has been a sustained decline in HIV and AIDS mortality from 120,000 in 1998 to 63,000 in 2012,” which is both attributed to increased access to ART, and may partially account for the increase in the number of people living with (rather than dying from) the disease (UAC 2015a, 10). The report proclaims the ambitious goal of achieving an “AIDS-free population” by 2040. The NSP does not define an “AIDS-free Uganda” or “AIDS-free population”; however, it does cite a vision of “a Healthy and Productive Population free of HIV and AIDS and its effects,” and goals of “Zero new HIV infections, Zero HIV-related deaths, and Zero stigma and discrimination due to HIV” [capitalization as in original] (UAC 2015a, vii). The three zeros match the UNAIDS 2011-2015 strategy “getting to zero”, and remain a key part of the UNAIDS 2016-2020 strategy “on the fast-track to end AIDS,” which emphasizes “putting people at the center of the three zeros” (UNAIDS 2010, 2015c). These visions and goals are not simply written in official UAC documents and then forgotten, but become the rallying cries for organizations and individuals working within the projectified landscape of HIV. For example, St. Damien’s staff often repeated UNAIDS slogans at organizational events such as the annual general meeting, and the slogans appeared on T-shirts distributed to staff and volunteers and on posters designed for St. Damien's events such as World AIDS Day and the grandmother's celebration (see figure 1.4).

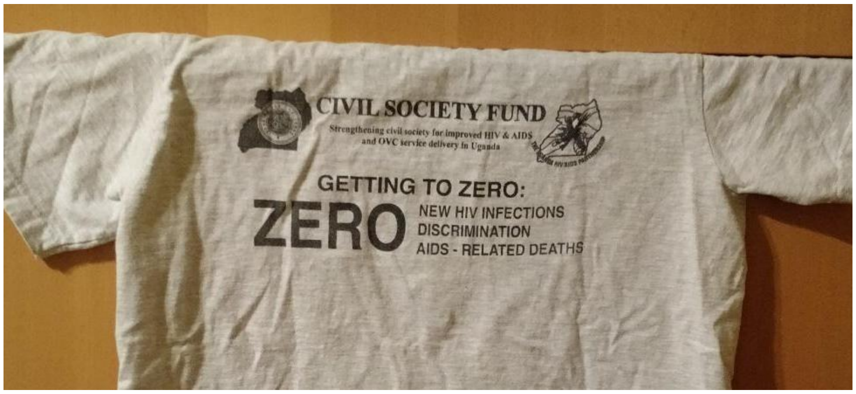

Figure 1.4 Back of St. Damien's Staff T-shirt

1.4 OVCs – Growing Vulnerability but Decreasing Direct Aid

Uganda was not only one of the first countries to respond to AIDS, but also one of the first to document and recognize the impact of HIV/AIDS on children (Foster, Levine, and Williamson 2005; Hunter 1990; Kalibala and Elson 2009; Müller and Abbas 1990). Although, as I have discussed above, the plight of children *infected* with HIV was largely overlooked initially, the plight of children *orphaned* by AIDS more quickly rose to international attention, and was often portrayed in the direst terms:

> To lose one or both parents to AIDS is to face *a childhood of pain and peril*. The suffering starts with the grief and horror of watching their parents waste away. Soon they suffer prejudice and neglect at the hands of their guardians and community. Every tenant of the Convention on the Rights of the Child is violated, from their right to education, health and development, to protection from exploitation and harm.
>
> Our experience tells us that orphans have alarmingly higher rates of malnutrition, stunting and illiteracy. Often their community shuns them, presuming that they, too, harbor the fatal virus. Relatives who take them in often seize their paltry inheritances, and local laws offer little recourse to these lonely children.
>
> Worse still, as surveys here in Uganda have shown, children whose parents have died often must shoulder heavier workloads and are treated more harshly than the foster family's own children. They are less likely to go to school and more likely to be depressed. One of our current district development plans reports that "orphan children [are] being defiled, married, neglected and… subjected to many forms of abuse."

> – Janat Mukwaya, Minister of Gender, Labour, and Social Development 1999 [emphasis added] (cited in: MGLSD and UAC 2002)

While AIDS brought anxiety around orphans to a new level, Uganda's concern with the "orphan problem/crisis"[46] actually predates the AIDS crisis (MGLSD and UAC 2002). The Ugandan government has always defined an orphan as a child under the age of 18 who has lost one *or* both parents, and since at least the 1990's, UNICEF, UNAIDS, USAID, and many African governments' censuses and demographic and health surveys have used the same definition.[47] Single orphans are children who have lost only their mother (also called maternal orphans) or their father (also called paternal orphans), and double orphans are children who have lost both parents. When reports refer to orphans without specifying, they are presumably including both single and double orphans. In contrast, western definitions of orphans, such as that used by immigration officials in the United States, requires the loss of both parents.[48] Whether the loss of one parent or both, in development parlance orphanhood becomes a permanent label (often associated with eligibility to receive assistance) for children, at times extending to adulthood (Beegle, De Weerdt, and Dercon 2005, 2007; Levy 2000; Wasserman 2015; Yamano 2007).

The concept of orphanhood as a permanent state contrasts with traditional Luganda terms for orphan (*mulekwa/enfuzi* for single/double orphan respectively) which were only used for a short period until a relative assumed responsibility for the child. Once in their new family,

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[46] I use the terms "orphan crisis" and "orphan problem" throughout this chapter in keeping with the terminology used by national and international policy makers, researchers, and humanitarian organizations to describe situations where the increasing number of orphans was perceived to be creating a crisis/problem.

[47] Earlier definitions shared the loss of one or both parents as orphan defining, but set the age cut off for orphans at a younger age. African censuses data dating back to the 1960's and demographic and health surveys dating back to the 1980's have defined an orphan as a child under the age of 15 who has lost one or both parents (K. Cheney and Rotabi 2017; Hunter and Williamson 2000).

[48] For immigration purposes to the United States, "A child may be considered an orphan because of the death or disappearance of, abandonment or desertion by, or separation or loss from, *both* parents" [emphasis added] (DHS 2017).

children called their new guardians mother/father, the guardians called the child son/daughter, and the child was only rarely referred to as “child of the late…” when necessary for clarification/identification (Dunn 1992). As this chapter describes, when concern regarding the orphan problem/crisis (especially in relation to AIDS) grew and many forms of assistance were linked to orphanhood, the label of orphan became permanent and, the English word “orphan” came to replace traditional terms not only in development and humanitarian circles, but also in daily speech.

1.4.1 Uganda’s First Orphan Initiatives - *Counting Orphans and Recommending Responses*

In 1979 during the aftermath of what Ugandans call the Tanzanian War, which ousted the internationally infamous Idi Amin, the government began enumerating widows and orphans with the promise of paying school fees for deceased veteran’s children (Hunter 1990). Initially scholarships were for those children whose parent(s) were killed by Idi Amin regardless of the financial situation of the child’s guardian. When people argued that other orphaned children should be included, the program was expanded to include all orphans. Unfortunately, the government could not afford the program, and it was terminated in 1985 during the Obote II regime (MGLSD and UAC 2002). Similar efforts to financially support war orphans ensued in the aftermath of the Luwero Triangle war which ultimately ousted Milton Obote and brought Yoweri Museveni to power in 1986 (Hunter 1990). Throughout these early interventions, assistance to orphans centered on paying school fees.

With the recognition of the AIDS epidemic, the focus on orphans in Uganda intensified, and ultimately exploded in parallel with the international response. In 1987, president Museveni promised to pay school fees for AIDS-orphans, but because of its limited budget, the government was unable to uphold its promise (Hunter 1990). At this same time First Lady Janet Museveni founded the Ugandan Women's Effort to Save the Orphans (UWESO). The increased attention to orphans, combined with the influx of international support, led to exaggerated reports, with some districts claiming that up to 50% of children were orphaned (Hunter 1990). UWESO's initial efforts focused exclusively on orphans, but this led to household inequalities (orphans attending school, but non-orphans unable to afford school-fees) and guardians relinquishing their roles (refusing to visit orphans in boarding school because "they are UWESO's children now") (K. E. Cheney 2010b). These early lessons helped shape national policy to focus on interventions supporting families and communities rather than on singling out orphans, but initially interventions still targeted orphans and their caregivers.

In 1989, the World Bank identified orphans as a key target for AIDS-related intervention, but good estimates of the number of orphans and their actual needs were still lacking. In an attempt to get a more realistic picture of the "orphan problem" researchers at Save the Children-UK[49] in collaboration with the Ugandan Ministry of Labour and Social Affairs conducted the first surveys of orphan prevalence. The preliminary results were published the following year (in 1990) in what was the first research article on orphans and AIDS in Africa, with the final report being published two years later (in 1992) (Dunn 1992; Foster, Levine, and Williamson 2005; Hunter 1990). The study compared orphanhood in two districts heavily affected by AIDS (Rakai and Masaka) with a district heavily affected by civil war (Luwero) and a district neither heavily affected by AIDS nor conflict (Hoima). Despite comparable rates of orphanhood in Masaka (5.0%), Luwero (5.6%), and Hoima (4.4%), the high rates of orphans (12.8% of children), double

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[49] From 1997-2002, Save the Child Fund used a definition of an orphan as a child under the age of 15 years who has lost one or both parents. They raised the age to under 18 years old in their 2004 report. The Ugandan census has used 18 years as the cut off age since at least the 1991 national census.

orphans (23% of orphans) and children living with a caregiver over the age of 50 years (43% of children) in Rakai quickly became the statistics most widely cited in reference to Uganda's orphan problem nationally, much in the same way that, in 1995, HIV prevalence rates in Mbarara's antenatal clinic were used to define Uganda's AIDS crisis (Dunn 1992). The report also warned that the orphan rates were only "the tip of the iceberg" and that rates would continue to climb as the AIDS pandemic worsened. In 1990, a Kampala-based study reported an even higher orphan rate (16%), but authors indicated that the majority of orphans in this region were the result of civil war and conflict (Müller and Abbas 1990). Another study from the early 1990's reported that, nationwide, 11.6% children were orphans, with 9.3% of orphans being double orphans. and most double orphans orphaned as a result of AIDS (Ntozi 1997). According to a report published jointly by the Uganda Ministry of Gender, Labor, and Social Development and the Uganda AIDS Commission, the percentage of orphans in Uganda due to AIDS rose from 17.4% in 1990 to 42.4% in 1995 and 51.1% in 2001 (MGLSD and UAC 2002). In conjunction with these early enumeration efforts, Uganda played a leading role in increasing the international recognition of the problems children orphaned by AIDS faced and in establishing the importance of family/community-centered responses rather than institutionalization.[50]

Initially, some scholars cautioned against prematurely concluding that extended family networks would be overwhelmed, and instead emphasized that "traditional fostering systems have been able to bear the additional burdens created by war and AIDS, and it is our bias that

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[50] While some have argued that Uganda's early focus on PMTCT contributed to the nation's rise in AIDS orphans (as uninfected children outlived their parents) (K. E. Cheney 2010b; Foster, Levine, and Williamson 2005), as previously discussed, rates of PMTCT did not reach 30% of affected mothers until 2007 (UAC 2010), and rates of mother-to-child transmission were still estimated at 30% (the same as without PMTCT treatment) in 2006 (KMCC 2012). It therefore seems unlikely that early PMTCT significantly contributed to the rise of AIDS orphans in Uganda, and in fact if PMTCT efforts had been more quickly implemented, orphan rates may have been even higher.

they continue to do so" (Hunter 1990, 687). Supporting the idea that traditional fosterage systems were not overburdened, Hunter's report found no difference in the gender of orphans, nor in school attendance rates between orphans and non-orphans and cautioned against over focusing on orphans. Another report discussed the problematic way in which the term "orphan" was being tied to forms of assistance and potentially preventing children from becoming full members of their new families (Dunn 1992).

However, Hunter's lack of concern that orphans would overburden family networks contrasted with most other reports. A household survey conducted in two Kampala-area villages found that 47% of households which were housing one or more orphans reported being unable to pay school fees for one or more children versus only 10% of households which were not housing an orphan (Müller and Abbas 1990). Two years later, the national census showed a higher proportion of orphaned children out of school compared with non-orphaned children (Ntozi 1997). Lastly, the final publication of that first orphan survey conducted in 1990 raised concerns regarding the ability of elderly and young guardians to adequately care for orphans and regarding the stigma and uncertain futures faced by AIDS-orphans (Dunn 1992). Similarly, in 1992-1993, researchers from Makerere University surveyed households which had had a death in the past year, and found that up to 54% of recent orphans were due to AIDS-related causes and that the leading problem faced by orphans was "lack of money" (reported by 58% of participants) (Ntozi 1997). Based on both their survey and focus group research, the researchers concluded that while relatives were still caring for orphans, they were becoming overwhelmed by increasing numbers of children and a lack of external support.

As concern grew over the plight of orphans, the question of how to respond to the crisis also came to the forefront, and the need for a national response crystallized. Overall reports from

Uganda emphasized the importance of supporting extended families through system-building development and stressed that institutions (i.e. orphanages) offered a "ridiculously short sighted solution" which would lead to the breakdown of traditional systems of fostering and were "culturally destructive" (Hunter 1990, 684). Rather than institutionalization, scholars encouraged culturally meaningful community-based "orphan-helping" schemes and supporting extended families through both income generating activities *and* direct services (such as providing school fees, clothing, and food subsidies) (Dunn 1992; Ntozi and Mukiza-Gapere 1995; Ntozi 1997).

In 1990, the Uganda Community-Based Association for Child Welfare was established with support from UNICEF. It was, worldwide, the first national-level organization formed as a consortium of government departments and NGOs for the purpose of improving collaboration among the growing number of programs responding to children orphaned by AIDS (Foster, Levine, and Williamson 2005). In 1991, in response to Janet Museveni's solicitation for assistance, USAID sent a team to Uganda to assist in assessing Uganda's "orphan problem" and response, the outcome of which was a report and a conference, both titled *Managing Uganda's Orphan Crisis* (Foster, Levine, and Williamson 2005). The conference, held in 1991, was the first national conference of its kind worldwide to be organized in response to orphaning due to AIDS. The report confirmed the serious and worsening orphan crisis in Uganda, the lack of funding for government programs, the need to identify regions with the highest numbers of orphans *and vulnerable children*, and that orphanages undermine the traditional response of placing children with extended families (Alden, Salole, and Williamson 1991). The report spurred efforts to establish a national orphan registry and the Ugandan Foster Care and Adoption Program to encourage next of kin to care for the orphans. Unfortunately, the national registry was not adequately funded, there were too few probation officers to oversee the foster care program, and both programs ultimately failed (MGLSD and UAC 2002). Despite these setbacks, in other ways Uganda made progress in promoting community care for and preventing the institutionalization of orphaned children.

In 1992, the Ugandan Department of Probation and Welfare in conjunction with Save the Children carried out a survey which found that about half of the children living in children's homes had both parents living, another 20% had one parent living, and another 25% had a known relative. Based on those findings, between 1992 and 1997 the organizations worked to enforce national policies and standards for children's homes, resulting in the closure of 40 out of 75 known orphanages and the reunion of 1,700 children with their families (MGLSD and UAC 2002).[51] In 1993, an article in the New York Times declared Uganda a "Nation of Orphans" and again described the national approach of keeping children on their land (in rural villages) and out of institutions so as not to "alienate them from their lineage and their culture" (Lorch 1993). In 1994, USAID funded one of the first microfinance programs targeting those regions most seriously affected by HIV/AIDS in Uganda, thus upholding the idea of broadly targeting areas affected by HIV/AIDS, rather than singling out orphans or even households with orphans (Foster, Levine, and Williamson 2005). In 2002, a Ugandan study estimated that orphanage care cost fourteen times more than community-based care (USAID, UNICEF, and UNAIDS 2002).[52]

Despite these early interventions, Uganda did not develop a dedicated national strategy for AIDS-orphans until nearly a decade later (in 2002), leading some scholars to claim that Uganda had a "lag in identifying the serious effects of HIV/AIDS on children" (K. E. Cheney

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[51] While a commendable achievement, the same report estimated that there were over one million orphans in Uganda as of 1990, thus the percentage of institutionalized children in Uganda has always been very small (MGLSD and UAC 2002).

[52] Given Uganda's lack of history of institutional care and official commitment to deinstitutionalization, it is ironic that it has recently become "the next destination for orphan addicts" with a growing "orphan industrial complex" (K. Cheney and Rotabi 2017).

2010b). However, I would argue Uganda did not delay in identifying the effects of HIV/AIDS on children, but only in its response. Indeed, the reports from the early 1990s indicate a great deal of concern for children affected by AIDS, and the government made several attempts at national interventions. However, the nation lacked the resources to address the needs of orphaned children. It was not until a joint UNAIDS, UNICEF, USAID, and WFP funded initiative in 2004 that Uganda was finally able to mount a national response to its orphan problem, twelve years after HIV prevalence in the country peaked (K. E. Cheney 2010b).[53]

1.4.2 The Rise of the OVC – Increasing Vulnerability but Decreasing Aid

Though concern with vulnerable children (presumably those vulnerable of becoming orphans due to HIV/AIDS) date back to at least the 1991 *Managing Uganda's Orphan Crisis* report, the term OVC did not appear in Uganda's national publications until the 2003 *National Strategic Plan for HIV/AIDS*. Yet by 2009, 96% of Uganda's children were identified as OVCs (Alden, Salole, and Williamson 1991; Kalibala and Elson 2009; UAC 2004).[54] In this section, I use governmental reports to track how ever increasing numbers of children were defined as vulnerable, yet paradoxically, direct aid to them was rolled back.

Starting in 2002, the Ugandan Ministry of Gender, Labour, and Social Development and the Uganda AIDS Commission began publishing status reports and policy recommendations on Uganda's orphans. Comparing the ways in which these reports refer to children, their

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[53] Foster, Levine, and Williamson (2005, 279) provide a more complete timeline of the steps in the evolution of the international response to orphans and vulnerable children affected by HIV/AIDS.

[54] The first use of the term OVC in international parlance is more difficult to trace, but may be the 1999 *Orphans and Vulnerable Children: A Situational Analysis* carried out in Zambia with funding from UNICEF and USAID (USAID, UNICEF, and SIDA 1999). The following year the 13th International AIDS Conference in Durban included a special track on orphans and vulnerable children (Foster, Levine, and Williamson 2005, 282).

vulnerability, and the kinds of interventions recommended demonstrates a shift in concern from AIDS-orphans (in the 1990's) to orphans and vulnerable children (still focused on HIV/AIDS) in the early 2000's and ultimately to an understanding of vulnerability which encompassed nearly all of Uganda's children (and was no longer necessarily related to HIV/AIDS) by the early 2010's. Paradoxically, while the notion of vulnerability was expanding, the kinds of direct services offered to children were contracting. In the name of sustainable development, direct aid to children and families was replaced with policies to "strengthen communities," and ultimately with more policies to better implement the existing policies.

The 2002 *Situation Analysis of Orphans in Uganda* focused almost exclusively on orphans, and AIDS-orphans in particular. In the foreword, Janet Museveni emphasized that while "the problem of orphans in Uganda did not begin with the advent of HIV/AIDS… the onset of the HIV/AIDS pandemic compounded and multiplied the burden of absorbing orphans" (MGLSD and UAC 2002). HIV/AIDS was seen as different from war/conflict because HIV/AIDS caused prolonged illness prior to "the almost certain death of *both* parents." The executive summary declared that, "the situation of orphans in Uganda today has reached crisis proportions" and warned that the two million orphans making up 15% of Ugandan children would become a "lost generation" as households struggled to meet the increasing demands of the growing number of dependents (MGLSD and UAC 2002). The report emphasized the importance of children in the future both with the subtitle "caring for the future-today" and by warning that the failure to address the needs of orphans "threaten the security and integration of the Ugandan state" and would lead to future violence and civil unrest. Thus, children were not only dependent, rather than productive, they were also potentially dangerous. In order to address the orphan crisis, the report recommended assisting the households that take in orphans more directly. The fact that one of the national newspapers published an article titled "Uganda in Orphan Crisis" shortly after the first situational analysis, indicates that concern for orphans reached beyond the government ministries and international discourses to the general public (Ngatya 2002).

In 2004, Uganda published its first *National Strategic Programme Plan of Interventions for Orphans and Other Vulnerable Children (NSPPI-1)*.[55] According to the NSPPI-1, one quarter of Ugandan households housed one or more orphans, Uganda had two million orphans, and the main causes of orphans were AIDS, other disease, and conflict. Despite the international emphasis on orphans, the report acknowledge that "not all orphaned children are vulnerable, especially if their extended family can absorb them, love them, nurture them and take care of their basic needs" and in fact, "after the death of one or both parents, the UDHS 2000/01 and UNHS 1999 database analysis indicate that most orphans are found in households with higher gross household income, higher per capita income, and tend to be in urban areas" in comparison to prior to being orphaned (MGLSD 2004, 19, 94). Moving beyond the orphan focus, the report emphasized the role of the environment in causing vulnerability, citing poverty, conflict, health, education, water/sanitation, and housing in addition to HIV/AIDS as contributing to children's vulnerability. It defined a vulnerable child as "one who, based on a set of criteria when compared to other children, bears a substantive risk of suffering significant physical, emotional or mental harm" and even went so far as to claim, "vulnerability broadly encompasses almost all children in Uganda" (MGLSD 2004, 19, 105). Interventions were to prioritize reintegrating vulnerable

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[55] The Ministry of Gender, Labor, and Social Development has published two documents titled the *National Strategic Programme Plan of Interventions for Orphans and Other Vulnerable Children*. Following the convention used in these publications, I will refer to these documents as NSPPI-1 and NSPPI-2. The *National Orphans and Other Vulnerable Children Policy (NOP)* was also published the same year as the NSPPI-1, but offers no new material for analysis.

children into adult-headed households and supporting vulnerable households, yet with almost all children defined as vulnerable, the plan recommended focusing on the *most* vulnerable children and households which could be identified using over a dozen criteria including institutionalization, poverty (and poor living conditions), orphanhood, illness (including HIV), caregiver vulnerability, and instability (see Appendix H for a complete list of criteria). Unfortunately, these criteria did little to narrow the category of vulnerability when the same report cited that 38% of households were in poverty with up to 90% of rural households having dung floors. The already very broad definition of vulnerability would only continue to expand in subsequent reports. Direct interventions, such as financial, material, and training/educational support for children and families were allowed, so long as they were designed "so that their [recipient's] capacity to take care of themselves may be strengthened over the long term" (MGLSD 2004, 29). In other words, basic assistance should be limited to the short term and interventions were explicitly geared toward being sustainable, defined as, "geared to provide adequate resources at the individual, household and community level to build a foundation that will allow a level of *independence* to be achieved *within three years* for the majority being assisted" [emphasis added] (MGLSD 2004, 62).

The 2009 *Situation Analysis of Vulnerable Children in Uganda* moved even farther away from singling out orphans and instead proposed the calculation of a "vulnerability score" for all children based on over 40 variables from household survey data in order to develop a "Uganda-specific definition of vulnerability" (see Appendix H) (Kalibala and Elson 2009). Based on this score, the report estimated that the vast majority of Uganda's children were vulnerable with 8% critically vulnerable, 43% moderately vulnerable, and 45% generally vulnerable. Using this approach, 96% of children were, to some degree, vulnerable and only 4% of Uganda's children were NOT vulnerable. The Situation Analysis also described how NGOs were primarily responsible for providing services to OVCs. While NGOs had a big impact on those children who they reached, they reached at most 15% of vulnerable children with medical assistance, and less than 10% of households with modern farming techniques (9.1%), agricultural inputs (7.7%) and educational support (6.9%). The report pointed out that "the qualifying criteria differed from one organization to another" and that the NGO response was overall uncoordinated and lacked networking (Kalibala and Elson 2009, 23). This lack of coordination and high fragmentation is hardly surprising given the similarities between the projectified landscapes of OVC care and of HIV care.

The 2011, the NSPPI-2 emphasized children as the "most vulnerable group" among the 31% of Uganda's population living in poverty, and focused on the 51% of children estimated to be critically or moderately vulnerable (MGLSD 2011). It included a list defining critical and moderate vulnerability which was more concise than the 2009 Situational Analysis' vulnerability survey, but considerably longer than the criteria used in the 2004 NSPPI (see Appendix H for complete list). Notably, simply living in a hard to reach area (defined as fishing, mountain, or nomadic communities) made a child moderately vulnerable and "orphans whose rights are not fulfilled" were critically vulnerable.[56] The report primarily identified poverty, conflict, AIDS, and other diseases as the drivers of vulnerability among children. While the NSPPI-2 noted over four thousand civil society agencies offering services to OVCs, it estimated that only 11% of vulnerable children had been reached with external support services. It criticized NGOs for being uncoordinated, incomprehensive and unsustainable, as well as sometimes inappropriate and fragmented – concentrating on only a few core program and geographical areas.

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[56] Somehow non-orphans whose rights were not fulfilled were not vulnerable, and orphans whose rights were fulfilled were generally vulnerable.

Interestingly, while the report in one sense criticized cultural practices, such as early marriage, for contributing to the "intergenerational vulnerability cycle", it also bemoaned the loss of traditional values and the rise of supposedly western values of individualism:

> The phenomenon of 'individualism' partly caused by economic hardship continues to limit communities' capacity to intervene and provide care for children when caregivers and parents are absent/dead. In certain cases, caregivers have been found to neglect and/or even violate the rights of children because of these hardships. This has been accentuated by the increasing adoption of western ideals against receding traditional values of child care. (MGLSD 2011, 6)

Given this critique of individualism, it is ironic that overall the goal of the NSPPI-2 was to address childhood vulnerability in a "sustainable manner," defined as strengthening household and communities such that vulnerable households could attain independence within three years.

The most recent *Situational Analysis of Children in Uganda*,[57] published in 2015, uses the same estimate for vulnerability as the 2011 NSPPI-2 reports, but takes an explicitly and emphatically rights focused approach toward identifying and addressing Uganda's children. Indeed, the foreword declares, "This Situation Analysis *focuses entirely* on the fulfillment of children's *rights* as enshrined in the UN Convention on the Rights of the Child ratified by Uganda in 1990" [emphasis added] (MGLSD and UNICEF 2015, x). These rights fall into four areas: survival, education/development, protection, participation. While predominantly focused on the rights of all children in Uganda, it does allow some focus on "target cohorts" – young children (age 0-8 years old), adolescent girls (age 10-19 years old), and marginalized/vulnerable groups (which it poorly defines with the statement "inequalities can increase the level of risk and vulnerability associated with certain situations – including being orphaned, having disabilities, being a girl, and *many more*" [emphasis added] (MGLSD and UNICEF 2015, 13)). Despite

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[57] Perhaps, given that all children are vulnerable, it was unnecessarily redundant to include the word "vulnerable" in the report's title.

recognizing limited systemic investments and an over-reliance on donor and NGO programming, the recommendations from this most recent situational analysis focused mostly on policy level interventions, especially implementing existing laws/policies and greater monitoring and enforcement. There was no mention or suggestion of direct aid to vulnerable families, presumably because such interventions are not "sustainable."

Similarly, comparing the ways in which children and notions of vulnerability are discussed in Uganda's HIV/AIDS NSPs reveals an ever-increasing concern with an ever-expanding notion of vulnerability, even as these reports maintain their focus on HIV/AIDS-related vulnerability. In addition to shifting concepts of vulnerability, the kinds of interventions deemed appropriate shift over a decade and a half with growing emphasis on sustainable interventions and a movement away from direct aid. In 2000, the NSP voiced concern over the estimated 1.9 million[58] AIDS-orphans in Uganda, especially "the girl-child" orphans who, according to the report, experience greater exploitation and heavier responsibilities. In response to "over-stretched families," the report recommended "provision of financial and material support (shelter, food, school fees) to AIDS-orphans, child-headed families, and guardians/foster families" (UAC and UNAIDS 2000, 28). In the 2003 NSP, the term OVC first appeared in a Ugandan governmental report, as concern expanded beyond children orphaned by AIDS, to include also children made vulnerable by the epidemic. Recommendations still focused on giving direct financial and material support to AIDS-affected children and their caregivers, but also included mention of psychosocial, nutritional and educational support as well as income generating activities. In 2007, the NSP expanded its concern even further beyond children to vulnerable populations which included OVCs, people having AIDS (PHAs), people with

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[58] The estimates for orphans in general, and AIDS orphans in particular vary wildly, not only in the past, but also today.

disabilities, the elderly, youth, women, internally displaced people, and rural and urban poor communities. The report pointed out how some vulnerable populations were not just more *affected* by HIV, but more at risk for becoming *infected* with HIV. At the same time the report began to encourage informal education in vocational- and life-skills training for OVCs as well as psychosocial support and "sustainable community and household livelihood and economic empowerment" (UAC 2007, 27). Notably in the 2007 report, mention of direct nutritional support for people living with HIV was replaced with national policies and guidelines concerned with *sustainable* food security. Still the report allowed for interventions which "facilitate the provision of financial and essential material to support PHAs,[59] OVCs, and other disadvantaged households affected by HIV/AIDS" and "advocate for appropriate social safety nets that benefit PHAs, OVCs, and vulnerable households" (UAC 2007, 29). The next NSP, in 2011, did not change concepts of vulnerability, but continued to emphasize "empowering households and communities" with livelihood skills, development programs, and opportunities rather than providing them with direct aid.

The most recent NSP, in 2015, again expanded the concept of vulnerability, explicitly tying it to "key populations." "Key populations" – defined as those at highest risk for becoming *infected* with HIV – included sex workers, truckers, men who have sex with men, fisher-folk, uniformed services personnel, prisoners, miners, plantation workers, *boda-boda* taxi-men, bricklayers, and salt-extractors. Vulnerable populations thus included OVCs, people living with HIV, the elderly, migrant and mobile populations, young women, adolescents, HIV-discordant couples, pregnant women, people with disabilities *and* "key populations." With such a long list of vulnerable people, it is hard to imagine anyone in Uganda escaping from the label of

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[59] PHAs = people having AIDS. I refrain from using this acronym unless directly quoting its use.

vulnerability. Interventions were to take a rights-based approach with lofty goals such as reducing stigma (specifically toward HIV, but also toward vulnerable groups more generally) and reducing gender inequality. Notably, there was limited funding set aside for nutritional and food security, and no mention of direct support, such as school fees or school supplies, for vulnerable households. Instead interventions were to strengthen community structures which would reduce economic vulnerability and empower families themselves to provide essential services for children (and other vulnerable members) in their care.

1.4.3 Making Sense of All this Vulnerability

Even as the first reports were made to quantify and describe the conditions of orphans, researchers cautioned that the use of the English term "orphan" to define recipients of aid was shifting local concepts of orphanhood from a temporary state to a permanent identity (Dunn 1992). As a result, "orphans" were constantly reminded of the loss of their parent(s) and caregivers never took full responsibility for orphans who were never fully integrated into their new families. Furthermore, while the term orphan was useful for raising donor awareness regarding the problems faced by Uganda's children, the term itself then became used as the sole criteria for service delivery, "rather than as an indicator of possible need, alongside others like poor health, poverty, lack of school and other social criteria" (Dunn 1992, 20). Because of this, some scholars argued that an expanding definition of vulnerability was necessary and useful. Indeed, "in a context where many children are poor, privileging orphans over other vulnerable children makes little sense" and therefore the notion of OVC allowed flexibility for brokers (from community members to aid organizations) to define who needed help (Watkins and Swidler 2013, 203).[60]

In the context of HIV, Malcom Bryant and Jennifer Beard (2016) argue that the global focus on the "AIDS-free Generation" has diverted funds toward PMTCT and the treatment of infected children at the expense of children orphaned/affected by HIV. Since children are affected by AIDS even before parents die, they argue, expanding HIV programming to include vulnerable children made sense. Furthermore, they argue, since HIV is responsible for only 16% of OVCs in Sub-Saharan Africa and poverty is a stronger predictor of negative outcomes than HIV status, programing *should* be expanded to include vulnerable children more broadly, rather than being limited to HIV-related vulnerability (Bryant and Beard 2016). They support the shift in the concept of vulnerability and decoupling vulnerability from either orphanhood or HIV. However, as others have pointed out, despite the rise of OVC terminology, the global preoccupation with orphans, and in particular AIDS-orphans, persists and continues to overly influence policy and program development (K. Cheney and Rotabi 2017; Meintjes and Giese 2006; Meintjes et al. 2010). Thus, the decoupling has only been partial: "in reality vulnerabilities due to HIV/AIDS are still those which receive most priority because they can be linked to funding" (K. E. Cheney 2010b, 12).

While not rejecting the importance of recognizing non-orphan, non-HIV related vulnerability, other scholars demonstrate some of the unintended consequences and complexities of expanding the definition of childhood vulnerability (Bluebond-Langner and Korbin 2007; K. E. Cheney 2010a; Henderson 2006; Hoffman 2012; Kendall 2010; Philip L. Kilbride 2010; Orgocka 2012; P. Reynolds, Nieuwenhuys, and Hanson 2006). Kristen Cheney points out how

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[60] Foster, Levine, and Williamson (2005) make a similar point.

expanding concepts of vulnerability defines children as objects for developmental and humanitarian intervention, creates untenable demands on public funds, "depoliticizes the roots of global poverty that have precipitated both the AIDS epidemic and its consequent 'orphan crisis,'" and reinstates "the neocolonial representation of Africa as a continent perpetually in need of assistance from outside sources" (K. E. Cheney 2010b, 13). Especially in Uganda, where now 96% of children are "vulnerable," we can certainly question the usefulness of such a category.

Today Uganda is still very much a nation of children. With a fertility rate[61] of 5.8, a population growth rate of 3.22%, a median age of 15.2 years, and 55% of the population below the age of 18 years, Uganda continues to be one of the youngest countries, if not the youngest country, in the world[62] (CIA 2016; UBOS 2016). Concepts of vulnerability are very broad, and utilized by aid organizations to define access to services and by children and caregivers themselves to access services. As is the case with HIV-care, NGOs are responsible for most OVC support and the majority of the Ugandan government's budget for OVCs comes from donor funding. There are over 4,000 civil society agencies providing services to OVCs, but because (as described in numerous government reports) the agencies are uncoordinated, incomprehensive, unsustainable, sometimes inappropriate, and fragmented "only 11 percent of 8.1 million children in dire need had been reached with external support services" (MGLSD 2011, 1). Additionally, despite a national OVC plan, overall children's issues are not prioritized

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[61] Total fertility rate is "the number of live births a woman would have if she survived to the end of her childbearing age (15-49 years) and experienced the current observed age specific fertility rates" (UBOS 2016, 16). The most recent census reported a substantial decrease in Uganda's fertility rate from early values of 7.1 in 1991 and 7.0 in 2002. However, Uganda still has the 5th highest fertility rate worldwide (CIA 2016).

[62] Uganda vies with Niger for the distinction of youngest country in the world. The CIA World Factbook, reporting data from 2014, lists Niger as the youngest nation with a median age of 15.3, and Uganda as the second youngest with a median age of 15.7. However, if the median age of 15.2 from the Ugandan National Census is used, Uganda is the youngest nation in the world (CIA 2016; UBOS 2016).

at the local level because, as one report explains "OVC and children issues are not one of the assessment areas at the district level which makes it of less priority by district administrators" (UAC 2015b, 51). Like ARVs, or perhaps even more so, OVC services form a projectified landscape that those children/caregivers who claim the label of OVC must learn to navigate in order to access essential services such as healthcare, education, and nutritional support. As neoliberal concepts of sustainable development have risen in prominence, direct support to children and caregivers has decreased. Thus, ironically, even as concepts of vulnerability have expanded, the support offered to the vulnerable has contracted. Baaliro provides a concrete example of this phenomenon which I present in chapter 8.

Paralleling its national response to HIV, Uganda stands out for its response to orphans and other vulnerable children. Uganda was one of the first countries to identify the AIDS-orphan-problem, though a coordinated response to the problem lagged behind this initial recognition. Uganda gained a reputation for eschewing orphanages and promoting community empowerment in its response to the orphan crisis. However, while official policies still emphasize the importance of community care and institutionalization as only a last resort, Uganda is also gaining a reputation as the new hub for international adoption (K. Cheney and Rotabi 2017). Over the years, Ugandan OVC policies and reports have emphasized children's vulnerability and expanded the definition of vulnerability to encompass up to 96% of children. But simultaneously, these reports have tended to increasingly emphasize sustainable development and decreasingly recommend direct aid to OVCs.

1.5 Conclusion

In this chapter I have described the historical, socio-political-economic context in which Baaliro came into being, and within which the children at Baaliro and their caregivers must negotiate in order to access services. In the first half of the chapter I reviewed the history of AIDS in Uganda, mainly focusing on those directly infected with the virus. I described Uganda's history as an AIDS success story, and how these early successes led to the creation of a projectified landscape of AIDS care, within which the roll-out of ARVs was dramatic and rapid, but unequal – especially for children who were, for many years, left behind. In the second half, I described shifting notions of orphanhood (which predate the AIDS epidemic) and vulnerability (which have expanded both in relation to and far beyond HIV). Overall, Uganda has been held up as a model country for both its response to AIDS and to orphans. While structural adjustment programs have the potential to undercut government legitimacy, the Ugandan government managed to create a national policy of decentralization based on using NGOs to deliver services which actually boosted its legitimacy. Understanding Uganda as a nation of NGOs and a nation of children (especially OVCs), Baaliro fits in well with the national strategy for both the AIDS- and orphan-crises. Baaliro is but one of many NGOs providing services to OVCs in Uganda. It works in partnership with other NGOs and governmental organizations to provide access to ARVs, which enable children to live with, rather than simply die from, HIV. In the following chapters, I will add complexity to the notions of vulnerability, responsibility, and sustainability introduced here.

Chapter 2: Research Setting: Organizational Structures, Physical Spaces, and the Children's Demographics

In the previous chapter I discussed why Uganda, given its historical role in the HIV/AIDS epidemic, its approach to the vulnerability of children, and its reliance on foreign funded NGOs to provide services, was an ideal location to research the experiences of children living with HIV and to address questions of responsibility, vulnerability, and agency. I now offer a description of my field-site, including the organizations with which I worked. In describing the history of these organizations and their physical spaces, I show how Baaliro existed at the intersection of both a locally-organized NGO and a European-founded and funded NGO, and operated within a larger network of both non-governmental and governmental AIDS care organizations. Understanding these relationships are important because they form the immediate landscape of care through which children and their caregivers navigated. In the latter half of this chapter I provide a comparison of the demographics of children and caregivers who enrolled in Baaliro's program with Uganda national statistics and with another study of children living with HIV in Uganda. While I acknowledge that presenting demographic descriptions of children risks homogenizing their diverse situations and experiences (Hecht 1998), requests for these descriptors were always among the first questions I received when presenting my research. Additionally, they were the kind of information staff, themselves, were most interested in producing and providing to donors.

East Central Uganda

Baaliro (my primary field site) was located in East Central Uganda, just across the Nile River from Jinja, about 80km east of the capital city of Kampala. The Nile begins its northward journey out of Lake Victoria at Jinja, which is on its eastern banks, and forms the border between two of Uganda's ethnic groups with Busoga on its eastern banks and Buganda on its western banks. Despite the newly refinished, tarmac road connecting Kampala and Jinja, it often took more than three hours to reach the city center due to traffic. In 1991, Jinja ranked the second largest urban area in Uganda, next to Kampala, but by the 2014 census, Jinja had fallen to the 17th largest urban center in the country (UBOS 2016). However, when combined with Njeru Town Council (located on the western bank of the Nile), Jinja-Njeru had a total population of 144,892 and ranked as the 8th largest urban center in Uganda.[1] This combined population more accurately represents the population of the urban and peri-urban areas, where people regularly cross the river in both directions for work, trade, education, and medical care.

While Jinja's population slowly increased in the 1990's and 2000's, other population centers boomed. Historically, industries had been attracted to Jinja's proximity to power generated by the Owen Falls Dam on the Nile River. However, approaching the turn of the millennium, companies were drawn to Kampala because of economic incentives offered to them in the capital city. Many in Jinja bemoaned these government policies which, from their perspective, had drawn industry away from Jinja and exacerbated overcrowding in Kampala (hence the traffic jams along the Jinja-Kampala highway). At the same time, Jinja locals explained, those who could afford to participate in Kampala's booming social scene and educational opportunities at expensive international schools began to prefer Kampala to the failing industrial city of Jinja. Despite the abandoned factories, Jinja has not yet completely collapsed, but maintains an industrial presence with several remaining factories and a vibrant, newly built central market. The multi-story concrete central market, which opened during my

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[1] Kampala and three of its suburbs have nearly 2.5 million people, Mbarara 195 thousand, Mukono 162 thousand, and Gulu nearly 150 thousand (UBOS 2016).

fieldwork, provided vendors with permanent stalls and offered better protection from both rain and sun, but many complained of the high rent.

Jinja also, for now, hosts an unusually high concentration of *bazungu*[2] who come for two reasons. The first is the search for adventure tourism along the internationally acclaimed whitewater of the Nile River. In particular, large overland trucking tours include a stop at the campsites a few kilometers north of the city to allow tourists the opportunity for bungee-jumping, whitewater rafting, and other high-adrenalin activities. Sadly, this tourism industry is eminently threatened by the construction of yet another dam which will be the third hydroelectric dam to be built along the Nile in Uganda. This dam is scheduled to flood most of the remaining whitewater in March 2018, and will likely destroy what remains of the tourism industry in Jinja, not to mention the livelihoods of those who live along the river.[3] The second is the desire to volunteer at one of the many, often faith based, NGOs which operate in the region. Many of these organizations focus on HIV/AIDS and/or vulnerable children. Jinja has also become a popular destination for international adoption, located beyond the easy regulatory reach of authorities in the capital but not too far from the comforts of Kampala for prospective parents to travel (personal communication with Kristen Cheney, and personal observation – see also Cheney and Rotabi (2017)).

While Jinja was the largest municipality near Baaliro, few of the children enrolled in Baaliro's program actually came from the urban center. My work regularly included travel into the more rural areas from which the children came in the surrounding districts and occasionally

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[2] *Bazungu* is the Luganda plural of *muzungu* an East-African/KiSwahili/Luganda term for a foreigner.

[3] While compensation packages are provided to relocated families, surveys have shown the negative impact on relocated individuals and communities outweigh any benefits of compensation (Bosshard 2009; Mayrhofer and Mersmann 2016).

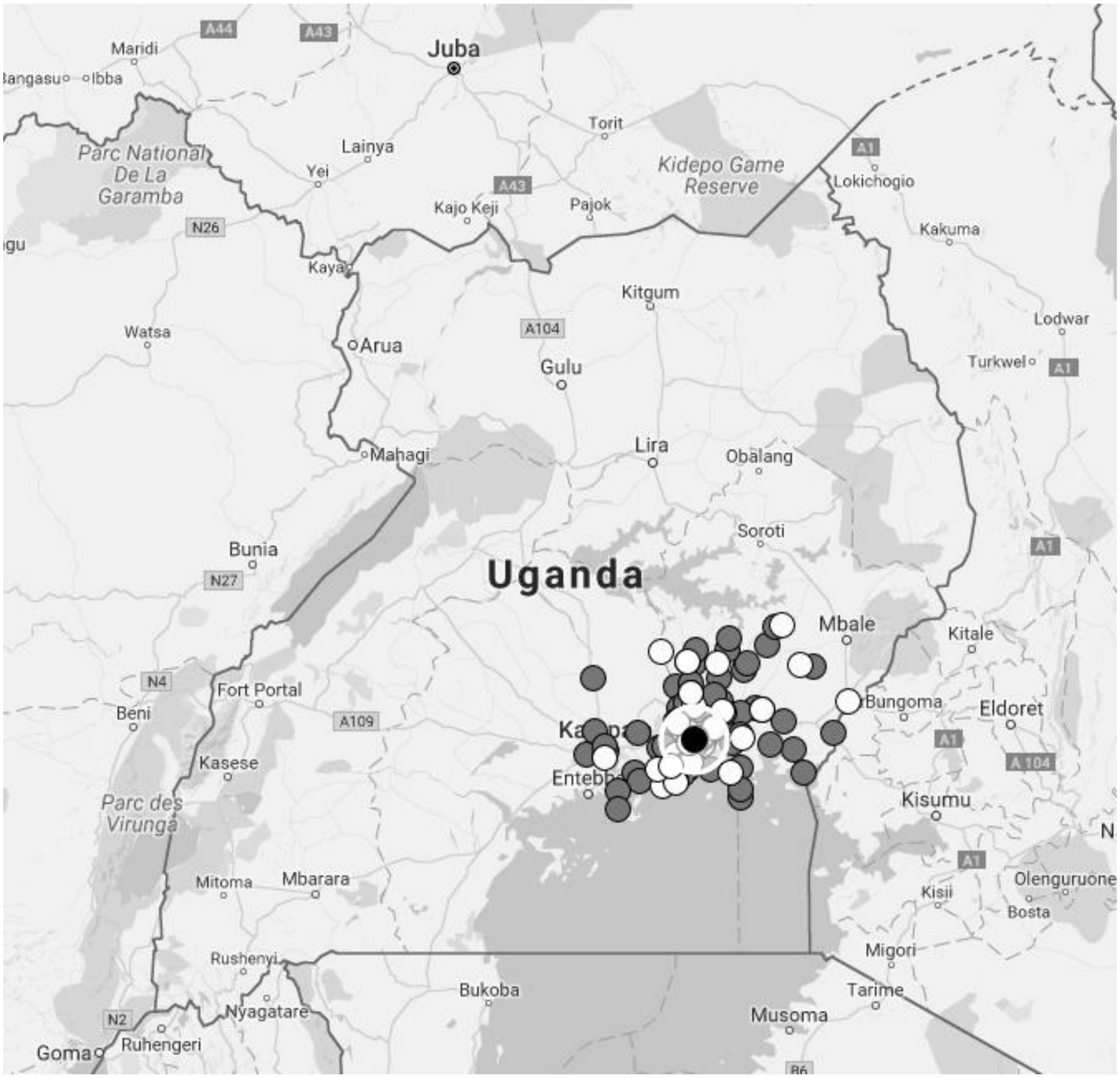

Figure 2.1 Baaliro Service Area Map

Map of home villages (gray) and schools (white) for children enrolled in Baaliro's program. The black dot surrounded by a halo represents Baaliro itself. Source: Google Maps. Position of villages and school are approximate, based on my recollection from field visits.

much farther away (see Figure 2.1). Therefore, I consider my field site to include East Central Uganda more broadly.

During the first few weeks of my fieldwork, Uganda carried out a national census, ostensibly enumerating the whereabouts of every person in the country on Aug 27, 2014 (UBOS 2016). According to this report, although urbanization[4] is increasing, nearly four out of five Ugandans (78.6% of the population) still live in rural areas.[5] Nearly 65% of Uganda's working population is involved in subsistence agriculture/fishing,[6] which the census report explains is hardly surprising given its moderate climate, loamy soils, and ample fishing sites.[7] Uganda is classified as a low income country, with 19.7% of its population living in absolute poverty and 43.3% categorized as "non-poor insecure."[8] Many of the children enrolled in Baaliro's programming came from fishing villages along the coast of Lake Victoria and nearly all the rest came from farming communities. Poverty greatly affected the daily lives of the children and caregivers with whom I worked as well as their ability to access and comply with medical treatment and clinicians' recommendations.

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[4] Urbanization was measured as increases in both the number and size of urban centers.

[5] Urban areas include the capital city, 33 municipalities, 163 town councils, and 62 townships. Administratively, the country is divided into 111 districts and one city (the capital city of Kampala) making for rather small administrative zones.

[6] Unfortunately, the national census did not report any distinction between agriculture and fishing. Subsistence agriculture/fishing accounts for 64.7% of employment and market oriented agriculture/fishing for 3.7% of employment.

[7] Uganda is a small (241,551 km^2) equatorial landlocked country roughly the size of Minnesota with a climate that is moderated by its relatively high elevation (averaging 1,100 meters above sea level). Most regions have two rainy and two dry seasons per year, though the climate in the north is notably drier and in the southwest it is notably wetter. Water covers nearly 20% of Uganda's surface area and the main bodies of water can be traced along the course of the White Nile River from Lake Victoria northward to Lake Kyoga, eastward to Lake Albert, and finally northward again to South Sudan and beyond to Egypt.

[8] The UNHS calculated and defined absolute poverty as "households which spend less than what is necessary to meet their caloric requirements and to afford them a mark-up for non-food needs" (UBOS 2014, 84), while non-poor insecure was defined as living below twice the poverty line.

2.1 Organizations – An Introduction to the Characters

2.1.1 Baaliro – A Rehabilitation Center for Children Living with HIV

Because of the stigma surrounding HIV in Uganda, the only way to access children living with HIV was via a pediatric HIV/AIDS organization or clinic. Baaliro, a European funded, locally run, child rehabilitation center, which focuses on the medical rehabilitation of severely ill children suffering from AIDS, offered just such an opportunity. Baaliro was established in 2008 with a mission of providing temporary residential care for HIV infected children, ages 4-18 years old, suffering from stage III/IV AIDS,[9] until they were medically stabilized, at which point the children were reintegrated into "the community."

Residential care (rehabilitation) included medical care, nutritional support, and education. Medical care included access to ARVs and treatment of opportunistic infections and was provided in partnership with several organizations discussed below. Nutritional support included a balanced diet and, when necessary, enrollment in the government hospital's nutritional rehabilitation program. Education was provided by enrollment in a neighborhood school (if the child was healthy enough to attend classes). Rehabilitation took from 2-20 months and, as I describe in detail in Chapter 4, focused both on numerical measures of physiological improvement (CD4 count and anthropometric measurements) as well as a child's behavioral, social, and emotional readiness. Children lived at Baaliro during their rehabilitation, but Baaliro's ultimate goal was to reintegrate rehabilitated children to be raised by their families in their home communities.

Once children were reintegrated, Baaliro staff, continued to follow up with the children, visiting them in their homes and schools and paying for school fees. Baaliro staff also monitored

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[9] These are WHO defined stages of AIDS (WHO 2005).

their adherence to medication (ARVs) through pill counts. In addition, Baaliro staff held what they called "awareness and sensitization" sessions in the communities (most often at schools) where children had been reintegrated. Ideally, these sessions served to destigmatize HIV in the school/community, so that children would be welcomed back. As of September 2015, a total of 188 children had been enrolled in Baaliro's program since its inception in 2008.

When a child was first enrolled at Baaliro, the social worker met with his/her caregiver(s) to explain the program and expectations – most importantly the caregiver's responsibilities. The key points that the social worker emphasized were: 1) Baaliro is *eddwaliro* (a medical treatment center – such as a clinic or hospital), not *ennyumba* (a house), so the child *will* be returning *eka* (home) to the community, and 2) the child is still YOUR child. This made clear not only Baaliro's commitment to reintegration, but more importantly its emphasis on caregiver responsibility. Caregivers were required to sign or thumbprint[10] a form stating that they understood the above conditions.

In short, the dual missions of Baaliro were primarily to *oku-jjanjaba*[11] (rehabilitate) children and then ultimately *oku-bazayo*[12] (reintegrate) them. Given its emphasis on reintegration and the possibility to both live with children being rehabilitated as well as to interact with children who had been reintegrated for five or more years, Baaliro offered an ideal site to study children's experiences living with HIV. I discuss the process of rehabilitation, the daily lives of children at Baaliro, and the ways in which the dual emphasis of rehabilitation and reintegration shaped the children's experiences at Baaliro in more detail in Chapters 4 and 6.

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[10] In many cases, when the caregiver was illiterate, they provided a thumbprint.

[11] *Oku-jjanjaba* literally means to treat or care for someone who is ill. It has a distinct meaning from *oku-wona*, which means to heal or to cure. Staff emphasized the importance of this distinction at the youth workshop when telling youth that AIDS cannot be cured (*siliimu ta woona*), but that medications (ARVs) can keep it under control, therefore it was important that they take their medications daily as prescribed, even when they were feeling well.

[12] *Oku-bazayo* literally means "to return them there," or to return [children] to where they came from.

Baaliro maintained working relationships with a variety of other NGOs and health clinics/hospitals in the region. For a table summarizing these organizations, see Appendix E. For the purposes of medical referral, Baaliro worked (more or less closely) with several hospitals, clinics, and children's organizations in East Central Uganda, at times going as far as Kampala. From a funding and organizational perspective, Baaliro existed at the intersection of two larger organizations: St Damien's Health Care Services and Child Network (see Figure 2.2). In brief, Child Network was a European NGO, which supported several income-generating-activity and education focused programs in East Central and Northern Uganda, and Baaliro was one of the programs Child Network funded. St. Damien's self-identified as a grassroots HIV/AIDS clinic

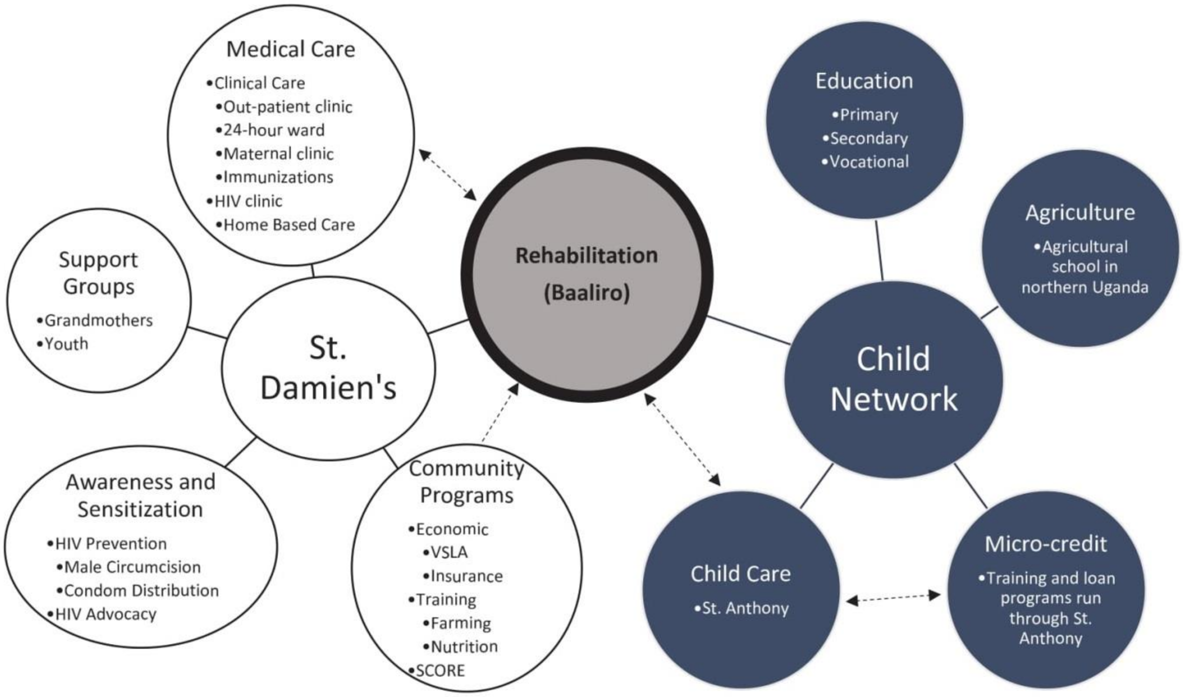

Figure 2.2 Organizational Matrix

This matrix depicts Baaliro (light gray) at the intersection of Child Network (dark gray) and St. Damien's (white). Dotted arrows represent movement of resources and/or clients between programs within an organization. Solid lines represent the formal connection between programs and their parent organization.

and service organization, and counted Baaliro among its many programs. The history, mission, and even daily operations of these organizations were separate, but also deeply intertwined, with Baaliro lying squarely at the intersection between them. To help untangle this complex networking, I will describe the background and current operations of these organizations, as well as my interactions with them.

2.1.2 Child Network – A European NGO

The history of Child Network dates back to 2002 when Julien, then a 16-year-old, came to East Central Uganda as part of a Swiss youth group that volunteered for two weeks at St. Anthony Child Care Center (St. Anthony), an orphanage sponsored by German citizens.[13] He returned the following year for six weeks and after returning to Switzerland from that trip decided to start raising funds to support the children at St. Anthony. By 2003, he had started an NGO which I call Child Network. In contrast to many faith-based organizations, Julien's philosophical underpinnings were completely secular. When I asked him about this he described his motivations for starting Child Network as defending his ideals of justice, adding that Bob Marley has influenced him more than Jesus Christ (email correspondence, January 30, 2017). Since his initial trip, Julien has returned to Uganda every year. Initially, he went for shorter periods (3-8 weeks), but later for longer periods (1-2 years) and in total he estimates that he has lived in Uganda for 6 years. Over this time, he has worked closely with a variety of local

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[13] Interestingly, St. Anthony was founded in 1974 by a Ugandan woman, when she adopted two children upon her return to her home country after more than a decade-long dance and drama career in Europe. Within two years, German volunteers began fundraising and financially supporting the "orphanage." Shortly after the founder's death in 1983, less than a decade after the founding of St. Anthony, one of the German volunteers took over administration of the organization, and it was not until 2005 that a Ugandan resumed the role of administrator.

children's service organizations and clinics, including St. Damien's and St. Anthony, as well as established Child Network and its many programs.

Child Network initially only sponsored children at St. Anthony orphanage and raised money through a variety of small fundraising events, such as concerts and bake sales, and by selling calendars and lighters. During this time, St. Anthony operated as it had since its beginning in the mid-1970's, by employing a traditional orphanage model where children stayed year-round at the institution and had minimal (if any) contact with their relatives. While this provided a structured, supportive, and even comfortable environment for children for the duration of their time at St. Anthony, it did not allow them to know or develop relationships with their family members or home communities.[14] This became problematic because once children who had grown up at St. Anthony graduated from primary school (typically around the age of 14-16 years) many had nowhere to go and nothing to do. St. Anthony continued to pay school fees for secondary education for those who had performed well in primary school, but the majority of children were left without support from St. Anthony once they left the institution. Without connections to their home community they lacked social support, and without job skills, they lacked a means of earning a living. Julien, along with St. Anthony's local staff, began to notice high rates of alcoholism, depression, and mental illness among St. Anthony graduates, which they perceived as being higher than among the general population, and which they attributed to the children's social isolation from their relatives and home communities. After witnessing the struggles of older St. Anthony graduates, Julien became convinced that children

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[14] Unlike the Western concept of orphans as having lost both parents and lacking families to care for them, as described in chapter 2, the definition of orphan in Uganda requires the loss of only one parent. Using this definition, the majority of orphans still have a living parent. Additionally, even those who have lost both parents in most cases have surviving relatives who take care of orphaned children. In recent studies of child care institutions in Uganda 64% of children living in institutions had at least one living parent (Walakira, Ddumba-Nyanzi, and Bukenya 2015), and 85% have living locatable relatives (Riley 2012).

needed to be connected to their communities and began to work toward a mission of not only directly supporting orphaned and vulnerable children but also supporting their families and ensuring that children maintained ties with their families and communities.

During its first five years Child Network grew substantially and was able to shift its fundraising strategies from concerts and calendars to attracting support from foundations, public funds, and individual donors – mostly from Switzerland. By 2008, Child Network established a microcredit program for vulnerable families in East Central Uganda (targeting those families whose children were staying at St. Anthony) and a scholarship program for children in Northern Uganda. Around this time, and with the collaboration of Child Network, St. Anthony changed its policies to encourage, and eventually insist, that children at the orphanage returned to their home villages over school holidays to reconnect with their families. This, in essence, made St. Anthony more akin to a boarding school rather than an orphanage, and in our communications Julien emphasized that he no longer considered St. Anthony an orphanage at all, since with the help of the microcredit program, St. Anthony returned children to living with family members as quickly as possible. However, St. Anthony still retained its original name, locally St. Anthony is still called an orphanage, and most of the children still stay at St. Anthony for five years – through the end of primary school (though they return home during school holidays). Fewer children were living at St. Anthony, and in 2014-2015, only three of the original six homes on the property were used to house children. The remaining homes were used as staff housing, for storage, and to house volunteers (either working at St. Anthony or other organizations in the area). Julien believed the success of Child Network's microcredit programs, in particular those affiliated with St. Anthony, demonstrated the efficacy of empowering families economically to care for their own children, and he cited this policy of empowerment as the foundation of all of Child Network's programs.

Most relevant for my research, in 2008 Child Network also began construction of Baaliro, and at the end of the year Baaliro opened its doors as a residential treatment center. Influenced by his experiences with St. Anthony, Julien emphasized that reintegration was always primary in Baaliro's mission.[15] In 2010, Child Network established a microcredit program in Northern Uganda and in 2012 constructed an organic agricultural training center in the same region. Meanwhile Julien graduated from The Institut Bioforce Développement[16] as Administrator for International Aid Projects in 2010 and received a Master of Advanced Study in Humanitarian Action (MAS) from Université de Genève (the University of Geneva, Switzerland) in 2014. Throughout his education, Julien remained directly involved in all of Child Network's programs, spending much of his time in Uganda and living at St. Anthony[17] until 2013, when he decided for personal reasons to return permanently to Switzerland. Since this time, his visits to Uganda have been shorter and less frequent, though he still comes for several weeks every year.

In his stead, Julien hired a program coordinator. The role of this individual was to live in Uganda, overseeing all of Child Network's programs and to communicate directly between Julien and Child Network's board in Switzerland and the individual programs in Uganda. Child Network's program coordinator is the only non-Ugandan on Child Network's pay-roll in

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[15] Interestingly, St. Anthony maintains a strict policy of not allowing any children infected with HIV to live on site.

[16] According to Bioforce's website, "as a school for those dedicated to humanitarian work, Bioforce proposes a range of professional training courses, certified by NGOs, centered on the two essentials: skills and *attitudes* for those wishing to join International Aid organizations" [emphasis added] (Bioforce 2016). Bioforce offered short (5-15 day) courses, certificate programs, diplomas, and master's degrees. Most courses are taught in French, a few are in English, and the school is based in Lyons, France.

[17] This was possible because both programs were designed for working professionals and involved only 3-6 months of coursework in Europe, with the rest of the time focusing on the students' individual field sites and projects.

Uganda.[18] All other program staff in Uganda are Ugandan, and the local staff have a great deal of autonomy in determining how to run their programs – though they must report back to Child Network's coordinator, who in turn reports to Julien and the board. During my 2014-2015 fieldwork, Child Network's new program coordinator was a young Swiss man who had been raised in South Africa. Julien met this project coordinator, Lucas, at Université de Genève while both were enrolled in the MAS program. I present both Julien and Lucas's education backgrounds to emphasize their explicit training in international norms of humanitarian action, a foundation which becomes important to understand their embrace of the concepts of sustainability and empowerment and their decisions to emphasize individual self-reliance.

Key points to take away from this history are 1) Julien has long been committed to helping orphaned and vulnerable children (OVCs) and 2) his motivations are secular. Also 3) based both on his on-the-ground experience of working with children who graduated from St. Anthony and his training in humanitarian action, Julian has come to believe strongly in the importance of caregiver empowerment. I discuss some of the consequences of this emphasis on empowerment, responsibilization, in more detail in Chapter 8.

2.1.3 St. Damien's Health Care Services – A Local NGO

The second organization with which Baaliro worked closely, and in many ways was actually a part of, is St. Damien's Health Care Services (St. Damien's). St. Damien's was founded in 1998 by a group of five Ugandans (including St. Damien's executive director who I call Thierry and Baaliro's program director who I call Sister Sally) as a healthcare organization dedicated to improving the lives of people infected and affected by HIV. The organization

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[18] Child Network also maintains a part-time staff in Switzerland.

started small with a handful of volunteers using rented space, but by 2014 St. Damien's had built a spacious and well-manicured multi-building compound and offered a wide variety of services which extended far beyond its physical grounds. Programs included clinical care, awareness and sensitization programs, grandparents and youth support groups, and community outreach programs. Through its services, St. Damien's attempted to mitigate the impact of HIV on clients at all life stages from infants to the elderly. Overall, St. Damien's services were targeted for HIV-positive clients and the prevention of HIV, but the medical clinic and maternity ward were available to any patient regardless of HIV status, and some of St. Damien's poverty reduction programs were open to HIV-negative patients. Here I discuss areas where Baaliro and St. Damien's programs intersected, but for a comprehensive list of St. Damien's programs see Appendix F.

To give a sense of the physical size of St. Damien's as well as the way in which Baaliro was physically contained within yet separated from St. Damien's and the ways in which children staying at Baaliro moved through St. Damien's, I map out St. Damien's structures and grounds (see Figure 2.3). St. Damien's grounds included several permanent and temporary structures. Permanent structures were the main clinic building, laboratory, and maternity ward. The main clinic building was immediately visible upon passing through the large steel gate, which importantly, was the only point of entry to the entire compound. Children staying at Baaliro passed through this gate on their way to and from school. The gate was open during daylight, but closed in the evening. Night watchmen remained within shouting distance of the gate to open it

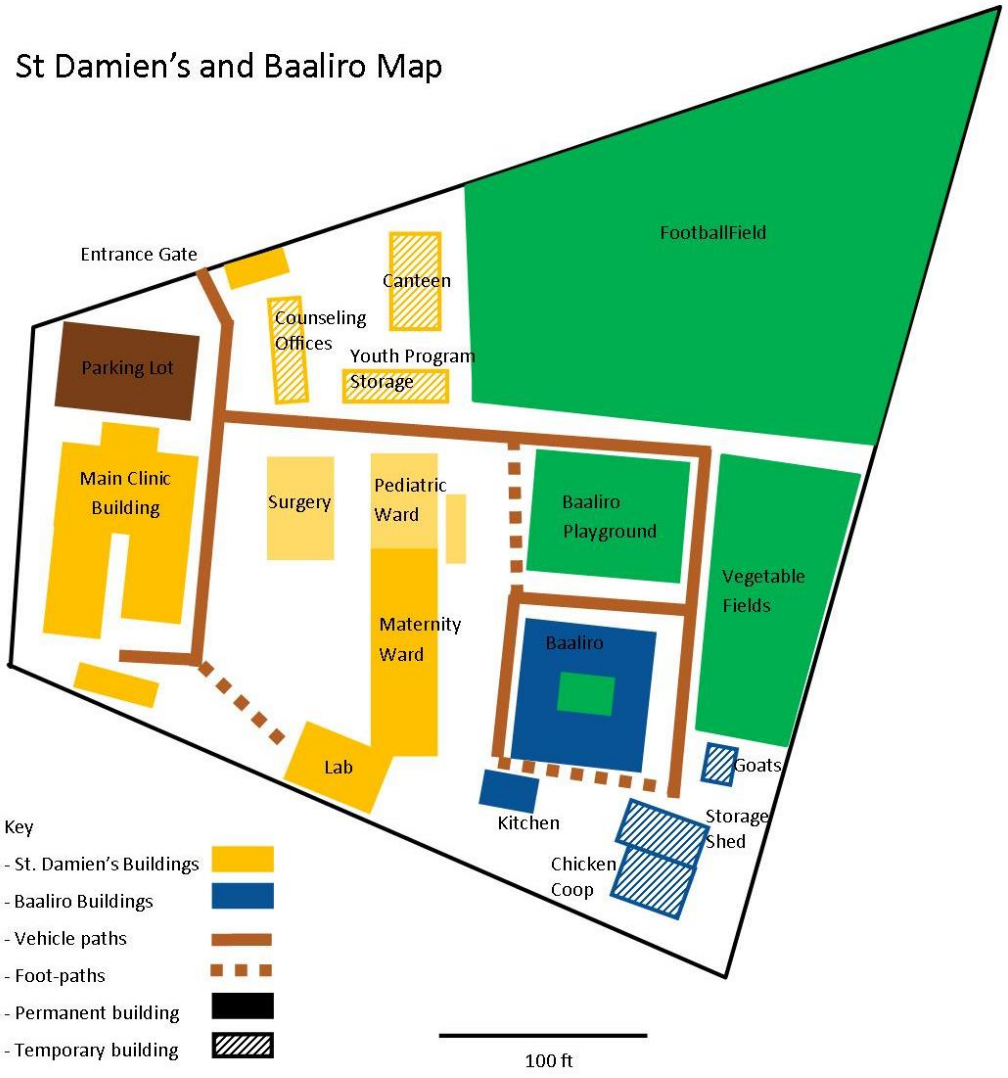

*Figure 2.3 **Map of Baaliro and St. Damien's Health Care Services***

The only way to enter the compound was via the main entrance gate. Map made using Google Maps satellite image as template.

in case anyone came seeking medical assistance after daylight since the clinic was ostensibly open 24-hours.[19]

The U-shaped clinic building had two hallways connected by the patient waiting area and a conference room forming the base of the U. Administrative and social services offices were along one hallway and clinic rooms lined the other, forming the arms of the U. Children at Baaliro received their medical care from St. Damien's main clinic. Baaliro staff would administer oral and topical medications at the center, but the children first needed to see a clinician for medical evaluation and then to receive their medications from the pharmacy, both of which took place at St. Damien's main clinic. When children staying at Baaliro were sent to St. Damien's for medical evaluation (which occurred whenever they reported or staff noticed a new symptom), they, like all patient seeking care, waited in the main waiting room before moving into the hallway, and ultimately to see clinicians in an individual clinical room. A separate room was used for injections and small procedures (such as draining an abscess). The pharmacy and the two inpatient wards were on either side of the open courtyard in the back of the building. Each inpatient ward (male and female) had only about 6 beds, and the wards were rarely full. When children were admitted at St. Damien's because they required more intensive care than Baaliro offered, such as an IV drip (most often for treatment of malaria), they stayed in the wards. HIV testing and ARVs were free for all clients at St. Damien's, but nearly all other medications and lab services had fees attached. When Baaliro children received medical care

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[19] The ability to staff the clinic for 24-hour operation depended on funding fluctuations. Additionally, though it remained open for 24-hour care throughout my 2014-2015 fieldwork, the clinician was often absent for an hour or more around the time of morning and evening shift changes.

from St. Damien's clinic/pharmacy, Baaliro was billed for the child's treatment/medications and Child Network paid the bills.[20]

The lab was a standalone building, impressively located at the far end of a field next to the clinic. After seeing a clinician, patients often had to go to the lab and then wait for their results to be processed. Children staying at Baaliro could return to Baaliro while waiting for their results, but most patients waited on concrete benches along the exterior veranda of the buildings. In addition to offering standard lab tests such as blood counts, kidney and liver-function tests, and tests for common infections such as typhoid and malaria, the lab also offered HIV testing, and most importantly, CD4 counts. [21] CD4 counts were used to track a patient's physiological response to ARVs as well as their adherence. Although viral-load is a more accurate indicator of the viral response to ARVs, viral-load testing was only available at a few HIV treatment centers at the time of my research.[22] Baaliro paid for all of the reagents used for CD4 testing at St. Damien's lab.

