Displacing AIDS

Therapeutic Transitions in Northern Uganda



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Thesis submitted in partial fulfilment of the requirements for the Degree of Doctor of Philosophy

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I hereby certify that this thesis is the result of my own work except where otherwise indicated and due acknowledgement is given.

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Thesis Abstract

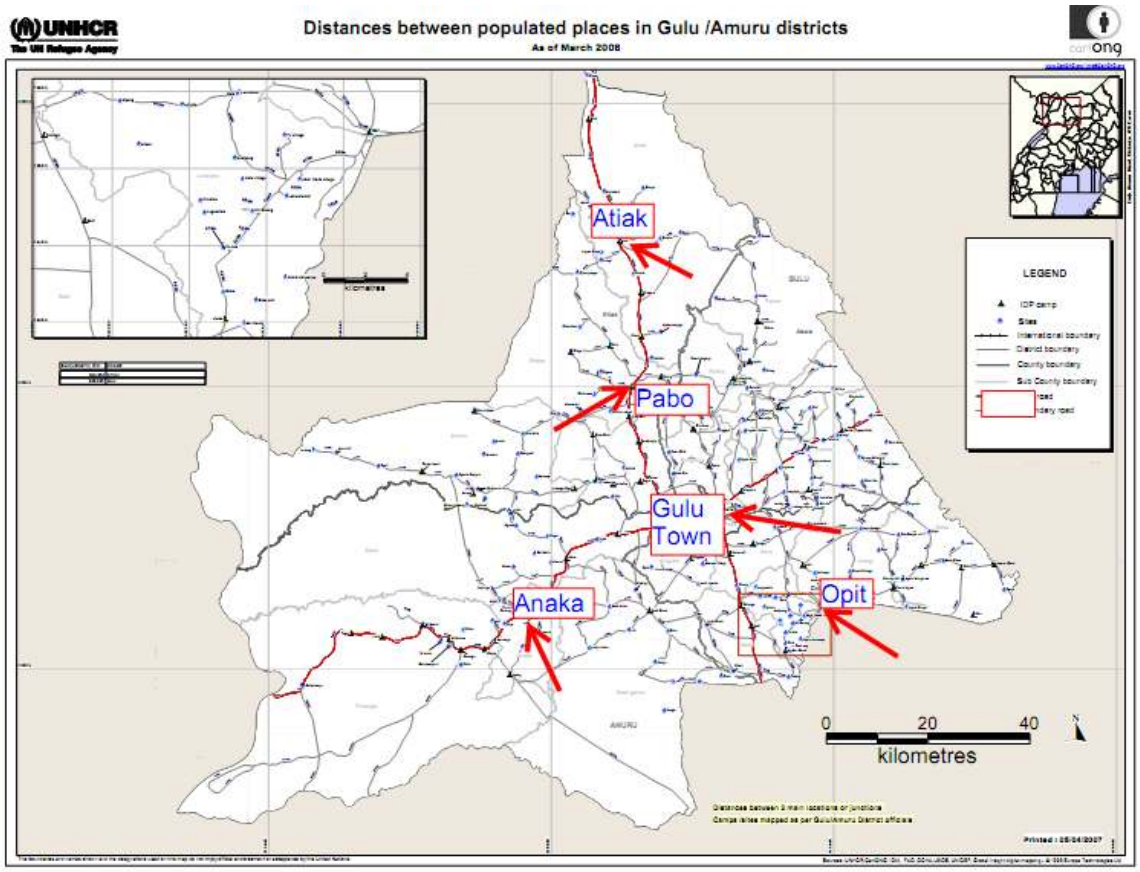
This doctoral project, entitled 'Displacing AIDS: Therapeutic Transitions in Northern Uganda' examines the biosocial transitions engendered by the treatment of HIV, focusing on antiretroviral therapy (ART/ARV) interventions, and the ways these are intertwined with the social transitions of conflict, displacement and return. The research involved an inter-disciplinary qualitative study with internally displaced communities living with HIV in northern Uganda, during 10 months fieldwork between 2006 and 2009. Northern Uganda has experienced a two decade civil war between the government of Uganda and the Lord's Resistance Army (1987 to 2006). In 2006, after a cessation of hostilities was signed, hundreds of thousands of the displaced began returning 'home'. The effects of conflict and social displacement were to significantly shape both the social and medical aspects of ART provision. I argue that northern Uganda was significantly excluded from widespread national community-based responses as a result of the war during the 1990s and early 2000s. Given this background, ART interventions were to engender rapid social transformations among those with HIV, but also in relation to the perceptions of HIV/AIDS in the broader community. I explore these intersecting biosocial and displacement-induced transitions through several streams: the social transitions of forced displacement and the return process; the transitions from illness to a precarious health; from social exclusion to a contested inclusion; transitions between local and biomedical understandings of healing; transitions in authority and biopower; as well as continually shifting forms of identity, support and affiliation. I give particular emphasis to forms of socio-spatial and medico -moral transformations. I argue that ARV interventions have been nested in the social and moral spaces of displacement. In particular the spatial configurations of encampment, involving extreme congestion and lack of privacy, have shaped patterns of disclosure and community and identity formation. The influence of Catholicism, shaped by missionary histories in the region, has also had a strong impact. Themes of militarism, lack of productivity, and encampment have shaped the language and perceptions of HIV and AIDS. Theoretically I engage with debates around biosociality, stigmatisation and 'clientship' within the emerging literature on ARVs. I trace the intersections of these questions with those in forced migration studies regarding the social transformations of displacement and return. Furthermore, I use this social analysis to engage with public-health perspectives on ARV provision. I argue that community-based strategies require adaptation to the social contexts of displacement. Such adaptations, involving attentiveness to the socio-spatial specificity of displaced contexts, are critical for the long-term provision and sustainability of antiretroviral therapy to displaced communities. In particular the return phase has created unexpected challenges for treatment continuity, arising from large-scale population movements. The thesis has a strong narrative focus and traces the experiences of several people living with HIV through the paths of displacement and return

Acronyms and Frequently Used Foreign Language Terms

Acronym/Term	**Explanation**
Ajwaka	*Traditional Healer*
ACP	AIDS Control Programme
ACORD	Association for Cooperative Operations Research and Development
AIC	AIDS Information Centre
ARC	American Refugee Council
ARVs	Antiretrovirals
ART	Antiretroviral Therapy
Aroga	Poison, witchcraft
Awola	Poison, witchcraft
Boda-boda	*Motorcycle Taxi*
Cik	*Law/Social Norm*
Cen	*A demonic and vengeful spirit*
Cimmotok	*Stigmatisation (* lit – to pointing at the back of someone's head)
cART	Combination Antiretroviral Therapy
CASA	Community ART Support Agents (TASO)
CDC	Centre for Disease Control
COSBEL	Community Life Seeking for Better Living
Cwiny	Mind or heart (lit – the beating of the heart)
CRS	Catholic Relief Services
DOT	Directly Observed Therapy
DFID	Department for International Development (United Kingdom)
EVI	Extremely Vulnerable Individual
FHP	Food for Health Programme
GHI	Global Health Initiative
Global Fund	Global Fund to fight HIV/AIDS, tuberculosis, and malaria
GoU	Government of Uganda
HAART	Highly Active Antiretroviral Therapy
HC	Health Centre
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome
IASC	Inter-Agency Standing Committee
IDP	Internally Displaced Person
IOM	International Organisation for Migration
JCRC	Joint Clinical Research Council
Kaka	*Clan / village-lineage*
Kipwaro	*A punishing spirit*
kwo tek	*Life is hard*
Jok	*Wild spirits*
LC	Local Commissioner
Leja leja	*Casual labour*
Lewic,	*Shame*
Lworo	*Fear*

