

The Politics of Triage: International Aid and AIDS Care in Northern Uganda

by

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Abstract

Uganda has been considered an AIDS success story since the late 1990s when prevalence rates decreased around the country. Recognizing Uganda's unique AIDS response, this thesis seeks to analyze HIV/AIDS in Uganda and challenges normative understandings of Uganda's 'success', specifically, in Northern Uganda. It explores how Ugandan HIV/AIDS policies targeting NGOs and the 'community' have depoliticized HIV/AIDS, creating new inequalities through triaged care. To understand the production of inequality, this thesis explores how clients and aid workers define 'vulnerability' and how relationships affect aid allocation. Newly emerging arenas of stigma are examined in order to challenge normative attitudes of HIV-status disclosure in health campaigns by demonstrating how HIV-positive people are facing new stigmas when they are incapable of being 'productive citizens.' As humanitarian aid leaves Uganda, HIV/AIDS NGOs seek to relieve the issue of aid dependency through development initiatives. This thesis ends by challenging development's understanding of 'us' versus 'them'.

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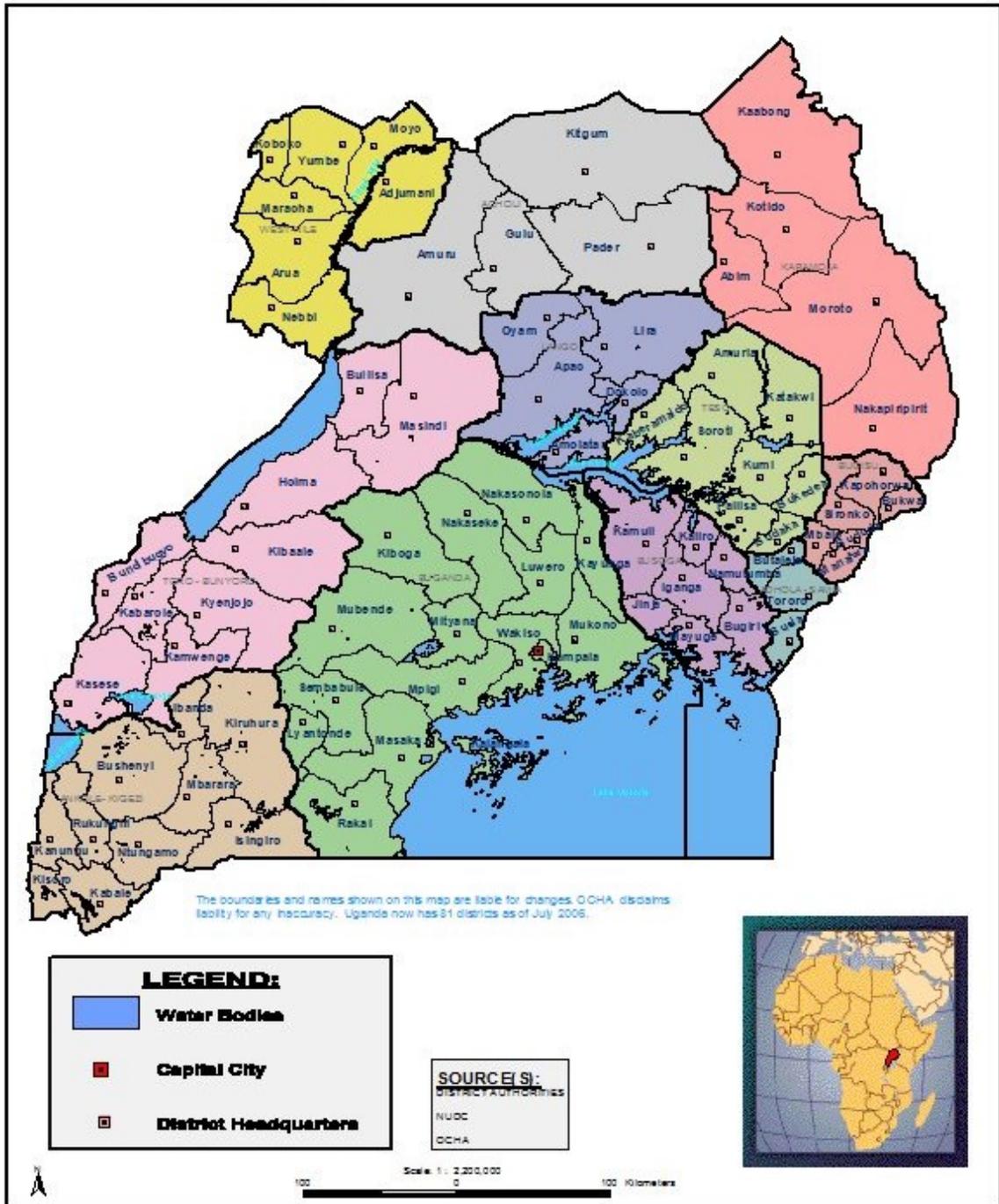
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Map of Uganda

This is a map of Uganda's 88 districts as of July 2006. The number of Uganda's districts increased to 111 as of August 2nd 2010.



United Nations Office for the Coordination of Humanitarian Affairs (OCHA).

2006 Map of Uganda Including New Districts by Region. http://reliefweb.int/sites/reliefweb.int/files/resources/ACFA064C7C4EA2138525734400468CE5-ocha_REF_uga061031.pdf, accessed June 2014.

Chapter One

Introduction

I first visited Gulu Regional Referral Hospital, the major publicly funded hospital for all of Northern Uganda, in 2011 with a Ugandan doctor who worked for the HIV/AIDS organization I was involved with. Years of regional instability had taken its toll on the hospital and the neglect was obvious. The buildings were old, the beds few, and most patients entered and left the hospital without seeing a physician unless they were also members of private organizations who sent their own physicians to check on their clients. If not, patients would be attended to by nurses and new medical students. The day I accompanied Dr. Esther to the women's ward was a day like any other and after prescribing medication for a few undiagnosed tuberculosis cases, we left.

When I returned to Gulu and Gulu Regional Referral Hospital to conduct master's thesis research in 2013, new buildings were under construction, outdoor walkways had been recently fastened with donated tin coverings, and a fresh coat of paint had been applied to older buildings. I was glad to see these improvements because to me, it represented some investment into the health of Gulu's population; a population that was used to being neglected by the government. I came to later realize the ignorance of my assumptions. Despite infrastructural improvements, the care people received had not changed much. Medications and basic necessities were often out of stock, hospital funds went missing, physicians remained few and far between, and there still were not enough beds. Although physicians, nurses, and medical students alike attend tirelessly to the sick, Gulu Referral remains a place of last resort. If it can be afforded, most Northern Ugandan

inhabitants would rather be cared for at one of the numerous private clinics or hospitals in the area. Although fees must be paid to use these centres, they are far better equipped than Gulu Referral.

That is why I was surprised to see Michael, a young man I had often chatted with at the HIV/AIDS organization I was conducting research with, hard at work scrubbing clothes in a basin when I walked by the male ward one day in 2013. He looked up at me and smiled like he always did, but his eyes were sad and sunken in and he looked as though he had not slept in days. I asked him what brought him to the hospital and he told me his father was ill. His father had AIDS and he had been admitted to the hospital a week before. Michael had stayed with him by his side, calming him, feeding him, and bathing him, but he told me it did not look promising. He did not think his father would leave the hospital. I asked Michael, rather naïvely, why he did not admit his father into a neighbouring privately funded hospital since they had better facilities. The organization I was conducting master's research with was a different organization than the one Dr. Esther worked for and it had a collaborative community-based program with a private hospital. I had heard from others that the organization paid for hospital bills, so I assumed the clients I saw at the organization's office attended the private hospital when they fell ill (I later found out the organization had stopped paying hospital bills). He told me, quietly, that his family did not have the money to admit his father into that hospital; Gulu Referral was his father's only option. I apologized embarrassedly for my carelessness, wished Michael and his father well, and left him there to continue washing.

A few days later I saw Michael at the office again. His entire body grieved sadness as he told me his father had passed away the previous day. During the

organization's daily prayer service, I expected there to be recognition of Michael's father's death since they often announced deaths of employees' relatives and other members of their community, but there was nothing. I was sure people knew because I had seen others consoling him before the service. The death of Michael's father left me angry and ponderous. As a member of the organization's community, why was Michael's family forced to admit his father into Gulu Referral? Why could the organization no longer pay for Michael's father to be cared for in the better-equipped hospital? Why could Michael's father not survive AIDS despite ARV adherence? Why was nothing about Michael's father's death mentioned at the prayer service?

The story that I present in the following pages is a response to these emotionally charged questions that followed me from Uganda back to Canada. It is a story of the changing tide of HIV/AIDS care in Northern Uganda, the Government of Uganda and international aid initiatives, and the negotiation of care and vulnerability in an evolving aid environment. For me, it is impossible to talk about HIV/AIDS care in Northern Uganda without situating the observations and analysis in recent history. I came to realize that although records will show complications from AIDS as the official cause of Michael's father's death, it is the events leading up to his father's hospitalization and the care within it that are the most important and the most telling. They are significant because they are the most difficult to address and even more difficult to resolve. My story seeks to address these difficult questions by exploring processes of inclusion and exclusion in access to AIDS care to open a space to consider AIDS both as a consequence of a virus, and as a legacy of the past.

In this introduction and first chapter of my thesis, I situate important theoretical perspectives that flow through and link together each chapter. I begin by exploring the importance of telling history in a way that reveals rather than conceals processes of structural violence. To do so, I use a political economy of health framework to locate systems of power and marginality that determine values of life. Categorization of people living with HIV/AIDS is a product of power relations but it also is a condition of humanitarian aid. In order to adequately address processes of inclusion and exclusion in access to aid, I explore humanitarian reason and action and situate my research globally. I then outline ethnographic methods used throughout fieldwork and end with descriptions of each chapter found within the pages of this thesis.

The beginnings of HIV/AIDS stereotypes: African promiscuity

A review of the literature on AIDS in sub-Saharan Africa demonstrates a need for a historically deep and geographically wide evaluation. History is one of the most important but also most commonly overlooked components necessary to conceptualize the complexity of the AIDS epidemic on the African continent. Early research on HIV/AIDS ignored historical dimensions of the disease that may have pointed to socio-economic determinants and political issues as precursors to high infection rates. Instead, explanations of HIV prevalence and development were often limited to cultural-behavioural interpretations; as if there were cultural specificities shared by all Africans that produced behaviours perfectly adapted to quickly spreading HIV. Because HIV was determined to be transmitted largely by sexual contact, early researchers credited

promiscuity as the main vector for HIV transmission (Fassin 2002: 65; Opong and Kalipeni 2004: 47; Packard and Epstein 1991: 771).

AIDS is different than other diseases because unlike other diseases, AIDS challenges the fundamental values of self, society, and culture (Thornton 2008: xix). Since it cannot be seen and is often passed through sexual relations (Marks 2002: 16), the West has fallen back on antiquated beliefs about 'African promiscuity' to account for Africa's high rates of infection and blame Africans for the pandemic. The belief of African promiscuity has powerfully deep roots that extend far before Europe decided to claim Africa as its own. Consequently, this myth has dominated much of the writing on Africa before, as well as after, HIV had been discovered (as discussed by Opong and Kalipeni 2004: 48; Packard and Epstein 1991: 773-774).

HIV/AIDS was first diagnosed as a distinct disease in the United States in the early 1980s. The first populations in the West to appear the most susceptible to AIDS were men who have sex with men (MSM), as well as prostitutes and intravenous drug users, many of whom were of African and Haitian descent (Chirimuuta and Chirimuuta 1989: 4). Therefore, not only was AIDS associated with the immoral fringe of society, but it fostered xenophobic, racist speculations about Africans and Haitians being risk groups for HIV/AIDS. These speculations, largely fuelled by age-old stereotypes about African promiscuity, were only reinforced when it was found that HIV/AIDS had become a heterosexual disease in Africa with prevalence rates much higher than the West's (Thornton 2008: 25).

One of the first theories to explain high heterosexual transmission rates in Africa focused on African heterosexual behaviour. As early as 1985, researchers were already

concluding that high transmission rates throughout Africa were caused by higher levels of sexual promiscuity, a condition assumed to be cultural (Chirimuuta and Chirimuuta 1989; Packard and Epstein 1991: 773; Serwadda et al. 1985). The business man with a handful of lovers, the truck drivers and migrant workers having irregular and sporadic sex across Africa, and above all, the pervasive female prostitute spreading her immorality with hundreds of lovers each year were identified as the main vectors of HIV transmission in Africa. Despite objection to this narrow hypothesis by a minority of researchers and Africans who argued that these situations promoting sexual relations could not be considered cultural because they were born out of economic deprivation, the association of AIDS in Africa with sexual promiscuity persisted and has directly informed attempts at controlling the disease.

One cannot deny that HIV in Africa is spread through sexual contact, but by ignoring larger political, economic, and social conditions, one ignores the ultimate reasons that inform sexual behaviours in the first place. The power external actors such as non-governmental organizations (NGOs), international financial institutions (IFIs) and donor countries exert in determining global responses to HIV also cannot be ignored. To most of the world outside of Africa, prevention techniques like education campaigns are considered the most appropriate tool to combat HIV/AIDS in Africa (Thornton 2008: 57), but to view the HIV/AIDS crisis in Africa through a centralized, top-down development lens is to disregard the inequalities and misjudgments placed upon Africans by external actors in the West. While these external actors may be well-intentioned in that eliminating HIV/AIDS is their main objective, well-intentioned or not, the way in which HIV/AIDS is conceptualized as a cultural-behavioural problem stemming from African

promiscuity is based on ahistorical, racist analyses that have so far been unsuccessful in eliminating the disease.

Using history and anthropology to uncover structural violence

From an anthropological perspective, to better understand the trajectory of HIV/AIDS in Africa, a historical approach that not only takes into consideration the political, economic, and social factors that have designed Africa to be the poorest continent on the planet, but also how these factors have been embodied within individuals and communities, is needed. Paul Farmer, who is both an anthropologist and physician, argues for a more biosocial approach to understanding AIDS in Africa (2001: 5, 14). What he means is that a proper analysis of the complexities of AIDS must draw on clinical medicine, social theory, epidemiology, history, ethnography, and political economy, because it is fundamentally social forces and processes that come to be embodied as biological events such as AIDS. The interdisciplinary nature of this approach is necessary because HIV/AIDS is itself multifaceted, and researchers, politicians, physicians, and Africans alike must focus attention on the interplay of both biological and social factors that facilitate the spread of HIV.

While the term *structural violence* has taken numerous forms since its first use by Johan Galtung (1969), Farmer (2004) identifies it as “violence exerted systematically—that is, indirectly—by everyone who belongs to a certain social order” (307). In the context of Africa, structural violence has everything to do with oppression, played out through racism, poverty, colonialism, disease, marginalization, and exploitation (Fassin 2002: 65). Structural violence, if understood through a proper syncretic biosocial

anthropology lens, can allow us to not only see that HIV/AIDS is associated with poverty and social inequalities, but also understand how structural violence creates inequalities that determine risk for HIV infection or produce adverse outcomes, including death (Farmer 2004: 305).

Understanding the layers of structural violence endured by people living with HIV/AIDS in Northern Uganda is a key component to my analysis. Employing a political economy of health framework grounded in a historically deep ethnographic critique of ‘community’ through one local HIV/AIDS organization in particular, I show how structures of power in household, organizational, and national terms have placed value on certain lives and changed ideas of HIV/AIDS care. A political economy framework rooted in sociocultural anthropology moves popular conceptions of HIV/AIDS as a behavioural issue to a considerably more dynamic plane that incorporates history, power, gender, and culture, thereby identifying and revealing the structural violence inherent in the world system. For Catherine Maternowska (2006), a political economy framework “accounts for the role of institutions as well as the social actors who live and struggle to survive within them” (38). Moving beyond an antiquated cultural-behaviourist or a reductionist ‘poverty causes AIDS’ framework, the political economy of health and AIDS teases out the processes that determine poverty and looks at how high HIV prevalence rates are determined by constantly fluctuating political, economic, and social forces.

The dynamic, still evolving world AIDS picture can only be understood in light of a wide range of social, economic, and political conditions; more specifically, global, national and local political-economic relations (Baer et al. 2003: 245). Much literature utilizing a political economy of AIDS framework explores Foucault’s concept of

biopolitics (Nguyen 2010: 112). Biopolitics, in the Foucauldian sense, is concerned with control of populations, concentrating on the power governments and nongovernmental authorities possess in ‘normalizing’ what constitutes a healthy population (Foucault 1990: 135-159). It impersonalizes the individual, manifesting itself as power over human conduct in general. In order to maximize a population’s health status, biopolitical strategies seek out mechanisms for enticing individuals to structure their behaviour around ‘healthy norms’ (Elbe 2005: 406). In the case of someone living with HIV/AIDS, a healthy norm is taking care of oneself and one’s body and abstaining from risky sexual behaviours as a way of preventing further spread of the disease; the responsibility falling on the moral domain of the individual and personal ‘will to health’ (Rose 2001: 6). This way of living, called ‘positive living’ will be explored in greater depth throughout the following chapters.

While Foucault’s biopolitics does have its place in understanding global power structures, it seems to fall short in explaining processes of inequality in low resource settings such as Uganda. Biopolitics concerns itself with technologies of power, where they reside and how they define truths, but to understand inequalities, the effects of this power must be explored. Foucault’s biopolitics focuses on normalizing individuals within a population and therefore cannot be applied adequately when the object of study is not a process of normalization but one of differentiation, between who will receive HIV treatment and who will not, and “the concrete ways in which individuals are treated and valued, under which principles and in the name of which morals” (Fassin 2009: 57). Didier Fassin (2009) observed that “inequality is a word that never appears in Foucault’s writings” (49). In today’s open-market driven world the cost-effectiveness of strategies is

evaluated based on the value of the lives of different individuals. Therefore, it can be said that global health initiatives have transformed biopolitics from a ‘power over life’ (Foucault 1990: 138) to a ‘power of life’ (Fassin 2009: 49; Nguyen 2010: 101). Life, then, has a certain value attached to it and the political economy of AIDS framework explores how people living with HIV/AIDS are categorized in Northern Uganda.

There are two ways of identifying the value of life. The first can be measured as economic value—the amount paid to keep someone alive and a government’s investment in improving living standards (or lack thereof). The second is the way in which morality and ethics are attached to life—the kind of life that is worth living; the ‘good life’; the ‘quality’ of life; and opinions on whose lives are worth living and who can be ‘rejected into death’ (Fassin 2009: 54; Marsland and Prince 2012: 459). Of course, these two values are intimately tied together and cannot be separated. Moral values affect our economic decisions and our economic decisions affect our moral values. Political ideology, which is deeply moral, is tied with decisions to implement health care programs. A tension exists in sub-Saharan Africa, where structural adjustment policies prevent states from implementing adequate healthcare and where the responsibility falls on humanitarian organizations whose projects are largely dictated by Western donor countries. On one side, there are the donor countries who value cost-effective programs for HIV/AIDS reduction; on the other are scores of donor dependent NGOs whose main purpose is to provide for those who cannot provide for themselves. Here there exists a paradox and Miriam Ticktin (2006) describes it as a “limited version of what it means to be human” (34). Because of economic and political constraints set by donors, professionals employed by HIV/AIDS NGOs must decide who, among the poor and sick,

are the most ‘cost-effective’ for treating and helping even though by the very nature of being humanitarian, NGOs have the moral responsibility to save lives, not ignore them (Farmer 2001: 268; Maternowska 2006: 42; Nguyen 2010: 109; O’Manique 2004: 4, 5; Ticktin 2006: 34).

Humanitarianism: globally governing a limited version of humanity

The prospect of ‘saving lives’ is rooted within the moral sentiment of compassion and, indeed, compassion is the defining fiber of humanitarian action. Compassion recognizes others as fellows, compelling worldwide feelings of solidarity, but compassion, as argued by Fassin (2013), is also derived from inequality. Humanitarian aid is structured so that the powerful help the weak, the fragile, and the vulnerable. Therefore, it is always practiced from top to bottom; benefactors give life-saving gifts and receivers give gratitude. The very nature of this social relation makes compassion a moral sentiment without equal reciprocity (Fassin 2013: 3) and within this unequal relationship, there exists tension between inequality and solidarity; between the relation of domination and assistance. It explains the ambivalence of donors who ‘help’ for the good of society and it accounts for the ‘donor fatigue’ that stirs feelings of indifference within aid workers. The inequality within the very nature of humanitarian aid can also account for shame and resentment felt by the poor who are expected to show their gratitude to those who see themselves as their benefactors (Fassin 2013: 3).

By its nature, humanitarianism is profoundly political in that it reveals and governs precarious lives. Power is stripped away from beneficiaries so instead of demanding rights to accessible healthcare, clean water, or food, beneficiaries are

expected show gratitude and humility to bringers of aid who have the compassion and morality to help in times of need. As Miriam Ticktin (2006) explains, in a globalized world of inequality that has seen the proliferation of humanitarian ideals in recent years, moral demands have increasingly filled the space of political action. Reflecting on the precariousness of the humanitarian clause in French law that gives people with serious illnesses the right to stay in France and receive treatment, Ticktin (2006) argues that it is impossible to separate out the political dimension of human life. Indeed, political subjects can be found in the most ‘apolitical’ of spaces. Politics’ cooptation of humanitarian processes has created a new form of governing comprised of a moral economy which seeks to protect a humanity composed of suffering bodies and “biological life devoid of social and political content” (Ticktin 2006: 35).

Humanitarianism reveals, defines, and governs precarious lives, and a politics based on humanitarianism creates a new moral economy. But how are humanitarian politics and its morals related and what is the importance of the public expression of moral sentiments? And how do the actors directly involved with aid allocation (both the benefactors and beneficiaries) use humanitarianism to their advantage? These are questions I seek to answer in the pages that follow through the exploration of how humanitarian action and its politics have shaped the lives of people living with HIV/AIDS in post-conflict Northern Uganda.

Exploring humanitarian action and politics in Northern Uganda means historically situating humanitarianism as a response to HIV/AIDS and conflict, which, consequently, reveals that humanitarian action and everything that comes with it is fundamentally global. NGOs, government organizations, and healthcare centres are linked to and have

connections with people, other organizations, and places outside of Uganda. Fieldwork made it clear to me that HIV/AIDS as a disease does not represent similar things to everyone. Through interviews and long conversations, I came to recognize that there was no definition of ‘appropriate’ HIV/AIDS care because care was never conceptualized the same way. NGO workers often talked about how important client independency was, while clients wished for more NGO support.

Interviews with aid workers and people living with HIV/AIDS clarified for me a central feature of the aid process that gave meaning to the production of certain values and inequalities with people living with HIV/AIDS in Northern Uganda. I came to realize that universal global claims—such as AIDS is bad and must be stopped—do not make everything everywhere the same. Reflecting on Anna Tsing’s (2005) idea of a *friction* that “reminds us that heterogeneous and unequal encounters can lead to new arrangements of culture and power” (5), I came to realize that it is precisely these ‘zones of awkward engagement’ (Tsing 2005) and the power relations within them that are integral for understanding the HIV/AIDS situation in Northern Uganda. ‘Zones of awkward engagement’ are when words, values, and concepts mean something different across a divide (Tsing 2005: xi). Historically situating how these zones are interpreted and acted upon must be explored in order to understand how things such as HIV/AIDS care and humanitarianism come to reproduce inequities.

Fieldwork settings and methods

This research examines a pivotal moment in the history of the HIV/AIDS epidemic in post-conflict Northern Uganda: Peace has persisted since 2006 and antiretroviral therapy

(ART) has been available for Ugandans free of charge since 2004. Studying HIV/AIDS initiatives in Northern Uganda in the second decade of the 21st century is significant because enough time has passed since the civil war for relief aid projects to end, new ‘development’ initiatives to begin, and the growth of a generation of people living with HIV/AIDS who have never known a life without ART. My study takes a local site and attempts to connect it globally through connections between one organization, its beneficiaries, its workers, its donors, and the wider community. Despite this, I cannot make any claims to know all there is to know about the organizations and events I mention. In reality, no single person can know everything about an organization no matter how long their fieldwork because organizations are global and shifting. However, Peter Redfield (2013) suggests in his study of the Nobel Peace Prize winning humanitarian organization, Médecins San Frontières (MSF), that “elements of an organization prove easy to trace and follow, and if one does that repeatedly, they grow familiar” (3). Taking familiar elements and exploring them is how I situated my research in Northern Uganda.