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[20] Overall user fees were small, and accounted for only a fraction of the cost of the medication or testing if a client were to have accessed services from a private pharmacy or for-profit clinic. However, user fees were a main point of contention between St. Damien's and its donors, as well as its clients. St. Damien's board argued that user fees were vital to ensure that clients were invested in their care and to cover funding gaps. They pointed to how user fees had allowed the clinic to stay open from January to June 2014, a period when "USAID cut ties with the Inter-Religious Council of Uganda due to the IRCU's support to the anti-homosexual [law]" (board meeting notes, August 9, 2014). The IRCU was, at that time, one of St. Damien's primary supporters. In contrast, however, both staff and clients hypothesized that one of the reasons St. Damien's maternity ward was so underutilized for deliveries despite the high utilization for antenatal care, was the 100,000UGS (roughly $40) delivery fee. Additionally, clients taking ARVs were frequently over-due for CD4 count testing because that test had a 10,000UGS ($4) fee attached.

[21] A CD4 count is lab test that measures the number of CD4 T-lymphocytes (CD4 cells) in a sample of blood. In people with HIV, it is the most important laboratory indicator of how well the immune system is working and the strongest predictor of HIV progression. A normal range is 500-1,600 cells/mm^3. A count of less than 200 is AIDS defining (aids.gov 2016).

[22] Viral-load also responds much more quickly to medications, whereas the CD4 count can take months, or even a year, to respond. As several of the cases in this dissertation depict, clinicians had to wait for 3-6 months to see if a child's CD4 count responded before changing their treatment regimen.

Next to the lab and stretching along the long end of the field was the maternity ward. The maternity ward was built in 2012, and included two large wards (each able to hold six to ten women) and a smaller delivery suite. The construction of the wards as well as the medical equipment they contained came from donations raised from former international volunteers. Several days a week pregnant women and new mothers lined up along the concrete benches built into the outside of the maternity ward to await antenatal care and/or infant immunizations. Despite the impressive turnouts for antenatal care, few women actually delivered at St. Damien's, and the maternity wards had no more than two to three patients at any given time. Even with this underused clinic space, during my fieldwork, St. Damien's completed the construction of a pediatric ward and started construction on a surgical unit. Thierry had ambitious visions of St. Damien's growing into a fully self-sufficient health center (an HC-IV), so that they would not need to refer patients out for any testing or treatment, and donors seemed eager to support the construction of new buildings (though they were less willing to pay for the staff salaries or utilities needed to run them).

The temporary structures at St. Damien's were all arranged around a second, smaller field and included four shipping containers turned into offices and a wood-plank canteen. Two of the shipping containers (set end to end) were used as offices for clients to meet with counselors during ARV clinic days, held twice a week. These offices were far from sound-proof, but offered at least some privacy for the personal questions counselors asked. Most of the children at Baaliro accessed ARVs through St. Damien's ARV clinic, and St. Damien's assigned them both an ARV clinic number and a counselor for formal discussions of disclosure and adherence.[23] When staff at Baaliro determined that it was time for a child to be disclosed to (i.e. to be told that he/she was

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[23] Some children continued to access ARVs from their original provider – most commonly TASO, JCRC, and ECCH (see descriptions of these under "other organizations").

HIV-positive), Mary (the social worker) would send the child to meet with his/her counselor in these containers. Although children had ostensibly been assigned a counselor and been meeting with their counselors since starting on ARVs, children frequently reported that their disclosure meeting was the first time they met their counselor.[24]

The second pair of containers formed the second side of the roughly square field and was used to store materials for the Saturday youth program, including a library of books and several computers.[25] Although children staying at Baaliro attended the Saturday youth program and stayed within sight of the containers, they did not have access to the program's library books or computers outside of the Saturday programming.[26] The canteen with a concrete floor, wood-plank walls, and a corrugated iron roof formed the final side of the square. All of the staff at St. Damien's, most of the staff at Baaliro, and volunteers received lunch in the canteen either for free or at reduced prices, depending on the funding in any given year. Portions were sumptuous, and staff agreed that the food was good quality, well prepared, and had enough variety. Additionally, the canteen served as the meeting point for the Saturday youth group. Except on rare occasions, Baaliro children only ate at the canteen on Saturdays when the canteen prepared the food for the youth group. If it rained on a Saturday, the youth group met inside the canteen, but because of the noise of the rain pounding on the corrugated iron roof, the organizers' lesson plans were often interrupted.

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[24] Many caregivers assumed that Mary was the children's HIV counselor, and Sister Sally insisted that Mary could disclose to children with the assistance of a book that guided the disclosure discussion. However, Mary herself claimed that she did not have adequate training, I never saw this disclosure book (though I inquired about it several times), and Mary always sent children to one of St. Damien's counselors for their initial disclosure.

[25] Both books and computers had been donated by foreign volunteers and youth groups.

[26] Additionally, even the children who attended the Saturday program had very limited access to the books and computers. The reasons given for this were that supplies and books had historically gone missing or been damaged when children were granted access without direct adult supervision, and often there was not enough staff to supervise.

In addition to their on-site services, St. Damien's organized a wide array of community based services. St. Damien's staff regularly traveled out to more rural areas for economic and educational programs, for HIV sensitization and testing, and to deliver community-based care to HIV-positive clients. For community-based care St. Damien's staff drove to centralized meeting sites so clients did not have to travel as far to pick-up their ARVs, but many still had to arrange transportation to reach the pick-up sites. These services were especially important for Baaliro, because many of the HIV-positive children at Baaliro were identified by staff during these outreach programs. Additionally, Baaliro had an easier time monitoring reintegrated children who lived along one of St. Damien's community-based care routes because St. Damien's staff saw them monthly. Many of the HIV-negative malnourished children enrolled in Baaliro's program were identified via St. Damien's involvement in the SCORE program. SCORE stands for Sustainable and Comprehensive Responses for Vulnerable Children and their Families. This program was supported by a consortium of foreign and national NGOs and development organizations in partnership with USAID. The SCORE consortium worked with local service organizations to implement their program which targeted "critically vulnerable children and their households."[27] St. Damien's was one of the local service organizations participating in the SCORE program and did many additional outreach activities as part of SCORE.

St. Damien's counted Baaliro as one of its programs, though all of the funds for Baaliro came from Child Network. The organizations were further enmeshed because Baaliro was physically located within St. Damien's larger compound, behind St. Damien's maternity ward on land leased by St. Damien's, yet was built with funding from Child Network. In order to access Baaliro, it was necessary to pass through St. Damien's main gate and walk past several of St.

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[27] For a greater discussion of vulnerability see Chapter 2.

Damien’s buildings and down a short path. However, once there, Baaliro was relatively cut-off from the rest of St. Damien’s. Baaliro was separated from the maternity and pediatric wards by a tall hedge running along the back side of the wards, and the only way between St. Damien’s and Baaliro was via a gravel driveway connecting the two. Although relatively flat, the landscape sloped gently “down” from St. Damien’s main clinic toward Baaliro, and thus people used the shorthand of going “up” [to St. Damien’s] and “down” [to Baaliro]. Generally speaking, children staying at Baaliro only went “up” for medical treatment, to attend the Saturday youth group, for special functions (such as the monthly mass or the annual general meeting), and to pass through on their way to school. Some of Baaliro’s staff frequently went “up” to access the internet and for staff meetings; however, St. Damien’s staff rarely, if ever, came “down.”[28]

To add to the physical and programmatic enmeshment of Baaliro and St. Damien’s, Baaliro paid the salaries for several of St. Damien’s staff members (including two midwives and a doctor), yet St. Damien’s paid the salary for the driver who drove the social worker to her follow-up visits. Nearly all of Baaliro’s staff were expected to attend St. Damien’s staff meetings. Lastly, Baaliro’s bank account was a sub-account of St. Damien’s, meaning that any large purchases had to be approved and co-signed by either St. Damien’s executive director (Thierry himself) or the accountant. However, until recently, St. Damien’s was actually not allowed to raise funds for Baaliro, so all of the money in Baaliro’s account came from Child Network (for a more detailed discussion of this peculiar fundraising policy see Chapter 8).

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[28] Baaliro staff cited this as an indication of the stigma HIV-positive children faced. They explained, if the supposedly well informed and discrimination-sensitive staff of St. Damien’s would not even interact with the children at Baaliro, less-well informed members of the community were expected to be even less accepting of HIV-positive children. While there is some resonance to this observation, it is notable that I rarely saw adults play with children in Uganda and while Baaliro’s staff had several reasons to go “up” to St. Damien’s (internet access, food at the canteen, staff meetings, etc.), St. Damien’s staff had little or no reason to go “down” to Baaliro.

Despite this interconnectedness, in many ways Baaliro functioned independently of St. Damien's. Baaliro staff meetings did not include St. Damien's staff, and recall that overall St. Damien's staff rarely visited Baaliro. Baaliro reported directly to Child Network regarding its finances and programing decisions. From the children's perspective, St. Damien's was the clinic they went to when they were acutely ill and for the Saturday youth group, but otherwise they stayed at Baaliro, and they ate Baaliro food, not St. Damien's food.

The overlapping relationship between Child Network and St. Damien's at times led to tensions among Baaliro staff. For example, Sister Sally was responsible for making the nursing schedule. Although it stated in their contracts that the midwives, whose salaries were paid for by Baaliro, were supposed to be preferentially assigned to Baaliro's programs, the other nurses complained when Sister Sally did so, and often Baaliro's midwives were pulled away from their duties at Baaliro for duties at St. Damien's. Another example of these tensions is that, shortly before I arrived in 2013, Child Network purchased a new vehicle for Baaliro's social worker, Mary, to use when doing follow up visits, but the vehicle was frequently co-opted for St. Damien's programs. Over the course of my fieldwork, I lost count of how many times a trip to the field with Mary was canceled due to "issues with transport" – almost always an oblique reference to the truck being used for one of St. Damien's programs. When Sister Sally complained about these issues to the human resources director of St. Damien's, she was accused of "personalizing" resources. Lucas saw Baaliro as a separate organization in partnership with St. Damien's. He believed Baaliro should make its decisions independently from St. Damien's, and became very frustrated by these issues. However, Julien later clarified that he viewed Baaliro as a program of St. Damien's which received sponsorship from Child Network, similar to the way St. Damien's grandmothers support groups received funding from the Stephen Lewis

Foundation. I emphasize the separate and yet enmeshed relationship of Baaliro and St. Damien's, both because it is an important descriptor of my field site, and because it demonstrates the complexity of inter-organizational and donor relationships which I explore more fully in Chapter 8. Given the complexity of the relationship between Baaliro and St. Damien's, even though Baaliro was my primary field site, it was not possible for me to ignore St. Damien's.

Additionally, St. Damien's was my original access to Baaliro. I first came to Uganda during the summer of 2006 to complete fieldwork for my undergraduate honors thesis in anthropology. Through a friend of a professor, I was introduced to Thierry and a few months later, with funding from the Institute for Scholarship in the Liberal Arts and the Glynn Family Honors Program, both at University of Notre Dame, I found myself at an HIV/AIDS organization (at that time) tucked behind a large open-air market just across the river from Jinja. St. Damien's had had many volunteers since their founding in 1998, but never an anthropology student, so I was quickly labeled a volunteer.[29] Interested in the relationships between maternal mortality, HIV, and malaria, I sought to interview pregnant women about their concerns for their pregnancies. Unfortunately, the antenatal program at St. Damien's had not yet completed its gestation, and I was only able to interview one pregnant woman that summer. Nonetheless, I completed my thesis and I remained in touch with the staff at St. Damien's, in particular Thierry, who updated me about the organization's progress. I was particularly interested when I heard of the construction of a children's rehabilitation center in 2008.[30] Six years after my initial visit, during the summer of 2012, I returned to begin conducting my preliminary research at Baaliro. I

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[29] While I discuss my more nuanced role in chapter 3, the label of volunteer has stuck with me among St. Damien's staff since that time.

[30] Notably, Thierry described Baaliro as one of St. Damien's new programs, and at the time I had no idea that Child Network even existed. Julien says he remembers meeting me in 2006 during my first trip to Uganda, but I confess that I do no recall meeting him during that time and was completely unaware of Julien's NGO.

returned in 2013 and in 2014. I lived at Baaliro for ten months from September 2014 to June 2015 with support from a Fulbright Student Award (Institute of International Education) and a Lamda Alpha Graduate Research Grant, and I returned in September 2015 for a few weeks. Between 2012-2015 I spent 15 months cumulatively in Uganda, with a little more than ten months living at Baaliro itself, four months living with host families, and one month living at St. Anthony.

2.1.4 Other Organizations

In addition to St. Damien's, Baaliro maintained a close relationship with several other healthcare organizations (see Appendix E). The most important was the East-Central Children's Hospital (ECCH), especially the ECCH Malnutrition Clinic and Ward. Child Network paid a bonus to a nutritionist on staff at ECCH. As will be discussed in more detail in Chapter 7, this relationship was important for facilitating children's access to care at ECCH, as well as in increasing referrals from ECCH to Baaliro. Since ECCH was the government funded regional referral hospital, it was the first point of referral when a child at Baaliro needed more intensive care than Baaliro could provide. However, at times ECCH was unable to provide necessary medical services – for reasons such as being out of stock of blood for transfusions, lacking equipment/technicians for x-rays or ultrasounds, or clinicians being on strike – and in such instances Baaliro utilized one of the pricey private clinics in the city. Baaliro also maintained a working relationship with The AIDS Service Organization (TASO),[31] where several of the children at Baaliro accessed their ARVs and TB treatment, and from which Baaliro frequently

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[31] NOT a pseudonym. There a numerous TASO offices and clinics throughout Uganda in almost every urban center. TASO is extremely well known nationally as well as internationally. For a variety of perspectives on TASO see Coutinho (2006), Grebe (2014, 2016), and Kleinman et al. (2011).

received referrals. Lastly, five of the children in Baaliro's program received their ARVs from the Joint Clinical Research Center (JCRC)[32] pediatric clinic in Lubowa (a suburb of Kampala). The JCRC clinics were widely considered the premier treatment centers for HIV/AIDS and had testing and treatments (especially ARVs) that were not available anywhere else in the country. Baaliro only took children to JCRC when they were extremely ill, as it was their last line of defense, and very expensive.[33] In the past, St. Damien's did not have access to second line ARVs, so Baaliro had to bring children to JCRC more frequently. Luckily, all of the children enrolled at JCRC during my fieldwork had stabilized medically and were only required to attend the ARV clinic every three months. These trips were expensive because they required Baaliro to hire a private driver and vehicle that could carry all five children and an accompanying staff member to Kampala. Baaliro was in the process of transferring children from JCRC to St. Damien's in order to lessen this burden. However, once children were enrolled at JCRC, Baaliro had a difficult time convincing JCRC staff to transfer children back to St. Damien's, even though St. Damien's now had access to second line medications. In addition to these named organizations, Baaliro also occasionally received children referred to them for treatment from other HIV-organizations or children's homes (some as far away as Kampala, Pallisa, Busia, and Tororo).

The main purpose of introducing all of these organizations, other than because I refer to them at various points throughout this dissertation, is to demonstrate how Baaliro was situated

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[32] NOT a pseudonym.

[33] Staff at JCRC assured me that outpatient treatment was free to all children, and that inpatient treatment was free to children who came on their own. However, inpatient care was not free for children who came from "an organization" (i.e. an NGO or an orphanage) or who arrived with a "private donor" (i.e. were accompanied by a foreign person). JCRC staff explained that the organization or private donor was responsible for paying inpatient treatment fees, which in Baaliro's experience often amounted to millions of shillings (hundreds of dollars) for only a few day's stay. In comparison, Baaliro's total annual budget for "referrals" (all medical care outside of St. Damien's) was 9 million Uganda shillings ($3,600).

within a network of medical and service organizations. Not only was Baaliro positioned at the intersection of a grassroots NGO and an international NGO, but also it relied on maintaining good relationships with other service providers including government hospitals, private clinics, and children's homes. These organizations had a long history of interaction and often formed complex networks of relationships among themselves. This, in essence, exemplifies the local projectified landscape of HIV treatment which children, caregivers, and staff navigated in their quest for care.

2.2 The Children of Baaliro and Their Caregivers by the Numbers

For the second half of this chapter I provide the demographics of the children and caregivers enrolled at Baaliro. In subsequent chapters I will provide a more in depth and qualitative presentation of the children at Baaliro; however, in this chapter I limit myself to a numerical and statistical analysis, and to comparisons with data from the national census and another study of children living with HIV in Jinja. While I recognize the many problems of reducing complex and individual stories, especially those of children, down to numerical representations (Hecht 1998; Hunleth 2013), I nonetheless find demographic data helpful to make comparisons (such as with national averages), for contextualization (such as how far the social worker traveled to visit children), and to support general claims (such as claims that most children lived with female caregivers) (Chibnik 1985). Additionally, when presenting my research, questions of the children's and caregiver's demographics always seemed to dominate discussion until I addressed them. Baaliro staff had generated the hand-written case files as part of their record keeping and had requested help in completing an electronic database. In order to more easily analyze the children's demographic data, I completed an excel database which contained all of the information in the children's case files.[34] While staff did not analyze the data in the same way that I present it here, they felt it was important to keep track of the children's demographics, and utilized the database (once completed) to generate the reports they provided to donors (namely Child Network).

2.2.1 Demographics of Children Enrolled in Baaliro's Program

Since opening at the end of 2008 until September 2015, Baaliro enrolled 188 children in its program. Children came from 141 different villages scattered across 19 districts in central and eastern Uganda, with most coming from seven districts (Buikwe, Iganga, Jinja. Kamuli, Kayunga, Mayuge, and Mukono) (see Figure 2.1). Most children lived on the mainland, but five children lived on islands in Lake Victoria. Islands are excluded from time and distance analysis because Mary never visited children on the islands. The ferries to these islands ran only once a day, so a visit would have involved spending the night on the island. Similarly, when children from the islands came to receive their ARV refills, they had to spend the night on the mainland before returning home. The social worker never visited certain children who lived too far away, and only visited some children once a year. I was able to estimate the travel time for 127 villages and distance for 124 villages. I estimated distance using Google Maps and travel times based on the time it took the social worker to reach the child's home for follow-up visits. The social worker used a privately driven four-wheel-drive pickup truck, so the time it would take children and caregivers to reach Baaliro using public transportation was considerably longer. Travel times and distances varied drastically from less than one kilometer/five minutes to 370km/four hours, with an average travel time of 66 ± 51 minutes and an average travel distance of 41 ± 33 km.

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[34] A volunteer had started this project at the request of the staff at Baaliro, but only had time to enter the first few children's information.

Most (n=151, 80%) children came from rural communities, with only 6 children coming from Jinja Municipality, 19 from Njeru Town Council, and 12 from other municipalities (including Kamuli, Busia, Lugazi, and Kampala). Thus, similar to the national statistics, 80% of the children enrolled in Baaliro's program came from rural areas.

Nearly three quarters (n=137, 73%) of children enrolled in Baaliro's program were HIV-positive. Because HIV-negative children were not the original target of Baaliro, nor the focus of this dissertation, and because HIV-negative children tended to differ from HIV-positive children in many ways, I will focus on the demographics of HIV-positive children in this section. For a comparison between HIV-positive and HIV-negative children see Appendix H.[35]

The average age at enrollment among HIV-positive children at Baaliro was 9.7 years (see Table 2.1). The children were evenly split between males (50%) and females (50%). Twenty-two of the children were related to one another, with ten sibling pairs (including one pair of twins) and one pair of cousins (their mothers were sisters). Children were either initially enrolled as inpatients (87%) or outpatients (13%). Outpatients received medical treatment and school-fees support from Baaliro, but the children did not stay at Baaliro.

The flowchart (see Figure 2.4) depicts how children's program category within Baaliro could change over time, and represents HIV-positive children's categorization as of September 2015. Children who were enrolled as inpatients stayed at Baaliro until they were transferred to another institution, were reintegrated, or died. Once reintegrated, Mary began following children and, over time, some children were lost to follow-up, died, were declared adults, or were transferred to another institution. The process by which children were declared adults is discussed in more detail in Chapter 8. Lost children sometimes returned to the program, or

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[35] For a discussion of how and why increasing numbers of HIV-negative children were being enrolled in Baaliro's program see Chapter 8.

Table 2.1 Demographics of HIV-Positive Children Enrolled in Baaliro’s Program

Age at enrollment (mean years ± SD[1])		9.7 ± 4.8		(n=137)
Gender (n, %)	Male	69	50%	(n=137)
	Female	68	50%	
Enrollment (n, %)	Inpatient	119	87%	(n=137)
	Outpatient	18	13%	
Program Category (n, %)	Being Followed	75	55%	(n=137)
	Dead	28	20%	
	Adult	12	9%	
	Transferred	11	8%	
	Inpatient	9	7%	
	Lost	2	1%	
Average Time Spent Inpatient (mean days ± SD)		248 ± 255		(n=113)[2]
Median Time Spent Inpatient (days)		181		
School Attendance (n, %)	Attending	73	68%	(n=107)[3]
	Not Attending	34	32%	
Reasons for Not Attending School (n, %)	Underage	12	35%	(n=34)
	Dropped-out	13	38%	
	Adult	3	9%	
	Other[4]	6	18%	
Years Behind in School (mean years ± SD)		5.8 ± 3.1		(n=107)[5]
Orphan Status[6] (n, %)	Maternal Orphan	20	16%	(n=128)
	Paternal Orphan	29	23%	
	Double Orphan	40	31%	
	Non-Orphan	39	30%	

[1] *Standard Deviation*

[2] *Outpatients are excluded from this calculation. In addition, this does not include the eight children who were on their first admission (being treated inpatient and having never been reintegrated) nor the additional days rebounded for the three children who were on their second admission as of September 2015.*

[3] *School Attendance excludes children who were dead or lost.*

[4] *Other includes sick, mental disability, and graduated. Two children fell into each of these categories.*

[5] *Data include children who died or were lost, based on years of school attendance and age at time of death/loss. Those children who had never attended school because they were underage (n=12) or had a mental disability (n=2) were not included in this calculation. Data were missing for 16 HIV-positive children.*

[6] *Recall that single orphans are defined as children who have lost only their mother (also called maternal orphans) or only their father (also called paternal orphans), and double orphans are defined as children who have lost both parents.*

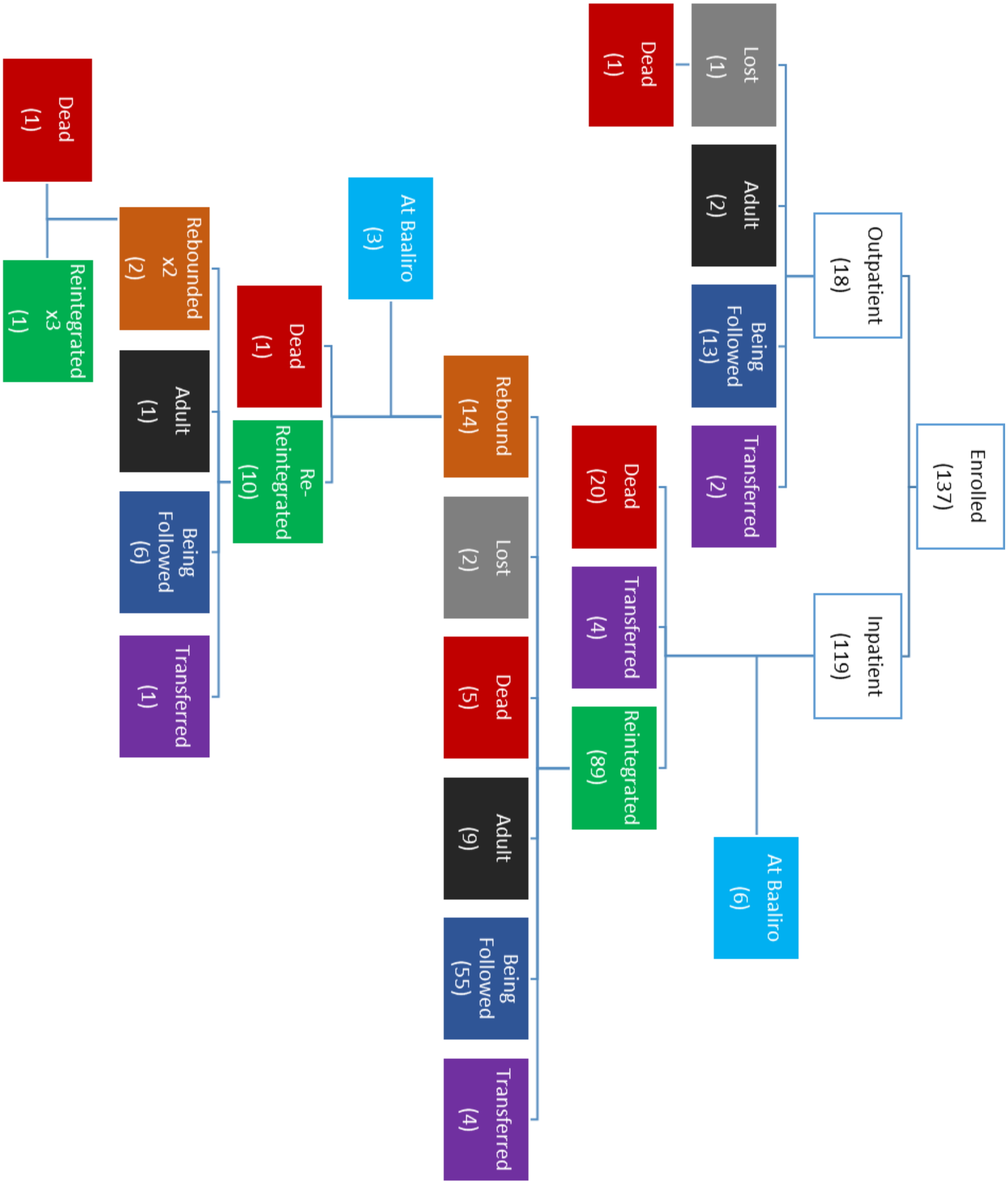

Figure 2.4 Flow Chart of Categorization of HIV-Positive Children in Baaliro's Program
It is possible to follow children's pathways from enrollment (dating back to 2008) to their current program category (as of September 2015) via this flowchart. The number of children in each category is indicated in parentheses. This flowchart only depicts HIV-positive children. For a flow chart depicting all children ever enrolled in Baaliro's program see Appendix H.

Baaliro at times received news of their deaths and their status would change to “being followed” or “deceased.” Since outpatients did not stay at Baaliro, immediately upon enrollment in Baaliro’s program, their status was “being followed.” Like reintegrated children, outpatient children’s status could change over time to lost, dead, adult, or transferred. In addition, sometimes children rebounded (i.e. were re-admitted to Baaliro) because their health deteriorated after reintegration.[36] Once they rebounded, children began the rehabilitation process again. Two children rebounded for a second time after being re-reintegrated. In total, Baaliro reintegrated 89 HIV-positive children.

As of September 2015, out of 137 HIV-positive children ever enrolled in Baaliro’s program, staff were actively following just over half (55%), and one in five (20%) children had died. The range for time spent inpatient varied considerably from less than 24 hours to five years. However, the majority of the children (72/131 [55%]) spent less than eight months inpatient and fewer than one in ten (9/131 [7%]) spent more than 18 months inpatient (see Figure 2.5). Most of the HIV-positive children who died, passed away while they were at Baaliro (22/28 [79%]) (see Figure 2.4).[37] Among those 20 HIV-positive children who died at Baaliro without ever having been reintegrated, their average stay was just over two months (64 days). Two children died within 24 hours of being admitted to Baaliro, and 40% (8/20) died within four weeks of being admitted. Staff attributed the death of children who were in their care to the child being too sick

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[36] Interestingly, no children enrolled as outpatients had ever rebounded. I interpret this as an indication that outpatient children were generally less sick than those enrolled as inpatients, keeping in mind that half of outpatients were HIV-negative vs. only 22% of inpatients.

[37] Keeping in mind that Baaliro had limited treatment capacities on site, children did not necessarily die at the rehabilitation center itself, but more frequently were admitted to a nearby hospital or clinic where they died. These children still counted as being at Baaliro, because they were still under Baaliro’s care and had not been reintegrated at the times of their deaths.

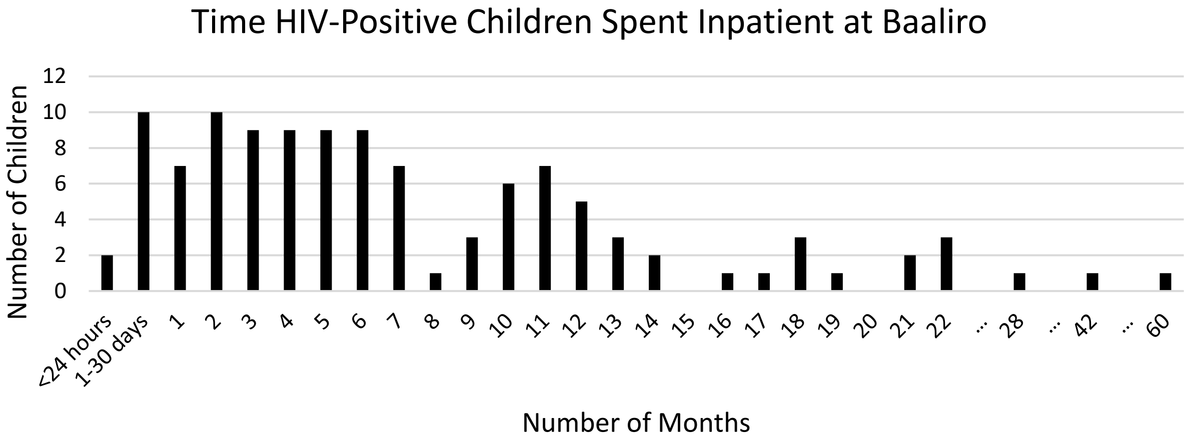

Figure 2.5 Time HIV-Positive Children Spent Inpatient at Baaliro
Children who were enrolled as outpatients (n=18) or were on their first admission to Baaliro as of September 2015 (n=6) were excluded, therefore the total number of children included for time spent inpatient is N=113. Additional time spent inpatient during a rebound was included for children who had been re-reintegrated (n=10), but was not included for children currently at Baaliro for their first rebound (n=3). Time spent inpatient was originally calculated in days, and then lumped into months using 30-day increments. Data include children enrolled from December 2008-September 2015.

upon admission to save.[38] They also pointed out that there had been many more deaths in the past, but in recent years far fewer children were dying (between 2010 and 2012, 19 HIV-positive children died, but between 2013 and 2015 only nine children died and only four died without being reintegrated). Baaliro staff explained this progress was because they were now well known by community health workers and local clinics, so they were receiving children before they became desperately ill. They also pointed out that in recent years when children died it was either due to parental and/or child refusal of treatment (sometimes after a child had been reintegrated and healthy for several years) or a complex medical problem like a heart condition or cancer. The cause of death was not recorded in the files, but the most commonly recorded contributing medical condition among deceased children was TB (n=6).

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[38] Adrienne Strong found that nurses in Tanzania told a similar story about women who died on maternity wards, claiming that they had arrived at the ward too late to be saved (Strong 2017). In her research, Strong was able to demonstrate that the claims were not backed up by the maternal mortality data; however, in my research the data seem to support Baaliro's staff claims.

2.2.2 Baaliro Children's Education

In 2015, 73 (68%[39]) HIV-positive children were attending school, and Baaliro paid school fees for 64 of them. Those children not receiving fees from Baaliro either received fees from another organization (n=6) or were self-funded (n=3). There was no difference between boys and girls in their likelihood to be attending school (40/56 [58%] for boys, and 33/51 [49%] for girls, $\chi^2(1, N = 107) = 0.56, p = 0.46$). The most common reasons for HIV-positive children to not be attending school was that they had dropped out (38%), or were underage (35%) (see Table 2.1). Additional reasons for HIV-positive children to not be attending school were that they were categorized as adults,[40] had graduated from school,[41] were too sick to attend, or had a mental disability which precluded their enrollment in school.

All but two of the children enrolled in Baaliro's program were over-age for their grade in school – meaning they were in a grade level or more below what would be predicted based on their chronological age. On average, the HIV-positive children enrolled in Baaliro's program were 5.8 years over-age for their grade in school (see Table 2.1). This statistic is less shocking considering that in 2006 (the most recently available reports) 79-86% of Ugandans enrolled in primary school were one or more years over-age for their grade level and 55-67% were two or more years over-age for their grade level (EPDC 2009; Huebler 2011). Another way to identify over-age students is the comparison of gross vs. net enrollment. Gross enrollment includes over- and under-age students,[42] whereas net enrollment only includes school-age students (for primary

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[39] All calculations of school attendance exclude children who were dead or lost as of September 2015.

[40] Again, for more discussion of the process of declaring a child as an "adult" see Chapter 8.

[41] Children were counted as having graduated if they had received some kind of graduation certificate for vocational training and as having dropped-out if they stopped schooling without a certificate. As of yet, none of the children supported by Baaliro had entered university.

[42] Though based on the previous statistics, most of these will be over-age.

school 6-12 years old).[43] The gross enrollment for Uganda is 110% vs. the net enrollment of 91%, indicating that roughly one in five children in Ugandan primary schools are over the age of 12 (EPDC 2014). Unfortunately, the average age of primary school students in Uganda was not reported. Children may be over-age due to late entry (i.e. starting school a year or more late), repeating grade levels, and/or taking time away from school due to sickness, civil unrest, or economic hardships. While children who are over-age are either equally or more likely to be promoted in early primary grades, they (especially those two or more years over-age) are much less likely to complete primary school (EPDC 2009). In Uganda, an average of 9.6% of primary school students repeat their grade level each year and just over half of students complete their primary education (54-58%) (EPDC 2014; UBOS 2016).

Among the children who were staying at Baaliro, those who were old enough (usually six years old and older) and well enough were supposed to attend a community school just beyond the main entrance to St Damien’s. However, for a variety of reasons, some children did not go to school while they stayed at Baaliro. First, the academic standards of this peri-urban school were relatively high compared to those of the rural schools from which many of the children came, and older children often could not keep up with their grade-level peers. In some cases, children entered a lower grade, but more frequently, especially for older children, they did not attend school while they were staying at Baaliro.[44] Second, some children, despite considerable

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[43] The Uganda education system, originally established under British colonial rule, begins at age six and has seven levels of primary education (P1-P7) and six levels of secondary education (S1-S6). Students take national qualifying exams at the end of P7, S4 (also called O-levels) and S6 (also called A-levels), which they must pass to move on to the next level of education. After S6, qualifying students can advance to university or other tertiary education programs.

[44] If a child only needed to drop back a single grade level, often he/she would attend school. But more frequently, for example, a child in P6 in their rural school would be pushed back to P3 and still be unable to keep up with the coursework. It was both a waste of school fees and demoralizing to the child to be pushed so far back, so both children and staff would agree to wait to resume schooling until the child was reintegrated.

encouragement and prodding, simply refused to go to school. While the staff highly valued education and made many attempts to get children who were well enough to attend school, they also recognized that they could not force a recalcitrant child to go to school if he/she did not want to go.[45] In most cases, children who refused to attend school at Baaliro wanted to attend school once they were reintegrated. When asked why they were refusing to study, they would simply say, "Saagala kusomera wano" [I don't want to study from here [Baaliro]]. [46] Additionally, staff did not want to waste either the time and energy or the school fees on a child who would make a scene of refusing to go to school every morning.[47] Third, the timing of a child's arrival at Baaliro sometimes delayed their enrollment in school. While nursery-school children were accepted year-round, older children faced a difficult transition if they entered school partway through the second or especially the third term. Thus, Baaliro sometimes delayed starting children in school until the new academic year started in January. Finally, children who had an infectious condition (namely *tinea capitis,* but also active TB) did not attend school, because Baaliro staff did not want to be held responsible for bringing the infection to the school. Often these children were too sick to attend school anyways, but staff evoked the infectious condition as an additional reason to keep them confined to the center.

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[45] In one example, after they found a then 6-year-old boy who had been refusing to go to school sitting by the side of the busy highway by himself staring at cars as they whizzed past. After this experience, they decided it was better to not force children who did not want to go to school to study while they were at Baaliro.

[46] I was not able to obtain a more detailed explanation from the children, but for further discussion of the importance of refusal (to go to school, to eat food, to take medicine, etc) as a form of agency and resistance see Chapter 6.

[47] Concerns over not wasting school fees on children who did not want to go to school or were failing were also exacerbated by the budgetary issues discussed in Chapter 8.

2.2.3 Demographics of Caregivers of Children Enrolled in Baaliro's Program

Information on caregivers was not as well recorded as that of children. Information on the caregiver's age, HIV status, and education were available for less than 30% of caregivers. However, nearly all case files included whether the child's biological parents were living or deceased (at the time the child was enrolled in Baaliro) and listed at least one caregiver and his/her source of income. Among HIV-positive children, 16% had lost their mother, 23% had lost their father, and 31% had lost both parents, making 70% orphans, with 39% single orphans and 31% double orphans (see Table 2.1).[48] Similarly, a recent study of 394 HIV-positive children in Jinja district, reported 67.8% of the children were orphans, with 53.9% of those single orphans and 46.1% double orphans (Kajubi, Whyte, et al. 2014, 2). This is much greater than Uganda's national average rate of orphanhood which is 8% (UBOS 2016).

Among the HIV-positive children enrolled in Baaliro's program, one or more parents were listed as the primary caregiver only 45% of the time, with grandparents (23%), aunts and uncles (22%), and siblings (4%) making up the remainder of relatives caring for children at Baaliro (see Figure 2.6). This means that the majority of children (55%) did not have a biological parent as their primary caregiver. This rate is greater than that reported by Kajubi and colleagues in their studies of HIV-positive children in Jinja district which found that 49-52% of children were not living with their biological parents, and is even more extreme when compared with national and regional statistics in Uganda which ranged between 15-21% (Kajubi, Bagger, et al. 2014, 41; Kajubi, Whyte, et al. 2014, 4; Uganda Bureau of Statistics 2012) (see Figure 2.7).

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[48] Recall that single orphans are defined as children who have lost only their mother (also called maternal orphans) or only their father (also called paternal orphans), and double orphans are defined as children who have lost both parents.

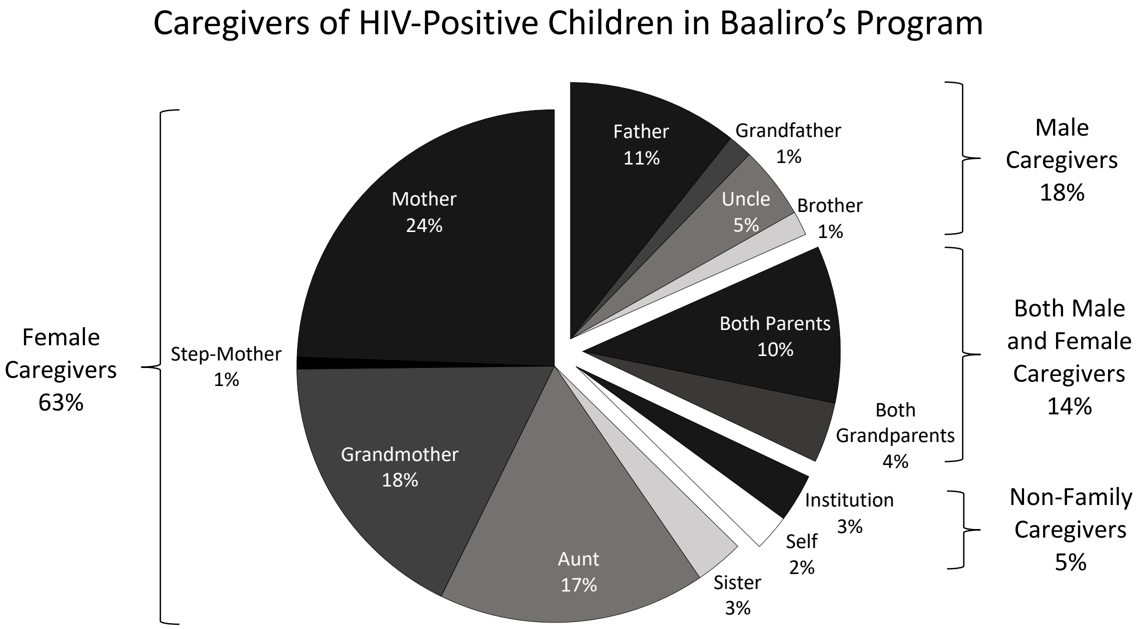

Figure 2.6 Caregivers of HIV-Positive Children in Baaliro's Program
One or more parents were listed as the primary caregiver just under half of the time (45%), with grandparents (23%), aunts or uncles (22%), and siblings (4%) making up the remainder of relatives caring for children at Baaliro. Female caregivers were listed as the sole primary caregiver 63% of the time, with male caregivers listed as the sole primary caregiver only 18% of the time. A male and female caregiver were listed together as the primary caregivers 14% of the time. This gendered distribution of caregiving is reflective both of traditional gender roles in Uganda (Nkwake 2013) *and of the well documented unequal distribution of the burden of caregiving between males and females* (Akintola 2004; L. Clark 1993; Harrison, Short, and Tuoane-Nkhasi 2014; Tarimo et al. 2009). *Data are based on caregiver(s) listed on children's intake forms (described in more detail in chapter 3).*

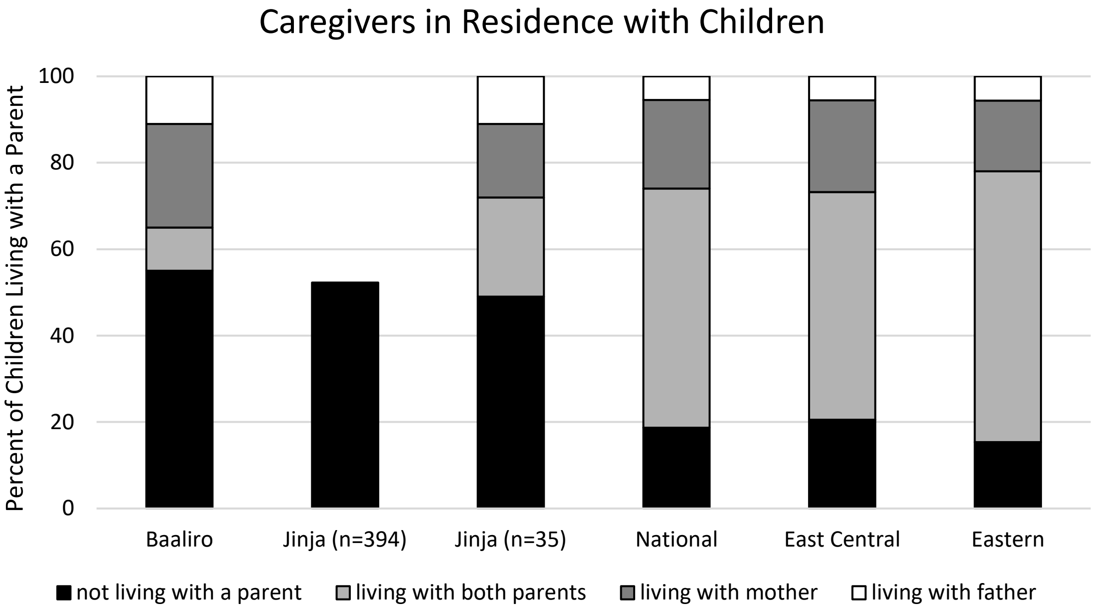

Figure 2.7 Graph of Caregivers in Residence with Children
Baaliro data reflect the primary caregiver on record when the child was enrolled in the program. Data for 394 HIV-positive children seeking treatment in Jinja district were published by Kajubi, Whyte and colleagues, however the published paper did not report the number of children living with each or both parents (Kajubi, Whyte, et al. 2014). *Data for 35 HIV-positive children were published by Kajubi, Bagger and colleagues* (Kajubi, Bagger, et al. 2014). *Data for national and regional (East Central and Eastern) statistics come from the Uganda Demographic and Health Survey of 2011* (UBOS and ICF International 2012).

Admittedly, I make this interpretation with caution, because the national and regional statistics are based on a survey which asked if parents were *living in the same household* as the child, whereas Baaliro's charts were concerned with which individual was the *primary caregiver* for the child. It is possible that some parents may have lived with their children but not been the primary caretaker. Thus, the number of parents living with their children may be underreported in Baaliro's charts. However, the fact that Kajubi and colleagues found similar results in their studies, supports my interpretation.

Overall, nearly two-thirds (63%) of caregivers of HIV-positive children were female, with males making up 18%, both genders 14%, and non-familial caregivers 5% (see Figure 2.6).

It is not surprising that female caregivers made up the majority of caregivers given that the traditional gender roles of woman as caretaker and man as breadwinner, remain strong in Uganda (Nkwake 2013). The gendered dynamics of caregiving place the majority of the burden on women (L. Clark 1993), especially in the case of HIV (Akintola 2004; Harrison, Short, and Tuoane-Nkhasi 2014; Tarimo et al. 2009).[49] Additionally, numerous studies across sub-Saharan Africa have emphasized the important role that female caregivers play in accessing health care for their children, whether related to diarrhea, malaria, or HIV and that the vast majority of caregivers who accompany their children to health care facilities are women (Aremu et al. 2011; Kamat 2006; Malangu 2011; Ogunlesi and Olanrewaju 2010)In their study, Kajubi and colleagues (Kajubi, Whyte, et al. 2014) found that an even higher percentage of caregivers were female (80.9%). The rate of institutionalization (defined as children who were living in an institution *after* reintegration) was 3% among HIV-positive children who enrolled in Baaliro's program, ten times the national average of ~0.3%[50] (Walakira, Ddumba-Nyanzi, and Bukenya 2015).

Among caregivers of HIV-positive children for whom a source of income was listed (n=128), nearly one-third (41/128 [32%]) listed more than once source of income (see Table 2.2). Only 2% claimed to be unemployed, but 9% mentioned that one or more of the adults in the household were sick, and 7% reported receiving financial assistance from other family members. Neither being sick nor receiving financial assistance from other family members were mutually exclusive with an adult working, but staff described these notes as indicators of precarity and

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[49] However, Kipp and colleagues offer an exception to these studies, finding that both male and female caregivers reported similar "care burden scores" when caring for AIDS patients (Kipp et al. 2006).

[50] I calculated this percentage from Walakira and colleagues' estimate of 50,000 institutionalized children out of a total population of 17 million children in Uganda.

Table 2.2 Caregiver Occupations

	Baaliro[1] (n=128)		National[2]
Occupation*	n	%	%
Agriculture, Forestry, and Fishery	70	55%	68.4%
Petty Business[3]	26	20%	8.0%
Casual Labor (Other Elementary Occupations)[4]	20	16%	4.8%
Other[5]	13	10%	6.0%
Technicians and Associate Professionals[6]	6	5%	2.0%
Service Workers[7]	5	4%	7.7%
Other Plant and Machine Operators[8]	5	4%	2.7%
Professionals[9]	5	4%	0.5%
Domestic Helpers (housekeepers)	2	2%	3.6%
Craft Workers	1	1%	4.2%
Clerical Support Workers	0	0%	0.4%
Unemployed	3	2%	9.4%
Sick (unable to work)	11	9%	n/a
Receive Assistance from Other Family Members	9	7%	n/a

** Occupation categories are those used in the National Census unless otherwise specified.*

[1] *Baaliro values are the number of children whose caregivers report each occupation as a source of income. Percent adds up to more than 100% because caregivers could list more than one source of income and because some children had multiple caregivers. In this table, only sources of income for the caregivers of HIV-positive children are reported. For data on all children enrolled at Baaliro see Appendix H.*

[2] *National values come from the 2014 Uganda National Census* (UBOS 2016)*(UBOS 2016). They are the percent of the working population (aged 14-64) who reported each occupation. They exclude the unemployed and students. Census respondents were only allowed to list one occupation.*

[3] *Petty Business was not listed as an occupation in the national census. However, the census did report that 8% of households are engaged in "business enterprise" as the household's primary source of income. Among Baaliro caregivers, Petty Business included managing a roadside kiosk, selling food, brick-making, and/or selling charcoal.*

[4] *Type of Casual Labor was usually not specified for Baaliro caregivers, but included assisting other farmers with cultivation, working as a sugar cane weeder, and washing clothes.*

[5] *Other Sources of Income for Baaliro caregivers included self-identification as a traditional healer/herbalist (n=3), a businessman/woman (n=3), maintaining rental properties (n=2), a pastor (n=1), or employed but not otherwise specified (n=1).*

[6] *Technicians and Associate Professionals among Baaliro caregivers included a nursing assistant, a medical assistant, a carpenter, a builder, and two tailors.*

[7] *Service Workers among Baaliro caregivers included shop attendants (n=3) and those involved in the bar business (n=2).*

[8] *Other Plant and Machine Operators among Baaliro caregivers included a driver, two mechanics, one individual involved in bicycle repair, and one boda-boda driver. Boda-boda drivers were reported separately in the national census (1.5%), but I have included them with Other Plant and Machine Operators.*

[9] *Professionals among Baaliro caregivers were mostly teachers (n=4). Additionally, one woman described herself as an interior designer.*

stability respectively. The most common sources of income were farming/fishing (55%),[51] petty business (20%), and casual labor (16%). Casual labor frequently involved agricultural work such as assisting other farmers with cultivation or working as a sugar cane weeder, but was distinct from an occupation in agriculture because it was a form of wage labor. Petty business involved such activities as managing a roadside kiosk or bar, brick-making, and/or selling charcoal.

Compared with national statistics, caregivers of HIV-positive children from Baaliro appear to be notably more involved with casual labor (16% at Baaliro vs. only 4.8% nationally) and somewhat less involved with agriculture (55% at Baaliro vs. 68% nationally). However, only 41.5% of caregivers in Kajubi and colleagues' study reported their occupation as subsistence farming (Kajubi, Whyte, et al. 2014). It is difficult to compare rates of involvement in petty business, since the census only reported home-based enterprises at the household level and only when they were the primary source of income for the household. At Baaliro the majority of caregivers involved in petty business (15/26, 58%) had one or more additional sources of incomes.

Mary did not begin asking about caregiver education until mid-way through 2012, and educational information was only available for 36 of the caregivers of HIV-positive children. Of these, 19% (7/36) had never attended school, 33% (12/36) had not reached the final year in primary school, 19% (7/36) had attended the final year of primary school, and only 25% (9/36) had attained any secondary education. In comparison with caregivers from Kajubi and colleagues' study (Kajubi, Whyte, et al. 2014), a similar amount of Kajubi and colleagues' caregivers had never been to school (21.6%), but considerably more of the caregivers had attained secondary education (50.3%).

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[51] I have lumped farming and fishing together to be consistent with the national census which counted both farming and fishing as "agriculture."

2.2.4 The Children Who Stayed at Baaliro During this Research

The children with whom I had the most contact were those who lived at Baaliro for a month or more during my fieldwork (n=24), or who stayed at the center for one to three weeks (n=9) (see Table 2.3). Five of the children who stayed at the center for more than a month were HIV-negative with the remaining 19 being HIV-positive, and all of the children who stayed one to three weeks were HIV-positive. The children were roughly evenly split between males and females (15/33 [45%] were males). The population at Baaliro changed as new children were enrolled and admitted to Baaliro and as rehabilitated children were reintegrated back to their home communities. During my fieldwork, at most a dozen children were admitted to the center at one time. Over the holidays[52] (Christmas and New Year's), the population dropped to a low of five children, only one of whom did not go home for a least a brief visit. Anywhere from two to four caregivers were staying at Baaliro with their children at any given time. Children who stayed at the center for more than one month ranged in age from 9 months to 24 years, though most were 6-15 years old (average age was 9.5 ± 5.9 years). They were either on their first admission (n=19), or had rebounded (n=5). Twelve of them were reintegrated while I was still in the field, one died, and one was transferred to another institution (a babies' home).

All but one of the children who stayed at the center for one to three weeks had previously been reintegrated. Those who stayed for one to three weeks were, on average, older than admitted children who stayed for a month or more, ranging in age from 6 to 16 years old (average age was 13.9 ± 4 years). They stayed at Baaliro for a variety of reasons. Some came to

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[52] In addition to allowing children to be with their families for the holidays (Christmas and New Year's), Baaliro staff preferred to reintegrate children in December because this corresponded to the end of the academic year and thus minimized the disruption to the children's education.

Table 2.3 Children and Caregivers Who Stayed at Baaliro During 2014-2015 Fieldwork

Children who stayed for one month or more

Name[1]	Age (years)	Gender	HIV-status	Admission[2]	Discharge	Caregiver[3]
Grace[4]	0.75	F	Negative	New	Transferred	Mother (Hellen)*
Mary	1.25	F	Negative	New		Mother*
Hope	1.5	F	Positive	New	Reintegrated	Mother*
Nalunga	1.5	F	Negative	New		Mother*
Omar	1.66	M	Negative	New	DOR[6]	Mother*
Nakisisa	3	M	Negative	New	Reintegrated	Aunt (Nabukwasi, 14 years old)*
Katassi	6	F	Positive	New		
Namata	6	F	Positive	New		Aunt* and Mother
Sanyu[5]	6	M	Positive	New	Reintegrated	Mother[5]*
Martin	8	M	Positive	New	Reintegrated	
Aisha	8	F	Positive	New	Reintegrated	
Onzi	9	M	Positive	Rebound		
Talya	9	F	Positive	New	Reintegrated	Mother
Peter	9	M	Positive	Rebound		Mother
Wemusa[5]	11	M	Positive	New	Reintegrated	Mother[5]*
Violet	11	F	Positive	Rebound		
Maurine	12	F	Positive	New		
Nantumbwe	13	F	Positive	New	Reintegrated	
Juliet	13	F	Positive	New	Reintegrated	
Kabiite	14	F	Positive	New		Mother*
Denis	14	M	Positive	Rebound	Reintegrated	
Tomas	15	M	Positive	School (P7)	Finished Studies	
James	17	M	Positive	Rebound	Died	Mother
Hellen[4]	24	F	Positive	New		

[1] *All names are pseudonyms.*

[2] *Reasons for admission*

[3] *Only caregivers who spent the night with their children at Baaliro at least once are listed. Those who stayed with the child for the duration of their stay are marked with an asterisk (*). As is convention in Uganda, I name caregivers based on their relationship with the child in their care – for example Maama-Peter is Peter's mother. However, some caregivers went by their given names, and in these cases I also gave the mother her own pseudonym.*

[4] *Grace was initially enrolled due to malnutrition. Hellen is Grace's mother and was staying at Baaliro with her baby. Hellen was subsequently enrolled in Baaliro's program because of her poor health, despite her age.*

[5] *Wemusa and Sanyu were brothers and had the same mother. Sanyu was healthy, but was admitted because his brother was very sick and staying at Baaliro with his mother (who herself was not well), so there was no one at home to monitor him as he started ARVs.*

[6] *DOR – Discharged on Request, when the caregiver insists on taking the child back to the community before Baaliro staff feel the child is ready for reintegration.*

Table 2.3: Children and Caregivers Who Stayed at Baaliro During 2014-15 Fieldwork (cont.)

Children who stayed for one to three weeks

Name	Age (years)	Gender	HIV-status	Reason for stay	Caregiver[1]
Hassan	8	M	Positive	Seizures	Mother and Brother
Ahmed	10	M	Positive	New	
Sam	11	M	Positive	ART refills	
Abby	13	F	Positive	TB treatment	
Solomon	13	M	Positive	Mother attending a workshop	
Gertrude	14	F	Positive	Vacation Visit	
Cindy	18	F	Positive	Vacation Visit	
Judith	18	F	Positive	Vacation, dentistry	
Wasswa	20	M	Positive	Requesting Transfer	

[1] Only Caregivers who spent the night with their children at Baaliro at least once are listed. Those who stayed with the child for the duration of their stay are marked with an asterisk (*). As is convention in Uganda, I name caregivers based on their relationship with the child in their care – for example Maama-Peter is Peter's mother. However, some caregivers went by their given names, and in these cases I also gave the mother her own pseudonym.

visit over their school holidays, some came during school vacations for an ARV refill or to attend the youth workshop and it took a week or more to organize transportation for them to get back home, and some came for treatment of an acute medical condition. One of the children was newly admitted to Baaliro during my last week of fieldwork.

Among caregivers, as with the children, I had the most interaction with those caregivers who stayed with their children during their stay at Baaliro (n=13), and especially those who stayed with their children for the duration of their stay (n=9). All but three caregivers who stayed with their children were the biological mothers of their children. The three remaining were a maternal aunt, a paternal aunt, and a brother. The paternal aunt was 14 years old, and in many ways was treated as a child at Baaliro despite her caregiving responsibilities. Another mother, whose child was initially enrolled for malnutrition, was ultimately enrolled in Baaliro's program due to her own poor health, even though she was 24 years old. These cases demonstrate the often fuzzy distinction between children and caregivers.

2.3 Conclusion

In summary, in this chapter, first, I introduced my primary field site, Baaliro, and the various organizations which 1) Baaliro existed at the intersection of (St. Damien's and Child Network), and 2) Baaliro interacted with in the projectified landscape of pediatric HIV care in East Central Uganda. Second, I provided comparative demographics of the children enrolled in Baaliro's program with national census data and with another study of children infected with HIV from the same area. Having thus situated Baaliro and the children enrolled in its program, in the next chapter I move on to the methods I used to research children's experiences living with HIV. For a more detailed description of daily life at Baaliro as well as the logistics of rehabilitation, reintegration, and follow-up, see Chapters 4 and 5.

Chapter 3: Working with Sick Children: Methodological Approaches

In this chapter I lay out my approach to working with children living with HIV. Researchers wanting to work with children, even healthy children, often run into a series of both bureaucratic and logistical hurdles, and in this way my research was no different than most. I describe the simple and classic anthropological methods that worked most effectively for me. Additionally, I highlight how my role as a researcher at Baaliro shifted over time and how working with sick children affected the roles I could (and could not) take on. This chapter does not offer a roadmap for future researchers, but in describing my approaches, I hope to offer at least some insight into working with children living with complex medical and social histories. At the end of this chapter I discuss several so-called "child-friendly" methods which were largely ineffective in my research, and I propose some reasons behind their failure. This is not meant to be a critique of participatory methods, but simply an acknowledgement that they do not work in all research contexts and did not work for me.

Like most anthropological researchers, I used a variety of methods including: participant observation, interviews, field visits, case file review and drawing activities. I also spoke with a variety of informants including children themselves as well as the organizational staff and the children's caregivers. Using multiple methods, multiple informants and repeating interviews/observations at multiple time points allowed me to triangulate my findings and ensure their reliability and validity (Bernard 2011).

3.0.1 Ethical Clearance

As anyone doing any kind of research in an American university today is aware, before research with "human subjects" can take place, ethical clearance must first be obtained from an institutional review board. Both St. Damien's and Baaliro authorized my research, and I received a letter of support from the Chair in the Department of Social Work and Social Administration at Makerere University in Kampala, Uganda. I received ethical approval from both the institutional review board at Washington University in St. Louis and the Uganda National Council for Science and Technology (UNCST). Both organizations approved a waiver of written consent for my interactions with and interviews of children and caregivers. As an institution, Baaliro granted preliminary permission for those children staying at the center without a caregiver to participate in my research, and I obtained informed verbal consent from guardians as soon as possible. Children verbally assented to the study. Despite the often cited concerns of ethics boards that children (as a vulnerable group) not be forced to participate in research, I found such concerns to be largely unnecessary. Put simply, if the children did not want to talk or engage with me, there was no way that I could force them to do so. Children, perhaps even more than adults, were adept at *not* answering questions and *not* participating in research activities if they did not want to. This is perhaps less surprising if we consider, as I describe in more detail in Chapter 6, that refusal was one of children's most powerful strategies. Children would at times refuse to talk to me or refuse to participate in a given research activity (such as drawing) and one parent was reluctant to allow me to record a disclosure session, but ultimately no staff, caregivers, or children completely refused to participate in my research.

To both children and adults, I described myself as a student and a researcher who wanted to write a book about children's lives and *empisa* (culture/customs/manners) in Uganda, especially children who took medicine every day. While children were obviously aware that they took medications every day, many children were not aware of their HIV status,[1] so to have described my research interests in HIV could have led inadvertently to disclosure of their status to them.[2] Similarly, it was not always clear whether all household members were aware of a child's HIV status, so I was careful not to mention HIV until a caregiver or child did so him/herself. More than preventing accidental disclosure to a caregiver (who was unlikely to be unaware of the child's status), this prevented accidental disclosure to any other household members (or neighbors) who might have been listening in on a conversation.

3.0.2 Host Families and Research Assistants

Between 2012 and 2015, out of the 15 months I spent in Uganda, I lived with host families for four months. I had two main reasons for wanting to live with host families. First, because many of the children at Baaliro did not speak English,[3] I needed to learn Luganda. I therefore attended an intensive Luganda training program on the outskirts of Kampala for a total of ten weeks and did long-distance language lessons via skype for a year between 2013 and

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[1] Though I did not do a systematic assessment of children's HIV disclosure/knowledge, out of 57 children (aged 7-22 years old) who I asked (via mini-interviews) why they took medications every day, only 31 (54%) responded with either an English or Luganda term for HIV/AIDS. Other common responses were that they did not know, had forgotten, or didn't remember (12, 21%); with a general response about their health] (6, 11%) (including that they took the medications for "*kuwona*" [to heal], to stay healthy, because they didn't want to die, or "*eddagala lya'bulamu*" [medications [are] for life]); or by naming another illness (5, 9%) (including that they took them for some other illness such as ulcers, TB, *ekifuba* [chest infection/cough], leg/joint pain, syphilis, or de-worming).

[2] I owe great thanks to Phoebe Kajubi who pointed this important point out to me, and who has written extensively on issues of (non)disclosure of HIV status to children in Uganda (Kajubi, Bagger, et al. 2014; Kajubi, Whyte, et al. 2014).

[3] English is one of the official languages in Uganda, and by far the most widely spoken official language in the region where I worked. However, most Ugandans do not speak English as their first language, but learn English in school. Many of the children who came to Baaliro either had no education, or received very poor quality education in rural schools, most of which teach in local languages (generically called "vernacular" in Uganda), rather than English, until at least the third grade level (P3). Uganda has 39 local languages, with Luganda being the most widely spoken local language, especially in the central and east-central regions (Lewis, Simons, and Fenning 2017). Baaliro itself was located at the border of two ethnic groups – the Buganda and the Busoga – and all of the children I encountered at Baaliro spoke either Luganda or the closely related language, Lusoga. Native speakers of Lusoga have little difficulty understanding Luganda and vice versa.

2014. While attending the language school, I chose to live with a host family both to provide opportunities to practice Luganda while not in class, and to address my second reason for staying with a host family – gaining insight into family life and daily lived experience in a household in Uganda. Since the aim of my research was to better understand children's experiences growing up with HIV, in order to compare how their experiences differed from uninfected children, I needed to have an understanding of the norms of Ugandan family life – including gender relations, expected children's roles and responsibilities, and important norms in child-rearing. The children in my first host family's home were all in their twenties or older, except for the two-year-old granddaughter. This offered relatively limited opportunities to observe how the family itself raised its children; however, even in this mostly adult household, I was able to observe interactions between my host-mother and children from the community who frequently helped her around the compound and to engage the family members in fruitful discussion of child rearing and household roles. In February 2015, I spent three weeks living with a second host family near Baaliro. Four children lived in the household of my second host family, ranging in age from 10 to 18 years old. Through staying with this second, more rural (rather than peri-urban) family with school-aged children, I gained more direct observations of family interactions. This second host family was also more similar in member composition to the households from which the children staying at Baaliro came, although they were considerably more wealthy than many of the families of Baaliro children. I engaged the members of my host families as well as my language instructors in informal conversations on topics of family life, social roles, and child-rearing, and observed the interactions among adults and children in both of my host-homes and the surrounding communities. Coincidentally one of the children in my second host family suffered from sickle cell disease. So, additionally, I was able to ask both his parents and him about their experiences living with a chronic illness (other than HIV).

Although all of the staff at Baaliro knew English and all official meetings were conducted in English, almost all informal conversations between staff were in Luganda. Therefore, in addition to being able to communicate directly with children, it was also important for me to understand Luganda in order to catch side conversations among staff. Additionally, almost all communication with clients, children, and caregivers was in Luganda. In order to assist my comprehension, I hired a research assistant, Joy, who accompanied me from 9:00am to 5:00pm five days a week (Tues-Sat). Sometimes Joy interviewed children independently and reported her findings to me, but usually we interacted with children together. Joy was HIV-positive and worked as a peer counselor at a different HIV clinic across the Nile. She had three sons. Two attended boarding sections of secondary school, and one was in P3 and lived with her. Everyone at Baaliro (children, staff, and caregivers) enjoyed sharing Joy’s company. She counseled reluctant caregivers to stay longer at the center, she encouraged children and caregivers to take their ARVs faithfully, she participated in the daily work at Baaliro – especially food preparation, and most importantly, she connected with the children. When children became upset, they frequently shut down completely, refusing to talk to anyone or do anything. In such instances, Joy was often somehow able to discover why the child was upset and coax him/her to rejoin daily activities. Joy helped me not only to communicate and comprehend when my Luganda still was not up to par, but also to contextualize cases and conversation within the norms of Ugandan childhood and child-rearing. Unfortunately, Joy was only able to work for me for two months before she fell sick with cryptococcal meningitis and was in and out of the hospital for another two months. Joy resumed working for me after the Christmas and New Year’s holidays, only to suffer a cryptococcal meningitis relapse two months later during which she was hospitalized for another month. She was discharged just prior the end of my fieldwork, but was too weak to resume working even part-time. After leaving the field I received updates that Joy was hospitalized twice more for cryptococcal meningitis, and once for intestinal TB. Ten months after I left the field, I learned that Joy had stopped taking her medications and died. I will forever appreciate the depth of the insights she offered whenever she was able to work with me, and will be forever confused and saddened by her death.

When Joy was unable to work with me, I mostly functioned without a research assistant. However, I did hire two post-secondary school students to assist with transcription and translation of audio recordings. Both youth were on the long vacation between finishing S6 and beginning university. One, Mutesa, had enrolled in Baaliro's program 4.5 years earlier, and was volunteering at Baaliro over the long holiday. He assisted Baaliro staff with whatever he was asked to do, which often involved cooking, cleaning, gardening, and caring for the chickens. Mutesa saw himself as providing a role model for the younger children and wanted to give back to the organization which he credited for saving his life. He hoped to become a doctor, but struggled with poor test performance. Because of his role at Baaliro, Mutese also provided me with translation and contextualization in Joy's absence, though he did not accompany me to the field as Joy had.

The second youth I employed was my host sister from my second host family. She was extremely bright and had attended one of the best boarding schools in Kampala. She scored a perfect score on her A-level exams, and later pursued a bachelor's degree in economics. Since neither youth was comfortable typing, nor had access to a computer, they did their transcriptions and translations by hand, and I later typed them and confirmed their accuracy by re-listening to the original recordings. Recordings included staff meetings with caregivers in the community (n=4), disclosure sessions between the counselor and children (n=5), sessions from the youth workshop (n=2), and Baaliro's quarterly staff meeting.[4]

3.1 Methodological Approaches and Role Negotiation

3.1.1 Participant Observation

At Baaliro I employed participant observation to immerse myself in the daily lives of children at the center. A total of 24 children lived at Baaliro for a month or more during the ten months in which I lived at the center, and an additional nine children stayed at the center for one to three weeks. Baaliro children and staff were familiar with *bazungu* volunteers, who would come (sometimes in large groups) and play with the children for a few hours at a time, usually taking as many pictures as possible.[5] However, as the first *muzungu* to ever actually live at Baaliro and as a researcher (rather than a volunteer), I had a rather unique role at the center, which also shifted over time. Initially I claimed the role of "objective researcher." In this role, I attempted not to take on any responsibilities at Baaliro and to remain neutral regarding children's behavior and their cases. I did not want children to view me as an authority figure, and I did not want my opinions to influence how staff talked about or treated the children. However, with time I found myself not only observing, but also playing an active role at Baaliro, more akin to what

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[4] Baaliro staff meetings were conducted in English, youth workshop sessions were in a mixture of Luganda and English, and meetings with caregivers, children, and community members were in Luganda.

[5] Every year two groups of teenagers from Britain would come to volunteer at St. Damien's for 2 weeks, and because of the irresistible attraction of having their pictures taken with the AIDS-children, they would come to play at Baaliro in the afternoons. Additionally, St. Antony and St. Damien's each hosted a pair of year-long German volunteers. These volunteers developed their own schedules and volunteer goals based on their interests, so some years (if the volunteers wanted to work with children) they would come to Baaliro 2-3 afternoons a week to teach the children English. However, with no teaching experience and limited teaching supplies, the success of these lessons was limited and more often they turned into play sessions. Baking cookies was an especially popular activity with the German volunteers in 2014-2015.

Nancy Mandell (1988) calls “complete involvement” and the “least-adult” role.[6] While I strove to attain a least-adult role, my success in doing so was variable, and especially in medical encounters, I felt to have done so would have been inappropriate and even, as I discuss below in more detail, unethical. Like Samantha Punch (2001), I found that it was important for me to be both sensitive and flexible as I negotiated my multiple roles as a researcher working with children.