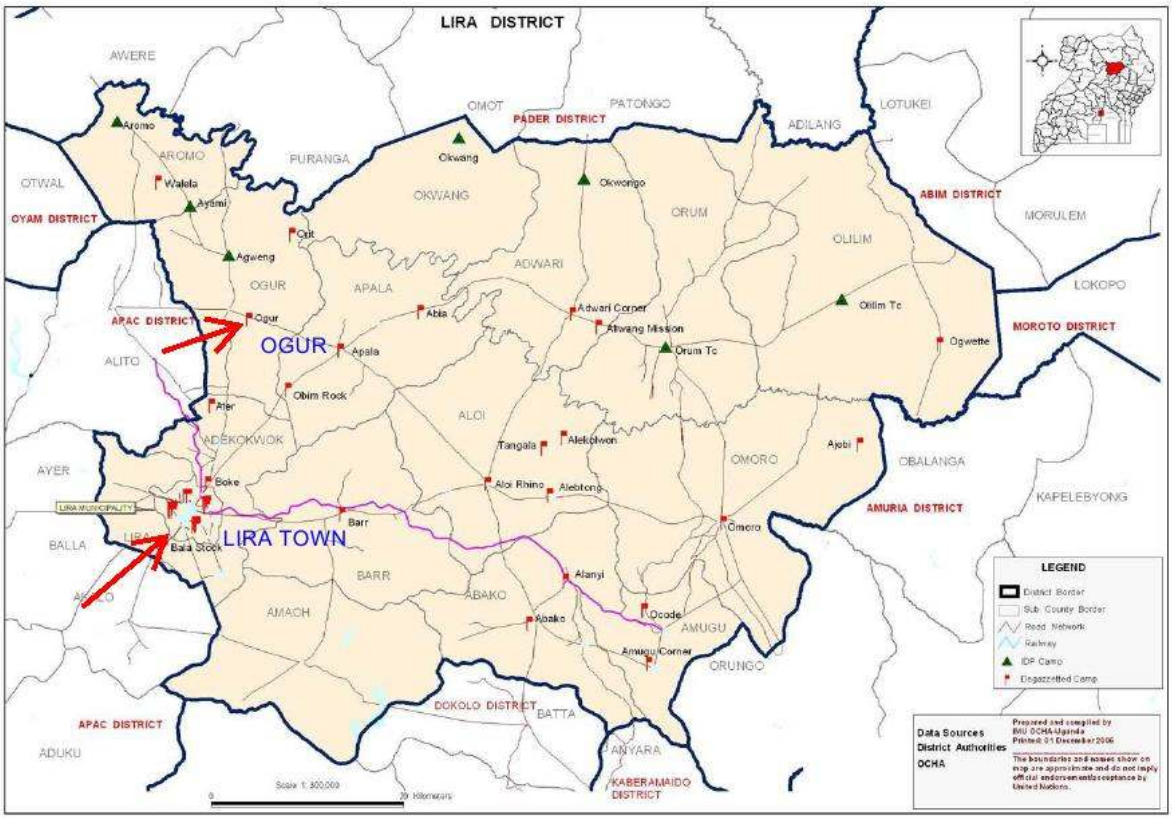
LRA	Lord's Resistance Army
Lujok	*Witches*
Malakwan.	A sour herb
Maleng	*Cleanliness, purity or holiness*
Malik	*Immorality*
Mony pa padi	*Soldiers of the Priest*
MOH	Uganda Ministry of Health
MSF	*Médicins sans Frontières*
NNRTI	Non-nucleoside reverse transcriptease inhibitor
NRTI	Nucleoside reverse transcriptase inhibitor
NRC	Norwegian Refugee Council
NRA/M	National Resistance Army/Movement
NUMAT	Northern Uganda Malaria AIDS/HIV and Tuberculosis Program
nwako tam	*Counselling (lit – sharing ideas or thoughts)*
OVC	Orphans and Vulnerable Children
PAG	Pentecostal Assemblies of God
PEPFAR	US President's Emergency Plan for AIDS Relief
PHA	Person with HIV/AIDS
PI	Protease Inhibitor
PLWHA	Person Living with HIV/AIDS
PMTCT	Prevention of mother-to-child (HIV) transmission
Rac	*Bad or immoral*
SACS	Southern African Clinicians Society
SPLA	Sudanese People's Liberation Army
TASO	The AIDS Support Organisation
THETA	Traditional and Modern Health Practitioners Together Against AIDS and other Diseases
Twoo jonyo, -	HIV/AIDS (lit - the disease that makes you thin)
UAC	Uganda AIDS Commission
UPDF	Ugandan People's Defence Force
UNDP	United Nations Development Programme
UNHCR	United Nations High Commission for Refugees/United Nations Refugee Agency
UNOCHA	United Nations Office for the Coordination of Humanitarian Affairs
VCT	Voluntary Counselling and Testing
WACFO	Woman and Children First Organisation
WFP	World Food Programme
WHO	World Health Organisation
Yat	*Medicine or poison/witchcraft*
Yabbo Wang Wu	*Open your eyes.*

Map 1: Gulu and Amuru Districts



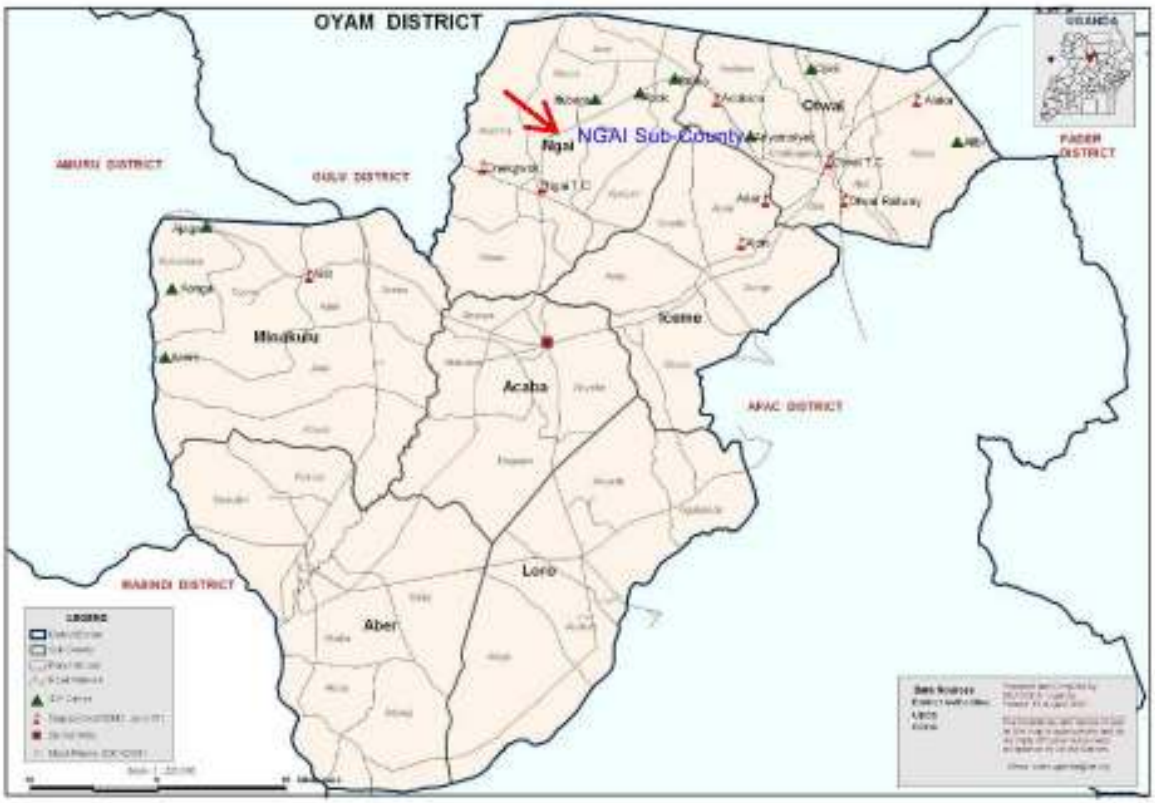
Source: UNHCR. Field sites marked in red and blue by the author

Map 2: Lira District



Source: UNOCHA & District Authorities. Field sites marked in red and blue by the author

Map 3: Oyam District



Source: UNOCHA & District Authorities. Field site marked in red and blue by the author.

Introduction

In August 2006, I was staying at the St Joseph's Mission in Opit camp. In the evenings, the village paths and wells were alive with movement. Rice fields, dipping into the valley, were lush with the recent rains. The conditions of camp life were dire; yet people were harvesting the benefits of the recent peace. At the mission, on an old television, powered by solar electricity, I heard that a cessation of hostilities had been announced between the Lord's Resistance Army (LRA) and the government of Uganda (GoU). There was widespread cynicism, and even indifference, to the deal. However, in spite of the two years of ultimately unsuccessful peace talks that followed[1], the event was to usher in a phase of momentous transition in Northern Uganda. It produced a tenuous peace in a region that had been plagued with various conflicts for almost three decades and was to pave the way for the return of hundreds of thousands of the internally displaced. St Joseph's Mission was a fitting place to hear this news: it was a place of meeting and sanctuary for many with HIV. It was a site at which I was to explore the ways in which the transitional experiences of conflict and of living with HIV become interconnected, in the sufferings they induce, but also the potential for biological and social regeneration they create.

Those displaced with HIV are, in a sense, doubly displaced: by both conflict and disease. *Displacing AIDS* - the title of this thesis - refers to the transition from HIV as fatal disease to a chronic illness, as a result of the provision of antiretroviral therapy (ART). However, HIV/AIDS is also displacing: it often pushes those with the disease to the margins of social

[1] In spite of the collapse of peace talks in Juba, Southern Sudan, the LRA had not by January 2011 returned to Northern Uganda after leaving for Sudan and the Democratic Republic of Congo.

relations. However, in spite of social exclusion, HIV status can also be a social resource (Fassin, 2007a:225). Those with HIV may access material resources through formal interventions, and disease-status opens up new channels of social engagement and forms of identity. I use the word 'transition' as more or less synonymous with 'transformation': I chose the former in the title to capture the sense of precariousness and uncertainty that characterises the experience of illness and displacement[2]. Experiences of HIV and displacement are characterised by several forms of transition: the transitions from conflict to peace; from forced displacement to resettlement or return; from illness to a precarious health; from social exclusion to a contested inclusion; transitions between indigenous and biomedical understandings of affliction and healing; as well as continually shifting forms of identity and social relations. These transitions are neither linear nor irreversible but involve continual negotiation and struggle. The biosocial transitions of HIV therapies must be grasped through local histories of conflict and displacement; inversely, a study of these interventions can illuminate some of more opaque dimensions of the displacements in Northern Uganda.

Hence, this thesis examines, through qualitative methods, the biosocial transitions engendered by HIV treatment, focusing on antiretroviral therapy (ART)[3], and the ways these are intertwined with the social transitions from conflict to peace, and from displacement to return. I focus here on antiretroviral therapy as part of a broader array of treatments and programmes including: treatments for opportunistic infections, food assistance, and associated counselling services. The use of 'therapeutic transitions' therefore alludes to the broader context in which biomedical treatment is provided and managed. I am guided in this

[2] Krulfield and Camino (1994:ix; also cited in Kibreab, 2004) describe the experiences of the displaced as 'experiences attended by liminality … in which they are caught in positions of transition from a more orderly and predictable past to a new and as yet unpredictable future.'

[3] This study focuses on combination antiretroviral therapy for the long-term treatment of HIV/AIDS and not ART provided to prevent mother-to-child transmission of the virus.

thesis by three broad and interlinked questions: first, how have HIV treatment interventions been shaped by conflict and displacement; second, what have been the effects of these ART interventions on the social relationships of their recipients; and finally, what are the social relationships necessary to ensure the sustainability of treatment under conditions of displacement and return? A key task of this thesis is to outline the specificity of the challenges to, and potentialities of, treatment to displaced communities in comparison with other resource-limited settings.