This thesis is based on fieldwork in Gulu, Uganda from July to October of 2013. Some observations also come from experiences during a preliminary visit from August to November, 2011, where I worked as a student intern at a national HIV/AIDS organization. In 2013, I travelled to Gulu, the largest city in Northern Uganda, to conduct research with a local HIV/AIDS organization I will call the Positive Outreach Network. The Positive Outreach Network was among the hundreds of international and national aid organizations that opened offices throughout Northern Uganda when armed conflict between Uganda’s national army and Northern rebel groups began, after current President

Yoweri Museveni's militant government takeover in 1986. Before the war, Northern people were mainly subsistence farmers, but they were forced into Internally Displaced People's camps when conflict erupted. Here, they relied upon humanitarian assistance for nutritional and material support (Chapter Two gives significantly more detail about Northern inhabitants' precarious camp situation and outlines the development of HIV/AIDS support throughout Uganda). The Positive Outreach Network is a Catholic non-profit organization whose focus has always been caring for those infected with, and affected by, HIV/AIDS. Since their formation in 1992, they have valued what they define a 'holistic' approach to HIV/AIDS care: stressing the importance of attending to the psychological, social, economic, and physical needs of people living with HIV/AIDS.

The Positive Outreach Network is appropriate for my research because its development is particular to Gulu's history of conflict and post-conflict reconstruction. Gaining a sufficient understanding of HIV/AIDS care as handled by the Positive Outreach Network in just three months required methodological flexibility. Prior to arriving in Gulu, I had established relationships with the ethics committee of the local hospital that acted as overseer of the Positive Outreach Network's anti-retroviral therapy (ART) program. Upon arriving in Gulu, I was integrated into the Positive Outreach Network's programs and began to build relationships with potential research participants. Due to time constraints, I immediately immersed myself in as many programs within the Positive Outreach Network as I could possibly manage. I found myself tagging along to outreach stations, clients meetings, hospital visits, ART adherence classes, drama presentations, and donor field visits. Within the Positive Outreach Network's offices, I attended daily prayer services, donor meetings, budget meetings, and also observed

artisan-clients creating art within the cooperative program. These experiences led to extensive participant observation. My daily presence at the main office also allowed me to build friendships, and although I ended up with a large number of recorded interviews, some of the most important data I gathered came from conversations over a beer after a day in the field or sitting in living rooms, eating pork and drinking Fanta.

From connections made in 2011 and a pre-fieldwork relationship with the organization, access to the field was relatively easy and because fieldwork was short, I made the conscious decision to be ‘always on.’ Though weekdays were filled with travelling for interviews or various activities conducted with the Positive Outreach Network, weekends usually consisted of ‘unofficial’ fieldwork since the organization was closed and many research participants either spent their days in church or doing farm work. I often talked to business owners about HIV or accompanied friends to traditional marriages and baptisms. Because I am relatively new to Gulu and Uganda, I took every opportunity to not only expand my research, but gain general knowledge about life in Northern Uganda.

My methods were standard for ethnographic research: semi-structured interviews, extensive participant-observation, and attendance at religious and political events. I also kept pamphlets, booklets, and workshop training manuals I found regarding HIV/AIDS in Uganda and cut out related news articles I read in both of the major Ugandan newspapers. Not having an idea of how well my research would be received among the clients of the Positive Outreach Network, I estimated that I would be able to get approximately 15 semi-structured interviews within the course of my fieldwork. In the end, I had 40 recorded interviews ranging from 30 minutes to as long as 150 minutes: 16 were

conducted with clients of the Positive Outreach Network; four were with client-volunteers; 13 were with employees of the Positive Outreach Network; one was with a donor representative from Europe; three were with local politicians (two of whom were also HIV-positive); and three were with business owners or aid workers working within Gulu. In general, within all categories, I was able to interview both males and females whose ages ranged from 27 to 68. Most interviews were conducted in English, as English is the official language of Uganda. For individuals who had very little education and were therefore never taught English, interviews were conducted in Acholi-Luo and translated with the help of a research assistant.

All clients, NGO employees and the HIV-positive politicians fully embraced the interview process and most were happy to have themselves audio recorded. Although they all signed consent forms, many of them commented that it was unnecessary ‘because they have nothing to hide.’ Many also insisted I use their full name so their story may be known to others (although for their protection, I have given all my research participants pseudonyms). For some clients of the Positive Outreach Network, interviews were a rare chance for them to express their concerns and frustrations to someone who would listen. Many also saw the interview as a chance to give personal testimony towards ART and the Positive Outreach Network, recounting their fundamental tale of survival against all odds. Many told me they saw themselves as a ‘living testimony’ of how faith, ‘positive living’ and ART could reshape an HIV-positive person’s world for the better, which will be discussed in more depth throughout this thesis.

Other research participants, such as the HIV-negative politician and other aid workers, were also happy to meet with me, though some of them requested I not audio

record our meeting. Although our meetings touched on personal issues, for the most part I used these interviews to gain more knowledge about the aid industry and public healthcare in Gulu since not everything is publicly available. For the most part, these interviews helped navigate interviews with individuals involved with the Positive Outreach Network and strengthened my knowledge of Northern Uganda's post-conflict situation.

All individuals in this study have been given pseudonyms, as well as all community organizations directly involved with my research. I chose to identify geographical locations as well as federal politicians and international organizations because their actions and histories are public knowledge and they are afforded much more security than most of the people they serve.

It has been generally agreed upon that writing within anthropology requires the author to contextualize observations within their personal and social history. Ethnography should include the voice of the writer because descriptions of places, locations and people always reflect the writer's own moral and ideological perspective (Clifford 1986: 98). To allow some reflexivity, it is important for me to contextualize myself as a young, middle-class, white Canadian female researching about Uganda among individuals who were sometimes impoverished and significantly older than me. Although I made lasting friendships, I remained an 'outsider' within the Positive Outreach Network. Most knew my presence was temporary and my proficiency at speaking Acholi-Luo was limited, regardless of my best efforts at learning. Therefore, my research is partial and is influenced by how my research participants saw me. Some of the people I spent time with assumed that, like most white development and humanitarian agency staff, I would bring

financial assistance. When it was made apparent that I would not be providing them with any significant source of finances, I became, for some, a messenger to tell their story to those who could effect change. Fieldwork made me acutely aware that although I was critiquing humanitarianism and the aid industry, I was for many the very representation of humanitarianism and development.

Chapter outline: situating the 'zones of awkward engagement'

This study is about ideas, relationships, and those 'zones of awkward engagement' (Tsing 2005) where definitions are vague and processes varied. In this chapter I have introduced HIV/AIDS as a global disease, and have proposed history to be an integral component to conceptualizing HIV/AIDS as a social disease as well as studying the development of HIV/AIDS programs. Most importantly, using a political economy of HIV/AIDS framework cannot exclude examining ideas of the value of life, which I have framed as part of humanitarian reasoning. For the remainder of this thesis, I will explore differences and similarities about ideas of HIV/AIDS care and treatment between those living with HIV/AIDS, the Positive Outreach Network and its volunteers, and, where information was available, the various international donors who provide financial and project management.

During fieldwork I became acutely aware of how important ideas of 'community' were to both beneficiaries of aid and their benefactors. Chapter Two engages with the idea of community and traces its roots to when Uganda first began developing a national AIDS strategy. Chapter Two historically situates major international organizations and their interest in HIV/AIDS in Uganda specifically. Many studies before mine have tended

to romanticize the importance of Uganda's 'community' response to HIV/AIDS, often crediting Uganda's leadership as the reason Uganda saw a decrease in prevalence rates in the early 20th century. I do not claim that locally mobilizing individuals and leaders did not help decrease prevalence rates, but instead, my research acts as a critique of community responses and explores their dangers. I argue that community responses remove blame or responsibility from the government or even other NGOs and place it squarely on the individual. This chapter gives details about Uganda's national HIV/AIDS development strategies and compares these responses to what was occurring in Northern Uganda, a place that is often forgotten about in HIV/AIDS studies conducted within Uganda.

Chapter Three explores a range of overlapping moral systems of client selection within aid organizations. It explores the meaning of 'clientship' within the HIV/AIDS industry in Northern Uganda that evolved when ART became widely available. There is an assumption that 'community' based programs are naturally more effective, but I explore how clientship and its neoliberal undertones muddles the meaning of community. Exploring the meaning of community and the processes of inclusion and exclusion in access to aid, I suggest that vulnerability indices, though often presented as objective ways to allocate aid, increase inequality among the Positive Outreach Network's clients. Officially, organizations use vulnerability indices as a way to determine who should receive support, but determining who is vulnerable is extraordinarily subjective and ambiguous and in reality, clients are in fact active seekers of aid. Measures of vulnerability and ways people are able to get aid seem to be taken for granted, rather than explicitly articulated by the Positive Outreach Network and those involved.

Labelling certain populations as more vulnerable or less vulnerable assigns expectations to behaviour. Non-vulnerable HIV-positive populations are expected to remain non-vulnerable, behaving in a way that does not put them or others at risk while those who are vulnerable, on the other hand, are given support and expected to try and lessen their vulnerability and dependency on aid. Using ethnographic data, in Chapter Four I explore how assumptions about behaviour can create new forms of HIV/AIDS related stigma that are directly related to poverty. Available ART has changed the appearance of people living with HIV/AIDS. Those on ARV medication no longer look sick so it is easier for them to keep their status hidden. This chapter discusses the idea of secrecy and nondisclosure and their associated stigmatization within the HIV/AIDS community. Despite good intentions to help, when organizations and other community members stigmatize nondisclosure practices, they ignore the moral field people living with HIV/AIDS must navigate when they are first diagnosed. This chapter reveals reasons people give for not disclosing their status that complicates the normative ‘bad client’ trope. While public health initiatives promote full disclosure as a way to eliminate barriers to care, disclosure does not erase the poverty that may factor into one’s decision to engage in ‘risky’ behaviour, nor does disclosure eliminate HIV/AIDS-related stigma.

In the final chapter, the intellectual cohesion of the HIV/AIDS aid industry in Northern Uganda is challenged further by questioning the meaning of ‘productive citizenship’ and why HIV-positive people who fit into this category have a higher chance of being members of development projects. Just as Emma Crewe and Elizabeth Harrison (1998) explored how ‘development’ was interpreted and used within various organizations and their beneficiaries around the globe, I too will begin to question

development discourses and explore how clients of the Positive Outreach Network create room to maneuver themselves as both members of the HIV/AIDS community and members of development projects designed to increase economic productivity.

Significance of the research

I argue that people use ideology and concepts such as *vulnerability*, *stigma*, *nondisclosure* and *clientship* to explain their past and present and position themselves within an extremely complicated web of interactions and reciprocity. By exploring the social constructs of HIV/AIDS care and clientship, this study offers an ethnographic account of changing ideas of what it means to have HIV/AIDS and what it means to receive care and support within a local HIV/AIDS organization in post-conflict Northern Uganda.

The only way to create appropriate solutions to the African HIV/AIDS crisis is to appropriately conceptualize explanations of the problem (Oppong and Kalipeni 2004: 54). Despite countless numbers of research reports from all academic disciplines, journal articles, and policy papers seeking to explain the AIDS pandemic, high prevalence rates persist in the most impoverished countries around the world, proving that the global community is failing to comprehend the complexity of AIDS. Over thirty years have passed since the first cases of HIV were diagnosed in Africa. Since then, countless social scientists, health care professionals, journalists, and historians have researched and written about various aspects of HIV/AIDS in Africa. As a result, there have been immeasurable developments in understanding the depth in which HIV is located within the world system.

Despite this, on-the-ground HIV prevention strategies still focus largely on education workshops aimed to change behaviours identified as high risk for HIV infection. These education workshops are based in research that suggests sexual promiscuity is a documented cultural factor among Africans that can and should be stopped. What education workshops fail to comprehend is that sex is more than just a behaviour. It is a social relation within a vast social network highly influenced by societal, political, and economic factors (Hunter 2010, 2007; Thornton 2008: 31). Simply teaching people to use condoms or abstain from sex does not address the structural political-economic factors promoting the spread of HIV.

The objective of this study is to contribute to the growing HIV/AIDS literature that uses a historically situated political economy of health and AIDS framework to analyze the HIV/AIDS pandemic. As a master's student of both anthropology and African studies, I hope that my research will contribute to literature in both fields. It will contribute to work in critical medical anthropology (CMA), a growing sub-discipline that "emphasizes the importance of political and economic forces, including the exercise of power, in shaping health, disease, illness experience, and health care" (Singer and Baer 1995: 5). Medical anthropologists using a CMA or political economy approach have produced only a relatively small body of local ethnographies that directly examine the effects of foreign aid and NGO activity (Maternowska 2006: 161). This research will add to that literature by specifically examining the ideological boundary between the HIV/AIDS industry and those they are meant to serve in post-conflict Northern Uganda.

As a student of African Studies, I believe the discipline lacks significant research within the crucial field of public health. Public health has been dominated by social

science theories and perspectives, but these studies have been done, for the most part, by researchers outside of African Studies. In his chapter exploring the interdisciplinarity of African Studies, Paul Tiyambe Zeleza (2006) ends by noting that research about health interventions are written within a particular racialized discourse that presumes Africa and Africans are the problem from whom no solutions can be expected (26). My study challenges these assumptions by offering alternative experiences to paradigms of Western universality that focus on individual behaviour outcomes. In hopes that my research will strengthen the importance of “the moral, ethical codes by which relationships and expectations in health behaviour are defined, measured, and rewarded” (Zeleza 2006: 26), I incorporate more recognition of cultural identity and values by opening up a space for discussion within HIV/AIDS discourse that gives significant credit to a history of inequality.

Chapter Two

History and the Development of ‘Community’ in Uganda

It was a breezy Monday afternoon and the interview had gone well over the thirty minutes initially scheduled. Martin sat in his large leather office chair, animatedly describing his apprehensions working within the development and healthcare sectors in Uganda. His attitude alternated between relaxed and excited as he critiqued the aid world with an unguarded boldness that I had not encountered previously in my experience interviewing NGO workers. Martin was a mid-level Ugandan administrator working within a local HIV/AIDS NGO in Gulu with an impressive employment history at numerous international and local aid organizations throughout the country. When I asked him about his perceptions of the aid industry and their dependency on donor funding, he leaned over and shouted, “Dangerous! The word is dangerous! It is just terrible, eh! It is just terrible because it means that many in the absence of aid must die. But should they die? So it is just terrible, it is dangerous.”

Martin’s irritation developed from experiences and knowledge about the precarious situations local HIV/AIDS NGOs in Gulu often find themselves in. He laughed about how Gulu used to be called the ‘NGO theatre’ because of the size of the NGO presence, which decreased significantly once the war ended. As Martin explained, there was a shift in focus when the war ended and many organizations moved from relief aid to development or left the area entirely. Other organizations continued at the community level. As Martin reflected on Gulu’s aid situation, he told me that the main problem with aid work is that programs implemented by international organizations only

run for three to five years before moving on to new areas, and the problem with local programs and the government's programs is that since they run from assistance from these international organizations, they are kept severely dependent. As a result of this dependency, Martin concluded that, "the point is we can't provide everything. We can only provide what we have. We don't give what we don't have."

Martin's concerns reflect a wider critique of the ambiguity of aid and the unstable relations between international donor agencies, governments, and local organizations that make project implementation so difficult. Uganda has welcomed international donor agencies as important contributors to HIV/AIDS policy and projects, but, as Martin reflects, short term donor aid in the form of HIV/AIDS prevention and treatment projects prevents governments and local organizations from establishing independence and thus integrating national long-term programs.

A solution, Martin explained, was for *everyone* to take responsibility to decrease the rate of HIV infection in Uganda. People who are still HIV-negative should promote getting tested and those who are positive should disclose their status and work towards 'living positively'. Despite his relative unique frankness in criticizing aid dependency, reference to a collective responsibility to decrease HIV rates in Uganda was noted among almost all interview participants and is reflected within the language of Uganda's national HIV/AIDS reduction strategy.

This chapter examines responses such as Martin's, a response that calls for collective responsibility and action against HIV/AIDS and addresses reasons why I found Martin's reference to a collective responsibility to be a common theme throughout my interviews. This chapter also challenges common assumptions about Uganda as an

‘HIV/AIDS success story’ and explores how Uganda’s HIV/AIDS approach was heavily affected by the agendas of large international donor agencies. I will first briefly present a social history of events outlining the development of Ugandan HIV/AIDS prevention policies since 1986 to situate the multi-sectoral approach within Uganda’s wider national response. I will then explore how ‘community’ is used as a tool for indirect governing and how neoliberal individualism depoliticizes HIV/AIDS. I will end this chapter by revealing inadequacies of the HIV/AIDS response in Northern Uganda and how ‘community response’ can fail when there is no ‘community’ to begin with.

A Brief History of HIV/AIDS Policy in Uganda

Uganda has been at the centre of the global AIDS pandemic since its discovery and holds a mythical status of sorts, representing a model for how to correctly approach prodigious rates of infection among populations. Being the first African nation to identify AIDS cases, Uganda was initially labelled as one of the worst affected countries by the early 1990s, with national prevalence rates reaching as high as 20% (UNAIDS 2002). Why Uganda had the highest rates of HIV infection in Africa is uncertain, but a link has been made between high AIDS prevalence rates and the social chaos of war. AIDS broke out in the general population as Uganda was undergoing intense political and social change. Idi Amin was driven from power in 1979 and until current president Yoweri Museveni and his National Resistance Movement (NRM) ascended into power in 1986, civil war ravaged the country (Kinsman 2010). Although Museveni’s coming to power coincided with the recognition of AIDS as a serious health problem, the epidemic had already taken

hold of the country, making it incredibly difficult for the new government to respond swiftly.

Conditions in Uganda during the civil war were extremely favourable for the spread of HIV: increased population movement, war, gender inequality, poverty, unstable health infrastructure, and nonexistent civil society are associated with the proliferation of the virus (O'Manique 2004; Parkhurst 2005; Parkhurst 2001; Schoepf 2003; Thornton 2008). Hence, AIDS in Uganda was able to spread for years, and is believed to have been endemic long before the war brought it into public view (Serwadda et al. 1985). In the mid-1970s, a situation was recorded where a small number of people living close to the shores of Lake Victoria began to fall sick with a disease that was unresponsive to treatment. Even into the early 1980s, little was known about the disease and given the political instability and lack of healthcare infrastructure, HIV remained undetected for some time. The first deaths from AIDS in Uganda are said to have occurred around 1981 in Kasensaro, a small fishing village in the Southwestern district of Rakai (O'Manique 1997: 22). These deaths were recorded around the same time as the new disease was beginning to be recognized in the United States (O'Manique 1997: 22).

Locally called 'slim' and named after the noticeable wasting and emaciation of those infected, the disease was concentrated in areas of Uganda known for their trading industry and high density of migrant workers. Specifically, people in trading centres on the shores of Lake Victoria closest to Tanzania seemed to be falling sick with slim most frequently. Despite its beginnings in the southwest, the disease quickly spread throughout the country, travelling east and then north. The first Northern case of AIDS was recorded

in January 1985 at St. Mary's Hospital in Lacor, indicating that AIDS had travelled to all corners of Uganda and was now indeed a nation-wide epidemic (Hooper 1990).

Uganda's first national response

The general population's knowledge of slim was essential for driving Uganda's early response and implementing AIDS policies because AIDS was recognized as an indigenous—rather than foreign—illness (Allen 2006: 12; Serwadda et al. 1985; Thornton 2008: 100). When Museveni came to power in January 1986, knowledge of the disease was relatively widespread in the most affected regions of the south, and even before the NRM overthrew then-president Tito Okello, plans were already underway to respond to the growing threat of AIDS. It was not until Museveni became president, though, that efforts to stem the tide of AIDS were pushed to the forefront of government action.

In contrast to many world leaders who ignored the looming threat, Museveni and his government were open about AIDS and began strategic policy planning immediately. In May 1986, less than four months after the new government's inauguration, the new Minister of Health, Dr. Ruhankana Rugunda, publicly announced at the World Health Organization's (WHO) 39th World Health Assembly: "Fellow delegates, I have to inform you that we have a problem with AIDS in Uganda, and we would like the support of the international community in dealing with it" (Asingwire and Kyomuhendo 2006: 347). Less than five months later, the National Committee for the Prevention of AIDS (NCPA) was formed. Shortly thereafter, with WHO funding, the WHO and the Ministry of Health developed the AIDS Control Programme (ACP) (AIDS Control Programme 1987, 1988).

The WHO assisted the Ministry of Health in drawing up the ACP five-year action plan on AIDS published in April of 1987, making Uganda the first nation in the world to develop a dedicated national AIDS response (Parkhurst 2005: 578; Putzel 2006: 175).

The international community had significant influence on the establishment of Ugandan AIDS policies, and early objectives remain closely aligned with international recommendations to place HIV within a public health framework (Parkhurst 2005: 579). Within the first four years, ACP had focused on establishing a HIV surveillance system, increasing health and HIV/AIDS education throughout the country and improving blood transfusion services (AIDS Control Programme 1987; Asingwire and Kyomuhendo 2006: 347). Though the WHO was the main source of funds for ACP in the late 1980s, other donors included the UK, Sweden, the USA, Denmark, Norway, and Italy. Direct bilateral support had been received by UNICEF, the EU, Germany, and several NGOs (AIDS Control Programme 1988). By 1989, the ACP project plan developed an even greater role for NGOs in the national HIV/AIDS prevention effort. NGOs were called upon to undertake HIV/AIDS control activities directly on behalf of the government (Parkhurst 2005: 580). While earlier HIV/AIDS policy documents recognized the importance of NGOs in the national response, the 1989-90 ACP plan explicitly established non-state actors as main supporters of the HIV response.

Uganda's 'open response'

As it was, the backdrop to all ACP's work was one core principle: that Uganda would pursue an 'open' policy towards AIDS (Kinsman 2010; Okware et al. 2001; O'Manique 2004; Parkhurst 2005). What this meant was that the government did not call on one

particular streamlined method of AIDS response, nor was the government closed to ideas of international assistance. As a senior official in the Ministry of Health explained to John Kinsman during his fieldwork, “the key person was the President, and he guaranteed that the government’s position would be open, frank, positive, and proactive dealing with [AIDS]” (2010: 71). This openness included the demand for a range of state and non-state stakeholders to participate in policy consultation and required elected officials from the national level to village level to discuss AIDS at every public meeting (Kinsman 2010: 71). To many, openness allowed different actors at all levels to approach HIV/AIDS in their own unique ways and within their own means. By the beginning of the 1990s, Uganda’s ‘open’ approach had resulted in the establishment of over one thousand AIDS NGOs involved in service provision activities, with each designing activities and interventions for the communities they served (Schoepf 2003: 554). Despite the saturation of non-state and state run AIDS projects and programs throughout Uganda, national HIV policy through the ACP placed the HIV/AIDS response squarely within the Ministry of Health. This meant that, at all levels, HIV/AIDS was treated as a health issue and projects focused solely on education campaigns to spread awareness and change behaviour.

In the early stages of the epidemic, when Uganda was developing its open response, a positive test for HIV was a death sentence for an infected person because treatment at the time was of limited effectiveness. Prevention, therefore, remained the only long-term solution and the only means of action in Uganda. The role of the ACP, before 1992, was simply to inform, and policy instructed other actors to do the same (Thornton 2008). A massive information, education and communication (IEC) campaign

focused on awareness of HIV/AIDS. Behaviour change was key to Uganda's early 'open' approach. Highly influenced by the President's Emergency Plan for AIDS Relief (PEPFAR) under George W. Bush, the Ugandan government, religious leaders, and non-state actors used mass media, pamphlets, booklets, and posters advocating abstinence, faithfulness ('be faithful'), and condom use (otherwise known as the 'ABC' method) as the main methods of HIV prevention.