I ate my meals with the children, eating the same food as they did and using my hand rather than a fork (which was always offered to guests, but never used by the children). The fact that I chose to eat with the children was notable, because none of the staff at Baaliro ate with the children or caregivers. Most staff ate in the canteen (which served better food), and even those who ate the food prepared at Baaliro, ate separately from the children and caregivers (staying in the kitchen or office).[7] I also observed medication times, assisted with food preparation and chores, and enjoyed play and free time with the children.

In participating with food preparation and chores I attempted to position myself as a helpful peer. I refused to complete a child’s assigned talk for him/her, but would either join in with a group of children completing a task (such as weeding, picking stones from beans, or de-shelling g-nuts[8]) or offer my assistance (such as helping a short boy to hang his clean clothes on a wire which was out of his reach). I never saw staff assist children with their work, but children

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[6] While Mandell suggests the “least-adult role” as one possible role that researchers can assume, Warming (2011) argues that the “least-adult role” grants the researcher unique/exclusive access to children’s perspectives (via shared bodily experience) which are inaccessible through other methods. I am hesitant to embrace the view that children’s perspectives are inaccessible unless the researcher assumes the least-adult role, because such logic seems to imply that to in order to access the perspectives of children living with HIV, I would also need to be infected with the virus, or at least to suffer myself from a highly stigmatized life-threatening chronic and relapsing illness. However, I did find that sharing children’s daily activities granted me perspective into their lives.

[7] I go into more detail regarding the food served at Baaliro in Chapter 6.

[8] G-nuts is short for groundnuts. In Uganda, g-nuts usually refer to peanuts.

at times helped one another in similar ways. I also attempted to be helpful to the children by reminding them to do tasks which they commonly forgot (such as making their beds or bringing their clothes which had been hung to dry inside at night) before the matron noticed and scolded them.

The fact that I played with the children was in some ways very odd and in some ways very typical. It was odd in that Ugandan adults (and even most *bazungu* adults) rarely played with children, and especially did not play with them on the playground. However, it was very typical in that most of the *bazungu* youth volunteers who came to visit did play with the children. My play with them, however, differed in several ways. First, most of the time I did not have a camera. Most *bazungu* who engaged in playing with children at Baaliro took many photos of the children as well as themselves. Sometimes they printed copies of photos to give to the children, but more often they presumably posted the photos on social media and shared them with family and friends back home.[9] I noted that the few times I brought my camera and/or gave a camera to the children to take photos resulted in more posing than playing (itself an interesting observation). Additionally, when most *bazungu* engaged the children in play, then tended to teach the children games. In contrast, I waited for children to initiate the play and then joined them in whatever game they were playing, sometimes having them explain the rules to me, which I often still did not fully understand. At times children were not feeling well, and we would simply sit and talk or play a matching card game which did not take much energy or even require talking.

As I describe more in Chapter 5, the children spent a great deal of time outside of direct adult supervision. This gave them considerable latitude in their behavior toward one another, and

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[9] This was less the case with the long-term volunteers, but even they brought their cameras more often than I did.

considerable room for misbehavior. While I at first refrained from commenting on children's (mis)behavior, as I learned the importance of good behavior, what constituted it, and that children themselves would call out one-another's misbehavior (concepts I also discuss more in Chapter 5), I began to encourage children when they behaved well, and call out children when they behaved badly. However, I was careful to never report a child's misbehavior to an adult, and explicitly reiterated to children that I would not tell the staff about what they were doing or talking about. In time, children who had been at Baaliro for a while would assure newcomers that I was not going to tell on them to adults ("Co-li-ni taloopa" [Colleen doesn't tell on us]).[10]

I also in part maintained a least-adult position by insisting that the children not use any kind of formal title with me. Nearly all adults were given a title – Auntie or Uncle, Mr. or Mrs., Doctor or Sister – however, I told children to just call me by my first name (Co-li-ni).[11] Additionally, I did not insist that children greet me as they would an adult (by kneeling). At first I attempted to discourage their kneeling, but as I learned more about the importance of showing respect to elders once children returned to their homes, I came to accept it and would thank a child who kneeled when greeting me for having good manners. However, I never told a child to kneel when greeting me as most adults would.

Over time I became even more directly involved in Baaliro's daily activities. Sister Sally frequently assigned me the unofficial role of "plumpy monitor,"[12] and when she began to suffer from poor health and was no longer able to spend the night at the center, she delegated the morning medicine administration to me. After accompanying Mary on numerous visits to

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[10] *Oku-loopa* means to accuse, to blame, to inform against, or to tell tales of.

[11] Despite my attempts to distinguish my name (Colleen) from the more well-known boy's name Colin, many people expressed surprise when they met me and found that I was a female. They insisted on telling me that I had a boy's name, and the fact that Colleen literally translates as girl in Irish (reflective of my paternal ancestry) could not dissuade them.

[12] See chapter 7 for a full description of this role.

reintegrated children's homes, and listening to staff discuss children's cases in the office, I began to contribute my opinions and observations to these conversations and to actively participate in staff meetings when discussing what to do about a particular child. During my post-fieldwork visit in September 2015, Mary was attending a training for a week, and decided to send me in her stead to do the follow-up visits and pay school fees for 16 children. During these visits a nurse accompanied me, and I insisted that she handle the money and sign the receipts, since I was not an official staff member of Baaliro and I did not want to overstate my role. However, because of my previous trips with Mary, I was more familiar with the children and their home situations than the nurse, and Mary had confidence that I would be able to adequately assess the children's cases without her and report back on their progress.

Ultimately, the least-adult role was appropriate and helpful for facilitating rapport and building trust with the children, but was unsustainable when staff requested that I assist them and even more so in circumstances relating to children's health and well-being. I often accompanied children to and/or visited them at other health centers. These other health centers included St. Damien's, East-Central Children's Hospital (ECCH) inpatient ward and outpatient nutrition clinic, JCRC in Lubowa, and Jinja's private health centers. Staff preferred that a child's guardian accompany a child for medical visits whenever possible, but in cases where the caregiver was not staying with the child, they frequently asked me to accompany the child. Whenever visiting another facility, I tried to emphasize my role as a student and that I was not a staff member, donor, or volunteer at Baaliro. Similarly, when accompanying children at St. Damien's, I initially tried to simply observe interactions between children and clinicians. However, as I began to know more about the children's health, I began to participate more in their care, especially advocating for medications to be given on time, and in one case advocating that the child be transferred to ECCH (see Martin's case in Chapter 6).

In my role as an observer I was granted access to witness five disclosure conversations – when a counselor told a child he/she had HIV, ostensibly for the first time. I requested and was granted permission to record these sessions. Additionally, I witnessed several family meetings, which took place at Baaliro between caregivers, children, and Baaliro staff. I did not record any family meetings that took place at Baaliro, but this is more reflective of my discomfort with recording early in my fieldwork than the refusal of caregivers, staff, or children to being recorded. I did not participate in, but only observed disclosure sessions and family meetings. Lastly, in addition to attending more informal meetings, I participated in two of Baaliro's quarterly staff meetings, and was invited to attend and participate in St. Damien's annual board meeting and their annual meeting with a major donor. In these more formal meetings, I was primarily interested in observing the meeting; however, I did offer my opinions when asked. I also observed several special events held at St. Damien's and Baaliro. These included the annual general meeting, the World AIDS Day celebration, and the grandmothers' annual celebration hosted by St. Damien's and a three-day youth workshop held at Baaliro.

Baaliro staff organized and hosted what they hoped would be the first of many youth workshops in April 2015. This workshop was specifically for children enrolled in Baaliro's program and 13 years old and older, and was conceived as a way to address what the staff identified as a growing problem of poor adherence among adolescents. Approximately 30 youth attended, 11 of whom spent the night at Baaliro because they came from villages too far away to return home each evening. Baaliro covered the costs of transportation for all of the youth, and served them better food than was usually prepared at the center.[13] Sessions were mostly didactic and included HIV specific sessions (the history of HIV, HIV transmission, common myths and misconceptions about HIV, medical aspects of HIV, adherence strategies for ARVs, and psychosocial issues for youth living with HIV) as well as sessions on general health and motivational messages (personal hygiene, vocational education, a motivational speaker, nutrition, relationships, and ethics and morals). Baaliro and St. Damien's staff taught most of the sessions, but they brought in guest speakers to talk about the benefits of vocational education and as the motivational speaker. While the sessions were primarily didactic, speakers encouraged the youth to ask questions throughout the workshop. However, only a handful of youth asked questions and some refused to speak even when directly asked for their feedback. Lucas was frequently frustrated by the youth's reluctance to ask questions and participate verbally, which he interpreted as their lack of interest. At the end of the workshop, the youth had a party at a nearby resort where they drank soda and enjoyed playing along the lakeshore.

Overall, my role at Baaliro was multifaceted. I strove to attain a "least-adult" role, but the needs of staff as well as children at Baaliro complicated this role and compelled me to take on more responsibilities than I initially desired. Even more so than Mandell and Warming (who were both working with healthy school children), working with the children who were at times very sick and staff who were both over-worked and themselves at times sick made maintaining a least-adult role full time untenable in my research. I had to weigh the potentially serious consequences of remaining silent about a child throwing away medications or hiding a symptom (such as vomiting, diarrhea, or a fever). Rather than a least-adult, I was perhaps a strange adult – one who was at various times friendly, helpful, playful, responsible for giving medications, and

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[13] When asked for their reviews of the workshop at the end of the three days, many of the children commented that the food was the best part of attending.

an advocate for children. At my going away dinner, one of the staff, Godfrey, asked children what they liked most about me. In response, several simply thanked me, "weebale kufaayo" [thank you for caring][14] or "weebale kubeera wa mukwano" [thanks for being a friend], others appreciated my help with the housework and the way I encouraged them (rather than scolded them) citing specific examples that they remembered which I had forgotten. Since I had never directly asked the children what they thought of my role at Baaliro, this was the closest insight I had into their perceptions of me – overall, they labeled me as a caring and helpful friend.

3.1.2 Field Visits

While living at Baaliro, I accompanied Mary (the social worker) on nearly all of her visits to reintegrated children. These trips centered around paying school fees for the children who Baaliro was supporting in school, but also offered an opportunity for Mary to monitor children's home lives, health, and adherence. Occasionally Mary brought a nurse with her to assist with drawing blood for CD4 count monitoring. Whenever Joy was well enough, she also accompanied us on field visits and assisted me both with interviewing the children and with enhancing my understanding of inter-staff conversations which took place as we bounced along the murram roads for hours at a time. During field visits, I primarily maintained the role of observer, watching the interactions among Mary, the children, the caregivers, and school staff, and avoided interrupting or sharing my opinions unless directly asked. I did not want to interfere with Mary's work, and most of the children and caregivers were unfamiliar with me. Once we had returned to the truck, I often asked Mary and/or Joy for clarifications. During my fieldwork, I made 181 field visits to a total of 74 children in the surrounding communities, including 45 schools and 62

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[14] Caring in this sense refers to being concerned with and interested in them and their lives – treating them as someone important, in contrast to taking care of (*oku-kuuma* or *oku-labirira*).

homes.[15] I visited 45 children more than once, and in one case, visited a pair of HIV-positive brothers eight times.

Additionally, Mary led educational programs in the children's schools. I attended four programs focused on HIV/AIDS and three programs focused on other topics – such as hygiene and early pregnancy. Lastly, when Mary identified that a child was having problems at home, she organized a meeting among the child's caregivers, nearby neighbors and community leaders. I attended three such community meetings.

3.1.3 Interviews and Life Histories

I conducted mostly semi-structured and informal interviews with staff, caregivers, and children themselves. When interviewing children, I was very sensitive to their body language and either stopped the interview or changed topics if a child appeared to become upset. Joy was especially helpful in helping me to recognize certain body language cues that were new to me (such as the arm flap used as an indication of annoyance in young children, but downcast eyes as an indicator of respect rather than discomfort). When talking to children I also had to be sensitive to their interest levels and interviews were often limited to only a few questions. I had many opportunities to ask the children living at Baaliro questions throughout the day and had ample time to build rapport with them. In contrast, interviews with children on field visits were more challenging. Because I did not want to lengthen Mary's already long days in the field, I only had a few minutes to talk to children. I also had less rapport with children I met in the field than

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[15] In 2015 Baaliro paid school fees for a total of 75 children at a total of 58 schools. The number of schools is less than the number of children because in some cases two or three children attended the same school. Five pairs of children were siblings and lived in the same home. Because Mary visited both HIV-positive and HIV-negative children during her field visits, I am including both in these tallies. If HIV-negative children are excluded, I made 154 field visits to HIV-positive children, visiting a total of 62 HIV-positive children in their home communities (and visiting 37 HIV-positive children more than once).

those who I had met while they were staying at Baaliro. To help address the issue of rapport and still keep interviews brief, Joy and I developed a semi-structured “mini-interview” procedure.

Adapting well documented interview protocol and Joy’s experiences as a peer-counselor, we began these mini-interviews by asking about safe and easy topics for children to discuss such as the children’s year in school and favorite subject, color, games and/or sport (Schensul, Schensul, and LeCompte 1999). These questions helped us gain a sense of children’s comfort in talking with us and helped to build rapport. Then we assessed children’s knowledge of their HIV status and medications by asking if they knew why they took medications, if they could describe and/or name their medications, when they had started taking them, who knew about their medications at home and/or at school, and who helped them take their medications. As previously mentioned, all children knew they took medications every day, but many did not know why. Focusing our questions on children’s medications allowed us to assess their knowledge without inadvertently disclosing their HIV status to them. If children were aware of their HIV status, we asked about when and how they found out, and how they felt both initially and currently about having HIV.

Finally, we concluded by asking about what work the children performed at home and what they wanted to be in the future. Some children became uncomfortable when talking about their medications and/or HIV status, especially if the way they learned about their HIV status was through a parental death, so ending mini-interviews by returning to safe topics (such a daily work) as well as with future oriented questions helped to leave the child in a positive state of mind. In order to make mini-interviews more conversational, I did not use any formal interview guide or checklist, but allowed conversations to flow naturally following the general conversation topics and questions as outlined above; however, this meant that not every question was asked in every mini-interview. We also ensured children's privacy, making sure to find a location out of hearing of other children and community members – often this meant interviewing children in the truck. Mini-interviews with children rarely lasted more than 15 minutes, and most took less than five minutes. I also asked similar questions to those in the mini-interviews to the children living at Baaliro.

Almost all children were most comfortable conversing with me in Luganda, though a few of the older children preferred to speak English. I attempted to talk with children of all ages, but in all cases children under the age of seven were either too shy or uninterested in engaging in conversation about their medications with me. I conducted mini-interviews[16] with a total of 57 children (age range 7-22yo, mean age 13 years), 27 of whom I was able to interview more than once. Multiple interviews proved important, especially when assessing a children's knowledge of why they took medications, because children frequently changed their answers over time.

In a few instances, I asked older children for a more complete life history. Two children (Mutesa and James) felt more comfortable writing their life histories rather than telling them to me. I interviewed a third child and recorded her life history (Nantumbwe). Two additional children (Tomas and a youth from the workshop) expressed an interest in sharing their stories with me and began telling me about their experiences growing up with HIV, but we were unable to finish before we were interrupted.

In addition to my interviews with children, I had many lengthy informal interviews with staff in a mixture of English and Luganda. We frequently discussed individual cases of Baaliro children, Baaliro's budgetary and staffing issues, and Baaliro's history and policies. We also

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[16] I had conversations with all 111 children with whom I interacted, but only counted these conversations as a "mini-interview" if I explicitly asked the child why he/she took medication. Mini-interviews were not applicable to the 18 children who were HIV-negative.

discussed broader topics relevant to this research, such as responsibility, discipline, and reintegration. Sister Sally (the program director) and Mary were my primary informants, but I also spoke to all of Baalio's staff[17] on numerous occasions. These conversations gave me a wealth of data regarding norms of child-rearing and behavior, as well as reactions to particular situations. Additionally, I had numerous conversations with caregivers who were staying with their children at Baaliro, bringing their child to Baaliro for ARV refills, and/or caring for children in the community. I had the most interactions with the 13 caregivers who stayed at Baaliro with their children.

3.1.4 Case File Review

I reviewed the case files for all 188 children who had been enrolled in Baaliro's program since it began enrolling children in 1998 and created a database of these cases. Upon enrollment in Baaliro's program Mary started a case file for each child and filled out an intake form. From her perspective the most important pieces of information in these files were the caregivers' phone numbers and directions to the caregivers' homes.[18] Case files included the children's demographic information (date of birth,[19] sex, home village, and age and sex of siblings), caregiver information (number of parents living, relationship of caregiver to child, caregiver's HIV-status and age, and number of children living with caregiver), and Baaliro program information (dates of enrollment, reintegration, rebound, transfer, and/or death, HIV-status,

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[17] Staff and their roles will be discussed in more detail in Chapter 4, when I discuss daily life at Baaliro.

[18] Sometimes the caregiver did not have a phone, so a neighbor's number was listed. Mary tried to get as many phone numbers and contacts form a caregiver as she could, because often one person's phone would not be charged or would be broken, but if she had many numbers the chances of reaching the caregiver were higher.

[19] In many cases files stated the estimated age of child at enrollment, which I then used to calculate an estimated date of birth. I assigned the date of January 1st to children with an unknown birth month, and the 1st of the month to those with an unknown birth date, but known birth month.

treatment regimen, category in Baaliro's program, counselor assignment, school sponsorship, and grade level). Additionally, I used the information in the files to calculate days spent inpatient at Baaliro, age at enrollment, current age (or age at death), and time/distance to reach the child's home/school (from Baaliro). Unfortunately, many case files, especially those from previous years, were incomplete. I attempted to fill in any missing data points by asking Mary and Sister Sally for their best recollections, however approximately 9% (467 of 5264) of data points remained blank. Another limitation to the use of the case files was that some information, especially the caregiver's information, was recorded upon initial enrollment in the program and not revised. If the child changed caregivers or the caregiver/parent died, Mary added the new caregiver's name to the contact information, but did not update the rest of the caregiver's demographics.

The case files also included ongoing monitoring sheets which Mary completed each time she visited a child in the field. Because of her heavy caseload, Mary did not fill out the monitoring sheets during a field visit, but instead took notes on the children and transferred these notes to a monitoring sheets whenever she had the opportunity.[20] Monitoring sheets changed somewhat in how they were formatted over time, but typically contained the same basic categories: academic attendance, academic performance, attitude toward academics, home sanitation, personal hygiene, adherence to ARVs, health, nutritional status, behavior at home, behavior at school, and a blank space for any other notes or comments. Notes and comments often included concerning issues (such as a caregiver's failing health or death) and/or recommendations for future visits. Mary also made a note in the children's files if a child visited Baaliro or if a caregiver called or visited. The staff rarely referenced the monitoring sheets.

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[20] The date on the monitoring sheets usually reflected the date Mary had filled out the sheet, rather than the date she had visited the child.

However, when a question arose regarding a child's timeline (i.e. when did he switch schools? Or when did her father die?), the staff did sometimes look back through the files to see roughly when the event in question occurred. Additionally, Mary would sometimes refresh her memory of a child by looking at his/her file before going for a field visit.

Through the monitoring sheets, I was able to gain a basic understanding of a child's social issues, so that I could more deeply engage in discussions both with Mary about the child and with the child him/herself. While I initially attempted to use the monitoring sheets to identify factors which may have predicted poor outcomes (death or rebounding), monitoring sheets were frequently missing for long periods of time (a year or more), and even completed sheets had too many missing data points for me to make meaningful predictions (2839/7447 [38%] of data points were missing).

Some of the most recent case files also contained a sheet with the caregiver's story of how they brought the child to Baaliro, Mary's assessment of the caregiver's knowledge of nutrition and HIV, and answers to questions about the caregiver's expectations for their (the caregiver's) roles in the future and for the child's future. The last questions in particular seemed to be a way for Baaliro to emphasize caregiver responsibility as well as the children's future productive potential. Unfortunately, the majority of files were either missing this sheet or it was incomplete, so I was unable to formally analyze this material.

3.1.5 Data Analysis

During the day, I wrote notes from participant observation and interviews in small notebooks, which I then typed into word documents as soon as possible (typically every evening). After returning to the US, I entered field-notes and transcripts into MAXQDA (version

12), and coded for participants, dates and locations, which facilitated looking up cases. Additionally, I utilized an iterative process to code for key themes (Bernard, Wutich, and Ryan 2016; Charmaz 2006). I entered quantitative data from the case files database into SPSS (version 24) and ran descriptive analyses for frequencies and crosstabs. For comparisons between HIV-positive and HIV-negative children, I analyzed for statistical significance using chi-square tests for categorical variables and independent samples t-tests for continuous variables (see Appendix H).

3.2 Unsuccessful Participatory Methods

Since the new sociology of childhood has gained prominence in childhood studies, researchers working with children have emphasized understanding children as social actors as well as the importance of conducting research *with* children as research subjects rather than *on* children as research objects (Christensen and James 2017; James and Prout 1997 [1st ed 1990]). In response to this call, researchers have developed a portfolio of child-centered methods which they claim *must* be inclusive and participatory (Barker and Weller 2003) and often require the use of multiple methodologies (Darbyshire, MacDougall, and Schiller 2005; Punch 2002a) in their attempts to capture children's voices. These techniques include verbal techniques such as focus groups, third-person story-telling and child-controlled voice recording, and visual techniques such as drawing, photo journals, and mapping, to name a few (Anderson 2008; C. D. Clark 2004; Eldén 2013; Hecht 1998; Hunleth 2011; Keat, Strickland, and Marinak 2009; Paulston 1996; Young and Barrett 2001).[21] The proponents of these techniques tend to

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[21] In addition, several books have been published designed for researchers interested in doing qualitative research with (rather than on) children including those by Greene and Hogan (2005), Christensen and James (2017), Tisdall, Davis, and Gallagher (2009), and (specifically dedicated to focus groups with children) Trakas (2008).

emphasize how the techniques facilitate children's participation, address differences in children's communication styles, and efface power differentials between the adult researcher and children participants. Some argue they can even overcome cross-cultural and multilingual barriers (Fournier et al. 2014; Keat, Strickland, and Marinak 2009). They explain that child-centered techniques are fun and engaging for children and will therefore generate better or at least more complete/complex data (Barker and Weller 2003; Eldén 2013; Punch 2002a). Furthermore, for researchers interested in influencing policy and social change, child-centered techniques purportedly assist in giving children's voices a kind of authenticity recognizable to (adult) policymakers (Darbyshire, MacDougall, and Schiller 2005).

However, the use of so-called "child-centered" techniques has not been without its critics. Many challenge the name "child-centered" pointing out that the methods are designed by adults and implemented for the purposes of adult researchers; are oriented by adult assumptions about children – what they will enjoy doing, and what activities (such as drawing) are considered "child-like"; and are not necessarily different than those used in research with adults (Christensen and James 2017; Hunleth 2011; Punch 2002b). Jean Hunleth (2011) points out that when so-called "child-centered" methods are used among adults they are called "participatory methods." Additionally, she encourages researchers to recognize children's motivations for participating in research along with the alternative ways in which children at times utilize research methodologies for their own purposes. Similarly, Punch (2002b) encourages using terms such as "researcher friendly," "person friendly," or "research participant centered." She argues that the need for "child-centered" methods is more a reflection of adult perceptions and assumptions about children and society's structural positioning of children as a marginal group than due to actual differences in children's developmental capacities.

Other researchers critique the emphasis on participatory techniques and of listening to children's voices as inherently beneficial methodologies. Sirkka Komulainen (2007) draws attention to the ambiguity of listening to children's voices, pointing out that adult constructions of children's voices are necessarily political. Komilainen questions assumptions that children always act as rational, autonomous, intentional agents and draws attention to the possible harms in having to talk. Meanwhile, Lesley-Anne Gallacher and Michael Gallager (2008) argue that participatory techniques are no better nor worse than other (traditional) techniques, are no less problematic, and are no more of a guarantee of research success. Additionally, they point out that participatory techniques conflate activity with agency by assuming that children must be active to participate. Furthermore, they argue, participatory techniques have the implicit assumption that adults must empower children to be active, since participatory techniques are almost always developed and implemented by adults. In his own piece, Gallagher (2008) questions assumption that adults are powerful and children powerless and even that power is inherently bad. There is almost as much work published on the difficulties and limitations of using participatory methodologies with children as there is on the benefits, much of which is authored by researchers simultaneously critiquing and embracing their own use of participatory methodologies with children (Barker and Weller 2003; T. Cook and Hess 2007; Darbyshire, MacDougall, and Schiller 2005; Eldén 2013; Hunleth 2011; Limb and Dwyer 2001; Punch 2001; Young and Barrett 2001).

Joining the call for critical reflection upon research methodologies used with children, I discuss some of my failed research methods. Bolstered by the recommendations of many researchers who had gone before me, especially those emphasizing the use of multiple techniques to prevent children's boredom, decrease bias, and to triangulate and cross-check findings (Darbyshire, MacDougall, and Schiller 2005; Punch 2002a, 2002b), I entered the field armed with a variety of participatory techniques. I planned to have children draw their homes and families, make maps of their communities, take pictures of what was important to them, and voice record their life stories. However, during my fieldwork these techniques were at best minimally fruitful. I hope that acknowledging these failures will assist future researchers in their work with children (either as they attempt to implement participatory techniques, or by assuaging their guilt if they do not). Additionally, some of the reasons behind my failures may offer insight into working with sick children in particular.

First, the children at Baaliro simply did not enjoy drawing. Whenever I attempted to ask them to draw anything they sat staring at the blank pages. Some would claim they did not know how to draw and others would simply say they did not want to draw. Those who did draw for me produced standardized images of objects which they had learned to draw in school[22] – a pot, a ball, a chicken, a flower, a sun. For their part, older children preferred to write about rather than draw a picture for any topic I gave them (a preference I could certainly understand given my own limited drawing skills). I am not the first researcher to make these observations. Reflecting upon her experiences with children drawing in rural Bolivia, Punch (2002b) also found that children produced stereotyped images which they had learned from blackboard or textbooks, that children's self-perception of their (in)ability to draw greatly affected their willingness to draw, and that older children preferred written work because drawing was viewed as an activity for young children. In contrast to Baaliro children's apathy for drawing, children of all ages in my research loved coloring. One of our shared favorite activities was to spend the afternoon coloring and talking. When the children were doing an activity that they enjoyed, they were much more

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[22] I came to know that they learned these stylized drawings at school both because children told me when I asked them, and because I saw these same drawings in nearly all children's school notebooks.

willing to answer my (at times annoying) questions. I acknowledge that if I had spent more time teaching the children how to draw, or simply drawing myself and allowing them to copy my work, they may have eventually become more comfortable with drawing and started creating their own works; however, my own self-perception of having limited drawing abilities in turn precluded the possibility of my teaching any drawing skills.

Second, getting children to make maps of their homes or communities was nearly impossible. Like drawing, children began learning about map-making in school. Most found maps to be difficult to understand and strongly (and negatively) associated mapmaking with school work. In the conversations I had with Ugandan adults, nearly all admitted that while they had learned mapmaking and map-reading in school, they had never mastered the skills.[23] Rather than rely on visual maps, people were very adept at giving and following detailed oral directions. For instance, Mary and the driver never once used a map to navigate to the home of a child and could not point out a child's home on a map when I asked. Instead, Mary used directions she had written down based on what the caregiver told her. Combined with her and the driver's impressively accurate recollections of the areas they frequented, they were always able to locate a child's home. Similarly, I found having children talk about their communities was far more effective than trying to get them to draw maps.

Third, my attempts at child directed photography were also only minimally successful. I had hoped to leave reintegrated children with a camera for a week and then have them share their photos with me, but this proved logistically challenging, because Mary only visited children a

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[23] A fellow researcher also conducting her fieldwork in Uganda at the time shared with me her failed attempts of utilizing maps in her research with adults. As an example of how much maps "don't make sense," one of her participants, a highly educated and literate woman, shared the story of how on a trip to Disney Land she simply could not understand the maps used by the concierge to give her directions. The rare exception to this difficulty with maps was my host sister in my second family, who actually enjoyed studying maps and geography.

few times a year. It would have added too much burden to her already busy schedule to have her bring me back to a child’s home after only a week, and I did not trust my navigation skills to travel to the children’s villages on my own. Additionally, my attempts at child-directed photography at Baaliro further convinced me that this technique was unlikely to produce meaningful results. Some children needed at least basic training in how to use the camera to capture the images they wanted. In my first attempt to have children at Baaliro take photos on their own, one-half to one-third of the images captured were completely unintelligible – either completely black with fingers obscuring the lens or so out of focus that the subject of the picture was unidentifiable. While I could probably have rectified this by having training sessions with children before giving them the cameras, I would still have been limited to only having children at Baaliro provide me with photos as the logistics of doing training for reintegrated children would again have been challenging, given that my interactions with children in the field were circumscribed by Mary’s schedule. Since I was already familiar with Baaliro, using child-led photography in this setting seemed less useful and interesting. I also found that older children and caregivers quickly took control of the camera either directing the child in what to take photos of or taking the camera themselves to take pictures. Thus, I was not confident that the photos I would receive from children if I gave them cameras would be their own. Additionally, I found that even those children who were proficient with the cameras would rapidly take photos until either the battery ran out or the memory card was full. These photos consisted almost entirely of children posing for the camera. While analyzing these poses could provide some information about gender and age relations and idealized presentations of self, the children already struck poses whenever I pulled out my camera, obfuscating the benefit of child-led photography.

Finally, I used voice recording sparingly, especially when interviewing children. Despite other researchers' successes with child-led voice recording (Hecht 1998; Hunleth 2011), I found the use of recording to be incongruous for two reasons. First, the children staying at Baaliro tended to freeze up and not talk freely in the presence of the technology. Second, some children were simply too sick to talk. For instance, James readily wrote his life story for me, but did not want to give it to me verbally because he was suffering from oral thrush which made talking painful. I acknowledge that I may have had more success if I had insisted on using the technology more frequently, giving children the opportunity to become accustomed to it, but I found it far simpler and less intimidating for children to keep written field notes in a small notebook which I typed up in the evenings. This was especially true when working with reintegrated children who were even less familiar with me. Additionally, I allowed children to look through my notebooks, and they enjoyed identifying their names and the names of their peers on the pages.[24]

Part of my failure with participatory techniques may have been my rapid abandonment of them after only a few attempts. I acknowledge that, in every case, if I had given the children additional training (in drawing, in map making, in the use of the cameras and voice recorder) these techniques could have proven fruitful. Additionally, there are many techniques I did not even attempt which could have proven useful – including role-play and focus groups. However, rather than forcing children to become comfortable with techniques and technology which they clearly did not enjoy or were overly distracted by, I chose to take the children's lead in my interactions with them. They wanted to talk to me about their homes, especially telling me about the food they ate at home (for more on this see Chapter 6), they wanted me to tell them about

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[24] I was not concerned about confidentiality because most of what I wrote was unintelligible to them since it was written in my own shorthand and the children had very low literacy and knew little English.

airplanes and pizza, or they simply wanted to play – going down the slide with me (in the words of a popular song at the time) “Neera, neera, neera!” [Again, and again, and again!].

Another reason for my lack of success with participatory techniques may be that, most researchers who successfully use these techniques with children work with healthy children[25] (Abadía-Barrero (2011), Bluebond-Langner (1978), Clark (2003), and Parsons (2012) are notable exceptions whose research focused on sick children). Many participatory techniques require children to feel well enough to engage completely with the researcher or with one another. While I do not want to frame the children at Baaliro as being perpetually ill,[26] many times they did not feel well. Sometimes when children were not feeling well, they simply wanted company. I recall an instance when 8-year-old Martin[27] curled up in a chair in the office while I worked at inputting data from the children’s case files. After a few minutes, Martin raised his head and told me, “Colini, okutulira wano naawe, mpulira mirembe” [Colleen, [when I am] sitting here with you, I feel at peace]. Martin was not feeling well enough to talk much that day, nor to participate in drawing, nor to run around Baaliro taking photos, but he instead sat with me. Later, when he was feeling better, he told me all about his home, but he still did not want to draw a picture or a map of it.

3.3 Conclusions

In this chapter I have described my methods for working with the children living at Baaliro and those who had been reintegrated to their communities. I offer reflexive assessments

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[25] My appreciation to Jean Hunleth for making clear to me this important point.

[26] See Chapters 4 and 5 for a discussion of how staff fought against the notion that children in Baaliro’s program were sick, and instead emphasized their wellness, their ability to do housework, and their future productive potential if they took their ARVs properly.

[27] See Chapter 6 for Martin’s story.

of failed techniques as well as of my role at Baaliro. In my work, I found that participatory techniques, the hallmark of “child-friendly” research, were not always well received by the children. Additionally, in my interactions with (at times) sick children, both their precarious health and the over-burdened staff demanded (both ethically and practically) that I take on a more active and responsible role than I had originally envisioned as an objective researcher.

Chapter 4: Baaliro is(n't) a Hospital: The Liminality of Rehabilitation

This chapter consists of two main parts. In the first part of this chapter, I describe the physical space of Baaliro as well as the children who were staying at Baaliro and staff who worked there. I demonstrate that Baaliro in many ways, despite staff's emphatic emphasis that Baaliro was *eddwaliro* (a clinic/hospital) and not *ennyumba* (a house), did not look or feel like a hospital. In the second part of this chapter, I discuss Baaliro's approach to rehabilitation and how they both used and did not use metrics to track children's progress. In contrast to many HIV clinics where patients are reduced to numbers such as viral load and CD4 count (Brada 2011; Meinert, Mogensen, and Twebaze 2009; Whyte 2014), Baaliro was concerned both with numerical measures of children's rehabilitation *and* with the child's social situation. What links these two parts together is that they show the many ways that Baaliro defied easy categorization and demonstrate the complexity of (for the staff) caring for children living with HIV and (for children) growing up with HIV. In a sense, both the children at Baaliro and Baaliro itself occupied a liminal space – betwixt and between – between sickness and health, between hospital and home, and between rehabilitation and reintegration (Turner 1964).

4.1 Description of the Staff, Children, and House

4.1.1 Baaliro's Staff -The Adults with Whom Children Interacted

Baaliro's full-time staff, all of whom were Ugandan, included the following: Sister Sally (the program director), Dorothy (the matron), Sadat (the handyman), and Mary (the social worker) (see Appendix D). Sister Sally, Dorothy, and Sadat primarily lived at the center, but all had homes elsewhere as well. Godfrey, while technically employed by St. Damien's, also lived on the clinic's grounds and through his work as a community organizer played an important role in finding children in need of rehabilitation. The clinical staff hired by Baaliro included a pediatrician and two nurse-midwives. These were the adults that the children who stayed at Baaliro knew and interacted with on a regular basis.

Sister Sally had numerous administrative responsibilities, and spent most of her time in the office at Baaliro. Additionally, she was trained as a nurse, and because of her medical training, many people referred to her simply as Sister.[1] She generally oversaw the health of the children, sending them up to St. Damien's if they were sick, and ensuring that they received the medications prescribed by the clinicians, but overall her role was more administrative than clinical, and she had the unenviable job of representing Baaliro in any negotiations with St. Damien's administrators. At Baaliro she was actively involved in children's cases – meeting with caregivers and children in the office upon arrival, throughout treatment, and after reintegration. She often took on the role of disciplinarian, and both children and caregivers frequently told me, "Mmutya" [I fear her]. Some attributed their fear to her corpulence, and though Sister Sally never used corporal punishment, she would occasionally threaten to use a switch when scolding children who were misbehaving.[2] Most of the time, however, Sister preferred to take a gentler approach, talking to children (and caregivers) and trying to coax them into good behavior *mpola mpola* (slowly-by-slowly).[3] She repeatedly told children not to fear her, and to come to her with

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[1] The title of "sister" in Uganda-English is used for both nurses and nuns. This is common throughout much of East Africa and in British colonies worldwide. The use of "sister" for nurses is commonly thought to date back to the early 19th century when most (if not all) nurses were also nuns.

[2] Threats of corporal punishment were extremely common at Baaliro, and while I never witnessed corporal punishment (likely due to Baaliro's strict policy forbidding it), I was told by children, caregivers, and staff that corporal punishment was very common in Uganda. Children who had been at Baaliro for some time would inform newly arrived children that the staff were not allowed to beat them.

[3] For more on what defined, as well as the importance of, good behavior, see Chapter 5.

their problems.[4] Historically, Sister spent the night at Baaliro in a room next to the main office; however, during my research she began suffering from a variety of health problems which she attributed to stress and high blood pressure, and so returned to her home most evenings. She explained that she was getting older and did not have the energy that she had in the past.

Dorothy, the matron, was responsible for ensuring that meals were prepared and served on time and for the cleanliness of Baaliro. While in reality the children themselves (or their caregivers) did most of the cleaning, food preparation, and housework, with Dorothy overseeing their work, this does not, in any way, mean that Dorothy had an easy job.[5] While Sister Sally did not always agree with Dorothy's methods,[6] she respected Dorothy for successfully managing the difficult task of maintaining the large house and compound and organizing all of the children and caregivers staying at Baaliro. Dorothy's main interactions with the children were waking them in the mornings, assigning them work, and overseeing that they did it. Without a written or codified list of rules and responsibilities, Dorothy established expectations of what work was to be done and by whom. Her work assignments took into account several aspects, including the physical health of the child as well as his/her temperament. Dorothy typically rested in her room in the afternoons and visited her family (including her young children) for only an hour each weekday evening and on Sundays. For her weekly day off, she left Baaliro Saturday evening after serving supper and returned Monday morning in time to serve tea.[7] Children generally associated the times when Dorothy was resting or away as enjoyable free time during which they did not have

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[4] For children at Baaliro this especially applied to any kinds of symptoms they were experiencing and also included any teasing they were experiencing from other children at the center. For reintegrated children, this applied to any problems they were having with school, with accessing their medications, or with being overworked by caregivers.

[5] I discuss children's involvement in housework and the important role work played at Baaliro in Chapter 5.

[6] As I discuss below, Dorothy had an abrasive personality, and a reputation for being verbally abusive. She did not hesitate to yell at and scold children (and caregivers), whereas Sister Sally took a much softer approach.

[7] Once, when I asked if she enjoyed this day of rest to spend with her family, she angrily replied that she never got a day of rest, because when she returned home she had to catch up on a week's worth of housework!

to work nor worry about being scolded. Dorothy's temperament was highly volatile – she could be chatty and approachable one minute and tight lipped or even verbally abusive the next. Most children (and even caregivers) approached her with caution explaining, "Mmutya" [I fear her], both because of her mood-swings and because of her propensity for assigning work. Dorothy scolded children far more frequently and harshly than any other adult and, not uncommonly, brought children to tears with her reprimands. One boy in particular preferred to go to school without having his morning tea, rather than to face Dorothy on some mornings. However, some, especially older children, formed a close relationship with Dorothy and confided exclusively in her. At times, Dorothy was very affectionate towards the children. She seemed genuinely happy when those who had been reintegrated visited and stopped in to see her, especially when they were doing well.

Although Sadat's official title was "handyman" he did much more at Baaliro. His responsibilities included house repairs and improvements, running and managing Baaliro's income-generating-activities (IGAs) (including the chickens, the goats, the vegetable fields surrounding Baaliro, and the farm), and security. Sadat lived in a small room behind the main house next to the kitchen, in part, so that he could hear and respond to any night-time thieves.[8] He was young, strong, and intelligent. Combined with his excellent work ethic, Sadat was always willing and usually able to solve any problem. He was very friendly with the children and enjoyed talking to and playing with them whenever he had the opportunity. They, in turn, enjoyed spending time with him, and would even volunteer to help him with the IGAs if they were feeling well.

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[8] There were several night-time thefts (and attempts) during my fieldwork.

Mary, the social worker, did not live at Baaliro. Tuesday to Saturday she arrived at the center around 9:00 am and frequently did not return home until 6:00 pm or later. Mary was intimately familiar with all of the children and their caregivers, and through her field-visits to pay for their school fees, she maintained contact with the reintegrated children. Her ability to remember the children, details about their cases, and the routes to their homes was truly impressive. Though she occasionally played a disciplinary role, few children or caregivers said that they feared Mary. Overall, she had less of a role in the daily activities at Baaliro, but was primarily responsible for enrolling children, preparing caregivers to receive children for reintegration, and monitoring children once they had been reintegrated. She also generated reports for donors (especially Child Network) and gave education talks at reintegrated children's schools on various topics including HIV/AIDS, hygiene, and nutrition.

Godfrey, though technically not a member of Baaliro's staff, was very involved with the children at Baaliro and lived at St. Damien's. Godfrey had volunteered and worked for St. Damien's since the beginning of the organization. He was employed as a peer-counselor and community organizer at St. Damien's, and because of his work in the surrounding communities he played a major role in identifying and bringing children to Baaliro for rehabilitation. He also frequently participated in community meetings and negotiations when Baaliro was dealing with a difficult reintegration situation – such as when two brothers' mother died and there was a dispute over who would care for them, or when a mentally-ill father repeatedly removed his son from other family members' care resulting in the child being neglected. Additionally, he maintained a friendly relationship with the children, often giving them sugar cane or sharing mangoes with them. He joked freely with them, and children never spoke of fearing Godfrey. Because of his friendly and approachable demeanor, he was often able to talk to children to find out why they were annoyed or upset when they refused to talk to other adults. He generally sided with children whenever there was a dispute and did not participate in disciplining children, although he would kindly correct children who were misbehaving and encourage good behavior. Part of Godfrey's pay included living in a two-room structure at St. Damien's main gate, so he lived on the same grounds as, but not in, Baaliro.[9] He was a close friend to Sister Sally and frequently joined her for supper at Baaliro. Whenever he visited, he would greet the children in the dining room with high-fives, "bongas," and/or song and dance. A bonga is a kind of fist bump, and Godfrey amplified the fun of this activity by pretending that the children were so strong they hurt his hand when they bonga-ed with him. He was truly one of the friendliest, jovial, and most caring people I have ever met.

Baaliro also paid the salaries for one doctor and two nurse-midwives. These clinical staff primarily worked at St. Damien's, but also had duties at Baaliro. The doctor, a pediatric specialist, headed the medical department at St. Damien's as well as his own private practice clinic. He worked at St. Damien's three days a week, and walked through Baaliro when he was working at St. Damien's. During these walk throughs, he greeted children, and might comment to Sister Sally that she should send a child up to the clinic for evaluation if he noted a new symptom. However, he did not formally evaluate children unless they were sent up to the clinic. Additionally, he emphasized that any of the clinicians at St. Damien's were able to treat the children from Baaliro, and that they did not need to see him in particular. He explained that his insistence that children could see any clinician stemmed from a time when the clinicians at St. Damien's were refusing to treat the children from Baaliro, because they claimed they were solely the pediatrician's responsibility. From his perspective, the clinicians should be more than capable

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[9] His room had no plumbing, so he used Baaliro's bathroom for bathing.

of handling most of the medical issues that the children presented, and they only needed to send children to him (or consult him for advice) if they ran into problems. Additionally, since he only worked at St. Damien's three days a week, if the other clinicians were refusing to see and treat the children at Baaliro, the could go several days without receiving a medical evaluation.

The nurse-midwives primarily served in the maternity ward, but also assisted Sister Sally in administering the children's daily medications and weighing and measuring the children. Sister Sally also had the midwives assist her once a year in generating a list of the children's CD4 counts, as part of adherence monitoring. However, outside of these brief obligations which brought them down to Baaliro, the midwives spent nearly all their time at St. Damien's. Occasionally a midwife accompanied Mary on her field-visits. The midwives were supposed to always accompany Mary on her field-visits, in order to assess children as part of their follow-up and to provide basic treatment, but usually they were unable to get away from their duties in the maternity ward. This was frequently a point of contention between Sister Sally and the human resources administrator at St. Damien's. The children largely viewed all of the medical staff as *omusawo* and did not distinguish between their official titles and roles.[10] Although these individuals were occasionally involved in counseling children on nutrition or adherence they generally did not form close relationships with the children.

One of the most striking things about Baaliro's staff was that none of the staff who stayed and spent most of their time at Baaliro were practicing clinicians. Only Sister Sally had any medical training, but her role at Baaliro was administrative and she very rarely applied her nursing training. The remaining staff who stayed at Baaliro had no formal medical training, and

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[10] *Omusawo* is often translated as doctor, but more accurately means clinician and can include almost anyone who works in a clinic such as a nurse, medical assistant, traditional healer or even social worker. Some children referred to Mary an *omusawo* (calling her "Musawo Mary") when the first were enrolled at Baaliro, though most quickly recognized that she had a non-clinical role and referred to her as "Auntie" Mary.

the clinical staff were rarely found at Baaliro because they spent the majority of their time at St. Damien's. Given Baaliro's insistence that they were *eddwaliro* (a hospital), and not *ennyumba* (a [children's] home), the lack of medical staff at Baaliro itself was surprising.

4.1.2 "Those Children Don't Look Sick"

I describe the daily routines of Baaliro in detail in the next chapter, but in brief, children's days were structured around school and housework. One of the things that was most striking about the children at Baaliro was that at any given time, many of them did not look sick and many of them did not act like sick children. Some children were visibly malnourished and others remained 'marked' with scars from their skin infections.[11] However, because Baaliro kept children at the center until they were fully stabilized, many children at first glance appeared well-fed with few visible signs of infection. Not only their physical appearance, but their activity level made children appear to be not sick. The children were very much involved in the housework and maintenance of Baaliro if they were not attending school or playing. All of these activities (work, school, and play) indexed those of healthy children. Obviously, when children first arrived or if a child was acutely ill (for example from malaria, a chest infection, or diarrhea), they could look terribly ill and often did not participate in Baaliro's activities. However, many visitors to Baaliro commented that at first glance the children did not look seriously ill.[12]

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[11] In his ethnography of children's experiences growing up with HIV in Zimbabwe, Ross Parsons (2012) describes the tell-tale marks left by un/under-treated AIDS-related skin infections which literally marked children as being infected with HIV. Some, but not all, children at Baaliro suffered from these visible indicators of their HIV infection. The main difference between the children at Baaliro and in Parsons study was that Baaliro provided treatment for opportunistic infections, so children were more likely to clear their skin infections before lasting scarring occurred.

[12] *Bazungu* visitors especially often did not recognize the signs of past/current skin infections, nor that these were indicators of HIV-infection.

4.1.3 Baaliro's Location and Layout

In addition to the staff and children inhabiting Baaliro being surprisingly non-hospital-like, the physical structure of Baaliro itself also did not look or feel like a hospital. Despite Baaliro's staff insistence that Baaliro be identified as a treatment center, it looked very much like a children's home. Children stayed in small rooms rather than large wards and moved freely around the house and surrounding compound. They ate together and were actively involved in maintaining the center, which neither smelled of disinfectant (typically associated with private hospitals) nor of waste/blood/illness (typically associated with public hospitals).

As previously mentioned, Baaliro was located on the grounds of St. Damien's, behind the maternity and pediatric wards, but was visually and physically separated from St. Damien's by a large hedge (see Figure 2.3 for a map of St. Damien's and Baaliro). Baaliro consisted of several buildings. The primary and largest building was the house, which also contained Baaliro's main office. The main entrance, with an impressive awning, looked out onto a playground, the wooden structures of which had been (re)built annually by a rotating group of British teenagers until a Ugandan-based charity constructed a more permanent metal-and-recycled-tire-based playground in 2014. The more practical structures such as the kitchen, shed, chicken coop, and latrine were located behind the main house. Since children spent a great deal of time both within the main house and moving around the back courtyard, I will describe these locations in some detail.

<u>The Main House: A Temporary Home</u>

The main house was organized around a large, open, rectangular courtyard in the center (see Figure 4.1). All of the permanent structures at Baaliro had red concrete floors and painted

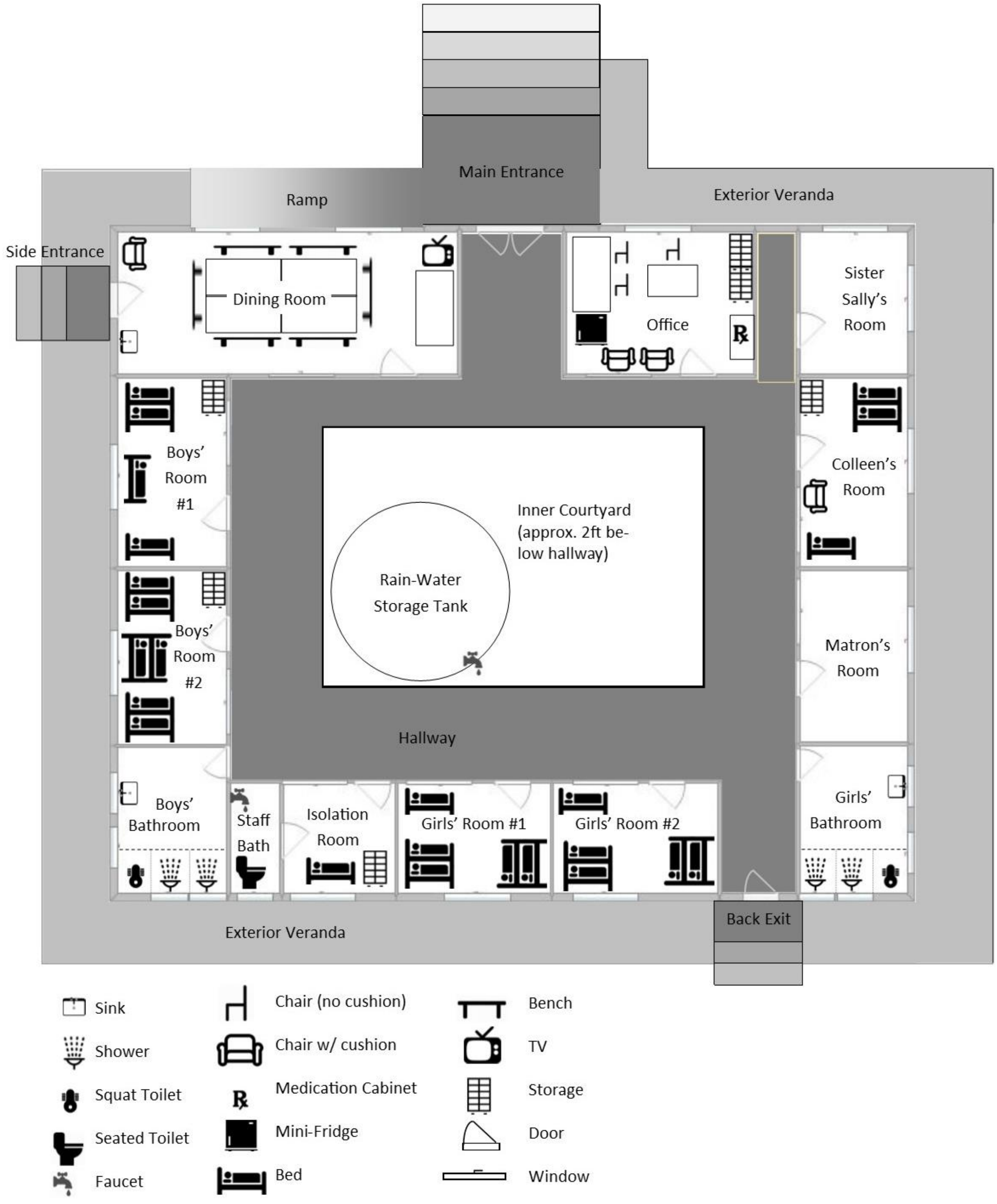

Figure 4.1 Map of Baaliro's Main House
The interior hallway was one to two feet higher than the exterior veranda and two feet higher than the interior courtyard.

concrete walls with a corrugated iron roof. The interior hallway was raised about two feet above the grass courtyard, and the water from the roof drained into a large water tank which took up nearly a quarter of the courtyard.[13] Ornamental plants decorated the courtyard's perimeter and cartoon safari animals had been painted along the walls. Once brightly colored, the animals were faded and worn, but somehow retained the playfulness originally intended. Other than these figures, all of the interior walls were painted a dull yellow, with a glossy finish along the bottom half of the walls to make cleaning young handprints easier. All of the rooms (except for the dining room) had wooden doors (with the name of an African country painted on them) which opened onto the interior hallway. Only the dining room (its doors were metal with large glass panes) had an exterior exit. The main entrance and back exit provided access between the outside of the house and the interior hallway. At dusk these gates were closed, so entrance was only possible via the dining room, and when Sister Sally went to bed in the evening, she locked the dining-room door, so no one could enter or exit the house without a key. All of the rooms, except for Sister Sally's, had windows facing the interior hallway, and all had exterior facing windows.

Six of the rooms in the house were designed to be bedrooms for the children, but two of the rooms were occupied by Dorothy and me during my time in the field. Prior to my arrival and after I left, my room was used as another room for children staying at Baaliro. Each bedroom housed up to six children – giving the house a maximum capacity of 24 children. But usually there were far fewer, and as I mentioned previously, during my fieldwork there were no more than a dozen children staying at Baaliro at any given time. The beds (either double bunks or single beds) were designed with children in mind, and even at 5'2" I barely fit on mine. I had to stoop low to duck under the top bunk and bonked my head on more than one occasion while

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[13] The original plastic tank ruptured and was replaced during my fieldwork by a larger interlocking-murram-brick and cement tank whose construction was funded through a grant from the Peace Corps.

getting out of bed. The sickest children were always given a bottom bed when they first arrived. When caregivers stayed with their children, they slept in the same rooms, often sharing a bed with the child. The bedrooms were gender segregated according to the children's gender, except for in the case of Nakisise, a four-year-old male child staying with his 14-year-old aunt whom his relatives had sent as his caregiver. In this case the two slept in one of the girls' rooms. The larger bedrooms (the boys' rooms during my stay) contained a storage area with shelves and a place to hang clothing, but the smaller rooms lacked a storage area. A few children had a metal trunk in which they stored their belongings, but more often children arrived without a trunk and Sister Sally provided them with a cardboard box or large plastic bag to serve this purpose. Mosquito nets draped over every bed but were often un-tucked and riddled with holes.

The door handles and locks for most of the children's rooms were broken, so the children had to place a piece of cloth in the doors to keep them closed at night. However, the locks for my room and the matron's room both worked, so we could lock our doors when we were not inside our rooms.[14] The children granted me free access to their rooms, though I would knock and announce my presence before entering. When a child told me not to enter, I obliged his/her request, but this rarely happened. I generally did not enter a room if a child was not present other than to retrieve a requested item or to quickly survey the room (such as when searching for a child or to assess the mosquito nets). I did not allow the children to enter my room.

The boys and girls had separate bathrooms, which contained a sink, two showers and a floor-level flush toilet. The doors for the toilet and one shower stall were missing in the boy's bathroom, and the remaining shower stall was locked and used only by Sadat and Godfrey. There

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[14] Sister Sally insisted on repairing the lock to my room before allowing me to move in. One of the children's rooms had a malfunctioning lock and once a 6-year-old girl accidentally locked herself in the room. She was so distressed that she both urinated and vomited in the room before staff found a way to open the door.

was no hot water in the building, but because of a private water tower constructed behind the house, the house usually had strong water pressure and continued to have water even during municipal water outages. Most of the children had never used a shower before coming to Baaliro. Some preferred to bathe using a basin rather than the shower, but others enjoyed playing in the shower. Similarly, most had never used a flush toilet prior to coming to the center, and it seemed the children only used the flush toilets for night-time urination, but otherwise used the pit latrines located behind the shed (see Figure 4.2). The handle to flush the toilet was far above the reach of all but the oldest and tallest children, and I never heard a child flush the toilet, though I did see them pour water down the toilet after they used it to dispose of vomit. The bathrooms' floors and walls were covered with half-inch electric blue tiles making them bright spaces.

Sister Sally insisted that I not use the girls' bathroom because "we have many infections, especially fungal." Instead she gave me a key to the staff bathroom, which could only be accessed by passing through the isolation room. Only Sister Sally and I had access to this bathroom, which contained a chair-height flush toilet (with no seat) and a thigh-high tap for bathing. The bathroom at one point had a shower, but it broke long before I began my research.

Originally, the isolation room had been constructed to house children with contagious conditions (namely TB) when they first came to Baaliro. As originally conceived, children in the isolation room would have their own bathroom and stay in the room until they were no-longer a threat to the other children. However, the isolation room was never used for its original purpose during my fieldwork. Newly admitted children were usually placed in rooms with the other children, or in a few cases where Sister Sally was concerned that the child may have TB, placed in a room alone. Newly admitted children were never fully isolated from the other children, though, and used the shared bathroom and dining facilities. Instead the isolation room was used as an overflow room when reintegrated children needed to spend the night either for a workshop or to pick up their medication refill. Along with the hallways, the isolation room was the only room with decorations painted on the walls, depicting a snowy mountainous landscape with a Swiss flag on one wall opposite a lush green hilly landscape with a Ugandan flag on the other.

The dining room had a sink, which the children used to wash their hands at mealtime, and (far more importantly, as far as the children were concerned) the TV. Four large tables pushed together with benches surrounding the perimeter formed the central eating and activity space. The walls were covered with coloring sheets and several large pages of handprints labeled with dates they were made and the names of children to whom they belonged. Both the exterior and interior doors to the dining room could be locked, a function which became important when children were staying up too late watching TV or refusing to turn the TV off during the day when it was time for work, although it was not normally locked. Children could usually be found in the dining room watching TV whenever they were not engaged in work or at school.[15] The dining room also doubled as the main meeting place and activity center at Baaliro. Afternoon activities (especially coloring) with volunteers, any special workshops (such as the youth workshop), and Baaliro staff meetings took place in the dining room.

The office housed the children's case files, a small refrigerator, the medicine cabinet, and several other storage areas containing school supplies, computer equipment, digital cameras, and other office materials. The medicine cabinet was divided into cubby-holes labeled with the names of children. In addition to a very small collection of first-aid supplies, the cabinet only contained the medications that the children were currently taking. Thus it did *not* function as a mini-pharmacy. While the cabinet had a lock, I never witnessed it being used; however, the

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[15] The regulation, or lack thereof, of TV-watching at times became a point of contention.

office door was usually locked whenever it was unoccupied. The concern seemed to be more for the personal belongings (purses, cell phones, etc.) of staff left in the office and the computer equipment, rather than for the confidentiality of files and/or medications.

Sister Sally spent most of her day in the office dealing with Baaliro's administrative issues. Similarly, Mary could be found in the office writing reports and updating the children's files whenever she was not in the field visiting children. Sister Sally and/or Mary met with caregivers in the office, and the office had several chairs to accommodate visitors. As far as the children were concerned, the office was the first place they saw when they came to Baaliro and the place they visited if/when they returned to the center. When they were living at Baaliro, children were called to the office twice a day to take their medications, as well as for disciplinary problems. A bulletin-board along one wall displayed photographs of children who had stayed at Baaliro. These photographs were not formal head shots, but photographs taken by volunteers of children playing, cooking, or posing for the camera. Occasionally children, especially those who were rebounding to the center, would look at the photographs, trying to find themselves or to name other children who they knew in the pictures. Even children who did not know anyone in the pictures enjoyed looking at them, and Sister Sally often had to chase children out of office so she could resume her work.

The house was surrounded by an exterior "veranda" – a two-foot-wide raised concrete walkway around the perimeter. The veranda was a level surface around the exterior, but varied in height from the ground, from a few inches to over two feet, as the ground sloped. Children and caregivers often used the veranda as a place to sit, talk, play, and work – especially the portion along the backside of the house and by the kitchens.

Behind the House: A Place for Work

Much of the day-to-day activity at Baaliro took place behind the house, centered around the kitchens (see Figure 4.2). The first kitchen, also referred to as "Dorothy's kitchen," had a large sink, water purifier,[16] and a few tables and chairs. This was the matron's main abode, and the point from which she oversaw most of the house's operations. Additionally, the kitchen often served as an informal staff meeting place. Sister Sally and Mary took morning and afternoon tea and in the evenings, Sister Sally, Sadat, and Godfrey chatted over their suppers in the kitchen. The building containing the kitchen also had a storage room for keeping supplies and Sadat's room. The second kitchen, built behind the first, contained a wood fire stove, used to cook porridge and almost all of the meals, and a small storage closet (for keeping pots, utensils, brooms, and rakes) and a wood-fire oven.[17] Additionally, Dorothy had several smaller charcoal stoves which she used to boil the milk for morning tea, to cook *chapati* (unleavened flatbread), and to prepare additional food for the sickest children.[18] The washing area and drying rack were located next to the second kitchen, but some distance from the exterior tap. Children used a jerry-can to haul water from the tap to the utensil cleaning area. Dorothy did not permit children to wash plates with water at the tap, because, she explained, this was wasteful, clogged the drain, and was not how things were washed in the village.[19] The tap also provided water for washing clothes and bedding – which children usually did along the main house's veranda closest to the

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[16] As in most low and middle income countries, the tap water was non-potable, and especially because of their compromised immune systems, the children at Baaliro needed to drink clean water. Prior to the donated water purifier, Dorothy boiled water for Baaliro's drinking water. Boiling water uses a considerable amount of fuel (firewood) and requires preparation because the water must be boiled for several minutes and then allowed to cool. The water purifier largely eliminated the need to boil water; however, if the power failed, the water purifier could not be used, so Dorothy still usually had a small pot of cooled boiled water ready for drinking.

[17] The wood-fire oven had been donated, and staff explained they could use it to make cakes or bread, but it was never used during my fieldwork.

[18] Additional food for sick children included eggs or an extra serving of *matooke* or potatoes in the mornings.

[19] Instead they poured water into one large pot and used this to clean all of the cooking utensils and plates.

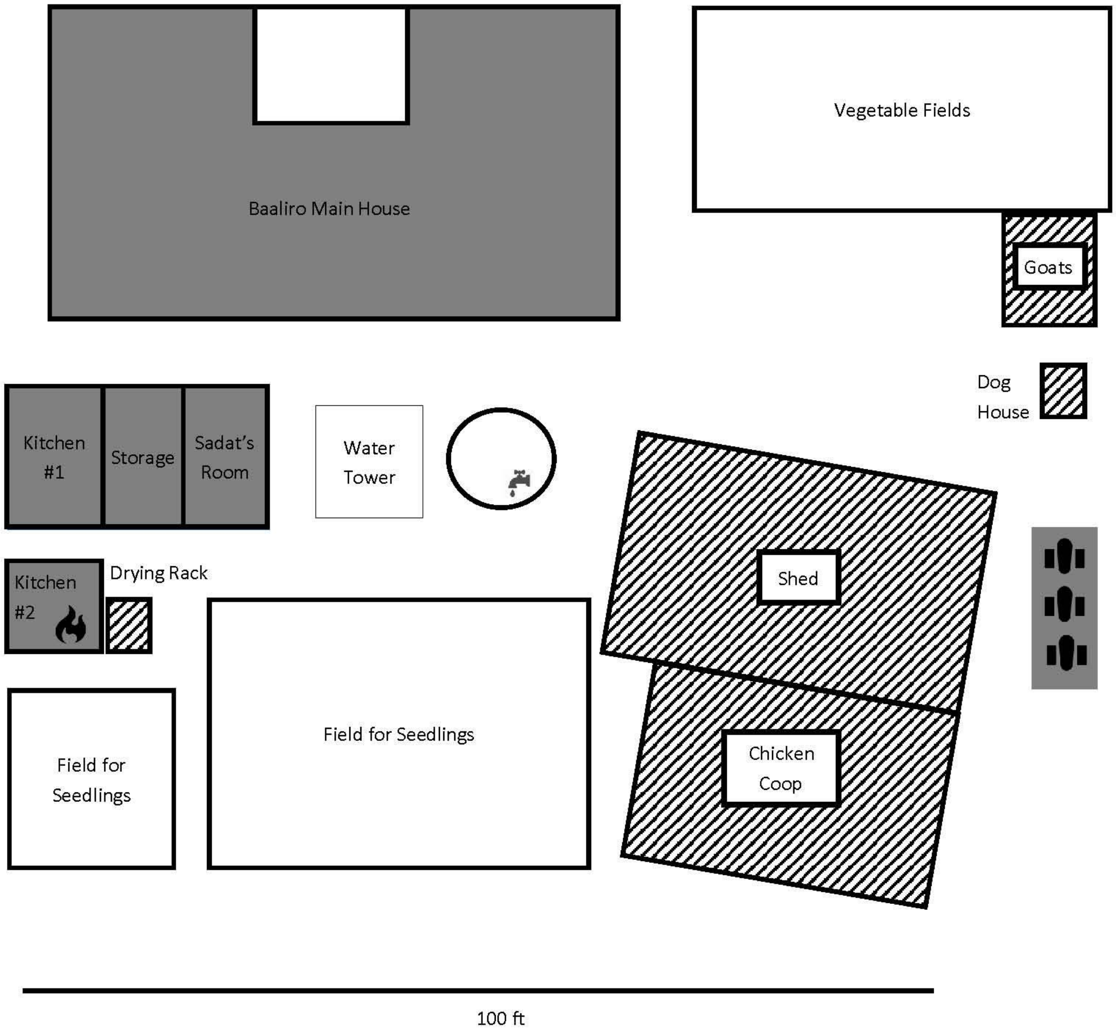

Figure 4.2 Map of the Back of Baaliro
Children spent the majority of their time behind Baaliro. Dorothy spent most of her time in Kitchen #1 where there was a sink. Kitchen #2 had a wood-burning stove, on which most of the meals at Baaliro were cooked. Prior to the construction of Kitchen #2 in 2013/2014 Dorothy had cooked the meals over an open fire in the shed. The pit latrines were located behind the shed.

tap. Meal preparation also took place on the steps and veranda surrounding the buildings, and if the weather was nice (which it usually was) children took their morning porridge there as well. Children who were feeling especially playful would climb and swing from the metal structure forming the water tower which provided water pressure for the main house. A stone and concrete walkway ran along the backside of the house, connecting the rear exit with the kitchen.

4.1.4 It is(n't) a hospital, it is(n't) a home

The layout of Baaliro both in terms of its relationship to St. Damien's (connected to yet separate from) as well as the layout of Baaliro's main building and satellite structures contributed to the feeling that Baaliro was more of a children's home than a hospital. The layout of the main house made it easy to see and hear any major commotion from the central corridor, but the doors and curtains as well as its division into many rooms prevented staff from detecting subtler physiological changes (such as labored breathing) which would have been monitored in a hospital. Perhaps more importantly, however, Baaliro was designed to facilitate children's involvement in housework, with the chickens, the gardens, and the kitchen nearby. However, Baaliro also lacked the organizational structures which are characteristic of many children's homes, such as placing children into (pseudo-)families and having the children call the matron "mommy."[20] Overall, Baaliro explicitly rejected the idea of being a children's home, and instead claimed its identity as a treatment center, although its construction left it feeling like neither.

While Baaliro identified itself as *eddwaliro*, it was not, in fact, a hospital and in actuality had minimal treatment capacities in the building where children stayed. Treatment at Baaliro was limited to administering previously prescribed medications and basic first aid (topical antibiotic cream and bandages). However, what did distinguish Baaliro from the children's homes in the community was the relative ease with which Baaliro could connect children to higher-level care facilities. When children required any treatment for (new) opportunistic infections they went only a few hundred yards up to St. Damien's to see a clinician and receive treatment. Sister Sally and Mary explained with pride that because of its proximity to and relationship with St. Damien's, Baaliro could quickly access treatment for children, day or night, and that caregivers

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[20] This contrasted with St. Anthony, where children live in "homes" with matrons whom they address as "mommy." At Baaliro children called both Dorothy and Mary by the title, auntie.

did not need to be present for children to get treatment from St. Damien's. The ability to treat children without a caregiver distinguished Baaliro from other treatment facilities, such as hospitals, which did require the presence of a caregiver. When children required more serious interventions, such as a blood transfusion or hospitalization, Baaliro then called a caregiver, to accompany the child, but drove the child and caregiver to the hospital. Baaliro continued to support them during the hospitalization by paying for the child's care and medications[21] and providing caregivers with any necessities they were lacking (such as sheets, a charcoal stove, a washing basin, soap, and food) to help ease the burden of caring for a hospitalized child. Baaliro staff also visited the child several times per week, if not daily, during their hospitalization. This higher level of care coordination contrasted especially starkly with children's access to care if they were living in a rural village, which could be limited by access to transportation, the cost of treatment, and caregiver availability.[22] Overall, Baaliro occupied a functional and physical space between that of a hospital and a children's home; it functioned as a medical home for the children under its care.

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[21] Children were always first admitted to the government run East-Central Children's Hospital (ECCH), where there were no fees for treatment or medications. However, frequently ECCH was out of stock for prescribed medications, in which case they had to be purchased from a private pharmacy. Additionally, at times ECCH was out of reagents to run certain lab tests, out of blood for transfusions, and/or the x-ray/ultrasound was broken, and in these cases, Baaliro had to transfer children to a private hospital for the necessary tests/treatments.

[22] Numerous studies cite the barriers children confront in accessing HIV care (Boender et al. 2012; Ferrand et al. 2007; Lowenthal, Bakeera-Kitaka, et al. 2014; Scheibe et al. 2013; Schenk et al. 2014). The difficulties children and caregivers had accessing care once they had returned to their communities and the rapidity with which an individual could deteriorate were made painfully obvious to me when Wemusa and Sanyu's mother died shortly after the boys were reintegrated. She had been sick for several days, but her husband refused to provide her with money for transportation to the clinic (see Conclusion: Caring and Precarity).