I argue that the therapeutic transitions elicited by ART have been deeply embedded in the social and moral worlds of conflict and displacement in Northern Uganda. The conflict has affected the provision of ART through the ways in which insecurity has shaped access to health services, but also in the ways in which the socio-spatial transitions of forced displacement have reordered social relationships. Treatment programmes using community-based strategies have had to adapt not only to the deprivations of conflict but also the exceptional social spaces of displacement. In addition, the treatment programmes themselves have produced forms of social transition, engendering new forms of social relationships and mobility within the disruptions of displacement. These social relations – formed during displacement – have been critical for both the long-term sustainability of ART but also in mitigating the vulnerabilities of HIV and displacement. However, the transitions from displacement to the return period have also constituted a major change that both patients and treatment providers have struggled to negotiate. I will argue that the post-conflict transitions have proved as great a challenge to ART provision as the period of conflict itself.

Research Justification

During the past decade, as a result of lowering drug prices and global pressure, over 5 million people worldwide have been provided with ART (UNAIDS, 2011:12), yet treatment to displaced populations has been neglected both in practice and research. In spite of initial cynicism, it has been repeatedly shown, throughout Africa and elsewhere, that antiretroviral treatment can be provided in resource-limited settings with adherence rates as high, or better than, wealthy countries (Bennet *et al.*, 2008:20). However, significant challenges remain. In particular, mobile and displaced populations are still often neglected in both research and practice (Kenny *et al.*, 2010). In recent years, there have been calls for the expansion of treatment to displaced and conflict-affected settings (Spiegel, 2004, Culbert *et al.*, 2007), though these efforts have been limited, and standards and protocols are still in development.

Providing sustainable long-term ART to conflict-affected communities requires transcending existing paradigms of healthcare. Health interventions in complex emergencies – humanitarian crises, caused by conflict, in which there is a near breakdown of local authority (Spiegel *et al.*, 2007b:3) - are often focused on emergency medical assistance and immediate health problems (diarrhoeal diseases, lack of water, and malnutrition, for instance). They often neglect long-term planning for the post-conflict phase. However, in long-term displacement situations, like Northern Uganda, there is a need to find a balance between primary and emergency healthcare models of medical intervention (Van Damme, 1998:157). This is particularly important for antiretroviral treatment which should be life-long, and requires long-term planning and monitoring, to protect patients' health and also to guard against the spread of drug resistance. In resource-limited and conflict-affected settings, with severe health staff shortages, it is critical to integrate non-medical community workers into treatment programmes. The long-term social dynamics of displacement are therefore central

to treatment sustainability. However, there is little research, on Northern Uganda or elsewhere, bringing together social studies of displacement with those of HIV treatment provision. This study is among the first.

Northern Uganda was chosen as the site for this research for several reasons. It was a fitting site as the region has been the recipient of what is likely the largest expansion of ART to a recently conflict-affected area in the world. Provision of antiretroviral therapy was started in 2002 in Gulu, the region's main urban centre and from 2005 onwards was expanded rapidly to rural areas and camps for internally displaced persons (IDPs). By March 2010, over 22 000 HIV-positive people were on ART – mostly free or at marginal cost - in previously conflict-affected districts (ACP, MOH, 2010). The strategies and failures of Northern Uganda therefore have significance for treatment provision in other conflict-affected and displaced communities.

Furthermore, Northern Uganda is of particular interest for historical reasons. The conflict in Northern Uganda was among the longest civil-wars of recent years, and displaced over 1.5 million people. The political dimensions of this conflict and its continuation are highly contested, as is the role of humanitarian intervention in the region (Dolan, 2009, Branch, 2005, Nibbe, 2010, Allen, 2006a). This thesis does not enter these larger debates; however as a micro-study on the social dimensions of displacement, I hope it makes a modest contribution to the area studies on Northern Uganda. In addition, Uganda's response to HIV/AIDS has been one of the most successful and renowned in the world. In the story of HIV/AIDS in Uganda, however, Northern Uganda is often neglected. I hope here to provide a corrective to this exclusion and particularly in the historical chapter, to situate Northern Uganda within the broader national response to HIV/AIDS.

Spaces of Transition in Northern Uganda

A brief history of conflict and displacement

Local histories and social spaces of conflict, displacement and transition have shaped the provision of ART. Here I introduce these spaces, providing a context for the discussion that follows. The war in Northern Uganda was a continuation of the war in which Yoweri Museveni's National Resistance Movement (NRM) took power in 1986. Following the NRM's takeover, several rebel groups emerged in the north, the most prominent and long-lasting of these was the Lord's Resistance Army (LRA) led by Joseph Kony. The LRA is a movement influenced by Christian ideology as well as Acholi spiritualism; Kony has claimed to be a spirit medium. Notably – and often ignored - the LRA also has a political agenda including: mobilizing for the rights of the Acholi within the Ugandan state; the formation of an ethnically balanced army and judiciary; equal education and health for all; as well as the implementation of the ten commandments through a religious affairs ministry (Allen, 2006:43, Finnström, 2008:ch3). However, while many Acholi are sympathetic to these political claims, the violent methods of the rebels, involving abductions and murder, came to delegitimise them as a political force (Branch, 2005, Finnström, 2008).

Violence against the population has not been the sole domain of the rebels. In 1996, the Ugandan army started forcing the rural population of Northern Uganda into what were termed 'protected villages.' Initially, there were a few hundred thousand people in these camps, but they grew to over 1.5 million people by 2004 (Branch, 2005:19). Virtually the entire rural populations of districts, such as Gulu and Kitgum were displaced either into the camps or into towns. While some migrated voluntarily as a response to the violence of the

LRA, many were forced into camps by the army. Protection in the camps was lax, and the population often suffered violence and coercion from armed groups of young men, under partial command of the army, as well from soldiers themselves (Branch, 2005:19, Dolan, 2009:59). The camps came to be viewed by many as a means for the Ugandan government and army, with the complicity of international NGO's, to exercise control over the population (Dolan, 2009).

During the conflict, in addition to attacks and abductions by the rebels, there were overcrowded living conditions, widespread outbreaks of epidemic diseases, like measles and cholera. The conflict has made access routes to camps dangerous, and caused a 'brain drain' of medical personal from the region (Coles, 2006). A World Health Organization (2005) mortality survey in Gulu, Kitgum and Pader found the crude mortality rates in the Acholi region are 'well above the emergency threshold' of 1 per 10 000 per day with 'staggering' excess mortality rates. The situation in the camps is far worse than in the municipal areas. The report found that HIV/AIDS is the second highest cause of death after malaria in a context where 'little if any treatment for opportunistic infections exists, highly active antiretroviral treatment is virtually unavailable, and large cohorts of persons infected in the 1990's are now developing AIDS' (WHO 2005:42). An estimated 13.5% of deaths were caused by HIV/AIDS. A 2004 to 2005 National Sero-Behavioural Survey indicates that the prevalence rate for the North Central Region is 8.2%, significantly above the national rate of 6.4% (MOH, 2004-5). However, this study did not sample in displacement camps (Mermin 2009) and so is not representative of conflict-affected rural areas. In spite of this high sero-prevalence rate, antenatal data at St Mary's Lacor Hospital – a Catholic hospital near Gulu

Town – recorded a prevalence rate of 9 % in 2007[4] - a significant decline from 27.1% in 1993 (Fabiani, 2008:3). No reliable data exists for many of the camps in the region.

In addition to its dire health implications, forced displacement has also caused the breakdown of agricultural production, leading to malnutrition and widespread dependence on food aid distributed by the World Food Programme, among other international organisations. These factors were viewed as 'a vector for social breakdown and moral disintegration' (Dolan, 2009:169), and created a strong sense of political and developmental neglect among the populace (Finnström, 2008). The association between the material conditions of encampment and a narrative of social and moral decline is a powerful feature of social space of the camp and figures strongly in the language and experiences of HIV/AIDS that will be discussed in this dissertation.

Displacement also produced a major transition in social and spatial relationships. Understanding these transitions requires a brief review of pre-displacement society in Northern Uganda. In Acholi society[5], the primary unit of social organisation has been the village-lineage, or *kaka* (translated primarily as 'clan'). It is through this patrilineal lineage system that rights over land are transferred (Girling, 1960: 55-58). Under Uganda's constitution, women have the right to inherit their husband's land, though this was rarely adhered to in Northern Uganda.[6]When forcible encampment or displacement took place, some moved into the camps as extended families and chose to live near relatives (Muyinda,

[4] Email communication with Massimo Fabiani, Researcher at the Italian National Institute of Health, 26 August 2009.
[5] The Acholi are the major community in Northern Uganda. However, the neighbouring Lango share the Luo language and similar structures of land ownership and kinship.
[6] Interview with Lydia Katami, NRC Legal Assistant on land issues, Gulu Town, 22 August 2008.

2008:74). However, as the process of displacement was phased over time, many extended families were also split and segregated: elected camp leaders, as well as the military, came to play an important role of authority in the camps (Westerhaus, 2007:4, Nibbe, 2010). Nibbe (2010) explains clearly how the process of encampment involved both continuity and rupture:

> In Acholiland, living spaces reflect spheres of social relatedness – closer kin live in an inner ring, and as one moves out of the living space one also moves into the extended family, the clan, and so forth into the larger identity of being 'Acholi.' In the camps, these living spaces were altered – and while the 'rules' of family living were mirrored in the camps as much as possible, available space did not allow people to set up their huts in the same configuration as in their homesteads. This meant that while immediate and close kin *tended* to live together in the camps, extended families were often spread out across the camp – (e.g. extended families were often in different sections of the camp depending where space was available to set up a hut at the time of their displacement.) As a result, people ended up living next door to people who had no kin relationship with them. After living next to one another for 6-12 years, many people created kin-like relationships with their neighbours, helping each other as necessary.

In this sense, encampment did not represent a total 'breakdown' of existing social relations (Hammond, 1999), networks of social obligation, or kinship-based access to land and resources (such as wood-fuel harvesting). However, it did induce fundamental disruptions in social relations, kinship obligations, productive relations and relations of authority. Some were displaced within walking distance of their village-land (though even with these people, restrictions on mobility and distance limited productivity), while much of the population was alienated from their village land. As Dolan (2005:149) noted of the war-time economy in the camps:

> although the situation created opportunities for those with sufficient capital [i.e. the sale of agricultural goods on the market], for the majority such activities was completely out of reach, and while there was a lot of activity in the market, most of it was of a very marginal nature.