Towards an official multi-sectoral approach

By the beginning of the last decade of the twentieth century, the government of Uganda began to recognize that AIDS could no longer be addressed solely as a health issue and sought proactive change. The government began consulting and discussing with various stake-holders an approach that would bring together all sectors of government, government supported institutions, and all civil societal organizations such as NGOs, community-based organizations, and faith-based organizations into an integrated national response that eventually became the Multi-Sectoral AIDS Control Approach (MACA) (Thornton 2008:131) that stated:

All Ugandans have individual and collective responsibility to be actively involved in AIDS control activities in a coordinated way at the various administrative and political levels down to the grassroots level. The fight against AIDS is not only directed at the prevention of the spread of HIV but also addresses the active response to, and management of, all perceived consequences of the epidemic. The process of preventing HIV infection, and controlling its consequences by the various organizations and individuals in the country, should be comprehensive and sensitive to all aspects of the epidemic and emphasize capacity building for sustainable activities among sectors and individuals. [Uganda AIDS Commission 1993: 3]

MACA was drawn up in February of 1993 and was the foundational document of the newly established Uganda AIDS Commission (UAC). The UAC was founded by an act of parliament in 1992 and was created to coordinate MACA's objectives. Under the UAC, MACA outlined a multi-sectoral framework which called upon *all* members of society to become involved with the fight against the disease (Uganda AIDS Commission 2003). This approach emphasized the collective responsibility of individuals, community groups, different levels of government and other non-state agencies for the prevention of HIV infection. It also focused on strengthening organizational capacity for government and non-governmental organizations to sustain AIDS activities. AIDS in Uganda was now addressed as being a problem cutting across all sectors of society and the responsibility of curbing the epidemic was placed in the hands of *everyone*.

Where the National Committee for the Prevention of AIDS (NCPA) was run by the Ministry of Health, the UAC was located within the Office of the President, giving it more power to coordinate and implement policy. UAC's responsibility was to plan, budget, and coordinate all MACA activities within the public and private sectors including reducing the spread of HIV, mitigating the health and socioeconomic effects, strengthening national capacity in the response to the epidemic, establishing a national information database on HIV/AIDS, and strengthening the national capacity to undertake research (O'Manique 2004: 154; Thornton 2008: 135). These objectives were strongly supported by international donors, including the World Bank, who began to take an increased interest in HIV/AIDS policy and health in Uganda with the introduction of the UAC, eventually becoming the largest single donor to the multi-sectoral strategy (O'Manique 2004: 154; Parkhurst 2005: 580-581).

Building on the multi-sectoral approach, the Strategic Framework for HIV/AIDS Prevention and Care for the 1998-2002 period was developed in 1997 by the UAC. This framework focused on strengthening the national, district, and lower level capacity to respond to the HIV/AIDS epidemic; establishing a national information base on HIV/AIDS; strengthening the national capacity to undertake HIV/AIDS research; and providing care, support, and protection to reduce vulnerabilities of individuals and communities to contracting HIV/AIDS with a specific focus on children, youth, and women (Uganda AIDS Commission 2000: 20).

The 'development' of HIV/AIDS

The multi-sectoral approach was Uganda's main documented policy response undertaken by the government to address HIV/AIDS. Since MACA, newer government documents have only added marginally to these policy initiatives. In 2000, the National Strategic Framework for HIV/AIDS prevention and care, which outlines overall goals of the UAC, readdressed key priority areas for the national response. This document emphasized a scale-up of the multi-sectoral approach through integrating HIV/AIDS issues into the Poverty Eradication Plan, Uganda's overarching national strategy for national development (Asingwire and Kyomuhendo 2006: 356). This new plan required all sectors of government to mainstream HIV/AIDS within their poverty eradication and overall developmental activity plans. Specifically, the plan focused on mitigation and outlined orphans and child-headed households as risk groups for infection, correlating the AIDS epidemic with adverse economic effects (Uganda AIDS Commission 2000). The plan acknowledged the need for psychosocial support, healthcare, and sources of income for

people living with HIV/AIDS and their families, and outlined key areas in which to bring about change at community, household, and individual levels.

The community was to be supported through income generating projects and microcredit loans as a means of minimizing the adverse socio-economic effects of living with HIV/AIDS, and non-state actors were to be further mobilized to support people living with HIV/AIDS. The plan defined social support by non-state actors as the dispersal of foodstuffs, counselling services, mutual support activities, and encouraging HIV testing (Uganda AIDS Commission 2000: 27). On an individual and household level, the plan encouraged subsidies to be given for people living with HIV/AIDS to treat opportunistic infections and financial support for orphans and child-headed households (O'Manique 2004: 163-164). Acknowledging the inadequate care for very sick people living with HIV/AIDS in Uganda, the plan also promoted home-based care as an important strategy for palliative care when hospitals could not be accessed regularly. The plan outlined training, sensitization, and education of communities, households, and individuals on healthcare delivery, counselling, hygiene, and nutrition so the sick may be taken better care of.

Since this plan, two more National Strategic Plans have been drawn up for 2007/08-2011/12 and 2011/12-2014/15. Both have expanded past strategies and have called for all Ugandans, stakeholders, and political and civil leaders to use these plans as a point of reference in planning and implementing future HIV/AIDS interventions (Uganda AIDS Commission 2012; Uganda AIDS Commission 2007). These plans have further emphasized HIV/AIDS as a national development priority, urging all government sectors to effectively mainstream and scale-up HIV/AIDS programs as a way to bring

about poverty reduction. While emphasizing non-state actor responsibilities has produced many different types of HIV/AIDS reduction strategies and has led to a general awareness about HIV/AIDS among most Ugandans, it is also a sign of limited finances to fund an integrated, nation-wide state-run response. The next section of this chapter will analyze community-based responses as methods through which HIV/AIDS prevention policies and care are implemented, and examine how Uganda's approach has indirectly depoliticized the causes and outcomes of HIV/AIDS among marginalized people within Northern Uganda.

An Analysis of the 'Community Response'

The Ugandan government's willingness to work with both state-run and non-state institutions led to the development of the multi-sectoral response that eventually, as research and policy on HIV/AIDS grew, sought to incorporate poverty reduction strategies as main prevention techniques. In all policy documents since MACA, HIV/AIDS reduction efforts have been framed as the responsibility of local and international NGOs, local level committees, district level counsellors, the private sector, traditional healers, individuals, and families, with the government only acting as overseer. As such, for Uganda, mobilization of resources at the 'community' level became essential for project implementation. Although community-based programming has become essential to Uganda's HIV/AIDS project mobilization strategies, what is exactly meant by 'community' is never made explicit. Because understanding how people have been influenced by Uganda's HIV/AIDS policy rhetoric is integral for understanding wider conceptualizations of HIV/AIDS as a disease within Uganda, this

section will deconstruct what is meant by ‘community’. It will also explore why community-based approaches to HIV/AIDS reduction strategies have become increasingly popular not only in Uganda, but across all aid-dependent countries.

Neoliberalism and the rhetoric of ‘community’

Nikolas Rose (1999) described ‘community’ as “a moral field binding persons into durable relations. It is a space of *emotional relationships* through which *individual identities* are constructed through their bonds to *micro-cultures* of values and meanings” (172). In Uganda, early efforts to control AIDS were folded together with national efforts to build a new Uganda, free from the political and economic turmoil of the past (Thornton 2008: 129). Hence, AIDS responses were linked to the creation of an *imagined community* (Anderson 2006) of Ugandans morally obligated to spread HIV/AIDS awareness and actively involve themselves in behaviour change initiatives.

To Rose, the community also represents a ‘third space’ where government has been re-invented, and his description of community as governmental can be useful for analyzing Uganda’s use of community in its HIV/AIDS response. As citizens, all Ugandans are called upon to work together to solve the HIV/AIDS crisis. Those not infected are encouraged to practice safe sexual behaviours and care for the sick, and the HIV-positive are expected to spread awareness and cease engaging in risky sexual behaviour. Rose argues that neoliberal pressures have transformed the political role of the state from a social state to an enabling state, whereby political government is relieved of its powers and obligations to steer from the centre and is no longer required to attend to all of society’s needs. Instead, “individuals, firms, organizations, localities, schools,

parents, hospitals, housing estates must take on themselves—as ‘partners’—a portion of the responsibility for resolving these issues” (Rose 1999: 174). These communities are to be made responsible for the destiny of society as a whole. Politics is within society itself, not within a centralized locality, and presents itself as a form of individual morality and organizational responsibility.

Rose’s theoretical inquiries into the state and community reflect idiosyncratic developments of countries within what is more commonly referred to as the ‘Western world’ and describe the historicity of political development specifically within these nations. Uganda, as a sovereign nation, is a product of Europe’s ‘Scramble for Africa’, and did not become independent from Britain until 1962 (Kasozi 1994: 59). Though Uganda’s political and social development as a nation is not considered in Rose’s theoretical interpretations of political power, I use Rose because Uganda’s HIV/AIDS strategies have been influenced strongly by Western nations who are almost always the main aid donors for Uganda’s HIV/AIDS projects. Not only do Western nations act as donors of aid, but Western NGOs often have on-the-ground programs that give direct aid to people living with HIV/AIDS.

According to Alan Fowler (2000), the Reagan-Thatcher era marked the beginning of the proliferation of non-state actors as agents of authority in a sovereign nation (2). This era reinstated neoliberal economic agendas and moved away from the government and towards the market as the engine of growth and progress. Accordingly, this translated to responsibility placed on citizens and their organizations rather than the state. In Uganda, due to the history of structural constraints placed on the government that limited its capacity to provide adequate state-run institutions, community approaches to

HIV/AIDS have become necessary in order to provide any sort of aid for people living with HIV/AIDS.

Despite the existence of a national HIV/AIDS approach, the Ugandan government's reliance on non-state actors to implement projects places responsibility for reducing rates of HIV infection at the community level while the limited resources that do exist are being used in the most 'cost-effective' and 'efficient' manner. O'Manique (2004) argues that Uganda's strategically developed HIV/AIDS program has created communities which have been sensitized about their own role in the management of HIV/AIDS but now need to identify local sources of financial, material, and spiritual support that will enable them to take full responsibility for their sick (157-158).

Accordingly, within the broad managerial framework of AIDS control and prevention organized by the government, targeted interventions are set up with the intention of tapping into local knowledges and capacities to empower individuals and local groups to foster self-reliance and deal with the AIDS crisis themselves.

Knowledge is power: education as prevention

In the early stages of Uganda's AIDS policy, before the association of HIV/AIDS with poverty or the scale-up of access to ARV medication, the roles of the government and non-state actors were to inform people about how the virus is spread and how to protect themselves from infection. The general consensus was that by telling people the risks, their instinct for self-preservation would help them avoid infection (Kinsman 2010: 73). For example, in an ACP report from 1989, an editorial message addressing healthcare workers states:

The information contained in this report gives you a clear picture of the AIDS situation in Uganda. It is not meant to frighten you. Knowledge is power. Now that you have information about AIDS, you are empowered to consciously decide to abstain from irresponsible and unhealthy sexual relationships, and similarly educate others...The decision to save your life is entirely yours. We wish you good reading. [Kinsman 2010: 73 from ACP 1989b: 1]

Responsibility for behaviour change was thereby passed to the individual with no reference to the wider structural issues such as poverty or gender inequality that may inhibit one from practicing 'safe' sexual behaviours. The danger in this was that making these barriers invisible placed blame on the individual when projects failed.

Non-state and state actors disseminated AIDS information to the general population through many channels made available through existing infrastructure. Schools, public officials, politicians, Ugandan celebrities, district health offices, churches, mosques, hospitals, NGOs, community-based organizations, and faith-based organizations all contributed significantly in spreading awareness and educating the public. One among many large international aid organizations was UNICEF. Working with the Ministry of Health, they undertook a major HIV/AIDS awareness campaign and by 1989, seven million pamphlets had been distributed (ACP 1989a: 8 from Kinsman 2010: 73). Nationally, a large collective effort was dedicated during the early years of HIV/AIDS to informing the public about HIV/AIDS and how to protect themselves.

Today, despite the availability of ARVs to treat AIDS, behaviour change remains an important prevention technique. During fieldwork, I was given a training manual written in 2004 by an Italian NGO stationed in Uganda that teaches secondary school

teachers how to talk to youth about preventing HIV/AIDS. In one activity, students are invited to repeat the following:

Life is a gift. I am an active participant in my life and growth, and I am responsible for how I handle this gift. I am the one who takes care of my life through what I choose. Every choice has its consequences, positive or negative. We are the ones who make the choices. We need to learn to make the best decisions in each situation. [AVSI 2004: 19]

Titled ‘The Value of Life’, this training manual describes life as a gift and directs teachers to use the manual’s activities as a way to promote behaviour change that will encourage sexually responsible behaviour.

Prevention programs targeting behaviour change were the main methods of addressing high HIV rates in Uganda in the early years before much was known about the disease. Despite HIV’s proven correlation with poverty, behaviour change initiatives remain an important component to Uganda’s national strategy for eliminating HIV/AIDS, though other types of techniques have grown in popularity in recent years. The following section will explore other techniques used by Uganda to reduce prevalence rates.

Uneven aid: exploring geographical variations in community responses

As professionalized knowledge about HIV/AIDS grew, prevention techniques changed. Education programs and behaviour change initiatives remained but psychosocial support as well as poverty reduction strategies became essential for the care of people living with the virus. Uganda’s pressure on community HIV/AIDS initiatives spurred numerous unique developments. Notable was the creation of The AIDS Support Organization (TASO), the first indigenous African organization focused on living with—rather than

dying from—AIDS. It was formed in 1987 by Dr. Noerine Kaleeba and a small group of people living with HIV/AIDS who wished to provide support and counselling, and to mobilize community care for people with HIV/AIDS (TASO 2002: 1). Aside from educating people on behaviour change, its main purpose was promoting stigma reduction and bringing discussions about HIV/AIDS into the public domain (Kaleeba et al. 1997). Today, TASO also provides ARVs and has significant medical support for opportunistic infections.

TASO was started in a small shed on the grounds of Mulago Hospital, Uganda's largest National Referral Hospital located in Kampala. Despite its meager beginning, TASO has grown and now has 11 service centres in major towns and cities across the country and has cared for over 300 thousand individuals living with HIV/AIDS. Over the years it has had collaborative projects with, or has received funding from, various large international organizations such as USAID, UNAIDS, and DFID. Although TASO boasts large client numbers, its services are by no means accessible to all Ugandans living with HIV/AIDS. In fact, Uganda, as a largely rural country ridden with poor road infrastructure and remote communities, has great variation in community-based HIV/AIDS activities. Most programs are implemented in the south-central region around the capital city Kampala, reflecting the centralized localities of international or highly influential national NGO head offices and the unevenness and inaccessibility of HIV/AIDS projects outside of densely populated urban areas.

Types of service provisions and care for people living with HIV/AIDS range across the country. On one end of the scale is TASO, an internationally respected national HIV/AIDS organization that commands a budget of hundreds of thousands of U.S.

dollars a year (O'Manique 2004: 158). On the other end, and what I frequently encountered during fieldwork, are small independent groups of men and women securing small grants or loans to start businesses or to aid in agricultural output for people living with HIV/AIDS. While both TASO and these small microcredit groups rely on community mobilization, small groups often falter quickly after they are formed due to inadequate financing or logistical problems. Whereas some areas of Uganda have very few services available for people living with HIV/AIDS, others have so many actors competing for resources and beneficiaries that project implementation is ineffective. A senior administrator at a local HIV/AIDS NGO in Uganda described competition as the most challenging aspect of project performance. He explained that since all HIV/AIDS NGOs serve the same beneficiaries if they are in the same area, each organization wants to “make the beneficiaries more on their side”. As he explained:

So you know, we do a lot of community training with a lot of community volunteers to create a network and make sure that we are really on the ground. And one of these challenges is at the beginning, our volunteers were volunteers without any pay. But when other organizations came, they started paying volunteers money and all our volunteers went away to them because they had money for them. For us we didn't have money to pay them. So again we had to start training new volunteers again. And then we had to start to talk to our donor at least to give some support to these community volunteers. [Interview with senior administrator, November 11th 2013]

Relying on NGOs and, in turn, NGOs' reliance upon external donor funding to provide services that the public sector is not equipped to provide, have distorted the provision of HIV/AIDS services and programs across Uganda. While some areas have no formal service provision at all, others have NGOs competing with one another for project funding, and the limited resources that do exist are being used in the most 'cost-effective'

and ‘efficient’ manner. Instead of expanding the capacity of state-run healthcare, reliance for solving the HIV/AIDS crisis has been placed squarely on the shoulders of the community. In the next section, I discuss the implications of this unevenness in HIV/AIDS resources for Northern Uganda.

Northern Uganda: The Invisible Disease

Within HIV/AIDS literature and among those working within development and aid, Museveni’s presidency is commonly associated with peace, prosperity, and stability, and his extraordinary level of commitment, leadership, and openness to address HIV/AIDS is believed to have directly steered the ‘successes’ of national HIV/AIDS policy implementation. Data from antenatal sites showing incredible decreases in national prevalence rates directly followed the formation of the UAC and, consequently, Museveni and his government were praised as visionaries for Uganda’s future (Thornton 2008: 42). The most important findings that transformed the view of the country from an HIV/AIDS disaster to a success story almost overnight, were the findings in the south-west of the country in 1995. Two studies in neighbouring south-west districts of Masaka and Rakai tracked populations from the end of the 1980s and began publishing findings in 1995. Results from the studies showed very little change in overall prevalence rates during the first five-year follow-up; from 8.2% in 1990 to 7.6% in 1994 (Mulder et al. 1995). However, a significant drop (3.4% to 1.0%) in prevalence rates among males aged 13 to 24 years was noted as well as a less dramatic drop in females of the same age (9.9% to 7.3%) (Mulder et al. 1995). This study represented the first recorded decline in HIV prevalence among young adults in sub-Saharan Africa and following its publication,

optimistic interpretations were strengthened by similar trends of declining prevalence throughout various antenatal sites across the country (Allen 2005: 10).

What is often not contested in discussions about Uganda's 'success' is the severe bias towards data from Southern Uganda and the lack of knowledge about early HIV/AIDS rates in the north of the country. Early national prevalence research took data from 21 antenatal sites, but 15 were located in the south and the six Northern sites only began operating in 1993, with one site covering the entire north-east (Allen 2005: 9). Data from antenatal surveillance in 2002 revealed an HIV prevalence of 11.9% for the Northern district of Gulu, far higher than the national median HIV prevalence for rural areas of 4.7% (Uganda Ministry of Health 2003). By 2006, this rate had reduced to 8.2%, but still remained well above the national average (Wilhelm-Solomon 2010: 16).

Though Northern Uganda's population is rural and often lives in remote villages away from large urban centres with better healthcare facilities, this does not fully explain its lack of antenatal infrastructure or why HIV rates in the north were rising when rates everywhere else were falling. Rather, despite Uganda's presentation as a successful case study of 'post-conflict reconstruction' (World Bank 1998; World Bank 2000), directly after Museveni's takeover, deep-seated political opposition stemming as far back as early colonization led to a civil war and mass forced displacement in Northern Uganda (Allen and Vlassenroot 2010: 3). Therefore, during early HIV/AIDS studies and data collection, social and political instability made research practically impossible and deplorable living conditions and breakdown of societal infrastructure contributed to mass poverty and helped fuel HIV prevalence in Northern Uganda.

To conceptualize why HIV/AIDS prevalence rates in Northern Uganda were not considered in early national surveillance data, and, more importantly, to understand why Museveni and his government kept silent about disparities in healthcare and HIV/AIDS programs between the north and the rest, it is essential to give a historical perspective on political development and the relationship between people of the north and south. This historical analysis reveals that HIV/AIDS in Northern Uganda has developed in a particular way, separate from the rest of the country.

A short history of the north

War in Northern Uganda broke out directly after Museveni became president due to the historical processes by which ethnic identities in Northern and Southern Uganda were constructed and politicized by colonial rule. In Uganda, British colonialism created a north-south ethnic divide by allocating government and military positions based on ethnicity. The Acholi and Lango people of the north made up the majority of the national military, which granted them considerable access to national government positions at the time of independence (Branch 2010: 28). The first head of state was Milton Obote, a Lango from Northern Uganda who entrenched Northern dominance within the armed forces. During Obote's reign, the army grew from 700 troops at the end of independence to 9,000 at the time of Idi Amin's coup, of which over one third were Acholi (Branch 2010: 29; Mudoola 1996: 97).

In 1971, Obote was thrown from power by Idi Amin Dada, a Muslim who came from the north-west part of Uganda. The 1970s saw the destabilization of the dominance of internal Northern ethnic political order with Amin's proactive eradication of Acholi

and Lango people from the military and national government (Branch 2010: 29). Amin was overthrown in 1979 following an invasion from Tanzania with the help of Museveni's National Resistance Movement (NRM) and Obote was returned to power. Despite Obote's return, there was no wide-scale reinstatement of Acholi within the national government, and instead they were brought into the state principally through the military and officer corps of the Uganda National Liberation Army (UNLA) (Branch 2010: 30). Some who opposed Amin were unwilling to accept Obote's return to power, including Museveni. During the early 1980s, Museveni waged a guerrilla campaign against the government with support from the Banyakole, his own ethnic group living in the south-west who viewed Obote's reign as an act of Northern dominance (Allen and Vlassenroot 2010: 7). During this time, political differences were gradually growing between the Northern Acholi and Lango and eventually Acholi soldiers removed Obote and placed an Acholi, Tito Okello, in power. Okello, in an effort to end political instability, wrote up a peace agreement that Museveni signed. Despite this, a few months later Museveni proceeded to march on Kampala, becoming president in January 1986.

No longer welcomed, the Acholi who were members of the UNLA fled north with Museveni's NRM at their heels. The NRM launched an insurgency in Northern Uganda, making no distinctions between ex-UNLA soldiers and Acholi civilians (Branch 2010: 34). This strategy eventually led to a full-on rebellion. Twenty years of Northern conflict ensued; the government's military fighting against Acholi rebel groups, the most famous of which was the Lord's Resistance Army (LRA). Numbering a few thousands at most, The LRA waged a highly effective campaign of regional destabilization despite their small numbers. One of the government's strategies for dealing with the LRA was to

remove people living in rural areas who might otherwise assist the rebels out of choice or fear of what would happen if they did not (Allen and Vlassenroot 2010: 14). In many cases removals were violently enforced. By the mid-1990s, the Acholi population who were not previously residing in large towns were relocated to internally displaced people's (IDP) camps.

Hundreds of IDP camps scattered the Northern countryside, growing exponentially with every year. In 1996, there were 200 thousand living within camps but by 2005, this number had increased to 1.8 million (Bøås and Fafo 2005: 1). Northern Ugandans were mainly farmers, but limited space due to severe overpopulation made cultivation within the camps practically impossible and returning to their land to farm was rare because movement outside of the camps was limited and strictly controlled (Allen and Vlassenroot 2010: 14; Bøås and Fafo 2005: 7). Whether people entered the camps by forced eviction or were seeking safe shelter from rebels, the government simply dumped them there and abandoned them. Inhabitants often lived without proper sanitation, healthcare and nutrition and relied entirely on humanitarian aid for survival. Despite millions of dollars invested by these organizations, camp life remained miserable. Deaths from camp life are estimated to have been one thousand people per week, extraordinarily higher than deaths caused by rebel attacks (Mwenda 2010: 56).

The war continued into the early 2000s and, following a series of events including the involvement of the newly formed International Criminal Court (ICC) and the promise of amnesty to any surrendering LRA members, the LRA fled the country (Allen 2010; Brubacher 2010; Finnström 2003; Simonse et al. 2010). Since 2006, stability and order has been sustained in Northern Uganda, despite Museveni's continued discrimination,

allowing for large numbers of civilians to leave the camps and return home. In 2007, the government announced a 'voluntary' return and camp phase-out operation which accelerated the close of IDP camps and the return home of hundreds of thousands of people.

When placed into IDP camps, civilians became reliant on humanitarian assistance for survival. In fact, the international humanitarian response was so large that Gulu Town, the largest town in Gulu district and the location where I carried out most of my fieldwork, grew from a small provincial capital to a centre for the humanitarian economy with a population well over 100 thousand, and where the local economy became based entirely upon access to foreign aid (Branch 2008: 2). It is important to realize that humanitarian assistance in Northern Uganda involved hundreds of organizations and as such, project implementation was highly political, severely contested, and irregular among the camps and their inhabitants. Though this chapter does not investigate the broad scope of the humanitarian regime in Northern Uganda, I use evidence from my own fieldwork to explain how the camps created only a temporary HIV/AIDS community that led to severe accessibility issues once people returned home to their villages after the war.