4.2 Rehabilitation – With(out) Numbers

In this section I will explore how Baaliro used (and did not use) metrics to assess children's progress in rehabilitation. Baaliro had guidelines for rehabilitation but no fixed rules or criteria for when a child was ready to be reintegrated. Instead, the staff took the individual circumstances of the child/family into account. In addition, Julien and Sister Sally emphasized the importance of loving the children. Recall that Baaliro always maintained two goals: *oku-jjanjaba* (to rehabilitate) and *oku-bazayo* (to reintegrate). These two goals were entangled and difficult to separate from one another, but at different times Baaliro emphasized one over the other. Children had to be rehabilitated before they could be reintegrated; however, throughout Baaliro's approach to rehabilitation, there are indications of their ultimate goal of reintegration. In this section, I focus more on Baaliro's approach to and use of metrics for tracking rehabilitation. Interestingly, given the emphasis Baaliro placed on caregiver responsibility once children were reintegrated (discussed more in Chapter 8), Baaliro took full responsibility for children's rehabilitation while they were at the center.

At Baaliro itself, rehabilitation focused on the two conditions that children were admitted for – HIV and malnutrition. At the most basic level, rehabilitation for these conditions required simply getting children to swallow their medications (in particular their ARVs) and to eat their food (both family foods, as discussed in Chapter 6, and technological foods, as discussed in Chapter 7). Baaliro tracked children's rehabilitation by monitoring their lab results and measuring their physical bodies. In practice, however, the tasks of taking medications and feeding were not always so simple, and the metrics used to track rehabilitation told only part of the story. However, in addition to these metrics, staff paid attention to several aspects of children's responses to ARVs and to food, including the ease with which children took their medications, their patterns of food refusal, and any side-effects the child reported. HIV and nutritional rehabilitation were not separate, but intertwined. As staff often said, "eddagala lyagala mmere" [medications [i.e. ARVs] need/want food]. Staff also took into consideration children's attitudes and behaviors which were predictors of successful reintegration (see Chapter 5 for a discussion of *empisa* (good manners/behaviors)).

4.2.1 Monitoring HIV Rehabilitation

If forced to identify a single criterion for determining if a child qualified for care at Baaliro or was ready for reintegration, the staff would point to the CD4 count,[23] because it provided a numerical indicator of immune system function which in turn served as a proxy for the response of the virus to the ARVs. However, as Baaliro staff themselves would attest, CD4 count is actually not the best metric for assessing a patient's response to ARVs. In people with HIV, CD4 count is the most important laboratory indicator of immune system function and the strongest predictor of HIV progression (UNAIDS 2015b) but does not directly measure the amount of HIV virus or its response to medications. Instead, a better test for this is the viral load, which measures the amount of HIV-virus in a patient's blood. As ARVs kill off the virus, viral load decreases, and ideally becomes undetectable.[24] As the viral load decreases, the immune system can improve, and (ideally) the CD4 count increases. Only a handful of children at Baaliro, namely those receiving their ARVs from the JCRC (Joint Clinical Research Center – the

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[23] A CD4 cell count is lab test that measures the number of CD4 T-lymphocytes (CD4 cells) in a sample of blood. A normal range is 500-1,600 cells/mm^3. A count of less than 200 is AIDS defining (aids.gov 2016). The Luganda term for CD4 count was *abaselikale* literally meaning soldiers. When children (and most adults) spoke about HIV in English, they would use the English word "soldiers" to describe the effects of HIV and ARVs on their immune systems. Brada (2011) noted a similar literal translation of the word "soldiers" in her work in Botswana.

[24] Undetectable viral load indicates that the amount of virus in the patient's blood is so low that it cannot be detected by the test. It DOES NOT mean that the patient does not have *any* virus in his/her blood, or that the patient is "cured" of the virus.

premier HIV treatment center in Kampala), had ever had their viral loads tested. At the time of my fieldwork, viral loads were only available at a few ARV clinics and were very expensive. However, the cost of the test was decreasing and availability was increasing (for example Joy received viral load testing when she accessed her medication from Jinja's Main Hospital), so it seemed likely that within a few years viral loads would become standard, at least for the children in Baaliro's program. However, in the meantime, Baaliro utilized CD4 count to track children's response to ARVs.

The CD4 count was so important that even once a child had cleared all of his opportunistic infections, Baaliro could delay reintegrating him/her because of his/her CD4 count. Baaliro did not have a set cut-off for children's CD4 count, but always became concerned if it dropped below 200 cells/mm^3, and a count below 50 cells/mm^3 was itself cause for immediate (re)admission to Baaliro. CD4 counts improved very slowly and therefore were only tested at most every 3 months. Among reintegrated children, who were supposed to have their CD4 count taken annually, low CD4 counts were one of the most common reasons for a child to rebound to the center. A low CD4 count meant that treatment was not working – either because of poor adherence (i.e. the child was not taking his/her ARVs), viral resistance to the medications (often assumed to be a consequence of poor adherence), or both.[25] Thus, in general, the CD4 count was the metric Baaliro used to measure the efficacy of their biomedical treatment (ARVs) for HIV. However, even this seemingly objective measure of HIV-rehabilitation, was not without nuance. Multiple clinicians[26] explained to me that unfortunately, in some cases, if an individual's CD4 count had dropped extremely low (below ~50 cells/mm^3) it might never recover above 200

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[25] See also Betsey Brada (2011) for a discussion of clinicians preferences for laboratory tests rather than patient reports to measure adherence to ARVs.

[26] From Baaliro, JCRC, Mulago hospital, and US institutions.

cells/mm^3.[27] In these cases, Baaliro had to adjust their metrics for rehabilitation or such a child would never have been reintegrated. Also, while reintegrated children were supposed to have their CD4 counts tested annually, Baaliro had a difficult time ensuring that children actually received the tests on time, and some children went 18 months or more without being tested.[28] Sometimes, this meant that a child's CD4 count dropped dangerously low before Baaliro realized he/she needed to rebound (be readmitted) to the center.

Additionally, monitoring children for side effects was another important part of assessing children's responses to ARVs. Staff reported that many children experience side effects (such as diarrhea, nausea/vomiting, skin rash/itching, lethargy, dizziness, appetite loss, nightmares, and headache) when they first started ARVs (or changed their ARV regimen), but that these side effects usually improved or completely disappeared over time.[29] Therefore, an important part of rehabilitation at Baaliro was supporting children through the initial side-effects associated with new treatment. The need to support children during this time was also one of the justifications for having children start treatment at Baaliro rather than in their communities. This support included medications to offset some of the side effects (such as anti-emetics to help with nausea and antihistamines to help with itching) and verbal encouragement.

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[27] Individuals living with CD4 counts below 200 are more susceptible to opportunistic infections, but the HIV-virus can be kept under control with ARVs, and opportunistic infections can be managed with other medications (both prophylaxis and treating early in the disease course), so the individual can still live a full/productive life, but he/she requires closer monitoring.

[28] This was one aspect of the program Baaliro was working hard to address during my fieldwork. They began sending a nurse along with Mary on her field visits so she could draw children's blood and bring it back for CD4 testing at St. Damien's. Unfortunately, scheduling issues and staffing issues at times prevented a nurse from accompanying Mary to the field.

[29] The counselors at St. Damien's emphasized this at the youth workshop that Baaliro hosted. Both the youth and counselors came up with a list of side-effects, and the counselors emphasized that they improve or disappear with time – and if not, that they can be switched to a different regimen.

In order for children to improve, they needed to take their ARVs. The vast majority of children, even those who “refused” in other ways,[30] cooperated in taking their medications, and at most only 1-2 children were recalcitrant about taking medications at any given time. Thus, while children’s refusal to take medication was a serious problem when it did arise, overall, it was a relatively uncommon issue. Staff utilized a variety of strategies with children who were reluctant to take their medications, ranging from positive encouragement and offering treats to threats of hospitalization and holding a child down to forcibly give him/her the medications. Physical restraint was usually ineffective and only used as a last resort. Overall the staff emphasized using positive strategies to get children to take their medications without a struggle, largely because they needed children to continue taking their medications once they were reintegrated.

Sister Sally watched the facial expressions of children when they took their medications, and later (out of the earshot of children) discussed her interpretations with me. She was attentive to children grimacing or wrinkling their noses as signs that they did not want to take the medications, or as she explained, “many of them, they fear taking the medications.” Since this indicated that a child would likely stop taking the medications once he/she returned home, Sister Sally explained that she needed to counsel the child.

Counseling, however, did not consist of scheduled sessions, did not require lengthy discussions, and did not even necessarily involve disclosure of the child’s HIV status,[31] but rather, consisted of frequently encouraging the child to take medications. For example, in the

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[30] Refusing to go to school, refusing to do work, refusing to bathe, refusing to eat (certain) foods were all common forms of refusal. The power of refusal as a strategy used by children is discussed more in chapter 6.

[31] While at first it may seem surprising that disclosure was not part of rehabilitation, many scholars have described the reluctance of caregivers and clinicians to disclose children’s HIV status to them (Kajubi, Whyte, et al. 2014; Lowenthal, Bakeera-Kitaka, et al. 2014; Midtbø et al. 2012; Ostrom et al. 2006; Szelag 2011; Vreeman et al. 2013 and many more).

case of a particularly recalcitrant developmentally-delayed 6-year-old girl, Sister Sally repeatedly asked her throughout the day, “are you going to take your medications tonight?” Over time the girl agreed to take her medications, and after a few weeks of this, she would willingly swallow her pills without discussion. Sister Sally also regularly reminded children that they took, “eddagala lya’bulamu” [medications for life].[32] Overall the staff took what they described as a “soft approach” to changing children’s attitudes toward medications, and similarly, towards food. It was important that children become used to taking medications and accept medications without argument or struggle because, once they had been reintegrated, staff explained, caregivers could not be expected to spend much time or effort getting children to take their medications. To give the children the best chance at adherence, and therefore life, they needed to take their medications easily.

4.2.2 Monitoring Nutritional Rehabilitation

Staff did not directly oversee meal times, but used anthropometrics to measure children’s nutritional progress and infer if the children were eating well. In particular, the staff, usually the nurse-midwives, weighed and measured children several times a week. They also recorded children’s height, weight and MUAC. MUAC, middle-upper-arm circumference, bands are used for screening in malnutrition programs worldwide. As their name implies, MUAC bands are used to measure the circumference of the upper-arm (around the non-dominant bicep, when the muscle is relaxed and the arm bent at a 90° angle). According to some of the nurses, they were supposed to weigh and measure all of the children at Baaliro daily. However, this was both impractical and unnecessary. Children’s measurements did not fluctuate significantly from day to

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[32] Whyte and her contributing authors (2014) also noted the double-entendre of ARVs being medications for life – both life-giving and life-long.

day and any changes from one day to the next were more likely the result of different people taking the measurements. Additionally, the measurements took time, making school-going children late for school and the nurses late for their work at St. Damien's. In practice children were weighed several times per week, their MUAC was taken at least weekly, and their height was measured at least every two weeks. The ECCH nutritionist completed a full nutritional evaluation of every child when he visited Baaliro twice a month. His evaluations focused on filling out the nutritional assessment forms in full, including all of the child's measurements as well as clinical symptoms (such as diarrhea, vomiting, fever, edema, etc.). Baaliro staff rarely reported clinical symptoms on the nutrition form, something which the nutritionist frequently complained about, however, they were in fact very aware of children's clinical symptoms and considered treating them as integral to the child's rehabilitation. They, however, considered the recording of clinical symptoms to be the responsibility of the clinical staff at St. Damien's who evaluated and treated children, rather than the staff at Baaliro who simply administered the medications.

The nutritional rehabilitation equivalent of the CD4 count used by Baaliro was the MUAC. While widely recognized as a useful screening tool for acute malnutrition among children under the age of five years, the use of MUAC tapes in older children and as a tool for monitoring nutritional rehabilitation remains unsupported. Nonetheless, Baaliro used several color-coded MUAC bands labeled for different age groups (6-59 months, 5-9 years, 10-14 years, and older than 14 years) to track children's nutritional recovery.[33] The colors on each band indicated children's malnutrition status: red=severely malnourished, yellow=moderately

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[33] I was unable to determine the source of the age-based MUAC tapes that Baaliro was using. Neither WHO nor UNICEF provide standard reference MUAC values for children over the age of five and they were also not in Uganda's national malnutrition guidelines.

malnourished, green=not malnourished. Unfortunately, since most of the children at Baaliro were stunted,[34] using these age-based MUAC-bands meant that even chubby children often measured in the yellow and only slightly skinny children measured in the red when using age-based bands. This was especially important (and frustrating to watch), because unlike medication times, which usually passed with little discussion, children and staff frequently counseled children during weighing and measuring.[35] The midwives, in particular, would praise children who were improving and chastise those who were not. They defined improvement as moving from the red portion of the MUAC tape to the yellow, and even better from the yellow to the green. However, because they used MUAC tapes which were color-coded based on *age*, rather than *height*, even if children were gaining weight and their MUAC was increasing, they could be scolded by the nurses for “not eating,” since they were “still in the red.” Additionally, MUAC was often slower to increase than weight, so even once very sick children regained their appetite and started eating, they could remain “in the red” (and thus continue to be scolded) for some time. The midwives’ reprimands could be harsh enough to bring children to tears. This was especially disheartening for children who were, in fact, already good eaters or were trying to eat more.

The nutritional rehabilitation equivalent of ARVs was ready-to-use therapeutic food (RUTF).[36] Although in contrast to ARVs’ life-long necessity, RUTF was only used for a few

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[34] For more of a discussion on stunting see Chapter 7. In brief, a stunted child is short for his/her age, and therefore would be expected to have a smaller MUAC. In Uganda, approximately ⅓ of children under the age of five are stunted (or short for their age) (UBOS 2014). Stunting is largely irreversible and results from chronic malnutrition and/or recurrent infections (which are common among HIV-infected children), especially during the first 1000 days of life (WHO 2014).

[35] Rather than the value-neutral connotation that counseling implies to most Western listeners, counseling in Uganda was highly directive. This was not limited to children, but was also common among adults, especially those seeking treatment for HIV and has been commonly reported across Africa (Moyer, Burchardt, and Dijk 2013; Nguyen 2013; Rasmussen 2013; Simbaya and Moyer 2013; Vernooij and Hardon 2013).

[36] I discuss the history and use of RUTF in great detail in Chapter 7. Briefly RUTF are packets of fortified peanut-butter-and-milk-powder-based paste which can be given directly to malnourished children to eat. RUTF has been very successful in decreasing morbidity and mortality for severely malnourished children, ages 6 months to 5 years.

weeks. However, similar to ARVs being necessary for the treatment of HIV, RUTF was considered emblematic of (if technically not required for) malnutrition treatment programs. Staff monitored children’s responses to RUTF similarly to their response to ARVs, noticing wrinkled noses and apathetic consumption, and believed that children who took RUTF seriously recovered faster than children who refused to eat it, or even those who ate it reluctantly. Once children had been discharged from RUTF, however, nutritional rehabilitation at Baaliro consisted of simply providing children with the typical foods that would be found in their home communities (also known as family foods). Although staff did not eat with children, they identified children as good eaters or picky/reluctant eaters, and encouraged children to eat well in order to gain weight and return home.

The daily schedule at Baaliro (see Chapter 5) reflected that the rehabilitation of children did not require any special activities, other than taking medications twice a day. There were no regularly scheduled counseling sessions, no physical therapy sessions, and no individual consultations with a nutritionist. Rehabilitation, staff often emphasized, took time, which was why the majority (57/113 [50%]) of HIV-positive children stayed at the center for six or more months and one in five (24/113 [21%]) stayed for more than a year. However, rehabilitation did not require time to be set aside during the day for the purpose of rehabilitation. Staff ensured that children took their medications and that they received nutritious food, and then “simply” waited for children (and their bodies) to respond. In the meantime, they provided love and tracked children’s developmental changes and the social situations back home.

In contrast to a managed care model (Lester 2011), Baaliro had guidelines for rehabilitation metrics and criteria, but also took into account children’s broader needs and circumstances and their individual development. Perhaps one of the things Baaliro did best was to treat each child as an individual, and to work to find a stable living situation before reintegrating children. However, this does not mean that numerical measurements played no role in rehabilitation. Staff measured children's bodily responses with metrics such as their CD4 count and MUAC, but also paid attention to children's development and well-being more broadly, for instance, by paying attention to children's reactions to taking medications, their willingness to report symptoms of illness, and their food consumption. Sister Sally and Julien even emphasized that at Baaliro, in addition to medicine and food, they were giving the children love. Overall, Baaliro's approach to rehabilitation was far more than rehabilitation by the book and by the numbers.

4.3 Conclusion

This chapter offers a fine-grained description of Baaliro's physical organization, the staff who worked there, the children who went there, and the approach to rehabilitation. These descriptions demonstrate how Baaliro maintained a liminal existence – between that of an *eddwaliro* (a clinic/hospital) and an *ennyumba* (a house), containing children who were simultaneously sick and healthy, and using but not relying on numerical metrics in their approach to rehabilitation. The fact that Baaliro defied easy categorization perhaps reflects the difficult task that the organization was taking on and the complexity of trying to rehabilitate and prepare children infected with HIV for reintegration and to grow up as members of their communities.

Chapter 5: Why So Much Work?: The Importance of Empisa and the Role of Work in Preparing Children for Reintegration

In the previous chapter, I introduced Baaliro as a liminal space, between that of a children's home and a hospital, populated by liminal children, between sick and healthy. In this chapter, I build upon that analysis by giving an account of a typical day at Baaliro and explore how daily life at the center focused on preparing children for successful reintegration. Recall that the aspect of its mission that Baaliro prided itself on most was the reintegration of children, because staff firmly believed that children should be raised by/in "the community" rather than in institutions. Overall, Baaliro's emphasis on reintegration influenced nearly every aspect of the daily routine at Baaliro – from the food the children ate, to the work they did, and to the ways they spoke (or rather did not speak) about medications. Applying a Bourdieuan perspective, reveals how the everyday practices at Baaliro both reflected the children's habitus (their set of dispositions and forms of behavior), and further shaped and reshaped their ways of being/doing/talking in preparation for their return to "the community." In Chapter 6, I will discuss how the focus on reintegration shaped the kinds of food served at Baaliro, but in this chapter I focus on children's *emirimu* (work) and the importance of *empisa* ([good] behavior/manners).

One of the more surprising aspects of daily life at Baaliro was the amount of work that children did, especially considering that Baaliro self-identified as a medical treatment facility. In American and European countries, no one would expect children staying at a medical rehabilitation center to be the ones cleaning the toilets and mopping the floors. Such activities would be taken care of by designated cleaning staff, and seen as separate from, if not detrimental to, rehabilitation. Consider, for example, Make-A-Wish Foundation's focus on granting children's wishes and the child-life departments at most children's hospital in the US whose programming includes art therapy, music therapy, and clown doctors, but certainly not having children involved in cooking or cleaning the hospital. However, as I describe in this chapter, at Baaliro, children's work was understood as integral to children's rehabilitation and to securing their future.

5.1 *Emirimu* (Work)

I use the English word "work" to describe children's assigned jobs or chores around Baaliro, because it is the literal translation of the Luganda word *emirimu*, which staff and children used to describe their activities. When I discuss children's work, I am primarily referring to children's contributions in and for their households, for which children do not usually receive direct financial compensation. This included household chores and unpaid economic activities for the household, usually in the form of agricultural work. I am not discussing children's labor, which usually occurs outside of the home and for direct pay. While in many high-income countries (and among the wealthy in lower and middle income countries), work is reserved for adults and childhood is idealized as a time of play, freedom from responsibilities, and especially freedom from work, this is not the case throughout much of the world (Boyden 1997; Hecht 1998). Numerous scholars have described the importance of children's contributions to their households, the role of work in transmitting knowledge and skill to prepare children for adulthood, and the various ways in which children's work is constructed in cultures around the world (Bourdillon et al. 2010; Kramer 2005; Lancy 2008, 2015; LeVine 2007; LeVine and New 2008; Nieuwenhuys 1996; Spittler and Bourdillon 2012). Discussions of children's work often highlight the tensions inherent in globalized notions of children's rights, with rights discourse emphasizing children's need for protection and failing to recognize children's responsibilities (of which work is one) (Bourdillon et al. 2010; K. E. Cheney 2007, 2015b).[1]

Additionally, and especially relevant to children from Baaliro, several scholars have noted the ways that children's work plays an important role in building and strengthening kin relations, which in turn are necessary for children to attain resources to secure their futures (Hecht 1998; Hunleth 2017; P. Reynolds 1991). Tobias Hecht (1998) describes the expectation that children participate in work as one of the factors which distinguishes nurtured children – who are "loved by virtue of *being* children" from nurturing children – who receive love "to a great extent [as] a function of what they *do*" and furthermore must "struggle to win the affection of their mothers" [emphasis as in original] (1998, 80). While Hecht's notion of the nurturing child frames children as independent, Jean Hunleth (2017) builds upon this idea, showing that children are not independent, but rather *interdependent*. Children both rely on adults to meet their basic needs, but also expect to (and are expected to) contribute to household labor. Thus, it is not possible to separate what children *do* from what they *receive*. Furthermore, Hunleth observes, children strategically direct their productive activities towards those relationships that will most likely become advocates for their future.

Finding accurate numerical estimates for children's involvement in work is difficult, as most reports focus only on child labor (with special attention to dangerous and exploitive occupations), and overlook children's unpaid economic activities and household contributions. A recent Ugandan government report, however, does pay attention to these usually overlooked activities, and found that in Uganda 72% of children age 6-17 years old participated in household

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[1] For discussions of the impact of globalization on concepts of childhood, and especially understandings of children's work see also (Andre and Hilgers 2015; Boyden 1997; James and Prout 1997).

work and 39% participated in economic activities of some kind (see Table 5.1) (UBOS, ILO, and IPEC 2013).[2] Among those participating in economic activities, 93% were in the agricultural sector and 81% worked as unpaid "contributing family workers," therefore the vast majority of children who engaged in economic activities (as defined in this report) were working in agriculture for their households without pay, in keeping with my use of the term work. Only 23% of children were "non-workers" – neither participating in household chores nor economic activities.[3] Overall, children spent an average of 25 hours per week participating in household work and/or economic activities.

Age and residence were important determinants in children's work patterns, but gender, perhaps surprisingly, was less important. As children aged, their involvement in economic activities increased, however this increase did not seem to affect school participation until the 14-17 year old age group, which also corresponds to the transition to secondary school. Not surprisingly the number of hours worked per week also increased as children got older; however, even children 6-11 years old reportedly worked over 18 hours per week on average. Sadly, data regarding the percent of children involved in household work as they aged was not reported.

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[2] The report focused on children 6-17 years old because children of this age should all have been in school. Household work included fetching water, fetching firewood, cleaning utensils, cleaning the house, washing clothes, cooking, and caring for [younger] children. Economic activities (also called "employment") did not include household chores, but included work in the agricultural sector (also called the primary sector, and including agriculture, fishing, hunting, and forestry), the industrial sector (also called the secondary sector, and including mining/quarrying, manufacturing, construction, and public utilities), or the service (tertiary) sector (including sales/trade, restaurants/hotels, transportation, storage, communication, finance, insurance, real estate, and community, social, and personal services). Because of the ways they are defined in this report, participation in household work and economic activities were not mutually exclusive, nor were they mutually exclusive with participation in school. 34% of children participated in both household work and economic activities (30% of them also attending school) and 35% of children participated in household work while attending school.

[3] 20% of children attended school without any household or economic obligations, and only 3% of children were neither attending school nor participating in household/economic activities.

Table 5.1 National Averages of Children's Economic Contributions[1]

		Gender		Residence		Age		
	Total	Male	Female	Urban	Rural	6-11	12-13	14-17
% household work	72%	70%	75%	64%	73%			
% economic activity	39%	40%	38%	17%	42%	25%	49%	57%
% in school	89%	88%	89%	90%	89%	91%	94%	83%
% non-workers[2]	23%	25%	21%	34%	21%			
% in school only[3]	20%	21%	19%	32%	18%			
# hrs worked (total)[4]	25	24	27	34	25	18	23	31
# hrs household chores	15	13	18	20	15	12	14	18
# hrs economic activity	19	19	18	35	17	12	16	24

[1] *Data come from the* National Labor Force and Child Activity Survey *(hereafter the child activity survey) (UBOS, ILO, and IPEC 2013).*

[2] *Non-workers include all children who denied participating in any economic activities or household chores. It includes both children who were attending school, and those who were not.*

[3] *Percentage of children who were attending school, but not participating in any economic activities or household chores.*

[4] *Average number of hours that children worked per week. Total is less than the average number of hours spent on household chores plus economic activities, because some children participated in only household chores or economic activities, but not both. Non-workers were not included.*

Grayed Boxes indicate percentages that differ by more than 10 percentage points and hours that differ by more than 10 hours per week

Overall, it is hardly surprising that children's responsibilities (including work) increased as they aged and that school participation dropped as children transitioned to secondary education.[4]

Residence was another significant factor affecting children's work patterns. Rural children were slightly more likely to participate in household chores than their urban peers (73% vs. 64%), but nearly 2.5 times more likely to participate in economic activities (42% vs. 17%) – and in farming in particular (40% vs. 10%). Urban children were nearly 1.8 times more likely to

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[4] There are many reasons for children to not attend secondary school including increased school fees, failure to pass the national Primary Leaving Exam (PLE), or the lack of a secondary school near their home.

have the luxury of attending school without any work obligations – neither participating in household chores nor economic activities (32% vs. 18%). Paradoxically, however, urban children who did work reported working longer hours than rural children (34 vs. 25 hours per week), with those engaged in economic activities working more than twice as many hours per week (35 vs. 17 hours per week). Despite these differences in economic participation and hours worked, there was no significant difference in school enrollment between urban (90%) and rural (89%) children. In summary, more rural children worked than urban children, and not surprisingly many more rural children worked in agriculture than urban children. However, those urban children who were working worked much longer hours than rural children who were working.

Despite much international and national concern regarding gender differences in children's work (Allais et al. 2009; De Lange 2009; ILO and IPEC 2009), "[t]here were no major differences in children's involvement in employment by sex, suggesting that gender considerations did not play an important role in the assignment of children's work responsibilities in Uganda" (UBOS, ILO, and IPEC 2013, 31). There was also very little difference in school attendance between boys (88%) and girls (89%), and in the percentage of boys (21%) and girls (19%) attending school without any work obligations. There was only a small difference in children's overall participation in household chores by gender (75% of girls vs. 69% of boys), and girls averaged slightly more time than boys working (27 vs. 24 hours per week), especially doing household chores (18 vs. 13 hours per week). The kinds of household chores children reported participating in differed somewhat by gender. Most notably 50% of girls but only 31% of boys reported cooking for their households. Overall, though, children's work patterns were relatively independent of gender with both boys and girls participating in similar household tasks and working a similar number of hours per week.

During mini-interviews, I asked 38 reintegrated children about what kinds work they did (see Table 5.2). By far the most common work activities reported by children were fetching water, washing plates/utensils, and washing one's own clothing (especially a school uniform).

Table 5.2 Children's Domestic Work – Reintegrated Children vs. National Averages

	Reintegrated Children[1]			National Percentages[2]				
	Total	Gender		Total	Gender		Residence	
Type of Work	(n=38)	Males	Females	%	Males	Females	Urban	Rural
Cleaning Utensils/ Plates[3]	26	13	13	57%	50%	63%	53%	57%
Mopping	5	3	2					
Sweeping	8	6	2					
Fetching Water	26	16	10	64%	62%	67%	53%	66%
Washing Clothes	25	13	12	49%	44%	53%	45%	49%
Cooking	8	2	6	41%	31%	50%	36%	41%
Farming ("digging")[4]	7	3	4	36%	37%	36%	10%	40%
Childcare	3	1	2	35%	29%	42%	29%	37%
Eldercare	1	0	1	0%	0%	0%	0%	0%
None[5]	4	2	2	23%	25%	21%	34%	21%
Fetching Firewood	0	0	0	52%	47%	56%	53%	57%

[1] *Reintegrated Children's responses come from mini-interviews conducted with reintegrated children (n=38).*

[2] *National Percentages come from the* National Labor Force and Child Activity Survey (UBOS, ILO, and IPEC 2013).

[3] *The child activity survey reported cleaning utensils/house as a single type of work, but reintegrated children distinguished between cleaning utensils/plates and mopping/sweeping.*

[4] *The total percentages of children participating in farming were not directly reported in the child activity survey, but were calculated based on the percent of children involvement in economic activity and the percent of economic activity spent on agriculture.*

[5] *"None" for reintegrated children indicates that the child denied doing any work at home. For national percentages "none" includes all children who denied participating in any economic activities or household chores. In both cases, participation in work is independent of school attendance.*

Grayed Boxes indicate percentages that differ by more than 15 percentage points.

Similar to the national survey, there was no significant difference in the kinds of work that the children reported by gender. However, my sampling of children regarding work lacked methodological rigor, so I am hesitant to make any broad assertions about children's work based on their responses alone. I also noted, however, that chore assignment at Baaliro seemed to be agendered with boys and girls completing the same tasks. Traditionally, Baganda children were not separated in their activities and play until girls started their menses, and most of the children staying at Baaliro had not yet completed puberty (Philip Leroy Kilbride and Kilbride 1990).[5]

For the remainder of this chapter I focus primarily on children ages 6-15 years old who were staying at Baaliro. Younger children were typically at the center with a caregiver, and the caregiver, rather than the child, was the one expected to do work. Children age 6-7 years old were only occasionally assigned work, and instead joined the older children and caregivers when they wanted to participate. Even very young children often wanted to contribute and mimicked their caregivers or older siblings as they went about their work. In one case, a 2-year-old at the center would cry for attention whenever her mother was busy mopping the floors, unless her mother provided her with a small rag, in which case she would happily mop alongside her mother. This exemplifies one way the line between play and work can be blurred for younger children.

Before returning to Baaliro, I must introduce and explore one more important concept, *empisa*, which Baaliro sought to instill in children. Later in this chapter, after describing a typical day, I will return to the concept of *empisa* to show how children enacted *empisa* through their

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[5] Pubertal delays are well-documented among undertreated HIV-positive children (Arpadi 2005; De Martino et al. 2001; Majaliwa, Mohn, and Chiarelli 2009). Parsons (2012) also noted this in his ethnography of HIV-positive children in Zimbabwe. However, access to ARVs can prevent HIV-related delays in the onset of puberty (Bakeera-Kitaka et al. 2008; Williams et al. 2013).

daily activities (especially their work) and why staff felt *empisa* was crucial for successful reintegration.

5.2 *Empisa*

Empisa is an important and difficult to translate Kiganda[6] concept. *Empisa* itself is a polysemic word, whose meaning is highly context dependent. One online dictionary listed *empisa* in the translation for 22 English words (Luganda Translation Collaborators 2016). I was first given the word *empisa* as a translation for "culture," such as in Apolo Kagwa's manuscript *Empisa za Baganda* [The Culture of the Baganda] and when my Luganda instructors gave me the phrase "*empisa za'baana*" [children's culture] as a way to describe my research (Kagwa 1905). Native Luganda speakers often offered "discipline" as the closest translation of *empisa*, and at least one other scholar has similarly received this translation (Ogden 1995).[7] Alternatively, missionaries have used *empisa* to mean "morals," such as in the book *Empisa Nungi Ezobukristayo [Lessons in Christian Morals in Luganda]* (Weatherhead and Candy 1917). Mikael Karlström agrees with morality as a partial definition for *empisa*, explaining that "When

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[6] The word Kiganda is the adjective used to describe the way things are done by the Baganda (ex. Kiganda customs). The word Baganda describes the people of Buganda. The word Buganda describes both the ethnic group and the geographic area that the Baganda traditionally inhabited, which is in central Uganda. Luganda is the language spoken by the Baganda, although many non-Baganda live in Buganda and speak Luganda.
Additionally, while throughout this text I use the Buganda as my ethnic group of reference, it is important to note that the neighboring ethnic group, the Busoga, share many of the same concepts and even use some of the same words – including *empisa* and *emirimu*. Since Baaliro was located on the border between the Buganda and the Busoga, and children were roughly evenly split between the two ethnic groups (with some coming from other ethnic groups as well – there are over 60 ethnic groups in Uganda), it would perhaps be more accurate for me to replace Kiganda with Kiganda/Kisoga, and Luganda with Luganda/Lusoga, etc… throughout this dissertation, but that would make reading the resulting document unnecessarily cumbersome.

[7] Of the definitions I list, discipline seems the least helpful for understanding *empisa* as was used at Baaliro. This is not to say that it is incorrect, as obviously it is hubris for non-native speakers to question a native speaker's translation. Being disciplined in one's actions and manners is a component of having *empisa*, but the actions and manners themselves seemed to better define *empisa* than the concept of discipline does (especially given the weight Foucault has placed on the word).

used without evaluative qualification *empisa* carries the implication of right or proper conduct and seems to be the closest thing in the Luganda language to the English 'morality'"(Karlström 2004, 602).[8] However, he also describes *empisa* as a broad and flexible category encompassing conduct, behavior, and habit, which can be old or new, indigenous or imported, and bad or good. Similarly, but less broadly, other ethnographers have defined *empisa* as "custom, habit, conduct" and noted that, as a culturally defined concept, *empisa* is variably constructed depending on one's gender, age, and social status (Philip Leroy Kilbride and Kilbride 1990, 89). Kristen Cheney defines *empisa* as "a code of conduct that applies specifically to children" and found that concepts of freedom and rights often clashed with the concepts of obedience and social order inherent in *empisa* (K. E. Cheney 2007, 59).[9] Jessica Ogden found that *empisa* was important to women living in the slums of Kampala as they strove to achieve what she referred to as "proper womanness," despite their circumstances. She additionally noted that since mothers were responsible for inculcating *empisa* in their children, "children that misbehave, act disrespectfully, or look dirty and unkempt reflect badly on their parents, their mother in particular" (Ogden 1995, 208). While all of these definitions are valid, and in fact interrelated, the most commonly used meaning of *empisa* that I encountered throughout my fieldwork could best be translated as "(good) behavior" or "manners." Children (and adults) were largely judged by their behaviors/conduct (their manners), and the definition of proper behavior reflected culturally defined norms, social roles, and customs – which emphasized respect, discipline, and responsibility.

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[8] For a discussion of the difficulty of translating morality and the interrelatedness of morality and good behavior in another African context see Jacobson-Widding and Howell (Jacobson-Widding 1997).

[9] Cheney's work (2007, 2013, 2015b) also provides an excellent analysis of the clash between concept of children's rights and responsibilities especially in relation to global rights discourse.

Empisa applied to all individuals in Uganda, but I primarily focused on concepts of *empisa* related to children. Almost any action could be described as being good or bad *empisa*, and an individual, based on his/her actions, would be described as either having good or bad *empisa*, or as having or not having *empisa*. *Empisa nungi* (good *empisa*) and *alina empisa* (he/she has *empisa*) were positive descriptors. *Empisa bi* (bad *empisa*) and *talina empisa* (he/she does not have *empisa*) were negative descriptors. Overall, as other ethnographers have noted, children's *empisa* mainly centered around demonstrating respect for elders, fulfilling one's responsibilities, and being sociable with peers (K. E. Cheney 2007; Philip Leroy Kilbride and Kilbride 1990). Children demonstrated respect for elders by listening to and obeying[10] adults and properly greeting elders.[11] Fulfilling their responsibilities included completing their work promptly and without complaint.[12] Additionally, *empisa* covered a wide range of behaviors which could be defined both in positive and negative terms, and I was frequently surprised at how widely the concept was applied. *Empisa* was frequently a formal topic at St. Damien's Saturday youth group, and both youth leaders and the children themselves said one of the reasons

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[10] In Luganda, the word for "to listen" and "to obey" is the same: *oku-wulira*. Thus, someone who does not listen (or even who cannot hear because he/she is deaf) also does not obey – *tawulira*. Several of the children at Baaliro suffered from either temporary or permanent hearing loss as a consequence of their illnesses. At times, it was difficult to determine if a child was intentionally not obeying, or simply could not hear an adult's command.

[11] Among the Baganda, "it is customary to kneel down when greeting, asking for a favour, serving food, etc. to someone you respect. Young people - boys as well as girls - should always greet or address their elders in this posture. While it is rare for grown men to kneel in greeting, adult women often do as an exaggerated show of respect. Sometimes it is done in an abbreviated form, as a kind of curtsy, if one is greeting along the road and cannot stop to chat. Generally wives are expected to greet and serve food to their husbands this way" (Ogden 1995, 251). In urban areas and workplaces, kneeling is less common. Mary, the social worker, did not kneel when she visited children's caregivers in the community and the female nurses and physicians did not kneel when greeting patients. Additionally, kneeling is not practiced among all of the 65+ ethnic groups recognized by Uganda's national census. Thierry, the executive director of St. Damien's, was Banyarwanda and delighted in telling foreign visitors that "his people" did not have such "backwards" customs.

[12] For an excellent discussion of the relationship between concepts of children's rights and children's responsibilities, especially protectionist vs. participatory models of rights, and how these concepts relate to and affect the practice of *empisa*, see Kristen Cheney's work (K. E. Cheney 2007, 2015b).

for children to attend the weekly programs was to learn *empisa*. During one session, children defined *empisa* as respecting elders, respecting one another, sitting well on the chair, sharing, being quiet, bathing, being smart,[13] not talking, not fighting, not abusing,[14] and not hitting. At Baaliro examples of good *empisa* additionally included offering a chair to a guest, bringing guests a fork with which to eat, offering food to others,[15] eating whatever food was served without complaint, taking medications without complaint, completing one's work quickly and without complaint, and helping others. At Baaliro examples of bad *empisa* included a wide range of behaviors such as stealing, running around naked (especially post puberty), purposefully destroying things, shouting, asking for gifts or money,[16] teasing, discrimination, hitting, throwing stones, rumor mongering, not reporting sickness to adults, not greeting adults properly, and (most commonly) any kind of stubbornness such as refusing to go to school, refusing to eat a certain food, refusing to do work, and refusing to take medications. For children living with HIV, adherence to medication was a vital aspect of *empisa*. Not unlike Bourdieu's concept of habitus,

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[13] Smart in this case comes from British-English and refers to being neat/clean/well dressed, and has no relation to intelligence or academic performance.

[14] The Luganda word *oku-vuma* is typically translated as "to abuse", but this has a different meaning in Ugandan-English than American-English. In Uganda, to abuse refers to verbally abusive comments but not physical abuse. Thus, when children complained of children or adults abusing them, they were referring to teasing, harsh criticism, or being yelled at. Children frequently complained that Dorothy abused them, because she frequently scolded them harshly, but she never hit them – and indeed Baaliro forbade physical punishment.

[15] Both at Baaliro and among my host families, adults frequently tested this aspect of *empisa* by pretending to be hungry while children were eating (especially if they had a particular desirable food such as a *chapati* or *sumbusa*, or a special drink such as a soda) and seeing if they would offer to share. Offering food without being asked was especially good *empisa*, but if the children did not spontaneously offer to share, adults would ask for some. As long as children offered to share, they were praised for having good *empisa*. If, however, they refused to share, they were called out as having bad *empisa*. Adults never took more than the tiniest bite of food, and usually returned the food/plate to the child without consuming any. They were not interested in actually sharing food with the children, but in instilling *empisa* in them. I saw adults (and even older children) engaging in this sharing training with children as young as two years old. However, in contrast, the one and only time I saw a child ask an adult for a bit of her *sumbusa*, the child was chastised, "*Oswadde!*" (shame on you!).

[16] Interestingly, this rule only applied to guests. I learned that it was appropriate, and even expected, that children would ask caregivers or staff-members that they had a friendly relationship with "what have you brought me?" when the adult returned from a trip to town or after an absence.

empisa can be understood as a set of dispositions and forms of behavior (Bourdieu 2000). *Empisa* was enacted through everyday action (practice), becoming internalized and characteristic of the individual him/herself (Bourdieu 1977).

Good/bad *empisa* could be used to describe either a particular action or behavior (ex. hitting is bad *empisa*), or to describe an individual based on his/her actions (ex. she has good *empisa*). However, whether an individual child had or lacked *empisa* could change over time, and even from day to day. For example, 9-year-old Peter was a particularly temperamental child.[17] Usually he was clean and smartly dressed, he enjoyed attending school, never resisted taking his medications, responded promptly when called for, and completed his work without much complaint. If he was in an especially good mood, he would even lend a hand with additional work, beyond his assigned tasks, such as assisting Sadat with feeding the chickens and watering seedlings in the garden or helping the workmen make and carry murram bricks for the new rain-water tank. However, if Peter was upset, he could shut down completely. It was not uncommon to find him lying on, or even under, his bed, facing the wall, and refusing to talk to anyone or do anything. Usually it was impossible to find out what had caused him to become upset, because he simply would not talk to anyone when he was in such a state. Refusal to talk was in and of itself, bad *empisa*, but in one instance Peter took his bad *empisa* much farther than usual. Peter was so enraged when a fellow child accidentally kicked him during a *futbol* game that he first went to bed, then got up and began shouting nonsensically at everyone (including the workmen who he had enjoyed helping the day before) to "leave me alone." Ultimately, he found a large stick and after repeatedly shouting that he was going to beat the offending girl with it, he

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[17] For this observation, I am referencing Peter's behavior once he had largely recovered from his illnesses. When he first arrived at Baaliro he was miserably sick (as I describe in Chapter 8). He was initially so weak he was excused from work, but he often refused to eat due to painful mouth sores, which earned him considerable scolding from Dorothy during his first few months after rebounding to the center.

actually took a swing at her. Dorothy, the matron, managed to de-escalate the situation without having to touch him.[18] She first spoke softly and calmly, attempting to appeal to his usually helpful nature, “Mukwano, janguwano onyambeko” [my friend, come here [in the kitchen, away from the offending girl] and help me]. Then she more firmly encouraged him to return to his room saying, “Lwaki togenda mu’nyumbayo?” [Why won’t you go to your room?] implying that he would be left alone if he went to his room. Finally, she scolded him harshly, “Olina empisa embi nnyo! Genda mu’nyumbayo!” [You are having very bad *empisa*!] and ordered him to go to his room. While Peter still refused to return to his room, Dorothy’s evocation of *empisa* stopped him in his tracks. He stood raging with the stick clutched in his hand until everyone was called to take their medications. After all the rest of the children had left, I implored him to go for medication time. He finally dropped the stick, went to the office and took his medication. For the rest of the evening he sat sulkily in the dining room, avoiding the other children, but by the next day he was again happy and helpful. Depending on the day, Peter was upheld as an example of a child having both good and bad *empisa*.

While *empisa* can be defined both in positive and negative terms, children were far more commonly chided for having bad *empisa* than praised for having good *empisa*. Adults scolded children for having bad *empisa* as a way to get them to change their behavior. Dorothy could be particularly harsh when she reprimanded children, often repeating multiple times, “Saagala mpisa mbi!” [I don’t want bad *empisa*] and reiterating that the child, “Alina empisa embi!” (he/she has bad *empisa*]. For example, she frequently chastised Onzi, a 9-year-old boy with a bed-wetting tendency and a reluctance for bathing and washing his clothes, for being dirty. Whether evoking *empisa* was actually an effective strategy for instigating behavior change in

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[18] Her ability to de-escalate this very tense situation demonstrated Dorothy’s mastery of managing the children’s emotional states as well as the respect they had for her, perhaps even demonstrating the utility of being “feared.”

children was debatable, and depended on both the adult evoking *empisa* and the child receiving the rebuke. Dorothy's scolding was usually successful in getting children to do what they were supposed to do in the moment, but it also made children feel bad (sometimes after a scolding they refused to eat or play or even cried), contributed to Dorothy's reputation among the children as someone *oku-tya* (to fear), and did not seem to cause lasting behavior change. Sister Sally felt that Dorothy was harsher than necessary with the children, but also sympathized with Dorothy for having a difficult job getting them all to complete their work. Sister Sally praised children more than Dorothy, especially emphasizing that taking medications was good *empisa*. Nonetheless, Sister Sally also maintained a role as a disciplinarian and the children also feared her. Sister Sally did not hesitate to tell children they had bad *empisa* if they were misbehaving. However, she took a softer approach, talking to children rather than yelling at them, and trying to "boost them" (build their self-esteem). Overall, Sister Sally was effective in getting children to change their *empisa* – as she said, "mpola mpola" [slowly-by-slowly], and she believed that her approach had a longer lasting effect. While she acknowledged that Dorothy's approach yielded more immediate results, she felt it was only effective as long as Dorothy was there to enforce it, and that it may have detrimental long-term effects on the children's psychological well-being.

Interesting not only adults, but children themselves called out one another (and in rare cases even adults) for having bad *empisa*. Both at the Saturday youth group and at Baaliro, children often delighted in telling others about the bad *empisa* of another child. Sometimes they told me, but more often I heard them discussing examples of bad *empisa* with one another. It was not uncommon for one child to tell another that he/she had bad *empisa*. The accused child would sometimes refute the claim or point out that the accuser also had bad *empisa*, and other times accept the charge and change his/her behavior. Children also pointed out when adults were lacking *empisa*. For example, one 11-year-old boy told me his father had bad *empisa* because he never gave his mother any money to support his brother and him. While children could, and often did, tell their peers that they had bad *empisa* face-to-face, children only talked about adults having bad *empisa* outside of the offender's presence, because to actually confront an adult in such a way would be, itself, bad *empisa*.

I had minimal authority to change children's behavior by evoking *empisa*. Initially, I refrained from evoking *empisa* (either negatively or positively) because I did not want to impose my concepts of good behavior/manners, and because I was attempting to attain the "least-adult" role (Mandell 1988).[19] However, as I learned both the norms of what was considered good and bad *empisa* and that children themselves evoked *empisa* to regulate one another's behavior, I began modeling the children's behavior and calling out instances of bad *empisa* when I witnessed them. Additionally, as I learned that having good *empisa* was an important predictor of a child's successful reintegration and future well-being, I decided to actively encourage good *empisa*. My encouragement primarily took the form of verbally praising children when they were enacting good *empisa*. I generally refrained from chastising children for having bad *empisa*, because the staff (Dorothy in particular) were already doing so, though I would agree with staff as they were talking about children's bad *empisa*. Occasionally, I would not allow a child who had bad *empisa* to participate in a certain activity (such as not allowing a child to color if he/she had refused to help clean the lunch dishes).[20] Overall, I had variable success evoking *empisa* with the children, but had the most success among the children with whom I had formed a close

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[19] I was only partially successful in attaining the least-adult role, and in large part due to the moral imperatives of working with children who were at times seriously ill, the actual role I play at Baaliro was far more complex. For more discussion of my role see Chapter 3.

[20] I only did this on two occasions, and always warned the child several times that he/she was having bad *empisa* and if he/she did not help clean the dishes, I would not allow him/her to color with me.

relationship and when I recognized them for good *empisa*. For example, at my going away dinner, Violet, a precocious 11-year-old, fondly remembered an incident when I had given her a mango because she always had to clean the bathroom by herself in the morning since the other school-going girls, especially Kabiite, refused to get up and help her.

Having introduced the important concept of *empisa,* I now return to Baaliro itself. In analyzing the daily routine, I will demonstrate how the daily activities at Baaliro reflected the center's ultimate goal of reintegrating children into their home communities, and how *empisa* was integral to both the daily activities and this ultimate goal.

5.3 A Typical Day

As the schedule below indicates, rehabilitation at Baaliro consisted of considerably more than just the biomedical management of the children's nutrition, HIV, and opportunistic infections. Recall that Baaliro prided itself on successfully reintegrating children, and thus the daily activities at Baaliro reflected the center's mission of preparing children for successful reintegration. A large part of this preparation included inculcating children with *empisa*. Most of the times below are approximate, and could vary by as much as a half an hour; however, the general flow of activities listed below occurred almost every day. In contrast to the flexibility in the rest of the schedule, medication times were always punctually observed emphasizing that rehabilitation came before reintegration, and therefore, medication came before other activities. This schedule reveals a considerable emphasis on children's work, and that children spent most of their time outside of direct adult supervision.

5:30am – Wake-up and Predawn Work

The school-going children get up in the dark and start their morning work. They clean the bathrooms (scrubbing the tiled floor and walls) and mop the interior hallway. They know their work assignments and typically set about their work with little discussion. Sometimes Dorothy wakes them, but more often they rise and start working on their own.

6:00am – Getting Brighter, More Work

The sky starts lightening, and by 6:15 it is light outside. Non-school-going children and caregivers start to get up and begin their work; although, some stay in bed as long as possible. These jobs include picking up litter, sweeping/raking the area behind the main house, and mopping the exterior veranda. The school-going children meanwhile bathe, dress, and make their beds.

6:30am – Early Morning Tea (for school-going children)

School-going children have "dry tea" (black tea without milk, but sweetened with sugar) with either chapati (unleavened flatbread) or g-nuts (groundnuts, aka peanuts). If Dorothy prepared chapati the previous evening, the children are happier to have a more substantial breakfast. If not, they make due with a cup of g-nuts. The water for tea was boiled the previous evening, and stored in a flask to keep it hot until morning. Milk is always unavailable this early because no one has yet gone to fetch it. Baaliro had a standing order, with a neighbor who kept a handful of dairy cows, for a small jerry can (~2 liters) of milk every morning.

7:00am – Medication Time

Sister Sally or one of the midwives tells a child to bring a pitcher of drinking water and cups to the office and then calls all of the children who take ARVs to the office to take their medications. If HIV-negative children are receiving any treatment, they also receive it at *this time. The children cluster around the door spilling out into the hallway, and one-by-one, the staff call a child's name, and he/she extends her hand to take the medications. Caregivers retrieve medication for children who are too sick to walk to the office, and those children who are unable to swallow the over-sized pills chew them before chasing them with the water. Sometimes Sister Sally asks them why they are taking medication to which they respond, "Eddagala lya'bulamu" [medications are for life] or, "Singa tolimira, ogenda kufa" [if you do not take them, you will die], but usually medicine time goes by quickly with little or no discussion.*

7:05am – School and Morning Work

Immediately after taking their medications, the school-going children go to school. The remaining children and caregivers start/resume their work. In addition to the previously mentioned jobs, cleaning the dishes from the previous night's meal (including hauling water from the tap to the utensil washing area behind the kitchen), cleaning the dining room, and mopping the kitchen are added to the list. Also, all children are supposed to bathe, make their beds, and tidy their rooms. The sickest children do not work and may return to bed after bathing. Most children/caregivers know their tasks and start working without much prodding from Dorothy, but sometimes they try to hide in their rooms to avoid work as long as possible. One of the children/caregivers goes to fetch milk which Dorothy uses to prepare tea and porridge.

7:15am – "Plumpy" distribution[21]

Sister Sally calls some of the children to receive a packet of "plumpy." It is usually a struggle to get the children to eat the peanut-based paste, and much to my chagrin, Sister

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[21] *Plumpy* is short for Plumpy'nut, a nutritional supplement for malnourished/underweight children. For a detailed description of *plumpy*, my role as *plumpy* monitor, and the children's reactions to *plumpy* see Chapter 7.

Sally often assigns me the unofficial job of "plumpy monitor," ensuring that the children do not just throw away their sachets or give their contents to another child or to the puppy.

8:30am – Morning Tea (for everyone else) and More Work

Dorothy serves milk-tea with chapati or g-nuts. Milk-tea is half freshly boiled whole milk and half water with a few tea leaves and heavily sweetened with sugar. Work usually stops during this time, though some children delay taking tea until they are finished with their work. They usually try to take tea in the dining room, where they can watch TV, and they linger as long as they can manage, before being called back to finish their work or being assigned a different task. If children take their tea on the back veranda, Sadat often takes a break from feeding the chickens and joins the children in talking and joking. Later morning jobs include peeling potatoes/matooke (cooking bananas) and cutting greens for lunch, watering the garden, washing clothes/bedding, and cleaning the latrine.

10:00am – Porridge time

School-going children return to Baaliro during their break and everyone gets a large cup of maize-based porridge. Children usually take their porridge seated around the veranda and steps at the back of the house. The school-going children drink their porridge quickly and run back to school. The remaining children drink more slowly, delaying resuming their work. After cleaning their cups and finishing off any remaining work, they may finally relax. Most head to the dining room to watch TV. The TV receives a handful of channels, but the children (none of whom speak English) almost exclusively watch NTV – the Luganda TV station which, during the day, plays an endless stream of popular music videos.

1:00pm – Lunch time

Children from school return and Dorothy (or one of the caregivers) serves lunch either directly from the kitchen or in the dining room. Wherever lunch is served, the children usually bring their plates to the dining room to sit and watch TV while they eat. The oldest children (in P3 or higher) eat quickly and return to school after lunch, but the younger ones do not have afternoon classes.

2:00pm – Afternoon Work

After cleaning their plates, the younger school-going children are supposed to wash their uniforms. The children only have one school uniform, so they must wash it by hand every day. Some are reluctant to do this tedious chore, but if they delay washing, it will not dry, and they then must put on a wet uniform the following morning. If a child fails to wash his/her uniform at all, he/she is often reluctant to go to school the next morning because he/she will not be smart in a dirty uniform, and could be punished at school for poor hygiene. Children usually use the veranda along the side/back of the house closest to the shed to wash their clothes.

2:30pm – Free time

Dorothy and Sister Sally often retire to their rooms in the afternoon, granting the children freedom from their oversight. The children may play on the playground or in the dining room, and as long as they get them before Sister Sally locks the office, they have access to a soccer ball and cards. The children especially enjoy coloring, but because the crayons and pencils will go missing if not collected at the end of each session, they only have access to this activity if additional adults are available (namely me or another volunteer). Some, especially those who lack the energy to run around the playground, enjoy sitting and talking, either on the veranda, or if the ground is not too wet, on grass mats under the trees *in the playground. Joy and I have some of our best conversations with children during this time. Several days a week, a pair of German volunteers who are spending a year working with St. Damien's come to play with the children. They usually color or play cards (a simple matching/memory game), but occasionally the Germans will try to teach them the alphabet and basic English vocabulary or organize an activity such as baking cookies or painting Easter eggs. School-going children may also finish their homework during this time; however, no one monitors their school work, and some wait till supper time to do their school work. Non-school-going children can start to play with the volunteers more quickly after lunch, because they do not have to wash their uniforms.*

4:30pm – More Work

Dorothy calls children to the kitchen and assigns them the final work of the day. These jobs usually include weeding the walkway, picking stones from beans/rice in preparation for the next day's meals, sweeping/raking leaves (again), scrubbing the stone walkway which runs along the back side of the house, chopping and hauling firewood, and cleaning and mopping the kitchen (again). Sometimes children also assist Sadat with feeding the chickens or weeding the garden. Older school-going children return from school around this time, and are immediately assigned work.

6:30pm – Bath time

Children are supposed to bathe before they eat supper, but often the older children delay bathing until later in the evening. Sometimes evening bath time is raucous and the children (especially boys) run around the hallways naked. Other times they simply bathe and return to the dining room to watch TV and wait for supper. Sometimes children try to avoid bathing by claiming they have already done so, in which case the easiest way to assess if *the child actually has or has not bathed is to ask, "Ani akulabye?" [who saw you?]. If a child has bathed, he/she quickly names a peer, who then bears witness. However, if the child has not bathed, he/she remains quiet, or may get up without answering and go bathe. Older school-going children, who have not yet had a chance to wash their uniforms, do so at this time. Their uniforms are often still damp when they put them on in the morning.*

7:00pm – Medication time

Similar to the morning medication time, Sister Sally or one of the midwives calls the children to bring cups and water to the office and to come take their medications, and medication time proceeds with minimal discussion.

7:30pm – Supper and TV time

Dorothy (or one of the caregivers) serves supper, and the children almost always eat seated around the dining room watching TV. The TV is still tuned to NTV, but at this time of night it plays foreign soap operas (Indian, Korean, Japanese, Filipino, or Spanish) dubbed into Luganda. None of the Baaliro staff eat with the children, monitor mealtimes, or monitor the TV. Dorothy goes to visit her family after serving supper, and Sister Sally eats supper in the kitchen with Godfrey and occasionally Sadat. Sister Sally then goes up to St. Damien's in the evenings. After the children finish eating, they pile the plates and place them on a table at the front of the dining room to be washed in the morning. Some children put themselves to bed when they start getting tired, others run around the hallways, but most watch TV for as long as possible.

9:00-10:00pm – "Bedtime"

At some point, Sister Sally and/or Dorothy return to the center and send any remaining children to bed. They scold the children who are running in the hallways, saying that they

> *are going to hurt themselves, and tell those watching TV to turn it off and go to bed. However, once the TV is turned off and children have retired to their rooms, the giggling begins. The girls, especially, seem to like staying up talking or singing late into the night. I often heard them giggling well past 10:30pm, while the boys usually settle down quickly. Children rarely turn off their room lights, and instead sleep with the lights on.*[22] *Sister Sally and/or Dorothy do not strictly monitor bedtime, and once they have told the children to go to bed, they usually return to the kitchen where they remain chatting and cleaning up past 11:00pm.*

Reviewing this schedule, we can see that while the day was structured around food, work, medicine, and play, the largest emphasis was on work. Additionally, while adults played a role in loosely structuring the day, most of the children's daily activities took place outside of direct adult oversight or supervision.

One might expect that children's lives at Baaliro would be dominated by HIV/AIDS. After all, the home was explicitly created to rehabilitate children suffering from AIDS and all of the children were undergoing some kind of treatment, most for HIV and the rest for malnutrition. However, surprisingly little time was spent on medical care. Aside from being called to the office twice a day to take medication, children's experiences at Baaliro were largely free from medical overtones in general, and almost entirely free from references to HIV in particular. Medication time could be over in as little as 5 minutes, and staff rarely talked with children about

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[22] When I asked Sister Sally about this, she said the children were afraid of the dark. I was surprised to hear this, since many of the children came from households which did not have electricity. Perhaps, however, since Baaliro was a new environment, they were less comfortable there than at home. When I asked the children why they kept the lights on, they either did not answer or said, "Simanyi" [I don't know]. Children were, however, very conscious of turning lights off during the day.

why they were taking the medications, and almost never talked to children directly about HIV/AIDS.[23] Recall, also, that children did not receive IV treatment while at Baaliro. When such treatment was necessary, children were admitted to the ward at St. Damien's. Many of the children attended school, and almost all were expected to participate in house activities, especially work.

Although relatively little time was spent directly engaging the children in their health, it is important to note that in principle children's physical/biological health still came before work. For example, if children were suffering from an acute illness (such as malaria) or were simply too weak to perform work, Dorothy either did not assign them work, or gave them very light tasks – such as removing the stones from the beans. Whereas more robust children did heavier work – such as chopping and hauling firewood to the kitchen. Overall, Dorothy did a very good job of assigning children work that was within their physical capabilities and taking into account their current state of health. Sister Sally liked to point out when a child began participating in work as a sign that he/she was beginning to respond to treatment (ARVs). Also, while the rest of the schedule remained flexible, medication times were fixed, even on weekends or if there was a special event.

5.4 Why So Much Work?

When I inquired why work was such an important emphasis at Baaliro, Sister Sally explained that the children and caregivers staying at Baaliro worked for several reasons. Of

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[23] Interestingly, adults would speak freely about HIV/AIDS in the presence of children. Thus, children could overhear discussions about HIV/AIDS with minimal filtering, but adults did not engage children directly in the topic. When I asked children why they took medications, only 54% (31/57) used either an English or Luganda word for HIV/AIDS in their response.

immediate importance, the house and compound needed to be clean and well maintained, because as a treatment and rehabilitation center they needed to maintain a high standard of hygiene. When asked why the children scrubbed the bathroom daily, Dorothy balked at the obviousness of my question and replied, "because we are an institution!" Clearly, in her mind, as an institution, Baaliro was held to a higher standard than a typical home[24] and both Sister Sally and Dorothy prided themselves on keeping Baaliro to what they considered an institutional standard of cleanliness. Practically, maintaining hygiene helped to reduce the transmission of infections, and the risk of transmitting infections among the immunocompromised children was a real concern. For example, when one boy arrived with a serious case of *Tinea capitis* (ringworm) despite Baaliro's hygiene efforts, the fungal infection quickly spread to the other children staying in the house. Those with the lowest CD4 counts (i.e. the most immunocompromised) were, unsurprisingly, the worst affected, and many suffered from hair loss and constant itching for months until their CD4 count finally improved.[25] This example also demonstrates that despite efforts to reduce the transmission of infections, Baaliro was not able to completely eliminate them. Given the high standards of hygiene, the size of the house, and the additional requirements to prepare food, there was too much work for Dorothy to complete alone, so children needed to contribute. In part, children's work at Baaliro can be seen as related to their health; however,

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[24] Even the typical Ugandan home was held to a high standard of cleanliness. *Bazungu* visitors often mentioned their admiration for the clean swept compounds and well organized homes, even in the most remote areas.

[25] The fact that St. Damien's physicians seemed unable or unwilling to prescribe the children with a sufficiently long course oral antifungal treatment also contributed to the protracted course of their infections. The children had been given oral treatment for 1-2 weeks, but stopped when the pills ran out (treatment for *Tinea capitis* should continue for 2-6 weeks *after* symptoms have resolved). Similarly, the doctors intermittently prescribed topical antifungals (known to be ineffective). I inquired why the children were not on oral antifungals, but never received a reason. I can hypothesize that the oral treatment was either only available in limited supplies or was expensive. Additionally, *Tinea capitis* was a very common condition even among uninfected children and not viewed as particularly serious. Therefore, the clinicians may not have prioritized treating it in the face of children's more serious medical issues. However, the cases among the children at Baaliro were more severe than typically found in the community. For a discussion of *Tinea* as a marker of poverty among children in Brazil see Hecht (1998).

both in terms of the jobs performed and the reasons behind them, work was about far more than maintaining an appropriately high standard of hygiene.

Beyond providing a source of free labor or reasons of pride and practicality, however, staff viewed the children's participation in housework as integral to preparing them for reintegration. Work itself functioned in several ways to prepare children for going home. I present these in roughly increasing levels of importance. First, through work children could learn important lessons about how to do things *bulungi* (well/properly), which they could then bring back to their families and communities. By evoking the idea of working to learn, the staff were implying that the children had not already been taught these skills, or at least that they had not yet learned them well/properly. Like most situations where children are learning practical skills, this learning did not take place through any formal education, but by participation in everyday work (Lancy, Bock, and Gaskins 2011). By participating in cleaning the house, children learned about hygiene and learned the proper way to mop, to clean the bathroom/latrine, to pick up litter, and to clean the pots, plates, and utensils. By assisting in preparing meals, children learned about nutrition and the proper way to prepare a balanced meal. By helping Sadat feed the chickens and weed the garden, children learned about income generating activities and the proper way to rear chickens and grow food. Ideally, children would learn these lessons at Baaliro and bring them back to their homes and communities once they were reintegrated. The staff often explicitly stated that, "children are learning skills that they will bring back to the community." They explained that the decision not to hire additional staff to clean/maintain the home was not due to budget shortfalls, but rather because children needed to learn and master these skills before going home. Indeed, the work children performed at Baaliro was largely the same as that performed by children in the community. On one hand this legitimates Baaliro's claim that children need to know and master housework skills before being reintegrated. However, since most of the skills – such as mopping the floor, starting and stoking the stove, sweeping the compound, washing clothes and gardening – were not new to them, it is reasonable to question how much new learning was taking place. Additionally, even when children were legitimately learning new ways to approach these tasks or new lessons about hygiene and nutrition, given the hierarchical social structures of traditional Buganda communities, it is reasonable to question the feasibility of children teaching these lessons to their elders.[26] The fact that undermining the authority of adults is bad *empisa* makes the claims of children's ability to bring back new skills to their community especially suspect and ironic given the major emphasis placed on instilling children with empisa.

Second, through work, children enacted one of the norms of childhood in Uganda. In Uganda, as in much of the world, children's labor makes a significant contribution to most households. Recall that over three quarters of children in Uganda perform household and/or economic work (UBOS, ILO, and IPEC 2013). One of the reasons children are traditionally valued in Uganda is because they help their parents (especially mothers) with their work (Philip Leroy Kilbride and Kilbride 1990). However, the norm of children's work is not only about economic contribution, but also is about fulfilling social roles. It is normal for children to work, and their inability or failure to work represents a breach of their expected social role. Parson describes how social roles are a combination of rights and responsibilities. In the case of the "sick role," individuals claiming the sick role must fulfill certain obligations (such as showing desire to get well) in order to continue to receive the rights associated with the sick role (namely exemption from normal social obligations), and if they fail to fulfill the sick role's

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[26] Lotte Meinert offers a similar observation and critique of children learning "modern" farming techniques as part of public education in Uganda (Meinert 2003, 2009).

responsibilities, the benefits of the sick role can be retracted (T. Parsons 1951). Applying the concept of habitus to the notion of roles and responsibility, Bourdieu explains that responsible individuals enact a regulated habitus (and are readily accepted), but that irresponsible individuals act outside of habitus (and are rejected), and meanwhile those who attempt but may be unable to enact habitus are still tolerated (Bourdieu 1977, 40). In Uganda, despite the permeation of international rights discourse (particularly in education), the social position occupied by children remained characterized more by its responsibilities than by its rights (K. E. Cheney 2007, 2015b). Demonstrating *empisa*, especially through work and showing respect to elders, were children's primary responsibilities.

Children, like adults, however, could be excused from work when they were ill, and children often cited being sick as a reason for not completing their work.[27] Despite children's attempts to claim the sick role, Baaliro staff rejected the idea that HIV-positive children were *unable* to work, denied children's claims to the sick role based solely on their HIV-status, and instead encouraged them to take on the role of a typical (healthy) child.[28] As part of the preparation for reintegration, staff explicitly told the caregivers who would be receiving the children and the children themselves that, once they had regained their strength, HIV-positive children should not be treated any differently than "any other child."[29] Mary and Sister Sally frequently discussed how caregivers (especially extended family members) fear (*oku-tya*) caring

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[27] Children also noted that sick children could not be beaten at school. Many of the children at Baaliro explained that the teachers (both at home and at the school that children attended while they were at Baaliro) were aware that they were sick and therefore did not subject them to corporal punishment used on other students.

[28] This is similar to the ways caregivers of children with cancer encouraged children to attend school and participate in household activities despite their terminal diagnosis (Bluebond-Langner 1978).

[29] There were some caveats to this idea, and Mary cautioned caregivers not to overwork reintegrated children, by giving them the hardest work – digging in the garden all day or carrying heavy jerry-cans to fetch water. However, she emphasized that children *could* work in the garden for shorter periods, or if the sun was not too intense, and they *could* fetch water in smaller containers or if the water source was not too far.

for a child with HIV. Rather than fearing that the children would infect other family members,[30] most feared taking on the responsibility of caring for a child with a chronic health condition. Many caregivers thought that children living with HIV required frequent hospitalization and a special (expensive) diet. Most relevant to the concept of work, caregivers feared that rather than contributing to the household, HIV-infected children would fall ill and become burdens.[31] To counter these fears, Mary frequently told caregivers, "Simulwadde, omulwadde abeera mu'ddwaliro" [he/she's not sick, a sick person stays in the hospital], when preparing caregivers to accept a child for reintegration.[32] Additionally, she and the staff repeatedly use the phrase "like any other child" when describing the children from Baaliro. Mary emphasized to caregivers that HIV-infected children simply required proper nutrition, just like any other child; that if they took their ARVs, slept under a mosquito net, and drank boiled water, they would only fall sick now and then from malaria and other common illnesses, just like any other child; and that HIV-infected children should do work around the house, just like any other child. Overall staff adamantly denied the idea that children living with HIV required special treatment because they were sick, and although children often attempted to evoke the sick role, staff rarely accepted their claims. Staff believed in emphasizing the normalness of children living with HIV, and they hoped that if children living with HIV could be seen and treated "like any other child" this would help to destigmatize the condition and help communities to more readily accept children living

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[30] Although most caregivers were aware that HIV could not be transmitted by casual contact, some children still reported caregivers isolating them from other family members by giving them designated utensils, clothing, and bedding and not allowing the child to assist in cleaning utensils, food preparation, or communal clothes washing.

[31] Jean Hunleth (2017) also discussed the burdens and benefits of taking even healthy children into one's home.

[32] Staff repeatedly emphasized this message at the youth workshop which adolescent children attended, adding for these children (who were ostensibly aware of their status), "Kale, olina akawuka kaleeta silimu, naye tolimulwadde!" [Okay, you have HIV, but you are not sick!].

with HIV.[33] Normalizing children living with HIV can be seen as an integral part of preparing them for reintegration.

Third, and most importantly, the staff emphasized that by working, children enacted *empisa*, and having good *empisa* was crucial once children returned to the community. As previously discussed, *empisa* covers a wide range of behaviors including showing respect for elders, fulfilling one's responsibilities, and being social with peers. Through work, the children embodied the roles and responsibilities of an ideal child, or in local terms, embodied *empisa*. Ogden discussed the importance of *empisa* among slum-dwelling women as a way for women to achieve "proper womanness" (Ogden 1995). In this context, *empisa* was especially important for widows whose identity had been spoiled when their husbands were presumed to have died of AIDS. Similarly, *empisa* was an important concept for all children in Uganda, but especially important for HIV-infected children who, like AIDS-widows, suffered from a spoiled identity (Goffman 1963). While not negating that logistical and economic barriers that contribute to stigma nor the potential of ARVs to reduce stigma, staff explained that children being reintegrated needed not only to be reasonably good children (well behaved, responsible, easy to manage), but in fact needed to be exceptionally good children, in order to overcome the stigma associated with HIV (Abadía-Barrero and Castro 2006; Castro and Farmer 2005).[34] Similarly, scholars have noted that women in Bangladesh overcame the stigma of childlessness by being

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[33] The main flaw in this plan was that most caregivers also feared HIV-stigma so strongly they did not disclose a child's HIV status to the community. Therefore, it is unlikely that reintegrated children were acting as ambassadors to make communities more accepting of HIV-infected children. However, as Pauline Peters and colleagues describe (2008), not naming HIV, may have, in and of itself, played a role in normalizing the children.

[34] Once again, this logic is somewhat ironic given that children themselves often did not know they had HIV, and caregivers often claimed that neighbors were unaware of the child's HIV status.