In addition, access to resources became primarily channelled through humanitarian institutions. In 1999 only 10% of arable land was being used in Northern Uganda indicating the extensive effect the war had on agricultural production – access to land was limited by distance, restrictions on mobility and the threat of violence or abduction (Dolan, 2005:149). Even with food assistance from the WFP, many still had to rely on cultivating plots (often rented) on the outskirts of the camps, exposing residents to risks of abduction and violence – and sometimes women to sexual violence (Westerhaus, 2007:4).

Hence, the socio-spatial conditions of the camp were exceptional. The camps – during the period of my fieldwork - were compressed villages, dusty and infertile. In the dry season, they were surrounded by kilometres of yellow grass. Wind storms blew through the camps carrying dust, wood and detritus. In the wet seasons roads and access routes are often damaged. However, during the years of this study, problems with late rains and drought were recurring, causing food crises in 2008 and 2009. In the camps the density of homesteads is extreme with huts within metres of one another, allowing little privacy. Army barracks were placed on the peripheries of the camps.

Research Impressions

When I visited people in their homesteads in rural villages during 2008 and 2009, the spatial difference between the camp and homesteads in rural villages was striking to me. In rural homesteads, the houses of family members are scattered around a compound – a place of

resting and eating. The compounds are surrounded by acres of fields. Sometimes adjacent compounds on their own 'hills' - terms for the space occupied by families - are not even within sight. Prior to displacement, the villages were scattered throughout the region, and there was some clustering of homesteads around trading centres. Market days and dances provided times when villagers would meet one another, trade, court and drink.

In the transitory world of the camps from 2006 onwards, the evenings came with the songs of funerals, voices from radios, the soft rhythms of girls pounding groundnuts and grain, the growl and puffs of white dust from mills. Children wandered around in groups. Women brewed pungent millet and cassava beer for card players. From the fields and bush emerged young men with spears and hunting dogs by their sides, and girls carry hoes, with sweet potatoes on their heads. At night huge fires lit areas of the camp baking pots of red clay.

There were also markers of urbanization – cell phone towers stood above many camps, and disco music pounded throughout the night playing hip-hop, reggae and dance-hall music. Beer halls played premier league football, with televisions powered by generators. One of the lodges I stayed at in Opit was a football viewing venue by night and a local court by day. The camps over the past few years were different worlds from the darkness and surveillance of the conflict, in which there was the constant fear of attack or abduction, and in which soldiers and reckless armed units terrorized those who moved at night, as many I spoke to recounted the period of conflict to me.

Since 2006, some residents of the camps moved into smaller 'satellite camps' closer to their home area: a process labelled by the government as 'decongestion.' In Lira, the return movements started in 2006 and the camps were mostly emptied by 2008. In Gulu and Amuru,

the major return movements started in mid 2007 and were still continuing in June 2009, which was the last time I visited Uganda. There was significant movement between the camp and villages. During my time of fieldwork, many were afraid of returning permanently to their villages and some chose to remain in the camps and towns. Significant numbers of those living with HIV were still in the camps during my time of fieldwork – the reasons for this, including the importance of ART in shaping decision-making around return, will be explored in this thesis.

Towns like Gulu have experienced a massive influx of displaced persons over the past decade. They too were spaces of transition and have undergone remarkable changes since I first visited in 2006. Whereas in 2006 I had to carry my money in a sock, by 2009 at least three banks had opened. Gulu was a post-conflict carnival of aid agencies; American volunteers: street stalls selling anything from pharmaceuticals and plastic bottles to chickens and motorcycles. The mentally ill and traumatised wandered the streets. The scenes of Gulu town were a peculiarly contemporary phenomena- the coalescing of extreme suffering and destitution, with the proliferation of wealth and markers of globalization – cell-phones, trucks with Chinese lettering, Land Cruisers, internet cafes, night clubs, and an incipient (disaster) tourism. In these transitional zones there was no clear division between the displaced and non-displaced. As a counsellor at TASO told me, 'everyone here is displaced.'[7] Displacement is not only a spatial uprooting but a more generalised condition of disorientation that permeates the social experience of conflict.

[7] Interview Charles Odoi, Counseling Co-ordinator, TASO Gulu, 07 August 2008.

Theoretical Approach

As discussed above, I have aimed to situate the questions of this thesis through understanding the intersections between displacement-induced and biosocial transitions. In this line of inquiry I draw on several disciplinary perspectives including medical anthropology, forced migration studies, human geography and public health. Each individual chapter sets up a theoretical perspective and reviews a literature around a debate. However, to set up the broad theoretical frame of inquiry that is explored throughout this thesis, I will introduce perspectives on displacement-induced and biosocial transitions.

Displacement-induced transitions

The theme of intersecting biosocial and displacement-induced transition will guide the analysis of this thesis. Here, I will briefly outline the forms of transition discussed, though more in-depth literature reviews will be given in the body of the thesis. First, displacement should not be viewed simply in terms of a paradigm of a *breakdown* (of social networks, production, morality, and so on), but also as a process of social transformation, in which individual and collective choices, resilience and creativity are of paramount importance (Castles, 2003, Hammond, 1999). As Castles (2003: 13) writes, 'forced migration needs to be analysed as a social process in which human agency and social networks play a major part.' These social transformations are linked to the spatial fragmentation of communities, changes in leadership, the dissolution of trust and undermining of social cohesion. Changes in productive relations may damage social networks formed around these activities (Holtzman

and Nezam, 2004:110). In addition, new social identities and 'communities of interest' can form around camps, neighbourhoods, or around shared grievances. Sometimes new groups form merely in name to receive aid benefits (Holtzman and Nezam, 2004:111, Krulfield and Camino 1994 cf Kibreab, 2004).

However, the experiences of displacement as 'transition' are often characterised by an extreme uncertainty, and attempts to maintain meaning and order (Kibreab, 2004, Finnström, 2008). Furthermore, displacement involves the reorientation of forms of social reproduction in which power relations, including gender and age relations, are contested, even though existing hierarchies may also be reinforced (Daley, 1991, Turner, 1999). While refugee assistance programmes may operate on the basis of equality, they often neglect that social reproduction of inequality are often reproduced within the household and reproductive sphere (Callamard, 1999:201). It is a widely report phenomenon that displacement elicits contestation over gender relations and may transform the gendered division of labour (Callamard, 1999:199). Changes in the demographic structure of displacements camps can also alter gender relations. (Boelaert *et al.*, 2004:168). Displacement, conflict and humanitarian crises also open the way - in addition to military control - for governmental transitions in which non-governmental actors play a significant part in managing the lives of the population (Duffield, 2008). Displaced populations may turn to non-state actors with 'demands, expectations, and accusations', thus disrupting existing social hierarchies (Landau, 2001: 2). The management of displaced populations in the humanitarian complex also creates new systems of bureaucratic labelling and control (Zetter, 2007).

In this thesis, I frame conflict and displacement in terms of a socio-spatial transition. I will not enter into the vast debates around space and place across anthropology and human

geography but will limit myself to outlining the guiding approach of socio-spatial transition used in this thesis. 'Social space' refers to the *relationships* between physical spaces and social relationships. Space is 'always in process' and 'the product of interrelations' (Massey, 2005:2,10). Spaces are not static but are produced through human activities, even while they shape and limit these (Lefebvre, 1991). Social space is not a normative concept, nor does it conceive space simply in terms of distances but encompasses the relations between the individual's body, and their social and material environment. As Lefebvre (1991: 405) writes, social space 'proceeds from the body.' Spaces are thus dynamic processes, and spatial orderings central to processes of social reproduction (Harvey, 2000:209). Space can be conceived through the interactions of its material, conceptualised and lived dimensions (Harvey, 2006:135). The mobility of people, information and objects form part of spatial relationships. Social spaces are inscribed with power relations – for instance, class or gender relations. They are structured around certain divisions of labour and inequalities and structure forms of social reproduction (Lefebvre, 1991:32). This may have a particularly gendered dimension – shaping the mobility and social access of women to certain resources, for instance (Silvey, 2006). The production of space serves to structure relations of domination and exclusion but is also the site of resistance and contestation. Paths of observation and categorization are also shaped spatially, and are part of power relations (Foucault, 1977). Debates within forced migration studies have largely focused on the relations between place and the territorialisation of identity (Malkki, 1992, Kibreab, 1999). In contrast, the concern in this thesis is with the ways the spatialities of displacement shape sociality and identity. I aim here to elucidate the contours of conflict and displacement, and the ways these shape daily life. War and displacement produce a certain spatiality: the congestion of homesteads in the camps; rapid urbanization in town areas as a result of flight; extreme geographic unevenness of development, services and infrastructure; new patterns of agricultural production and food

distribution; new patterns of trade, among other processes. It is argued here that these dimensions not only shape access to antiretroviral treatment but also its social outcomes.

Biosocial Transitions

It is only in the context of displacement-induced transitions that the biosocial transitions of ARV interventions in Northern Uganda are intelligible. These transitions and the associated literature will be discussed extensively in following chapters, so I limit myself here to introducing a few key concepts. First, how I understand medical systems and therapeutic interventions, and second how I conceptualise biosocial transitions. Drawing from the perspective of medical anthropology, I understand 'medical systems as social systems, not just systems of knowledge and treatment practices' (Nichter, 2002:81). In this view, studying 'therapy management' involves viewing medicine provision as 'nested' in local social relations, social values and institutions, economic and power relations, and forms of local contestation (Nichter, 2002:82). Both the experiences of chronic illness as well as the impacts of biomedical interventions are socially situated. As Kleinman (1988:31) writes, 'in the context of chronic disorder, the illness becomes embodied in a particular life trajectory, environed in a concrete life world.' The experience of illness may become embedded in 'a history that is both individual and collective' and illness may be a lens through which social marginalisation and history are interpreted (Fassin, 2007a:175). Furthermore, biomedical interventions do not only affect individuals but can transform social settings and relations. A fundamental assumption guiding this thesis is that 'biomedical technologies… cannot be understood without an appreciation of how they are incorporated into the historical trajectory and everyday social life of the locales in which they arrive' (Lock and Nguyen, 2010:5). This study situates antiretroviral interventions as nested in the social spaces of conflict,

displacement and transition. In particular, in this thesis I focus on the 'social lives of medicines,' exploring 'what giving and taking medicines does for the social relations of those involved' (Whyte et al., 2002:170). In addition to this, a guiding perspective is the 'biosocial framework' proposed by Farmer (2005b). 'Biosocial' refers to the continuous and dynamic interaction of biological and social processes (Castro, 2005:1218, Farmer, 2005b). As Farmer (2005) writes, 'It must assess not only impact on morbidity and mortality but also questions of stigma and equity; it must offer a resocialized understanding of how inequalities come to take their toll through disparities of risk for infection, radically different courses of disease, and disparities of access to proven therapies.' In the course of this research I have aimed to be attentive to both the biomedical and social concerns and outcomes of ART interventions.