HIV/AIDS community responses: the case of Northern Uganda

Ugandans who worked in Northern Uganda's aid industry during the conflict often reflected on how relatively easy project implementation and follow-up was when people lived so close together in camps. When given the opportunity, I often asked NGO workers what differences in care for people living with HIV/AIDS existed during and after the

war. One counsellor, who had been working with people living with HIV/AIDS since the 1980s, explained:

During the time of the war when people were staying in the congested camps, it was more like, you plan and go and give the service to people where they are in the camp. But after the war, when people settled back in their villages, the way of care also changed. Because now you need to follow an individual where he or she has settled. Then it was easy to reach so many people at the same time because they were together. But now the people are scattered. It is a bit challenging for the NGOs to follow every person. So, it now depends on the individuals and those who are able to seek for services are more at the advantage than those who have settled deep in the villages and they are not seeking for any support. So the care has changed. [Interview with counsellor, October 2nd 2013]

While in the camps, people living with HIV/AIDS were easily accessible so their health and wellness was easily monitored. Psychosocial support and counselling were easily done by NGO workers and often during interviews these NGO workers would lament the loss of these advantages in older times.

Now, organizations working with HIV/AIDS populations in Northern Uganda are faced with accessibility challenges. Not only are roads often in such deplorable conditions that render them inaccessible, but if the organization was not informed when their client left the camp or where they travelled to, it becomes the responsibility of the person living with HIV/AIDS to contact the NGO to record their whereabouts. Therefore, when the camps started to close in 2007, organizations working with people living with HIV/AIDS lost contact with many clients.

Return movements have made treatment and care for people living with HIV/AIDS more complicated and, accordingly, the lack of an appropriate post-conflict transitional HIV/AIDS strategy in Northern Uganda has transferred responsibility for

follow-up to the people living with HIV/AIDS. The scattering of populations and increased distances between patients and their nearest health centre have created difficulties for patients and providers, especially with the scale-up of ARV access in 2004 (Wilhelm-Solomon 2010: 17), which will be discussed in further detail within Chapters Three and Four. ARVs require rigorous life-long adherence, but in a situation such as post-conflict Northern Uganda, many individuals are so sick they cannot travel the long distance to collect their medication, and those who have lost all relatives due to war or disease have no one to collect their medication for them. These issues are serious problems that all organizations have had to deal with.

To contend with accessibility problems and the severity of ARV adherence issues, many organizations have created ‘community-based responses’, similar to those discussed earlier in the chapter. A popular strategic development among HIV/AIDS NGOs in Northern Uganda has been to use community members to monitor and track clients, and often these community members are themselves HIV-positive so have to manage their own health on top of many others’. Other organizations, such as TASO, have developed decentralized treatment distribution points in remote rural areas (Wilhelm-Solomon 2010: 17). These points allow TASO clients to access treatment and counselling without having to travel the sometimes extraordinarily long distance to the centre located in Gulu Town. While many of these changes have been met with positive feedback by the organizations’ employees and clients alike, the history of war and the under-estimation of potential challenges during the return period nonetheless left Northern Ugandans living with HIV/AIDS at a severe disadvantage.

Community-based practices have been implemented to overcome issues of inaccessibility, but understandings of community and who belongs to HIV/AIDS communities were challenged when organizations lost clients after they left the camps. The unequal landscape of community-based programs across Uganda, resulting from the government's 'open' multi-sectoral approach, poses questions as to whether or how a HIV-positive 'community' exists at all. Although Uganda's actions and focus on community responses have been celebrated in academic and policy research alike, this chapter has questioned ideas of what a 'community response' can effectively be, and has revealed the dangers of relying on the 'community' in Northern Uganda when, in fact, there may not be a 'community' at all.

Conclusion

Language within Uganda's policy documents and international organization reports suggests admiration for Uganda's multi-sectoral AIDS policy framework and promotes Uganda as a role model for other African states to follow. Common understanding among policy makers is that Uganda's strategy conceptualizes AIDS as a generalized social, political, and economic problem and continues to appropriately seek to create broad-based social, political, and economic responses by focusing on 'grass roots' community-based strategies to include all Ugandans within the national response (Uganda AIDS Commission 2000; Uganda AIDS Commission 2007; World Bank 2001; World Bank 2007). While including all Ugandans in responding to the AIDS crisis has undoubtedly produced incredible awareness of the disease nationally, Uganda's multi-sectoral strategy can also be conceptualized as a consequence of Uganda's limited capacity to undertake a

state-run AIDS response. This chapter has demonstrated that due to boundaries circumscribed by international neoliberal agendas, the multi-sectoral strategy's dependency on community mobilization has further depoliticized HIV/AIDS in Uganda by victim blaming, through placing responsibility for good health on individual behaviour. To overcome limited capacity to implement a state-run AIDS response, Museveni and his government strategically developed AIDS responses to play into the international community's policies by providing only the foundation for broader action, such as awareness campaigns, health education, and surveillance of HIV rates (Parkhurst 2005: 587). Most service provision on the ground has been left to non-state agencies with the state acting as manager, allowing for Ugandans to receive AIDS related services without overstretching the capacity of the government.

In Northern Uganda specifically, years of conflict has not allowed for the development of accessible healthcare centres for many rural populations and inaccessibility reigns as a limiting factor in providing adequate HIV/AIDS care, support, treatment, and prevention programs, especially once ART became financially accessible to all Ugandans. As I will explore further in the following chapter, the introduction of ART within an uneven landscape of HIV/AIDS programs has produced life-threatening inequalities. Vulnerability measurements reign as objective tools through which resources are allocated, thereby determining who are members of the 'community' and receive care, and who are not.

Chapter Three

Unequal Vulnerabilities

In Uganda, treatment options have changed dramatically within the past decade, from palliative care to anti-retroviral therapy (ART). Despite the existence of various forms of anti-HIV drugs since 1989, until only recently have lifesaving anti-retroviral medication (ARV) ‘cocktails’ been accessible to impoverished populations throughout sub-Saharan Africa. Before then, the extraordinarily high price of drugs made them inaccessible to the majority of populations. In Uganda, the Joint Clinical Research Centre in Kampala provided ART from 1991, but it remained accessible only to the privileged few who could afford to spend hundreds of US dollars a month to survive. In the 1990s, inequality in life-expectancy between countries who could afford ARVs and those who could not exploded and pressure, brought on by activists and humanitarian organizations, mounted on the pharmaceutical industry to provide affordable ARVs to those who could not pay (Nguyen 2010).

Access to treatment in some parts of Africa began to move forward in the late 1990s with UNAIDS’ Drug Access Initiative (DAI). Uganda, Côte d’Ivoire, Vietnam, Chile, and Senegal were part of the project’s first phase (Seeley 2014: 94). Although Ugandans had to pay upwards of \$700 per month for the drugs, thereby severely limiting those involved, the DAI’s goal was to establish the necessary infrastructure to meet the increased access to treatment in the future. As a result of the project, healthcare workers were trained on how to administer the drugs, thereby laying the foundation for the expanded provision of ART in later years (Iliffe 2006: 148; Kinsman 2010: 113; Seeley

2014: 94). Dramatic changes. came about with the falling cost of ARVs, a result of competition from generic producers of drugs in Brazil, India, and increasingly, Africa. Uganda's policy of openness about HIV/AIDS and Museveni's support for non-state funded HIV/AIDS projects aided in the rollout of ART programs both within and outside of government health facilities. The initiation of WHO and UNAID's launch of the "3 by 5 Initiative," which aimed to provide life-long ART to three million people living with HIV/AIDS in poor countries by the end of 2005 (Macklin 2004), coupled with the Global Fund to Fight AIDS, Tuberculosis, and Malaria, and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) saw a huge influx of free ART programs in Uganda.

PEPFAR was by far the largest single donor, but, because of a lack of homogeneity within Uganda's national response, PEPFAR funded many different projects: some by faith-based NGOs, some by secular NGOs, some parastatal, some directly state run, and each of these had their own concepts about how to treat and prevent HIV (Whyte et al. 2013: 143). The uneven distribution of pre-existing HIV/AIDS prevention projects was another factor influencing ART implementation, as many ART programs cut costs by using previously existing aid infrastructure. Many HIV/AIDS organizations that were established before ART rollout saw numerous managerial and departmental changes take place in order to successfully manage the new treatment. For the Positive Outreach Network, this meant joining with the major privately-run hospital in the area to implement ARV treatment. The Positive Outreach Network would continue their community-based prevention programs, but they now would have the responsibility of monitoring ARV users who were registered with the hospital, ensuring adherence, proper drug storage, and care.

This chapter follows the Positive Outreach Network post-ARV rollout by exploring how a recognition of ‘clientship’ has transformed the relationship between care provider and receiver. With diminishing budgets for non-biomedical HIV/AIDS programs, the Positive Outreach Network has had to change how they provide aid and who they give it to. By exploring discourses of ‘vulnerability’ through ethnographic examples, this chapter suggests the development of unequal processes of inclusion and exclusion in access to aid that rely on ‘ideal’ clients and personal relationships.

Changing Healthcare Regimes

Biomedical experts emphasize overwhelmingly the importance of ARV adherence and life-long treatment to prevent the development of drug-resistance, so HIV/AIDS programs across the globe have to ensure their members do, indeed, follow directions. Because Uganda does not have just one standard state-run package of HIV/AIDS care, each ART program recruits its own members, monitors their medication and health status, and keeps their files. They have also started to refer to their members as ‘clients’. To be a client means to belong to an organization that registers one’s information and provides free ARVs and other medication. But to be a client also means that the organization has certain expectations of you (Whyte et al. 2013: 144). While a ‘patient’ may submit to reduced agency and passivity in care from health professionals, the relationship between a ‘client’ and their care providers generally can be considered reciprocal; the provider will continue to give ARVs and care as long as the client follows instructions. There is a neoliberal undertone where ‘clientship’ shifts HIV/AIDS from its

associations with illness and patienthood toward the idea of freedom and choice (Mol 2008: 107; Prince 2012: 24).

With the blossoming of ‘clientship’ in Ugandan healthcare practices, a new problem at the Positive Outreach Network has emerged. The Positive Outreach Network’s programs rely on and promote community involvement for the care of its clients as well as all people living with HIV/AIDS, but the introduction of ARVs altered this relationship. Increased monitoring made clients of the Positive Outreach Network more visible to the wider non HIV-positive community. Healthcare facilities stressed the importance of adherence so, to compete with increased need for surveillance, the Positive Outreach Network hired community volunteers, who were often HIV-positive themselves, to go and monitor clients’ adherence, ensuring compliance with the medication regime. These volunteers were responsible for checking-up with clients periodically and reminding them of upcoming hospital visits for drug refills and testing, which also increased with the introduction of the Positive Outreach Network’s ART program. I learned early on in fieldwork that although clients were closely monitored and general adherence was going relatively well, increased visibility of the Positive Outreach Network attending to people living with HIV led to the assumption among HIV-negative (as well as HIV-positive) community members that clients ‘belonged’ to the Positive Outreach Network. Relatives and neighbours began assuming the Positive Outreach Network would take care of their clients, freeing others of the responsibility and thereby unraveling the foundation of the Positive Outreach Network’s ‘community response’ aid techniques.

In every way to an onlooker, the Positive Outreach Network's clients did 'belong' to them: they housed all clients' names, personal information, and medical history in individual files; they visited clients to ensure adherence; they cared for clients when they fell ill; they supported children in school; and they gave clients living essentials. After registering with the Positive Outreach Network, clients were also discouraged from receiving care from other organizations to prevent treatment duplication that may lead to noncompliance and drug resistance. This, however, created some problems.

When humanitarian organizations flooded Northern Uganda in response to displacement and war, many people living with HIV/AIDS capitalized on the opportunity to receive material support and registered with as many organizations as possible in order to be given goods and services provided from all. But with the implementation of ARVs, belonging to more than one organization could significantly affect ARV monitoring and adherence. The drugs given by different organizations could also be slightly different, and so, registering as clients to numerous organizations stopped, leaving clients the ability to 'belong' to one organization only.

Uncertain care

Despite the common assumption about the Positive Outreach Network's responsibilities to their clients, in fact, the only guaranteed consequence of being a client of the Positive Outreach Network is access to ARVs. All other material or financial support that clients of the Positive Outreach Network receive is not guaranteed, which is a process of aid provision that has changed significantly from pre-ART rollout. Previous to ART projects, HIV/AIDS organizations focused on prevention and care, and in Northern Uganda, when

people were living in IDP camps, organizations often provided emergency material support like blankets, jerry cans for storing clean water, and mosquito nets. Those who were HIV-positive were allowed access to additional services in a process that Vinh-Kim Nguyen has described elsewhere as *therapeutic citizenship*; where disease status legitimizes claims for treatment and recognition (2010; see also Petryna 2002 on *biological citizenship*). People living with HIV/AIDS in IDP camps were also granted access to additional food and nutritional support through the World Food Program, (Cordeil et al. 2008) and psychosocial support and behaviour change workshops through community-based organizations.

When ART projects were implemented, HIV/AIDS became ‘pharmaceuticalized’. Increased provision of ART became and remains the goal of national governments, PEPFAR, and NGOs alike, while non-biomedical forms of care have lost their importance and support. Although ART allows people living with HIV/AIDS to live longer, the singular focus on drug access reflects a growing world-wide recognition of ‘treatment as prevention’ (Garnett and Baggaley 2009; Granich et al. 2009; Seeley 2014 among others), a technique based on the assertion that “where long-term ART is combined with drug tolerance, viral loads are suppressed and the virus is less likely to be passed between sexual partners” (Seeley 2014: 96). Although there is less risk of passing on the virus when undergoing ART, ‘treatment as prevention’ concerns itself solely with biomedical intervention, ignoring the social, economic, and political reasons for high HIV/AIDS prevalence. In Northern Uganda, serious concerns include practical issues such as social, economic, and political barriers to care and support.

Although ART and ‘treatment as prevention’ have brought hope and life to thousands of Ugandans, Uganda’s lack of a standardized HIV/AIDS care package and dependence on international donor organizations meant that it implemented ART without long-term solutions to social and economic problems closely associated with HIV/AIDS prevalence rates. In Northern Uganda especially, poverty was, and remains, a significant barrier to treatment and care. While treatment may be free, the cost of transportation required to travel to the health centre, or a day or more’s wages lost as one waits to see a physician, can significantly affect drug adherence, ultimately causing treatment failure (Whyte et al. 2004). For clients of the Positive Outreach Network, they must also pay a four thousand Ugandan shilling (approximately 1.75 CAD) user-fee for each visit to the private health centre to receive ARV refills. User-fees are not uncommon amongst private hospitals or clinics; the belief is that cost-sharing allows for better facilities and care than what is found at the public centres. While other parts of Uganda—especially the central region around Kampala—have comparable public and private healthcare systems, Northern Uganda’s history of unrest has destroyed public healthcare infrastructure. A routine ARV refill at the hospital for a client of the Positive Outreach Network can therefore become inaccessibly expensive.

When the Positive Outreach Network first paired with the private hospital to implement ART, treatment barriers were recognized and were often taken care of. The Positive Outreach Network implemented donor funded programs to pay user-fees and transport clients to the hospital on their refill days. The clients had the responsibility of getting to the Positive Outreach Network’s office, but once there an ambulance would drive them the few kilometres to the hospital, wait with them, and take them back. One

hot afternoon I asked Florence, a mid-level administrator of the Positive Outreach Network, if she remembers how the care provided to clients has changed over the years since the war and ART rollout. She explained:

There were a lot of benefits that were actually given to the clients, like blankets, food items. I remember on holidays, the clients at times were even given chickens. But with time, things started changing slowly because there was limited funding. So certain things were not provided. Transport was not provided. Hospital bills were paid for a long time but think it was of late that it was stopped... Officially, we are not providing. But at least in small scale...there is a basket for contribution during prayers. That money is for emergencies for beneficiaries. Like, if someone is stuck in the hospital and doesn't have anything. That is the money that is used for catering for hospital bills or transport.... So those are the changes I have seen. [Interview with Florence, October 4th 2013]

Florence was not the only staff member of the Positive Outreach Network to mention funding problems as a main barrier to care. The Positive Outreach Network relies completely on outside funding to run their programs and, as such, many employees found the organization's donor dependence the most challenging aspect of providing adequate HIV/AIDS care. They were frustrated with relying on donors who often blamed the 'failing economy' for their diminishing annual budgets and cutbacks. Beyond stresses on the economy, the growing popularity of 'treatment as prevention' and Northern Uganda's changing aid landscape also significantly contributed to donor fatigue. Biomedical solutions to reducing HIV rates have taken precedence over community responses worldwide, which are often seen as less important now that ART is available. In Northern Uganda specifically, ART implementation came at a time of significant social change. Donors who had been providing relief aid since the early 1990s began leaving Northern

Uganda as conflict ceased, no longer seeing the need to continue relief aid when life was no longer threatened.

The emphasis on treatment in response to HIV rates throughout the world has affected the Positive Outreach Network's programs severely. As it is still a community-based organization, the Positive Outreach Network sees value in alternative forms of treatment and prevention that involve the clients, their families, and others who may or may not be living with HIV/AIDS. They stress the importance of what they describe as a 'holistic approach' to the HIV/AIDS pandemic by focusing on psychological, social, economic, and physical needs of people affected and infected with HIV/AIDS. Faced with financial constraints to managing alternative forms of HIV/AIDS care within a network of aid that values biomedical treatment above all others, it is worthwhile to explore how the Positive Outreach Network chooses recipients of care. The remainder of this chapter will discuss 'official' and 'unofficial' methods the Positive Outreach Network used to choose who is in need of extra support.

Discourses of Vulnerability

In practice, humanitarian aid, driven by the moral sentiment of compassion, seeks to save the lives of the neediest and most deprived of basic needs; in other words, humanitarian aid seeks to help the most vulnerable. Ideologically, vulnerability is defined as a set of characteristics belonging to a group or individuals in terms of their capacity to anticipate, cope with, resist and recover from the impact of an identifiable event in nature or society. In conflict-ridden Northern Uganda before accessible ART, the most vulnerable population included *all* people living with HIV/AIDS. Today, since all HIV-positive

Ugandans can eventually qualify for free ARVs once their disease progresses, many lead normal lives and no longer fit the traditional description of ‘vulnerable,’ in contrast to the case during the war. In fact, if HIV-positive clients are able to work and provide for themselves and their families, employees of the Positive Outreach Network do not consider them vulnerable at all. Alexander, a mid-level administrator, explained to me that the Positive Outreach Network “targets those who are vulnerable. Within the community, not all the people living with HIV/AIDS are vulnerable. Some of them are working” (Interview with Alexander, September 30th 2013). He told me that the Positive Outreach Network supports those who cannot afford to pay their children’s school fees or who are not able to travel for medical services. Being able to work is a marker of independency so it becomes a critical identifier of one’s (lack of) vulnerability.

Measuring vulnerability: moral and cost-effective triaged care

In the aid world, beneficiaries’ independence from aid is what organizations like the Positive Outreach Network strive for. Therefore, although diminishing program budgets prohibit them from giving all of their clients the same services and aid, the Positive Outreach Network wants their clients to be self-reliant so they do not have to depend on outside help. For both of these reasons, the Positive Outreach Network depends on vulnerability measurements as a way to negotiate non-ARV aid distribution and to ensure resources do not end up with those who are not vulnerable. The Positive Outreach Network use vulnerability indices created by the Government of Uganda to help them choose who to allocate their resources to. One important index, the Uganda OVC (Orphans and Vulnerable Children) Vulnerability Index Tool (see Appendix), is used by

the Positive Outreach Network's Education Department for choosing clients' children who will be sponsored to go to school. This index was created by the Ministry of Gender, Labour and Social Development with support from USAID and the Centers for Disease Control (CDC) and is used by many organizations for their OVC programs throughout Uganda (Ministry of Gender, Labour, and Social Development 2012). The focus of attention of tools designed to assess vulnerability among clients are social characteristics such as age, gender, health status, and disability, among others.

Determining vulnerability in such a way can be understood as a process of *triage*. Deriving from the French word *trier* (to sort), triage is a medical term used to describe the procedure for prioritizing those who must receive medical treatment immediately over those who may wait (Nguyen 2010: 10). The practice began during the Napoleonic Wars as a means to sort out soldiers who could be treated and return to the battlefield from those who could not. Assessing the wounded with a medical eye, the rank of the soldier was not considered. Surgeons were instructed to see only bodies and not the uniform (Redfield 2013: 168). By the First World War, triage was a standard routine of military medicine, but had developed further criteria of selection to meet the growing needs of war. Triage became a practice that prioritized military interest rather than those of the patient and thus made selections based on criteria that served the greatest good for the greatest number (Iserson and Moskop 2007; Redfield 2013: 168). The needs of battle became the most important criteria for resource allocation.

In areas of resource abundance, triage assumes all will eventually receive care. But when discussing HIV/AIDS care in Uganda, triage occurs amid a condition of relative resource scarcity, where triage means that low priority individuals receive only

basic (medical) support. Measurements of vulnerability become the tool through which triage is performed. Since ART rollout, ARVs are available for those whose CD4 counts measure below 350, but other forms of care and material resources are only available to those who are considered vulnerable. Working with limited resources, triage allows HIV/AIDS organizations to help the largest number of people with the lowest costs.

Although Uganda's OVC Vulnerability Index Tool was used for choosing beneficiaries for programs specific to children and normally not used for others, their remained the assumption throughout the implementation of all programs and aid distribution that households with children had a higher potential for vulnerability. The tool is designed in such a way as to produce detailed checklists that make it easier to probe for vulnerabilities of those affected or infected with HIV and, hence, is very useful and efficient for aid workers and policy-makers alike, but there is no explanation as to why children are more vulnerable or why aid must be given first to households with children (Blaikie et al. 1994: 9; Wisner 2004: 190). Assigning household vulnerability first and foremost among households with children can be conceptualized as both *cost-effective* and *moral*, as I will discuss below.

The Positive Outreach Network focuses their care towards households with children instead of individuals or adults living alone as a way to allocate resources cost-effectively. Aid is not given to the child only for the benefit of that child; the aid must be given to help the entire family. For example, paying the school fees of one child to attend school is not done to benefit only that one child, rather, resources are allocated in hopes of a 'trickle down' effect. By obtaining a higher education, it is hoped that the child will secure a well-paying job that will eventually help to provide for the family and perhaps

pay the school fees of other siblings. If all goes as planned, the Positive Outreach Network's support, though given to one person directly, ends up benefitting the entire family.

Looking at the Positive Outreach Network's triage another way, children and households with children are almost always considered more vulnerable than single adult households because of the moral implications of not helping a child in need. Although the Positive Outreach Network seeks out children for aid, they also make a point to try to give aid to the *most* vulnerable child within the household. I was told by an employee working within the Positive Outreach Network's Health Department that children are chosen because of their lack of independence and total dependency on adults. He asserted, "a person who is vulnerable is a child who first of all, does not receive the care that is expected; all of the services that should be provided for the child without [the child] straining her mind of 'what will I eat tomorrow? Where shall I get my school fees?' A child is a child, you know?" (Interview with employee, October 4th 2013). Adults are considered much less prone to vulnerability because they are able to make decisions for themselves. As Florence, a mid-level administrator, explained:

Adults can be vulnerable, but at least for adults, the person has a decision to make. He is already grown up. The vulnerability can be with an adult [who]...has some disabilities, like a mental disability or physical disability. But somebody who is above 18 can make a decision. They are able, the person may be vulnerable but be able to provide for themselves. By deciding that [they] want to casually work so [they] can eat, they are able to. They have the strength and the ability to earn a living. But a child cannot do that. They need to be provided for until the person grows up... Though adults can be vulnerable...it depends on the presence of disability. [Interview with Florence, October 4th 2013]

To Florence, adults take responsibility for their actions whereas children cannot and, despite having a chronic illness, adults with HIV are only considered vulnerable when they, like children, are dependent on other people to survive.

Vinh-Kim Nguyen (2010) places processes of triage within the wider moral economy surrounding global health interventions and HIV/AIDS treatment and care. Nguyen (2010) argues that by placing certain criteria for processes of triage, “life itself was subjected to different calculations of value” (10). In Nguyen’s research, those with access to HIV/AIDS medication had lives believed to be more valuable than those without. In my research, those with lives more valued are those who receive aid and care from the Positive Outreach Network. Though Nguyen explores the limitations surrounding the rollout of life-saving ART programs in West Africa, and these processes of triage may seem more cruelly selective than the triaged non-biomedical care in Uganda today, non-biomedical forms of HIV/AIDS care are also important in so far as they serve to reduce social, economic, and political barriers to medical treatment and drug adherence.