"exemplary women" (Nahar and van der Geest 2014).[35] Sister Sally succinctly explained, "We need to teach [the children] *empisa*, so their families will take them back." This was especially important for the majority of HIV-positive children whose parents (especially mothers) were deceased or otherwise unable to care for them. Of the HIV-positive children enrolled in Baaliro's program only 24% listed the mother, 11% listed the father, and 10% listed both parents as the primary caregiver at the time of enrollment. In actuality, even fewer children were cared for by their parents, because 1) these reports were not updated when a parent died and 2) in cases when the father was listed as the primary caregiver, in reality he was rarely involved in daily childcare activities, but rather a female relative or step-mother filled this role. Staff and children often referred to all female caregivers by the same term used for mothers (*Maama* so-and-so), but upon further questioning would reveal if she was not (to use their term) the "real mother."[36] Tobias Hechet also identified the practice of "child shifting" (not infrequently shifting among households and growing up under a maternal figure other than one's biological mother) as characteristic of nurturing childhoods (in contrast to nurtured children who grew up with their biological parents) (Hecht 1998).

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[35] Interestingly, Nahar and van der Geest (2014) also found that childless Bangladeshi women remained quiet and simply tolerated abuse as part of their strategy to overcome stigma. Similarly, the children in Baaliro's program often said "I just keep quiet" when I inquired about how they dealt with verbal abuse. Initially, this seemed to be part of good *empisa*, given that talking back to adults was considered very bad *empisa*. However, the fact that children also kept quiet in the face of abuse from peers, indicates that this strategy may have been about more than *empisa* and is more complex than I can address in this chapter. Cheney encourages "approaching silence as a distinct form of communication, rather than an absence of it" (K. E. Cheney 2015a, 38). This seems to especially apply when working with children affected by HIV.

[36] "Real mother" referred to a child's biological mother (and "real father" could similarly be used for biological fathers). However, staff at times debated whether children were better off with their biological parents. In cases where biological parents abandoned their children, but were still alive, staff noted that relatives were often reluctant to take the children into their homes. However, once both parents were dead, relatives would more frequently fully accept the responsibility of caring for the children. At the same time, however, staff generally agreed that no one would love children (and care for them) as well as the "real mother."

Staff observed that non-parental caregivers were less tolerant if a child had bad *empisa* and were more likely to become tired (*oku-koowa)* of the child and to chase (*oku-goba*) him/her to a different caregiver. Conversely, non-parental caregivers were more likely to keep (*oku-kuuma*)[37] a child with good *empisa*, and seemed more willing to invest in the child's welfare and education. Ugandan children in Kristen Cheney's (2007) research also cited stepmothers as the most guilty of abusing children and contrasted them to parents who care for and love children. Similar to the nurturing childhood Tobias Hecht (1998) described among the working-class in Brazil and similar, too, to Caroline Bledsoe's (1990) observation that fostered children in Sierra Leone had to struggle to achieve success within their foster families, the reintegrated Ugandan child's virtuousness was not innate or essential to childhood, but rather, was achieved through having good *empisa*.

Changing caregivers often had negative consequences on the child's education and health. Changing caregivers usually also required changing schools which, especially if the change took place mid-year, often meant the child had to repeat a grade-level and sometimes the child dropped out of school completely.[38] The fact that changing schools was both costly and detrimental to children's academic progress contrasts with Jean Hunleth's (2017) findings that "tactical school hopping" was a strategy employed by poor families to improve children's educational opportunities (2017, 42). Additionally, new caregivers were often unaware of or misinformed about the child's medications and the need for monthly clinic visits and medication

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[37] *Oku-kuuma* also means to take care of, to protect, and to foster. Staff regularly thanked caregivers for keeping a child (*weebale kukuuma omoana*) and emphasized that Baaliro did not keep children. Keeping did not seem to have the negative connotation that Jean Hunleth (2017) found in her research.

[38] Mary was also frustrated when children changed schools frequently, because each time a child changed schools Baaliro had to pay for a new school uniform. According to Baaliro's budgeting, a uniform should last at least two to three years. Children were also only allowed to repeat a grade level twice before Baaliro stopped paying school fees.

refills. In some cases, the new caregiver was not even told that the child was HIV-positive, making adherence to ARVs extremely problematic.

In addition to the daily emphasis on *empisa* at Baaliro, at the youth workshop Baaliro hosted, the speakers repeatedly emphasized the importance of *empisa*, and encouraged children to use good *empisa* as a strategy to improve their lives. The motivational speaker shared his life story, emphasizing that through hard work and having good *empisa*, he was able to become a successful businessman, despite beginning orphaned at a young age.[39] By being respectful and helpful, children were told, they could acquire sponsors who could potentially pay for school fees, give them transportation for their clinic appointments, and generally help them in times of need. The idea that children can strategically employ *empisa* is not unique to Baaliro. As part of the 2011 National Strategic Plan for OVCs, the authors interviewed children aged 9-18 years old about their roles in reducing their own vulnerability, and most children named behavioral strategies which would fall under the practice of good *empisa* such as, “staying in school, ensuring respect, and being obedient to parents, teachers and elders”, “avoiding video halls, free things, hitch-hikes or gifts and relating with strangers”, “helping parents and other people with work, avoiding laziness”, and “seeking advice from elders” (MGLSD 2011, 8–9). Though the report did not use the term *empisa* (governmental reports are generated in English), their responses demonstrates that children recognize that the practice of *empisa* can be strategically employed to their benefit. Interestingly, and as I discuss more in Chapter 8, the goal of having good *empisa* was not to attain independence, but rather to increase the possibilities for interdependence through sponsorship and relational supports.

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[39] Many of the children attending the workshop reported that, although the speaker was not HIV positive, his story of orphanhood, abandonment, and discrimination resonated with them, and that hearing about his successful outcome gave them hope for their futures.

Overall, many children faced difficulties when they returned to their communities, but those whose caregivers reported that the child had bad *empisa* tended to have even more difficulties than most. Because of the number of children that Baaliro had reintegrated, Mary had a difficult time following-up with all of them as regularly as she would have liked. Recall that originally she was supposed to follow-up with children monthly, but during my fieldwork, she visited only those children for whom Baaliro was paying school-fees, and she only visited them on average three times per year. Thus, given the logistical difficulties of follow-up, Baaliro needed children to have good *empisa*, so that they could avoid problems such as school and medication failure. Baaliro staff sought to inculcate children with *empisa* through their daily practices at the center, especially through their participation in work.

5.5 Children's Responses to Work

For their part, children had a variety of responses to the work required of them. Certain kinds of work were actually highly desirable. In addition to daily work, several times a year Baaliro staff took children to Baaliro's farm (located about 10 km away) to spend the day "digging" (hand-plowing the soil, planting crops, weeding, and/or harvesting crops depending on the season). This work was physically demanding, so only children who were well enough were supposed to go. Going to the farm also was a kind of "field-trip" where children got to ride in the truck, spend the entire day away from the center, and eat lunch at the farm. The day before going to the farm, children would talk in anticipation about going, and it was often difficult to get them to go to bed because of their excitement. However, children who had refused to work at Baaliro were also told they would not be allowed to go. In this instance, participating in work, even physically difficult work, was highly desirable, and children who were denied the opportunity to go, either because they had refused to work at Baaliro or because they were too ill, quite literally cried at the thought of being left behind. Eleven-year-old Wemusa, who had always been particularly stubborn about doing work at Baaliro, threw such a fit when he was not allowed to go to the farm that his mother appealed on his behalf and the staff relented, reasoning that it would be easier to allow him to go than to try to deal with him at the center. Everyone was surprised when they returned in the evening and the fellow children and caregivers reported that Wemusa had worked very hard and been well behaved at the farm.

Work at Baaliro was on average less exciting than the trips to the farm, but some children seemed to actually enjoy the process of the work itself. Peter and Onzi could be very helpful when they were in a good mood, for example, helping the brick-makers who came to construct a water-tanker to mix the murram and cement and later carrying the bricks. These jobs were physically challenging, but Peter and Onzi seemed to take pride in their ability to complete them and in demonstrating that they were strong enough to do so. The boys also enjoyed helping Sadat with gardening and caring for the chickens. Peter continually requested that Sister Sally give him a chicken so that he could start to rear them like Sadat. Interestingly, Onzi's helpfulness when working with Sadat contrasted with his reluctance to wash his clothes, which led to harsh scolding from Dorothy.

Most children, presumably having been inculcated with *empisa*, dutifully completed their work, so they could resume more desirable activities such as watching TV or playing (especially if there were *bazungu* to play with). However, sometimes children would intentionally have tea out of the sight of Dorothy to try to avoid her assigning them work. Other strategies for minimizing the amount of work assigned included working slowly (since if they finished work too quickly, Dorothy would often assign them another task) and delaying in responding to

Dorothy's call to work. These "weapons of the weak" were risky because, if Dorothy suspected children were avoiding work, she would scold them harshly for having bad *empisa* (Scott 1987).

A few children refused to do work entirely – often evoking the sick child paradigm, which the staff fought so hard to debunk. Such children were labeled as problematic and difficult, and as lacking *empisa*. While Dorothy would at first harshly scold children who refused to work, she eventually gave up on them and assigned their work to other children. Sometimes this meant that helpful children became overburdened with more than their fair share of the work, and occasionally Sister Sally stepped in on the child's behalf to more evenly redistribute the workload. Sister Sally did not approve of giving up on a problematic child, and would continue to encourage *empisa*, but since she was occupied with administrative matters, she had little time to oversee the children directly.

Interestingly, despite staff's emphasis on *empisa* and work, children's behavior at Baaliro did not always foretell of their behavior once reintegrated. In several cases, children who had horrible *empisa* at Baaliro were model children in their communities, whereas children who had been good workers at Baaliro became stubborn and disobedient when they returned home. Thus, while *empisa* was a predictor of successful reintegration once a child returned to the community, his/her *empisa* at Baaliro was not always indicative of his/her *empisa* at home.

5.6 Conclusion

In this chapter I have demonstrated how the daily lives and practices of children at Baaliro were shaped almost entirely by the organization's larger emphasis on and commitment to preparing the children for reintegration in the community. Part of the rehabilitation process was to transform HIV-infected, sick children, into capable, productive children who would be welcomed back to their communities and treated like “any other child.” This transformation was achieved, in part, through the daily practice of work. Work was an important part of the children’s day at Baaliro which served several functions. Through the completion of their work, children (in theory) learned lessons they could bring back to their communities, they enacted the social role of a healthy child, and, perhaps most importantly, the children embodied the culturally important concept of *empisa*. In this context, *empisa* itself reflected the roles and responsibilities of an ideal child, emphasizing respect for elders, sociability with peers, and fulfilling one’s responsibilities. Having good *empisa* was especially important for children admitted to Baaliro because they (potentially) suffered from a spoiled identity due to their HIV-status, and caregivers, especially non-parental caregivers, were often reluctant to take on the responsibility of caring for a child with HIV. Looked at another way, when children fulfilled their responsibilities, the children themselves lightened their caregivers’ responsibilities, thus making caregivers more willing participants in the children’s care.

Chapter 6: Food-Talk: Using the Meanings of Food for Children and Staff to Interpret the Strategies Surrounding Food Refusal

In the previous chapter I explored how Baaliro's ultimate goal of *oku-bazayo* (reintegration) shaped the daily lives of children living at Baaliro. In particular, I analyzed the culturally important concept of *empisa* and how, through their daily-work, children enacted *empisa*. In this chapter, I return to the daily lives of children at Baaliro but instead focus on the more proximate goal of *oku-jjanjaba* (rehabilitation) and, in particular, the role that food played in this process. That food was important is hardly surprising given the obvious role of food in nutritional rehabilitation as well as the numerous scholars who have discussed, already, the emotional and symbolic importance of food in general (Lavis and Abbots 2013b; Lupton 1994; Mintz and DuBois 2002; Weismantel 1988), and the importance of food in ethnic identity in Uganda in particular (Amone 2015). However, staff and children held different views about why food was important and what defined good food, as demonstrated in their food-talk, or the way they talked about food. Children's food-talk emphasized food's relational properties, whereas staff's food-talk emphasized food's nutritional properties. Given the importance of food to both children and staff, and the limited modes of resistance available to children, children frequently employed food refusal as a strategy to express emotional distress, to attempt to change their circumstances, or to receive the food they most wanted. In the final part of this chapter I analyze several cases where children refused to eat with variable success and outcomes. Given their attention to children's individual circumstances (as discussed in Chapter 4), it is surprising that staff were unable to effectively address children's emotional relationships with food, and may indicate their attempts to manage the ethical dilemmas of caring for children in under-resourced circumstances.

6.1 Baaliro Staff's Food-Talk

Recall that Baaliro had a two-part mission – *oku-jjanjaba* (rehabilitation) and *oku-bazayo* (reintegration), and that Mary and Sister Sally often reminded caregivers that Baaliro was an *eddwaliro* (treatment center or hospital), not an *ennyumba* (house). Although Baaliro defined itself by its primary goal of medical rehabilitation, the organization's approach to rehabilitation was shaped by their ultimate goal of reintegration. Rehabilitation centered on healing children's bodies, but preparing children for reintegration also required attention to their development and readiness for social interactions. The idea that they were *both* (medically) rehabilitating children *and* preparing children for reintegration produced the background for the staff's attitudes toward food which emphasized both the nutritional importance of food and the importance of eating "family foods."

In the weaning and malnutrition literature, "family foods" [1] are contrasted to complementary foods (foods used during weaning), supplementary foods, manufactured therapeutic foods, and micronutrient powders or pastes. At Baaliro, family foods additionally meant those foods which would be consumed daily in homes in the community, and were contrasted with special foods and/or *obumpwakipwaki* (snack foods). The concept of family foods at Baaliro had nothing to do with familial relationships, but was about what foods were commonly consumed in the homes and communities that the children came from. Nationally, the most common foods consumed in Uganda are *matooke*[2] (cooking bananas), cassava, sweet

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[1] In this chapter I am talking about "family foods" in contrast to "technological foods." The center also utilized the technological food of ready to use therapeutic food (RUTF) – also known as "Plumpy'nut" – as a nutritional supplement, and I discuss this in the next chapter.

[2] *Matooke* is the Ugandan word for the East African Highland banana (*Musa* AAA-EAH). They are look similar to, but are genetically distinct from "true" plantains (*Musa* AAB group) and Pacific plantains (*Musa* ABB group). Thus they are technically "cooking bananas" rather than plantains.

potato, and beans (FAO 2017). Traditionally, the national staple food of Uganda (especially in the Central and Western regions) has been *matooke*, making up upwards of 20% of caloric intake (FAO 2017; Haggblade and Dewina 2010; Ssewanyana and Kasirye 2010). However, since the spread of banana xanthomonas wilt (BXW), which devastated the Central region's *matooke* crop decreasing yields by up to 50% (Karamura et al. 2010), production of maize has increased, and since 2008 the per-capita caloric consumption of maize has exceeded that of *matooke* (FAO 2017).

There is considerable variation in staple foods among the regions in Uganda, and some foods are associated with certain ethnic groups (see Table 6.1). At the risk of oversimplifying the ethnic diversity in various regions and homogenizing food preferences, I found most Ugandans agreed with the general patterns of regional food production and ethnic food identification that other researchers have identified (Amone 2015; Haggblade and Dewina 2010; Ssewanyana and Kasirye 2010).[3] Because Baaliro was located on the border between Central and Eastern Uganda, and most of the children at Baaliro came from areas traditionally occupied by the Baganda and the Basoga (see Figure 2.1), I highlight the food patterns in these regions and ethnic groups.

The Baganda, located in Central Uganda, consider *matooke* to be their staple food.[4] Just as Japanese will say they have not eaten if they do not consume rice, many Baganda, whether speaking English or Luganda, will say they have not had any food if they have not consumed *matooke* (Amone 2015; Allison 1991; and personal observation). The Basoga, located in Eastern

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[3] In contrast to Amone who emphasized the importance of food in ethnic identity, Kristen Cheney (2007) found that urban children made no mention of food in conjunction with ethnic identity, but instead cited village visits, traditional ceremonies, and language as important to their ethnic identity. Interestingly, though, children cited food in connection with village life and for its role in traditional ceremonies. From my observations, staple food preference (especially *matooke* or sweet potatoes) was an important marker of ethnic identity for the children staying at Baaliro.

[4] This ethnic claim persists, despite the fact that *matooke* was more commonly planted and contributed to a higher percentage of caloric intakes in Western (especially Southwestern) Uganda (see Table 6.1).

Table 6.1 Patterns of Food Consumption and Production in Uganda

	Region	National	Central		Eastern		Northern		Western	
	Sub-region		Cent 1	Cent 2	East Central	East	West-Nile	North	South West	West
% caloric intake*[1]	Cereals[4]	28	25	24	32	35	15	45	18	16
	Roots[5]	29	20	30	43	32	61	29	15	30
	Matooke	20	31	20	6	15	2	0.3	49	28
	Legumes[6]	14	11	13	8	10	19	20	13	18
% farmers growing each crop*[2]	Maize	57	46		78		48		58	
	Millet	18	2		27		19		30	
	Sorghum	17	3		23		31		30	
	Cassava	46	41		51		42		50	
	Sweet potato	44	41		57		29		50	
	Matooke	40	42		42		2		68	
	Beans	53	45		45		43		78	
	Groundnuts	23	13		19		25		29	
Ethnic Group*[3]			Baganda		Iteso	Basoga	Lugbara	Acholi		
Food Most Closely Identified with Ethnic Group*[3]			matooke		cassava/ millet bread	sweet potato	cassava bread	millet bread		

Sources of Data: [1](Ssewanyana and Kasirye 2010), [2](Haggblade and Dewina 2010), [3](Amone 2015)

[4] *Cereals include maize, millet, sorghum, rice and bread*

[5] *Roots include sweet potato, cassava, and Irish potatoes*

[6] *Legumes include beans, groundnuts, and peas*

Grayed boxes indicate the areas where most of the children Staying at Baaliro came from.

(or more specifically East Central) Uganda, traditional identify white sweet potatoes as their staple (Amone 2015; and personal observation). While the same percentage of farmers (42%) plant *matooke* in both Central and Eastern Uganda, *matooke* accounts for only 6% of caloric intake in the East Central sub-region vs. accounting for 20-31% in the Central region (Haggblade and Dewina 2010; Ssewanyana and Kasirye 2010). Maize is most often prepared as *posho*[5] (a dish of maize flour cooked with water to the consistency of a stiff dough) or as a drinkable porridge. *Posho* and porridge are the most affordable and easy to prepare foods for institutions, especially schools, and are not associated with any ethnic identity in Uganda. As indicated above, maize production and consumption has increased nationally, although Eastern Uganda has the highest percentage of farmers who plant maize (78%). Cassava is widely considered to be a food security crop, which can be harvested during times of hardship; however, different ethnic groups have vastly different attitudes toward cassava.[6]

Beans are the most important source of protein in Uganda, supplying an average of nearly 14 grams of protein per person per day (FAO 2017). Maize comes in second with nearly 10 grams of protein per person per day, and animal sources lag far behind, providing 3.7 or fewer grams of protein per person per day. Meat makes up less than 2% of daily caloric intake and is very expensive, costing 2,700 UGS (Ugandan Shillings) ($1.08) per kilo vs. only 700 UGS ($0.28) per kilo of beans (Ssewanyana and Kasirye 2010).

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[5] Posho is actually the English word for this dish. It is called *akawungu* in Luganda and *bando* in Lusoga. A similar though less thoroughly cooked dish is called *ugali* in Kiswahili.

[6] Amone (2015) contrasts the Lugbara of the West-Nile region where cassava is the staple food of preference with the Acholi in Northern Uganda who only eat cassava during desperate times. However, other scholars with whom I have spoken and who work in Northern Uganda refute his claim that the Acholi consider cassava a food of last resort. Other researchers have described groups in Western Uganda (notably the Banyankore) who, similarly do not “respect” cassava, and would only serve it to guests in times of scarcity (Nziza, Mbaga-Niwampa, and Mukholi David 2011).

Wheat and rice are available in Uganda, but are expensive and do not make up a significant percent of daily caloric intake nationally (FAO 2017). According to one study, the price per kilo of rice was 1,067 UGS ($0.43) and 1,200 UGS ($0.48) per kilo of bread vs. only 533 UGS ($0.21) for maize flour, 182 UGS ($0.07) for sweet potatoes, and 161 UGS ($0.06) for *matooke* (Ssewanyana and Kasirye 2010). Most Ugandans consider pasta, bread, and rice to be luxury foods, reserved for the wealthy, though rice is often served at special events such as holiday celebrations, weddings, and funerals. Potatoes (called Irish potatoes or just "Irish" to distinguish them from sweet potatoes) are also available, but are considered a luxury food or an *obumpwakipwaki* (snack food) when fried as chips.[7]

Most meals in East Central Ugandan households consist of *emmere* and *enva*. *Emmere* literally means food, but when talking about what one has eaten, Ugandans almost always refer to the staple starches as the *emmere* – *matooke*, *posho*, cassava, or sweet potato. On average Ugandans consume 2157 kcal/day with 70% coming from staple starches (UBOS 2014). *Enva* is the sauce, and the most common sauces are beans or g-nut[8] sauce. Along the lakeside, dried *mukene* (small dried silver fish) is also commonly used to make sauce. Leafy green vegetables (such as amaranth[9] and collard greens) and other vegetables (such as local pumpkin, bitter berries, eggplant, and cabbage) are used in sauces or served as a side, but are usually considered insufficient as a sauce on their own. From a strictly nutritional perspective, government reports explain that Ugandans eat "monotonous and unvaried diets, which frequently cause

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[7] However, according to some scholars both the Banyankore and Banyoro regarded potatoes as unfit to serve guests (Nziza, Mbaga-Niwampa, and Mukholi David 2011). Unfortunately, the text does not distinguish between sweet potatoes or Irish potatoes, so it is unclear to which type of potatoe the authors are referring.

[8] Groundnuts are oilseeds and the family of groundnuts include peanut (*Arachis hypogaea*), *Arachis villosulicarpa*, bambara groundnut, hausa groundnut, and others which also belong to the family *Fabaceae* or *Leguminosae*. Additionally, groundnuts can refer to tubers or beans of *Apios Americana*, *Conopodium majus* and Dwarf ginseng. In Uganda, g-nuts usually refer to peanuts.

[9] In particular, *Amaranthus dubius*, locally called *doodo*.

micronutrient deficiencies" (UBOS 2014, 115). Nearly half of children under the age of five in Uganda are anemic,[10] nearly 40% have vitamin A deficiency, and between 20-69% are zinc deficient (FANTA-2 2010b; UBOS and ICF International 2012). These dietary deficiencies are not surprising considering that only 34% of mothers reported feeding children foods rich in iron and 61% reported feeding children foods rich in vitamin A in the same survey.[11] Children, however, are not the only ones to suffer micronutrient deficiencies, with 23% of women aged 15-49 anemic and 36% deficient in vitamin A (FANTA-2 2010b).

At Baaliro, staff were keenly aware of the macronutrient content of food and ensured that every meal included both proteins and carbohydrates. For the two main meals of the day (lunch and supper) beans were the primary protein source and *posho* was the primary carbohydrate source, and in a typical week we ate *posho* and beans for 10 meals. Though neither the traditional staple, nor the most desired food, *posho* and beans were served almost universally at schools and other institutions. In addition to keeping the costs of feeding the children within budget, the combination provided a complete source of amino-acids and met the carbohydrate and protein intake needs of the growing (and rehabilitating) children. The beans were cooked in oil with tomatoes and green-peppers which the staff explained provided enough nutrients to help prevent the development of micro-nutrient deficiencies.[12] Seasonally g-nut sauce was substituted for the protein, and white sweet potatoes or cassava (grown on Baaliro's farm) for the

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[10] Anemia can be caused by deficiencies in iron (either due to inadequate dietary intake or increased blood loss due to parasitic infections such as hookworm or malaria), folate, or vitamins B and B12. Rates of iron deficiency may actually be much higher than rates of anemia.

[11] Dietary deficiencies can be compensated through the use of supplements, and 57% of children under five receive vitamin A supplementation, but only 7% receive iron supplementation. Because parasites also contribute to anemia, deworming is also important, but only half of children receive deworming medications. No information about zinc consumption or supplementation was available. Iodine deficiency is not a common problem in Uganda today because iodized salt is used in 99% of households.

[12] However, as a nutritionist at Wash U pointed out to me, it is unlikely that this was actually sufficient to prevent micronutrient deficiencies, especially of zinc, iron, choline, vitamin A, and vitamin B12.

carbohydrate. Beef was prepared at Baaliro once a week and *matooke* or rice was prepared about twice a week. Additionally, on Saturdays the youth group served heaping plates of rice with a few mouthfuls of beef, a dish the children called *pilau*. Chicken, the most desirable meat locally, was a rare treat, and fish was served even more infrequently and was almost always brought as a gift rather than purchased by Baaliro. The availability and preparation of greens depended largely on the motivations of Sadat and Dorothy, so they were intermittently served. *Mukene* (small dried silver fish) was irregularly available. Staff regarded *mukene* as highly nutritious and rich in protein, and often encouraged families to feed their children *muekne*, but as Sister Sally explained, she only purchased it if she had money and she could get it for a good price.[13] It was, therefore, difficult to quantify how often the children were served *mukene*. Some children loved the little fish, but others hated them. Fruits, most typically avocado, *ffene* (jackfruit – *Artocarpus heterophyllus*), bananas,[14] and mangoes and sugarcane were brought from the farm when ripe, but overall were rarely available. In addition to the two main meals, children had breakfast and mid-morning porridge.[15] Breakfast consisted of either *chapati*[16] or g-nuts and sugary tea. School-going children had black tea with sugar, because milk was unavailable in the early morning, but those not attending school had milk-tea. Additionally, Dorothy prepared an extra morning meal of potatoes and/or *matooke* which she only served to the sickest children (as identified by Sister Sally). All children had mid-morning porridge made from maize flour with milk added to enrich

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[13] This depended on the budget; for an overall discussion of the budgetary constraints facing Baaliro see chapter 8.

[14] These included little sweet bananas (*ndiizi*), large sweet bananas (*bogoya*), and roasting bananas (*gonja*).

[15] According to a 2012/2013 Uganda national survey, children under five most often (33%) received tea or porridge with some kind of solid food for breakfast (UBOS 2014). Other common breakfasts were tea alone (17%), solid food alone (18%), and porridge alone (14%), but 13% of children did not receive anything for breakfast. The fact that children at Baaliro received tea, solid food, *and* porridge therefore was more than most children in Uganda received in the morning.

[16] *Chapati* is a type of flat bread.

the porridge.[17] Despite Baaliro rearing chickens, the children rarely had eggs, which were instead sold as part of Baaliro's income generating activities.[18]

When explaining why it was important to eat, staff encouraged children to eat by saying "emmere eleeta amaanyi" [food brings energy/strength] and "emmere ezimba omubiri" [food builds the body].[19] These phrases were also used as the Luganda translations for carbohydrate and protein respectively. Unfortunately, these phrases did not mean much to the children. They seemed confused about which foods were "bringing them energy" or "building their bodies" and the distinction between the two was meaningless to them. During the nutrition session at the workshop which Baaliro hosted, the youth (all 13 years old or older, and many of whom had learned about nutrition in school), said that using the English terms protein and carbohydrate made more sense to them than the Luganda phrases, but still they often did not understand in which category a certain food belonged. Staff also emphasized that medicines "lyagala emmere" [want/need food] to work properly. Aware that most children preferred to be at home rather than at Baaliro, staff reminded children who were reluctant to eat that if they ate well and gained weight they would be allowed to go home. For Baaliro's staff the food itself was not understood as an index of affective relationships but was viewed simply as means for achieving caloric intake, which in turn led to weight gain, and ultimately a return to the village. Food, therefore,

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[17] In most places porridge was not enriched with milk, but Baaliro commonly added milk to increase the porridge's protein content. School-going children returned to Baaliro during their morning break to have porridge.

[18] For more discussion of the income generating activities at Baaliro and their struggle to meet donor's demands for sustainability see chapter 8.

[19] These phrases seemed to be commonly used among individuals (both Ugandan and foreign) running nutrition education programs. A third category of foods, those which "protect the blood" (i.e. vitamins) are also commonly sighted, but were less common referenced at Baaliro. At the Saturday youth group, using a variation on the usual categories, one week Peace Corps volunteers taught about food which make you "go" (carbohydrates), "grow" (proteins), and "glow" (vitamins).

did not build or enact relationships for Baaliro's staff, but was a mechanism by which children could return to being under family care.

In general, staff talked about food in terms of its nutritional and medicinal properties. Food was constructed as a vital aspect of the children's biomedical rehabilitation while at the center. The more children ate, the faster they would recover, and the sooner they could return to the community. Additionally, the emphasis on reintegration shaped the kinds of food served at the center. The staff rejected the idea of feeding the children a diet that they perceived as substantially different from what they would find once they returned to the community and insisted on serving "family foods," not special foods. Recall that Baaliro staff's use of the term "family foods" had nothing to do with familial relationships, but instead referred to foods eaten by people living in the villages from which the children came. Despite this goal, as I describe in the next sections, children reported that the food they ate at Baaliro was different from that which they ate at home, and they applied a very different meaning to food.

6.2 Children's Food-Talk

Although staff typically ate at St. Damien's canteen, which offered a greater variety of food, I ate my meals with the children. Eating meals was an important way for me to build rapport with the children. I shared in their monotonous diet, and since I actually ate with the children, I had better knowledge of which children were in fact eating well, and which ones were not. This enabled me to speak-up in defense of children who were being chastised for "not eating" because their MUAC was "still in the red." I also chose to eat with my hand, rather than use a fork (which was offered to guests). I told the children, and truly believed myself, that the food tasted better when eaten by hand rather than with a fork, and I wanted to position myself as a member of Baaliro, rather than a guest. When I had access to it, I shared my supply of dried hot peppers with those who wanted to "add flavor" to their food.[20] In addition to eating with them, I participated in food preparation with the children.[21] This included picking through beans and rice for stones, removing kernels of corn from the cob, and de-shelling g-nuts. Throughout the day, the children and I often engaged in food-talk. The children's food-talk with me coalesced around three main themes – exotic food, food preferences, and village food. In all cases, children's food-talk differed significantly from that of the staff described above.

Exotic food discussions involved the children asking me about what foods *bazungu* eat. Some of these discussions centered on familiar but rarely acquired foods (rice, potatoes, pasta, and bread) and never-experienced but heard-of foods (sandwiches, burgers, and pizza). Children assumed that since *bazungu* were rich, they must eat these expensive and highly desirable foods all the time. I also tried to explain, with limited success, those foods which they had not experienced. More often, however, our discussions of exotic food were truly exotic, taking the form of the question "Do you eat [insert animal name]?" with animals including snakes, snails, monkeys, crocodiles, etc. This game went both ways – all of us asking about ever more exotic (and repulsive) animals/foods with each round. The children would squeal with simultaneous disgust and delight when told that (some) *bazungu* eat snails (escargot) and later call to me, "jangu olye nyama" [come eat meat], whenever they found a snail in the yard. Discussions of exotic food served primarily as a rapport building activity, and, in a reversal of traditional

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[20] Some children loved to spice their food with these hot peppers, others preferred milder cuisine. As a general rule, older children were more likely to prefer spicy food than younger children. Salt was the other commonly used flavor enhancer. Dorothy did not use much salt in her cooking when there were children suffering from mouth sores, but then the other children complained that the food lacked flavor.

[21] Recall that food preparation was a significant part of the daily schedule and work at Baaliro, as discussed in more detail in chapter 5.

research patterns, one that the children themselves typically initiated and seemed very much to enjoy.

Food preferences offered another top topic of conversation. While there were exceptions, the children generally did not enjoy *posho* and beans. They ate it “okulya bulyi” [to eat only for eating], and strongly preferred rice, *matooke*, or Irish potatoes and meat – especially chicken and fish. Children also did not accept the idea that beans (as a source of protein) could “build the body” as well as meat, and they especially rejected the idea that *posho* was equally as nutritious as *matooke*.[22] Overall, children were ambivalent about *mukene* (dried small fish) and greens; some liked them, some refused to eat them all together, and very few listed them among their favorite foods. Other highly desired foods were *obumpwakipwaki* (street foods/snacks) – most of which were fried – such as: *chapati*, *sumbusas* (samosas), *mandazi* (fried doughnut-like bread), *kabalagala* (fried banana ‘pancakes’), *kikomando* (sliced *chapati* and fried beans), and *rolex* (fried egg omelet rolled in *chapati*).[23] Such food preferences are important to remember when it comes to the strategies children employed and the labeling of certain foods as “special food.”

Often children contrasted the food eaten at Baaliro with food eaten at home. Such discussions usually implied that the food at home was better than at the center – emphasizing less *posho*, more *matooke*, and more variety – including local yams, cassava, sweet potatoes, and

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[22] Based on USDA estimates, *matooke* and *posho* were roughly equivalent in terms of total caloric (232 and 311 kcal) and fiber content (4.6 and 2.25g), and both were high in carbohydrates (62 and 45g) per cup of cooked *matooke* and *posho* respectively (USDA 2015). Whereas *matooke* had a very high sugar content (28g), *posho’s* sugar content was under 1 gram – presumably indicating more complex carbohydrates. Additionally, *posho* contained larger amounts of protein (4 vs. 1.6g), lipids (2.3 vs. 0.4g), phosphorus (159 vs. 56mg) and zinc (1 vs. 0.3mg), but *matooke* contained larger amounts of potassium (930 vs. 185mg), folate (52 vs. 15µg) and vitamins C (22 vs. 0mg) and A (90 vs. 6.5µg). In summary, as a source of carbohydrates, they were roughly equivalent, with *posho* providing more complex (and therefore longer-lasting) carbohydrates, but *matooke* providing more vitamins and micronutrients and *posho* providing a small amount of protein and lipids.

[23] It took several trips to Uganda for me to realize that the term *rolex* derived from the phrase “roll eggs” rather than the Swiss luxury watch.

even occasionally rice. While *posho* was a standard institutional food in Uganda, it was, in fact, not necessarily the most commonly served food in the communities from which the children came. Given the high cost of meat, children rarely made claims of eating more meat at home, though those from fishing villages said they more frequently ate fish. Even more than these differences in staples, children spoke longingly of abundant fruit at home, many of which I had never heard of before and was unable to get a translation for. *Ffene* (jack fruit - *Artocarpus heterophyllus*), *empafu* (a kind of olive - *Canarium schwinfurthii*), *entuntunu* (gooseberries - *Physalis minima*), and many different varieties of mangoes and bananas were among the most commonly cited fruit children said they ate at home. Children explained that in the village they had the freedom to roam and pick fruit as they wanted. These claims were substantiated by adults and even in a national newspaper article which started, "For many, the mention of *entuntunu* (gooseberries) evokes childhood memories. Children, especially in rural areas, go to the wilderness to hunt for this sweet and succulent fruit" (Kyotalengerire 2011). Lastly, some children reported that family members or community members would give them *obumpwakipwaki* (snacks) – especially *chapati*, *sumbusas*, and *kabalagala*. Such stories were told with the explicit moral that gifts of food were a demonstration of how much the individual loved the child and/or was his/her friend.

One must be skeptical of these representations of food at home, given that the children typically arrived at the center in various states of malnutrition. Indeed, the children's reports of home diet likely depicted an idealized construction of home contrasted to the institution (ie Baaliro). Kristen Cheney also noted this tendency toward idealizing the village (K. E. Cheney 2007). When urban children in her research argued that "village life is better than town life," the village became an imaginary space tied to ethnic identity and kinship relations. Urban children also idealized the village as “a reserve of ‘free food’” in contrast to the city where “food costs money” (K. E. Cheney 2007, 153). Whereas the children who stayed at Baaliro had actually lived in the village, and many of the children in Cheney’s study had never visited, let alone lived in, a village, nonetheless both the urban and (temporarily) institutionalized children were away from the village at the time of our studies and both groups shared in their idyllic constructions of village life, especially that village food was better than what they were currently eating.

On the other hand, the children staying at Baaliro’s claims may not have been idealized. The fact that many of them were receiving sub-therapeutic ARVs (if any at all) may better explain their malnourished states upon arrival rather than an absolute lack of food. The virus multiplying unchecked in their blood, weakening their immune systems, and causing a variety of gastrointestinal conditions likely contributed to malabsorption which could explain their malnourished bodies, even if they were being given abundant food. This gives validity to children’s glowing reports of the food served and available at home. When they were in their home villages, children likely had access to a greater variety of foods, at least seasonally, than at Baaliro, and their freedom to roam in rural areas contrasted starkly with the confinement of staying at Baaliro where children were explicitly prohibited from leaving the grounds of the center without permission from the staff.[24]

The idea that food was a means by which one could demonstrate love also requires consideration. Though overall caregivers rarely came to visit children who were staying at Baaliro, those that did almost always brought some kind of food. Most often they brought food acquired directly through their own labor – avocados, mangoes, bananas, and, especially for those from fishing villages, fish – rather than purchasing food. However, some caregivers

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[24] Sister Sally rarely granted permission for children to leave unless accompanied by a caregiver; however, the children also rarely asked for permission to exit the compound, assuming they would not be allowed to go.

purchased and brought snacks – especially bread, *sumbusa*, and *ensenene* (fried grasshoppers – a seasonal delicacy). One of the easiest ways to tell if a child had received a visitor was to note the appearance of food in the office. Staff would comment that the gifts of food demonstrated that the caregiver loved the child, and children would shyly nod when asked if they agreed. They used the word *okw-agala*, which can also mean to like, to want, and to need, but both contextually and when I asked staff for translation, they insisted that caregivers were demonstrating their love. Since the caregivers brought food for a specific child, the food became the property of that child, and was stored in the office. However, children almost always shared their food with the other children at Baaliro. They usually shared equally among all of the children, and risked being scolded for having bad *empisa* if they refused to share, or shared only with the children they liked. However, sometimes children still chose to only share their food with a few special people and doing so both demonstrated and strengthened their relationships with chosen recipients. Both the way children received food as a gift and shared it demonstrate how food played an important role in children's social relationships.

Other researchers similarly have described the ways material exchange both reflects and builds relations of love, especially in caregiving for the sick (Klaits 2010). In Zambia, Jean Hunleth (2017) observed children giving fruit to sick adults as a sign of their love, emphasizing the reciprocal nature of affective relationships. In Botswana, Bianca Dahl concluded that food is an indicator of love because "a suitably plump child is one who is well fed, *well loved*, and not overworked" [emphasis added] (Dahl 2014, 632). In Kristen Cheney's (2007) Kampala based research, children cite caregivers' provision of food as signs of love: "Asir knew his father cared about him because he brought him food" and "[my stepmother] is now giving me food. She now loves me" (K. E. Cheney 2007, 129, 238). In contrast to scholarship emphasizing the affective properties of food, Karen Coen Flynn's (2005) discussion of the moral economy of food in urban Tanzania emphasizes that not all gifts of food are equal, and that it is important to pay attention to the kinds of food being given because, "sometimes food gifts were offered for no particular reason other than that there were leftovers from a meal and the giver had no means to preserve them" (Flynn 2005, 42).

In Summary, Baaliro's staff and the children staying at Baaliro spoke about food in very different ways. The staff saw food as a key component of both the children's rehabilitation at the center (the proximate goal) and their preparation for reintegration into the community (the ultimate goal). The center needed children to eat the food provided in order to gain weight so that they could be reintegrated. As such, it strove to provide children with affordable, nutritionally complete food that was not significantly different from the food available at home. Despite children's claims that *posho* and beans were not eaten at home, the staff insisted that they were the staple food for (medical) institutions,[25] and they certainly were the most affordable food for the center to provide. When staff talked about food with children, they emphasized its nutritional and medicinal properties. The children meanwhile, with rare exception, did not enjoy *posho* and beans. They remembered food from home as being not only different, but also better and more varied than that served at Baaliro. Children's food-talk focused more on the relational properties of food, rather than its nutritional properties. For children, talking about food was a way to build relationships (such as with the 'exotic' anthropologist), to reminisce about home, and to express personal preference. Given the well documented emotional, symbolic, and ethnic significance of food, the fact that children's food-talk was about more than its nutritional properties is hardly

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[25] Recall though that Baaliro did not consider itself a childcare institution (a children's home) but a *medical* institution (a hospital).

surprising. Receiving and sharing food also gave children a way to recognize and build affective relationships.

6.3 Food Strategies

In addition to agreeing that food was important, both the staff and children at Baaliro shared the goal of returning the children to their homes as quickly as possible. Between work, Dorothy's scolding, their restricted mobility, and the monotonous food, most children did not want to stay at Baaliro. Even those who did not mind staying at Baaliro and enjoyed spending time with *bazungu* or watching TV, got homesick and eventually wanted to return home. Children, however, had relatively few ways with which to express their discontent, most of which involved refusal of some kind – refusal to work, refusal to attend school, refusal to bathe, or refusal to eat. The first three forms of refusal earned children the reputation of having bad *empisa*, but since caning was not permitted at Baaliro, there was relatively little staff could do other than scolding a child for refusing. While undermining Baaliro's ultimate goal of preparing children for successful reintegration, Baaliro staff could gradually work to improve a child's *empisa* "slowly-by-slowly." However, refusing to eat directly undermined Baaliro's primary goal of rehabilitation, and was thus more serious, and demanded more urgent attention and immediate action. Unfortunately, as shown in the cases below, because staff focused on the nutritional properties of food, rather than its relational properties, they remained, at times, unable to get children to eat.

The goals of the children who refused to eat can be grouped into two main categories – to be sent home or to get special food. Ironically, in the case of children refusing food in order to be sent home, refusing to eat actually prolonged their stay at the center. I begin with two cases where children strategically refused to eat food in an attempt to be sent home. These cases were two of the most extreme cases of food refusal; however, I use them because they are powerful accounts of the children's attempts to exercise agency over their lives via one of the few means available to them. The final case is that of a child who refused to eat certain foods in order to get special food – i.e. food that she preferred and wanted. This strategy was variably effective for her, depending on how sick or healthy she was and whether her mother was available when she employed it.

6.4 Cases of Food Refusal

6.4.1 James – "Bakwatagana" [They grapple with each other]

James' appearance was striking from the moment I saw him. From a distance, I noticed his angular frame and shuffling gait. As he came closer his sunken cheeks and visible forearm bones became obvious. When he spoke, it was impossible not to notice the cauliflower growths of candidiasis sprouting along his gum line. He was severely malnourished, suffering from a relapse of TB, and had numerous opportunistic infections due to poor adherence to his ARVs. James was well known to Baaliro; having been admitted twice previously (when he was 12 and 15 years old). I first met him when he was 17 years old and reappeared at the center in this deteriorated state. Everything about James's physical appearance was weak and frail – his fine hair, his brittle nails, his emaciated body – except for his eyes which shone brightly from their sunken sockets. James was extremely intelligent and articulate and was one of the few children at Baaliro to have attended secondary school. His social history was very complex, and he was the only child at Baaliro with a court order regarding his guardianship and the responsibilities of his parents.[26] Both of James' parents were alive, healthy, and living within 15 minutes of the center, though on opposite sides of the Nile. Surprisingly, both had been tested several times and were HIV-negative.[27] Despite *Maama*-James' legal responsibility to care for James, he was living with a neighbor immediately prior to coming to the center.[28] When James came to St. Damien's for medical treatment, he was resistant to being admitted to Baaliro for rehabilitation. With much coaxing, however, he eventually agreed. At first, with the staff closely monitoring him, he took his medications and ate well.

One of the first things James told me when I asked him about his health was that his parents did not get along – "Bakwatagana" [they grapple with each other], he told me, meaning they fought a lot. Initially, I was confused by what his parents' marital issues had to do with his health, but over time it became clear that James was deeply affected by their broken relationship. He talked openly about his plan to bring his father and mother back together though visiting him at Baaliro; however, both parents remained aloof. One morning another child, Wemusa, called me to James' room where I found James crying, whimpering in pain, and gasping for breath. We carried him up to St. Damien's and after a blood test, the clinicians determined that he needed a blood transfusion, which required that they transfer him to ECCH (the public pediatric hospital). Sister Sally called James' parents, and while both came, they did not actually see or speak to one another. *Taata*-James[29] saw him at St. Damien's, and *Maama*-James met him at ECCH. I accompanied James throughout the day, and at one point, when *Maama*-James had gone to take

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[26] Per the court order, James was supposed to be living with his mother and receiving financial support from his father.

[27] Discussion of how James could be HIV-positive when his parents were HIV-negative centered around theories of him being bewitched or of viral transmission via traditional medicine. However traditional medicine in this region did not generally involve cutting and no specifics were offered even upon further inquiry.

[28] Whether James moved to the neighbor's house of his own volition, his mother neglected to care for him, or she chased him to the neighbors was a point of contention among the staff at Baaliro.

[29] James' Father. *Taata*-[child's name] is the usual term of address for a child's father.

another blood sample to the lab at a neighboring hospital (the lab at ECCH was not functioning at the time), I asked James how he was doing. Again, rather than discussing his own health, he wistfully spoke only about how his parents would not talk to each other.

The day after receiving the transfusion (which, required a transfer to a private hospital because ECCH's blood stores were out of stock), James wrote a letter insisting that he wanted to go home to his father's house, and not to stay with his mother. Additionally, he further explained to me his plan to get his mother to quit her work to take care of him, and that his father would support them all. He claimed it would be easy to get his parents back together because his father was not in a relationship and his mother was the best at cooking and cleaning. *Taata*-James expressly rejected the idea and insisted that James could not come live with him because there was no one (no woman) at home to take care of him and because *Maama*-James was his legally assigned caregiver. As it became clearer that his plan was not likely to succeed, James began refusing food and was caught throwing away pills.

One day when James refused to eat, Sister Sally had the other children pack up his things, threatening to send him to the nutrition ward of ECCH where, "they will put a tube in your nose if you refuse to eat."[30] In the end, Sister was unable to follow through with this threat, because James' parents refused to accompany their son to the hospital. *Maama*-James cited her responsibilities working and caring for her younger children at home and said *Taata*-James could accompany him to the hospital this time since she had done so last time. Soon similar, though slightly less dramatic, scenes surrounding food and medication refusal took place almost daily. The staff redoubled their efforts to encourage James to eat and take his medications, but food and medication times quickly grew into scenes of fighting and resistance.

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[30] She was referring to an nasogastric tube (NG-tube), which is placed into the nose and passes down the back of the throat and into the stomach to bypass the mouth and deliver liquefied food directly into a patient's stomach.

Meanwhile, James' requests to be sent home (specifically to his *father's* home) became more fervent – even though his father explicitly refused such a living arrangement. Sister Sally arranged multiple family meetings, and each time the meetings resolved with James agreeing to stay at Baaliro, eat well, and take his medications and with Baaliro staff imploring James' parents to both take responsibility for and show love to their son. *Maama*-James began staying with him in the evenings. However, she left early in the morning and returned after dark and was never present for medication times. *Taata*-James demonstrated his love for James by bringing him special food – *ensenene* (fried grasshoppers – a seasonal delicacy), bread, pasta, sugar biscuits, bananas, mangoes, passion fruit, and even ice-cream and chicken – and by giving James money. The later proved problematic, because, with money, James could leave the center and use public transportation to move around, which was against the rules of Baaliro. On several occasions, James visited his father or other family members attempting to convince them to take him in, but they always returned him to Baaliro, saying he was too sick to stay with them. Not only did James' disappearances worry staff, but also, through his failed attempts to go home, James began to lose hope. He literally cried aloud that he wanted to go home and was tired of Baaliro. He began verbally abusing his mother and refusing to eat even the special food his father had brought for him.

One evening, after a failed attempt to go home, James tried to squeeze through the bars of the main gate to escape again. At only 20kg, were it not for his head, he would have been thin enough to manage it. When confronted by the night watchmen, he cried that he wanted to die. During his last week at Baaliro, James began talking about how at his funeral he would be returned to his father's house, and how everyone would eat rice and chicken after his burial. A few days later his condition rapidly deteriorated. With James unable to walk and suffering from severe diarrhea, Sister Sally was finally able to convince *Maama*-James to accompany her son to the hospital. He was admitted on a Saturday afternoon and by the early hours of Monday morning he was dead. The weekend staff at ECCH did little to stall his demise. They explained to Sister Sally that they did not place an NG-tube or an IV because the doctor, who did not come in over the weekend, had left no orders for treatment, and they thought he would survive until Monday morning rounds. However, ECCH was only the last step in James' long and painful death.

James refused to eat as a strategy to go home and to bring his parents back together. Ultimately, his strategy accomplished neither, but hastened his own death. Staff at Baaliro witnessed his distress but were powerless to force him to eat because they could not meet his demands to repair his parents' fractured relationship. Despite several family meetings, little changed in the relationship between James' parents and their son. James' body was ultimately buried behind his father's natal home. Baaliro paid for the coffin, and *Taata*-James paid for the remainder of the funeral expenses. Though a child, James had more people turn out to his funeral than most adults. The juxtaposition of having so many community members come to honor him in his death, but no one able to support him in his life was difficult to resolve. They served chicken and rice at his funeral – but none of the staff from Baaliro could stomach to eat it.

6.4.2 Martin – "Why are you keeping me here? I want to go home!"

The staff, in particular Godfrey, had been working with Martin's parents for several months to try to convince them to bring their children for rehabilitation. During this time Martin's older brother, also HIV-positive and the original child being targeted for rehabilitation, passed away. The loss of his son, in part, prompted Martin's father (himself HIV-positive, but ambivalent about taking ARVs) to seriously consider treatment for his remaining son, Martin. Martin cried uncontrollably when *Taata*-Martin left him at the center. At eight years old, Martin was deemed old enough to stay at Baaliro by himself. Upon admission, his health was poor (he was suffering from cough and diarrhea) but not critical, and he was underweight (18kg), but did not qualify as severely malnourished.[31] The staff expected that with the initiation of ARVs and nutritional supplements, he would be able to go home in 2-3 months. Despite his young age and minimal schooling, Martin was extremely intelligent and verbose, and loved telling stories – most especially about home. He told us he came from a fishing village on one of the islands in Lake Victoria, and he spoke with Joy at length about the types of food he did and did not like, of the fish his father would bring home, and of the special treats community members bought him and his (deceased) brother because they were sick and because "batwagala" [they love us]. Staff repeatedly exclaimed that Martin talked a lot(!) and that he talked "ngamukulu" [like an adult]. His loquaciousness with adults contrasted greatly with most Ugandan children who, even when talkative with their peers, were reluctant to talk to adults.

Martin was unhappy and cried almost daily that he wanted his parents and that he did not want to stay at Baaliro. Martin had started attending school at home and said he liked it very much and wanted to continue studying, but he absolutely refused to go to school while at Baaliro.[32] Initially, Martin did not resist medications or food. He had seen his brother die, and he wanted to get better. He ate more when foods he liked were served (such a rice and beef from the Saturday youth group), but he also ate the standard *posho* and beans served at Baaliro. Additionally, Dorothy prepared an extra serving of food for him in the mornings, usually potatoes or *matooke*, which he willingly ate. Godfrey befriended Martin, putting him to bed his

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[31] For more about the clinical distinctions between moderate and severe malnutrition see chapter 7.

[32] "Sagala kusomera wano" [I don't want to study from here [Baaliro]].

first evening at the center,[33] sharing tea with him his first morning, and buying chicken and *sumbusas* for him when he went to town for a chest x-ray.[34] Martin was also initially friendly with other children, and though sometimes he lacked energy and went to bed in the afternoon, other times he joined them in play. Dorothy did not assign him work, but occasionally he voluntarily joined the other children to help wash the plates and cooking utensils or to help Sadat. He also willingly bathed and made his bed. A few days after he arrived, the clinicians placed a cannula in his right hand to facilitate giving him injections to treat his chest infection. Although staff knew that Martin would need to stay at Baaliro much longer before he was healthy enough to return home, Martin convinced himself that he would be able to go home as soon as he completed his injections and the cannula was removed. He counted down the days until (he believed) his father would come and take him home. While he finished the course of injections, the cannula was removed, and his father returned after two weeks, Martin did not go home with his father.

After this visit, Martin's crying and resisting heightened in fervor to include standing in the hallway and shouting, "Nga ndeekebwa wano, nga sirina maama ne taata!" [[it is] as if I am left here, as if I don't have a mother and father!]. He told me explicitly that he was not going to eat or bathe "from here [Baaliro]"[35] and that he would do those things only "from home." He packed his belongings, and insisted that his father was going to pick him up *enkya* (tomorrow). In addition to refusing to eat, Martin stopped playing with the other children claiming, "Simanyi

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[33] This is especially notable because children at Baaliro usually put themselves to bed (see daily schedule in chapter 5)

[34] On this occasion, Martin commented that he had to eat the chicken quickly before returning to Baaliro so the other children would not see him with it. While he did not explicitly state why he did not want other children to see him with the chicken, based on my observations, I assume he was afraid that they would either be jealous or make him share it with them.

[35] Sigenda kuliira wano! Sigenda kunabira wano! [I'm not going to eat from here! I'm not going to bathe from here!]

kuzanya” [I do not know how to play]. He also stopped washing his plate, began bossing other children around, and began shouting at nearly everyone to leave him alone (“Ndeeka!” [leave me alone!]) when they attempted to greet him.[36] He decided he no longer liked Joy or Godfrey, because they tried to convince him that he needed to stay at Baaliro. He started talking about how his brothers had died, and staff learned that in addition to the older brother who they knew had passed most recently, Martin’s younger brother had also died when his parents failed to get treatment for the child’s HIV. Martin talked about seeing his deceased brothers in his sleep, saying that they were calling to him to join them. Martin told Joy, “Singa tebanzizayo, njagala okufa” [if they don’t take me back [home], I want to die]. His medical condition deteriorated, and he began vomiting even the small amounts of food that he did eat.

Within two weeks he lost 2kg (weighing in at 16kg) and now qualified as severely malnourished. Staff were very aware of his precarious medical condition; however, they could neither force the boy to eat, nor take him to the ECCH malnutrition ward (where NG-tubes were used) because the hospital required that a caretaker accompany him and neither of his parents were willing to do so. They were afraid to let him go home, because they believed his parents would not give him his ARVs and he would die like his brothers had done. The staff were aware of Martin’s emotional distress, and tried to encourage him by reminding him that if he ate well he would be able to return home sooner. Additionally, they began offering him even more special foods. Sister Sally instructed Dorothy to prepare eggs for Martin in the morning and she purchased whatever food he requested for lunch and supper. Meanwhile, other children continued to eat g-nuts for breakfast and *posho* and beans for lunch and supper. Accommodating a child’s requests for food was highly unusual at Baaliro, but staff were almost as desperate to

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[36] Ndeeka! [Leave me [alone]!]

get Martin to eat as he was to go home. They determined that, since Martin was such a bright child, perhaps if they disclosed his HIV status to him, he would better understand why he needed to stay at Baaliro and stop refusing to eat. Sister Sally called *Taata*-Martin to come, so that they could disclose his status. When Martin learned that his father was coming, he again convinced himself that his father was going to take him home and packed his things.

During this second visit, *Taata*-Martin initially insisted on taking Martin home, citing his worsening condition, but the staff (in particular Sister Sally, Mary, and Godfrey) convinced him to let Martin stay, arguing that they (and the medication) needed more time and that the boy surely would die (like his brothers) if allowed to go home. Martin was present in the office for these discussions, and began crying and flapping his arm in anger as his father gradually changed his mind and agreed to have him stay at Baaliro. *Taata*-Martin was also initially reluctant to allow the counselor to disclose Martin's HIV status to the boy, but ultimately, he agreed. In the late afternoon, *Taata*-Martin left Martin at Baaliro telling him to be a good boy, to eat well, and to take his medications, and that his health would improve. He also left Martin gifts of sweet bananas and dried fish. Martin cried so hard and uncontrollably when his father left that he vomited. Later than day, he stood in the middle of the entryway sobbing and repeatedly shouting after Mary as she left to go home for the evening, "Lwaki onkuumira wano? Njagala kuddayo eka!" [Why are you keeping me here? I want to go home!].

Although the staff redoubled their efforts to give Martin whatever foods he wanted – upping the ante to include *sumbusa*, *chapati*, *mukene* (small dried silver fish), and mangoes as well as continuing to offer rice, *matooke*, dried fish, and eggs – Martin was aware that the staff had prevented him from going home, and he became more recalcitrant in his refusal to eat. He said he hated Godfrey for convincing his father to make him stay at Baaliro and he hated the counselor (who had disclosed his status to him) for saying that he had HIV. A few days after *Taata*-Martin's second visit, Sister Sally contacted the grandmother of another child who, by chance, lived near Martin's paternal grandmother. After being told about her grandson's condition, *Jjajja*-Martin[37] arrived in the afternoon with her brother. At first Martin said he did not like his *jjajjas*, and that he would have run away if he had known they were coming, but *Jjajja*-Martin quickly began joking with her grandson that he was her *mugole* (groom) and it became clear that the two had a loving-joking relationship. *Jjajja*-Martin informed the staff that Martin (and his older brother) had been living with her and that she was the one who had brought them to be tested and started on ARVs at St. Damien's several years ago. She understood the importance of ARVs and had ensured that the boys took them properly. They had both been informed that they had HIV and had both been healthy in her care. However, their mother (her son's wife) had insisted on bringing the boys back to the island, and they started missing appointments. Even when *Jjajja*-Martin brought the medications to the mother, she still failed to have the boys take their ARVs as prescribed. Martin's elder brother deteriorated first, and *Jjajja*-Martin accompanied him to the hospital where he died. She then convinced *Taata*-Martin to bring Martin to Baaliro, so that he would not "go the same way" as his brother had.

This visit turned out to be the factor that likely saved Martin's life, though it took several days to put any changes into action. The same morning *Jjajja*-Martin arrived, Martin weighed 15kg, and the clinicians decided that the ARVs he had been taking (first line treatment) were not working and switched him to second line ARVs.[38] The nutritionist also recommended that

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[37] *Jjajja*-[child's name] is the term of address for children's grandparents (both maternal and paternal grandmother and grandfather) and their grandparent's siblings. Throughout this vignette, when I use the name *Jjajja*-Martin I am referring specifically to Martin's paternal grandmother, other *jjajja* are not capitalized.

[38] This decision was based on clinical observation – persistent vomiting and diarrhea – and CD4 count, rather than viral load testing which was not available. The switch to second line ARVs was significant because second line

Martin go to the ECCH nutrition ward since he was refusing to eat and suffering from vomiting and diarrhea, but Sister Sally was reluctant to send him because 1) ECCH required that a caregiver accompany children in the nutrition ward, and so far, none of Martin's family members had agreed to do so, 2) the hospital was, in her words, a "new hell" which she described as dirty and having many infections, and 3) he had only just started on second line treatment, and so needed to wait another 2-3 weeks for the medications to start working. *Jjajja*-Martin was also not excited to accompany her grandson to the hospital, but as a compromise she agreed to stay with Martin at Baaliro for a few days. While *Jjajja*-Martin was at Baaliro, Martin started eating more (though he still ate reluctantly) and stopped vomiting. He also smiled for the first time in weeks.

However, on Good Friday *Jjajja*-Martin returned to her home, promising to come visit after Easter. She explained that she had many responsibilities at home, including caring for other grandchildren and planting crops, and that she wanted to spend the Easter Holiday at home. Later that evening, Martin began complaining of back pain – pointing to his spine. The following morning (the day before Easter) he weighed only 14kg, and the nurse weighing him directly questioned me, "Why don't you take this one to the hospital?" Her question reaffirmed what I had been thinking for some time as I had watched Martin's cheeks melt away until his jawbones protruded: that Martin's condition was worsening at Baaliro and he needed to go to ECCH. I feared that if we waited another 2-3 weeks for the new ARVs to begin working, Martin would die. The fact that the nurse directed her question at me finally prompted me to more directly involve myself in getting Martin transferred to ECCH.

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medications were considerably more expensive than first line medications, and also if a child developed resistance to second line treatment it was extremely difficult to access additional treatment. Therefore, the clinicians first attempted to reinitiate first line treatment rather than jump straight to second line treatment when children arrived at Baaliro.

Later in the morning, Martin again complained of back pain, and Sister Sally sent me with him to St. Damien's to see a clinician. At the visit, I pleaded with the clinician to write a referral to ECCH, and he obliged my request. Sister Sally then called *Jjajja*-Martin to ask her to accompany her grandson to the hospital. *Jjajja*-Martin promptly abandoned her Easter preparations and arrived at Baaliro by lunch-time. We waited for Sister Sally to return from the farm, and arrived at ECCH around 4:00pm. Because it was Easter weekend, there were literally no staff at ECCH to admit Martin. After waiting for about an hour, Sister and I left. *Jjajja*-Martin called Sister Sally around 8:30pm to report that Martin had finally been admitted to the nutrition ward.

Martin spent Easter and three more weeks in the nutrition ward. Though he would not have believed it possible before going to ECCH, Martin was more miserable in the nutrition ward than he had been at Baaliro. For the first two weeks, he was not permitted to eat anything other than fortified milk[39] and he continued to have diarrhea. The twice daily injections of antibiotics through a cannula in his hand burned so much that he cried, and he shouted at nearly everyone who came to visit him, "Vaayo!" [Go away!]. After two weeks, however, he had gained a kilogram, his cheeks had visibly started to fill in, his diarrhea decreased, and he was allowed to slowly start eating solid foods (at first eggs and Plumpy'nut, later porridge and carrots). *Jjajja*-Martin stayed with her grandson the entire time he was admitted at the hospital, and Baaliro staff visited him nearly every day often brining supplies for *Jjajja*-Martin and medications for Martin. Additionally, *Jjajja*-Martin's brother and his wife, *Jjajja*-Martin's friends, and her older grandchildren all came to visit Martin. *Maama*-Martin also visited once, but *Taata*-Martin never visited.

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[39] For more details about the fortified milk and the protocols at ECCH nutritional ward see Chapter 7.

Overall, Martin's recovery was painfully slow, but ultimately, he was discharged and reintegrated into his grandmother's home.[40] When I left the field, he was still living with his grandmother and had transformed into a vibrant and lively child with chubby cheeks, still verbose and with another interesting story to tell about the time he spent at Baaliro and ECCH. Martin's strategy of refusing food in order to return home (with his mother and father) was again not successful in its original intent, and in fact prolonged his time in rehabilitation. But, in his case, Martin's desperate condition drew the attention of his grandmother, who was ultimately able to provide both the medical care and social support that he needed.

James and Martin demonstrate children employing the strategy of refusing food in order to "go home." Going home must be understood as more than a return to a physical place. In addition, the children were attempting to manipulate and mend the social relations of their family to meet their needs. Both boys refused to eat food as a means to express their strong desires to go home and, perhaps more importantly, to gain the attention of loved ones. Interestingly, the boys were never at Baaliro at the same time. James died several months before Martin arrived. The final case I present is that of Kabiite, who presents a more typical strategy of food refusal as a means to get special food, and provides a contrast to the cases of James and Martin.

6.4.3 Kabiite[41] - "The mother loves her too much"

Kabiite was in very poor health when I first met her. She had been at Baaliro for nearly two months, but was still too weak to walk unassisted and was so skinny that the other children

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[40] Initially *Maama*-Martin had insisted that she was going to take the boy back to the islands with her, but she ultimately agreed to allow Martin to stay with *Jjajja*-Martin. Shortly after Martin was discharged from ECCH *Maama*-Martin fell seriously ill, and she passed away within a few months of Martin's reintegration. Martin continues to live with his *Jjajja* and is doing well both physically and academically.

[41] Kabiite is a Luganda name meaning "love".

called her “skeleton” behind her back. She was unable to hear their jeers because severe ear infections made her temporarily deaf and ultimately permanently damaged her hearing. Communication was difficult because, in addition to her hearing loss, painful throat infections made it impossible for her to talk – sadly these infections also had long-term consequences and left her with a permanently hoarse voice. Because she was too ill to care for her most basic needs – unable to go to the bathroom or eat unassisted – her mother stayed at Baaliro with her. Kabiite was also a very picky eater. She refused to eat *posho* and beans and similarly refused porridge. In the first few weeks of our acquaintance, through a combination of her mother’s and Sister Sally’s purchases, Kabiite was able to get whatever she requested to eat – *matooke*, fish, *empafu*, and even ice cream. For many months, Kabiite’s health was tenuous; her lab results indicated that she was in kidney failure, and the physicians were uncertain if she would recover. However, gradually her kidney functions improved, she gained weight, the ARVs worked to reduce the HIV in her body, her immune system strengthened, and her health stabilized.

As her health improved, Baaliro staff stopped asking Kabiite what she wanted to eat, and gave her the same food as everyone else. However, Kabiite was still able to get her special food, because her mother, who was still staying at Baaliro and by this time was often responsible for preparing the food at Baaliro, would purchase and prepare a separate dish for Kabiite whenever she refused to eat *posho*. Most children accepted the fact that since *Maama*-Kabiite was preparing the food, Kabiite would get something special, though they eyed her food with envy. Kabiite’s special treatment, however, eventually came to an end when Mama-Kabiite was given a job working at Baaliro’s farm. Kabiite, by this point, was attending school and was healthy enough to be reintegrated, but the center needed someone to work the farmland for their income generating activities, and Mama-Kabiite needed the income. Since leaving her home nine months earlier to accompany Kabiite to Baaliro, *Maama*-Kabiite had been unable to do any of her usual income generating activities, and had fallen farther and farther in debt to the community-savings-and-loans group(s) to which she belonged in her home village. After accepting the job, *Maama*-Kabiite lived and worked on Baaliro's farm during the week and visited Kabiite at Baaliro on the weekends, filling in for Dorothy on her day off. Kabiite's health was no longer precarious, so when she refused to eat a meal of *posho* and beans without her mother around to provide an alternative she either simply went without or (more often) sulkily ate her food after it became apparent that there truly was no other option.

When Kabiite refused food, it was because she did not like it, and she wanted to eat something different. Having had success with this strategy when she was sick, she tried to continue using it once she was healthy. However, refusing to eat in order to get "special food" was only an intermittently successful strategy – and its success depended on 1) the severity of the child's illness and 2) the presence of someone willing to provide special food. *Maama*-Kabiite was a steady and stable presence of love and support throughout Kabiite's life. In fact, Baaliro staff, Joy, and even staff from St. Damien's all commented that *Maama*-Kabiite loved Kabiite "too much" and vice versa. They explained this was likely because Kabiite was the "last-born" (or youngest) of *Maama*-Kabiite's children. They often said, "We Africans, we spoil the last-born." *Maama*-Kabiite spoiled her daughter by giving her special food once she had recovered from her illness, at which point she should have been eating the same food as the other children at Baaliro. Similarly, *Maama*-Kabiite did not require Kabiite to do work at home, nor did she discipline her for not participating in work at Baaliro.[42] Returning to the concept of *empisa* from

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[42] Kabiite was one of the children who most frequently refused to complete her assigned work. She often simply refused to get out of bed in the morning until the morning work was completed, and then rushed off to school without bathing, after taking her morning medications. In the afternoons, she would lie about having washed her

Chapter 5, staff worried that if anything were to happen to *Maama*-Kabiite (who was HIV-positive, but healthy and taking ARVs) no other caretaker would be able to manage Kabiite because no one other than her mother would tolerate such behavior. Kabiite did not experience the emotional and familial distress and abandonment that James and Martin did and, in fact if anything, was "loved too much" by her mother.

6.5 Analyzing Strategies of Food Refusal and Responses

James and Martin refused to eat as a strategy to return home, whereas Kabiite refused to eat as a strategy to get special food. However, staff treated all cases of food refusal using the same guidelines. As a general rule, Sister Sally did not like to purchase "special food" for children who were refusing to eat, but, as both Kabiite and Martin's cases show, she made exceptions when children were seriously ill. In keeping with their proximate goal of rehabilitation, when children were severely ill, the staff at Baaliro focused on the nutritional content of food and strove to get children to consume calories in whatever form they could. However, once a child's health stabilized, Baaliro's ultimate goal of reintegration once again took priority, and staff explained that children needed to learn to eat the same food as every other child and to not anticipate special treatment.

Baaliro's response of acquiescing to children's requests for special food when they were sick again demonstrates their focus on food's nutritional properties. Similar to anorexia treatment units, at Baaliro food was understood as medicine, especially for acutely ill children, and this focus at times obscured alternative meanings that children associated with food (Lavis 2016; Lester 2014; Long et al. 2012). Since food was integral to rehabilitation, Baaliro's proximate

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uniform so she could play, and then hide in her room to avoid evening work. Dorothy gave up chiding her for having bad *empisa*, saying it was the responsibility of *Maama*-Kabiite to teach her daughter this important lesson.

goal, giving sick children special food was acceptable as a temporary means to an end which worked in the majority of cases when children were refusing to eat as a strategy to get special food, because most children wanted to eat special food. However, using special food was a risky strategy, because once started, it was difficult to stop. Once children succeeded in using food refusal to get special food, they, like Kabiite, often tried to continue to refuse to eat in an attempt to continue getting special food. Similarly, when less-sick children saw some children getting special food, they often tried refusing to eat in an attempt to get special food as well. However, once the child's health had stabilized, staff refused to provide special food and most children quickly learned that they had to eat what was served or go hungry. Kabiite persisted in her strategy of refusing food longer than most because her mother was able to meet her demands. This demonstrated *Maama*-Kabiite's love for her daughter, but may also have risked spoiling Kabiite, making her more vulnerable if anything were to happen to *Maama*-Kabiite in the future. In most cases in which children were refusing to eat as a strategy to get special food, Baaliro's response to food refusal, that of giving children special food, worked: children ate and rehabilitation continued.

Even the way children and staff talked about food refusal revealed differences in the meaning of food to them. When talking about refusing to eat, children's food-talk focused on food preferences – the most common response when I asked a child why he/she was not eating was, "Saagala!" [I don't like/want [it]!]. In contrast, even when providing acutely ill children with special food, staff's food-talk still focused on food's nutritional properties, "this one will have an egg, [because] it is very nutritious." Only sick children received eggs with any kind of regularity, because they needed extra nutrition.