Antiretroviral therapy, along with associated treatment and diagnostics, incite forms of transition, both biophysical and social. The transformative social experience of treatment includes the formation of new social networks, and new social and family obligations, but also may have negative consequences, such as new forms of stigmatisation as treatment becomes a marker of illness (Desclaux, 2003:45-46). Closely linked to the idea of 'biosocial' is the concept of 'biosociality'. The term 'biosociality' is used by Rabinow (1996) to refer to actual and hypothetical forms of social organisation based on genetic conditions. However its reference to the 'formation of new group and individual identities' based on shared biological features as well as a set of therapies and technologies to manage genetic risks, can be easily adapted as a powerful conceptual lens for understanding the social relations developing around HIV and AIDS. For, like a genetic condition, HIV is an incurable biological condition, and the virus attaches itself into human DNA protein. HIV therapy also comes with a set of diagnostic and therapeutic practices that shape social practices and behaviour. The biosocial transitions catalyzed by the introduction of ART involve changes in

bodies, and body perception; shifts in livelihood strategies; new forms of social networks and identities; and the renewal of sexual relations. The usefulness of biosociality as a concept to understand ARVs has been criticised (Meinert *et al.*, 2009, Gibbon and Whyte, 2009) for abstracting disease-related socialities from broader networks of family, kinship and clientship. These critiques will be given deeper discussion, particularly in Chapter Three. While I agree that biosociality is nested within broader social networks,, I argue here that the concept is useful though in a broader manner than Rabinow's usage. Biosociality, in my usage, extends beyond the narrow forms of sociality around biological status and diagnostic practice to the ways the disease becomes a socially embedded condition. Biosociality is intimately tied to other forms of social relations, and forms of social recognition.

A final concept that recurs in this thesis is that of vulnerability – understanding HIV-related vulnerabilities is important for grasping the social transitions induced by ART. However, my use of vulnerability extends beyond its common use in economic and public health literature, where it is conceived in terms of resilience to an external shock. For instance, Barnett and Whiteside (2006:178-179) define HIV-related 'vulnerability' as 'those features of a society, social or economic institution or process that make it more or less likely that the excess morbidity and mortality associated with a disease will have negative impacts' and the concept can be applied at multiple levels from the individual, to the household or state. In this conception, different vulnerabilities may be a result of wealth, skill, labour, access to care as well as the degree of a 'strong, cohesive and compassionate civil society' (Barnett and Whiteside, 2006:179). While not disputing the importance of these factors, I conceive vulnerability differently here. Vulnerability is not simply a biological characteristic or the degree of resilience to disease or poverty, but is reflective of forms of social recognition: 'when a vulnerability is recognised, that recognition has the power to change the meaning

and structure of vulnerability itself' (Butler, 2004:43). In this perspective, forms of vulnerabilities arising from disease-status are not simply a result of resilience or social compassion, but are also integral to the ways disease-based identities are symbolic resources that people draw upon in negotiating adversity. Vulnerability expresses the exposure of the body to its environment as well as to norms and recognition. As Butler writes that the 'social vulnerability of our bodies' arises from their quality 'as a site of publicity at once assertive and exposed' and that vulnerability arises from 'our being socially constituted bodies, attached to others, at risk of losing those attachments, exposed to others, at risk of violence by virtue of that exposure' (Butler, 2004). Vulnerability, in this view, is a deprivation, an exposure to violence, both manifest and structural, but can also be a resource for the formation of communities bound together through shared vulnerability and loss. Following this HIV-related vulnerabilities and the ways in which therapeutic interventions can help overcome those are related both to physical well-being, but also to social relations and stigmatisation. These themes will be explored throughout this thesis.

Methodology

This thesis is based on ten months doctoral and masters field work, conducted in four separate visits to Northern Uganda between June 2006 and June 2009[8]. The doctoral research significantly expanded on masters research conducted in 2006. The period of research took place over the immediate post-conflict period and while the return process was getting underway. A qualitative approach to healthcare is adept at situating the clinical encounter

[8] August to September, 2006; November 2007 to April 2008; July to August 2008; June 2009. My assistant Ajok Flavia Susan also conducted, recorded and translated a number of interviews and focus-groups in my absence from Northern Uganda between April and July 2008, as well as during 2009 and 2010, based on question guides.

within a broader web of social relationships, and emphasising the social processes that shape both health and therapeutic practices (Katz and Mishler, 2003). In particular, in this thesis, I focus on the 'social lives of medicines,' exploring 'what giving and taking medicines does for the social relations of those involved' (Whyte et al., 2002:170). I outline the methods and design below.

A multi-sited approach

The methods and outcomes of this thesis have been strongly shaped by the experiences of moving through the landscape of Northern Uganda and observing the multiple spaces of displacement As Ingold (2006:14) writes, 'beings do not simply occupy the world, they inhabit it, and in so doing – in threading their own paths through the meshwork – the contribute to its ever-evolving weave.' My research methods involved moving between sites, camps and towns, clinics and homes, of travelling with field-officers on their motorbikes to patients' homes to deliver medicine, of walking with our respondents between the clinics and their homes, or of trying to find people we had met in the camps back in their rural homes, for instance. As a student moving in these transitional spaces, I too came to inhabit this world, as it has left its imprint on me. The social spaces I visited were not merely sites in which research was conducted, but formed part of the object of study itself.

In choosing field-sites, I adopted and adapted the approach of multi-sited ethnography used alongside extensive qualitative interviews. The multi-sited approach explores both the inter-connections and juxtapositions of different sites (Marcus, 1995). Applied to the study of HIV/AIDS treatment, this approach can be used to study treatment provision at both an institutional and community level. The instruments of this method may include interviews,

case histories, observation of clinical practice, and village-level ethnography (Whyte, 2005). Following this approach, I conducted research in NGO, health centre, and community settings. Treatment organizations included The AIDS Support Organization (TASO), St Mary's Hospital Lacor and with their community support the Comboni Samaritans, as well as the Uganda Ministry of Health Programmes. I also conducted research in town, camp and rural settings in conflict-affected regions of Northern Uganda. This included two towns, Gulu and Lira, as well as six camps and five rural sub-counties. The primary field sites for this thesis were Opit camp in Gulu district, Layibi on the outskirts of Gulu Town, Pabo in Amuru district, Ngai sub-county in Oyam district, Ogur sub-county in Lira district[9].

Interviews and focus-groups

The research relies on both observation and extensive interviews. The primary form of interview used is the semi-structured interview which is 'conducted on the basis of a loose structure consisting of open-ended questions that define the area to be explored, at least initially, and from which the interviewer or interviewee may diverge in order to pursue and idea or response in more detail' (Britten, 1999:12). The value of this method is that it provides some thematic standardisation while still allowing flexibility. I used a series of question guides which were constantly evolving once saturation on a particular topic was reached, and in order to pursue new themes that arose in the course of the research. This research was based on interviews with 242 individuals (132 HIV-positive, the rest including health workers, members of NGOs, government and the broader community whose HIV

[9] These field sites are indicated with arrows in the maps at the beginning of this doctorate.

status was unknown) as well as 55 focus groups (33 with HIV-positive respondents, and 22 with those whose HIV status was unknown).[10]

The large number of interviews allows for some degree of generalisation about the processes described. In using these interviews throughout the thesis I have chosen quotes that I consider broadly representative of the issues being described, or indicated where they seem exceptional. Focus-groups provided a similar role in this regard: they gave an impression of the broader array of concerns and debates facing the population.

In addition, to provide a more intimate perspective, I also conducted in-depth life histories and follow-ups with several interviewees, whom I interviewed a number of times over the three years of research. In this I was attentive to how both conflict and disease had shaped individual life-histories. Furthermore, the advantages of the life-history approach for this topic is that, as Catherine Campbell points out, it corresponds 'with the view of social identity as a resource that people draw on in constructing narratives which provide meaning and a sense of continuity in their lives, and which guide their actions (Campbell 2004). I aimed from these interviews to understand how the social transitions of displacement and disease had shaped individual lives, but also the forms of identity and metaphors that people drew upon in relating their condition.

Luo-English translation was given primarily by Ajok Flavia Susan with support by David Tom Orace in the latter stages of research. Acan Lucy translated interviews during the Masters period. While my Luo was not adequate for interviews, significant time was spent discussing terminology and meanings. Complex translations, for instance over terminology

[10] Susan Ajok also conducted, transcribed and emailed a number of interviews and focus-groups to me while I was absent from Uganda.

relating to sex, were back-translated to ensure consistency and clarity of meaning. Several language sources were consulted (Blackings, 2009, Okidi, 2000, Odonga, 2005). Interviews were both recorded digitally and by hand-written notes. Key interviews were transcribed and coded using NVIVO – a qualitative data analysis programme. However, in order not to lose context, I also studied transcriptions in their totality. With other interviews I consulted field-notes directly though checked quotations against recordings. In analysing interviews, I sought to 'allow the social configurations to come alive in individual histories,' and to explore how social relations shape and constrain individual histories (Creswell, 2007:54, Fassin, 2007a:202). In presenting the interviews, when there is extensive repetition of the same points, I have chosen representative quotes indicating a broader trend. I have also chosen a number of quotes from selected individuals to maintain some narrative continuity through the thesis.