Despite vulnerability’s seemingly objective calculations, it is important to recognize vulnerability not as an objective, quantifiable property belonging to certain individuals identified as ‘at risk’ groups, but rather as a product of social relations (Hilhorst and Bankoff 2004). As I will demonstrate below, measures of vulnerability have not been static through the course of the HIV/AIDS crisis in Uganda because vulnerability, in all its forms, is an extraordinarily subjective and ambiguous measurement and its definition is, or at least its measurement values are, completely reliant upon social constructs and the power relations within them.

Ambiguous vulnerability

During the war in Northern Uganda, people living with HIV/AIDS had access to additional foodstuffs and often enjoyed more healthcare benefits because their illness alone was enough for aid providers to consider them vulnerable persons. Since the introduction of ARVs and the rollback of other forms of HIV/AIDS care, ideas of vulnerability have changed. Though employees of the Positive Outreach Network use official definitions of vulnerability and may have a cost-effective or moral understanding of it through years of working in the aid industry, the majority of their clients have access to no such literature and are not subjected to learning about humanitarian theories or practices. Odit and Alice are two clients not considered to be vulnerable, and both have very different understandings of what vulnerability is and how one becomes vulnerable.

Odit, a male client of the Positive Outreach Network, was a business owner and soon-to-be retired military personnel who lived with his family in a village not far from Gulu. He denied that he was vulnerable at all despite being almost 60 years old with AIDS and high blood pressure because he did not feel sick. He compared his health to those without HIV:

[I am not vulnerable] because of my health. From time to time it is not bad! It comes like any other person. And when I go to the hospital...the only thing they told me was that my blood pressure is high. So I go back home and they aren't even going to give me any drugs because it is still controllable. They told me to go and do A, B, C, D.... So in me, I feel as if I have no problem. I am *living* with HIV! So I don't think I am vulnerable yet. [Interview with Odit, September 26th 2013]

Odit considered vulnerability to develop only when one becomes noticeably ill and he associated vulnerable people with those “not following directions given...at the

counselling centre” (Interview with Odit, September 26th 2013). According to Odit, one’s vulnerability develops only with not behaving the way one is taught to behave as a person living with HIV/AIDS. In other words, not ‘living positively’: not taking one’s drugs correctly and engaging in behaviours considered high risk for viral transmission. He did not consider himself to be vulnerable because as far as he was concerned, he followed directions, was never sick, nor did he ever need or ask for anything else but ARVs from the Positive Outreach Network.

Other clients had different understandings of vulnerability. Alice, for example, was a middle-aged woman living alone in a single grass-thatched hut. While, like Odit, she associated vulnerability with illness, she did not think that decision making increased or decreased one’s vulnerability. Rather, vulnerability depended on one’s lack of support system and, as a single, childless, aging woman, Alice thought of herself as highly vulnerable.

While many households normally have numerous huts, each acting as a kitchen, bedroom, living room and play area, Alice has just one, with a thin mud half-wall separating her bed from her smoky kitchen. Her house, along with the others in the compound, belonged to her brother who lived in a neighbouring district. He let her stay in it as long as she kept an eye on his other tenants. She told me that she was forced to leave her home and take refuge in her brother’s place in Gulu when her husband and four children were killed by the rebels in 1996. When she first arrived, she sold second-hand clothing in a nearby market, but when her mother fell sick and died, all of her savings went towards her funeral arrangements. From then on, she lived off the little sales made from selling charcoal by the side of the road, but has since run out of charcoal and cannot

afford to buy more. At the time of our interview, she was fermenting cassava, hopeful she would make money selling alcohol made from the fermented root.

Alice started ARVs three years before our interview. When asked what the hardest part about living with HIV is, she told me it is during the times she falls sick. Being alone puts Alice in a unique position, as most middle-aged women with HIV/AIDS have their children and extended family around to care for them when they fall ill. The last time she woke up too weak to move, she lied in bed without food, without water, and without the ability to call a friend or neighbour because she did not own a phone. What saved her, she explained, was the Positive Outreach Network's field officer who, by coincidence, happened to be visiting her home that day. Seeing her in such a state, he granted her access to some of the Positive Outreach Network's emergency food supply. That was the only time the Positive Outreach Network paid Alice any kind of special attention or gave her any extra material support.

To Alice, those without children are the most vulnerable. Children help because they are often relied upon to go and alert the Positive Outreach Network or hospital of recent bouts of illness. Alice's greatest fear, she explained, was waking up too sick to leave her bed and dying of illness or starvation because no one cared to visit her. Because of Alice's lack of nearby family or social support, she asked the Positive Outreach Network to replace her grass roof because it had begun to decompose and let in large amounts of water when it rained. She thought her request valid because she had known other clients who had their roofs replaced with either new grass or tin. Unfortunately for Alice, her request was never acknowledged and eventually her brother came and replaced it, but not before serious damage was made to her interior walls.

Answers to why Alice's request had not been met or why Alice did not receive any material or social support prior to falling ill can be understood by examining the differences between her understanding of vulnerability and how vulnerability is 'officially' measured by the Positive Outreach Network. For Alice, family support is an essential component of determining vulnerability, thus her lack of children makes her a highly vulnerable person. On the other hand, because the Positive Outreach Network's official vulnerability discourse associates vulnerability with having children, Alice cannot be considered vulnerable. It is ironic, then, that it was her lack of children that prevented her from accessing life-saving care and support and thus placed her in the precarious situation where her illness brought her close to death.

According to Odit, vulnerability is determined by one's rational decision making. While it is likely true that following directions has allowed him to live a life relatively free of AIDS-related illnesses, the Positive Outreach Network considers Odit to not be vulnerable not only because of his health, but because of his ability to provide for his family. Not only did he bring in the income of a military professional, but he bought and rented properties around the country, which allowed for his children to attend university. Both Odit and Alice's understandings of vulnerability differ significantly from the Positive Outreach Network. Instead of understanding vulnerability through a humanitarian lens, they draw their understandings from personal experience. Consequently, their understandings of vulnerability were diverse and were not laden with neoliberal considerations of the superiority of cost-effectiveness. Despite Alice and Odit's insights, their understandings of vulnerability are not supported by the Positive

Outreach Network, so cannot help them gain access to aid or resources if they desire them or think they need them.

The co-optation of a certain definition of vulnerability as a state of affairs by aid programs around the world fails to recognize how these programs actually aid in generating vulnerabilities through value production and unequal exchanges. Because one's vulnerability opens or closes doors for HIV/AIDS care and support, it is of the upmost importance to examine what traits are valued above others when measuring vulnerability and why. Children are helped before adults because, according to one employee, "you never know how long their parents will live" (Interview with employee, October 2nd 2013). If a child is born to HIV-positive parents, even if that child is not HIV-positive, that is already one qualification that the child is vulnerable "because the mother or father may not live another day" (Interview with employee, October 2nd 2013). Although rationalizing aid this way seems moral, cost-effective, and humane, a discussion about a client with a close friend of mine who also happened to be a Positive Outreach Network volunteer, reminded me of the unquestionable inequalities of aid in Northern Uganda.

I was sitting with Amaro on her porch, watching the mid-afternoon rain fall, when I inquired about a newly bed-ridden client whose case I was following. Living across the street from the client, Amaro checked in on her regularly. The client lived in a modest brick house with her son and husband and while out monitoring other clients, Amaro and I were called to her house when she became ill. She was incredibly weak and could not hold down any food or water so we called the Positive Outreach Network for an ambulance. After an hour the vehicle showed up and took her to the hospital where she

stayed for a few days. Upon arriving back home, her husband stayed home from work to look after her but he eventually had to return when his job was threatened. Amaro did not know, but suspected that the woman's son was now staying home to take care of his mother. I asked Amaro if the client had received the nutritional support the Positive Outreach Network usually gives to its bedridden clients. She looked at me and stated angrily that she had not yet received anything. Amaro did not understand why the Positive Outreach Network was delaying and lamented how the entire situation could have been avoided if aid was allocated differently: "You see, this is what bothers me. The Positive Outreach Network only gives food after you fall sick. Not before! If these people get food or whatever when they are healthy, they won't fall sick ever!" (Personal communication with Amaro, October 13th 2013).

Before falling ill, the client and her family were not considered vulnerable; they lived in a brick house, her husband had a good job, and her son attended a good school. The conversation I had with Amaro led me to understand the limitations triage, vulnerability measurements, and humanitarianism have when people living with a chronic, debilitating, and often unpredictable illness such as HIV/AIDS start to be ignored. It also left me to wonder about the son's situation. If his mother was so ill, did this not increase his vulnerability and chances of getting aid from the Positive Outreach Network? If so, why was he forced to stay home from school to look after her? Through fieldwork I realized that although vulnerability measurements are the 'official,' visible ways in which the Positive Outreach Network allocates care and aid, processes of inclusion and exclusion in access to aid are much more complicated. Because vulnerability is subjective and peoples' situations are unique, there are countless

‘unofficial’ ways through which the Positive Outreach Network allocates its aid and care. The remainder of this chapter will explore the Positive Outreach Network’s use of unofficial ways of aid allocation that go beyond vulnerability measurements, and will explore how clients navigate a landscape of ‘clientship’ that places more importance on relationship building and reciprocal exchanges than of discourses of human rights and healthcare.

Ways of Navigating Care

In principle, from a policy perspective, the Positive Outreach Network provides services and care to their clients who have been recognized as the most vulnerable. However, in practice, access to services and care relies on relations with other people. Many people learn about the Positive Outreach Network’s services through various channels such as employees, local politicians, and fellow clients and often receive care because of existing contacts. Whereas official practices of measuring vulnerability presents clients of the Positive Outreach Network as passive recipients of aid, in reality, clients are, in fact, very active seekers of aid.

The importance of relationships as conditions for receiving aid reveals the inequality within the HIV-positive population because some people are better connected than others (Whyte et al. 2013: 147). The Positive Outreach Network’s clients are well aware of their organizations’ recent financial crisis and work in many ways to make themselves visible or seek to capitalize on outside relations. A woman once complained to me that because she had a tin roof, which is considered a sign of wealth, the Positive Outreach Network overlooked her household when they were choosing new children to

sponsor at school. Because she was a HIV-positive widow with many dependents, she believed her children qualified as most vulnerable and should be sponsored. Instead of addressing her concerns directly to the Positive Outreach Network, she went straight to a local politician whose respect within the community granted her a successful vulnerability evaluation with the Positive Outreach Network. Similarly, Odit's brother and son work at healthcare centres and their connections granted Odit access to additional drugs if he fell too ill to journey to the hospital or if his ARV supplier were to ever run out. People like Alice, on the other hand, with no family or other connections to the Positive Outreach Network, have a much more difficult time navigating care.

Clientship: a social process of unequal relations

Networking to access services and care is not just about having a set of connections that can be worked, however, because members of the Positive Outreach Network capitalize on relations and negotiate services as 'clients'. Although the term 'clientship' is often used when services are exchanged for money, it can also apply to non-monetary relationships. In such relationships, a client is the dependent of a patron and the relationship is unbalanced and hierarchical in that the patron will perform services in return for intangible conditions such as client loyalty (Wolf 1966: 16-17). Research done by Whyte et al. (2013) explores the unequal relationship between patron and client during the roll out of free ART programs in Uganda. While those who paid for ARVs were engaged in a direct, limited monetary exchange, the free programs involved a more generalized form of reciprocity. In exchange for ART, clients of free programs gave not only discipline and a promise of adherence, but they also gave openness and offered their

stories and personal testimonies for the moral support of others (155). Being a ‘good client’ meant making their status public and telling others about their bodily and social troubles. It also meant engaging in a dialogue with other clients and care providers and confiding in them for advice. Whyte et al. (2013) found that openness was most valued by organizations when it involved discussing HIV and the benefits of treatment with others (156). My analysis extends Whyte et al.’s discussion to include not only the valuation of discussing the benefits of treatment, but also promoting ‘positive living’ and knowing one’s status.

To ensure the success of its ART program, the Positive Outreach Network, as part of the wider movement towards ‘treatment as prevention’, uses forms of *biopower* (Foucault 1990) to monitor and control the actions of people living with HIV/AIDS by instilling particular ‘positive living’ habits and attitudes towards the life-saving medication. These habits revolve around neoliberal ideas about one’s body and risk. In this way, clients are considered rational decision makers and are expected to take full responsibility of their actions. ‘Positive living’ means to be a ‘good client’ and a good, rational, independent client attends clients meetings, publicly discloses their status, keeps contact with volunteers, and does not engage in high risk behaviours like drinking, smoking, and casual sex. ‘Positive living’ is encouraged because it is considered integral to drug adherence for ‘treatment as prevention.’ Clients receive medication, checkups, and counselling, but to be defined as ‘doing well’ with HIV requires an HIV-positive person to take ARVs twice a day, on time, at exactly 12 hour intervals for the rest of their life (Prince 2012: 24). Failure to do so and therefore, failure to ‘live positively’ may

result in a resurgence of the disease and worse, the virus may become resistant to ARVs and create the risk of an untreatable HIV epidemic.

Though Whyte et al.'s research focused on early ART rollout programs and my research is about other forms of HIV/AIDS care, openness, the 'good client', and 'positive living' remain a critical basis for reciprocity within the patron-client relationship, the most cogent example being found in the relationship between the Positive Outreach Network and its community volunteers. The Positive Outreach Network employs volunteers for three key areas of work. There are volunteers for the home-based care program, where volunteers take care of bed-ridden clients; the education department, where volunteers evaluate household vulnerability; and lastly, the health department, where volunteers help with monitoring and evaluation of client ART adherence. All the volunteers I interviewed worked officially under the health department (despite often performing duties belonging to other programs), so I will speak only of the relationship between these volunteers and the Positive Outreach Network.

The Positive Outreach Network's volunteers were voted in by clients, and were more times than not, clients themselves. Their purpose, besides monitoring adherence and correct drug administration, was to promote the values of the Positive Outreach Network specifically, and Uganda's HIV/AIDS campaigns more generally. They acted as counsellors for clients, sharing in their experiences and promoting the value of openness and knowing your status. Although by law, Ugandans do not have to disclose their HIV status to anyone, the volunteers encouraged clients to confide in loved ones in order to help decrease HIV stigmatization. Volunteers are, in many ways, perfect clients who strive for and actively promote 'positive living' as the only way to live with HIV/AIDS.

In exchange for their services and good clientship, all volunteers received a bicycle for transportation, which they had to repair themselves; a small stipend, which had recently decreased; and countless hours of training through workshops and other programs. Volunteers were also highly visible to the Positive Outreach Network, so were often beneficiaries of other material support or had children who were sponsored in school. Indeed, some clients complained to me that the reason they were not recipients of services was because the Positive Outreach Network chose their friends, family, or volunteers first. Of course, these clients did not actually know the number of volunteers receiving extra care or support, or even if it was true, but to them, favouritism was the only plausible explanation about why they had not received any support from the Positive Outreach Network.

Despite being clients, the volunteers often acted as ‘gatekeepers’ to services and care, putting them in a position to act the part of patron themselves. Therefore, ‘living positively’ and thus receiving extra care also meant following the directions laid out by the volunteers. For example, one of the Positive Outreach Network’s volunteers, Amaro, explained to me how she was able to get more people to come to monthly community meetings by managing who receives the recently donated starter kits. Starter kits are donated periodically by an international HIV/AIDS NGO and usually contain a clean jerrycan for carrying water, water guard tablets to purify contaminated water, and a piece of cloth to act as a filter. They sometimes also contain mosquito nets, but I was told that nets have not been included for some time now. Amaro told me that starter kits were given to people initially at their own homes, but at the last meeting, the kits were transported directly to the meeting place and were given only to those present. The

reason, as Amaro explained, was because the attendance at meetings was declining: “You go to a meeting and you find that there are only five people, so you sit and ask yourself why?...So I told [the clients], if you don’t go for the meeting, you won’t ever get anything from the Positive Outreach Network” (Interview with Amaro, July 27th 2013).

Amaro went to one of the field officers and told him that if somebody wants something, let them first contact the volunteer instead of the Positive Outreach Network directly. That way, as Amaro explained, it would be known what materials the client had received previously, and it would also make clients attend the monthly meetings. In this way, Amaro was able to manage access to projects distributing material support. Clients had to take on the responsibility of making themselves visible to the volunteer because Amaro, as she stated, will not go out of her way to provide starter kits for clients she did not know or who missed meetings without explanation. These clients did not deserve starter kits because they were failing to adhere to the ‘positive living’ mandate. Those who have social connections to the NGO, attend monthly meetings, are home when volunteers check in, and practice ‘positive living’ are more likely to access resources than those who remain invisible to the Positive Outreach Network and its volunteers.

Conclusion

This chapter has explored the transformations of HIV/AIDS care in Uganda that developed with the introduction of free ART programs. ‘Treatment as prevention’, while promoting the dissemination of life-saving drugs, has devalued other forms of care that target social, economic and political factors associated with HIV/AIDS and has severely affected the Positive Outreach Network’s ability to care for their clients. While

measuring vulnerability as a way to arrange hierarchies of care may seem like a simple, yet moral process, upon closer reflection this method of triage assigns values to certain lives over others, reproducing inequalities in new ways.

The most important theoretical premise in the construction of ‘positive living’ as a form of triage is that it is subject to the principle of *governmentality* and therefore has, for the most part, been free of lengthy criticism despite its depoliticizing effects.

Governmentality stems from Foucault’s (1990) concepts of biopower and it is the idea that societies, economies, and government bureaucracies respond in a rather straightforward way to policies and plans (Ferguson 1994: 194). It neutralizes the actions and ideas of those in power. As James Ferguson (1994) explains, *governmentality* makes government itself tend to appear as “a machine for providing social services and engineering economic growth” (194). Conceptualizing the state and NGOs this way inevitably takes little account of the fact that those governing and implementing policies always do it as an exercise of power. Instead of addressing such things as the political, economic, or social reasons for policy implementation or the very deep-rooted politics within the HIV/AIDS industry, apolitical representations of those governing are promoted.

Uganda’s lack of structured national ART programs and the reliance on NGOs and other international organizations to carry out surveillance and drug distribution makes it difficult to produce a comprehensive picture of free ART programs, what they provide, and how they provide it. Given the complexity of the HIV/AIDS aid landscape in Uganda, it is not surprising that most clients have little understanding of how they are able to access free treatment and other services and who makes it possible. Despite the

presence of vulnerability indices, I have demonstrated that choosing beneficiaries is not a simple process, one that is subjective and highly political. Because the Positive Outreach Network runs programs on small budgets, not everyone considered vulnerable receives aid. Accordingly, among clients, reasons for being labeled as ‘vulnerable enough’ are not necessarily known. As Alice put it, “[being considered vulnerable] depends on your luck. If it is your luck, despite the fact that you have a child or not, you will be selected and grouped amongst those who are vulnerable... It is all about luck at the Positive Outreach Network.” Defining vulnerability, despite official systematic investigations, is considered more of a lottery rather than a concrete approach because social relations between clients, volunteers, and staff, humanitarian efforts to engage in a ‘rational’ form of triage, and utilitarian concerns for cost-effectiveness create webs of complexities with no guaranteed outcome that any particular individual will receive care.

It is important to realize that the Positive Outreach Network does not exist as a single entity acting on a single population, and the way in which processes of inclusion and exclusion in access to aid are performed depend on the opportunities for and constraints on multiple trans-local connections. As argued by William F. Fisher (1997), the flows of funding, knowledge, ideas and people that move through NGOs must be understood as acting within a ‘fluid web of relationships’ rather than a set of organizations (450). The Positive Outreach Network exists only as a ‘fragmented site’ within a larger national and global political context of aid (Marcus 1995) and therefore acts within a lopsided hierarchical exchange system, similar to their relationships with their clients.

As is typical of the way the global aid industry is organized, the Positive Outreach Network is entirely dependent on funding from outside sources, where higher level donors—who are often large international NGOs—control the amount of services and resources the Positive Outreach Network has to give their clients. As Swidler and Watkins (2009) and Whyte et al. (2013) demonstrate, hierarchies of exchange and access extend from clients to local organizations, to national centres all the way to overseas donor offices and headquarters. Therefore, the Positive Outreach Network's triage is precarious and exists within hegemonic discourses of 'vulnerability' by carefully choosing clients who will represent the organization well to donors, while simultaneously showing the constant dire need for more funding. At the same time, clients navigating themselves as beneficiaries of aid are subject to the opening and closing of doors for HIV/AIDS care that indirectly choose what lives are allowed to live and what lives are left to die.

Chapter Four

Secrecy and ‘Regained Life’: How Stigma has Changed Ideas of Health and Illness

There has been a recent resurgence of interest in AIDS-related stigma and discrimination, perhaps because even with the increasing accessibility to life saving ART worldwide, stigma has persisted as an important barrier to treatment and care. In 2005, when ART programs were being rolled out within impoverished nations, Castro and Farmer optimistically predicted that greater availability of care and treatment would result in a sharp decline in AIDS-related stigma (2005: 53-54). Their prediction was based on their own experiences in Haiti where they had witnessed the dramatic changes life-saving ARV medications had on HIV-positive people at the brink of death. Castro and Farmer had not considered that the experience of living with HIV/AIDS and its associated stigma is not uniform across the world and it is this inconsistency that large-scale HIV/AIDS programs often fail to address (Seeley 2013: 98).

Castro and Farmer were not alone in their optimistic predictions; AIDS activists who fought for accessible ARVs also believed ART would reduce HIV/AIDS-related stigma (Nguyen 2010). In 2000, the Joint United Nations Programme on HIV/AIDS (UNAIDS) placed the need for a “renewed effort to combat stigma” (Piot 2000 *in* Park and Aggleton 2003: 14) at the top of the list of the ‘most pressing items’ for the world HIV/AIDS agenda. Peter Piot, the Executive Director of UNAIDS, further emphasized the need for an “all-out effort, by leaders and by each of us personally. Effectively addressing stigma removes what still stands as a roadblock to concerted action, whether at local community, national or global level” (Piot 2000 *in* Park and Aggleton 2003: 14).

This chapter explores reasons why, even with the introduction of ARVs, stigma has not decreased and instead has changed and formed in new ways. Before exploring ethnographic examples within the Positive Outreach Network in Uganda, stigma needs to be placed in the correct framework in order to understand why it persists despite years of policy revision and large-scale HIV/AIDS program implementation. UNAIDS and the Government of Uganda seek to improve the quality of life for people living with HIV/AIDS and realize the detrimental impact stigma has on efforts to control HIV/AIDS, but their policies draw largely from individualizing conceptualizations of stigma. This chapter explores these conceptualizations and, using more recent HIV/AIDS related research on stigma, suggests stigma in Northern Uganda needs to be understood as a social process fuelled by *structural violence*, namely poverty.

Placing stigma within this framework allows for a reconceptualization of processes that cause stigma. This chapter focuses on the rollout of ART and ways in which HIV/AIDS-related stigma is still highly prevalent, though changed. The need for a ‘regained life’ was a main theme during interviews with ARV users and this chapter explores how this ‘regained life’ is affected by stigma, and how stigma affects one’s ability to live a ‘regained life.’ Research revealed that ‘regained lives’ are only regained in so far as bodies are able to ‘pass,’ that is, are able to be ‘productive’ and ‘healthy’ HIV-positive bodies. This chapter will conclude with an exploration of how poverty limits expectations of ARV users, challenging the assumption that development programs designed for people living with HIV/AIDS can effectively confront poverty and curtail stigma.

Stigma: Definitions and Conceptualizations

I find the work of Parker and Aggleton (2003) useful to explore the limitations of popular conceptualizations of HIV/AIDS related-stigma and why it continues to persist. In general, HIV/AIDS programs have been heavily influenced by a history of research which draws from the work of Irving Goffman (1963). Parker and Aggleton (2003) reveal that discussions of stigma, particularly in relation to HIV/AIDS, have drawn heavily from Goffman's (1963) interpretation of stigma as a 'discrediting attribute' which, in the eyes of society members, reduces significantly the person who possesses such attributes. According to Goffman, stigma occurs as a discrepancy between *virtual social identity* (how a person is characterized within society) and *actual social identity* (the attributes really possessed by an individual) (Goffman 1963: 2). Parker and Aggleton argue that identifying stigma as an attribute has "led to the focus on stigma as though it were a *kind of thing*...a relatively static characteristic or feature" (2003: 14). Most early work on stigma has come from the field of social psychology that has located stigma as a characteristic of the individual. For example, Jones et al. (1984) emphasize Goffman's idea of stigma as an attribute by using the term 'mark' to describe a deviant condition identified within society that defines the individual as flawed.