The cases of James and Martin even more powerfully demonstrate the gap between the meanings children and staff held towards food. When children were not refusing to eat as a strategy to get special food but rather as a strategy to be sent home, proving children with special food was not an effective response. James and Martin continued to refuse to eat, citing their desire "okulira eka" [to eat from home], despite the offer of special food which staff presented due to its nutritional properties. While James and Martin were not refusing to eat as a kind of paradoxical self-care, as seen in anorexic patients (Lavis 2016), it seems that they did refuse to eat in an attempt to mend their ruptured social networks – or as a kind of relational-care (Lavis and Abbots 2013a). Staff commented on Martin and James' social problems by evoking the concept of love – "he has no one," "he has many social problems," and "the parents do not love him."[43] But while staff were aware of the ruptured social relations that James and Martin were attempting to mend, they did not interpret the boys' *food refusals* as attempts to mend them. And even if they had, Baaliro did not have the means to address the boy's underlying social issues and emotional distress. They could not force the boy's parents to stay at Baaliro nor to get back together, and they had neither the staff nor the training to offer meaningful counseling to the children themselves. The fact that staff recognized children's social problems, but were themselves powerless to address them opens the possibility that like the borderline talk observed in eating disorder clinics, staff's food-talk "became a way for clinicians to work through the ethical imperatives of care in a no-win situation" (Lester 2009, 292). Instead of focusing on the emotional distress of the food refuser and social problems which they were unable to address, staff focused on the nutritional properties of food in all cases of food refusal.

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[43] This contrasts starkly with *Maama*-Kabiite loving her daughter too much.

We can understand children's refusal to eat as one of the few "ordinary weapons" available to them (Scott 1985). While the children were not peasants engaged in class struggle and resistance, they were, in many ways, a subordinate group in Uganda's hierarchical society (Kajubi, Bagger, et al. 2014; Philip Leroy Kilbride and Kilbride 1990; Meinert 2009), and certainly within the context of the clinic. Because of their social position, children employed strategies which "require little or no coordination or planning; they make use of implicit understandings and informal networks; they often represent a form of individual self-help; they typically avoid any direct, symbolic confrontation with authority" (Scott 1985, xvi). Similar cases of women refusing to eat as a means of both expressing emotional upset and tension and in an attempt to get their husbands to change have been observed in India (Snell-Rood 2015). Like the children at Baaliro, in this setting the woman had limited means which were socially acceptable to express their distress or to change their situation. Indeed, there is a long history of writing about women's food refusal in eating disorders as a form of social protest (Brumberg 2000; Orbach 1986), and more generally about hunger strikes as a form of political protest used by disempowered peoples throughout history and around the globe (Annas 1995; McGregor 2011; Sweeney 1993; Ziarek 2008). Though much less attention has been paid to *children's* use of food refusal, it should hardly be surprising that they would use one of the most historically powerful weapons of the weak as they attempt to express their distress and mend ruptured social relationships.

While we can understand children as social agents working within the structural confines of Baaliro and Ugandan society (Ortner 2006a, 2006b), we must also be careful not to romanticize their agency, especially when it is directly damaging to their health (Gigengack 2008). James' strategy of food refusal most certainly hastened his death, and Martin's complicated and prolonged his rehabilitation. Martin's grandmother ultimately came to his rescue (although this was not Martin's original goal), but Martin quite literally risked death in his attempt to be sent home. Even Kabiite's strategy was potentially risky, especially if she were to find herself under the care of another adult in the future. While *Maama*-Kabiite tolerated her daughter's food refusals and found ways to procure special food for Kabiite, any other caregiver was unlike to grant Kabiite the same indulgences. In fact, refusing to eat whatever food is served earned Kabiite a reputation as having bad *empisa*, and as was discussed in Chapter 5, having bad *empisa* could hinder children's ability to access care in the future. [44]

6.6 Conclusion

In the first part of this chapter, I described how the staff and the children at Baaliro had different relationships with food. The staff saw food as a key component of both rehabilitation and reintegration. Meanwhile, the children enjoyed talking about food – both as a way to explore the exotic other (me), to reminisce about the desired familiar (home), and to create an ideal home that may only have existed in their imaginaries. Children used food both to build and as an indicator of social relationships, whereas staff used food to (re)build children's bodies as an indicator of their rehabilitation. Despite their differences, both the staff and the children agreed

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[44] Another strategy available to children at Baaliro was also a commonly used weapon of the weak – the refusal to work. Like Kabiite, frequently children refusing to eat also refused to work. However, the use of this 'negative agency' by refusing to work was a potentially damaging strategy (Wardlow 2006). In Chapter 5, I explained why work was highly valued at Baaliro and how work indexed *empisa*, (an important Kiganda concept roughly equivalent to good manners, behavior, and respect), which in turn predicted successful reintegration. Biological parents would tolerate bad *empisa* because they had a moral obligation to care for their children and to try to change their *empisa*. However, if children came under the care of non-parental caregivers, children who refused to work and had bad *empisa* risked being chased from home and denied access to care.

that food was important and shared the goal of returning the children to home as quickly as possible.

Given the shared importance of food, and the relatively few modes of agency available to the children, refusal of food seems to have become a mechanism through which children attempted to express their desires and to have their demands met. In some ways food refusal appeared to be a powerful strategy – especially if a child was underweight and/or sick, the child gained the staff's attention and concern. However, the strategy was also in some ways impotent – if children were not sick, their food refusal could easily be ignored; and it did not necessarily result in the child's desired outcome. In the end, Kabiite no longer received special food, James' parents did not get back together, and Martin did not return to the island with his parents.

Whether expressing the desire to get special food or to be sent home, staff responded in similar ways – offering special food if a child was very sick, but refusing special food if the child was not very sick. Offering special food to very sick children was in keeping with Baaliro's emphasis on the nutritional properties of food and their primary goal or rehabilitation – i.e. getting calories into the sick child. Refusing special food to non-sick children was in keeping with Baaliro's ultimate goal of rehabilitation – i.e. ensuring that HIV-positive children were treated the same as (including eating the same food as) "any other child."[45] The staff's approach worked when children were refusing to eat only as a strategy to get special food, but was unfortunately unsuccessful when children were refusing to eat in an attempt to mend broken relationships. I suggest that staff's myopic focus on the nutritional properties of food may have acted as a protective strategy for staff unable to assist children with their social and emotional problems and, also, (ethically) unable to allow them to return home before they had sufficiently

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[45] For a similar argument about the importance of work in preparing children for reintegration see Chapter 5.

recovered. As a whole, these cases open the possibility to more deeply explore the links between sickness and special treatment, caregiving and nutrition, agency and idioms of distress, and food and social relationships.

Chapter 7: Technological Food: Extrapolation and Manipulation

Half a dozen children are seated on the bench, each with a red and white striped sachet in his or her hand. They are 4-14 years old and all are HIV-positive, except for the youngest boy. After being given their morning medications, the program director calls these children back, cutting open and handing each a packet of peanut-based paste. It is a ready-to-use therapeutic food (RUTF) which frequently goes by the brand name "Plumpy'nut." At Baaliro they simply call it "plumpy."[1] Sister Sally asks me to sit with them until they finish eating, effectively assigning me the unofficial role of "plumpy monitor." I don't like this job, but I do as she asks.[2] On this particular day, two of the children – the sickest of them – are especially reluctant to consume the paste. One of the girls, 9-year-old Talya,[3] squeezes her packet until a large glob of paste sticks out of the top. She stares at it with a look of disgust, wrinkling her nose. "Lya ko" [Eat some], I softly coax her. "Buwooma!" [It is tasty!][4] She nibbles slowly at the glob, avoiding eye-contact with me. Talya and I get along well, except for when it comes to doing things she doesn't like – namely eating plumpy and going to school. Like most of the children at Baaliro, Talya is small for her age. She is both short and skinny, and looks like she is at most six years old. Talya's oversized

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[1] The packets distributed to Baaliro were not labeled as Plumpy'nut, and were labeled RUTF (ready-to-use therapeutic food), but the staff still called it Plumpy'nut, or *plumpy* (pronounced pu-lám-pi) for short. Occasionally younger children called the paste *odí*, the Luganda word for a peanut based paste used in cooking.

[2] Refer to Chapter 3 where I describe my positionality in Baaliro and my relationship with the children. In an attempt to build rapport, I avoided positions of authority or being responsible for disciplining the children.

[3] Despite its similarity to the English name, I am evoking the Luganda phrase, "*talya"* [she doesn't eat]. Talya was generally a picky eater, and especially disliked *plumpy*.

[4] I said this not only as encouragement, but also because I had sampled it. On one of the many occasions a child failed to finish his/her packet, I decided to taste a bit. I found it to be thicker and grainier than Jiffy peanut butter, and more similar to natural peanut butters sold in the US. It was also substantially sweeter. Though it was dry, overall, I found it to be quite tasty!

dress and protruding belly emphasize the small circumference of her arms and leg. Despite being visibly malnourished, Talya doesn't want the plumpy.

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For its success in treating severely malnourished children, RUTF is one of the most widely praised magic bullets in global health today. However, as the vignette above hints, not all children who are offered RUTF respond as its developers might expect. In this chapter, I explore how the magic of RUTF is transformed as a consequence of extrapolation. By extrapolation I refer to the process by which technologies are applied to problems beyond those for which they were originally designed.[5] I argue extrapolation promotes the development of alternative meanings and uses for the magic bullet's "magic."

In order to understand this process of extrapolation and the shifting magic, I first need to introduce some key terminology as well as provide a background to malnutrition treatment, RUTF, and the use (and transformations) of magic bullets in global health more generally. This background is necessary to understand how the children at Baaliro are different from the children for whom RUTF was originally developed, and to give meaning to extrapolation and magic shifting. I will then return to Baaliro to explore how the process of extrapolation plays out for the children living there. I analyze the assumptions made in the process of extrapolation as well as how RUTF's "magic" was altered by the staff and, more so, the children in their reactions to *plumpy*.

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[5] I recognize that in global health circles, the term "generalized" would more commonly be used to describe this process. I choose to use the word extrapolated, because it emphasizes extending the application of a technology to a new population by assuming that existing trends will continue.

7.1 Malnutrition in the Biomedical Paradigm

Malnutrition is highly medicalized, and as such the words used to describe malnourished children have very specific definitions (see Table 7.1). Wasting, or being too skinny, is defined as weight-for-height < -2 standard deviations (SD) of the WHO Child Growth Standards median (WHO 2010b). Wasting indicates acute weight loss, and is a sign of acute undernutrition. The causes may be insufficient food intake or high incidence of infectious disease, especially diarrhea. Wasting also impairs the immune system, heightening the risk and severity of infectious disease in affected individuals. Stunting, or being too short for one's age, is defined height-for-age < -2 SD of the WHO Child Growth Standards median (WHO 2010b). Stunting is largely irreversible and results from chronic malnutrition and/or recurrent infections, especially during the first 1,000 days of life (WHO 2014). Stunting is also associated with developmental delays across several domains (including language, motor, social, and emotional development), poor school performance, and reduced intellectual capacity. It is also associated with obstetric complications, low birth weight infants, and the intergenerational cycle of malnutrition. Most of the children at Baaliro were stunted and almost all appear 2-3 years younger than their chronological age. In addition to being short, most were thin, or wasted, at least when they were first admitted to the center.

The main distinction between wasting and stunting is that wasting indicates acute undernutrition or illness whereas stunting indicates chronic undernutrition, chronic micronutrient deficits, or chronic/recurrent illness. Additionally, stunting generally does not respond to nutrition rehabilitation after a child is two years old, meaning that even with nutritional rehabilitation, a child over the age of two years is unlikely to catch up with his/her age-mates and is likely to remain both short for his/her age and developmentally delayed. Wasting, however,

Table 7.1 Malnutrition Terminology

Term	Technical definition	Common language	Cause	Consequence
Wasting	Weight-for-height < -2 SD[1]	Skinny	Acute undernutrition/ infection	Increase risk mortality (reversible)
Stunting	height-for-age < -2 SD	Short	Chronic undernutrition/ infection	Shortened stature, development delays (irreversible)
Underweight	weight-for-age < -2 SD	Small	Wasting, stunting, or both	See wasting and stunting
Severe Acute Malnutrition (SAM)	Wasting (weight-for-*height* below -3 z-scores)[2] or nutritional edema	Severely malnourished	Wasting	Medical emergency, increased mortality
Moderate Acute Malnutrition (MAM)	weight-for-*age* between -3 and -2 z-scores, absence of edema	Moderately malnourished	Wasting, stunting, or both	Risk progression to SAM, See also wasting and stunting

[1] SD = standard deviation, -2SD based on the WHO Child Growth Standards median

[2] Z-score (or SD-score) is found by the equation: (observed value - median value of the reference population) ÷ standard deviation value of reference population.

does respond to nutritional rehabilitation, no matter the child's age, meaning that with nutritional rehabilitation children can regain lost weight and as children approach discharge from the nutrition program, they may even appear chubby. At Baaliro, 4-year-old Nakisisa[6] provided a clear example of this distinction. Nakisisa had been neglected since his mother abandoned him when he was one year old. By the time he arrived at Baaliro, he was both severely stunted and wasted, he could not sit without support, and his ribcage protruded painfully. Since his arrival, Nakisisa had always been a good eater, both of food and *plumpy*, and staff frequently pointed to him as an example of a child who "recovered quickly" because he enjoyed eating the paste. As

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[6] Nakisisa means child of the shadows, reflective of the severe neglect he experienced prior to coming to Baaliro.

his discharge approached, Nakisisa looked like a chubby 18-month-old who enjoyed running and trying to clumsily kick a soccer ball. Despite his successful weight gain and the restoration of his health, he remained very short for his age and delayed in many domains. Nakisisa could not jump, could not talk, and was not potty-trained. While these developmental delays might improve, staff felt it was unlikely that he would fully overcome the intellectual, language, motor, and social-emotional deficits caused by his prolonged nutrient deficiencies and neglect.

The technical term for a child being small for her age (like Talya) is being underweight. Underweight is defined as weight-for-age < -2 SD of the WHO Child Growth Standards median (WHO 2010b). Because weight is easily measured it has been the most commonly used indicator of malnutrition in the past, and being underweight is associated with higher mortality in children. However, because both stunting and wasting can result in a child being underweight, it can be difficult to interpret, especially when used as a population level indicator.

Severe Acute Malnutrition (SAM) is defined by severe wasting (weight-for-*height* below -3 z-scores[7] of the median WHO growth standards) or by the presence of nutritional edema. SAM is considered a medical emergency, and severely malnourished children have an eight to nine fold increased risk of mortality (Black et al. 2008; Pelletier 1994). A less serious condition, Moderate Acute Malnutrition (MAM) is defined as a weight-for-*age* between -3 and -2 z-scores below the median of the WHO child growth standards and the absence of nutritional edema. MAM may be due to stunting (low height-for-age), wasting (low weight-for-height), or a combination of both (WHO 2017c). While not as immediately life threatening as SAM, MAM still increases a child's risk of mortality and has the potential to progress to SAM (Pelletier 1994). The WHO estimates that 45% of deaths in children under five years old are due to

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[7] The z-score (or SD-score) is found by the equation: (observed value - median value of the reference population) ÷ standard deviation value of reference population.

malnutrition (WHO 2016b). While there are many kinds of malnutrition, including micronutrient deficiencies (with or without adequate caloric intake) and over-nutrition (excessive caloric intake), for the purposes of this chapter, unless otherwise noted, malnutrition refers to undernutrition (specifically SAM or MAM).

Overall, approximately 33% of children in Uganda under the age of five years are stunted, 14% are underweight and 5% are wasted.[8] Of those children that are wasted, 2% have SAM (UBOS and ICF International 2012). While the peak prevalence varies across geographical areas, in almost all cases the onset of acute malnutrition (wasting) follows the onset of weaning and/or with the introduction of non-breastmilk liquids, which increase(s) the risk of infection (Duggan, Watkins, and Walker 2008; FANTA-2 2010a). But, in Uganda wasting is highest in children 0-8 months old (14%) and lowest in children 24-36 months old (2%) (UBOS and ICF International 2012).[9] Rates of wasting did not vary by gender, birth-interval, or urban/rural residence. However, children were more likely to be wasted if their mothers described them as "very small" at birth (12%)[10] and/or if the mother herself was underweight[11] (13%). These factors point to the importance of maternal nutrition. Overall, the Ugandan ministry of health estimates that the high rates of malnutrition in Uganda contributes to 60% of the country's under-five mortality (MGLSD 2011).

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[8] Rates of stunting, wasting, and underweight are not reported for children over the age of five in keeping with international standards.

[9] In contrast, in a study in Pakistan, the highest number of malnourished children were 25-36 months old, with the lowest number found in 7-12 months old (Masood-us-Syed, Muhammad, and Butt 2011). And, in a study in Tanzania the highest rates of stunting and wasting were among children 11-25 and 36-40 months old (Matee et al. 1997). I was not able to find an explanation for why wasting rates were highest among the youngest children in Uganda.

[10] Just over half (51%) of children in Uganda are weighed at birth, so surveys including child's birthweight rely on maternal recall and estimation as a proxy when recorded weight is unavailable.

[11] For mothers being underweight was defined as having BMI <18.5. BMI is body mass index, and is based on an individual's height and weight.

7.1.1 History of RUTF and Malnutrition Treatment

Ready-to-use Therapeutic Food (RUTF) is the generic name for "Plumpy'nut" [12] – a nutrient dense peanut-based paste fortified with vitamins and minerals, which was originally developed to treat severe acute malnutrition (SAM). SAM, by definition, is a medical emergency and requires rapid intervention in order for children to survive. In the first WHO survey on SAM in the 1930s physicians reported mortality rates of 70-90% among those children who actually accessed medical care; presumably nearly all untreated children died (Tappan 2013). RUTF was specifically designed to intervene in crisis situations, and as I explain in more detail below, it not only worked, it worked much better than anything before. In both the popular press and on NGO websites RUTF has been widely praised as "magic stuff," a "silver bullet," or the "miracle food" which has revolutionized the treatment of severe acute malnutrition and saved children (CBS News 2007; Clayton 2005; Klonick 2006; Morrison 2013; MSF 2005; Rice 2010; Silver and Singh 2015; Stuart 2011; WHO 2017a). Researchers have been more reserved with their descriptions in the academic and medical journals, describing "acceptable results" of 85-89% recovery rate (Linneman et al. 2007). This reserve is not because they were any less passionate about the extraordinary properties of the product but because they allowed the statistics to do the talking.

To better understand why RUTF has received so much praise (and been imbibed with near magical properties), I review the state of malnutrition treatment prior to RUTF. Like so

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[12] Plumpy'nut was the first RUTF developed. It is a trademark of the company Nutriset. In 2015, Nutriset and its franchises were the largest producers of RUTF around the world. The fact that Nutriset holds the patent to the lifesaving product has caused considerable debate and consternation (Arie 2010; Rice 2010; Sachs, Fanzo, and Sachs 2010; H. Schofield 2010; Zirulnick 2011). I attempt to use the generic term RUTF unless I am specifically referring to Plumpy'nut, but in keeping with the terminology used at Baaliro I call the product *plumpy* in my ethnographic descriptions.

many topics in this dissertation, Uganda was at the center of malnutrition treatment historically. In the 1950s, Dr. Rex Dean developed the first standardized treatment protocols for treating malnutrition while treating children at Mulago Hospital in Uganda utilizing a skim milk powder based refeeding formula. His medicalized approach to malnutrition treatment, termed "dietary discipline," "transformed [malnutrition] treatment into a hospital-centered cure involving [NG-]tubes, formulas, syringes, IVs, and injections" (Tappan 2013, 96). While the formula of milk has been refined over the years, Dr. Dean's approach of hospital-based treatment with formulated milk powder remained the standard of care until the advent of RUTF.

Into the 1990s, children admitted for SAM underwent a two-step process: 1) initiation (or stabilization), which took 4-9 days; and 2) rehabilitation, which took 2-6 weeks. Therefore, inpatient stays averaged a total of 30 days (Collins 2007; WHO 1999). During each phase children were fed a specialized milk-based formula (F-75 and F-100 respectively). While these milk formulas could be "easily prepared from the basic ingredients: dried skimmed milk, sugar, cereal flour, oil, mineral mix and vitamin mix" or from commercially available powdered products, in either case preparation involved the use of clean water (which nearly always required that the water be boiled prior to preparation of the formula), and once mixed the milk formula needed to be used immediately to minimize the risk of spoilage. Because of the risk of bacterial contamination, fortified milks were restricted to inpatient use. According to the guidelines, during the initiation phase, feeds were given every two hours and, during the rehabilitation phase, every four hours. Once children's weight-for-height reached only -1 SD (or z-score) of WHO reference values, they could begin transitioning to a home diet (a.k.a. "family foods").[13] Ideally during a child's admission caregivers also received education about proper feeding and practice preparing recommended foods.

Both historically and as I witnessed in my fieldwork,[14] inpatient treatment was extremely burdensome for the family. For inpatient treatment, a caregiver, most typically the mother and occasionally the grandmother, was required to stay in the ward to assist in feeding the child every two to four hours, including through the night. In many cases, caregivers were responsible for preparing the milk at night, since staff would return home. Not only was this exhausting for the caregivers, who were only able to sleep in two to four hour increments, but also, they were unable to fulfill their duties at home – including caring for other children and family members, working the fields, tending livestock, and/or selling their produce. Since inpatient treatment for malnutrition typically took three to seven weeks, caregivers were forced to stay at the hospital for prolonged periods of time, potentially missing an entire harvest or planting season. In addition, the nutrition wards typically did not provide food for the caregivers. During this time, caregivers depended on extended family and friends to maintain their homes and fields in their absence and to provide them with food.

In addition to the drain on families, the efficacy of inpatient care was highly variable with case fatality rates ranging from 3.5% to 35% (Lenters et al. 2013) and even as high as 50-60% in cases of edematous malnutrition (C. Schofield and Ashworth 1996). While the success of some treatment programs demonstrated the validity of the WHO inpatient nutritional rehabilitation guidelines under *ideal* conditions, the widespread failure in many low and middle income countries to reach mortality rates any lower than those seen in the 1950s raised questions about the real-world applicability of such intensive care, especially in low resource settings. Those who

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[13] See also Chapter 6 for a description of family foods in Uganda.

[14] See description of Martin's stay in the ECCH nutrition ward in Chapter 6.

supported the WHO guidelines attributed the stubbornly high fatality rates to poor knowledge and advocated that with better training, the standard WHO guidelines would be enough to bring SAM deaths down (Ashworth et al. 2004; Bhan, Bhandari, and Bahl 2003; Karaolis et al. 2007; C. Schofield and Ashworth 1997). However, in at least one study, WHO guidelines were followed to the letter, yet fatality rates remained at 19% (Maitland et al. 2006). Meanwhile others pointed to larger issues with the health systems such as insufficient numbers of staff and overcrowded wards as well as the centralized nature of hospital care which delayed or prevented caregivers from bringing children to the nutrition wards (Collins 2007). For example, when specialized feeding centers were used to treat malnutrition, the overall coverage rate[15] was 20%, and ranged from 0% to 50% with the highest coverage in areas closest to the feeding center or along major roadways (Myatt et al. 2005).

In addition to delayed presentation, it has long been known that much of the mortality in SAM is attributable to infections (Kerpel-Fronius 1984). Part of Dr. Dean’s approach in the 1950s included daily injections with penicillin for the first week as well as automatic treatment for malaria (Tappan 2013). Malnourished children suffer from compromised immune systems, making them particularly susceptible to infections (Puri and Chandra 1987).[16] This combined with both their prolonged hospitalization and exposure to other children with transmissible infections makes it hardly surprising that up to half of children admitted with SAM develop *new*

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[15] Coverage rates are calculated by one of three formulas (Myatt et al. 2005):

$$\frac{\text{Number of respondents attending the feeding program}}{\text{Number of cases not attending the feeding program} + \text{Number of respondents attending the feeding program}} \quad \text{OR} \quad \frac{\text{Number of cases attending the feeding program}}{\text{Total number of cases}} \quad \text{OR} \quad \frac{\text{Number of recipients attending the feeding program}}{\text{Estimated prevalence of SAM x estimated population}}$$

[16] Interestingly, malnutrition and HIV have similar effects on the immune system, with both suppressing mechanisms in T-cells. The immune system dysfunctions caused by malnutrition have even been referred to by the similar sounding NAIDS (nutritionally-acquired immune deficiency syndrome) (Duggal, Chugh, and Duggal 2012).

infections while in the hospital (Isaack, Mbise, and Hirji 1992; Jones and Berkley 2014). Diarrhea and malnutrition can be thought of as two sides of the same coin with diarrhea often precipitating or exacerbating malnutrition, and malnutrition increasing the severity of diarrhea (Faruque et al. 2014). Given the tenuous balance of malnourished children's electrolyte and fluid levels, a bout of severe diarrhea can kill in a matter of hours. Even under stringent conditions, hospitals around the world are home to numerous pathogens and, by definition, the source of nosocomial infections (Emori and Gaynes 1993; Raymond, Aujard, and European Study Group 2000; Schabrun and Chipchase 2006; Slimings and Riley 2014). Compounding this problem, it was not uncommon for malnutrition wards, like many hospital wards in under-resourced areas, to be overcrowded. Thus, even with routine administration of antibiotics in accordance with WHO guidelines, infectious diseases could spread rapidly through the patient population, raising the question of whether the hospital was really the best place to treat children with SAM (Sunguya, Koola, and Atkinson 2006). These issues were far from novel, as debates about the cost effectiveness and efficacy of treating malnourished children in hospitals had been circulating since at least the 1970s (R. Cook 1971). Given both the burden and low success rate of inpatient treatment for SAM, it is hardly surprising that caregivers were reluctant to have their children admitted.

7.1.2 RUTF Revolution

It was in this context of burdensome, costly, and surprisingly ineffective inpatient treatment of malnutrition that RUTF came onto the scene. André Briend and Michel Lescanne first developed Plumpy'nut in 1996 and published the first study comparing Plumpy'nut to existing treatments for SAM in 1999 (Briend et al. 1999; Nutriset 2017). RUTF gained popularity in the early 2000's with its successful use in crisis situations in Ethiopia, Sudan, and Niger. As numerous studies demonstrated the efficacy of outpatient care for SAM using RUTF (including Ciliberto et al. 2005; Collins 2001; Collins and Sadler 2002; Diop et al. 2003; Manary et al. 2004), the calls of its widespread use increased in both academic and popular presses, with Médecins Sans Frontières (MSF, a.k.a. Doctors Without Borders) being particularly vocal (Clayton 2005; Gross and Webb 2006; MSF 2005; Wines 2005). Finally, in 2007, UNICEF and the WHO officially endorsed RUTF and the outpatient treatment of SAM (WHO et al. 2007). Since then RUTF production has risen drastically, and generic manufacturers entered the market in 2009. In 2007, UNICEF[17] purchased less than 5,000 metric tons (MT) of RUTF, and in 2013 they purchased 34,000 MT (UNICEF 2014).

Although RUTF was nutritionally nearly identical to the standard of care at the time (F-100 milk powder) (see Table 7.2 for a comparison of the composition of therapeutic feeding options), the advent of RUTF was truly a revolutionary shift in the treatment of SAM because it enabled caregivers (most women) to effectively treat malnutrition *at home* without hospitalization and even made children themselves *active participants* in their own rehabilitation. In contrast to the fortified milks, which were difficult to prepare, spoiled easily, and required inpatient treatment, the high lipid and low water content of RUTF eliminated the risk of spoilage, children could feed themselves directly from the RUTF packets, and RUTF required no preparation on the part of the caregiver who could oversee feeding from home. With RUTF both caregivers and children were more actively involved in their care. Additionally, because caregivers did not have to travel (as far) to centralized feeding centers, or anticipate spending a month or more at the centers, caregivers were more likely to bring malnourished children to

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[17] UNICEF is the largest but not the only purchaser of RUTF. Other purchasers include MSF, the Clinton Foundation, and other NGOs.

Table 7.2 Nutritional Composition of Therapeutic Foods and Dietary Reference Intakes

Ingredient	units	Therapeutic Food Composition (units/100g)		Dietary Reference Intakes[†3] (units/day)						
				Recommended Dietary Allowance						Tolerable Upper Intake
		RUTF[†1]	F-100[†2]	Child	Child	Male	Female	Male	Female	
				1-3yr	4-8yr	9-13yr		14-18yr		
Energy	Kcal	520-550	520-550	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Proteins	%[#]	10-12%	10-12%	5–20%^	10–30%^ (4-18yr)					n/a
Lipids	%[#]	45-60%	45-60%	30–40%^	25–35%^ (4-18yr)					n/a
Sodium	mg	290	290	1000*	1200*	1500*	1500*	1500*	1500*	2000
Potassium	mg	1100-1400	1100-1400	3.000*	3800*	4500*	4500*	4700*	4700*	n/a
Calcium	mg	300-600	300-600	700	1,000	1,300	1,300	1,300	1,300	2750
Phosphorus (ex. phytate)	mg	300-600	300-600	460	500	1,250	1,250	1,250	1,250	3500
Magnesium	mg	80-140	80-140	80	130	240	240	410	360	236
Iron	mg	10-14	0.2	7	10	8	8	11	15	41
Zinc	mg	11-14	11-14	3	5	8	8	11	9	19
Copper	µg	1400-1800	1400-1800	340	440	700	700	890	890	4250
Selenium	µg	20-40	20-40	20	30	40	40	55	55	230
Iodine	µg	70-140	70-140	90	90	120	120	150	150	500
Vitamin A	µg	800-1100	800-1100	300	400	600	600	900	700	1500
Vitamin D	µg	15-20	15-20	15	15	15	15	15	15	85
Vitamin E	mg	20	20	6	7	11	11	15	15	475
Vitamin K	µg	15-30	15-30	30*	55*	60*	60*	75*	75*	n/a
Vitamin B1 (Thiamine)	mg	0.5	0.5	0.5	0.6	0.9	0.9	1.2	1	n/a
Vitamin B2 (Riboflavin)	mg	1.6	1.6	0.5	0.6	0.9	0.9	1.3	1	n/a
Vitamin C	mg	50	50	15	25	45	45	75	65	1013
Vitamin B6	mg	0.6	0.6	0.5	0.6	1	1	1.3	1.2	53
Vitamin B12	µg	1.6	1.6	0.9	1.2	1.8	1.8	2.4	2.4	n/a
Folic acid	µg	200	200	150	200	300	300	400	400	525
Niacin	mg	5	5	6	8	12	12	16	14	19
Pantothenic acid	mg	3	3	2*	3*	4*	4*	5*	5*	n/a
Biotin	µg	60	60	8*	12*	20*	20*	25*	25*	n/a
n-6 fatty acids	%[#]	3-10%	3-10%	5–10%^	5–10%^ (4-18yr)					n/a
n-3 fatty acids	%[#]	0.3-2.5%	0.3-2.5%	0.6–1.2%^ (1-18yr)						n/a

[†]Sources: [1](WHO 2009), [2](ICRC 2002), [3](NIH 2011)

[#] Percent of total energy

^ Acceptable Macronutrient Distribution Ranges (Recommended Daily Allowance not provided)

** Adequate Intake (Recommended Daily Allowance not provided)* clinics to seek treatment. Estimates of coverage rates rose from 20% to 70-77%, and children were presenting to the clinics earlier with less severe cases of malnutrition and with fewer complications (Collins 2007).

Not only was outpatient treatment a better situation for caregivers but, according to one of the earliest studies, children who received home-based RUTF were actually more likely to recover (80% achieved a weight-for-height score >-2 SD), less likely to relapse or die (8.7%) and gained more weight (3.5kg) compared to children on standard milk therapy (46%, 16.7% and 2.0kg respectively) (Ciliberto et al. 2005). Numerous studies followed reporting case fatality rates of around 5% and recovery rates of around 80% (see Steve Collins (2007) for a summary of early studies). In contrast to the burden and ineffectiveness of using inpatient treatment with fortified milk formulas, it is easy to see how RUTF became the magic miracle food which revolutionized the treatment of SAM. To say that RUTF has been widely accepted by the international community as the standard of treatment for SAM would be an understatement.

7.2 What Makes a Magic Bullet?

Knowing the history of malnutrition treatment, it is easy to see why RUTF has been called magical. Supporters share accounts of children coming back from the brink of death. The change is visible, and often depicted in graphic before-and-after photos, showing skeletal/puffy[18] miserable crying children before and smiling bright-eyed healthy (even chubby) children after. Such transformations are truly magical. In this section I explore how the "magic" of magic

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[18] Children with SAM without edema appear wasted and skeletal with collar bones, ribcages, and hip bones protruding. Children who have SAM with edema appear puffy. Edema starts in the legs, and can work its way all the way up to the face. While edema is often less worrying in appearance to those unfamiliar with malnutrition, edematous SAM has a higher mortality rate. In either case, children are usually photographed crying or staring apathetically at the camera.

bullets in general has expanded and changed since the concept was originally developed. In brief, the magic has shifted from an emphasis on specific targeting to the simplification of complexity, the ease of implementation, and the extrapolation of benefits to problems beyond its original intent. The magic can even extend to include proximity and ownership, regardless of actual application. These shifting meanings of magic set up a framework for understanding the limitations and critique of global health magic bullets more generally, and of RUTF in particular.

The term "magic bullet" was first used in 1900 by Paul Ehrlich, a German scientist to describe how antibodies search for specific toxins (Tan and Grimes 2010) The *zauberkugel* (magic bullet) Ehrlich envisioned would, when injected into patients, hone in on a *specific* pathogen, leaving other cells undisturbed (Heynick 2009). In 1913, he present the first magic bullet, Salvarsan, as new cure for venereal disease[19] (Gelpi, Gilbertson, and Tucker 2015). The quests for magic bullets fit well into the conceptual framework of early 20th century allopathic medicine (Pelligrino 1979; Rosenberg 1977). Some historians argue that in the context of tropical medicine, the proclaimed successes of so-called[20] magic bullets such as methylene blue against malaria and tryphan red against trypanosomes facilitated the transition of medicine as a whole to focus on defeating the pathogen (Prins 1989). Under the biomedical paradigm, diseases were considered mono-causal, meaning that one simply had to identify the most proximate and simplest cause of disease in order to develop the magic bullet which would cure it. Since biomedicine was based on scientific truth, treatment was considered to be value free,

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[19] Salvarsan is an arsenical compound. While it had antisyphilitic activity, Salvarsan was chemically unstable, making it difficult to prepare and administer. The unwanted side effects of Salvarsan (rashes, liver damage, and "risk of life and limb") were largely attributed to improper handling. Despite these issues salvarsan and its more chemically stable but less effective cousin Neosalvarsan (also developed by Ehrlich) remained the standard of care for syphilis until the discovery of penicillin (which actually cures the disease and does not require special handling) which rapidly became the standard of care in the early 1940s. (Singer 2016).

[20] Like Salvarsan, these treatments were not particularly effective against the pathogens they sought to wage war against, but were embraced as magic bullets at the time of their discovery.

meaning that a medication's efficacy was irrespective of a patient's mental or spiritual state or belief in treatment. The magic did not depend on the patient's participation in or acceptance of treatment but was innate to the bullet itself. Lastly, both disease and treatment were wholly somatic (of the body). This neglected not only the mind, but larger social factors which contribute to health and wellness as well. Overall, treatment was emphasized over prevention, and a targeted approach to disease was emphasized over holistic healing (Feierman 1985; Prins 1989). Especially in the context of colonial medicine, the development and administration of magic bullets were considered key, not only to fighting disease, but also to building the empire (Vaughan 1991). This legacy of colonial medicine can still be seen in international health priorities and agendas today which often focus on targeted interventions (J. Greene et al. 2013).

Since its original use in the fields of immunology and tropical medicine, which focused on specific targeting of the pathogen, the concept of the magic bullet has been widely extrapolated and applied to such interventions as oral rehydration solution, microfinance, information technology and trade reform to name just a few examples (Cohen 1987; Hiscox 1999; Kabeer 2005; Markus and Benjamin 1997; Ruxin 1994). With this expanded and altered use of the term, one of the main promises of the magic bullet became that it offered a quick and simple (often technological) solution to a difficult and complex (often social) problem. Here the emphasis was less on the supernatural specificity of the bullet for its target, and more on the ease of firing it, and the rapidity with which it solved (or perhaps killed) the problem.

Another property of today's magic bullet is that it can offer a solution to several problems at once. Marcos Cueto (2013) provides a phenomenal account of the cyclical return of malaria control/eradication efforts to the ever alluring magic bullet, despite failures with such attempts in the past. While many acknowledge the social and political complexity of poverty and disease, and embrace the idea, for example, that health, poverty, education, politics, and women's empowerment are all interconnected, and are all part of fighting malaria, many also continue to cling to a conceptual framework in which science and technology will provide the solution to these complex problems. Therefore, in contrast to Ehrlich's original concept of a "magic bullet" targeting only a specific pathogen (or problem), today's magic bullets act more as shotgun fire, supposedly able to address many complex and interconnected problems at once.

The final magical property of today's magic bullets is described by Amy Moran-Thomas (2013) in her chapter "Salvage Ethnography of the Guinea Worm":

> After all, the label 'magic bullet' comes startlingly close to the 'magic ammunition' (Evans-Pritchard 1937:180) that Azande witch-doctors use to symbolically control danger and sickness. This is not to deny that public health's "magic bullets" do have obvious biomedical applications and technological capacities, but rather to question why they are sometimes treated by health officials as having *value and efficacy beyond their observable worth*, as if their *distribution alone* somehow taps into a distant all-protective power regardless of how they are used in practice. [emphasis added] (2013, 223)

She calls us to explore not just the "highly functional sideways purposes," but also the magical-logic behind magic bullets' distribution, and how, especially when distributed without any attempt to address infrastructural development, they become enmeshed in the existing systems of knowledge and meaning (Moran-Thomas 2013, 224). Thus, while the *magic* of the magic bullet remains, the meaning of the magic may be different among those responsible for its distribution than among those receiving it, and the power can come from simply possessing the technology, regardless of how it is used. In keeping with the bullet analogy, today's magic bullets may be valued for their use in arts and crafts rather than for being shot from a gun (see search "bullet crafts" on pintrest.com for examples). I argue that this kind of alternative logic magic is especially prevalent in cases of extrapolation – when the bullets target is redefined to encompass more than it was originally designed to address.

There are countless instances of biotechnology being put to alternate uses. They may be rejected entirely – such as parents who refuse to bring their children to be vaccinated (Streefland, Chowdhury, and Ramos-Jimenez 1999). They may be kept, but underutilized – such as owning mosquito nets, but not sleeping under them, or having guinea worm straws, but not using them to filter drinking water (Githinji et al. 2010; Moran-Thomas 2013; Pulford et al. 2011). They may be given more power to heal than can reasonably be expected – such as the belief that neonatal incubators alone will save premature babies (Baker 2000; Christensson et al. 1998; and personal observation). Lastly, they may be used in ways completely independent from their originally intended use – such as fishermen using mosquito nets to haul or dry their catch (Gettleman 2015; Minakawa et al. 2008). Whether one sees the underuse, overuse, misuse, or alternative-use as positive or negative depends greatly on his/her position in the global community. For the purposes of this chapter, I am most interested in how the success of RUTF has led to its *extrapolated use* far beyond its original target population and the ways in which, through the process of extrapolation, its magic was transformed at Baaliro.

7.2.1 Limitations and Critiques of Magic Bullets

Understanding RUTF as a magic bullet, in this section I explore how many of the critiques levied against RUTF are the same ones levied against many magic bullets, or even the concept of magic bullets in general. While it is easy to understand the appeal of the magical simplicity of magic bullet approaches to global health, many technologies have not lived up to expectations or have unleashed unintended consequences (Cueto 2007; J. Greene et al. 2013; Good, Good, and Grayman 2010; Larson et al. 2011). In the case of RUTF, first despite promises of being able to completely cure malnutrition, outpatient treatment with RUTF has not completely eliminated the need for malnutrition wards. While 70-80% of children are able to be treated solely as outpatients, the remaining 20-30% require hospitalization due to medical complications, severe edema, or poor appetite. In such cases the guidelines for treatment with fortified milk remain largely unchanged (Ashworth et al. 2003).[21] Meanwhile mortality rates for inpatient treatment, which also largely remain unchanged, range from 11% to 46% (Desta 2015; Munthali et al. 2015; Nyeko et al. 2016). Whether these relatively high mortality rates are because of the type of intervention (i.e. inpatient treatment) or the health status of the child when admitted (i.e. that only the sickest children are admitted), remains unclear. However, what is clear is that inpatient treatment continues to struggle with the same problems today that it did previously: prolonged and complicated treatment regimens, high burden to caregivers, overcrowded and understaffed hospitals, and infection concerns both due to hospital crowding and lack of clean water sources (Heikens 2007).

A second shortfall of RUTF comes from the claim the RUTF “solves” the access to clean water problem. Michael Latham and colleagues (2011) point out that RUTF is a very dry product, and that children consuming RUTF as their only source of nutrients (like the guidelines prescribe), require water to prevent dehydration. In contrast to porridges, which are always boiled during preparation, drinking water may not always be boiled. My observations at Baaliro support these concerns. Children frequently asked for water when consuming *plumpy*, and the national malnutrition guidelines indicated that children should be permitted to consume as much water as they desire while on RUTF (MOH 2010b). Dorothy laughed at my ignorance when I asked her if she thought the children drank boiled water at home, and the children themselves

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[21] UNICEF (the main purchaser of therapeutic milk products worldwide) procurement of therapeutic milk products dropped significantly from 2,400 MT in 2003 to 846 MT in 2011 due to the introduction of RUTF. Demand increased slightly to 1,125 MT in 2012 due to expansion of nutrition programming and is anticipated to “increase moderately” for the foreseeable future and as scale-up of nutrition programming continues (UNICEF 2015).

reported that they did not drink boiled water at home. It takes substantial time, energy, and fuel to boil a large pot of water for the sole purpose of drinking it a significant time later – once it has cooled – and is not an insignificant task, especially when using wood fuels.[22] People were well aware of the health risks of drinking contaminated water, but sometimes the burden of preparing (and especially for children, the difficulty of accessing) boiled water precluded their consumption of it.

One of the biggest unintended consequences of RUTF is that it can undermine breastfeeding[23] and the use of local foods (Latham et al. 2011; Sachs, Fanzo, and Sachs 2010; UNICEF 2014). These fears likely stem from the history of malnutrition treatment in Uganda in the 1950s and 1960s when the widespread distribution of skim milk powders as supplements to prevent "protein-malnutrition" inadvertently lead to increased rates of bottle feeding and early weaning (Tappan 2013).[24] UNICEF itself acknowledges these risks and emphasizes the importance of local food, breastfeeding, and locally produced RUTF (UNICEF 2014). India and Bangladesh have both banned aid agencies from using RUTF in the past due to concerns over dependency on a foreign product and the commodification of malnutrition (bdnews24.com 2015; Nagarajan 2009). While no longer banned in India, even with local manufacturing, the use of RUTF remains both limited and somewhat controversial (Ali 2015; Nagarajan 2013).

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[22] Wood fuels are the most common source of fuel for cooking in Uganda. The vast majority of households (95%) use wood fuels (wood and charcoal) as a main source of energy for cooking, with firewood used in rural areas (86%) and charcoal used in urban areas (70%) (UBOS 2010).

[23] Although RUTF is not suitable for children under six months of age (during which time the WHO recommends exclusive breastfeeding), the concern is that RUTF could interfere with breastfeeding children between the ages of 6-24 months (WHO 2016c). The WHO also strongly encourages HIV-positive women to take ARVs and to breastfeed exclusively for the first year.

[24] Tappan clarifies that this is *not* the same as the well-known controversies over corporations' marketing of infant formulas. Caregivers were given explicit instructions to mix the powder into foods (as a supplement), not to give it to children to drink as milk, and the physicians and scientists advocating the use of milk powder supplements strongly encouraged breastfeeding. However, poor instructions and inadequate labeling contributed to the confusion.

A second major source of criticism aimed at magic bullets includes social scientists and health policy advocates who emphasize the importance of recognizing the political and social determinants of health, and caution against too narrow of a focus on technological interventions (Farmer 2001, 2004; Farmer et al. 2013; Hahn and Inhorn 2008; Nichter and Kendall 1991; Nichter 2008; Rhodes et al. 2005; Singer and Baer 2011; Whyte et al. 2013). As early as the 1960s, Thomas McKeown demonstrated that the declines in mortality seen in the industrialized world occurred before the introduction of medical innovation – the magic bullets of antibiotics and immunizations – and were largely the result of systemic improvements in sanitation and overall nutrition (McKeown and Record 1962; McKeown 1979). These scholars do not discount the power of (medical) technology to improve human health, but rather emphasize that, while necessary, such magic alone is insufficient. Furthermore, magic bullets absolve governments and the world capitalist system from any responsibility for addressing the structural inequalities which promote and maintain poverty and human suffering in the first place.

RUTF has been widely criticized for its failure to address the socioeconomic and political factors underlying malnutrition, as highlighted by how RUTF both medicalizes and commercializes malnutrition (Latham et al. 2011; Sachs, Fanzo, and Sachs 2010; UNICEF 2014). These scholars and activists point out that chronic hunger (and undernutrition) is far more common yet remains hidden compared to the more impressive cases and recoveries of SAM.[25] They emphasize the importance of addressing macro-level issues contributing to (chronic) malnutrition such as poverty, poor infrastructure and sanitation, and gender disparities. The commercialization of malnutrition is especially troubling, as exemplified by the controversy over

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[25] Recall that one third of Ugandan children under five years old are stunted, but only 2% suffer from SAM (UBOS and ICF International 2012). Similarly, globally stunting affects nearly one in four children, but the rate of severe wasting is only 2.5% (UNICEF 2017).

Nutriset's patenting of Plumpy'nut (Arie 2010; Rice 2010; Sachs, Fanzo, and Sachs 2010; H. Schofield 2010; Zirulnick 2011). However, the focus on SAM is understandable, because as Rainer Gross and Patrick Webb (2006) succinctly state in defense of the medicalization of malnutrition (SAM in particular), "the wasted child cannot wait." Children who have reached the point where their health requires immediate intervention cannot delay waiting for political stabilization or improved farming strategies. It is too late for preventing diarrhea with proper hygiene and sanitation because they are already sick.

A final criticism of magic bullets is what Tom Scott-Smith (2013) calls the "fetishism of humanitarian objects." Using the Marxist theory of commodity fetishism, Scott-Smith analyzes the technologies which have come to define malnutrition treatment – RUTF packets and MUAC[26] bands. Scott-Smith demonstrates how the processes of concealment, transformation and mystification have occurred with humanitarian objects. RUTF is often framed as a completely novel approach to treating malnutrition, though attempts to manufacture peanut-based products for the treatment of malnutrition date back to at least the 1960s, and as was discussed, the nutritional formula of the paste is nothing new (Tappan 2013). As a result, such objects are perceived as recent discoveries (masking historical complexity and ambivalent research findings), they facilitate humanitarian focus on aggregate survival and efficacy (overlooking treatment failures), and they become imbibed with "a mystical and autonomous spirit" becoming conceptualized as intrinsic solutions to suffering. If MUAC and RUTF are intrinsic to the treatment of malnutrition, then malnutrition therefore cannot be (and must have never been) adequately treated without them. Furthermore, in resonance with those scholars attempting to draw attention to the social and political determinants of health, Scott-Smith

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[26] MUAC is middle-upper-arm circumference, and MUAC bands are used for screening in malnutrition programs worldwide

emphasizes how commodity fetishism prevents more flexible and people-centered approaches to relief.

Despite this long-standing criticism of and cynicism toward quick-fix promises, the appeal of magic bullets remains strong to donors and NGOs alike. For example, the Bill and Melinda Gates Foundation continues to emphasize funding innovative research in the hopes of finding technological fixes to the world's challenges.[27] The fetishism of magic bullets both obscures their critique and assists in their extrapolated use. Both MUAC bands and RUTF packets were originally designed for the screening or treatment (respectively) of SAM in children between the ages of six months and five years. However, more recently, the technologies are being used to screen and treat older children and adults for malnutrition, especially those living with HIV, as well as pregnant women.

7.3 Calls for Extrapolation

With all of the magic surrounding RUTF, it was not long before supporters of the product began to call for expanding its use (Clayton 2005; Wines 2005). As discussed above, there are many kinds of malnutrition, and just because MAM and stunting are not immediately life threatening, does not mean that they are benign – they have serious consequences, contributing to both individual and national underdeveloped potential (Black et al. 2013). As early as 2005, MSF was advocating for the use of RUTF not only in emergency situations and for SAM, but also for its expanded use in areas with chronic undernutrition for children suffering from MAM in order to close the "hunger gap" (MSF 2005, 2007). The calls for extrapolation were based on

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[27] In recent years, they have been making efforts to incorporate broader development interventions into their funding such as gender and behavior change, but still the foundation retains its emphasis on science and technological interventions ("Bill & Melinda Gates Foundation" 2017).

the logic that if RUTF is good for SAM, and MAM can develop into SAM, RUTF should be good for MAM in order to prevent children from becoming emaciated in the first place (Enserink 2008). One supporter of such an approach was quoted as saying, "It seems simple to me; what's the downside to me giving *every child* who's over four months old a tube of Nutributter[28] per day?" [emphasis added] (Rice 2010). According to its website, Nutriset currently offers over a dozen products to treat not only SAM but also MAM and even chronic malnutrition, in children of all ages, adults, and pregnant and lactating women. However, I did not witness any products other than generic RUTF (based on the original Plumpy'nut) being used in my field site. Therefore, I focus on how RUTF in particular is being extrapolated to populations beyond those for which it was originally developed – namely older children (and adults) living with HIV.

AIDS was originally named "slim disease" in east Africa because of the wasting syndrome associated with untreated HIV infections, and more recent research has demonstrated that HIV and malnutrition are related in several ways. Opportunistic infections and HIV itself can lead to poor absorption and utilization of nutrients exacerbating malnutrition, and both HIV infection and malnutrition impair the immune system in similar ways such that "malnutrition and HIV form a vicious cycle and ultimately aim at reducing the immunity of the patient" (Duggal, Chugh, and Duggal 2012). In Uganda, 20-25% of adults enrolled in HIV clinics are malnourished (underweight) (FANTA-2 2010a). The Ugandan Ministry of Health emphasizes the importance of HIV in exacerbating malnutrition and, based on a study at Mulago Hospital, estimates that 40% of acutely malnourished children presenting at inpatient facilities are HIV-positive, and sadly, that even with treated nearly half of HIV-infected, severely malnourished

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[28] Nutributter is a Nutriset product designed for supplementary feeding and the *prevention* of malnutrition. Like Plumpy'nut it is based on peanuts, sugar, vegetable fat, skimmed milk powder, maltodextrin and whey, enriched with vitamins and minerals.

children die (Bachou et al. 2006; FANTA-2 2010a; MOH 2010b). HIV-positive children in Uganda suffering from SAM are five times more likely to die before their second birthday than their HIV-negative non-SAM peers. Finally, a study of 6-12 year olds in Uganda infected with HIV via vertical transmission who had never been treated with ARVs found that such children were significantly more likely to be acutely malnourished than either HIV-negative or recently infected peers (Bagenda et al. 2006).

Given the lethal combination of HIV and SAM, it is hardly surprising that HIV-positive individuals were among the first population targeted for the extrapolated use of RUTF. RUTF first appeared in Uganda's *National HIV and AIDS Strategic Plan* in 2015, and was listed among the strategic actions to strengthen the integration of HIV care and treatment (UAC 2015a). All HIV clinics are supposed to conduct nutritional assessments (using weight or MUAC tapes) and be able to either treat patients with RUTF or connect patients to services where they can receive the product. As I explain below, Uganda's malnutrition treatment national guidelines have expanded the recommended use of RUTF to include HIV-positive children (and adults) with *moderate* malnutrition (MAM).

7.4 Extrapolating and Rejecting RUTF's Magic

Within this context, I now return to Baaliro, where (under the guidance of the national malnutrition program) RUTF was prescribed to and variably consumed by children well over five years old who were moderately malnourished and HIV-positive. In this next section I look at the connections and discrepancies between malnutrition treatment in the government program and Baaliro, the assumptions required by the extrapolation of RUTF treatment to older children, and the ways that staff and children assign magic to RUTF, alternately encouraging or resisting consumption, and restricting access or trying to score a packet.

7.4.1 Treating Malnutrition at ECCH – Protocols and Assumptions

While living at Baaliro, Sister Sally often sent me with children to the malnutrition clinic at East Central Children's Hospital (ECCH). Baaliro maintained a close relationship with ECCH, especially the malnutrition program. In fact, the hospital's head nutritionist received a small supplement to his salary from Baaliro. Although Lucas, Child Health's program coordinator, regarded the payment to the nutritionist with some skepticism, Sister Sally insisted his payment was crucial for facilitating the admission of Baaliro children at the hospital, for ensuring they received prompt and proper care once admitted to the hospital, and for facilitating referrals from the hospital to Baaliro for those children who needed additional support upon discharge. In addition, the nutritionist visited Baaliro every two weeks to weigh and measure *all* of the children staying at Baaliro and provided occasional continuing education lectures to staff regarding malnutrition. Perhaps most relevant to this discussion, another reason to maintain a good relationship with the nutrition program staff was that children could only access *free*[29] RUTF though the hospital's malnutrition clinic. RUTF was not otherwise included in Baaliro's budget, but since RUTF was considered crucial for nutritional rehabilitation, Sister Sally explained that maintaining a good relationship with ECCH was critical to Baaliro's claims of nutritionally rehabilitating children. Baaliro brought newly enrolled children to the ECCH nutrition program in order to see if they qualified for enrollment in the hospital's malnutrition program and to receive RUTF.

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[29] Staff reported that RUTF was available in the markets, but that it was very expensive. I never witnessed RUTF being sold.

For its part, the ECCH malnutrition program used the Ministry of Health's *Integrated Management of Acute Malnutrition* guidelines (IMAM), derived from WHO malnutrition treatment guidelines, to assess and treat children for SAM (MOH 2010b). At the malnutrition program, staff measured a child's MUAC to determine if he/she qualified for enrollment. Children qualified if they had SAM or if they had MAM (moderate acute malnutrition) and HIV or TB. Children were then required to pass an "appetite test" (eating half a packet of RUTF) to prove that they would eat RUTF at home, and if they failed they were supposed to be admitted to the inpatient ward.[30] Once they were enrolled in the outpatient nutrition program, children were issued blue "ration" cards (see Appendix I). On each line, the date and the child's measurements (weight and MUAC) were recorded. On the first visit, the child's "target weight" was calculated (based on an increase of 20% from their admission weight) and recorded. After weighing and logging the children's measurements both on their ration cards and in the clinic's log, the staff calculated the amount of RUTF the child should be eating per day (based on their current weight, using the formula of 175-200 kcal/kg/day),[31] and determined the number of RUTF packets to give out. Caregivers then provided a bag into which a clinic staff member then counted out enough RUTF packets to last until the following appointment date, usually two weeks later.

Before analyzing these guidelines, recall that most cases of SAM occur in children less than five years old. Therefore, RUTF was originally developed for children under five years old (and targeted children 6-24 months old). The guidelines for administration, in particular the formula used to calculate how much RUTF should be prescribed, were originally developed assuming an outpatient population of children under the age of five years who would be fed

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[30] Additional criteria for admission included bilateral pitting edema and/or medical complications.

[31] Meaning that each day a child should consume 175-200 calories of RUTF for each kilogram they (currently) weigh.

exclusively on RUTF during their recovery and gradually transitioned to "family foods" *after* nutritional rehabilitation. As one pediatric physician from the US explained to me when discussing RUTF, the question of exclusive RUTF feeding was primarily one of physics – or rather the ratio of calories to volume of food. Children eating "family foods" would fill up on less calorically dense foods, and not receive the total number of calories, fat, protein, or micronutrients that they needed to make up for their nutritional deficit. Furthermore, the fact that children did not need any other source of calories while on RUTF was, by definition, part of RUTF's magic – no need for the caregiver to prepare food for the child, simply open the pack and give it to the child who can self-feed. With this in mind, it is useful to highlight several assumptions and extrapolations involved in ECCH practices and the IMAM guidelines.

First, although according to the IMAM guidelines children could be admitted to the malnutrition programs based on MUAC, weight-for-height, *or* BMI-for-age in practice, MUAC seemed to be the primary, if not only, screening criteria utilized at ECCH, and MUAC cut-offs were based on the child's age, regardless of height. While MUAC is highly effective in identifying children in need of nutritional intervention, because it does not take into account a child's height, it may confound stunting with acute-malnutrition. This is especially the case for children over five years old. Alternative screening tools have been developed, but they are not widely used, and were not available at ECCH (Mei et al. 1997). In short, the reliance on MUAC for determining eligibility may have led to more children being enrolled than needed rehabilitation. Interestingly, although MUAC was measured at each visit, there was no "target MUAC" for discharge. At ECCH, staff tended to focus on children's weight as the criteria for monitoring improvement. This contrasted with staff at Baaliro who did use MUAC for monitoring children's malnutrition rehabilitation, which at times led to children being inappropriately scolded for “failing to eat” (see chapter 4 for a discussion of Baaliro’s (mis)use of MUAC tapes).

Second, the discharge criterion (child’s target weight) was calculated based only on the child’s weight at admission, without taking into consideration the child’s age or height, or even the severity of malnutrition at enrollment. This sometimes resulted in the target weight being surprisingly high – especially for young children admitted with moderate malnutrition – but more frequently, target weights seemed surprisingly low, and children would be discharged from the program while still visibly quite thin. Consider the difference between a 4-year-old and an 9-year-old who are both enrolled weighing 15kg. In both cases the child would be discharged once he reached 18kg, leaving the 4-year-old rather chubby, but the 9-year-old still quite skinny; or even more extreme, consider that had 17-year-old James been admitted, weighing only 20kg, his target weight would have been set at 24kg – still obviously far below a healthy weight for a 17-year-old. These examples demonstrate the danger of linearly extrapolating guidelines developed for the treatment of children under five years old to all children.

Third, the amount of RUTF prescribed in accordance with the IMAM guidelines was calculated solely based on the child’s *current weight* and most importantly, these calculations were based on the linear extrapolation of the original guidelines (developed for children under five years old). This meant 1) children were prescribed more RUTF as they gained weight until they were finally discharged, and 2) older children (those weighing 13kg or more) were prescribed up to five or more sachets per day from their first visit. Recall that *each sachet* of RUTF contains >500 calories, so based on caloric content alone, eating five sachets in a day would be a difficult task, even for most adults. Additionally, RUTF is fortified with vitamins and nutrients, and eating five sachets would exceed the recommended dietary allowances for most nutrients, and even exceed the tolerable upper intake for many nutrients – most notably vitamin A (see Table 7.2).[32] Despite the fact that nearly all studies have found benefits to vitamin A supplementation in HIV-positive children (similar to uninfected children) (Mehta and Fawzi 2007; WHO 2009), consuming it at levels so far above the tolerable upper limit could potentially lead to acute vitamin A toxicity.[33] Individuals with compromised liver function are at greater risk for developing vitamin A toxicity, and since some ARVs cause hepatotoxicity (compromised liver function), HIV-positive children could be at increased risk for developing vitamin A toxicity. It is possible the national guidelines for the number of RUTF packets to be given to children were derived with the assumption that additional family members (whether children or adults) would consume some of the child's ration. However, based on the charts in the clinic, it seems more likely they are based on the linear extrapolation of guidelines designed for younger children.

Fourth, all of these calculations assumed the child would only be consuming RUTF, without taking into consideration children's food preferences and the social dynamics of eating. Just because a child, especially an older child, passed the appetite test (which only required them to eat half a packet) did not necessarily mean they would eat a full packet at home, let alone eat five packets per day. All of the children I worked with, even those who actually liked RUTF, wanted to eat other foods, and would not accept only eating RUTF for any period of time.

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[32] Other nutrients whose tolerable upper intake would be exceeded include iron, magnesium, zinc, copper, iodine, vitamin D, folic acid, and niacin.

[33] In children, signs of vitamin A toxicity include irritability, drowsiness, dizziness, delirium, coma, vomiting, diarrhea, increased pressure in the brain with bulging fontanelles in infants, headache, swelling of the optic (eye) disk, bulging eyeballs, visual disturbances, and skin redness and peeling (Mayo Clinic 2013).

7.4.2 Administering RUTF at Baaliro – The Paradox of RUTF

Before leaving ECCH, the RUTF sachets were counted out for all of the children staying at Baaliro, and we often returned to the center with a full box[34] or more. Once back at the center, the box was kept in the office. Sister Sally maintained control over the sachets – giving them to 'malnourished' children and, as I will discuss later, refusing to give them to 'healthy' children. Malnourished children were usually called to the office twice a day and given a sachet.

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Back on the bench at Baaliro, Wemusa,[35] *an 11-year-old boy, and Sanyu,*[36] *his 6-year-old brother, sit next to each other. The boys are about the same height. Though HIV-positive, Sanyu doesn't technically need nutritional or medical rehabilitation, but he is staying at the center with his older brother and mother, both of whom are in poor health. Like Talya, Wemusa hates the paste, but Sanyu enjoys the sweet and salty treat. Previously, Wemusa kept trying to give his portion to his brother, who was eager to help, so in an attempt to keep the boys from sharing, Sister Sally eventually decided to issue Sanyu his own packet. Wemusa, meanwhile, continued to look for ways to avoid eating the nutritious paste. He tried feeding it to the dog, sticking it to the underside of the bench, "accidentally" dropping it on the floor, and hiding it in his pocket (to name just a few strategies). This day, I catch him putting it down the shirt of Nakisisa who giggles with delight. I separate Wemusa from the others but am too weary to keep a close eye on him.*

Within fifteen minutes, Sanyu and the rest of the children have finished their packets and returned to doing housework, but Talya, Wemusa, and I sit on the bench, staring at their less than

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[34] Each box contained 150 sachets.

[35] Wemusa is a Luganda name meaning "never satisfied." This both reflects his stubbornness and his tendency to demand gifts and special food. He was generally considered a difficult child with bad *empisa*.

[36] Sanyu is a Luganda name meaning "happiness." In stark contrast to his brother, Sanyu was easy-going and easy to please.

half eaten packets. "Sagala!" [I don't want [it]], Wemusa declares. Repeating the phrases I have heard the staff use, I tell him if he eats he will grow and become strong. He just stares at me. "Lwaki toyagala?" [Why don't you want it?] I ask. He continues to stare and says nothing. "Nkooye" [I'm tired], Talya whines. I tell her she can rest after finishing, but she means she's tired of eating, not that she actually wants to go to bed. "Nzikuse" [I'm full], she pleads. "Osobola okulya ekitundu" [You can to eat [at least] half], I try to cajole her. A few minutes later she tries her final strategy (for the day) "Njagala kufuka" [I have to go to pee], she insists. I know from experience that if I allow her to leave and go to the toilet, she will not return to eating. We make eye contact, and she knows that I know this game too well. But, she is patient… and so is Wemusa. After about an hour, the program director comes by. Seeing that the children have, by this point, each eaten half a packet, she tells them they can go, and they drift away. She places the remainder of their packets on pieces of paper with their names written on them. "They can finish them later," she explains. "Indeed, they can," I think, but I know they never will.

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This vignette exemplifies one of the great paradoxes I observed among the children consuming *plumpy* at Baaliro. Like Talya and Wemusa, many of the sickest children undergoing nutritional rehabilitation refused to eat *plumpy* (which was to them a dreaded substance) despite staff's efforts to get them to eat the magic miracle food. Meanwhile, non-malnourished "healthy" children would ask for *plumpy* and were usually denied access to the RUTF packets. Children were reluctant to articulate the reasons why they hated (or for that matter wanted) RUTF, but after living with them and talking to older children who reflected on times when they themselves did not want to eat *plumpy*, I was able to hypothesize and induce some of the reasons behind their refusals. I believe one of the main reasons sick children were so reluctant to eat *plumpy* was a consequence of the extrapolation of RUTF to a population for which it was not designed. Meanwhile those healthy children who wanted RUTF valued it not for its magical nutritional properties but for its alternative applications. While children were rejecting or changing the medicinal magic of *plumpy*, the staff at Baaliro fully accepted and even expanded the magic of *plumpy* to even further uses for which RUTF was not originally intended. Analyzing the uses of *plumpy* at Baaliro shows how the extrapolation of "magic bullets" leads to these kinds of alternative logics and uses of magic.

7.4.3 Sick Children Reject Plumpy's Magic

Like Wemusa and Talya, the children who did not want to eat *plumpy* had innumerable strategies for avoiding the dreaded substance. Perhaps the most common strategy was that of attrition – simply sitting and waiting for the adults to get distracted or to give up trying to get them to eat the repugnant paste before eventually slipping away. Meanwhile, Baaliro's staff held that, "if children take *plumpy* seriously, they will recover quickly." Believing *plumpy* to have been imbued with near "magical" powers, staff tried a variety of strategies to get the children to eat – even a little – of the purported life-giving miracle food. They would encourage and negotiate – telling the children to just eat half the packet, or eat *mpola mpola* (slowly-by-slowly). They would bring water for those who said it was too dry.[37] They would try to mix the *plumpy* into the child's porridge. In their own attempt at attrition, they would threaten to keep children in the office until they finished. However, none of the staff strategies were particularly effective in getting children to eat *plumpy*. Even if a child was convinced to eat half of a sachet, the "later"

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[37] The guidelines for administering RUTF encourage caregivers to provide children with water when taking the substance, since it was intentionally designed with a low water content to prevent bacterial growth. However, as previously discussed, this need to consume water with RUTF, undermines the claims that RUTF eliminates the need for clean water during nutritional rehabilitation.

when they were supposed to eat the remainder almost never came – staff had many responsibilities to attend to and often lacked the time to call children back. Even if a child was called back to finish a packet, the same stand-off would resume. Similarly, keeping children in the office until they finished only worked until the first client needing to meet with the staff arrived. Finally, the children could tell when the *plumpy* had been added to their porridge, and often refused to drink it all together once they detected the contamination – resulting in the child consuming even fewer calories than if they had just taken the porridge alone. I found this (failed) strategy to be especially interesting, given that according to the IMAM guidelines, RUTF was ideally supposed to be the only source of calories for children undergoing nutritional rehabilitation, yet putting RUTF into porridge was also a strategy which the hospital's nutritionist himself suggested. In summary, given the difficulty of getting children to consume even a single packet, it was infeasible to reach the prescribed target of five sachets per day. Even the most cooperative eaters ate at most three in a given day.

Children often would not respond directly to my questions asking them *why* they did not want to eat *plumpy*. As exemplified by Talya and Wemusa, they would simply stare at me with fixed expressions, repeat various excuses about being full and tired, or simply say "Sagala" [I don't want [it]]. However, after witnessing, and participating, in many of these exchanges and talking to both staff and older children,[38] I was eventually able to gain an understanding of why children might not want to eat *plumpy*. Almost all sick children – those who were currently enrolled in the nutrition program and being prescribed *plumpy* – claimed that the paste was too sweet or too salty or both. Often these children had numerous AIDS related opportunistic infections – including mouth sores and thrush. The high sugar and (especially) salt content

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[38] Older children who were still being followed by Baaliro and supported with school fees would recollect their initial stay at the center.

burned their open wounds making eating painful. Many also suffered from abdominal bloating and cramping due to high parasite loads or other gastrointestinal infections and diarrhea. The high nutrient density almost certainly worsened these symptoms. Over the course of a year, I witnessed several children who had initially been stubborn *plumpy* refusers come to request and even hoard the sachets once their health improved. Even Wemusa and Talya eventually began requesting the packets. In addition, some children seemed reluctant to eat *plumpy* because they wanted to eat other food. This was especially the case when there was a special event, such as the Annual General Meeting. Even when the serving of food was delayed by numerous long-winded speakers, and some children started crying because they were so hungry, they refused to accept *plumpy* and instead waited for the long-anticipated feast of rice and meat to be served.

7.4.4 Why Deny Healthy Children Plumpy?

While children prescribed *plumpy* often made every effort to avoid it, those children who were healthy – meaning they either never qualified for or had been discharged from the government malnutrition program – would request *plumpy* and were usually denied it. I initially found the staff's reluctance to give *plumpy* to children who wanted it perplexing, especially given the surplus of *plumpy* in the office, until Sister Sally explained both the need to keep a surplus, and the need to keep close control over its use. She rationalized that it was necessary to keep a surplus because the government program at times ran out or RUTF, but Baaliro had to keep it on hand for those children that still needed it. She felt that to be caught without any *plumpy* would be a major failing for a rehabilitation center, especially one which claimed to be treating malnutrition. Sister Sally's assertion is hardly surprising given, as previously discussed, that RUTF and MUAC tapes have come to define nutritional rehabilitation in low and middle income countries. Furthermore, since Baaliro had no budget for RUTF – they were expected to utilize the public resource of the government hospital to meet this need – meaning that they could not restock if supplies did get low. Indeed, about six months into my stay, the government program ran out of RUTF sachets, and the surplus in the office was barely enough to last until the clinic was re-stocked over a month and a half later.

Baaliro staff also felt it was important to keep *plumpy* on hand to give to children for alternative medical reasons, most commonly for those taking malaria treatment. According to the instructions printed on the fixed-dose packets, the medication was to be consumed with milk or other fatty foods,[39] but since milk was only available in the mid-morning at tea time (served around 8:30am), and medications were usually given at 7:00am and 7:00pm children were often given *plumpy* with their malaria medications. Also, some antibiotics were "very powerful" as indicated by the fact that they made children nauseous, so Sister Sally occasionally gave those children a packet of *plumpy* with their morning medications to help settle their stomachs.