Observation

As Uli (2005:75) notes, participant observation establishes a direct relationship between a researcher and the lives and activities of their informant. For this research I relied on field-notes from my experiences. I stayed in both the towns and the camps for extended periods, and spent time with those living with HIV, chatting, sharing meals (and sometimes beers - *contra* the moral guidance of the treatment programmes), going to a family wedding, and so on. I also stayed at St Joseph's mission for around two weeks allowing me to view the activities of the mission, visit the fields, attend church and interact with those around the mission. These experiences both contextualised and informed my interviews and approach. Observation of the sites and contexts of ARV provision, both in the clinic and the home, allowed me to understand the practicalities of ART provision but also situate this provision in

its social context. As Whyte (2009) argues, it is important to understand the effects of ARV provision on home-life and not just through the clinic as this can abstract treatment provision from every-day life. Much of this research was conducted outside of clinic settings, in people's homes and other community spaces. Through this method, I have attempted to understand ART provision in its social context.

Other Data Sources

As there was very little published on HIV in Northern Uganda during the 1990s, I conducted an extensive archival survey using archives at the AIDS Control Programme, Kampala; The AIDS Information Centre, Kampala; TASO, Kampala; Acord, Gulu; St Mary's Hospital Lacor, Gulu; World Health Organisation, Gulu; as well as the limited information available online. Though documented evidence on Northern Uganda is disparate, these archives were used to substantiate and triangulate oral histories. In this research I also had access to the data sets of TASO and St Mary's Hospital Lacor, provided by the Centre for Disease Control, as well as to limited data provided by the Ministry of Health. I have conducted my own analyses of this data using Excel. While this is primarily a qualitative study, I have used this data to contextualise and give support to accounts in interviews, particularly in the sections on the return period.

Research limitations and challenges.

The choice of a multi-sited research approach was made in order to grasp the regional scale of social transitions, and to attempt to trace the lines between humanitarian and medical

institutions and the lives that they affect. The chosen approach had both advantages and limitations. Conducting several field-work periods over three years allowed me to follow the rapidly changing context of the transition from conflict to peace as well as how individuals negotiated these transitions over several years. However, the shorter term periods – chosen for both personal and methodological reasons - limited the ethnographic depth of the research and made relationships difficult to maintain. I never learnt the language to a proficiency to conduct interviews or hold an in-depth conversation. A multi-sited and multi-organisational approach with a large number of interviews on ARV provision has inevitably led to the diminishment of some ethnographic depth: a more localised ethnographic study may have produced richer material around medical pluralism and the continuing use of both biomedical and traditional healers, as well as about community politics – issues people were wary to talk about to strangers.

Particularly challenging was working in health settings. Research in clinical settings poses both methodological and ethical problems in terms of access and positionality (van der Geest and Finkler, 2004): there is a difficulty of accessing settings where resources are constrained, but also a difficulty in taking a position that is not simply associated with the hospital itself. I had to be extremely attentive not to take away the time that health-workers could give to patients. This involved long periods of waiting. However, this also had a methodological purpose: I gained a detailed knowledge of how the practice of treatment worked, including filing systems, patient selection, and so on. At clinical sites, we conducted interviews while patients were waiting, ensuring that the health-workers knew this and we did not delay the patients. There were also further difficulties conducting regarding my positionality: as a foreign male conducting research in situations where respondents were often living in extreme adversity, I was sometimes associated with humanitarian organisations and NGOS

and had to emphasise that I was not formally attached to any institution and could not promise any services.[11] The unequal power relations also shape in the interview context (Bell and 2005, Mullings, 1999). Working closely with a female research assistant in a context where gendered hierarchies remain strong, helped negotiate the gendered dynamics of interviews. Still, there are inevitably domains of intimacy and experience that were kept from me – I have tried to respect these and not cause any discomfort for interviewees. In addition, while I could not promise changes in services, I did explain that I would report findings back to the organisations I worked with - throughout the course of fieldwork, through written reports as well as giving presentations and a workshop.

The ethics of research with AIDS are fraught, particularly given the potentially dangerous situation that may arise from involuntary disclosure. With all interviews I explained orally in depth the purpose of the research and the uses of data[12]. I have used real names where consent was given to do so. Where those with HIV are open about their status in their own communities, I see no reason to hide names, unless the publication shows them in a negative light; in fact, to do so could be complicit in the secrecy surrounding the disease. However, in cases where anonymity was requested, I clearly respect this. The research received formal ethical approval of the Central University Research Ethics Committee (CUREC) of Oxford University. In addition my research protocol was reviewed by the Uganda Council for Science and Technology and by each institution with whom I conducted research.

[11] Most interviews we offered a small contribution to the household, for instance, soap and salt to contribute for lost time.

[12] I opted for verbal over written consent as many respondents were illiterate.

Thesis Structure

This thesis is structured broadly chronologically as a social narrative of HIV responses and therapeutic interventions in Northern Uganda, and the ways these intersect with different phases of the conflict and transition. However, there are many temporal and thematic overlaps between chapters. For instance, while *Chapters Three* to *Five* focus on the camps, towns and experiences of displacement, and *Chapters Six* and *Seven* focus on the return, these process were interwoven and do not express a clear rupture. Encampment and the process of return continued throughout the period of research, though the processes of return accelerated in the later years of the research. Therefore, it would be misleading to understand these transitions as simply chronological; rather they should be understood as overlapping and characterised by forms of cross-migration and uncertainty. As stated, the notion of transition here is not simply linear, but one characterised by uncertain movements back and forth between places and conditions. These motions are reflected structurally in this thesis.

Chapter One focuses on the social responses to HIV preceding the ARV interventions, particularly in the 1990s. It argues that Northern Uganda was largely excluded from the Ugandan HIV/AIDS 'success story', viewed in terms of extensive community-based responses to the pandemic. The spatial inequality of the conflict, as well as encampment also significantly shaped responses to HIV/AIDS. *Chapter Two* introduces the treatment programmes, and situates their strategies in relation to the challenges of conflict and displacement. I argue that the conflict shaped access to treatment by focusing treatment access around municipal areas. I also aim to outline the specificities of these interventions in comparison with other resource-limited settings.

Chapter Three moves from an institutional to a community-based perspective, focusing on the social lives of ARVs in displaced communities, and the forms of biosociality developing through treatment programmes. It analyses these forms of biosociality as intimately bound up in the transitions of encampment and displacement. In particular it focuses on the gendered dimensions of biosocial transitions. These themes are continued throughout the following chapters. *Chapter Four* focuses on forms of disclosure and stigmatisation in displacement camps. These are shaped by the spatiality of the camps. Furthermore, the language of stigmatisation reflects the perceptions of militarism and idleness of encampment. *Chapter Five* focuses specifically on forms of biopower and morality operating through treatment programmes, particularly Catholic programmes, and how these intersect with the social and moral uncertainties of displacement. It integrates both an institutional and community-based perspective. It also argues that medical pluralism - multiple interpretations of healing and affliction - persists in Northern Uganda but alternate forms of healing are largely excluded by ART interventions.

Chapters Six and *Seven* continue the themes of previous chapters exploring how they impact on the return process and the challenges facing both treatment organisations and those living with HIV in negotiating these transitions. *Chapter Six* focuses specifically on the decision making processes facing those with HIV, as well as the challenges and shifting strategies of the treatment organisations. *Chapter Seven* focuses exclusively on the experiences of return to home areas and the ways in which the intersections of conflict and displacement continue to shape vulnerabilities in home areas, but also the ways in which biosocial relations are transposed from spaces of displacement to spaces of return. It questions the conceptual

repertoire of ‘durable solutions’ and ‘sustainable return’ for understanding HIV-related vulnerabilities in the return period.

Chapter One: The Disease that Sucks Your Blood: Success and Exclusion in Northern Uganda

Introduction

Conflict and forced displacement radically shaped social responses to HIV/AIDS prior to the introduction of ART. Grasping these changes in Northern Ugandan society provides an important backdrop for conceptualising the intersections of displacement-induced and biosocial transitions engendered by ART. This chapter explores this history, surveying the period from the 1990s to the early 2000s. I argue that the conflict limited information about, and social responses to, HIV/AIDS in rural areas of Northern Uganda. In the early years of the conflict, rural areas were excluded from HIV/AIDS responses. Forced encampment from 1996 onwards changed this: the symptoms of AIDS became more visible, and there was greater access to HIV testing and information. Displacement camps also created new social and moral uncertainties that reshaped interpretations and causative understandings of illness. However, progress was still fragmentary and slow. Low levels of knowledge about HIV/AIDS, and negligible community-based organisation, persisted in rural areas and camps into the 2000s. A central argument of this chapter is that the spatial and social reorganisation of forced displacement had distinct effects on the dissemination of knowledge and social responses to HIV/AIDS from the pre-displacement effects of conflict.

This chapter will compare the social responses to HIV/AIDS in Northern Uganda with trends taking place elsewhere in Uganda. The response to HIV/AIDS in Uganda has widely been considered a 'success story' in reducing HIV prevalence, reducing stigmatisation and

improving community-based support. I argue here that Northern Uganda was largely excluded from the intensive national response to HIV. While there is no evidence of a specific intention on the part of the state or NGOs to exclude the North from national programmes, the limited response to HIV was, de facto, part of the broader political and developmental marginalisation of the North. Responses in the region were limited in reach and resources, fragmented and uncoordinated. Community-based support groups were not present to any significant extent in the rural areas and the conflict provoked the retreat of state health services. Extensive Luo-language radio broadcasting was absent for most of 1990s. As a result of these deficiencies, faith-based hospitals and churches played a prominent role in responses to HIV/AIDS in the region. This in turn eventuated in a disproportionately strong emphasis on abstinence-based responses to HIV and reproductive health. Furthermore, Church hospitals and missions were also early sites for the formation of HIV-related support groups. However, pluralistic understandings of HIV/AIDS – particularly interpretations of this affliction in terms of witchcraft - persisted well into the 2000s. This chapter will first outline the broader context of the HIV response across Uganda and then move on to a detailed discussion of social responses in Northern Uganda.