Other social psychology literature, such as the study done by Crocker et al. (1998), defines stigma as occurring when an individual is believed to possess an 'often objective' attribute or feature that is identified as a flawed condition within a social context. Despite understanding stigma as an individual attribute, these authors observed that the condition is not located entirely within the person, but occurs within a social context that defines the attribute as devaluing. Yang et al. (2007) summarize that social

psychological definitions of stigma generally agree that stigma, “consists of an attribute that marks people as different and leads to devaluation; and... is dependent both on relationship and context—that stigma is socially constructed” (1525). Although this field has developed important research about the processes that lead to labelling and stereotyping, these frameworks have been criticized for placing too much emphasis on forces located within the individual rather than on the countless societal forces that shape exclusionary perceptions and practices (Castro and Farmer 2005; Link and Phelan 2001; Parker and Aggleton 2003; Yang et al. 2007).

The conception of stigma as a static *thing*, rather than a “constantly changing social process” (Parker and Aggleton 2003: 14), has seriously affected the ways in which HIV/AIDS-related stigma has been conceptualized and the ways in which HIV/AIDS programs have addressed stigma as a barrier to care (Malcolm et al. 1998). An individualistic understanding of stigma has produced a plethora of HIV/AIDS-related stigma literature focusing on beliefs, attitudes, and behaviours of those being stigmatized and those perceived to be the ones stigmatizing, often resulting in research centered on people’s beliefs about HIV transmission (see, for example, Blendon et al. 1992; Burkholder et al. 1999; Lawson 2006; Lee 2002; Violeta 2013). Not surprisingly, as Parker and Aggleton (2003) explain, beliefs associated with people living with HIV/AIDS become the defining cause of stigmatization. Efforts by individuals, governments, and organizations alike have, in response, aimed to increase tolerance for people living with HIV/AIDS within the community through sensitization programs, while programs for people living with HIV have focused on ‘coping’ skills through empowerment initiatives and psychosocial support. Despite these various actions

undertaken to address HIV/AIDS-related stigma, they have not been grounded in a broad understanding of stigma that recognizes its intimate link to the reproduction of social difference (Castro and Farmer 2005; Parker and Aggleton 2003).

Though creating a safe space for people living with HIV/AIDS may seem like an appropriate way to target stigma reduction, I argue that framing stigma in this way produces a simplified belief that stigma is something people do, which can be fixed by changing people's beliefs about it. Northern Uganda's HIV/AIDS programs have done a sufficient job in HIV sensitization, in fact most of my research participants living with HIV/AIDS were well taken care of by their families and community. Despite a general acceptance of HIV-positive community members, stigma was still highly prevalent during my fieldwork, and in fact in many ways has increased and developed in new ways with the introduction of ART. The only way to account for this stigma is to recognize that stigma is not a static attribute based on people's beliefs about HIV transmission; rather it must be recognized as a result of deep-seated power differences and social inequality.

In recent years there has been a development of literature addressing stigma as a social product rather than an individual one. For the purpose of this chapter and as a way to understand the stigma that exists in Northern Uganda within the era of accessible ART, I understand stigma as intrinsically linked to social, economic and political power. Link and Phelan (2001) have explained this process of stigma when the following interrelated components converge:

In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labeled persons to undesirable characteristics—to negative stereotypes. In the third, labeled persons are placed in distinct categories so as to accomplish some degree of separation of 'us' from 'them'. In the fourth, labeled persons experience status loss

and discrimination that lead to unequal outcomes. Finally, stigmatization is entirely contingent on access to social, economic, and political power that allows the identification of differences, the construction of stereotypes, the separation of labeled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination. [367]

Link and Phelan's (2001) first four components of their definition identify social processes that can be observed within the individual and his or her social relationships, while the last component—status loss and discrimination—also includes structural discrimination, representing a critical step towards conceptualizing stigma as processual and created by power differentials (Yang et al. 2007:1525). Link and Phelan (2001) conclude that a better understanding of stigma requires an understanding of how these power differentials and structured inequality impact stigma. Castro and Farmer (2005) build on Link and Phelan's definition and propose *structural violence* as an appropriate conceptual framework for understanding how power differentials impact HIV/AIDS-related stigma.

Every society is shaped by societal forces such as sexism, poverty, political violence, and other social inequalities rooted in historical and economic processes, and these forces together comprise what we call structural violence. Castro and Farmer argue that structural violence is the only appropriate way to understand HIV/AIDS-related stigma because it “predisposes the human body to pathogenic vulnerability by shaping risk of infection and also rate of disease progression” (2007: 55; Farmer 2001: 50-53). These authors argue that despite the social barriers racism and sexism create, poverty is the most influential inequality for HIV/AIDS-related stigma. Worldwide, the poor almost always experience violations of their economic and social rights. Therefore poverty

already represents a universal stigma and will be the primary reason that poor people living with HIV/AIDS suffer from greater HIV/AIDS-related stigma (Castro and Farmer 2007: 55).

I find Castro and Farmer's arguments useful because throughout fieldwork, despite HIV/AIDS-related stigma being represented in multiple ways across various spaces, I came to recognize that poverty was an undeniable component of *all* HIV/AIDS-related stigma I encountered. Despite increased access to ART, the majority of individuals in Northern Uganda remain impoverished; accessing drugs did not increase their overall economic wealth. Their impoverishment, as I will later demonstrate, became a key component for the production of new HIV/AIDS-related stigmas. In fact, ART sometimes *increased* HIV/AIDS-related stigma because ART blurred the opposition between 'healthy' and 'sick,' complicating the perceived abilities of people living with HIV/AIDS.

ART and changing concepts of stigma

Though it has been established in recent years that stigma is a social construct dependent on power differentials perpetuated by structural violence, and while it has been generally recognized that the nature of stigma varies across illnesses and spaces, before HIV/AIDS, stigma had not been considered as changing and emerging over the course of a single illness. Recently, the rollout of ART across the world has seen a dramatic development of new HIV/AIDS-related stigmas and these new stigmas have been observed and analyzed through various research studies. For example, two studies analyzing stigma in South Africa around the time of ART rollout produced very different results. Mall et al. (2013)

found that stigma is lower when individuals have knowledge about HIV, have gone for an HIV test, or have had a friend or close relative become infected or die from HIV/AIDS (199). In contrast, Brendan Maughan-Brown (2010) found that:

In the minds of respondents, interactions with PLWHA [people living with HIV/AIDS] probably refer to extremely sick individuals who were dying of AIDS rather than individuals who were living healthy, productive lives with HIV. Instead of normalizing the disease, interactions with PLWHA when they are sick with AIDS might perpetuate associations between HIV and illness, perpetuate fears of HIV/AIDS, and perpetuate negative moral judgment towards those affected, i.e. perpetuate stigma. [373]

In his study, stigma increased among young people who had known someone with HIV/AIDS who had died when ART was first becoming available to the public. He also suggests that increased publicity about HIV/AIDS' association with death led to increased stigma (373).

It has also been found that access to ART itself may increase certain dimensions of stigma in new ways. Though the availability of effective treatment has transformed AIDS into a manageable condition contributing to reduced self-stigma, new stigmas associated with the ability to 'hide' one's status have appeared. Roura et al. (2009) conducted a study in Northern Tanzania where people were worried that individuals on ART could 'hide' their infection and hence be better able to spread the disease to unsuspecting partners. They also found that ARVs were believed to cause gluttony, greed, aggressiveness, and mental disorders (310). Roura et al.'s study is important because it was one of the first studies to demonstrate the existence of a complex interplay between ART roll-out, HIV/AIDS-related stigma, and normalization processes.

A longitudinal, qualitative study in the Eastern Ugandan city of Jinja shows interesting developments of stigma that closely resemble my own encounters during fieldwork. The study, conducted by Mbonye et al. (2013), included interviews with 41 members of TASO from 2005 to 2008 with follow-up interviews conducted in 2011. At the time of the first interviews, ART was newly available and the participants had just been initiated onto the drugs. Most participants had experienced HIV/AIDS-related stigma and abuse prior to ART but expressed hope that ART would improve health and their social standing. Once on ART, most participants experienced a decrease in stigma in the early stages of ART and began to feel as though they were back in control of their lives. However, surprisingly, the situation began to change.

Researchers observed that three years into ART, stigma returned in new ways. As participants progressed in re-establishing their lives, developed new sexual relationships, and gained employment, HIV/AIDS-related stigma returned when others found out about their status. Stigma was especially high among those who had bodily signs from ART side effects. An increase of stigma meant that participants were less likely to disclose their HIV status, expressing a desire to distance themselves from TASO and anything that would allude to their illness.

The personal desire among HIV-positive populations to conceal their status during asymptomatic phases before ART roll-out as a way to prevent stigma has been studied in the past by Alonzo and Reynolds (1995) who suggest concealment becomes a defense against enacted stigma. Alonzo and Reynolds also found that people who can, generally will keep their status secret (1995: 309), reflecting Goffman's (1963) earlier thoughts: "Because of the great rewards of being considered normal, almost all persons

who are in a position to pass will do so on some occasion by intent” (74). In both Mbonye et al.’s (2013) study and Alonzo and Reynolds’ (1995), people living with HIV/AIDS, whether on ART or not, did not want to be defined by their illness if their illness was not obvious; they wanted to be considered ‘normal’ so they hid their status.

‘Speaking is Healing’: Secrecy and Nondisclosure

Nondisclosure among people living with HIV/AIDS has long been defined as a response to varying forms of HIV/AIDS-related stigma. Both felt and enacted stigma are reasons people living with HIV/AIDS may choose to keep their status secret. Individuals may harbour feelings about their condition and so choose to hide their status (‘felt stigma’), or individuals may choose to hide their status based on the discrimination experienced by others who have disclosed (‘enacted stigma’) (Jacoby 1994; UNAIDS 2000: 9). Before understanding why people may choose nondisclosure or selective disclosure, it is important to understand secrecy as inherently social and intrinsically linked to agency.

Hardon and Posel define secrecy as “...the act of withholding information from others, which may also include elements of self-deception” (2012: S3). Secrecy is a well-established concept in sociological, anthropological, and historical literature (see, for example, Cohen 2001; Piot 1993; Simmel 1906; Snyder 2009; Taussig 1999). Within this literature, secrecy has been defined as a relational practice, which is “embedded in a social milieu with particular repertoires of truth telling and histories of power” (Hardon and Posel 2012: S3). Most importantly, as George Simmel (1906) argued in his critical article on the sociology of secrecy, analyses of secrecy are rooted in the assumption that secrecy is fundamentally social, albeit in varying degrees, and acts of truth telling and

concealment are essential components to the relationships between social beings. Everyday experiences are never fully transparent; what is revealed and what is concealed are continuous sites of negotiation (Hardon and Posel 2012: S4). This negotiation is integral for the way in which human beings inhabit and navigate the social world.

Whether people conceal their HIV status or reveal it depends largely on the context in which they live, and literature has shown that secrecy and concealment are often consequences of stigma (see, for example, Derlega et al. 2002; Gostin and Hodge 1998; Malcolm et al. 1998; Seeley 2014). When discussing HIV/AIDS, support of family members or friends, availability of medications, gender, marital status, possibility of sexual encounters, and age are all factors contributing to decisions about disclosure. Disclosure also depends on how one decides to manage his or her HIV status. As Seeley et al. (2012) observe, some people do not want anyone to know their status, while others gain strength from openly embracing the identity as someone living with HIV/AIDS because of the sense of community that comes with membership in an HIV/AIDS-related organization.

In Northern Uganda's landscape of privatized, donor-funded public health, Hardon and Posel's (2012) discussion about secrecy as an *embodied practice* is particularly useful. 'Speaking is healing' is a confessional imperative within HIV/AIDS initiatives that juxtaposes secrecy to truth telling (Hardon and Posel 2012: S1). Disclosing one's status represents the truth, while nondisclosure becomes denial. While stigma may be at the core of nondisclosure, it is important to recognize that nondisclosure should not nor cannot be mistaken for denial of being HIV-positive. During my time in Uganda, I never encountered a story or situation where someone outright denied their

positive status. People who choose nondisclosure are not engaged in a collective denial of the existence of AIDS, but rather by choosing silence, they, like the South Africans in Fraser McNeill's (2009) research, were actively constructing degrees of separation to create and maintain a distance between them and AIDS, thereby separating themselves from accusations and stigma.

Normative understandings of secrecy in public health

The existence of 'speaking is healing' within public health discourse on HIV/AIDS suggests that members of free ART programs are not afforded the same rights as the others when discussing patient confidentiality. In the West, patients often have the right to keep health issues and serious illnesses silent, therefore their health is *private* rather than *secret*. Privacy is an act which is neutral or valued by society while secrecy implies the concealment of something negatively valued (Warren and Laslett 1977: 44). When nondisclosure is recognized as 'secrecy', obligations to disclose are revealed through the morality of those harbouring secrets. Private issues, that are issues related to health, become public. One's right to disclose their status is transformed from something to be respected and supported to something shameful to be avoided. Throughout this chapter I refer to nondisclosure as 'secrecy' to better reveal the inequalities within HIV/AIDS public health initiatives in Northern Uganda.

Privacy is the act of choosing to set boundaries about what personal information one shares with others and in healthcare, privacy is something valued. One's right to privacy in healthcare is the reason healthcare providers are expected to keep silent about their patients' health issues. It is also the reason why people have the right to maintain

that privacy without being accused of malicious intentions or bad behaviour. In Northern Uganda and across the sub-Saharan, people living with HIV/AIDS do not hold this same right. The health of the public and people's rights to gain information is considered generally more important than individual rights such as privacy, liberty, and security, which may have to be restricted (Vorster 2009). It is believed that in order to limit HIV/AIDS-related stigma and prevent the spreading of the disease, one's HIV status cannot be a private concern. By choosing nondisclosure from this hegemonic perspective, one's status becomes a secret with heavy moral implications.

While healthcare professionals and employees of the Positive Outreach do not reveal clients' status to others (either because of ethical or legal ramifications), their assumptions and beliefs about disclosure remain within the popular discourse of HIV/AIDS global health interventions. Global health interventions generally problematize nondisclosure and label it as 'secrecy' because it is linked to a series of assumptions and ways of thinking about personhood that contradict efforts of behavioural change and drug adherence. The need for individuals to take charge of their own well-being, to be 'empowered' to think and act in more 'healthy' ways, or, as it has been referred to in previous chapters, to 'live positively' has been well documented (See, for example, Bond 2010; Hardon and Posel 2012; Malcolm et al. 1998; Obermeyer et al. 2011). In the words of Hardon and Posel (2012):

Feeling confident enough to disclose one's HIV status, to defy hegemonic norms of concealment is an integral element of this way of thinking: an *a priori* psychological and social good, a presumed condition of psychic and social health and an ethical imperative in the concerted effort to de-stigmatize HIV/AIDS. [S2]

Emphasis is placed on the individual to become an ‘empowered,’ well-informed, socially assertive self who is confident enough to disclose his or her HIV status. To do otherwise is to harbor a secret. Instead of drawing attention to reasons people may choose to not disclose, silence becomes the obstacle to overcome in global health interventions. It is this assault on nondisclosure reformulated as secrecy that, as I will later demonstrate, has actually aided in forming new HIV/AIDS-related stigmas.

Although my research is about practices I encountered in Northern Uganda that often trend across sub-Saharan Africa, it is important to note that every corner of the world has had and continues to have deep ethical controversies for how to deal with HIV/AIDS and those living with it. For example, the debate in the West about health information privacy and the conflict between confidentiality and privacy on one hand, and the right to know and the duty to warn on the other, has been going on since HIV/AIDS was first recorded in the 1980s. Although laws have been made protecting those living with HIV/AIDS, when someone is tested positive for HIV, the results are almost always shared with persons in healthcare and the government (Gostin 2003). In addition, forced screening of certain populations such as criminal defendants, military personnel, prisoners, and immigrants is practiced around the world and is often considered an invasion of privacy and imposes social risks on vulnerable populations.

Despite various confidentiality risks in the West, I argue that people living with HIV/AIDS in Northern Uganda are subject to many more coercive practices promoting full disclosure that in turn, limit the rights of people living with HIV/AIDS. With the advent of increased accessibility of ART programs, secrecy has been reframed as death while disclosing one’s status is life. In fact, in order to participate in HIV/AIDS care

programs, including the Positive Outreach Network's, people living with HIV must disclose their status. The 'empowerment' imperative of disclosure assures that people can only demand their right to life-saving treatment once they have 'come-out' and made their status known, dovetailing with *therapeutic citizen* discourse where HIV-positive people must 'confess' to receive treatment (Nguyen 2010). In the West, this is much less likely to happen. HIV home testing kits are largely available and if one decides to attend a clinic for testing, countries with strong public health departments are much more likely to maintain the confidentiality of reported information because both patients and physicians may perceive the reporting of test results and risk behaviours to a government agency as a breach of trust (Gostin 2003: 161). In Northern Uganda, though patient confidentiality exists, the Positive Outreach Network must ensure targets are met. Institutionalizing the disclosure imperative, most HIV/AIDS care programs demand that before treatment can be accessed, clients must disclose to at least one person who is expected to monitor and help them adhere to the ARV regime (Hardon and Posel 2012: S2).

To better understand such a publicly supported assault on secrecy specific to donor-dependent countries and why the demand for disclosure is common across sub-Saharan African HIV/AIDS programs, the relationship and networks between international donors and aid recipients must be placed within a global framework of ART rollout. Organizations providing HIV/AIDS care and treatment work within a neoliberal model of service so as to provide accessible ART, and donors demand rigorous monitoring systems to account for their investment with adherence monitoring emphasized at the level of individual patients (Hardon and Dilger 2011: 146). Patients

must take the drugs in accordance with strict time and dosage guidelines in order to prevent drug resistance, so consequently most ART programs require monthly clinic visits and pill counts to monitor adherence (Hardon and Dilger 2011: 146; Hardon et al. 2007). These guidelines reveal that although impoverished people are able to gain access to expensive but life-saving drugs, structural violence has created a situation where the poor are not afforded the same rights and are pushed to reveal private information that may be detrimental to their wellbeing.

By law, Ugandans do not have to disclose to anyone, and forcing one to disclose their status is illegal. Despite this, as mentioned in Chapter Three, the Positive Outreach Network is one such organization that, as part of their philosophy to encourage HIV-positive people to ‘live positively,’ encourages clients to disclose their HIV status to family, friends, and neighbours. They also promote client engagement within the organization by embracing new responsibilities such as becoming members of support groups, HIV/AIDS educators, community volunteers, and drama group members who help spread messages about HIV prevention and self-care. Engaging with the organization ensures disclosure and makes adherence monitoring easier. Despite efforts by the Positive Outreach Network to promote clients’ confidence and thereby encourage them to disclose, becoming open about one’s status remains a highly precarious situation which many clients choose to navigate carefully and deliberately. Mary’s story below projects the ways in which clients of the Positive Outreach Network navigate disclosure depending on their situation, how it changes, and ways in which their disclosure will affect themselves and others.

Mary is the widow of a police officer and resides in the local police barracks. The metal house she lives in is too small to hold all of her children so when home from boarding school, they stay with her extended family in a neighbouring town. Only her youngest daughter lives with her. Mary tested positive for HIV in 2001, but had suspected her status prior to testing since she assumed that is what her husband had died of in 1991. Though she was not shocked about her test results, knowing she was HIV-positive scared her because in her words, “everyone knew that if you are HIV-positive, the next step is death” (Interview with Mary, September 9th 2013). Despite being HIV-positive, Mary did not show any signs of illness. Not wanting to burden her family unnecessarily, she decided to not disclose her status to anyone. She did not disclose to her children because she was worried they would only see her as a sick person.

Mary’s decision to disclose came only after her daughter’s HIV-positive diagnosis. At the time Mary got tested, her daughter, who was only two at the time, was regularly ill. Eventually Mary took her to get tested and results showed that her daughter was also HIV-positive. By then, Mary decided that her daughter’s diagnosis was worth letting her family know so she gathered her other children and counselled them; disclosing her status while at the same time sharing advice she received from the hospital. She worried about telling her brother, but eventually did so. Though her children took the news well, her brother did not. At the time she disclosed to her brother he was completing university. He told Mary that it was his responsibility to help her so he began planning his future around procuring her drugs, which, at the time were exceedingly expensive. At that time, ARVs were financially out of reach for most Ugandans so her brother was

worried that his sister would soon die. He decided that he would graduate university and immediately look for a job in order to buy the expensive drugs.

Mary's story alludes to the precarious situation many newly tested people living with HIV find themselves in. Not only did Mary have to navigate careful processes of disclosure but she also had different motives for disclosure. Her motives for not wanting to disclose included protecting those she cared about, protecting herself, and not wanting to appear as a burden to others. She did not initially disclose to her children for fear it would severely depress them and change how they saw their mother, so when she did disclose, she took effort to counsel them and educate them about AIDS. Eventually she disclosed not for herself, but for the protection of her daughter. It would also be hard to hide her own status once her daughter, who was a small child at the time, was known to be HIV-positive. Despite Mary's involvement with the Positive Outreach Network's activities and her enthusiasm for spreading HIV/AIDS knowledge to the community, she confided that had it not been for her daughter's diagnosis, she would probably still hide her own status.

Mary's story demonstrates that HIV disclosure remains "a navigation in a moral field" (Bond 2010: 6). Deciding to disclose and to whom is not an easy decision because it leaves one vulnerable; to be completely open with one's HIV status is to lose control over how others see one (Hardon and Posel 2012: S4; Nyberg 1993). Mary's secrecy and selected disclosure allowed her to live a *double life* with those who thought they knew Mary and those who 'really' did (Goffman 1963: 77). Similar to Goffman's double life, I find a concept developed earlier by George Simmel (1906) to be useful for understanding HIV/AIDS-related stigma and resistance to disclosure. Simmel understood secrecy to be

the creation of “the possibility of a second world alongside of the obvious world, and the latter is most strenuously affected by the former” (1906: 462). Before disclosure, Mary was able to lead a life free from any association with HIV/AIDS as long as her body let her. Seeley (2014) engages with Simmel’s (1906) *second world* as a framework for conceptualizing the discrepancy between understandings of disclosure within the public health community and HIV-positive clients. According to Seeley (2014), the public health community fears the second world because it is concealed. They understand disclosure as a positive and necessary action to rid society of an environment in which disease can spread (Seeley 2014: 101). Without disclosure, public health authorities cannot track the epidemic in order to stop it.

Secrecy and living with ART

Mary did not disclose because she did not find it necessary; at the time she showed no visible signs of illness and there were no accessible ARVs to prolong life. Today, newly tested HIV-positive clients of the Positive Outreach Network have the ability to start ART immediately depending on their CD4 count. Accessible ART has only become available in parts of sub-Saharan Africa within the last decade, so extensive research concerning the social, economic, and political consequences of persistent and long term use of ART in sub-Saharan Africa has not yet been available, though research such as Mbonye et al.’s (2013) study in Jinja shows unexpected developments of HIV/AIDS-related stigma. Similar to Mbonye et al., I, too, found that long-time users of ART began to disassociate themselves from HIV and HIV/AIDS organizations and did not want their partners knowing their status.

Discussions with numerous employees of the Positive Outreach Network about challenges they face in the field revealed stories and scenarios about clients who, despite their ART compliance, refuse to disclose to their sexual partners. Though many women are afraid to tell their husbands for fear of physical consequences and blame, many others do not disclose because they, like Mary, do not find it necessary and do not want to make HIV the most important aspect of their identity. Many times clients who want to marry but do not want to reveal their status to their partner, move away with their partner without giving the Positive Outreach Network any indication of where they went. One employee told me that some even give their family members wrong phone numbers in case the Positive Outreach Network comes looking for them. This way their status would be safely hidden. Another employee of the Positive Outreach Network explained the difficulties of disclosure especially among children born with HIV who are verging on adulthood:

So disclosure is very important, but many times disclosure is very hard. It is even harder with children who are born with HIV. When they reach the age of marriage, they are on ARVs so they are strong, and people go to them proposing for love and you find them, really!... So it is so stigmatizing on their side, especially when they try to disclose and someone is in denial. And then when they discover that she is HIV-positive, they are rejected and sometimes even threatened to be killed.