Sister Sally cautioned, however, that they were careful about giving *plumpy* to healthy children, because children who were well enough to attend the local school had previously been found selling sachets to classmates. I identified at least one such case when a boy who had been discharged from *plumpy* requested a sachet and ran to school before it could be opened. In the afternoon, he returned with a toy car and dodged my questions about where the new toy had come from. For this child, the magic of *plumpy* was its economic, rather than nutritional properties, but for Sister Sally this was a misuse. For his part, the nutritionist offered a unique rationale for why healthy children should not eat RUTF. He explained that children's guts become "lazy" if they are on RUTF for prolonged periods, since the nutrients are so easily

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[39] The recommendation is based on a study which showed that the treatment success rate for the medication was 15% higher when supplemented with milk or fatty foods (Denis et al. 2006).

accessible in the specially formulated paste. By this logic, once it became "lazy," a child's gut would then be unable to properly absorb nutrients from family foods which were more difficult to absorb. He was the only individual I spoke to who offered such a rationale, and I am unclear whether he developed this understanding independently, learned it via official training programs, or heard it from colleagues. There is no biomedical justification for this claim regarding the availability of nutrients; however, malnutrition materials do emphasize that children should be transitioned from RUTF to family foods as soon as possible once they have reached their target weight, because not consuming family foods for a prolonged period could affect the development of children's tastes, especially for different food flavors and textures.[40] Therefore, the lazy-gut rational may represent a way for the nutritionist to explain to caregivers why it was important that they and the children not become dependent on *plumpy*.

7.4.5 How (and Why) Healthy Children Score Plumpy

There were occasions when a healthy child could score a sachet. Often this was when Mary, rather than Sister Sally, was in the office. As mentioned in Chapter 4, the children did not fear the Mary as much as Sister Sally, and Mary was generally thought to be an easier target. Alternatively, if the child had been asking Sister Sally for some time, she occasionally relented, especially if she could give *plumpy* as a reward for good behavior. Lastly, Sister Sally occasionally attempted to use good eaters as an example for other children. Staff noted that children often (though certainly not always) succumbed to peer pressure. They were anxious when children, like James (from Chapter 6), made a scene of refusing to eat because they feared that other children might follow his example. To counter such negative examples, the staff

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[40] Once again, this would seem to be greater issue for young children (6 months – 5 years old), but less of a concern for older children, who have presumably already developed a taste for local foods.

overtly praised the good eating/growing/fat children for their accomplishments in front of the reluctant eaters, and sometimes even gave them a packet of *plumpy* to eat alongside their more reluctant peers.

For these children, scoring a sachet of *plumpy* was doubly beneficial. The healthy children not only got what they considered a tasty treat, but also, they often managed to delay or completely avoid doing assigned chores while eating *plumpy* – since as a medical activity eating *plumpy* (focusing on rehabilitation) took priority over housework (focusing on reintegration). Healthy children generally seemed to genuinely enjoy the taste of *plumpy* in contrast to their sick peers. The fact that healthy children liked *plumpy* is perhaps not surprising considering other adults generally enjoyed the taste. In fact, Sister Sally explained that one of the reasons they needed to keep the sachets under lock and key in the office was that previously staff from St. Damien's had been known to take packets to smear on their bread. Everyone at Baaliro agreed that this was a clear violation of how plumpy was to be used, and that such misuse must be prevented, but it indicates the general consensus the *plumpy* was delicious. In addition to enjoying the taste, when children were eating *plumpy*, they were excused from their normal work responsibilities. Eating *plumpy* offered only a temporary reprieve, since once they had finished, children were supposed to return to work, but sometimes children could prolong eating long enough to avoid work altogether (for that one morning or afternoon).

Additionally, as described above, school-going children could barter *plumpy* in exchange for toys, even more tasty *obumpwakipwaki* (snack foods), or other desirable items. Staff attempted to have children eat at least part of a packed under supervision to prevent this kind of misuse. Finally, some children seemed to simply hoard the *plumpy*, claiming that they would eat it later, but seemingly never actually doing so. This may indicate their development of anticipatory strategies to buffer against scarcity once they return home and, interestingly, paralleled Sister Sally's efforts to maintain a surplus of *plumpy* in case of a break in the supply chain at ECCH.

7.5 Conclusion

In summary, the role of *plumpy* at Baaliro differed wildly from the original intentions of the creators of RUTF. Paradoxically, the sickest children who would benefit the most from the nutrient dense miracle food were the most reluctant to eat it whereas the healthiest children who did not qualify for any nutritional intervention begged for it. Returning to the analogy of the magic bullet, the "magic" of *plumpy* was largely accepted by the staff in terms of its nutritional properties and its power to rehabilitate malnourished children quickly – that is, if only they could get them to eat it. The staff even expanded RUTF's magic further, using it for administering anti-malarial medications and antibiotics, as a reward for good behavior, and as a way to use peer-modeling to their advantage. The children however, especially malnourished children, refused to grant *plumpy* any supernatural healing power and rejected it all together. Healthy children, meanwhile, manipulated it to serve their needs – via economic empowerment and as a way to avoid undesirable tasks, such as housework.

I argue that the development of alternative logics and use of a magic bullet's magic is especially prevalent in cases of extrapolation. As is the case with many successful magic bullets, the effectiveness of RUTF for treating SAM has led to the extrapolation of its use into populations beyond those for which it was originally intended, and at Baaliro (and ECCH) this includes children with moderate acute malnutrition and HIV. International guidelines, the setting of the rehabilitation home, and the resourcefulness of the children themselves coalesce to produce alternative meanings and uses for the product and its magic.

Chapter 8: Landscapes of Need and Responsibility: Islands of Care for Children Living with HIV in Uganda

In chapter 1, I discussed the history of NGOs in Uganda and located Baaliro within the projectified landscape of HIV care. In this chapter, I return to the concept of landscapes, using Baaliro as an example of how NGOs define childhood in particular ways, which in turn determines which children are able to access care and what kinds of assistance they receive. Numerous scholars have explored how donors, NGOs, and their staff – both local and international – participate not only in the identification, but also the construction of need (L. A. Allen 2009; Delcore 2003; I. Feldman 2007; Nguyen 2010; Redfield 2005; Timmer 2010). We can conceptualize these as landscapes of need which recipients must navigate in order to access care (AAA 2015; Bornstein 2002; Redfield 2011). Additionally, in thinking about the construction of landscapes of need, I was struck by another landscape created by NGOs – landscapes of responsibility. Landscapes of responsibility are themselves produced by the process of responsibilization. Applying neoliberal discourses of individual responsibility, responsibilized citizens come to understand themselves as responsible and independent agents (Clarke 2005; Gray 2009; Rose 1999; Shamir 2008). Responsibility, in this sense, stresses morality – itself an unstable assemblage of what is deemed reasonable and decent – and making reasonable (rational/good) choices. John Clarke (2005) describes this as the flipside of activation and empowerment in neoliberal governance: "at their core is [citizen's] responsibility to produce the conditions of one's own independence – ideally by becoming a 'hard working' individual or family" (2005, 451). Responsibilization has been criticized for being overly individualistic, ignoring socio-structural factors and economic pressures and resulting in victim blaming (Gray 2009). At its worst, responsibilization masks abandonment and "appears as a smokescreen behind which the state is systematically divesting its responsibilities" (Clarke 2005, 453). The process of responsibilization, however, is not restricted to governments, and many NGOs are also undergoing the process of responsibilization (Shamir 2008). Through a kind of trickle-down ideology, I argue that NGOs pass on the process of responsibilization to the recipients of their services. Thus, the process of responsibilization at the level of NGOs shifts the landscapes of responsibility, resulting in islands of care. Utilizing Henrik Vigh's concept of social navigation – movement within a moving landscape – I look at how the children and caregivers at Baaliro navigated the shifting terrains of need and responsibility to access islands of care (Vigh 2009).

I explore the landscapes of need and responsibility and the ways in which responsibilities become overlaid onto needs resulting in new landscapes of access which, at times, create islands of care – alternately placing children on these islands, or leaving them stranded on the mainland with no way to access them. The tensions between vulnerability and responsibility, dependency and entitlement manifested at Baaliro as children and caregivers attempted to navigate the terrain created by both on the ground service providers and distant donors. I begin with a very brief analysis of the idea of sustainable development, concepts of independence, and Kiganda ethics of interdependence. In the remainder of the chapter, I analyze the ways in which the landscapes of need and responsibility have shifted and collided at Baaliro as notions of responsibility have intersected with inclusion criteria, and as international donor pressures for sustainable development have interacted with Kiganda ethics of interdependence. First, I describe how the landscape of need has flattened as inclusion criteria were less strictly enforced, making it easier for some children to qualify for services. However, this flattening was contingent on notions of responsibility, where perceptions of caregiver responsibility interacted with inclusion criteria to determine enrollment in (or rejection from) the program. In recent years, the emphasis placed on responsibility has grown, not just for individual caregivers and children, but also for (and perhaps because of) Baaliro itself and its international donors. The consequences of the increased emphasis on responsibility (responsibilization) were often felt most acutely by the children. Therefore, when describing these broad shifts in landscape, I focus on their stories and experiences. Ultimately, the children and their caregivers had to navigate these shifting landscapes in order to access services.

8.1 Sustainability, Independence, and Kiganda Ethics

The term "sustainable development" has been used in a myriad of ways (Lélé 1991). For clarification, the concept of sustainable development I employ has little to do with the ecological movement, but rather is tied to neoliberal economic rhetoric and concepts of responsibility. Numerous scholars have both documented and offered critique of the international paradigm shift toward sustainable development (Escobar 2011; M. Green 2000; Hart 2001; Kremer and Miguel 2004; Scherz 2014; Stirrat and Henkel 1997; Swidler and Watkins 2009). One example of the continued emphasis on sustainable development was the replacement of the United Nation's Millennium Development Goals with the new revised Sustainable Development Goals (United Nations 2015). Concerns of dependency date back to at least the French Revolution and the concept of sustainable development is nothing new. Colonies were supposed to become less dependent on (though still remain loyal to) home governments, and missionaries strove to found self-supporting churches.[1] Prior to the 1990's, the requirement for sustainability was largely restricted to national governments, as measured by their ability to pay back loans to the World Bank. However, concepts of sustainable development made a substantial shift toward a

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[1] For a succinct review of the history of sustainable development, especially as it relates to development in Uganda, I highly recommend *Having People, Having Heart* by China Scherz (2014).

participatory development paradigm in the 1990's which required community contributions and that even individual villagers be able to pay back a loan. As part of this shift, NGO donors and governments sought to fund projects that would have an impact beyond the project itself, that were "community-owned" and that, perhaps most importantly, would exist after the project's completion and after the *funders* had left (Kremer and Miguel 2004; Mosse 2013; Scherz 2014). Thus, independence became synonymous with sustainability. As part of this phenomenon, sustainable development projects eschewed providing handouts with the rationale that such gifts caused dependency thereby undermining sustainability.

The ultimate goal of sustainable development is for the development project to become obsolete. Therefore, in final form, the recipients of the project also become independent – no longer needing the project's (or ideally anyone's) assistance. Such an orientation makes sense in a moral framework in which dependence on others is viewed as a sign of weakness, and charity is understood to be harmful to the recipient (Bourdieu 1977; Douglas 1990; Mauss 1925 [1925]). However, as China Scherz (2014) states, "ideals of independence and self-reliance, which lie at the heart of sustainable development, are socially and historically constructed …. In opposition to the tremendous value placed on independence and self-reliance in many Western cultures, in much of the world personhood is achieved through relationships with other people" (2014 location 103).[2] In her research, Scherz explores how within Kiganda ethics "strategies of self-making involve creating and using networks (which are often hierarchical) to secure support (which is often material)" (2014 loc 110). Utilizing strategies of hierarchical interdependence, those with resources gain respect and moral capital by taking on dependents, but also those without wealth gain access to resources by attaching themselves as dependents. In both cases,

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[2] See also Caroline Bledsoe's (1990) analysis of patronage and dependency in the case of fostered children in Sierra Leone, and Parker Shipton's (1995) analysis of entrustment and obligation among the Luo in western Kenya.

individuals improve their economic and social standing by attaching themselves to one-another, not by becoming independent. To say it another way, both clients and patrons gain by "having people" and only those without people are truly destitute. Furthermore, the freedom of the client came from the multitude of opportunities for dependence, rather than through attaining independence from patrons (Ferguson 2013).

Scherz's research is especially relevant to my own, as she describes how concepts of sustainable development butt heads with Kiganda concepts of interdependence.[3] She describes how when an aid organization in central Uganda shifted from giving material donations directly to individual households to community educational programs and support groups, clients responded by accusing NGO staff of "eating the money" (Scherz 2014). The recipients in Scherz's fieldwork felt the ground shift beneath them, as sustainability became synonymous with individual responsibility and as the NGO re-defined the landscape of responsibility that clients were required to navigate.[4] While these broad shifts in the landscape of need are well documented across development strategies worldwide, I now explore how landscapes of need have shifted and the terrain of responsibility has changed at Baaliro in particular.

8.2 Baaliro's Financial Landscape

Recall that Baaliro's original mission was to provide temporary residential care for children, aged 4-18 years old who were suffering serious medical complications from AIDS. Children were to stay at Baaliro, undergoing rehabilitation, until they were medically stabilized,

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[3] This is not to claim that there is no concept of individual responsibility in Kiganda ethics, but rather to emphasize the importance of *interdependence* relative to western, and especially neoliberal, emphasis on individuality.

[4] The emphasis on responsibility was widespread in national discourse in Uganda. For example, Uganda's NSPs for HIV/AIDS has listed personal responsibility as their its guiding principal since 2007, and the latest report had the subtitle "An AIDS Free Uganda, *My responsibility*!" [emphasis added] (UAC 2007, 2012a, 2015a).

and then would be reintegrated to be raised by their families. Baaliro was supposed to follow-up with reintegrated children monthly, paying for their school fees and ensuring that they were adhering to their ARVs. Additionally, Baaliro was supposed to run awareness and sensitization programs in communities where children had been reintegrated. These programs were designed with the idea that destigmatizing HIV would help children to be welcomed back into their commuunities.

Since opening in 2008, Baaliro had become the flagship program for Child Network (a Swiss NGO). Baaliro was such a popular program with donors that whether it was an independent program or a program under St. Damien's was a major source of contention, especially with Child Network's project coordinator, Lucas who (as described in Chapter 2) quickly became frustrated with St. Damien's regular interference with Baaliro operations. While Baaliro brought in the most funds for Child Network, it was also the most expensive program that that Child Network supported (especially per capita).[5] According to Baaliro and St. Damien's staff, when they first began fundraising for Baaliro in 2008, Julien (Child Network's founder) forbade them from getting funds from "any other donor" besides Child Network. This legacy became another important point of contention during my time at Baaliro. Julien later clarified that the original 2008 memorandum stated, "That running costs [of Baaliro] will be met by [Child Network] and [St. Damien's] will not ask any other donor for funds for running costs. It may ask for other funds for other priorities after contacting [Child Network]." According to Julien, the original intent of the memorandum was to avoid double funding. He anticipated that St. Damien's would easily be able to solicit donations for "these poor children" but then "use the

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[5] The costs of caring for severely ill children could be very high, especially if they required treatment at a private facility, and the costs of following up with children who often lived far from the center (namely fuel and vehicle maintenance) were also high.

money for something else" (presumably still for St. Damien's programming, but not necessarily actually to the benefit of the children at Baaliro) (email correspondence September 21, 2016). Julien's concern was well founded, as I witnessed several instances where St. Damien's used funds raised for one project to support another. Thierry (the executive director of St. Damien's) explained the strategy of transferring funds between projects as necessary to balance budgets and pay bills in the face of uneven funding streams. He insisted that funds were not misused, because they were being used for St. Damien's projects (rather than personal gain) and ultimately were repaid to the accounts that they were taken from.[6] Child Network's initial policy on Baaliro's fundraising is important as it sets the stage for the later shift in fundraising responsibilities and the impact of this shift on Baaliro's program. Given the background of Baaliro – its identification as an HIV rehabilitation center, its reliance on foreign donors, and its emphasis on reintegration and responsibility – I will now explore how the shifting notions of need and responsibility altered the landscape of care delivery among Baaliro's recipients and indicate key factors that motivated these shifts.

8.3 Leveling the Landscape – Flattening Need

When I first visited Baaliro in 2012, all of the children were HIV-positive, all but one (a 20-year-old) were 7-17 years old, and all but one who refused to stay at the center were treated inpatient for four months or more. However, when I returned in 2013, I was surprised to find many children not fitting the original enrollment criteria. In particular, I noticed a lot of very young children and babies. In total, there were five HIV-negative children staying at the center, all less than two years old, and an HIV-positive two-and-a-half-year-old. Additionally, Baaliro

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[6] Adrienne Strong (2017) noted administrators using similar strategies in her research at a rural government hospital in Tanzania.

had enrolled five HIV-negative children for outpatient care, all of whom were two to four years old. It seemed Baaliro had expanded their criteria to include HIV-negative severely malnourished children, children both younger and older than their original age cut-offs (though mostly younger), and children who were never admitted as inpatients. When I was granted access to the children's files, I learned that while initially these were rare exceptional cases and only accounted for a handful of children, over the years these exceptions had become more normal. During Baaliro's first year (2008-2009), out of 34 children enrolled, two children were under the age of four years, two were HIV-negative, and three were treated as outpatients, but by 2014, out of 34 children enrolled, 14 were under four years old, 10 were HIV-negative, and 15 were treated as outpatients.[7] The target for the number of children enrolled (30 per year) had not shifted, but the composition of the children had (see Figures 8.1 and 8.2).

Staff explained that this shift was due in part to three factors. The first was Baaliro's increased willingness to find a middle ground with caregivers who were unable (or unwilling) to stay at the center with their children due to family obligations (thus the increase in outpatients). While caregivers were not required to stay with children as long as the child was well or old enough to care for his/her most basic needs – feeding, bathing, dressing, toileting, etc. – those children who were unable to care for themselves, especially very young children, did require a caregiver.[8] Understandably caregivers were reluctant to abandon their responsibilities at home as well as any income generating activities they had in order to stay at a center to care for a sick child. Thus, the staff would compromise with caregivers who were willing to care for a child at

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[7] A single child may fulfill more than one of these categories at a time – for instance being two years old and HIV-negative.

[8] Recall, this was one of the most significant differences between Baaliro and a typical hospital. In most hospitals, both government run and private, caregivers were required to stay with admitted children (and even adults) as basic nursing care, food, bedding, and laundry services were not provided by hospitals.

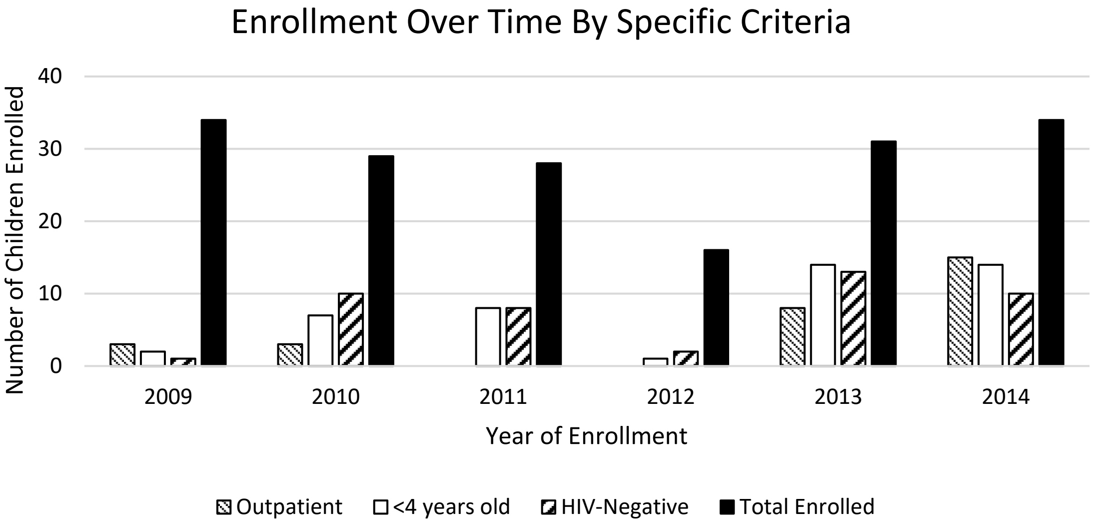

Figure 8.1 Enrollment Over Time by Specific Criteria
Enrollment in Baaliro shifted over time to include more children who previously would have been ineligible for care based on the inclusion criteria. Baaliro originally defined inclusion criteria as ≥4 years old, HIV-positive, and being enrolled as an inpatient. Exclusion criteria included children who were <4 years old, HIV-negative, or enrolled as an outpatient. A child may be counted in more than one exclusion category – such as being a 2-year-old HIV-negative outpatient.

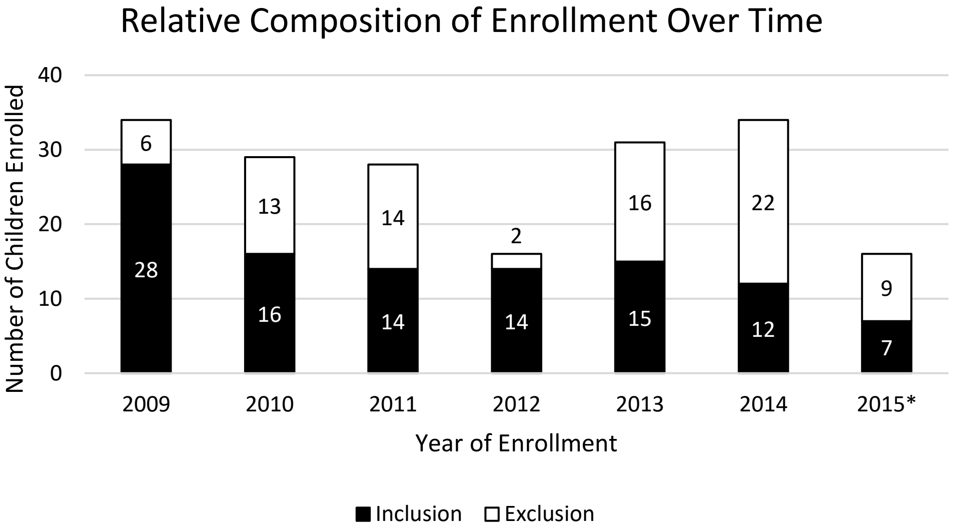

Figure 8.2 Relative Composition of Enrollment Over Time
Exclusion criteria include being <4 years old, HIV-negative, or enrolled as an outpatient. Since 2013, the majority of children enrolled at Baaliro have not met the inclusion criteria (52% (16/31) in 2013, 58% (22/38) in 2014). This graph visually depicts that the number of children meeting inclusion criteria has tended to remain the same or decrease over time, whereas the number of children not meeting inclusion criteria has tended to increase over time.
**Data through September 24, 2015.*

home, but still bring the child to the center for weekly or bi-weekly check-ups. This offered closer monitoring than typical outpatient care, but allowed caregivers to fulfill their other obligations. Typically, this compromise only worked for caregivers who lived very close to the center because there was no funding to support paying for the caregiver and child's transportation to and from Baaliro.

The second factor listed by staff was a decreasing number of children suffering from AIDS. Staff claimed that rates of mother-to-child-transmission were dropping and that since ARVs were more widely available in the growing network of clinics throughout the country, children were starting on treatment sooner, and thus fewer were reaching stage III/IV disease. Whether these claims could be supported by statistical data remained a point of contention with Lucas. While rates of mother-to-child transmission (MTCT) were dropping nationally,[9] in 2013-2014 Jinja district reported MTCT rates of 15.7%, substantially higher than the 5% national and international goal (JHD 2014). Also, considering that the average age of enrollment among HIV-positive children in Baaliro's program was 9.7 years, any drop in mother-to-child-transmission would not affect the children who presented to the center until nearly a decade later. Perhaps more importantly, according to the *2014 Uganda HIV and AIDS Country Progress Report*, only 31% of children living with HIV were receiving treatment nationwide (UNAIDS 2015a).[10] However, the number of clinics in the area providing access to pediatric ARVs, certainly had

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[9] From 2009 to 2015 Uganda reported an impressive 86% drop in rates of new HIV infections among children, mostly due to impressively high rates of >95% of pregnant women living with HIV receiving ARVs, thus reducing mother-to-child-transmission rates to 2.9% (UNAIDS 2016b). While this report was published after my fieldwork ended, there was much discussion at St. Damien's about Uganda Ministry of Health's goal of "elimination of mother-to-child-transmission" of HIV.

[10] A UNAIDS report in 2016 more than doubled that estimate to 63% receiving treatment (UNAIDS 2016b).

increased since Baaliro's opening,[11] so children may have had easier access to ARVs as outpatients, thus possibly decreasing (but not eliminating) the need for Baaliro's intensive inpatient services.

Finally, staff explained that an improved partnership with both the main hospital's nutrition clinic and St. Damien's SCORE program led to an increase of HIV-negative, severely malnourished children being admitted into Baaliro. It was important for Baaliro to accept such children in order to maintain a positive relationship with its partners. The relationship with the nutrition clinic and the main hospital was especially important, so that when Baaliro children needed to be transferred for inpatient care they would be well received.[12] Despite these changes in client population, Baaliro still primarily identified itself as a rehabilitation center for children with HIV.

Based on my observations, Baaliro staff tried not to turn away children and families who presented reasonable cases for assistance. Their ability to be flexible with their inclusion/exclusion criteria in order to provide services in such cases enabled them to take on children who they described as "in desperate situations" and who were in many cases referred to them via other service providers. A few examples included children not infected with HIV, but with other medical needs such as TB or a compound leg fracture in need of surgical repair. In these cases, the child's medical expenses were covered by Baaliro and then he/she was taken on for school fees as well. Other children were HIV-positive and doing well on medications, but in need of school fees. These children were taking ARVs, had high CD4 counts, and were not

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[11] When I first visited St. Damien's in 2006 (prior to the construction of Baaliro) children had to be bussed to a JCRC clinic located at a sugar plantation nearly 20km away to access ARVs. At the time of my research in 2014-2015, children could access ARVs from at least 3 clinics in and near Jinja, and numerous county and sub-county health centers throughout the region. See also the roll-out of pediatric ARVs in Chapter 1.

[12] For more on the importance of this relationship see Chapter 7.

suffering from opportunistic infections – meaning that, although they were HIV-positive, they did not technically meet the inclusion criteria of the center because they were not in stage III/IV AIDS. Staff determine that by supporting such children in school, they were more likely to continue taking their treatment well, rather than having to first fail treatment, so they could qualify for services (which all agreed ran counter to the idea of serving children infected with HIV). Thus, the staff were able to flatten the landscape of need for some children so that they could access the services that Baaliro provided.

8.3.1 Intersection of Responsibility and Inclusion Criteria

The staff's definition of a reasonable case, i.e. a case which qualified for Baaliro's services, often hinged upon responsibility, especially when children did not clearly fall within Baaliro's inclusion criteria. In contrast to the cases above, staff were quick to turn away caregivers who they perceived as wanting to "dump children" at the center. At least once every two to three months a woman came to Baaliro looking to leave one or more children at the center. Sometimes this was a mother herself and sometimes a relative – because the mother was either not alive or had abandoned her caregiving responsibilities. Staff were especially critical of cases where the children were healthy (either HIV-negative or doing well on ARVs) and a woman wanted to leave the children at Baaliro because she was "tired of looking after them" or "looking for a place to take children." Taking healthy children away from their communities ran opposite to Baaliro's fundamental mission of reintegration. Staff refused to accept such children, explaining that they failed to meet Baaliro's inclusion criteria. However, as we have seen, inclusion criteria could be quite flexible. The staff also labeled such caregivers as irresponsible, and thus it became easier for Baaliro to deny their requests for aid.

For older children, especially post-pubescent children, assessing the child's responsibility could be more important than the caregiver's. For example, at the beginning of 2015, two secondary school students who were actively involved as leaders in St. Damien's weekly youth program approached Baaliro for school fees assistance. They had sought sponsorship elsewhere and been unsuccessful. Though the boys were HIV-positive, they were healthy and so would not have normally qualified for Baaliro's programming. However, because they had demonstrated such a strong commitment to being responsible role models through their leadership roles in the youth group, Baaliro agreed to pay their school fees.

Cases of children meeting the inclusion criteria, but with an irresponsible caregiver, were very common among Baaliro's caseload, and the most common cause of frustration for the staff, especially Mary, who had the most direct interaction with reintegrated children and their caregivers. Countless conversations between staff and myself, whether in the office or the fieldwork vehicle, centered around the topic of caregiver responsibility. On multiple occasions Mary and Sister Sally identified irresponsibility[13] as the number one[14] problem with which Baaliro had to deal, and they linked many poor outcomes to caregiver irresponsibility. Rebounders provided a concrete example of why responsibility (especially caregiver responsibility) was so important. Out of 115 total children reintegrated by Baaliro, 17 rebounded and required re-admission to the center for at least two weeks (15%).[15] Two rebounders died

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[13] This included caregivers being irresponsible from the start, the difficulty of identifying responsible caregivers to look after reintegrated children, and the difficulty of getting caregivers to accept increasing responsibility for the child's needs (providing school supplies, shoes, etc…).

[14] At other times, they identified adolescent adherence failures, and at still other times the failure of Baaliro to provide meaningful financial support to caregivers. So, there were at least three "number one" problems Baaliro was attempting to manage.

[15] These statistics include all HIV-positive and HIV-negative children who had ever been enrolled as inpatients and subsequently reintegrated. For HIV-positive children the rebound rate was similar at 16% (14/89). However, both of the deaths among rebounders were HIV-positive children.

either during or shortly after they rebounded, giving rebounders a death rate of 12%. This compares to only six deaths among the 98 children who had been reintegrated and who had not (yet) rebounded to the center, giving non-rebounders a death rate of only 6%.[16] The high death rate among rebounders was likely due to do the fact that children tended to rebound because of poor adherence, and rebounders often presented in a severely deteriorated condition and were found to have developed resistance to first line ARVs. Staff attributed poor adherence to irresponsible caregivers. Despite the importance of a responsible caregiver and in contrast to cases where children did not meet inclusion criteria, in cases where the child clearly met Baaliro's inclusion criteria, but the caregiver was irresponsible, children were never turned away. In fact, staff spent additional time convincing some caregivers to bring their children to Baaliro in the first place, and then often spent extra time and effort (as in Peter's case, which I recount in detail below) involving multiple trips to the field and negotiations with multiple family members, in order to identify a responsible caregiver for reintegration.

8.3.2 Peter's Story – The Importance of Responsibility

Baaliro staff frequently pointed to Peter's mother (*Maama*-Peter[17]) as a paradigmatic example of an irresponsible caregiver. Peter was first admitted to Baaliro in June 2012 when he was seven years old. Although he had tested positive for HIV in 2009, he did not start taking ARVs until his admission to Baaliro. He also had not attended school prior to arriving at Baaliro,

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[16] This statistic should be interpreted with caution, however, because children may rebound a year or more after reintegration, and some rebound as late as five years after their reintegration.

[17] Women were typically referred to by the names of the children in their care (often the eldest child, and at Baaliro the name of eldest child who was staying at Baaliro) rather than by their own names. *Maama*-so-and-so was the default title, and could be used in reference to aunts, cousins, non-relatives and even grandmothers (though once women reached a certain age *Jjajja*-so-and-so (grandmother) was more common). In this case, *Maama*-Peter was actually Peter's biological mother.

but while at the center he started in baby-nursery[18] class and was quickly promoted to middle-nursery class after only half a year.[19] While at the center, Mary's reports described Peter as being very interested in schooling, clean/smart,[20] helpful, disciplined, respectful, and overall well behaved (having good *empisa*).[21] One comment declared, "indeed he is a good influence to others," and my own recollection of Peter from the summer of 2012 was that he was a vibrant intelligent child who was a joy to interact with. Peter stayed at the center for nearly 10 months and was reintegrated to his mother's care in March 2013, near the end of the first school term.

Upon reintegration, Peter's mother was given the responsibility of finding and registering him in a school, so that Baaliro could pay for his school fees, however she never found a school for him to attend. As early as May 2013, Mary ominously noted in Peter's chart, "the mother is experiencing a lot of social problems which might affect the child's future." For the rest of 2013, *Maama*-Peter changed homes several times and never enrolled Peter in school. In September, Mary noted that Peter's health had started to deteriorate and identified the fact that Peter lacked a "definitive home location" as the cause of both his poor adherence to ARVs and lack of schooling. By January 2014, Baaliro staff were unable to locate Peter or his mother, and Mary summarized the situation:

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[18] Nursery classes are not included in Uganda's national Universal Primary Education. However, many primary schools offer nursery classes, and even insist that children without any prior education start in nursery classes. There are three levels of nursery classes: baby, middle, and top. Children can begin attending baby classes as young as 3-4 years old, and some children can skip a class (going from baby to top, or middle to P1). Children ideally enter primary school (P1) at age 6.

[19] The Ugandan school years correspond to the calendar year, with children finishing their grade level in December and being promoted to the next grade starting in January. There are three academic terms with breaks in April/May, August/September, and December/January.

[20] Smart here refers to the British usage of neat, clean, or well dressed, rather than the more common American usage of quick-witted or intelligent, though in Peter's case he was both.

[21] For a discussion of good manners (*empisa*) and the importance Baaliro placed on *empisa* see Chapter 5.

> We have been trying to get in touch with the mother [of Peter] but have failed. [Godfrey] went to make inquiries at the [maternal] grandfather's place,[22] but they told him the mother had left the home and went to live with [Peter's] other grandmother[23] in some village in Buikwe. They haven't heard from her and do not know of her whereabouts. (case file note, January 2014)

At this point Baaliro staff had not seen Peter for 3 months. Mary documented their plan: to find Peter and once found to enroll him in a boarding school and identify another relative to look after him during school holidays, "because the mother is irresponsible and will not look after him well." In February 2014, *Maama*-Peter brought Peter to Baaliro and reported that he had not been taking ARVs for over two months. The staff informed her of their decision to enroll Peter in boarding school and noted no objection. Later that month, Mary visited Peter's paternal *jjajja (Jjajja*-Peter)[24] who lived near the boarding school where Peter was to be enrolled. *Jjajja*-Peter agreed to visit Peter while he was at school and to have him stay with her over the holidays.[25]

Maama-Peter accompanied her son as he was enrolled in the boarding school and a few weeks later she reported that she had checked-in on him and he was doing well. However, by the time *Maama*-Peter brought Peter to Baaliro in the last week in October 2014 for his medication refill and CD4 count test, Mary, with her propensity for understatement said simply "he did not look happy".[26] When the results came back, his CD4 count was only eight[27] and staff determined

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[22] Peter's maternal grandfather lived near Baaliro, but he refused to take any responsibility for Peter or to allow Peter to stay with him. He was also not always on good terms with his daughter (*Maama*-Peter).

[23] It is unclear if this refers to Peter's paternal great aunt or a different relative.

[24] *Jjajja* is typically translated as grandmother, however it can mean maternal or paternal grandmother, grandfather, great-aunt, or great-uncle, and may even be extended to cousins of that generation. In this case, I use the name *Jjajja*-Peter to refer to Peter's paternal *jjajja* who was his great-aunt (his father's mother's sister). Peter's paternal grandmother was deceased. Peter also had a maternal grandfather who lived near Baaliro, but to prevent confusion, I will not use the term *jjajja* when referring to him in this vignette.

[25] She was apparently not willing to take on the responsibility of having Peter live with her full time, otherwise he would not have been sent to the boarding section of the school.

[26] I missed seeing him because I was on a trip to Kampala to pick up the hard copy of my research clearance letter.

[27] As described in chapter 4, CD4 count is used to measure the immune system in HIV-positive patients. The normal range is 500-1,600 cells/mm^3, and <200 cells/mm^3 is AIDS defining. A CD4 count in the single digits indicates an *extremely* compromised immune system and that the patient is at very high risk for opportunistic infections.

that urgent action was needed. On November 4, 2014, we made a special hour-and-a-half drive to pick him up from the boarding school and bring him to Baaliro to be re-admitted. When we met Peter at school he looked miserable. In contrast to the vibrant and talkative child I met in 2012, he was sullen and quiet. He seemed small, thin and frail. In both photos and to the touch, he was bony everywhere – his collar bones, hip bones, shoulder blades, and spine were all prominent, along with bony knees and elbows which emphasized the thinness of his limbs. Fungal rings merged together to cover nearly his entire scalp and a silver-dollar sized patch on his right temple seemed ready to take over his eye. This was only the visible fungus, and he continued to suffer from thrush in his mouth and throat for many weeks.[28] As Mary described it, "the fungal infection has eaten him."

Despite multiple attempts to contact her, the staff were unable to directly inform *Maama*-Peter of their decision to bring Peter back to Baaliro. They told the school's bursar where Peter was going in hopes that when *Maama*-Peter came to check in on him the school would inform her of Peter's whereabouts and she would come to find him at Baaliro, and they continued to attempt to call *Maama*-Peter using the phone number(s) they had on file. They also called Peter's maternal grandfather (who lived near Baaliro), but he said he did not know where *Maama*-Peter was. Somehow, *Maama*-Peter got the word that her child was at Baaliro, and on December 17 (more than a month after Peter had rebounded), she came to the center. However, she only spent one night with her son before leaving. *Maama*-Peter came because she wanted to take Peter to her home for the holidays (Christmas and New Year's), but the staff considered such a request irresponsible, since her home was "deep in the village," far from Baaliro and other medical care.

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[28] These fungal infections are a classic opportunistic infection among HIV-positive patients with a severely compromised immune system. Given his extremely low CD4 count, they were not surprising, and it was expected they would clear as his immunity improved with treatment on ARVs.

Given Peter's fragile medical condition, they refused her request. Rather than stay at Baaliro with her son, or bring other family members to the center, she left him at Baaliro, and Peter was the only child who did not spend any time over the holidays with his family.[29] *Maama*-Peter next visited her son after the Christmas and New-Year's holidays in January 2015 and continued to visit Peter every one to two months. She would usually stay only a day or two, but would wash Peter's clothes before leaving, and at least once she also trimmed his nails and hair. Despite these visits, staff still considered her rude and irresponsible. In addition to her history of failing to find a school for Peter in 2013, they pointed to her lack of a permanent home, her own poor adherence,[30] and her desire to take Peter home before she had a permanent place to stay. Also, they pointed out that she was not helpful around Baaliro[31] and that her visits were suspiciously timed with national holidays. The timing of her visits with holidays implied that she came in anticipation of beef or (better yet) chicken being served, and on at least one occasion when she arrived and discovered that only posho and beans were being prepared, she left almost immediately.

At the end of April 2015, Mary brought Peter to visit *Jjajja*-Peter and learned that when Peter had previously lived with her, he had been taking his medications well and even used to help *Jjajja*-Peter remember to take her ARVs.[32] Apparently, when Peter was with her for the school holiday in August 2014, *Maama*-Peter came and took the boy, which initiated a quarrel

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[29] Peter's maternal grandfather (who lived near Baaliro) refused to allow Peter to stay with him over the holidays, and *Jjajja*-Peter (the paternal great-aunt) lived too far from Baaliro for staff to allow him to return to her care while he was still so sick.

[30] In April 2014, when she visited Peter she was found coughing up blood. She admitted to having stopped taking ARVs two years prior. She was evaluated for TB, but based on a check x-ray, the doctors declared she did not have TB. She agreed to start taking ARVs again at that time, but her adherence remained poor. She complained of side effects and told Joy and I that she would not continue taking the medications.

[31] For discussion of the importance staff placed on being helpful and doing chores at Baaliro see chapter 5.

[32] The fact that the grandmother was herself HIV-positive and taking ARVs was considered a good sign, because it meant that she understood the importance of taking ARVs and of Peter's condition.

between *Jjajja*-Peter, *Maama*-Peter, and Peter's father. *Jjajja*-Peter and Peter's father still had strained relations; however, after Mary facilitated discussion between them, *Jjajja*-Peter agreed to once again take on the responsibility of caring for Peter when he was reintegrated. This time, the plan was that Peter would live with her full-time attending a nearby day school, since the boarding school had "failed completely." Additionally, Peter's father agreed to assist *Jjajja*-Peter with financial support. Mary implored Peter's father to visit the boy while he was at Baaliro and assured *Jjajja*-Peter that Baaliro would involve community leaders to ensure that *Maama*-Peter would not take the boy away again without permission. While they reached this agreement in April (between the first and second school terms), Baaliro staff decided to keep Peter at Baaliro until the end of the year both so that they could ensure that his CD4 count was increasing[33] and so that he could complete the school year without changing schools.

By the time Peter was reintegrated in December 2015, the staff's assessment of responsible guardianship had shifted once again. Neither *Jjajja*-Peter nor Peter's father visited Peter while he was at Baaliro which, according to Mary, demonstrated "a lack of commitment from that side." Meanwhile, *Maama*-Peter continued to visit Peter every few months, began taking her ARVs consistently, and insisted that she wanted Peter to stay with her. The staff were still concerned about her history of lacking a stable home and of "disappearing," so they "gave the mother strict conditions that she had to live in [a village near Baaliro] and that she has to bring the boy for [ARV] refills, which she agreed upon" (email correspondence with Mary, September 30, 2016). Based on the latest report from Mary, both Peter and his mother were

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[33] They only started him on second line ARVs in January 2015 and it usually takes 6-12 months for CD4 counts to increase significantly, especially when they start extremely low.

doing well, living with Peter's maternal grandfather[34] in a town near Baaliro. Peter was healthy and actively attending school, and *Maama*-Peter was also healthy and was earning money selling charcoal. Baaliro's staff remained cautiously optimistic. They had plans to involve *Maama*-Peter in a micro-credit program to improve her economic status, but emphasized that "monitoring at home and counseling is still done so that she can still fulfill her responsibilities over the boy" (email correspondence with Mary, September 30, 2016). Peter's case demonstrates why Baaliro staff put such a strong emphasis on identifying a responsible caregiver, that staff made considerable efforts to identify responsible caregivers, and that they constantly re-evaluated their assessment of whether or not a caregiver was responsible. This case also helps to complexify the notion of responsibility.

8.4 Steepening Landscapes – Increasing Responsibility

While caregiver responsibility had always been a concern for Baaliro, more recently and especially under the authority of the new project coordinator, Lucas, the importance of responsibility grew. As Sister Sally explained, Julien had tried to get caregivers to love their children, but Lucas emphasized getting them to take responsibility, regardless of their affective bond to the children in their care. Baaliro staff, caregivers, and children themselves generally perceived Lucas as being stricter than Julien had been. Staff were also becoming concerned with what they termed "dependency syndrome" appearing among the children who had been enrolled in Baaliro's program for many years. This created a paradoxical situation where, at the same time that Baaliro staff were flattening the landscape of need by extending services to children

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[34] Interestingly this is the same grandfather they contacted when Peter was brought back to Baaliro in 2014 and who had previously refused to allow Peter to stay with him. Although the grandfather clearly knew when Peter was at Baaliro, he never once visited Peter, despite his proximity to the center.

who would not have originally qualified for Baaliro's program (HIV-negative children, younger children, HIV-positive "healthy" children, and outpatient clients), they were also steepening the landscape of responsibility. The ways in which landscapes of responsibility mapped onto the landscapes of need resulted in islands of care, which children and caregivers sometimes had difficulty navigating toward.

Historically, as Sister Sally recalled, "When [Baaliro] started, children were provided with each and everything." While Julien disagreed with the idea that Baaliro provided "everything," he did acknowledge that children initially received more material items – school shoes, towels, and sandals to name a few items they no longer provided.[35] He insisted that guardian participation was considered important from the beginning, but admitted that it may not have been as explicitly emphasized as it was at the time of my fieldwork. Over the years, due to growing concerns of dependency syndrome and a growing emphasis on sustainability coupled with practical constraints, Baaliro had gradually pulled back the services it offered.

First and foremost, the local staff identified a problem with dependency and entitlement among families, which they called "dependency syndrome." They reported that caregivers expected Baaliro to provide for all of the needs of the children. As Sister Sally explained, "once you help someone, they expect you to give them each and every thing." Certain caregivers began to expect and demand that Baaliro cover *all* of the living expenses for the reintegrated children they cared for, and some began referring to the children in their care as "Baaliro's children"

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[35] Presently, children received a much smaller list of items when they arrived, including only: bed sheets, a mosquito net, a bathing basin, and a tooth brush. Over the years Sister Sally discovered that many children, especially those from the villages, did not know how to properly use some of the items she was providing – such as a towel. In the warm climate, most were accustomed to dripping dry.

rather than their own.[36] These sentiments ran counter to Baaliro's idea of children being raised in their communities, by family members, with caregivers taking the primary responsibility. Furthermore, some of the first children enrolled in Baaliro's programs began demanding that "their money" be given to them directly. For example, when they failed out of school, they argued that they should continue to receive money that would have been spent on their school fees and that it should be given to them directly to spend as they wanted. Staff chafed against such demands, and identified dependency syndrome as a problem they faced in their interactions with many children and caregivers. The problematization of dependency was compounded by the ideology of international donors, which emphasized sustainability.

Baaliro's staff's concerns with dependency syndrome were not unique and reflected widespread discourse throughout Uganda. Local and national media often featured stories expressing distress at Uganda's dependency syndrome. On a national level, Ugandans expressed concern with the government's dependency on foreign aid and called NGOs the new colonial power (Anena 2012; Mwesigwa 2011; Zakumumpa 2009). NGOs were often blamed for creating dependency syndrome among their recipients, and dependency syndrome itself was identified as the root cause of poverty (Ladu 2014; Ochola 2007). One report identified more than half of Uganda's population as suffering from dependency syndrome (Mafabi 2005). In many conversations that I had with volunteers and NGO staff, both foreign and local, within and outside of St. Damien's and Baaliro, concerns of dependency syndrome often surfaced.

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[36] Recall that as a consequence of their response to supporting AIDS orphans, the Uganda Women's Effort to Save Orphans (UWESO) also experienced problems with guardians relinquishing their responsibilities for children and saying, "They're UWESO's children now" (K. E. Cheney 2010b).

8.4.1 Nangoma – A Case of Dependency Syndrome

At Baaliro, staff repeatedly brought up the case of Nangoma whenever the conversation moved toward dependency syndrome. Nangoma was one of the first children admitted to Baaliro, along with her sister. Julien had met Nangoma several years prior to the construction of Baaliro, and along with several other children first admitted, Nangoma's case had been the inspiration for Baaliro's construction. She was first admitted to the center in February of 2009 when she was 13 years old and was reintegrated by December of that year. Even prior to coming to Baaliro, Nangoma and her grandmother (*Jjajja*-Nangoma) had gained a reputation for being demanding and ungrateful through their interactions with St. Damien's. After being reintegrated, the social worker's case reports repeatedly mentioned poor school attendance, poor hygiene, and poor adherence, and that Nangoma would lie about going to pick up her medication as an excuse to miss school. By 2012 Nangoma's health was declining, but she refused to be readmitted to Baaliro. Her health continued to deteriorate slowly until Baaliro staff eventually decided to bring her to JCRC's pediatric hospital/clinic just outside of Kampala. There she complained to the JCRC staff that she was abused at Baaliro, yet Baaliro bore the cost of her medical bills which amounted to millions of Ugandan Shillings (thousands of dollars, and far more than Baaliro spent on most children).[37] Most egregiously, after being discharged from the JCRC, Nangoma and *Jjajja*-Nangoma went on a local radio program begging for assistance and claiming that they had no one to help them. This act was viewed by the staff as the epitome of ungratefulness, especially given Baaliro's payment of Nangoma's highly expensive medical care at JCRC and their continued support of her education. Furthermore, Nangoma and *Jjajja*-Nangoma had

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[37] Somewhat interestingly, the staff at JCRC informed me that if Ugandan children come to them *without* a foreign-sponsored organization, they receive care free of charge. But, since Nangoma was brought by Baaliro, they were charged the full rate.

refused to attend any skills training or support groups offered by Baaliro. Throughout my time at Baaliro, Nangoma continued to be a difficult case for the staff. Although she lived in a neighboring community, and her sister attended the Saturday youth group, Nangoma refused to attend. She never reported to Baaliro to pick up her medication refills, but would wait for them to be delivered to her home. On the days when she was to be driven to Kampala for medical appointments, she failed to report to Baaliro as she was told to do and instead would wait for the driver to pick her up from home – thus making everyone late. Toward the end of 2015, *Jjajja*-Nangoma became ill, and a previously unknown maternal aunt appeared to take care of her. Given the long history of deception and manipulation, staff accused Nangoma and *Jjajja*-Nangoma of hiding the existence of this potential caregiver as a way to seem more desperate and to access more resources.

Analyzing Nangoma's case, it is clear that the staff at Baaliro were very concerned with dependency syndrome. Baaliro staff frowned upon Nangoma's strategy of begging for handouts, both because it made their assistance feel unappreciated[38] and because they viewed asking for additional assistance as undermining their goal of producing independently responsible individuals. Staff interpreted Nangoma's failure to travel the short distance to Baaliro to pick up her medications or to meet the vehicle which would take her to Kampala for her doctor's appointments as clear signs of irresponsibility and dependency syndrome. However, one could argue that Nangoma was simply being strategic. She knew that Baaliro staff would eventually deliver her medications, since they were so concerned about adherence, so there was no need for her to spend the time or money to travel to the clinic. Additionally, since her home was only a short distance out of the way along the road to Kampala, it was a waste of *her* time to have to

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[38] For another viewpoint on the importance of clients expressions of gratitude toward patrons see Bledsoe (1990).

travel to the clinic just to backtrack past her home. Nangoma's appearance on the radio program especially makes sense when viewed through the lens of Kiganda ethics of interdependence previously discussed (Scherz 2014). According to these ethics, amassing patrons was neither devaluing nor dehumanizing, and declarations of dependence (and solicitation for patrons) were used as a means to improve one's life. In essence, acquiring a wide range of patrons – "having people" – was a good strategy. Especially in a context in which Baaliro was more clearly defining the boundaries of its services, it is hard to fault Nangoma for seeking additional resources elsewhere. Additionally, we can see Nangoma's strategies as a kind of social navigation – trying to navigate towards islands of care in an ever shifting landscape (Vigh 2009, 2010). While not all Baganda would agree with the way Nangoma went about securing resources, most people who I shared her story with were at least sympathetic of her attempts to amass sponsors; although they also agreed that she should have been more appreciative of Baaliro. I argue that even as her strategies sought to create dependencies with others, they also can be understood as demonstrating her agency and independence (acting separately from Baaliro).

However, we must be cautious about over-analyzing Nangoma's case. In our correspondence Julien rightly emphasized that Nangoma was an exceptional case. In his estimation, *Jjajja*-Nangoma was particularly manipulative and would do anything to get free handouts, but he felt that this was not a reason to let Nangoma (a child) suffer. When he first started helping Nangoma, he determined that he *had* to give her support otherwise she would have died. To Julien, Nangoma and *Jjajja*-Nangoma represented a rare case where it was their nature to be dependent, despite efforts to make them independent and responsible citizens.

Nonetheless, I believe, given how much Nangoma's case upset Baaliro staff and Lucas, it offers insight into the extent of their concern about dependency syndrome.

8.4.2 Responsibilizing – Trickle-Down Responsibility

In order to combat dependency, Baaliro increasingly emphasized caregiver responsibility. School supplies were considered a minimal expense that the responsibilized caregiver should be able to provide. Just as user fees[39] are often charged at health clinics, this was considered a way to ensure that caregivers were involved and committed to their children's education. Staff hoped that by increasing caregiver responsibility from the start, dependency syndrome, such as that observed in Nangoma, could be avoided in the future. However, both as China Scherz (2014) observed in her work and Nangoma's case exemplifies, caregivers often interpreted this as their patrons failing to fulfill their roles. Caregivers frequently requested additional support and were frustrated when Baaliro staff failed to meet their requests, at times accusing Baaliro staff of keeping "their money." In turn Baaliro staff tired of always being asked for more, especially when they, themselves were feeling squeezed by the pressure of budgetary responsibilities.

Baaliro's emphasis on responsibility was not restricted to individual caregivers, but also applied to the organization as a whole. Even as Baaliro provided services, including at times high-cost medical treatment, to among the most vulnerable of populations, the Swiss donors also wanted to support sustainable programs, in the sense of being less reliant on donor support. As a way to help Baaliro become more independent (from donor support), they provided the seed money for several income generating activities (IGAs) at Baaliro. Child Network acquired land

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[39] Hutton (2004) provides an excellent history of the rise of and shifts in the World Bank's user fees policies. User fees, like most neoliberal policies, have their roots in structural adjustment programs (SAPs) in general, and in the Bamako Initiative in particular (UNICEF 2007, 36).

for Baaliro to establish a farm in 2011 and funded the construction of a chicken coop in 2012. Thus, in addition to providing medical treatment at the center, Baaliro was a poultry and produce farm as well. In 2013, Julien and the board of Child Network established a goal that programs cover part of their operational costs from sources other than Child Network, and in 2014 they set the threshold for the goal at 20%. Through the IGAs as well as by obtaining contributions from other donors, Baaliro was supposed to make up the 20% budget gap. In response to this new requirement, staff repeatedly emphasized that when Baaliro started, Julien had explicitly stated he did *not* want Baaliro to get sources of funding external to Child Network. However, from Julien's perspective, St. Damien's had been complaining about not being able to raise funds for Baaliro from the beginning, but when they were told they could fundraise, and in fact would be responsible for finding 20% of operating costs, they then complained that fundraising was too hard. Unfortunately, though perhaps not surprisingly given the odd marriage between medical care and agriculture, Baaliro struggled to maximize the profits of its IGAs, which were likely insufficient to make up the 20% gap, even when functioning at their maximum.

In 2014, due to several strokes of bad luck, Baaliro fell well short of its goal – ultimately raising less than 5% of its budget. The chickens caught a disease and stopped producing eggs. Thieves stole over a dozen chickens and several pieces of farm equipment at night. Poor growing seasons resulted in fewer crops, which not only meant there was less to sell, but also that Baaliro had to purchase more food to sustain the inpatient children. Staff were constantly stressed about the budget shortfall and struggled to find ways to maintain services to the children they served, while at the same time cutting costs. As the end of the year approached, much of the talk in the office centered on the budget. Staff eliminated all "non-essential" services they had been providing to reintegrated children, passing the responsibility and cost of such services on to caregivers. School shoes were out of the question, school supplies went to only the neediest of children, and school lunches were only paid for children who lived far from their schools. At Baaliro, Sister Sally moved the soap from the general storage room next to the kitchen and locked it in her desk so she could keep strict tabs on how the soap was used. She cut the bars into pieces which she rationed to both Dorothy and the children. Additionally, children at Baaliro ate few (if any) eggs,[40] and for several weeks at a time they literally had peanuts for breakfast because the flour for making *chapati* ran out.[41] Ultimately, Child Network stepped in to make up the difference in the budget, but staff did not receive their Christmas bonuses, resulting in poor morale. Meanwhile, Child Network staff, especially Julien and Lucas, could not understand why Baaliro was unable to raise funds from external donors, given that, as Lucas told me many times, "[Baaliro] has everything donors want – children, HIV, IGAs, reintegration rather than institutionalization." The fact that staff had only received minimal training in grant proposal writing and were already overburdened with the responsibilities of daily operations and follow-up visits did not mitigate his optimism.

8.4.3 Onzi's Story – Losing his Footing

Onzi provides an excellent example of a child who lost his footing – or rather his shoes – on the slope of responsibility as the landscape of care became steeper. I first met Onzi in 2012 during his first admission to Baaliro. He was reintegrated at the end of that year, but by September 2013, he had been hospitalized for nearly two months due to a relapse of TB which

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[40] Although they acknowledged eggs' high nutritional content, Baaliro staff conceptualized the eggs as part of the IGAs, rather than part of the children's nutritional rehabilitation. Therefore, only the occasional broken egg was provided to the children, since all intact eggs needed to be sold to try to increase the profits of the IGAs.

[41] Once this *chapati* deficit was prolonged because Dorothy had a wound on her hand which prevented her from making *chapati*, for an additional week or two after the flour arrived.

was almost certainly caused by poor adherence, and he rebounded to Baaliro. Sister Sally described his conditions as critical when he first rebounded, and Onzi stayed at Baaliro through the end of 2015 making him one of the children to stay the longest at the center. He started taking second line ARVs about a month before my arrival in September 2014, because his CD4 count failed to rise even after he had been closely monitored by Baaliro staff for ten months. In addition to the new ARVs, he continued taking TB treatment for several months.[42] Being on pediatric formulation for both second line ARVs and TB treatment, Onzi had a truly impressive pill burden, but he never struggled to take his medications.[43] Despite his underlying health conditions, by September 2014 Onzi had regained his energy and playfulness, and at first glance he did not appear sick, except for having skin rashes. No one actually knew Onzi's age. He appeared the size of a six-year-old, but estimates ranged from nine to twelve years old, and his voice was beginning to crack and deepen (indicating the beginning of puberty). Overall Onzi had good *empisa* (manners/behavior),[44] but he could be at times stubborn and quick to anger. Dorothy constantly berated him for his reluctance to bathe and wash his clothes,[45] but he was, almost certainly, the best eater in the house.

Onzi also loved going to school, and every morning he struggled to jam his small but growing feet into a tiny pair of well-polished shoes. He would stomp and kick his feet into submission, so he could attend school looking "smart." By the end of the first term of 2015, it was not physically possible for him to fit into the shoes, so he folded down the backs and let his

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[42] Onzi received both his TB treatment and ARVs from TASO, and so treatment decisions were not under the direct control of Baaliro's staff or physician.

[43] Onzi took at least a dozen pills per day. While he never resisted taking medications, he was unable to swallow even the smallest pills. He would place the handful of pills in his mouth all at once and chew them before washing them down with water.

[44] For a discussion of the importance of *empisa* see Chapter 5.

[45] This was compounded by the fact that Onzi regularly wet his bed, which also caused him great embarrassment.

heel hang out. By the end of the second term in 2015, his entire heel hung out the back of his shoe, and he balanced on his toes as he walked to school. The staff at Baaliro were well aware that Onzi needed new shoes, but such a purchase was not “in the budget.” School shoes were expensive and children outgrew them quickly. Furthermore, previously staff had found that children often did not wear their shoes to school in rural settings even when they did fit properly and that children did not take good care of their shoes. These practical concerns, combined with the desire to reduce dependency meant that, while Baaliro had provided school shoes in the past, they no longer did so. The provision of shoes had been the responsibility of caregivers since 2013 (presumably when Onzi received the pair he still had). Ironically, given his overall poor hygiene, the one thing Onzi did demonstrate responsibility for was taking care of his ever-shrinking shoes. He diligently cleaned, brushed, and polished them nightly. Once, when the shoe polish ran out and Onzi was sent to bed before the matron returned from her nightly visit to her home and children, he sullenly shuffled to school the following morning in his unpolished shoes.

Unfortunately for Onzi, one of the reasons he spent so long at Baaliro was the difficulty staff had in identifying a responsible caregiver willing to accept him into his/her home in the community. Onzi had rebounded because the caregiver responsible for him, his aunt, had been unable to oversee his twice daily medication regimen due to her job as sugar cane weeder. She rose before dawn and was already in the fields when Onzi was supposed to take his morning dose of ARVs. Staff explained, “Onzi akyalimuto” [Onzi is still [too] young] to take medication independently, or to say it a different way, he could not be responsible himself, so he needed the oversight of a responsible caregiver. Onzi’s father was alive, but did not live with the boy and offered no financial support. Because Onzi had rebounded in such a serious condition, Baaliro staff were adamant about finding a truly responsible caregiver the second time around, and ultimately enlisted the help of neighbors to ensure that he would take his medications at home. Furthermore, they hoped that since Onzi was by this point several years older, he might start to take responsibility for taking his medications himself – but this was more aspirational than expected. Given the low income of his aunt and the failure of his father to offer financial support, it seemed highly unlikely that Onzi's caregivers would be able to afford to purchase a pair of shoes for him, no matter how responsible they were.

Overall, requests for shoes were among the most common requests from children who had been reintegrated. Each time, Mary reiterated that shoes were the responsibility of caregivers. Some caregivers both accepted the responsibility and were able to mobilize resources or save up enough to purchase shoes for their children. However, in the end many children went to school without shoes. In this example, whether or not children need shoes in order to study and stay healthy is less important than the phenomenon that the shoes represent, the phenomenon of responsibility, especially for material provisions, being handed off to the caregiver rather than assumed by the organization.

8.4.4 Defining Adults

The final phenomenon which contributed to the steepening landscape was that the demands of follow-up began to outstrip Baaliro's capabilities. Since opening, Baaliro had continued to add approximately 30 children to their program every year.[46] For the first few years, Mary was able to follow up with children monthly, when they were initially reintegrated, in accordance with Baaliro's plan. However, despite the ever-increasing caseload as more children were reintegrated each year, and despite Child Network's offers to hire additional staff, Baaliro

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[46] Thirty children per year is the organization's stated target, and it was met almost every year, but in 2012, only 16 children were enrolled.

had not yet taken on an additional social worker.[47] By the time I began accompanying Mary on her visits to the field in 2014, she saw most children only three times a year, when she paid their school fees, and she saw some children, those who lived too far away, only once a year. Children who were not in school, either because they were too young to start or because they had failed out of school or quit going, were visited less frequently, if at all. This did not in any way reflect a lack of commitment from Mary, but simply that the logistics of following all 117[48] children living in the community proved to be more than one social worker could handle. Recall from the map depicting Baaliro's children's homes (see Figure 2.1) that many children came from regions distant to the center. Over half of children lived in villages more than 30km from Baaliro, and it took Mary more than 45 minutes to reach the majority of children, even using a 4-wheel-drive pick-up truck. I estimated that travel time alone accounted for at least 25% of Mary's time in any given week, and in the 2015 budget, Baaliro spent more on fuel and transportation than on Mary's salary.

In 2015, the Baaliro staff officially identified a dozen children as "adult (no home visit)." Like readiness for rehabilitation (see Chapter 4), adulthood was not easily defined by any single or even constellation of criteria, exemplifying the fluidity in categories of childhood and adulthood. Baaliro staff took into account an individual's chronological age, participation in school/training, and medical status. The legal age of adulthood in Uganda is 18, and most of the individuals that Baaliro categorized as adults were in their twenties, but one boy was 16 and one girl was 18. However, chronological age alone was not sufficient for Baaliro's definition of

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[47] Child Network repeatedly asked Baaliro if they needed a second social worker, and Baaliro declined the offer for additional staff. Starting in 2016 Baaliro hired a second social worker, but this was after my fieldwork had ended.

[48] This number includes both HIV-positive and HIV-negative, reintegrated and outpatient children who had not been identified as lost to follow-up, transferred to another organization, or dead. It also does not include children being treated inpatient at Baaliro.

adulthood, as exemplified by the fact that six of the children Mary was actively following were 18 or older, and one of the inpatients was 24 years old.

Participation in schooling was another important criterion for Baaliro's definition of adulthood. None of the individuals categorized as adults were attending school. Most had either graduated from or (unfortunately, more frequently) failed out of school and rejected Baaliro's multiple offers of vocational training. Only two of Baaliro's adults had completed and graduated from formal vocational training programs and only two had attended secondary school. However, like age, lack of school participation alone was not sufficient for making a child an adult. At least six children who Mary was following were also not attending school because they were too old, had failed out of school and refused vocational training, or had run away from home.

Lastly, medical status, and in particular adherence, also defined adulthood at Baaliro. Frequently, the individuals Baaliro identified as adults also had discontinued medical treatment; in particular, they had stopped taking ARVs.[49] Whereas when *children* had poor adherence or stopped attending school, Baaliro involved family and even community members to keep children in school and taking their medications, those dubbed as *adults* were deemed responsible for their decisions because (using somewhat cyclical logic) they were *mukulu* (old/adult). As responsibilized citizens, they were no longer children, and therefore did not require protection afforded to children.

Clarke describes how abandonment is the natural consequence of responsibilization (Clarke 2005). Staff, however explained that they were not abandoning adults by emphasizing

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[49] In one case, the adult was re-tested and determined to be HIV-negative, but in all other cases adults were HIV-positive. Seeley (2012)(2012) provides an interesting perspective on patients who unexpectedly test negative after years of being TASO clients (assumed to be HIV-positive).

that they could return to the center to initiate vocational training and/or medical treatment whenever they wanted, and that Baaliro would cover the costs. Thus, the center fulfilled its responsibility to not abandon the children in its care. However, both the medical management and education follow-up were no longer the responsibility of the social worker – but had become the responsibility of the newly minted adults.

This transfer of responsibility from Baaliro to family to child occurred gradually. Therefore, in actuality, the designation of children as adults did little to lighten Mary’s load. She already had not been visiting most of these newly recognized adults for a year or more, and was still (on paper) responsible for visiting 105 children who she was actively following. The labeling change simply made official what had been happening for some time, relieved Baaliro from moral responsibility, and made explaining the status of children easier to donors – especially if they had negative outcomes in the future, which for those who had stopped taking ARVs, seemed likely.

In addition to officially designating some children as adults, Baaliro became stricter in enforcing its school fees policy. The policy officially stated that if a child failed a grade level three times, Baaliro would no longer pay for his/her school fees. However, the policy had not always been strictly enforced. Lucas was adamant that children needed to be responsible and to work hard in school; failing three times in a row was unacceptable and indicated that a child was not serious about his/her schooling. In his opinion there were many children in Uganda who needed school fees, and Baaliro should not spend funds on children who were not at least making forward progress in their education. In some cases, where children had a clear learning disability, Baaliro staff compromised, and parents were responsible for a portion of the child’s school fees. Mary also refused to pay fees for students who did not show up at school. In one case the child’s family brought her to a relative's home for the holidays, and she did not return until the middle of the next term.[50] Mary followed up on such cases and offered to resume paying fees once the child resumed attending, but often this meant the child lost at least a term, if not a year of schooling.

Overall, Baaliro seemed to be returning to their original inclusion criteria when determining which children to continue supporting. Staff seemed to more readily withdraw support from HIV-negative children who were failing in school than from their HIV-positive peers. Similarly, staff seemed to more readily declare HIV-negative children as lost to follow-up than their positive peers (of the nine lost children, seven were negative). When discussing children who were either already lost or who Mary had had difficulty finding, Baaliro staff frequently evoked the child's HIV-status as they decided how much effort to put forth into finding the child. For example, in one of Baaliro's quarterly meetings, after discussing several children who Baaliro had been struggling to locate, Lucas concluded, "upon the negative children I wouldn't dedicate too much effort. We already have a rather tight schedule with the number of children we have here, so it's good that we try, but if, let's say if nothing comes up from this [next] thing, that we don't look further" (transcript of quarterly meeting June 19, 2015). Both Sister Sally and Mary agreed, having themselves previously made similar statements.

Despite their agreement, staff did not make decisions about who to withdraw services from lightly. They were very much aware of children's need for support, but also were responsible to the donors who supported their program. Like governments whose responsibilized "citizen-consumers must make 'reasonable' and 'responsible' choices when consuming public services (rather than abusing or wasting taxpayers' money)," Baaliro staff felt the pressure to not

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[50] Also note Hunleth's (2017) analysis of children traveling to different relatives' homes for the holidays (see also Hunleth et al. 2015).

waste or abuse donor money on children/caregivers who were making unreasonable claims and irresponsible choices (Clarke 2005, 451). In the end, the decision to not try too hard with negative children came down to budgetary concerns, which were dictated by Child Network's (and their donors') desire for sustainability. Since field visits used fuel which was expensive, and Baaliro needed to reduce budgetary expenditures to try to reach their goal of 20% contribution, they decided to focus expensive follow-up on the HIV-positive children who were, after all, originally targeted as Baaliro's recipients. Thus, somewhat ironically, even as the landscape of need flattened to more easily allow some children to enroll in Baaliro's program, the landscape of responsibility steepened to more easily allow others to slide off of the islands of care provided by Baaliro's program.

8.5 Conclusion

Baaliro offers a unique example of the ways in which NGOs define particular kinds of childhood to decide who has access to services and what those services entail. Baaliro was started to provide residential treatment and rehabilitation for HIV-positive children, but over time expanded its services to include HIV-negative malnourished children, outpatient care, and even children with other ailments, as the needs of such children presented themselves to the center. At the same time, Baaliro initially provided more material benefits, but scaled back as concerns of dependency syndrome grew in local, national and international discourse, and as the need for sustainability heightened the importance of responsibility. This sense of responsibility was not only directed at children and families, but also at Baaliro itself as international donors preferred to support sustainable programs. While landscapes of need flattened to be more inclusive of the categories of children who were eligible for services, the landscapes of responsibility became steeper, and the actual services offered grew more restricted, creating a landscape characterized by islands of care. Children and caregivers used a variety of strategies to navigate this ever-shifting landscape, some of which staff found reprehensible, but which were arguably in keeping with a Kiganda ethics of interdependence (Scherz 2014; Vigh 2010). However, some children simply fell off the islands of care as the slopes of responsibility steepened.

In describing these shifting landscapes, my aim is not to critique Baaliro itself. As Peter, Onzi, and Nangoma's stories demonstrate, the children's social situations and medical conditions were complex and dynamic. Baaliro staff work very hard to provide services to children living in difficult and unstable circumstances, and children (and caregivers) similarly used a myriad of strategies and ethical frameworks to navigate these landscapes in order to mobilize support and meet their needs. Rather than critiquing Baaliro or the children and caregivers, I join the many scholars who have criticized the dominance of sustainable development rhetoric (Escobar 2011; M. Green 2000; Hart 2001; Kremer and Miguel 2004; Scherz 2014; Stirrat and Henkel 1997; Swidler and Watkins 2009). Researchers have found that children are the main beneficiaries of social assistance programs, that concerns over dependency syndrome are greater than the empirical evidence supports, and in fact, that social assistance programs are effective and do not contribute to dependency syndrome (CPRC 2011). As Onzi's story highlights, children are also the first to suffer when assistance is withdrawn. I wish to complicate the responsibilization of children and young people, not denying their agency, but recognizing the circumstances which constrain it. In evoking the Kiganda ethics of interdependence, I also want to demonstrate that dependency is not necessarily irresponsible nor disempowering, but is a viable strategy for development and, as Nangoma's story demonstrates, a viable way for children and caregivers to navigate landscapes of need and responsibility. In conclusion, I join the call to reconsider the viability of unconditional aid and the politics of distribution (Ferguson 2015; CPRC 2011).