The Ugandan HIV 'success story'

Uganda was the first country in Africa to show major declines in HIV sero-prevalence. National antenatal sero-prevalence data from 15 antenatal sites demonstrate that national HIV prevalence declined from 21.1 percent to 9.7 percent from 1991 to 1998 (Low-Beer and Stoneburner, 2004:166). However, the urban bias of antenatal data in Uganda casts some doubt over the applicability of the data to rural areas (Parkhurst, 2002:78). In addition, declines in HIV incidence that were reported in Southwest Uganda (Mbulaiteye *et al.*, 2002) do not necessarily apply to elsewhere in the country. In spite of some questions about

robustness of available data, there is a broad consensus that prevalence reductions and behavioural change did take place, and that these were the outcome of an expansive HIV response involving different levels of government, the army, NGOs, and churches (Allen and Heald, 2004, Thornton, 2008, Iliffe, 2006, Hooper, 1990, Dyer and Wendo, 2004, Low-Beer and Stoneburner, 2004). Below I briefly outline these responses.

In the mid to late 1980s, fear of a disease called *Slim* spreading through Uganda created a sense of urgency in the country as mass death was becoming a social reality. First identified in 1982, the epidemic was received for several years with secrecy and panic, but this gave way to a strong governmental and civil society response (Hooper, 1990). Yoweri Museveni, president after a 1986 coup, took an early lead in the response, partly motivated by the realisation that it was affecting his army (De Waal, 2006:97). An AIDS Control Programme (ACP) – perhaps the first in the world – was created in 1986 to direct the HIV/AIDS response. In 1987 the government drew up a five-year strategy with the World Health Organisation (WHO). HIV/AIDS education was integrated into the school curriculum in 1987 and Museveni and other politicians started openly speaking about HIV/AIDS at rallies (Iliffe 2006:71). In 1990 the Uganda AIDS Commission (UAC) was founded and a multi-sectoral response was developed, focusing on decentralised and community-based mobilisation. The AIDS Information Centre (AIC) was formed to provide testing services. In 1987 The AIDS Support Organisation (TASO) was founded by Noerine Kaleeba, whose husband had died of AIDS. TASO became 'African's best known NGO', providing support for those with HIV, mobilising against stigma, and spreading HIV information (Iliffe, 2006:99). Groups for those with HIV formed throughout the country, and the response was driven by churches as well as the pop star Philly Lutaaya, who was open about his HIV status. The collective effort was to

result in the first major HIV sero-prevalence declines recorded in Africa (Iliffe, 2006:129, Dyer and Wendo, 2004, Hooper, 1990).

Early campaigns used pamphlets and posters, broadcasts on radio and television, and particularly interpersonal communication through community networks. Pamphlets from 1986 had slogans such as *love carefully*, and *work carefully.* Churches from an early stage got involved in the "Love Faithfully" campaign (Hooper, 1990:253). Museveni was initially opposed to condoms, which were not promoted in the early stages of the campaign, and access was extremely limited in the 1980s. In the 1990s access to condoms increased with social marketing campaigns reaching wide audiences (Allen and Heald, 2004, Hooper, 1990, Iliffe, 2006). Early campaigns were focused on partner reduction and faithfulness. These campaigns used the metaphor of 'zero-grazing' which referred the practice of tethering cattle so they would graze within a circle (Allen & Heald, 2004:1148). By the early 1990s this had become a formalised part of the national campaign strategy. Its meaning – whether it entailed sticking to a single partner or to a few partners – was, however, open to interpretation. The zero-grazing model perhaps took hold because it could be interpreted as applying to both polygamous and monogamous relationships (Epstein, 2008:195-196).

Another key dimension of the HIV/AIDS response was the expansion of education and community support into rural areas. In the 1980s, the campaigns were predominantly focused around town areas; during the 1990s, campaigns spread to rural areas, particularly high-prevalence areas like Rakai. These involved the training of village-based educators who would travel around rural areas (Kirby, 2008:31). In rural Masaka, another high-prevalence area, TASO extended their counselling services beyond clinics to village and home-based settings, providing services to both those who are HIV-positive and their families (Seeley *et*

al., 1991:211). While this expansion was not uniform, the successful targeting of high-prevalence areas was a major advance. Allen and Heald (2004) argue that, while AIDS was understood in terms of 'local bio-moral interpretations', Ugandans showed an openness to public-health messages as a result of long-term experience of the disease. Similarly, Thornton (2008) writes of the 'indigenization' of HIV/AIDS in Uganda, arguing that an important element in the response was its incorporation into local terminology and understandings. Early understandings of HIV/AIDS were also framed in terms of witchcraft and sorcery, but several authors argue that these were supplanted by biomedical explanations in the early phases of the campaign (Hooper, 1990, Allen and Heald, 2004).

Other than the targeting of high-prevalence town and rural areas, the causes of Uganda's success story are difficult to isolate as there are different interpretations regarding the behavioural effects of the campaigns in scholarly and policy documents. US funders and religious groups argued that abstinence campaigns based on religious values were the drivers of prevalence reduction (Iliffe, 2006:130). Epstein (2008:180-185) argues that UNAIDS for many years claimed that condom use, not partner reduction, was the main reason for the decline of prevalence in Uganda, in spite of evidence to the contrary. She claims this is explained by a statistical error as well as an ideological agenda opposed to the Christian right and aimed at fundraising. Several studies, including Epstein's, show that partner reduction played the major role in prevalence reductions and behavioural change, with condoms playing a secondary role (Low-Beer and Stoneburner, 2004:170-172, Green *et al*., 2006, Kirby, 2008, Epstein, 2008). Thornton (2008) also supports the concurrency argument but gives greater emphasis to the severing of locally oriented sexual networks. Epstein (2008) stresses 'a sense of compassion and common humanity' as the 'invisible cure' in Uganda.

Allen and Heald (2004) give attention to more coercive dimensions of the response: local councils interfered in dances, mobility and even the sexual lives of unmarried women.

Even while there are divergent interpretations of the causes of the sero-prevalence decline, there is a broad consensus that Uganda experienced a widespread and strong response to HIV at multiple levels of the state and from civil society organisations, churches and community-based groups. The result of this was widespread knowledge and discussion about the disease through media, state and community-based channels. However, from a social perspective, a consistent argument is that the success of the campaigns relied on their acceptance in local communities and in fostering communicative openness about the disease as well as networks of care for the ill (Low-Beer and Stoneburner, 2004:129, Epstein, 2008:169, Iliffe, 2006).

I argue below that these defining features of the Ugandan response to HIV were not present in Northern Uganda throughout the 1980s and 1990s. Responses were fragmented, had little reach into rural areas, and there were few community-based organisations providing support for those with HIV. Viewed in terms of the social, political and institutional response to HIV, Northern Uganda was largely excluded from the HIV/AIDS 'success story' even while there is evidence that it has experienced similar declines of HIV sero-prevalence.

Responses to HIV/AIDS in Northern Uganda

The conflict in Northern Uganda had a profound effect on responses to HIV/AIDS in the region. First, the region as a whole was relatively excluded from national responses to the epidemic. Second, within Northern Uganda, there were stark divisions in access to health information and services between the towns and deeper rural areas. These were outcomes of

the social geography of conflict, as is discussed below. This section will explore these divisions in turn.

Northern Uganda has been given little discussion in the literature on the HIV/AIDS 'success story' in reducing sero-prevalence, overcoming stigmatisation and galvanising social support. Where there has been discussion, views have been divergent. For instance, Finnström (2008:64) claims that

> The postcolonial nightmare is finally over, so the widespread feeling goes, and Uganda is held to be a success story of economic liberalization, development, progress, and increasing political stability, celebrated for its fight against HIV/AIDS. Ravaged by twenty years of war, the Acholi have not shared any part of this success story.[13]

Ciantia offers an alternate perspective: 'It seems that despite the chronic and complex conflict these elements of social cohesion have served as catalysts to affect changes in Northern Uganda, which appear consistent with trends in the rest of the country" (Ciantia, 2004:174). He argues that, like elsewhere in the country, 'information about AIDS and about persons affected by AIDS is more likely to be transferred through personal communication networks, compared to other countries in Eastern and Southern Africa'(Ciantia, 2004:174). Ciantia (2004:173) points to recorded declines in HIV sero-prevalence taken from ante-natal records at St Mary's Hospital Lacor. Antenatal data at St Mary's Lacor Hospital – a Catholic hospital near Gulu Town – indicated a prevalence rate of 11.9 percent in 2005, which represents significant decline from 27.1 percent in 1993 and correlates to declines recorded

[13] While Finnström makes this claim about HIV/AIDS, his work is not focused on HIV/AIDS and he provides very little substantive evidence in support of this claim.

elsewhere in the country (Fabiani, 2007). Regrettably, no reliable data exists for many of the camps in the region

I argue here that Ciantia's claim the responses to HIV/AIDS in Northern Uganda were consistent with trends in the rest of the country does not apply to the rural areas of Northern Uganda included in my study. There are two points here: first, the available data does not provide substantive evidence for areas outside of the main town, including camps. Second, declines in sero-prevalence may have been caused be factors other than social organisation, communication and behaviour change. Here, correlating declines does not show correlating causes. The conflict in Northern Uganda may have led to declines in sero-prevalence as a result of the closing of trade routes and limitations of mobility, and the breakup of sexual networks as a result of conflict, thus slowing the spread of HIV to rural areas (Allen, 2006b, Spiegel *et al.*, 2007a, Westerhaus, 2007). It is beyond the scope of this thesis to provide an in-depth discussion of the transmission dynamics of the conflict and so I will limit myself to discussing the extent of the social responses to HIV/AIDS including both information as well as social support to the ill.