[Interview with employee, October 4th 2013]

Many young adults born with HIV/AIDS have been able to live successfully in a *second world* by selective disclosure. By disclosing to potential sexual partners, they run the risk of being denied access to important life stages like motherhood and fatherhood. To overcome these challenges, young adults may choose to disassociate themselves from

organizations like the Positive Outreach Network, similar to the clients who move away and give wrong contact numbers.

ART has transformed HIV/AIDS into a manageable chronic illness, but it can only become a chronic condition if one is aware of his or her status and takes ARVs correctly. Global health campaigns have also added the importance of telling others one's status to prevent further infections since drug adherence cannot be guaranteed. Although it is a criminal offense in many countries including Canada to not disclose before exposing someone or transmitting HIV through unprotected sex, global health campaigns throughout sub-Saharan Africa promote full disclosure, beyond disclosure to partners alone. These campaigns have been sponsored by international organizations, and, with the rollout of ART, have pushed hard for Voluntary Counselling and Testing (VCT), especially within sub-Saharan Africa. Despite good intentions for promoting HIV testing and disclosure, intensive support for universal HIV testing and full disclosure inadvertently stigmatizes those who do not wish to disclose.

During fieldwork, people often told me stories of people living with HIV/AIDS who had intentionally infected others and many considered this behaviour to be a significant reason why HIV prevalence rates in Uganda had begun to increase. They are reminiscent of the infamous 'AIDS Mary' and 'AIDS Harry' legends, where an HIV-positive individual deliberately spreads AIDS to men (in 'AIDS Mary') or women (in 'AIDS Harry'). The stories end with the victim receiving a taunting message written on the wall: 'Welcome to the World of AIDS' (Brunvand 2001: 5-6). Though no one ever confided in me that they had done such a thing, and such stories in Uganda may be largely urban legends, stories about such people were often preceded by discussions

about non-disclosure and young people who do not want to be associated with HIV despite their positive status. Decisions about disclosure are complex. Mary's situation and others I have eluded to thus far address such complexities, showing how people who test positive for HIV must navigate between "conflicting moralities of disclosure" (Hardon and Posel 2012: S5): the 'positive living' campaign promoted by HIV/AIDS organizations and public health officials, and the quest for respect from families and communities that may require discretion or concealment.

Countless researchers have observed the incredible stigma associated with HIV status disclosure around the world, but my research also suggests that not disclosing is also stigmatizing in the world of AIDS treatment and activism. Urban legends about people intentionally infecting others stem from the assumption that those who do not want to disclose must have malicious intentions, but disclosure and nondisclosure both have moral consequences and as this chapter demonstrates, decisions about disclosure are exceedingly complex. Instead, Hardon and Posel (2012) suggest that rather than judging people who choose not to disclose or coming to rash conclusions about their intentions, "...a culturally sensitive balance between truth-telling and silence may sometimes be more appropriate" (S5).

Unequal Opportunities and the 'Healthy' Productive Person Living with HIV/AIDS

As I have demonstrated, HIV/AIDS-related stigma has changed in new ways since the introduction of ART. Though many individuals on ART may choose to conceal their status for various reasons, I also found that even those individuals publicly open about their HIV-positive status face new forms of stigma related to ART rollout. These stigmas

are associated with the ‘regained life’ many ART users try to attain and expectations by community members and HIV/AIDS organizations alike.

The idea of a ‘regained life’ was a common theme during interviews with clients of the Positive Outreach Network, as they often credited their lives to ARVs saying, with pride, that the drugs had made them ‘fat and happy.’ In other words, they were not as prone to illness and had the potential to work and provide for themselves and their families without having to rely on the Positive Outreach Network for material or social support. During our interview, Mary told me that since taking ARVs, she has no physical challenges with HIV and often tends to forget she is HIV-positive. Another client, a widow living with her in-laws and her six children, talked about how her recent initiation onto ART has changed her life and her ability to do work:

When I was still on Septrin [a brand name for a combination of antibiotics], I was always sickly and was taken to the hospital and was always suffering from malaria. So of late, when I was introduced on ARVs, I was given the drugs for one month... so within that one month I have never fallen sick yet! If you are to compare it with the past, at least in [one] month, I could fall sick many times. When I started the ARVs, I would have a headache, I would find my body weak. Currently, my body is now getting used to the drugs and I am finding it normal. [Interview with client, August 27th 2013]

‘Regained life’ through ART was not only a common framework for clients to conceptualize their new symptom-free bodies, but it was also used by the Positive Outreach Network and the general public to account for the dramatic changes they had seen in their HIV-positive family members, friends and neighbours who had begun ART. Many Positive Outreach Network employees were very happy with how their clients’ treatment progress was coming, comparing it to when most Northern Ugandans were

living in IDP camps. While living in camps, ARVs were inaccessible for most, so not only were many dying, but many relied completely upon humanitarian relief aid for survival. Inadequate living conditions paired with a highly stigmatized terminal illness made life for Northern Ugandans quite difficult. ARVs had made their clients generally happier and less reliant on the Positive Outreach Network for support.

ART rollout began just as conflict was ending and camps were closing. The concurrence of these events was significant for the Positive Outreach Network because it changed fundamentally their approach to the epidemic. A healthcare professional working at the Positive Outreach Network explained it well:

During the period of insecurity when the LRA was here and activities in the region were so intense, first of all, what most of the organizations were doing were giving support to these people. Like support like the food items, they distributed food to these people... Many NGOs were giving clothes to these people, food on a monthly basis, and also paying [the hospital] how we used to pay, even the consultation fee. What the clients normally did, when they wanted to go for their refill, they'd come to the organization and they are given some small treatment sheet. They go with it [to the hospital]. They are given all the services that [the hospital] normally gives. The bill came at the end of the month and [we] paid it. And it was common with very many organizations...their food, medication treatment, even transportation...but at the moment we are moving towards recovery and development. So, even many organizations, even the government now are encouraging that. They are discouraging a system of handouts to the beneficiaries. That is why at the moment, like paying medical bills is now cut off and our focus now is on long term development. That is why we are dealing with microcredit, so that they are able to sustain themselves on their own. Even food distribution is now going down. We want them to produce their own food. [Interview with employee, September 30th 2013]

ARV rollout within a development agenda is not specific to Northern Uganda. Self-help projects have long been favoured among international organizations and NGOs alike

because of their cost-effectiveness. Development projects that seek to help the beneficiary help themselves are products of free market ideology, where the rational individual is the fundamental unit of society and people are required to be their own entrepreneurs (O'Manique 2004). When such development projects are specifically designed for people living with HIV/AIDS, the material conditions that allow the virus to thrive, the broader social, economic and political factors that condition access to treatment, and the lived realities of those affected by and infected with HIV are effectively erased. In their place resides the illusion that good or bad health is a matter of choice based upon one's rational decisions. Northern Uganda's history of war and convenient timing of ART rollout have amplified the situation and have produced unrealistic expectations of people living with HIV/AIDS.

Before ARVs and when most lived in camps, people living with HIV/AIDS were not expected to live long and those in Northern Uganda were given extra material support to lessen the impact HIV/AIDS had on their lives and their families' lives. ARVs have transformed HIV-positive bodies from sick bodies to healthy bodies and with this transformation have come new ideas about what 'healthy' HIV-positive bodies can and should do. The proliferation of development projects designed for people living with HIV/AIDS has contributed to these new ideas about 'healthy' HIV-positive people and, based on fieldwork observations, I gathered that 'good', 'healthy' clients should strive for independence from aid and should try, and succeed, at economic self-sufficiency through hard work. Those who do not behave in an acceptable way are more likely to face stigmatization. Therefore, in post-conflict Northern Uganda, new stigmas around

productivity and the ability to do work as a person living with HIV/AIDS are emerging beside old stigmas around contagion beliefs and moral behaviours.

Generally speaking, the Positive Outreach Network's clients knew what was expected of them by the organization and most were able to actively engage in work or labour to support themselves and their families. Their intentions of engaging in hard work also aimed to fight the old belief that people living with HIV/AIDS were helpless. In fact, actively disproving this belief and the stigma associated with it was a common reason clients gave for wanting to involve themselves in income-generating activities. When I asked Alice, a client of the Positive Outreach Network, why she joined a saving scheme group despite her inability to save enough money to be actively involved, she told me that aside from acting as a socializing opportunity, she joined as a way to fight stigma within her community: "Because if you are HIV-positive and you are sitting around and waiting for things, claiming things, there is a saying that you are actually adding to your problems by not doing anything yourself" (Interview with Alice, August 28th 2013). She explained that because of this stigma, there is a fear among HIV-positive people that when they do fall very sick, no one will come to help them because they did not help themselves. In her words, when HIV-positive people complain, "Please give me! Please give me! People get so tired of you. It's true! You become like a pussycat. You know this word 'mia' ['give me' in Acholi-Luo], that is how a pussycat cries! "Mia, mia, mia! Give me! Give me! Give me!" So you become a pussycat in the community" (Interview with Alice, August 28th 2013).

Though her small income prevented her from saving money, her membership in this group symbolized much more. By being physically part of the savings group, she

became visible within her neighbourhood and community as an actively productive person living with HIV/AIDS who does not expect the Positive Outreach Network to give her all she needs. Joining this group was also a way of legitimizing her need for aid if the situation were to arise in the future. The example of Alice shows that those with HIV/AIDS who look healthy must *act* healthy or else they run the risk of being stigmatized as lazy or greedy.

Despite Alice's general awareness of the community and organization's expectations of her as a person living with HIV/AIDS and her active engagement with development programs, she still believed the Positive Outreach Network should provide her with material support to help with the management of her illness. Alice complained that although ARVs reduced HIV/AIDS-related symptoms, they were not a cure for AIDS and often came with their own symptoms that affected her economic productivity. Alice made the distinction between HIV/AIDS support, which was stigmatizing, and ART support, and believed the Positive Outreach Network should provide care to help clients manage drug side effects that may prevent them from doing work. Because HIV management projects are promoting economic independence specifically through self-help, drug side effects such as serious muscle weakness, fatigue and nausea, or general depression and anxiety as a result of having a highly stigmatizing illness are made invisible alongside social, political, and economic barriers to HIV/AIDS prevention and treatment.

ARV side effects were a common cause of complaint among clients of the Positive Outreach Network because they prevented some from living their 'regained life' the way they wanted. Depending on the severity of the side effects, people on ARVs

could face increased stigma if these side effects were serious enough to prevent them from acting 'healthy'. Muscle weakness and fatigue were common among ARV users, and were amplified if these clients did not have sufficient food to take with the drugs. A long-time ARV user named Ochen used to run his own carpentry business but left it once his illness progressed to AIDS and he started taking ARVs. He opened up a small shop that required much less physical labour but it was robbed by the landlord, forcing him to close. He has since joined a microcredit loan group that provided him with enough money to purchase a motorcycle to rent out, but when I arrived at his home for our interview, the renter had not yet paid him. Due to AIDS and persistent ARV side effects, Ochen could no longer continue with his carpentry business that had supported his family, forcing him to look for a less labour-intensive job, and such jobs are often harder to come by. Ochen's difficulty in procuring a job following his HIV-positive diagnosis and initiation of ART challenges the assumption that healthy-looking ARV users can easily regain the life they once had and highlights issues like poverty and unequal access to resources.

The danger of normalizing the chronic condition of HIV/AIDS is developing the assumption that a person can return to their earlier life, pre-illness (Russell et al. 2007: 345). Conrad (1990) explains that living with chronic illness requires people to manage the 'medicalization' of their lives which make their strategies and daily work to normalize life all the more difficult. For ARV users in Northern Uganda, though they may *look* healthy, their illness limits their ability to work and intensifies economic vulnerability. For Ochen, returning to his old way of life was not an option and living with HIV/AIDS became a personal struggle he had to face every day:

The hardest part of living with the virus is that it takes away the energy to do heavy work like farm work and the usual support that I would give to my family was not regular. At times you can be in a situation where you cannot even get to the hospital [because you are too weak]. One day I had a negative thought of killing myself but realized that it was useless... This virus does not make you feel pain but you just find your energy going little by little... day by day you may even fail to get up [Interview with Ochen, September 4th 2013]

Ochen's struggle was not uncommon; in fact, the struggle of coping with AIDS symptoms and ARV side effects, paired with the stress of procuring food to take with ARVs and financially supporting family members, was a significant burden to many clients. Samuel, an elderly client of the Positive Outreach Network, despite his involvement with clients' meetings and his attempt at starting a savings scheme, faced significant difficulties maintaining his adherence to ARVs.

Samuel lived in a small brick house in the police barracks with his wife and young grandson. He was 68 years old and had been diagnosed with HIV in 2004. Since his viral load was extraordinarily high when he was first tested, he was immediately put on ART and has been steadily maintaining adherence ever since. When he disclosed his status to his relatives, he faced significant stigma. A number accused him of having many women and blamed him for his illness. He recounted, "And they were wishing me death. There were some who hate me up to now and whenever I go home and request for a glass of water, no one offers one to me because they believe that I will spread the disease to them" (Interview with Samuel, September 9th 2013). He also faces significant stigma within the community in which he lives. Samuel commented that many neighbours want him to return to his village where his son is. Although he would love to go back to his

village where his relatives live, he cannot because his son will not construct a house for him to live in.

Before Samuel's diagnosis, he harvested cotton on land owned by his uncle, but AIDS and ARVs made him too weak to do physically demanding labour. Now he cuts grass for his neighbours and police officers who will hire him. Living on ARVs is difficult for Samuel because his life has changed dramatically. His inability to do farm work has made his situation financially unstable which has increased his food insecurity. The morning I arrived at his house for the interview, he had made a small amount of money by cutting a police officer's grass. He had not eaten anything that morning despite taking ARVs, so had used his earnings to buy beans which were simmering in the pot by the time I arrived:

Today I have not taken anything like food and yet I have swallowed the drug in the morning. I [have only taken] the soda that you have given me right now. Whenever I feel hungry I drink water and wait for whatever [food] I prepare. I usually swallow my drugs on an empty stomach because food is usually late. [Interview with Samuel, September 9th 2013]

While other clients of the Positive Outreach Network had no problem adhering to strict ART guidelines, Samuel struggled every day and found ART a burden, though this was not always the case. When Samuel was first tested and found to be HIV-positive, the World Food Program (WFP) was still present in the area and ran a special program that gave nutritional support for people living with HIV/AIDS. Samuel commented that when the WFP was still around, he was doing quite well and his weight was up to 75 kilograms. He looked so healthy that at the time people did not believe he was HIV-positive. At the time of our interview, though, he weighed only 62 kilograms because he rarely found enough food to eat. He was also wearing the same clothing that had been

given to him by a priest in 2004. His emaciated frame and old clothes could not hide his positive status.

Samuel's HIV-positive diagnosis seriously affected his relationship with his wife. His wife is HIV-negative and since his diagnosis, has refused to engage with him in any sexual relationship. He feels he has lost all power to tell his wife to prepare food for him. When the WFP's HIV/AIDS-related project was there, Samuel said that the way in which HIV had affected his social relationships had not bothered him because he did not need to rely on his wife or any other member of his family for support. He "never bothered about what people would say" (Interview with Samuel, September 9th 2013). His 'fat and happy' body could also hide his status from passersby who did not know otherwise. Samuel considered himself happy and healthy during that time, but now that the WFP's nutritional support for people living with HIV/AIDS has ended, Samuel stresses daily about how to feed himself. He told me, "the thoughts about how I will feed myself almost kill me" (Interview with Samuel, September 9th 2013). He, like Alice, believes that HIV/AIDS organizations like the Positive Outreach Network should provide nutritional support for those on ART.

Samuel's inability to feed himself makes his sickness visible and exposes him to a heightened degree of stigmatization. When the WFP was active in Northern Uganda, Samuel could 'pass' in society and live in a *second world*. This made him happy and 'healthy,' though the changing landscape of aid that paralleled the introduction of ARVs significantly altered Samuel's ability to live his 'regained life.' Though he disclosed his status early in his diagnosis, his physical appearance at the time gave no indication of his

illness, but at the time of our interview, it was hard not to ignore his body's tell-tale signs of AIDS.

Conclusion

The situations of Alice, Ochen, and Samuel merge issues of stigma, expectations of ARV users, poverty, and vulnerability into a framework for better understanding the complicated web of interactions within, and the limitations of, HIV/AIDS programs in Northern Uganda. Following the Government of Uganda's vulnerability indices, Samuel would not be considered vulnerable. He lives in a brick house, has no dependents since his children have grown up and moved away, and his wife is not HIV-positive. Though Samuel believes it is the Positive Outreach Network's duty to give clients such as him material and nutritional support, on paper, Samuel appears as the perfect HIV-positive client: he is actively involved with the Positive Outreach Network; he has publicly disclosed his status; and he is adhering to ART.

Samuel's circumstance makes visible the dangers of labelling certain populations as more or less vulnerable because it assigns expectations to behaviour. Non-vulnerable people on ARVs are expected to remain non-vulnerable by 'living positively' in a way that does not put them or others at risk for infection, and provides for their own material needs. Yet people like Ochen have a difficult time providing for themselves and their families due to ARV side effects, which are exacerbated by poverty that impedes the ability to eat properly while taking ARVs. As has been shown, despite considerable economic barriers, ARV users must act healthy because not only are HIV/AIDS programs discontinuing relief aid, but if non-vulnerable people on ARVs do not act

healthy, they may face serious stigmatization. Recognizing this, Alice actively engages in a savings program to prove her ‘healthiness’ to the Positive Outreach Network and her neighbours.

Poverty continues to be a barrier to care and, as it has been demonstrated, is a serious component affecting HIV/AIDS-related stigma. While public health initiatives promote full disclosure as a way of eliminating barriers to care and treatment, disclosure does not erase the poverty that may factor into one’s decision to engage in ‘risky’ behaviour, nor does disclosure eliminate HIV/AIDS-related stigma. Even the institutional arrangement of ART rollout that made life-saving ART accessible perpetuates stigma. Though ARVs are given away free of charge at most hospitals and many NGOs across Uganda, they still come at a cost: patients who cannot pay for private services have to attend adherence classes and must publicly line up at the hospital or organization for drug refills every few months. On the other hand, patients who pay for ARVs in private hospitals and clinics that do not depend on donor funds have shorter waiting times and confidentiality is much higher (Hardon and Dilger 2011: 148). An impoverished person’s HIV-positive status is much harder to keep secret.

This chapter has sought to make visible how limitations of poverty have engaged with the interactions between new physical, social, and psychological vulnerabilities brought on by ART. Poverty is intrinsically linked with the social experience of HIV/AIDS-related stigma which has been affected profoundly by the advent of effective ART. Poverty is a barrier to healthcare for HIV/AIDS, while the limitations on health being HIV-positive (such as muscle weakness, severe fatigue, skin rashes) also further entrench poverty by impeding economically productive work. Not being able to work

leads to even greater poverty and poorer nutrition that can severely affect one's ability to adhere to ARVs. This negative cycle of poverty, poor nutrition, and health problems is produced by structural violence and is perpetuated because people living with HIV/AIDS are expected to disclose their HIV status despite these stresses. People living with HIV are also expected to act healthy and be productive even if they suffer from weakness, poor nutrition, and drug side effects, thus adding psychological burdens to the physical ones.

The often unattainable social expectations created by HIV/AIDS global health initiatives and its programs perpetuate these social, psychological, and physical vulnerabilities. Accordingly, people are made less sick through ART, but more stigmatized and vulnerable by these changes in the structures of aid and their social interpretations. Hence, stigma is not just individual; it is fundamentally imbedded within social relations, influencing and being influenced by themes of structural violence and inequality.

Chapter Five

Developing AIDS and the Future of Care

The political economy of health framework that I have used to analyze the HIV/AIDS situation in Northern Uganda has documented processes of triage that, as I have shown, have created and reformed unequal processes of inclusion and exclusion in access to aid. These unequal processes have been explored by studying the encounters and interactions between NGO workers, people living with HIV/AIDS, and the communities in which they live. These interactions, or multiple ‘zones of awkward engagement,’ (Tsing 2005) have revealed the messiness of universal claims and have demonstrated that understandings of and actions toward HIV/AIDS are dependent on unequal arrangements of culture and power.

In addition, my thesis has sought to demonstrate the importance of a historically situated ethnographic analysis in order to critique how structures of power have placed value on certain lives and changed ideas of HIV/AIDS care. It has also uncovered the multiple mechanisms that explain the unintended and sometimes negative consequences of using the ‘community’ as a tool for aid distribution. To begin, HIV/AIDS policy has been tied to a neoliberal political agenda that has moved away from the government and towards the market as the engine of growth and progress. Structural constraints placed on the Government of Uganda have limited its capacity to provide adequate state-run institutions, so community responses often led by external actors have become necessary in order for people living with HIV/AIDS to receive adequate treatment, care, and aid.

Chapter Two demonstrated how Uganda's reliance on non-state actors to implement HIV/AIDS programs has created communities of people affected and infected with HIV/AIDS who have been sensitized about their own role in the management of the disease. Despite a general knowledge about HIV/AIDS among most Ugandans, a preoccupation with 'cost-effective' management and 'efficiency' among state-run and non-state actors has left many people living with HIV/AIDS with the responsibility of locating their own sources of financial, material, spiritual, and social support. Accordingly, HIV/AIDS interventions are created with the intention of empowering individuals and local groups to foster self-reliance so they may become independent from organizations and develop the capacity to handle HIV/AIDS themselves.

This case study situating the Positive Outreach Network within a moral field of HIV/AIDS care has shown that a significant part of choosing beneficiaries rests in fact with preconceived notions of who their clients are. As explained in Chapter Three, 'treatment as prevention' mechanisms have created a need for cost-effective processes of triage that locate beneficiaries of holistic care. These processes of triage, though, have specific guidelines about who needs aid and who does not, which are reformulated into vulnerability indices, despite their partiality in determining who qualify as 'vulnerable' persons.

Fieldwork has shown that because of accessible ART, not all people living with HIV/AIDS are considered vulnerable. Though they rely completely on these drugs for survival, if people living with HIV/AIDS can access work and provide for themselves and their families, they usually cannot access additional support services. As I have shown in Chapter Four, labelling certain populations as more or less vulnerable assigns

expectations to behaviour which can lead to HIV/AIDS-related stigma if one does not act as expected. Non-vulnerable HIV-positive people are expected to remain non-vulnerable. They are expected to ‘live positively’, behaving in a way that does not put them or others at risk. Those who are vulnerable, on the other hand, are given support and are expected to try to lessen their vulnerability and dependency on aid.

AIDS and development

When the Positive Outreach Network first formed, their intention was to increase HIV awareness and care for people living with HIV/AIDS with dignity and respect. Early on, they were also concerned with fostering self-reliance among those living with HIV/AIDS and encouraged those who received the Positive Outreach Network’s support to also try to work to make money. Since many living with HIV/AIDS pre-ART rollout did not have the strength to farm, they chose to sell items instead. When this project was assessed, it was found that one woman who had been embroidering tablecloths was able to support herself much better than others. The Positive Outreach Network asked her if she would train members who were interested in learning. She accepted and they started making embroidered items together. Eventually, as more people were trained, their operation expanded and began selling handmade clothes and jewellery to various places overseas. From its beginning, the Positive Outreach Network has been aware of, and concerned about, the severe aid dependency that formed as a result of Northern displacement and HIV/AIDS, and has attempted to lessen this dependency through encouraging self-reliance.

Although it was their sincere concern for their clients' aid dependency which led the Positive Outreach Network to organize economic empowerment programs, these programs also align with Uganda's National Strategic Framework for HIV/AIDS Prevention and Care. As outlined in Chapter Two, this document, first written in 2000, called for a scale-up of Uganda's multi-sectoral approach through integrating HIV/AIDS issues into its Poverty Eradication Plan, thereby effectively integrating HIV/AIDS programs and development. The community was to be supported through income generating projects as a means of minimizing the adverse socio-economic effects of living with HIV/AIDS. Therefore, while the Positive Outreach Network was already doing their own version of these development projects, the development of this document led to a much more public and official means through which people living with HIV/AIDS were to be chosen for development assistance.