Conclusion: Caring and Precarity

This dissertation explores the experiences of children living with HIV in Uganda. I began with a scene of children dancing, because it depicted many of the themes which repeatedly surfaced throughout my research. Through their dancing the children were demonstrating their vitality and successful rehabilitation; they were acting not like sick children with HIV, but like "any other child." Through their respectful greetings and thanking Baaliro, the children were demonstrating good *empisa*; they were showing appreciation to the NGO that had helped them and were being responsible recipients of aid. Yet throughout their performance no one was paying the children any attention; just like children's experiences living with HIV have been largely ignored while the successes of eMTCT and the roll-out of ARVs have been celebrated, the children's performance fell into the background of the big event.

In my work, I seek to bring children to the forefront of the analysis in engaging with broader theoretical frameworks of critical medical anthropology and theories of agency. Through thick description of the historical processes which have built the projectified landscape of HIV care generally and pediatric HIV care in particular (Chapter 1) and the physical and organizational structures within which Baaliro functions to provide HIV care to children (Chapters 2 and 4), I have attempted to show the complexity of the context in which children living with HIV access care in Uganda. Within this context, the processes of medicalization and responsibilization interact in at times surprising ways. Although staff relied on biomedical definitions of disease and rehabilitation – such as measuring children's progress with MUAC bands and CD4 count (Chapter 4), focusing on the nutritional properties of food (Chapter 6), and extrapolating the magic of RUTF (Chapter 7) – they also attended to children's developmental processes (Chapter 4) and emphasized the importance of children learning proper *empisa* (manners/behavior) for successful reintegration (Chapter 5) and of children (and caregivers) becoming responsible clients of the NGO (Chapter 8). The tensions between children's vulnerability and children's (at times destructive) agency, between sustainable development paradigms which emphasize responsibility and patronage networks of interdependence, and between the biomedical and social meanings of food and health are amplified when viewed through the lens of children's experiences. In this conclusion, I offer one final example which emphasizes the complexity of children's lives, and interrogates the concepts of responsibility and agency, which appear throughout this dissertation.

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Maama-Wemusa and her sons, Wemusa and Sanyu (11 and 6 years old respectively), had been staying at Baaliro receiving treatment. All were HIV-positive and Wemusa and *Maama*-Wemusa were very sick when they were admitted. For the first few weeks, Wemusa could not stand without assistance and required constant IV-treatments, so the family spent most of their time in the ward at St. Damien's. Though Sanyu was not sick, he was permitted to stay at Baaliro with his mother and older brother since he had no one else to care for him at home and, in accordance with new treatment guidelines, he was starting on ARVs. Wemusa and *Maama*-Wemusa's health had substantially improved after six months, and the family was anxious to return home, so Baaliro staff permitted them to return to their community, even though *Maama*-Wemusa was still underweight. *Maama*-Wemusa had been very active in maintaining and even improving Baaliro. She took it upon herself to create a brick border along the walkway to the shed, to tame the flower garden in the inner courtyard, and to take care of the goats. These gestures required both time and effort and demonstrated her industriousness and vitality to the staff at Baaliro.

Six weeks after the boys had been reintegrated, Sister Sally received a phone call over the weekend about *Maama*-Wemusa. Her husband (*Taata*-Wemusa) was calling to tell her to come and get “omulwadde wo” [your sick one], but refusing to pay to transport *Maama*-Wemusa to the clinic, though they lived only 25km (about a 35-minute drive) from Baaliro. By the next day, when Sister Sally was able to organize transportation to pick-up *Maama*-Wemusa, and they brought her to St. Damien’s, *Maama*-Wemusa was struggling for her life. She had a high fever and labored breathing and was barely able to sit without support. She improved slightly with the IV-fluids administered at St. Damien’s and survived the night, but the next day the clinic staff decided that she needed to be transferred to the main hospital. By the time I went to visit her at the main hospital in the afternoon, she was already dead. The fall-out of *Maama*-Wemusa’s death reverberated for months to come. At her funeral, Godfrey convened a meeting between the family members in attendance and at first everyone agreed that the boys would continue to stay with *Taata*-Wemusa. Traditionally, children are part of their father’s clan, so it seemed appropriate for the boys to stay their father. Wemusa and Sanyu also liked their new school and continuing to attend school there gave them a sense of stability. Unfortunately, it quickly, though perhaps not surprisingly, became apparent that just as he had refused to pay for his wife’s transportation when she was sick, *Taata*-Wemusa would not bring the boys to St. Damien’s when they were sick or for drug refills. He also refused to pay for or otherwise assist with the boys’ transportation to school, and the boys began missing classes because of the distance they had to walk. Godfrey and Mary invested considerable time identifying alternative caregivers, convincing them to accept the boys, and convincing *Taata*-Wemusa to let the boys move away, and ultimately Wemusa and Sanyu moved in with a maternal *jjajja*[1] and his wife who lived near

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[1] It was unclear to me whether this was *Maama*-Wemusa’s half-brother or her uncle.

an urban center much farther from Baaliro (over 45km, and nearly an hour drive), but who promised to provide more support for the boys. In total, Mary and/or Godfrey visited the boys' caregivers eight times within the six months after *Maama*-Wemusa's death.

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Only six weeks prior to her death, *Maama*-Wemusa had been carrying heavy bricks and gardening at Baaliro. Only a month prior we had visited her home, and commented that the boys were adjusting well to their school, that *Maama*-Wemusa was looking strong and healthy (though still thin), and that the home and children were well cared for. Less than a week prior, *Maama*-Wemusa had been seen by a clinician at St. Damien's for an ARV check-up and was doing fine. The rapidity of her demise demonstrated the precariousness of health in particular and of children's home situations more generally. Wemusa and Sanyu's story is only one of multiple cases where the situation of a child who seemed to go back to a stable, loving, supportive home rapidly deteriorated. Yet in other cases, children who the staff were very concerned about at reintegration, thrived when returning home.

The difficulty of predicting the stability of children's home environments highlights the precarity of life, especially in low and middle income countries, and raises questions about the usefulness of concepts of responsibility: What makes an individual responsible? Who is responsible when children do not do well? How does this play out in a precarious context where children and caregivers may have little control over their circumstances, no matter how responsible they try to be? Sustainable development paradigms which emphasize individual responsibility and independence fail to acknowledge the interdependence of social actors and the agency and effort required to acquire and maintain patrons (Ortner 2006a; Scherz 2014). In the end, in sharing children's experiences living with HIV in Uganda, I seek to emphasize the complexity of their lives, to write against sustainable development rhetoric which privileges independence over interdependence, and to hold both children's vulnerability and their agency in frame simultaneously. Additionally, I highlight the importance of children's social navigation – movement within an ever-moving landscape (Vigh 2009). It is easy to see how in such precarious contexts, assembling a network of patrons and building a respectable identity (through *empisa*) remain important strategies for securing one's future (see also Trond Waage (2006) for a discussion of youth's use of patronage and constructing identities of respectability as ways of coping with unpredictability).

Final Thoughts and Recommendations

Anthropological scholarship tends to end at the level of analysis and critique, but I wish to finish this conclusion with some final thoughts and recommendations. As I mentioned at the start of this dissertation, I chose to do my research at Baaliro not because I saw it as a problematic organization, but rather because I was impressed by the staff's attention to not only the immediate needs of child rescue (rehabilitation), but also their recognition of the importance of connecting children to their communities (reintegration) and their long-term commitment to children once they were sent home (follow-up). More than most foreign funded organizations (especially most children's homes), Baaliro was committed to being culturally sensitive and to recognizing children as part of their families and communities. I have great respect for the founders and staff, and for their commitment to helping children and running what they envision as a model program for HIV rehabilitation and reintegration. However, even as they recognized children's need to be connected to their social networks, negotiated a liminal identity as hospital/home with sick/healthy children (Chapter 4) and worked to prepare children for reintegration so that they would be treated like “any other child” (Chapter 5), Baaliro still tended to overemphasize biomedical aspects of rehabilitation (Chapters 6 and 7) and uncritically endorse processes of responsibilization (Chapter 8). I direct my critique not toward Baaliro itself, but to the dominance of sustainable development rhetoric (Chapter 8).

I initially direct my recommendations to Baaliro, and then towards those implementing sustainable development paradigms more generally. One of the reasons why staff may have relied on biomedical markers of rehabilitation, and especially the nutritional properties of food (Chapter 6), could have been to protect themselves from becoming emotionally involved in situations which they could not change. Staff often told me they did not have the training, nor the resources, to adequately address children’s mental and social problems. I would therefore encourage Child Network to consider hiring an additional staff member with culturally-sensitive training in addressing children’s mental health. Child Network could also increase the social support provided to caregivers such as providing caregivers the opportunity to attend workshops (where they can network with one another) and providing them with start-up funds for business opportunities. While there still may be little that Baaliro can do to directly intervene in situations of marital distress, at least providing caregivers with such social and economic support could help to stabilize caregivers’ financial situations and give them a source for social support.

More generally, Child Network should abandon the budgetary definition of sustainable development. The time, effort, and energy that staff spend trying to make Baaliro’s income generating activities successful could be better directed towards attending to the social and emotional needs of children in its care. While small scale agriculture (such as the gardens directly behind Baaliro and keeping a handful of goats/chickens) could provide children with an opportunity to learn useful skills, maintaining hundreds of chickens and a distant farm detracts attention from what Baaliro does best – rehabilitating and reintegrating children with complex medical conditions. Additionally, by embracing the Kiganda ethics of interdependence, Baaliro could meaningfully position itself as a patron, avoiding the development of dependency syndrome, but also providing meaningful and lasting support to its clients.

Overall, I join a long line of scholars who seek to shift the discussions surrounding sustainable development, which currently sees dependency as harmful and focuses on the need to construct independent responsible actors, toward recognizing the power of interdependence and seeing the process of forming dependencies as active and negotiated. Perhaps rather than asking if a project is sustainable, we should be asking if it making a positive impact – and if so looking for ways to engage with it. Life itself is not sustainable without constant inputs, and health is precarious – we are always just one injury or sickness away from being unhealthy. Such a perspective also draws attention to the structural and social determinants of health, and cautions against the linear extrapolation of magic bullet interventions, no matter how powerful their magic seems to be.

Does this mean building infrastructure or providing severely malnourished children with RUTF? Does this mean empowering caregivers to provide for their children or paying for children's school supplies directly? Does this mean treating children with HIV as having special needs or treating them "like any other child?" Does this mean focusing on the prevention of mother-to-child transmission or treating children who are already infected? Does this mean focusing on children's vulnerability or their agency? In every case, my response is, "yes." These questions phrased as either/or, need to be reframed as statements of both/and.

Epilogue

On December 10th, 2016, a little more than a year after I had completed this research, Thierry sent me a message via Facebook:

> Hello Colleen, greetings, hope you [are] doing well. This [is] sadly to let you know that we have lost everything of [the St. Damien's] you know. The new standard gauge Railway is passing through all our buildings, right from [Baaliro], up to my office. We are waiting for valuation so that we can relocate to another site. The land right now is very expensive we [are] likely not to get a good site nearby. Pray for us. Kind regards, [Thierry]

It remains unclear how much compensation St. Damien's/Baaliro will receive, if it will be enough to re-build, where/when they will re-locate, and how they will continue to provide services to their clients in the interim.

Appendices

List of Appendices

Appendix A: Terminology

CD4 count	A CD4 count is lab test that measures the number of CD4 T lymphocytes (CD4 cells) in a sample of blood. In people with HIV, it is the most important laboratory indicator of how well the immune system is working and the strongest predictor of HIV progression. A normal range is 500-1,600 cell/mm^3. A lower CD4 count indicates greater susceptibility to opportunistic infections. A count of less than 200 is AIDS defining (aids.gov 2016).
g-nut (groundnut)	Groundnuts refer to peanuts and peanut-like leguminous crops that mature and ripen underground as well as specific kinds of roots and tubers. In Uganda g-nut typical refers to peanut (*Arachis hypogaea*).
IV	An apparatus used to administer a fluid (such as medication, blood, or nutrients) intravenously (directly into a patient's blood). Also, called a "drip."
murram	laterite (clayey material) used for road surfaces and in brick making
NG-tube	Nasogastric tube. A flexible tube made of rubber/plastic that is passed through the nose and down through the nasopharynx (back of the throat) and esophagus into the stomach. Allows for the administration of food/medication directly into a patient's stomach.
orphan	A child (under the age of 18) whose parent (single orphan) or parents (double orphan) have died.
tarmac	Paved road
Tinea capitus	Fungal infection on the head/scalp (a.k.a. ringworm)
vertical transmission	Transmission of an infection from a mother to her child during pregnancy, childbirth, or breastfeeding
WHO clinical staging	The clinical staging and case definition of HIV for resource-constrained settings were developed by the WHO in 1990 and revised in 2007. Staging is based on clinical findings that guide the diagnosis, evaluation, and management of HIV/AIDS, and it does not require a CD4 count. This staging system was used in many countries to determine eligibility for antiretroviral therapy, particularly in settings where CD4 testing was not available. Clinical stages are categorized as 1 through 4, progressing from primary HIV infection to advanced HIV/AIDS (AETC NCRC 2014)

Appendix B: Luganda and East-African Language Glossary

Word	Meaning	Origin
abaselikale	CD4 count, in the context of HIV care (literally "soldier")	Luganda
akawuka	microbe (virus, bacteria, fungus), often used to refer to HIV (although to specify HIV one must use the complete phrase "akawuka ka siliimu/mukenenya") (literally "small insect")	Luganda
akyalimuto	he is still [too] young	Luganda
bazungu	Foreigners (Luganda plural of muzungu)	Luganda
-bi	bad	Luganda
boda (boda)	motorcycle taxi	East African English
chapati	unleavened flatbread, originally from India	East African English
eddagala	medicine	Luganda
eddwaliro	hospital or clinic	Luganda
eka	home	Luganda
emirimu	work	Luganda
empafu	a kind of olive - *Canarium schwinfurthii*	Luganda
empisa	culture, discipline, morals, custom, habit, conduct, manners (see Ch 4)	Luganda
emmere	food (often refers to staple starches)	Luganda
emmere eleeta amaanyi	carbohydrate (literally food [which] brings energy/strength)	Luganda
emmere ezimba omubiri	protein (literally food [which] builds the body)	Luganda
ennyumba	house	Luganda
entuntunu	gooseberries - *Physalis minima*	Luganda
ensenene	fried grasshoppers – a seasonal delicacy	Luganda
enva	sauce	Luganda
futbol	football (or soccer only in American English)	East African English
ffene	jackfruit – *Artocarpus heterophyllus*	Luganda

Word	**Meaning**	**Origin**
jjajja	grandmother, grandfather, great-aunt, or great-uncle (maternal or paternal); may also refer to any elderly person	Luganda
kabalagala	fried banana ‘pancakes’	Luganda
kikomando	sliced *chapati* and fried beans	Luganda
maama	mother or maternal aunt; may also refer to any female taking care of a child	Luganda
matatu	minivan taxis which follow a fixed route (originally designed to carry 14 passengers, frequently carry 18+ passengers, especially in rural areas)	East African English
	a two-player Ugandan card game	Luganda
mandazi	fried bread, often translated as “doughnut”	Luganda
matooke	cooking banana (similar to plantain)	Luganda
mpola	slowly	Luganda
	often in used in phrase “mpola mpola” = “slowly-by-slowly” (little by little)	
mugole	bride or groom	Luganda
mulwadde	sick person	Luganda
mulamu	healthy person	Luganda
mukenenya	wasting [disease] (AIDS)	Luganda
mukene	small dried silver fish (eaten as a snack or cooked in sauce)	
mukulu	old/adult/mature	Luganda
musawo	clinician (including doctor, nurse, medical professional, traditional healer, social worker) (singular- *omusawo*, plural – *abasawo*)	Luganda
mwana	child (singular – *omwana*, plural – *abaana*)	Luganda
muzungu	foreigner, literally translated as “wanderer”	Kiswahili/ Luganda
-muto	young/immature	Luganda
-lungi	good	Luganda
neera	again	Luganda
Ndeeka!	Leave me [alone]!	Luganda
obulamu	life	Luganda
obumpwakipwaki	snacks	Luganda
oku-bazayo	to reintegrate (literally to return them there)	Luganda

Word	**Meaning**	**Origin**
oku-faayo	to be concerned with, to care about	Luganda
oku-goba	to chase away, to exile, to evict, to defeat	Luganda
oku-jjanjaba	to rehabilitate (literally to treat [medically], to care for [medically], to nurse)	Luganda
oku-kuuma	to keep, to take care of, to protect, to foster	Luganda
oku-koowa	to tire of	Luganda
oku-kwatagana	to grapple with one another	Luganda
oku-lya	to eat	Luganda
oku-loopa	to inform against or to tell on, also to accuse, to blame	Luganda
oku-pima	to measure	Luganda
oku-tya	to fear, to dread	Luganda
oku-vuma	to abuse (verbally such as an insult or curse)	Luganda
oku-wona	to heal, to cure	Luganda
oku-wulira	to hear, to listen, to obey, to pay attention also to feel (ex. I feel bad/sick), to smell (ex. It smells bad/good)	Luganda
oku-yiga	to learn	Luganda
okw-agala	to like, to love, to want, to need	Luganda
pilau	rice pilaf	Luganda
plumpy	Plumpy'nut or any other RUTF	Luganda
posho	Commonly used word in Uganda for a staple dish made of maize flour cooked in water until it achieves a dough-like consistency. Ugandan *posho* is typically cooked longer and thus is stiffer than the similar dish served in surrounding regions which goes by the name *ugali* [Kiswahili]. The word *posho* is derived from the "portions" (daily rations) given to laborers and soldiers working for British during colonial times (Iliffe 1979; Oxford University Press 2017). Ugandan local languages have their own unique words for posho including *kawunga* in Luganda and *bando* in Lusoga.	Ugandan English
rolex	fried egg omelet rolled in *chapati* (literally "roll-eggs")	Ugandan English
Saagala.	I don't like/love/want/need.	Luganda
siliimu	slim disease (AIDS)	Ugandan English

Word	Meaning	Origin
sumbusa	Fried triangular pouch most often stuffed pigeon peas. Similar to Indian samosa, but locally distinct in seasoning. Less common fillings include ground beef, fish, chicken, and rice.	Luganda
taata	father or paternal brother	Luganda
takisi	Luganda word for matatu (minivan taxi)	Luganda
Vaayo!	Go away!	Luganda

Appendix C: Notes on Luganda Alphabet, Orthography, and Pronunciation

Luganda orthography was standardized in 1947 at the All-Baganda Conference (Ssemakula 2017). There are a number of resources available for a complete explanation of Luganda orthography, grammar and pronunciation (Chesswas 1974; Kamoga, Stevick, and FSI 1968; Ssemakula 2017), however, for the purposes of assisting the reader of this dissertation, I present a more user-friendly explanation of Luganda pronunciation, as described in the *An Introduction to Survival Luganda* produced by the Peace Corps Uganda and in the *Luganda Language Manual*[1] used by City Language Center (Byakutaga et al. 2008).

Luganda predominantly uses the English Alphabet. However, there is no letter Q or X, and the Luganda alphabet additionally has the letter ŋ (which is often written as ng') and ny (which for orthographic purposes counts as a single letter). Consonants are pronounced the same as (or very similar to) English letters with a few notable exceptions as described in this table:

Consonant	Pronounced	As in	Notes
b	always a soft b		similar to Spanish v
c	ch	church	never a hard k
gi	ji	jeans	Otherwise g is pronounced as a hard g (garden)
ki	chee	cheese	otherwise k is pronounced as in English (skit)
ky	ch	chair	kyi does not exist in Luganda
l and r	l	load	Although technically r is written after e and i, and l is used in all other cases, l and r are commonly interchanged in spelling.
ny		lasagna	
ŋ (ng')	back of the mouth ng	singing	
ng	front of the mouth ng	finger	

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[1] Also, originally produced by the Peace Corps Uganda, but printed without a date, authorship, or other citation information. This manual is unavailable online, but City Language Center maintains a copy which can be re-printed and purchased by students.

Doubling a consonant denotes that it is pronounced with emphasis and/or there is a delay on the consonant while it is being pronounced.

Luganda has five vowels and three diphthongs. The vowels (a, e, i, o, u) are pronounced roughly the same as in Spanish, or Japanese. Vowels may be pronounced as short or long sounds. A double vowel denotes prolonged pronunciation. There are only three diphthongs in Luganda.

Vowel	**Pronounced**	**As in**
a	ah	father
e	eh	egg, they
i	ee	see
o	oh	open, toe
u	oo	sue, boo

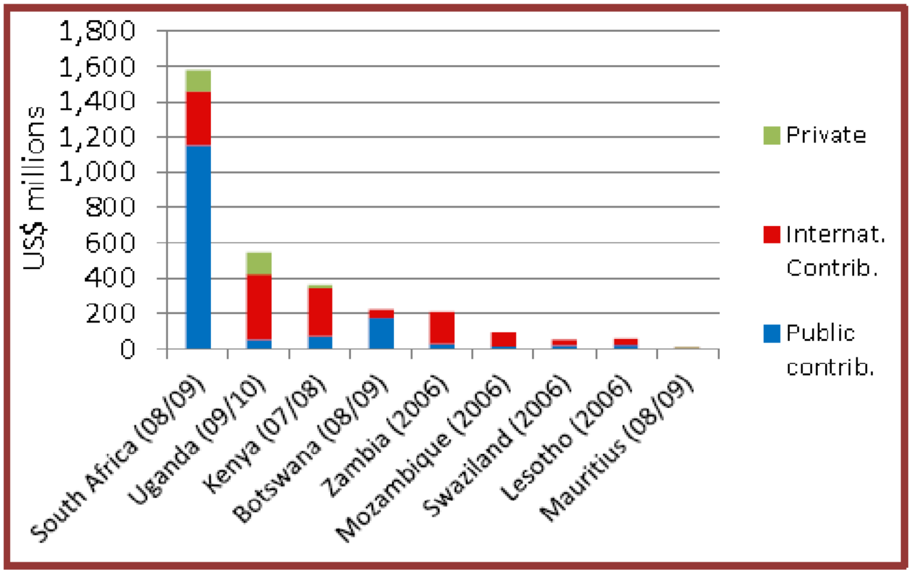
Diphthong	**As in**
ai	height
ei	reigh
oi	oil

Luganda has two tones, but (thankfully) tones are not written. My language instructors assured me that it is possible to speak and understand Luganda without tones (though being aware of them improves comprehension and communication, and distinguishes a native from a non-native speaker).

Appendix D: Regional Comparison Figures

These Figures are reproduced from the *National AIDS Spending Assessment* (UAC 2012c). Page numbers where the figures can be found in the original document are in brackets.

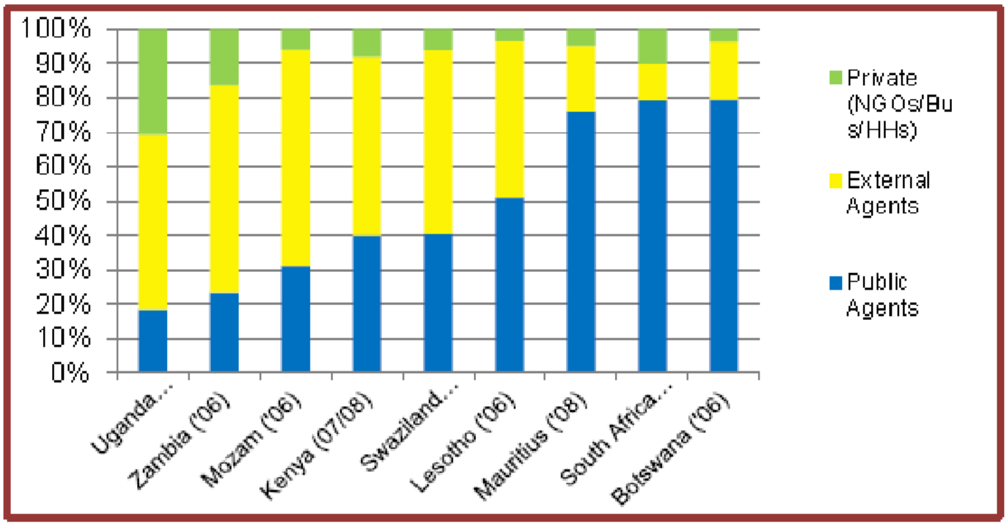
Figure 20: Regional Comparison of HIV/AIDS Funding Levels and Sources



Source: CEGAA (2012) Regional Comparisons for HIV/AIDS Spending

[62]

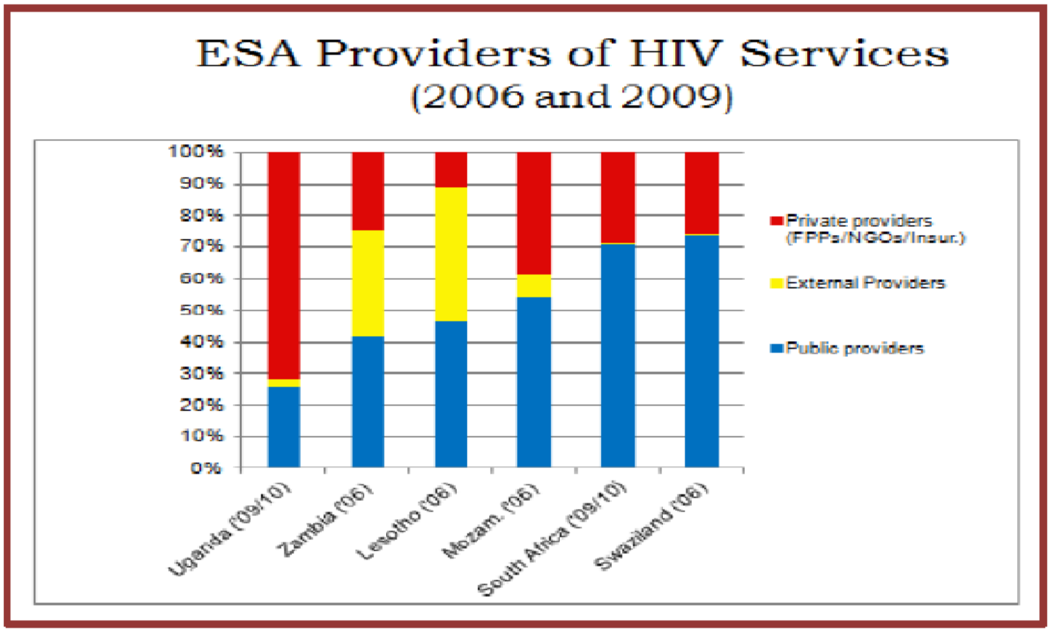
Figure 22: Regional NASA Comparison of Spending by Financing Agents



Source: CEGAA (2012) Regional Comparisons for HIV/AIDS Spending

[64]

Figure 23: Regional NASA Comparison of Providers of Services



Source: CEGAA (2012) Regional Comparisons for HIV/AIDS Spending

[65]

Appendix E: Staff Members Referenced in Dissertation

Name[1]	Job Title	Organization
Sister Sally	Project Manager Co-Founder	Baaliro St. Damien’s
Julien	Founder	Child Network
Lucas	Project Coordinator	Child Network
Mary	Social Worker	Baaliro
Dorothy	Matron	Baaliro
Sadat	Handyman	Baaliro
Joy	Research Assistant	n/a
Thierry	Executive Director	St. Damien’s
Godfrey	Community Liaison	St. Damien’s (Baaliro)
	Doctor (Pediatrician)	St. Damien’s and Baaliro
	Nurse midwives (2)	St. Damien’s and Baaliro
	Driver	St. Damien’s
	Counselor	St. Damien’s
	Nutritionist	ECCH and Baaliro

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[1] *All names are Pseudonyms.*

Appendix F: Primary Organizations Named in Dissertation

Organization Name[1]	**Description**
Baaliro	Rehabilitation center for children with HIV and malnutrition, which also provides support for reintegrated children. (Primary field site)
Child Network	Swiss founded and funded NGO, which supports Baaliro, and several other service projects in Uganda. Child Network is also intimately involved in the daily operations of Baaliro.
St. Damien’s Health Care Services	Locally founded NGO, which has many HIV-related programs as well as a 24-hour health clinic. St. Damien’s sees Baaliro as one of its (many) programs.
St. Anthony Orphanage	German founded orphanage, which now functions as a boarding school and training center for micro-credit and income generating activities programs.
East-Central Children’s Hospital (ECCH)	Government pediatric hospital. Provides inpatient care for any children in the region requiring hospitalization, and has an outpatient HIV clinic.
ECCH Nutrition Clinic and Ward	Located at ECCH, the nutrition clinic provides both inpatient and outpatient nutritional rehabilitation. It is located on ECCH grounds, but both registration and the ward are separate from the rest of ECCH.
The AIDS Service Organization (TASO)*	Country-wide AIDS service organization. Provides outpatient HIV-clinic.
Joint Clinical Research Center (JCRC)*	Historically one of the first centers to offer ARVs to patients in Uganda. JCRC clinics are the premier HIV/AIDS treatment hospitals/clinics in Uganda and provide treatment in accordance with international standards. The central office is in Kampala, but it has several satellite sites.
JCRC-Kakira*	A satellite site of JCRC that was once located on Kakira sugar plantation, near Jinja, but is now closed. This site was one of the first to offer pediatric ARVs in the region.
JCRC-Lubowa*	The Pediatric center of JCRC that was located in Lubowa, between Kampala and Entebbe, at the time of this research.

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[1] *All names are pseudonyms, unless indicated by an asterisk (*)*

Appendix G: St. Damien's Programs as Reported in 2014 Annual Report

Medical Care	Clinical Care	24-hour clinic (inc. pharmacy, lab, inpatient ward)		2,544	Outpatients
		Maternity Care	Antenatal Care	331	Mothers
				11	Positive
			Delivery	164	Births
				29	Mothers positive
				0	Babies positive
	HIV Clinic	HIV-positive Clients	Newly enrolled (2014)	196	Clients
			ART[3] (since 2008)	2,589	Clients
			ART (currently active)	1,947	Clients
			Pre-ART (currently active)	400	Clients
			Deaths (2014)	14	Clients
		Community Based Care		4	Locations
				>300	Clients
Awareness and Sensitization	HIV Prevention	HIV counseling and testing	Facility based	3,536	Tested
				391	Positive
			Community based	9,479	Tested
			(inc. moonlight, corporate)	204	Positive
		Male Circumcision	(all outreach)	405	Men
		Condom distribution	(all outreach)	166,641	Condoms
		Community Education and Trainings	Village health teams	62	Teams
			Peer educators	58	Peers
			STAR[1] Trainings	65	Trainings
				1,400	Participants
	HIV Political Advocacy	Advocacy meeting with community leaders (LC1[2], counselors, religious leaders, etc.)		1,800	Leaders
		Reactivation of District and Sub-county AIDS coordination committees		6	Sub-counties
Community Programs	Economic Strengthening Programs and Trainings*	Village Savings and Loans Associations*		41	Groups
				932	Members
		Social Insurance Schemes		89	Premiums paid
		Small Business Trainings (Financial literacy and skills for starting IGAs[4])*		>200	People
		Apprenticeship (hairdressing, auto mechanics, carpentry)		12	Youth
		Farmer Field School (Demonstration farm)		66	Farmers
		Backyard Gardening (Training)*		68	Beneficiaries
		Nutrition, Cooking, and Sanitation Education and Demonstrations*		292	Households

Appendix G: St. Damien’s Programs as Reported in 2014 Annual Report

Special Groups	Grand-mothers	*Jjajja*’s Support Groups (participants also receive clinical care, school fees and supplies for grandchildren)		300	Grandmothers
		New Homes		9	Homes
	Youth	Saturday Youth Group		~200	Children/month
		HIV-positive children in Youth Group		~50	Children/week
		OVCs[5] school fees and supplies		300	Children
Other Programs	Baaliro	Child Rehabilitation	New children	29	Children
			Total on ART	92	Children
			Total on Pre-ART	2	Children
	New Construction	Pediatric Ward	Completed, not operational – funded by foreign donors		
		Incinerator	Completed, operational – funded by foreign donors		
		Playground	Completed, operational – funded by foreign donors, St. Damien’s, and a local NGO		
		Surgical Theater	Construction Begun – funded by St. Damien’s		

**Indicates programs that are part of the SCORE program – see Chapter 2 for more information.*

[1] *STAR – Societies Tackling AIDS Through Rights. “These training involve adults learning and describing the community identifying and analyzing HIV related issues… During these meetings, members are informed of how they can address issues of sexual and gender based violence, alcohol and drug abuse, gender inequality, early and polygamous marriages, and prostitution in their communities in order to reduce HIV infection fueled by such drivers.*

[2] *LC1 – Local Chairman 1*

[3] *ART – Antiretroviral Treatment*

[4] *IGAs – Income Generating Activities*

[5] *OVCs – Orphans and Vulnerable Children*

Appendix H: Comparisons Between HIV-Positive and HIV-Negative Children Enrolled in Baaliro’s Program

A total of 188 children had ever been enrolled in Baaliro’s program since it started in December 2008 until the conclusion of my fieldwork in September 2015. Nearly three-quarters of children enrolled were HIV-positive (137/188 [73%]), but HIV-negative children differed from HIV-positive children in several important ways, which are the focus of this appendix (see Table H.1).

Age

The average age at enrollment was 8.0 years, with HIV-positive children averaging 9.7 years and being significantly older than HIV-negative children who averaged 3.6 years (t(186) = 7.931, p<0.001). Figure H.1 visually depicts the distribution of children’s ages at their enrollment in

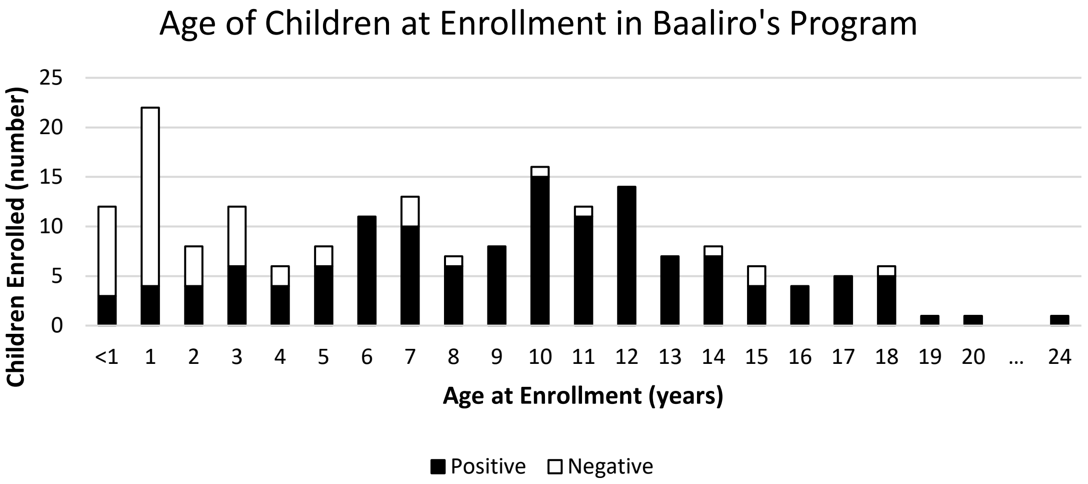

Figure H.1 Graph of Age of Children at Enrollment in Baaliro's Program – Comparison between HIV-Positive and HIV-Negative Children
This figure visually depicts the distribution of children’s ages at their enrollment in Baaliro’s program. The median age at enrollment was 8.0 years, with HIV-positive children having a median age of 10.0 years, and HIV-negative children having a median age of 1.7 years. Thus, HIV-negative children tended to be much younger than HIV-positive children at the time of their enrollment in Baaliro’s program.

Baaliro’s program according to their HIV-status. The majority of HIV-negative children were under the age of two, whereas the majority of HIV-positive children were 10 years old or older. Thus, HIV-negative children tended to be much younger than HIV-positive children at the time of their enrollment in Baaliro’s program.

Gender

The children were roughly evenly split between males (48%) and females (52%), and despite a higher observed percentage of females among HIV-negative children (58%) compared with HIV-positive children (50%), the difference was not statistically significant ($\chi^2(1, N=188) = 1.257, p=0.262$).

Relationships with other Children

Among the children enrolled, 42 of them were related to one-another. There were 20 sibling pairs (seven of whom were twins) and one pair of cousins (their mothers were sisters). Six out of the seven pairs of twins were HIV-negative, and 39% (20/51) of HIV-negative children were related to one another vs. only 16% (22/137) of HIV-positive children. This is not surprising given that the main reason for HIV-positive children to be enrolled in Baaliro’s program was malnutrition, and that twins are more at risk for malnutrition and for dying from malnutrition (Jaffar et al. 1998; Magadi 2011).

Table H.1: Demographics of Children Enrolled in Baaliro's Program – Comparisons Between HIV-Positive and HIV-Negative Children

		Total	HIV-Positive	HIV-Negative	p-value
Age at enrollment		(n=188)	(n=137)	(n=51)	
(mean years ± SD[1])		8.0 ± 5.4	**9.7 ± 4.8**	**3.6 ± 4.3**	**<0.001^**
(median years)		8.0	10.0	1.7	
Gender		(n=188)	(n=137)	(n=51)	
(n, %)	Male	90 48%	69 50%	21 41%	0.262*
	Female	98 52%	68 50%	30 58%	
Relatives Among Enrolled Children	Pairs of Siblings	20	10	10	
	Pairs of Twins	7	1	6	
	Pairs of Cousins	1	1	0	
	Total Number	42	22	20	
Enrollment		(n=188)	(n=137)	(n=51)	
(n, %)	Inpatient	152 81%	**119 87%**	**33 65%**	**0.001***
	Outpatient	36 19%	**18 13%**	**18 35%**	
Program Category		(n=188)	(n=137)	(n=51)	
(n, %)	Following	105 56%	75 55%	30 58%	0.741†
	Dead	34 18%	28 20%	6 12%	0.205†
	Transferred	17 9%	11 8%	6 12%	0.406†
	Adult	12 6%	12 9%	0 0%	0.038†
	Inpatient	11 6%	9 7%	2 4%	0.731†
	Lost	9 5%	**2 1%**	**7 14%**	**0.002†**
Time Spent Inpatient		(n=144)	(n=113)	(n=31)	
(mean days ± SD)[2]		219 ± 236	**248 ± 255**	**114 ± 93**	**0.005^**
(median days)		159	181	90	
School Attendance		(n=145)	(n=107)	(n=38)	
(n, %)[3]	Attending	88 61%	**73 68%**	**15 39%**	**0.002***
	Not Attending	57 39%	**34 32%**	**23 61%**	
Reasons for Not Attending School		(n=57)	(n=34)	(n=23)	
	Underage	35 61%	**12 35%**	**23 100%**	**<0.001†**
(n, %)[4]	Dropped-out	13 23%	**13 38%**	**0 0%**	**0.001†**
	Other	9 16%	**9 26%**	**0 0%**	**0.008†**
Years Behind in School		(n=120)	(n=107)	(n=13)	
(mean years ± SD)[5]		5.6 ± 3.1	5.8 ± 3.1	4.1 ± 2.2	0.057^

Table H.1: Demographics of Children Enrolled in Baaliro's Program – Comparisons Between HIV-Positive and HIV-Negative Children

		Total		HIV-Positive		HIV-Negative		p-value
Orphan Status		(n=171)		(n=128)		(n=43)		
	Maternal Orphan	23	13%	20	16%	3	7%	0.199[†]
	Paternal Orphan	34	20%	29	23%	5	12%	0.129[†]
	Double Orphan	45	26%	40	31%	5	12%	0.015[†]
	Non-Orphan	69	40%	**39**	**30%**	**30**	**70%**	**<0.001**[†]
Caregivers' Relationship to Children		(n=180)		(n=131)		(n=49)		
	Mother	48	27%	32	24%	16	33%	
	Step-Mother	1	1%	1	1%	0	0%	
	Father	19	11%	14	11%	5	10%	
	Both Parents	17	9%	13	10%	4	8%	
	Grandmother	34	19%	23	18%	11	22%	
	Grandfather	2	1%	2	2%	0	0%	
	Both Grandparents	8	4%	5	4%	3	6%	
	Aunt	28	16%	22	17%	6	12%	
	Uncle	6	3%	6	5%	0	0%	
	Sister	4	2%	4	3%	0	0%	
	Brother	2	1%	2	2%	0	0%	
	Institution	8	4%	4	3%	4	8%	
	Self	3	2%	3	2%	0	0%	

[1] *Standard Deviation*

[2] *Outpatients are excluded from this calculation. In addition, this does not include the eight children who were on their first admission (being treated inpatient, and having never been reintegrated) nor the additional days rebounded for the three children who were on their second admission as of September 2015.*

[3] *School Attendance excludes children who were dead or lost.*

[4] *Other includes sick, mental disability, and graduated. Two HIV-positive children fell into each of these categories.*

[5] *Data include children who died or were lost, based on years of school attendance and age at time of death/loss. Those children who had never attended school because they were underage or had a mental disability were not included in calculation. Data were missing for 31 children (16 HIV-positive and 15 HIV-negative).*

[6] *Recall that single orphans are defined as children who have lost only their mother (also called maternal orphans) or only their father (also called paternal orphans), and double orphans are defined as children who have lost both parents.*

* *Pearson chi-square, significance set at p<0.05*

^ *Independent samples t-test, significance set at p<0.05*

[†] Fisher's exact test of post-hoc pairwise comparison. Chi-square was performed to detect significant differences in distribution. Post-hoc Fisher's exact test was used (due to small sample size) for comparison of the value of each nominal variable vs. the sum of all others. Applying the Bonferroni correction p must be <0.0167 when there are 3 nominal variables, p must be <0.0125 when there are 4 nominal variables and p must be <0.008 when there are 6 nominal variables to be significant at P<0.05 level.

BOLD indicates statistical significance

Enrollment and Program Categorization

HIV-negative children were significantly more likely to be enrolled as outpatients than HIV-positive children (35% vs. 13%, $\chi^2(1, N=188) = 11.783$, p=0.001). Once enrolled, the distribution of children by program category differed between HIV-positive and HIV-negative children ($\chi^2(5, N=188) = 18.822$, p=0.002). In post-hoc analysis the only statistically significant difference in categorization was being declared lost (see Table H.1).[2] Figure H.2 depicts children's categorization in Baaliro's program, and includes both HIV-negative and HIV-positive children.

The majority of children who had ever been enrolled in Baaliro's program were being followed-up with as of September 2015. Both HIV-positive children and HIV-negative children were being followed at similar rate (55% vs. 58% respectively). Many more HIV-positive children had died than HIV-negative children, and the death rate among HIV-positive children was 20% (28/137) vs. only 12% (6/51) among HIV-negative children, although this difference was not statistically significant (p=0.205). This trending rate difference may reflect the medical complexity of treating HIV-positive children vs. HIV-negative children as well as the severity of the children's illness at the time of their enrollment.

All of the children declared as adults were HIV-positive, and HIV-negative children were more likely to be declared as lost than HIV-positive children (14% vs. 1%, p=0.002). The former likely reflects the fact the HIV-positive children were significantly older than HIV-negative children, whereas the latter may indicate that staff more readily declared HIV-negative children

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[2] Post-hoc analysis using Fisher's exact test (due to small sample size) was done to compare the value of each program categorization vs. the sum of all others. Applying the Bonferroni correction p must be <0.008 when there are 6 nominal variables to be significant at P<0.05 level.

as lost, but put forth more effort to locate HIV-positive children with whom they had lost contact. I discuss the reasons behind these phenomena in more detail in chapter 8.

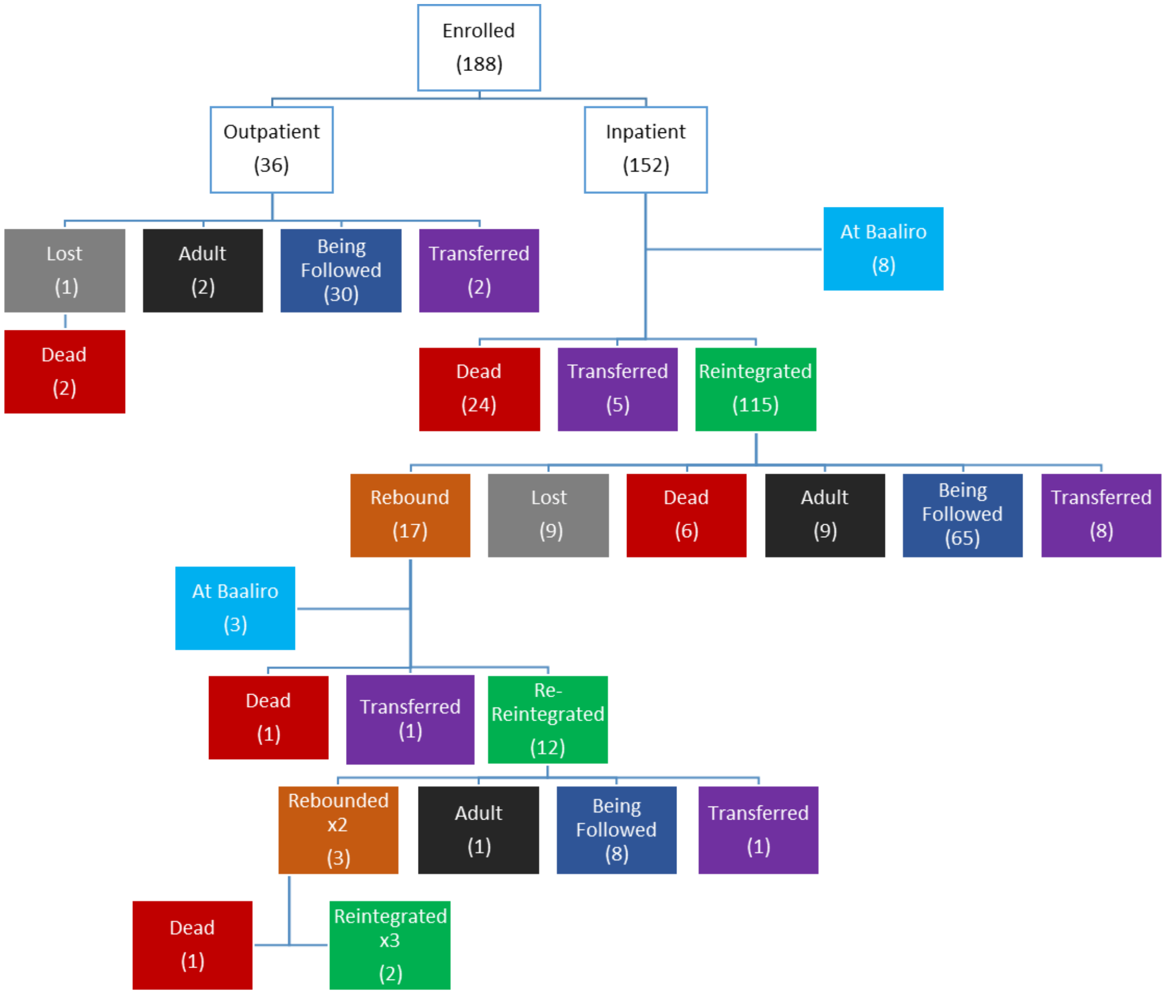

Figure H.2 Children's Categorization in Baaliro's Program
The bottom row in this chart indicates the children's categorization as of September 2015. It is possible to follow a child's pathway from enrollment to their current status via this flowchart. Number of children in each category is indicated in parentheses.

Time Spent Inpatient

HIV-positive children on average spent more time inpatient than HIV-negative children (t(142) = 2.859, p=0.005). The strength of this correlation held, even when the exceptional cases of the three children with the longest stays (28, 42, and 60 months) were removed from the analysis (t(139) = 3.203, p=0.002). The median time spent inpatient was over twice as long for HIV-positive children as for HIV-negative children (181 vs. 90 days) (see Figure H.3). The fact that HIV-positive children generally took longer to recover than HIV-negative children reflects the complexity of managing their HIV disease.

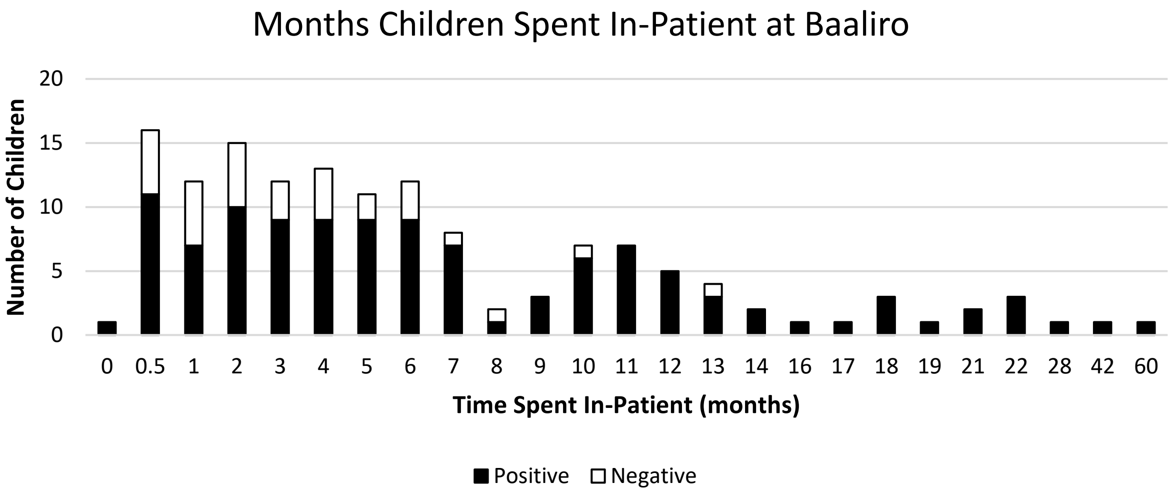

Figure H.3 Graph of Months Children Spent Inpatient at Baaliro – Comparison between HIV-Positive and HIV-Negative Children
There was considerable variability in the amount of time children spent inpatient, but as this graph depicts, most HIV-negative children spent less than 6 months inpatient, whereas many HIV-positive children spent more than a year inpatient. The average stay at Baaliro was 6.9 months, with HIV-positive children averaging 7.8 months and HIV-negative children averaging 3.5 months. The median stay was 5.0 months (6.0 months for HIV-positive children and 3.0 months for HIV-negative children).

Education

HIV-positive children were significantly more likely to be attending school than HIV-negative children (χ^2(1, N=145) = 9.716, p=0.002) and the reasons why children were not attending school differed between HIV-negative and HIV-positive children (χ^2(2, N=57) = 24.237, p<0.001). HIV-negative children were more likely to be underage (p<0.001), and HIV-positive children were more likely to have dropped-out of school (p=0.001) or to not be attending for another reason (p=0.008, see Table H.1).[3] In fact, all HIV-negative children not attending school were too young to begin attending. This is not surprising given that, as previously mentioned, HIV-negative children were on average younger than HIV-positive children. Interestingly, there was no significant difference between HIV-positive and HIV-negative children with respect to being over-age in school (t(118) =1.925, p=0.057).

Caregivers

HIV-positive and negative children did not differ with respect to their biological relationship to their caregiver (χ^2(3, N=180) = 4.155, p=0.245).[4] HIV-positive and negative children also did not differ with respect to their caregiver's gender (χ^2(3, N=180) = 2.056, p=0.561).[5] HIV-positive children and HIV-negative children did differ with respect to their orphan status[6] (χ^2(3, N=171) = 20.787, p<0.001). In particular, HIV-positive children were much less likely than HIV-negative children to *not* be orphans (30% vs. 70% respectively, n=171, p<0.001).[7]

Caregiver occupations are listed in Table H.2. Overall the caregivers of HIV-positive and HIV-negative children had a similar distribution of occupations, and any differences were not significant (χ^2(3, N=202) = 1.588, p=0.662). The majority of caregivers were involved in agriculture, with petty business and casual labor also prominent sources of income.

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[3] Post-hoc analysis with Fisher's exact and Bonferroni correction, (p must be <0.0167).

[4] For this analysis caregiver relationships were grouped into 4 categories: parents, grandparents, other family, and non-family.

[5] For this analysis caregiver gender was grouped into 4 categories: male, female, both genders, and non-family.

[6] Recall that in Uganda, an orphan is defined as a child (under the age of 18) who lost one or both parents. Those who have lost one parent (mother or father) are called single orphans, and those who have lost both are called double orphans. Those who have both parents living are generally not considered orphans, although sometimes in cases of abandonment a child can be considered an orphan if a parent cannot be located.

[7] Post-hoc analysis with Fisher's exact and Bonferroni correction, (p must be <0.0125).

Table H.2 Caregiver Occupations

Occupation*	Baaliro Total (n=169)		**Baaliro[1]** HIV-Positive (n=128)		HIV-Negative (n=41)		**National[2]**
	n	%	n	%	n	%	%
Agriculture, Forestry, and Fishery	91	54%	70	55%	21	51%	68.4%
Petty Business[3]	36	21%	26	20%	10	24%	8.0%[3]
Casual Labor[4]	29	17%	20	16%	9	22%	4.8%
Other[5]	15	9%	13	10%	2	5%	6.0%
Other Plant and Machine Operators[6]	11	7%	6	5%	5	12%	2.7%
Professionals[7]	7	4%	5	4%	2	5%	0.5%
Technicians and Associate Professionals[8]	5	3%	5	4%	0	0%	2.0%
Service Workers[9]	6	4%	5	4%	1	2%	7.7%
Domestic Helpers (housekeepers)	2	1%	2	2%	0	0%	3.6%
Craft Workers	1	1%	1	1%	0	0%	4.2%
Clerical Support Workers	0	0%	0	0%	0	0%	0.4%
Unemployed	8	5%	3	2%	5	12%	9.4%
Sick (unable to work or work fully)	15	9%	11	9%	4	10%	n/a
Receive Assistance from Other Family Members	13	8%	9	7%	4	10%	n/a
Multiple Sources of Income Listed	55	32%	41	32%	14	34%	n/a

** Occupation categories are those used in the National Census unless otherwise specified.*

[1] *Baaliro values are the number of children whose caregivers reported each occupation as a source of income. Percent adds up to more than 100% because caregivers could list more than one source of income and because some children had multiple caregivers.*

[2] *National values come from the 2014 Uganda National Census* (UBOS 2016). *They are the percent of the working population (aged 14-64) who reported each occupation. They exclude unemployed and students. Respondents were only allowed to list one occupation.*

[3] *Petty Business was not listed as an occupation in the national survey. However, the census did report that 8% of households are engaged in "business enterprise" as the household's primary source of income. Among Baaliro caregivers, Petty Business included managing a roadside kiosk, selling food, brick-making, and/or selling charcoal.*

[4] *Type of Casual Labor (aka Other Elementary Occupations) was usually not specified for Baaliro caregivers, but included assisting other farmers with cultivation, working as a sugar cane weeder, and washing clothes.*

[5] *Other Sources of Income for Baaliro caregivers included being a Traditional healer/Herbalist (n=3), a businessman/woman (n=5), a pastor (n=1), maintaining rental properties (n=2) or employed NOS (n=1).*

[6] *Other Plant and Machine Operators among Baaliro caregivers included two drivers, two mechanics, one individual involved in bicycle repair, and four boda-boda drivers. Boda-boda drivers were reported separately in the national census (1.5%), but I have included them with Other Plant and Machine Operators.*

[7] *Professionals among Baaliro caregivers were mostly teachers (n=5). Additionally, one woman described herself as an interior designer and one as a news anchor.*

[8] *Technicians and Associate Professionals among Baaliro caregivers included a nursing assistant, a medical assistant, a carpenter, a builder, and two tailors.*

[9] *Service Workers among Baaliro caregivers included shop attendants (n=3) and those involved in the bar business (n=2) or waitressing (n=1).*

Appendix I: Ugandan Definitions of Vulnerability

2004 Definition of Vulnerability
Criteria for the "*Most* Vulnerable Children in Uganda" (MGLSD 2004)

1. Living on their own/institutionalized
2. Psychosocial status poor/potentially poor
3. Unstable environment (abusive, conflict, migratory)
4. In need, as determined by consensus but could include: inadequate food (one meal or less), inadequate clothing (fewer than three sets including uniform), poor shelter (grass thatch and mud walls), lack of/irregular education, regular cash income < US $1 equivalent per day
5. Orphaned
6. Single/widowed caregiver or head of household
7. Chronically ill adult in household
8. Female caregiver or head of household
9. Elderly caregiver or head of household
10. Abandoned (parents known to be alive or assumed alive but cannot be located)
11. Parents or guardians cannot be located or are absent (are assumed dead or known to be missing and cannot be located)
12. Chronically ill child
13. Illiterate/not going to school
14. Disability

2009 Definition of Vulnerability
Survey criteria and scoring used to calculate the "Uganda-specific definition of vulnerability" (Kalibala and Elson 2009)

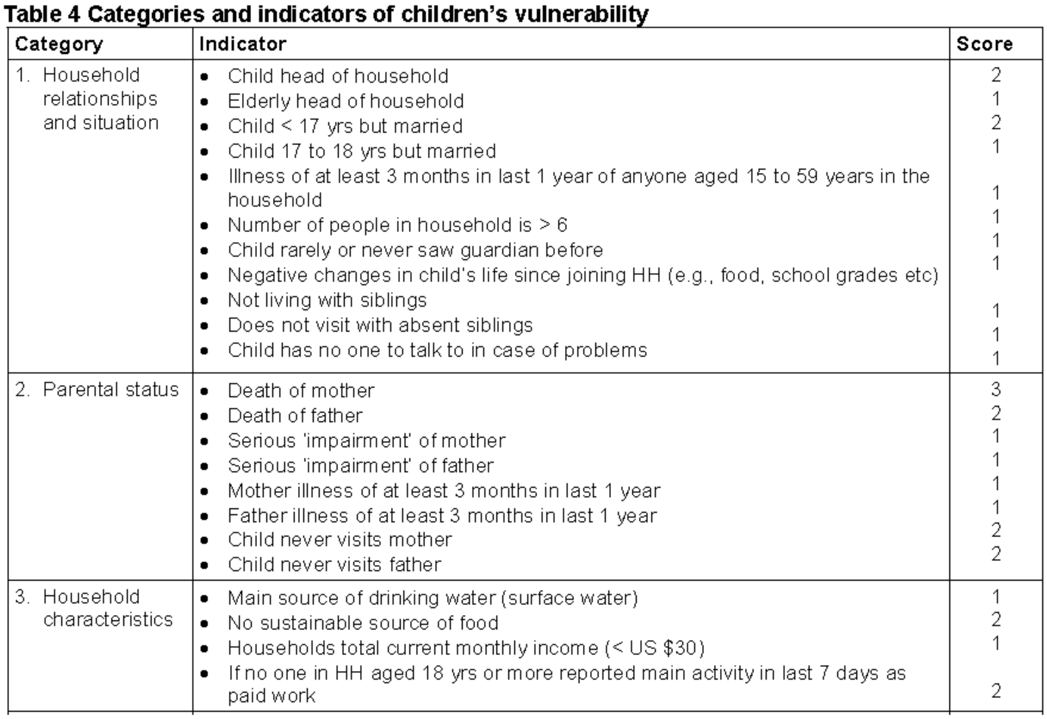

Table 4 Categories and indicators of children's vulnerability

Category	Indicator	Score
1. Household relationships and situation	Child head of household	2
	Elderly head of household	1
	Child < 17 yrs but married	2
	Child 17 to 18 yrs but married	1
	Illness of at least 3 months in last 1 year of anyone aged 15 to 59 years in the household	1
	Number of people in household is > 6	1
	Child rarely or never saw guardian before	1
	Negative changes in child's life since joining HH (e.g., food, school grades etc)	1
	Not living with siblings	1
	Does not visit with absent siblings	1
	Child has no one to talk to in case of problems	1
2. Parental status	Death of mother	3
	Death of father	2
	Serious 'impairment' of mother	1
	Serious 'impairment' of father	1
	Mother illness of at least 3 months in last 1 year	1
	Father illness of at least 3 months in last 1 year	1
	Child never visits mother	2
	Child never visits father	2
3. Household characteristics	Main source of drinking water (surface water)	1
	No sustainable source of food	2
	Households total current monthly income (< US $30)	1
	If no one in HH aged 18 yrs or more reported main activity in last 7 days as paid work	2

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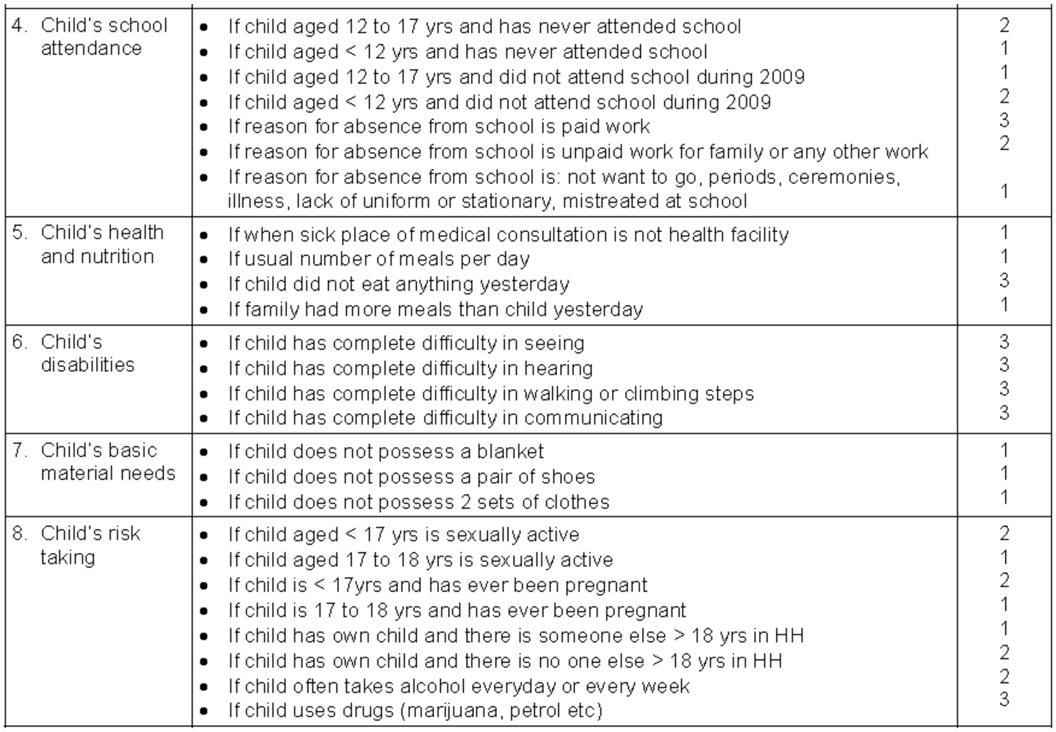


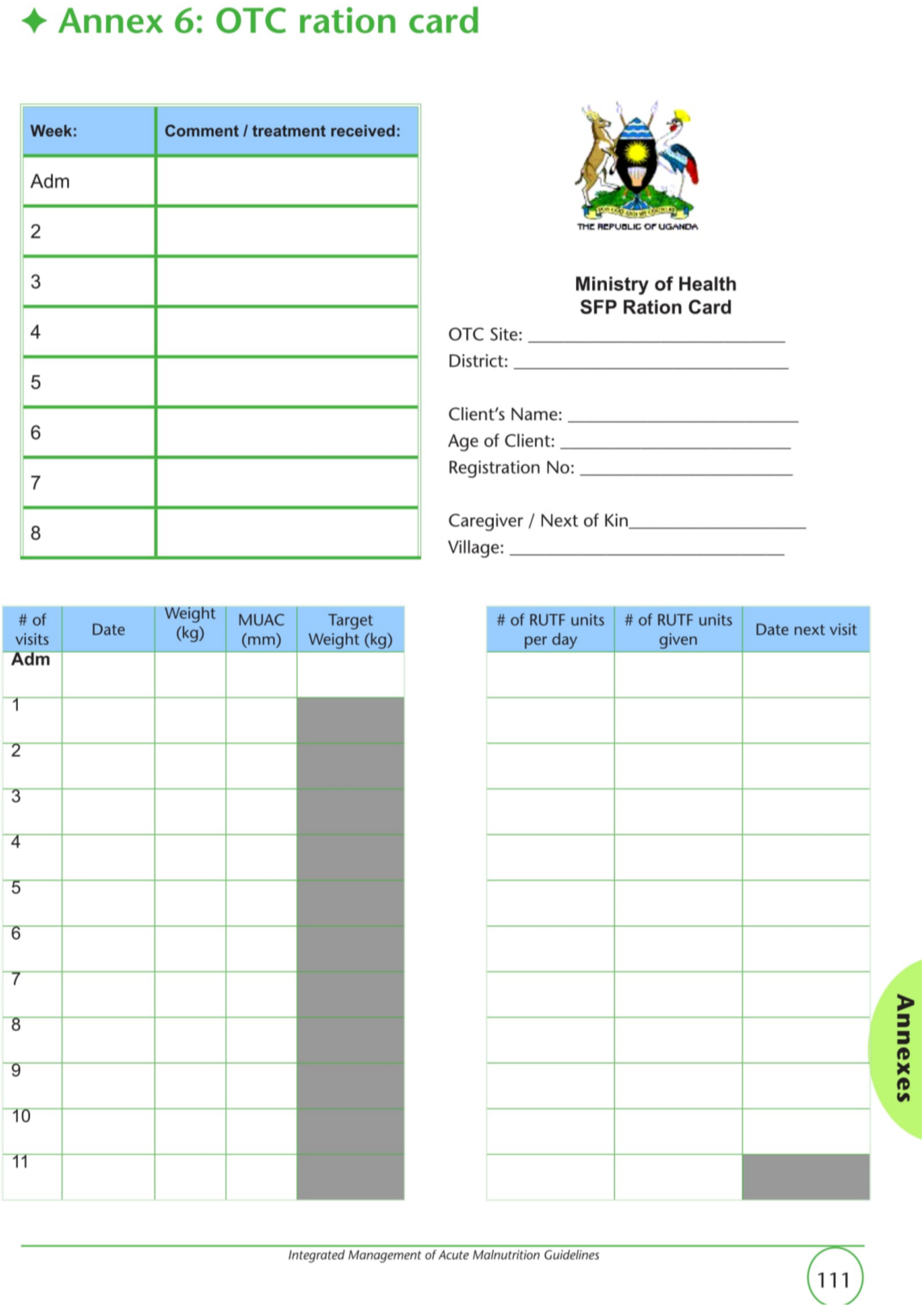
4. Child's school attendance	• If child aged 12 to 17 yrs and has never attended school • If child aged < 12 yrs and has never attended school • If child aged 12 to 17 yrs and did not attend school during 2009 • If child aged < 12 yrs and did not attend school during 2009 • If reason for absence from school is paid work • If reason for absence from school is unpaid work for family or any other work • If reason for absence from school is: not want to go, periods, ceremonies, illness, lack of uniform or stationary, mistreated at school	2 1 1 2 3 2 1
5. Child's health and nutrition	• If when sick place of medical consultation is not health facility • If usual number of meals per day • If child did not eat anything yesterday • If family had more meals than child yesterday	1 1 3 1
6. Child's disabilities	• If child has complete difficulty in seeing • If child has complete difficulty in hearing • If child has complete difficulty in walking or climbing steps • If child has complete difficulty in communicating	3 3 3 3
7. Child's basic material needs	• If child does not possess a blanket • If child does not possess a pair of shoes • If child does not possess 2 sets of clothes	1 1 1
8. Child's risk taking	• If child aged < 17 yrs is sexually active • If child aged 17 to 18 yrs is sexually active • If child is < 17yrs and has ever been pregnant • If child is 17 to 18 yrs and has ever been pregnant • If child has own child and there is someone else > 18 yrs in HH • If child has own child and there is no one else > 18 yrs in HH • If child often takes alcohol everyday or every week • If child uses drugs (marijuana, petrol etc)	2 1 2 1 1 2 2 3

2011 Definition of Vulnerability

Criteria for the "*Most* Vulnerable Children in Uganda" (MGLSD 2011)

- Critically vulnerable
  - Orphans whose rights are not fulfilled
  - Street children/abandoned children/neglected children
  - Children infected and affected by HIV/AIDS
  - Children in contact with the law
  - Children with disabilities
  - Children in child-headed households
  - Children in the worst forms of child labor (commercial sexual exploitation, illicit activities, paid domestic work, work that interferes with school attendance)
  - Children in armed conflict (captives or soldiers, IDP)
  - Children experiencing various forms of abuse and violence (survivors of sexual violence, in abusive home/institution)
  - Any other category of children who are assessed to be in need of immediate care and protection [as per community assessment]
- Moderately vulnerable
  - Children out of school
  - Child mothers
  - Children in hazardous work (domestic services, informal sector, commercial agriculture, trafficked)
  - Children living w/ elderly and/or cg w/ disabilities
  - Children in poverty stricken households
  - Children in hard to reach areas (fishing, mountain, nomadic)

Appendix J: RUTF Ration Card



✦ Annex 6: OTC ration card

Week:	Comment / treatment received:
Adm	
2	
3	
4	
5	
6	
7	
8	

THE REPUBLIC OF UGANDA

Ministry of Health
SFP Ration Card

OTC Site: ______________________________
District: ________________________________

Client's Name: ___________________________
Age of Client: ___________________________
Registration No: _________________________

Caregiver / Next of Kin____________________
Village: ________________________________

# of visits	Date	Weight (kg)	MUAC (mm)	Target Weight (kg)
Adm				
1				▨
2				▨
3				▨
4				▨
5				▨
6				▨
7				▨
8				▨
9				▨
10				▨
11				▨

# of RUTF units per day	# of RUTF units given	Date next visit
		▨

Annexes

Integrated Management of Acute Malnutrition Guidelines

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