Since 2000, development aid as an appropriate strategy for HIV reduction has become normalized throughout Uganda, changing the actions of givers and recipients of care and aid. The Positive Outreach Network continues to implement development programs and, as outlined in Chapters Three and Four, for people living with HIV/AIDS, this means the beginning of a new moral economy of survival, where they must navigate themselves as both individual sufferers of disease and economically productive, 'deserving' recipients of development aid (Nguyen 2010).

Donor values and recipients of aid

This thesis has sought to explore how people living with HIV/AIDS are sorted into categories of needing aid or not, but many of the difficulties in these processes stem from

the fact that the clients' world is so different from that of the more elite NGO workers, government officials, and donors. The problems faced by clients and their communities are completely different from the problems discussed behind closed doors in boardrooms of organizations. The fundamental difference in values between donors and recipients was made very clear when Scott, a representative of a major European donor, visited the Positive Outreach Network for a few days to organize another three year plan with his organization.

The project Scott was evaluating provided care for bed-ridden clients and, among other things, gave loans. According to a third-party consultant, the last three years of the program were deemed 'effective, efficient, and sustainable.' It was effective because targets were met, efficient because the program was implemented despite limited resources, and sustainable because of its income generating activities and the involvement of community volunteers who can continue monitoring clients after the program has ended. For the next three years, the program would continue with few changes. The program's evaluators stressed the importance of meeting and keeping targets, which act as evidence to keep resources flowing from program funders who must prove to their constituents that their money is being used appropriately.

While meeting targets has become an important prerequisite for international aid distribution, emphasizing the importance of numbers for development initiatives targeted for HIV/AIDS populations produces a reductionist perception of development and threatens to fall into the trap HIV/AIDS prevention policies have long been part of. Reaching targets requires that people be identified and grouped so that they may be enrolled into a program where the results can be quantified. Processes of access to aid

inclusion and exclusion become standardized and evaluating those who have been chosen to receive aid is emphasized in reports to bring back to donors. This form of systematic triage identifies those who meet criteria, but what about those who do not?

The Positive Outreach Network's clients are not concerned about the efficiency, or cost-effectiveness of Scott's projects and many have a very different understanding of how the Positive Outreach Network should run their programs. Chapters Three and Four discussed some of these issues about the Positive Outreach Network's practises, from ambiguous vulnerability measurements to reasons for nondisclosure. In addition, many clients suggested donors increase their budgets to help more people gain access to resources or increase the amount and types of aid they currently receive. Another important concern to most clients I talked to was ensuring the continuity of receiving ART free of charge. While, theoretically, clients can voice their contentions to the Positive Outreach Network if they want to, many have no idea of who to contact or the process involved. Some told me they would talk to a volunteer, but others believed volunteers blocked their access to discussing their problems with the Positive Outreach Network.

The proliferation of words about development and HIV/AIDS, from academic studies to media coverage, to donor organizations to beneficiaries, rehearses very different conceptualizations of what development is and how people living with HIV/AIDS should be treated. As it has been demonstrated, discussing development and the Positive Outreach Network's programs with employees constructs a different conversation from that to be had with a client, and even then, a conversation with a client who receives aid is different than a conversation with a client who does not. The way in

which development was discussed in the Positive Outreach Network's boardroom was very much a display of the familiar oppositional tropes Nguyen (2010) argues against: of victims and heroes, vulnerability and empowerment, and illness and redemption (184). When clients become numbers and the developmental language of measures, outcomes, targets, and programs reign, other problems that may affect clients or issues clients believe are important, become invisible.

Who are the experts?

Excluding clients in the day-to-day workings of HIV/AIDS organizations that seek to incorporate development schemes is a rather regular occurrence within development projects. In fact, this model of development, as with most, relies on a number of dichotomies that have been discussed thoroughly in Emma Crewe and Elizabeth Harrison's *Whose Development? An Ethnography of Aid* (1998). Although dichotomies of developers/recipients, local/non-local, traditional/modern, culture/economics, state/NGO, and expert/non-expert exist throughout development language and policy implementation, these dichotomies merge when explored in context (177). I take their analysis one step further: by implementing development schemes based on these dichotomized presumptions, especially ones aimed at poor, sick people living with HIV/AIDS, economic and social inequality cannot be defeated.

Underlying all of these dichotomies is the belief in a fundamental difference between 'us' and 'them'; a dichotomy that exists in most implemented models of aid allocation (Crewe and Harrison 1998; Escobar 1995, Grillo 1997). The presentation of such models was exemplified when the Positive Outreach Network took Scott on a field

visit to interact with various clients who had received aid from the projects Scott's organization funded. The first stop was in a neighbouring district to visit three groups who educate others about HIV/AIDS through drama, dance, and song. They are clients of the Positive Outreach Network and many were trained in business and now receive loans. These groups had been told far in advance of Scott's visit and our arrival was nothing less than impressive. As the vehicle pulled onto the property, women and men in bright shirts with the Positive Outreach Network's logo formed a receiving line singing and dancing to welcome their guests. Scott, the administrators, and I were welcomed and led to a makeshift canopy with large, overstuffed couches underneath. The members of the groups sat on mats or benches under a nearby tree, out of the heat of the midday sun.

A representative stood up and spoke to us, and most especially to Scott, thanking us. He did not understate the importance of the groups and told us that they have seen stigma and discrimination reduce in their communities because of the messages and advice they impart through drama presentations. But this man also acknowledged points of contention expressed by members. Although he and his fellow members could not thank Scott's organization enough, he had issues with how the loan money had been distributed because not all the groups present were receiving financial support. He also stressed the importance of agriculture and farming among members and asked if Scott's organization could start funding an agricultural project. Scott acknowledged the representative and made a note to bring the issues up when he was back in Europe. The meeting ended with an impressive spread of food, including wild buffalo, served to us. We ate, thanked the cooks, and left to visit the next clients on our list. The rest of the day was spent asking clients in neighbouring villages how they spend their loan money given

to them through Scott's organization's program and visiting child-headed households and bed-ridden clients.

I found the interaction between the drama groups, loan beneficiaries, Scott, the Positive Outreach Network administrators, and even myself unsettling because it demonstrated, quite explicitly, who are 'us' and who are 'them' within aid and development praxis. We sat under a shaded canopy while they sat on mats under a tree; we ate delicious food, they ate nothing; we arrived hours late, they had to wait for us; they performed as 'perfect clients' while we watched and took notes. Beyond this exemplary performance of a dichotomous relationship, more needs to be said about the ways in which us/them exists within aid and development literature. Thinking about aid as a problem between us and them implies assumptions about others which are often based on racist, preconceived notions of aid beneficiaries, especially within Africa. It also implies that beneficiaries are passive recipients. Conceptualizing aid this way, what can be made of the Positive Outreach Network's volunteers who act as gatekeepers of aid but who are also clients themselves, or employees who are also clients? And what is the Positive Outreach Network, but not a beneficiary in its own right? They give resources and implement programs, but they are also dependent on donors to fund these programs. Even Scott's organization receives its donations from others. All individuals and organizations, including governments, are involved in endless transactions that form networks of exchange. Donations, ideas, and beliefs do not flow in one direction.

Us/them understandings of development are dangerous because their reductionist idea of beneficiaries ignores their agency and makes assumptions about how and why they want to receive aid. For example, Chapter Four mentions Alice, a client who joined

a savings scheme to, assumingly, save money and become self-reliant. On the contrary, as I later found out, she did not join for financial benefits. Rather, she joined to resist stigma and so she would appear, to everyone else, like a productive client. Similarly, the Positive Outreach Network has, more than once, implemented programs that have been dictated by unyielding Western donors that have developed into something different than what was initially intended. For example, the Positive Outreach Network once implemented a program that gave bicycle ambulances to communities whose roads were impassible by vehicles. Instead of using the bicycles as they were intended, community members removed the ambulance accessories and rode them as regular bikes.

Dependency vs. empowerment: wishing for aid and inequality

Central to the Positive Outreach Network's mission was the dichotomy of dependency vs. empowerment. HIV/AIDS in Northern Uganda started as a humanitarian problem and grew steadily into one of development. Although humanitarian compassion still governs much of the aid in Northern Uganda, with every passing year, aid dependency among the HIV-positive becomes a more pressing matter. Aid dependency is considered a negative, but inevitable, outcome of the aid apparatus, and many clients of the Positive Outreach Network take pride in their independence and ability to provide for their families despite their illness. 'Empowering' clients to help themselves gain independence and, thus, freedom, is the purpose of the Positive Outreach Network and most similar organizations. Indeed, numerous employees of more than one organization said that they would one day like to see the elimination of the need for their place of employment if it meant their clients could live happily without them, hence overcoming the pervasive inequality

embedded within the aid system. But is empowerment the opposite of dependency? And does succeeding at this reality really mean that inequality has been defeated? Or, as Ferguson (2013) suggests, do methods of overcoming inequality this way lend themselves to something worse, that is, *asocial inequality*, an inequality that removes one entirely from the domain of ‘the social’ (232)?

Ferguson’s argument suggests that those suffering from asocial inequality actively try to turn it into the social kind. For Ferguson’s South African research participants, social inequality and dependency is a more favourable inequality than asocial inequality because it is at least an inequality established within important social relationships. The Positive Outreach Network has created a community of clients, and for many clients, this community is an important component of their social lives. Staying dependent on the Positive Outreach Network means they still have a place and a purpose as persons living with HIV/AIDS.

Although ‘independence’ is, for many, synonymous with freedom and the ability to make one’s own decision, independence may also mean exclusion from the social world, which is already a world where the HIV-positive must tread carefully. If the Positive Outreach Network stopped existing, not only would those dependent on its resources fall, but the community it has created would begin to collapse. Clients I have mentioned throughout the pages of this thesis such as Alice, Ochen, Mary, Samuel, and others who rely on or wish for more aid from the Positive Outreach Network, may not only wish to make their lives easier, this aid may also represent a social connection to others just like them and a belief that their lives are valued enough to be helped. Therefore, upon further analyses, the simplicity in the empowerment/dependency

relationship fails and becomes a complex social situation in need of a dialogue that incorporates the knowledge and needs of recipients into the decisions surrounding them.

The future of AIDS communities

Communities have agency and this thesis was, in no way, an attempt to discredit the hard work, credibility, and care of all the individuals I had the privilege of meeting during my short time in Uganda. Rather, it was meant to shed light on some of the not-so-talked about experiences and assumptions that govern the humanitarian and development industries of HIV/AIDS aid in Uganda. Community-based practises, however they define 'community', cannot nor should not be expected to 'fix' the HIV/AIDS problem on their own. And as my thesis has shown, communities, however small or large they may be, do not act as independent governing bodies. In Uganda, they are completely connected either to other communities, neighbours, volunteers, hospitals, government agencies, or international NGOs. Hence, in the case of the Positive Outreach Network, what they do and their strategies of development or aid allocation are reliant upon what other people think is best.

On numerous occasions the Positive Outreach Network employees explained how projects fail because donors have their own idea of what works best. Even Scott's organization, an organization that gives the Positive Outreach Network significant agency to choose their own beneficiaries and methods of project implementation, can only fund their projects if the Positive Outreach Network complies with the areas of intervention the organization wants to support. What my thesis has demonstrated is the fundamental disconnect between operating from an imbalanced model of aid reliant upon both

‘community’ and Western neoliberal ideals without actually involving the community, that is, the people affected and infected with HIV/AIDS, in decision making processes. The Ugandan government’s focus on addressing HIV/AIDS through education and behavioural change rather than healthcare reform has placed the burden on international actors, and community-based programs have been the tool through which these actors have implemented their programs.

The problem with HIV/AIDS is that its patterns of infection and its relentless persistence of visibility among the most marginalized cannot be dealt with by the ‘community’ or even well-meaning NGOs alone. It requires political restructuring, proper financial management, a strong support system of national and international actors, but most importantly, it requires the dichotomous praxis within aid to undergo serious reform. HIV/AIDS-related needs will continue to be left unaddressed as long as those living with HIV/AIDS are forced to comply and follow very narrow, Western ideas of aid allocation and continue to be excluded from the decision-making process. What my thesis has shown, most importantly, is that those with HIV/AIDS in Northern Uganda do not fall into the simple categories of ‘dependent, black, impoverished sick people.’ They have ideas, knowledge, agency, needs, and beliefs that deserve to be recognized by the world and they deserve to engage in meaningful dialogue not as poster-children of Africa, or HIV/AIDS, or poverty, but as agents of their own future and the future of HIV/AIDS in Northern Uganda and their communities. As this thesis has demonstrated, though, they will not be fully recognized and ‘engaged’ as long as a reductionist, nearsighted, neoliberal goal of generating ‘independency’ excludes the targeting of felt-needs that the

clients themselves identify, nor as long as ‘community-based’ means *targeting*—rather than *engaging the knowledge of*—the community.

Appendix

Uganda OVC Vulnerability Index Tool

The Uganda OVC Vulnerability Index (VI) is intended for the selection of vulnerable households into OVC programs. The tool helps to determine a household's level of vulnerability (slight, moderate, and critical) based on individual and household level questions you will ask across all core program areas.

PRE-SELECTION CRITERIA

INSTRUCTIONS: Please use the following indicators to pre-select households where the VI tool will be administered. Pre-selection of vulnerable households requires the participation of community members and community workers. This ensures that the selection process is conducted in an efficient and transparent manner if critically and moderately vulnerable are to be identified.

HOUSEHOLD HEALTH STATUS			
			Yes
			No
1.	Does the household have ANY adult member who has been very sick for at least three months during the past 12 months? <i>(By very sick, I mean that the household head or any adult member was too sick to work or do normal activities around the house for at least three of the past 12 months)</i>		
2.	Does the household have ANY severely disabled person? <i>(Applies to both children and adult household members)</i>		

CHILD EDUCATION STATUS			
			Yes
			No
3.	Does the household have children not currently enrolled in school? <i>(Children between the ages of 6-17)</i>		

HOUSEHOLD ORPHANHOOD STATUS			
			Yes
			No
4.	Does the household have or care for any orphans?		

DECISION: If you selected "Yes" for at least ONE of the pre-selection criteria questions above, please proceed to administer the remainder of the tool at this household.

HOUSEHOLD INFORMATION

INSTRUCTIONS: Please administer this section to heads of households, spouses, or to OVC in case of child-headed households. Ask each question and circle the appropriate response option. After circling the response, please write in the corresponding score to in the far right-hand column (labeled “SCORE”).

At the end of each CPA, please add up the scores for all questions and write them down under the “CPA TOTAL” row. Finally, add up all CPA scores, and enter them under “HOUSEHOLD TOTAL SCORE”.

CPA 1: ECONOMIC STRENGTHENING										SCORE
1.	Who is the MAIN household income earner?									
Option	Children (6 – 17 years)		Grand or Elderly Parents		Relatives		Mother		Father	
Score	4		3		2		1		0	
2.	What is the MAIN SOURCE of household income? (emphasis is main source only)									
Option	None	Remittances	Causal Labourer	Informal Employment	Peasantry/hiring out labour on other farms / gardens	Petty Business	Formal Business	Commercial Farming	Formal Employment / Wage	
Score	4	3	2	2	2	1	0	0	0	
3.	Does this household have access to land?									
Option	Does not own, not able to access land		Does not own, but able to access land		Owns but not able to access land		Owns and able to access land			
Score	4		2		1		0			
4.	In the last 12 months (MENTION THE MONTH), did the household experience any adverse event that led to an economic loss? (e.g. job loss, death in household, migration, loss of property, etc.)									
Option	Yes					No				

Score	4			0			
							CPA 1 TOTAL ↗
CPA 2: FOOD SECURITY AND NUTRITION							
							SCORE
5.	Over the past month (MENTION THE MONTH), what has been the MAIN source of food consumed by your household?						
Option	Donated	Given in return for work	Bought from the market	Home grown			
Score	4	2	1	0			
6.	Over the past month, did anyone in the household ever go without food for a whole day because there wasn't enough?						
Option	Yes, more than 5 times a month	Yes, 1 – 4 times a month	Never				
Score	4	1	0				
							CPA 2 TOTAL ↗
CPA 3: HEALTH, WATER, SANITATION AND SHELTER							
							SCORE
7.	What is the distance (in Km) to the health care facility your household often uses?						
Option	More than 5 Km or miles	2 – 5 km or 1 – 2 miles	Less than 2 km or 1 mile				
Score	4	1	0				
							SCORE
8.	Does the household head or caregiver have any form of disability that's severe enough to affect their daily activities? (e.g., physical, speech, visual, hearing, or mental handicap?)						
Option	Yes			No			
Score	4			0			
9.	What is the main source of water for members of your household?						
Option	River, Stream, Lake, Pond, Unprotected well / spring	Public taps, Bore hole, Rainwater, Protected spring/well, Gravity flow scheme	Private Connection				
Score	4	1	0				
10.	How long does it take to collect water for domestic use from the main source? (Time in minutes) Consider time TO and FROM the source of water, INCLUDING waiting time.						
Option	More than 30 minutes	16 – 30 minutes	15 minutes or less				

Score	4	1	0
11.	What is the MAIN type of dwelling?		
Option	Temporary (mud, grass and wattle)	Semi-permanent (mud, iron sheet)	Permanent (Sand brick cement)
Score	4	1	0
12.	What is the type of a latrine/toilet facility used by members of your household?		
Option	Bush	Pit Latrine / Public toilet	Functional flush toilet, VIP
Score	4	1	0

CPA 3 TOTAL



CPA 5: PSYCHOSOCIAL SUPPORT AND BASIC CARE

			S C O R E
13.	In the last year, how often have you felt so troubled that you felt you needed to consult a spiritual, faith or traditional healer, counselor or health worker?		
Option	Most of the time	Sometimes	Never
Score	4	1	0

CPA 5 TOTAL



CPA 6: CHILD PROTECTION AND LEGAL SUPPORT

			S C O R E
14.	What would you do if any of your children experienced or became a victim of any form of child abuse or violence?		
Option	Nothing	Talk to neighbour / family only	Report to LC/Police/Probation, CDO, Human rights office
Score	4	1	0

15.	In the past 12 months (STATE MONTH), have you or another adult in the household used the following method of discipline with any child in your household? (Please select all the methods that apply)	Punched, kicked or hit a child
		Withheld a meal to punish a child
		Using abusive words/language towards the child

Option If TWO or MORE of the | If at least ONE of the methods is | If NONE of the methods are

	methods are checked	checked	checked
Score	4	1	0
			CPA 6 TOTAL ↗
HOUSEHOLD TOTAL SCORE (ALL CPAs) ↗			

DIVIDUAL INFORMATION

INSTRUCTIONS: Please administer this section to each child in the household. In particular, please interview the caregiver if the child is 12 years of age or below. Children who are 13 years and above should answer for themselves. Ask each question and write in the corresponding score for each child under his/her respective column (labeled "SCORES").

At the end of each CPA, please add up the scores for all questions and write them down under the "CPA TOTAL" row for **each** child. Finally, add up all CPA scores, and enter them under "INDIVIDUAL TOTAL SCORE" for **each** child.

					SCORES					
					Child 1	Child 2	Child 3	Child 4	Child 5	Child 6
Child's Name										
Child's Identification Number										
Child's age (in years)										
CPA 2: FOOD SECURITY AND NUTRITION										
1.	How many meals (including breakfast) has (Name) had in the past 24 hours? (SKIP if child is breast feeding)									
Option	None	One meal	Two meals	Three meals or more						
Score	4	3	1	0						
2.	What does the child usually eat? Write down "Yes" or "No" for each type of food consumed by the child. Instructions: <ul style="list-style-type: none"> • Applicable to children of all age brackets (Breast feeding children take all the food values) • "Usually" means at least 3 times a week 									

	<ul style="list-style-type: none"> Ask the parent/guardian and then a child where applicable (13 -17 yr.) to double check 								
	a. Energy foods: (potatoes, banana, oils, posho, millet, rice, maize, bread, cassava)								
	Yes	No							
	b. Body building foods: (beans, meat, soya, peas, milk, eggs, chicken, fish)								
	c. Protective and regulative foods: (tomatoes, oranges, pawpaw, mangoes, pineapple)								
	Yes	No							
Option	ALL of the options are selected as "No"	One or Two of the options are selected as "No"	All options are selected as "Yes"						
Score	4	2	0						
				CPA 2 TOTAL ↗					
CPA 3: HEALTH, WATER, SANITATION AND SHELTER									
3.	Last night, did (Name) sleep under an Insecticide Treated mosquito Net (ITN)?								
Option	Yes	No							
Score	0	4							
4.	Has (Name) been very sick for at least three months during the past 12 months? (By very sick, I mean that (Name) was too sick to go to school, play or do normal activities around the house for at least three of the past 12 months)								

Option	Yes	No							
Score	4	0							
				SCORES					
				Child 1	Child 2	Child 3	Child 4	Child 5	Child 6
5.	Has (Name) received the required immunization at his/her age? (Applicable to 0-5 yrs ONLY and ask for the immunization card/book)								
Option	Yes	No							

Score	0	4							
			CPA 3 TOTAL ↗						
CPA 4: EDUCATION									
6.	If the child is enrolled, what is his/her school attendance status? (Children aged 6; Days can be non-consecutive within the week)								
Option	Misses school 3 or more times per week or NOT in enrolled in school	Misses school twice per week	Attends school regularly (attends 4 or more days per week)						
Score	4	2	0						
			CPA 4 TOTAL ↗						
CPA 5: PSYCHOSOCIAL SUPPORT AND BASIC CARE									
7.	How many set (s) of clothing does (NAME) own? (Exclude school uniform)								
Option	Owens at least two sets	Owens one set of clothes	Owens no piece of cloth OR child is walking naked OR has tattered clothing						
Score	0	1	4						
8.	How often does (Name) feel sad, worried, withdrawn, or hopeless?								
Option	Often	Sometimes	Never						
Score	4	1	0						
9.	Over the past 3 months (STATE MONTH), how often have you seen someone in the your household being kicked, beaten, slapped, hit with a fist, threatened with a stick, had something thrown at, or being shouted at? (13-17								

	years)								
Option	Most of the time	Sometimes	Never						
Score	4	1	0						
				CPA 5 TOTAL					
CPA 6: CHILD PROTECTION AND LEGAL SUPPORT									
10.	Does (Name) have a birth registration certificate?								
Option	Yes		No						
Score	0		4						
11.	Has (Name) ever been into marriage? (10-17)								
Option	Yes		No						
Score	4		0						
12.	Has (Name) been sexually active in past 12 months (STATE MONTH)? (10-17)								
Option	Yes		No						

Score	4	0							
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						SCORES					
						Child 1	Child 2	Child 3	Child 4	Child 5	Child 6
13.	In the past 3 months, how often has (NAME) drunk alcohol? (age 5-17)										
Option	Everyday	Minimum of once a week	Less than once a week	On special occasions	Never						
Score	4	3	2	1	0						
14.	Has (Name) experienced any form of the following child abuses in the last 30 days? Please CHECK ALL that apply to the child. Probe or observe for any types or signs of abuse.										
	a) Denial of socialization with other children					a					
	b) Denial of legal rights/access to justice					b					
	c) Stigma and discrimination due to illness or					c					

	disability									
	d) Physical violence/abuse inflicting pain or injuries			d						
	<i>bruises, scratches, wounds</i>									
	e) Emotional abuse (e.g. shouting at the child, public humiliation)			e						
	f) Sexual abuse (<i>forced sex, raped, defiled..</i>)			f						
			g) Denial of food	g						
Option	If THREE or MORE behaviours are selected	If ONE or TWO of the behaviours are selected	If NONE of the behaviours is selected							
Score	4	2	0							
				CPA 6 TOTAL						
				INDIVIDUAL TOTAL SCORE						
				GRAND TOTAL SCORE (HOUSEHOLD + INDIVIDUAL SCORE)						
				(USE THIS SCORE TO DETERMINE LEVEL OF VULNERABILITY)						

DETERMINE THE VULNERABILITY LEVEL

INSTRUCTIONS: After totaling all the scores under “GRAND TOTAL”, look at the table below and determine **WHERE** that child’s GRAND TOTAL score falls in the score range below.

LEVEL OF VULNERABILITY	GRAND TOTAL SCORE
Critically Vulnerable	90 – 116 points
Moderately Vulnerable	50 – 89 points
Slightly Vulnerable	Less than 50 points

	Child 1	Child 2	Child 3	Child 4	Child 5	Child 6
WRITE DOWN EACH CHILD’S VULNERABILITY LEVEL						

Write the level of vulnerability for each child below.

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