I will argue below that there is little evidence of extensive communicative networks and social cohesion in response to HIV/AIDS during the 1980s and 1990s. In the 1980s and 1990s Northern Uganda was not a target area of major government and civil society HIV/AIDS responses in Uganda. As Hooper notes in 1990 (1990:280), 'there was as yet [in the late 1980s] no formal governmental or ACP policy on AIDS being implemented in many up-country districts.' Likewise, there were few consistent HIV/AIDS programmes throughout the 1990s in Northern Uganda. The largest and best-funded civil society and governmental agencies were absent in the North. TASO only started its Gulu branch in Northern Uganda in

2003. The AIC – the largest provider of testing and counselling services in the country – was absent for the entire 1990s, and only opened a branch in Lira in 2004. TASO and the AIC were among the core funding beneficiaries of USAID, the largest funder of HIV/AIDS in Uganda between 1998 and 2002 (Lord 2002). The reason given by members of TASO for not entering Northern Uganda earlier was the constraining impact of the security situation. As a founding member of TASO explained, **'**The North was very hostile during the time of the insurgency and it wouldn't have been prudent for TASO to risk its staff. TASO knew there was a need, but could not go during the insurgency.'[14]

This is not to argue that there was no response to HIV/AIDS in Northern Uganda. The institutions whose presence was longest and most extensive in the North during the 1990s were St Mary's Hospital Lacor, World Vision and the Association for Cooperative Operations Research and Development (ACORD). However, within Northern Uganda responses to HIV/AIDS were shaped by the geography of conflict and primarily focused around town areas and, from 1996 onwards, displacement camps in close proximity to major towns. Community-based organisation was challenging and extremely limited outside of these areas.

For instance, ACORD was the only NGO to provide consistent support to the formation of community-based organisations in the 1990s. However, a report in 1997 revealed the limited reach and success of these programmes: 'At present, most groups ACORD started with are now non-operational, due to the continuous insecurity in the area. Only those in the Gulu municipality and its close environment are in ad hoc contact' (Scheltema and Kitanda, August 1997). A 1997 survey of the socio-economic impact of AIDS in the Gulu District

[14] Interview with Reverend Watinga Abdenego, Former TASO centre and regional manager (1992 to 2007), Kampala, 11 June 2009.

found that only 33 percent of informants reported that social support networks for people with AIDS existed in their communities, and also found that 'no major organizations had come up to assist the people in the district to support the terminally ill'(Levi and Odong, 1997:32). While the first HIV support group in Gulu District, Waloko Kwo, began at Gulu Hospital in 1991, it did not expand significantly outside of Gulu Town.15 In Gulu District (including Amuru at the time) there was negligible support HIV-positive people during the 1990s. This exclusion is typified by the case of Pabo, one of the largest camps in the north with a population of over 50 000 at its peak. The first community-based HIV/AIDS support group in the camp was formed in 2000, and it was only a few years later that they received some support from NGOs and the local Catholic mission.[16]

An indication of the general absence of programmes in the North is shown by a quarterly report of the governmental AIDS Prevention and Control Project in September 1994. It shows few programmes in the North and existing ones providing AIDS awareness training and support for orphans were 'made difficult because of security problems in both Kitgum and Gulu' (Oryema-Lalobo, October 26, 1994). A quarterly report of the National Guidance & Empowerment Network of People Living with HIV/AIDS (NGEN, July to September 1999) stated that in Lira:

> There are no HIV/AIDS counsellors in the majority of sub-counties, which makes awareness very difficult because the population has no place to resort to after getting general information. The general level of awareness about HIV/AIDS in the population is very low.

[15]Interview with Galtino Odong, 29-year-old HIV positive man, member of Waloko Kwo, Gulut Town, 10 April.
[16] Interview with Evelyn Aber, 38-year-old HIV-positive woman & founding member of 'Yabbo Wang Wu' HIV/AIDS support group, Pabo, 20 May 2008.

There was also little response by local political leadership to HIV/AIDS in Gulu, as those who were in the region at the time reported.[17]

Data on HIV/AIDS knowledge levels and behaviour during the 1990s are scarce and, like the sero-prevalence surveys, were generally focused on town areas. In town areas, knowledge that HIV/AIDS was sexually transmitted was likely good. For instance, a 1997 study in Gulu and Layibi on the outskirts of Gulu Town found that 91 percent of respondents knew that HIV was sexually transmitted, though knowledge of transmission by blood was very low (Levi and Odong, 1997:12). However, this survey is not representative of rural and camp areas, and my oral evidence – discussed below – shows that biomedical understandings of HIV/AIDS transmission were limited in rural areas.

The fundamental reason for this was that the conflict significantly barred HIV/AIDS programmes from accessing rural areas. James Otim was working in Northern Uganda on HIV programmes with World Vision between 1989 and 1995 and then from 2003 onwards, in both Gulu[18] and Lira. Otim confirmed that there were few agencies focusing on HIV education in the region during the early 1990s. There were some small community-based groups trying to duplicate the work of TASO elsewhere in the country but they were tightly constrained by a lack of resources. Otim explained that health staff deserted rural health centres as they became prime targets of abduction for members of the LRA. Health centre rehabilitation activities were hampered by insecurity, and it was difficult to organise education gatherings. World Vision soon abandoned trying to reach distant areas like Atiak, and avoided Opit due to its proximity to the rebels' base.

[17] Interview with Galtino Odong, 29-year-old HIV-positive man and member of Waloko Kwo, Gulu Town, 10 April 2008; Interview with James Otim, NUMAT Deputy Chief of Party, Gulu Town, 30 July 2008, among others.
[18] In 2006 Gulu district boundaries were redrawn and the district of Amuru created. Otim therefore also worked in the area now designated as Amuru.

In the Pabo area, visits were more frequent but, as Otim explains, 'There was some information but I wouldn't say it was much,' and in northern Lira the situation was too insecure. Even in closer and more accessible areas, gatherings were dependent on the security situation and often infrequent. He explained:

> If the security situation was good, we would go out. If the situation was bad you stayed away from the community. You wouldn't want to put people at risk. There was a risk of gathering people to speak to them; it was like you were mobilising potential abductees from the rebels. So, you also don't want to organise the communities and the rebels come and sweep the whole village, it would really complicate matters.19

As a result, HIV/AIDS response programmes– including information, social support and testing initiatives –became focused around the municipalities.[20] Despite this limitation, the process of encampment, escalating from 1996 onwards, did increase the accessibility of many rural Northerners due to the increased density of populations – a finding which I discuss in greater detail below.

A further limitation on responses was the lack of a media response. Throughout Uganda, in the development of the HIV/AIDS 'success story,' intensive media and radio campaigns played a major role. Radio was an excellent way to reach rural and largely non-literate populations. However, there was little accessibility to radio programming in the Acholi region in the 1990s. Otim recalled:

19 Interview with James Otim, NUMAT Deputy Chief of Party, Gulu Town, 30 July 2008.

20. Even when I first visited Northern Uganda in August 2006, many camps had no access to HIV testing. During the 1990s, World Vision and Red Cross offered some mobile HIV/AIDS testing in camps, but again this was infrequent.

> One of the limitations was at that time we didn't have FM radio stations. We had the national radio station whose transmission was poor and not many people could afford short wave radios, and so the access to information was limited. But now we have many FM stations and FM stations are cheap and available. You don't need a complicated radio to get reception.[21]

Radio access in Northern Uganda was very limited throughout the 1990s. The first Acholi language radio station, Radio Freedom, was founded in 1989 but had little financial support and its broadcasting reach was limited.[22] As a 1999 Gulu District Development Plan (1999) reported:

> In 1996 an FM radio station was opened at Gulu Post Office which has tremendously improved the reception of radio signals in the District. The station is not used for broadcasting but only relays transmission from Radio Uganda in Kampala.

Radio Uganda has some but very little Luo language radio programming and it is unlikely that even with the new transmitter it reached many people. By 1999 Radio Freedom remained the only Acholi language radio station, but with funding from the UK's Department of International Development (DFID) it managed to expand its programming and reach, including HIV programming. The intensity of HIV/AIDS Luo language programming increased when Radio Freedom was converted to Radio Mega in 1999.23 Many of those I spoke to first heard about HIV/AIDS and its modes of transmission through radio, and yet intensive Luo language broadcasting had been significantly delayed in the region. This can be

[21] Interview with James Otim, NUMAT Deputy Chief of Party, Gulu Town, 30 July 2008.
[22] Interview Richard Omona, manager of Radio Freedom, (conducted by Maggie Ibrahim, personal communication 12 July 2010).
[23] Interviews with Sarah Odong, News Anchor and Host of HIV/AIDS Talk Show, Radio Mega, Gulu Town, 26 February 2008.

viewed as part of the broader developmental neglect of the region, as the conflict should not have prevented the establishment of local-language radio broadcasting from town areas.

Faith-based responses

In the context of a general lack of social and institutional responses to HIV/AIDS in the North, the major exceptions were the Catholic hospitals, and their links to networks of missions within conflict-affected areas. In Gulu, the largest hospital in the region was St Mary's Hospital Lacor. A dramatic story underpins the history of St Mary's Lacor;it that has been the subject of two biographies (Arsenault, 2003, Cowley, 2005), two television documentaries and a film title *Lucille Teasdale: Doctor of Courage.* Lucille Teasdale, was a Canadian doctor working as an intern in Uganda, who was married to Piero Corti, an Italian doctor. In 1961 the couple set up the hospital at the site of a dispensary run by Comboni nuns. Over three decades Corti and Teasdale worked at the hospital, turning it into a research and training site. The hospital was visited by Idi Amin and was several times attacked by rebels and soldiers, including the invading Tanzanian army, the Holy Spirit Movement, and the Lord's Resistance Army. The discovery of AIDS in the early 1980s had a major impact on the work of the hospital. As Cowley (2005:85) describes,

> The unexpected arrival of AIDS meant an ever-increasing workload for the hospital staff at Lacor. Lucille was now seeing well over two hundred people a day in the outpatient clinic as well as doing many emergency operations beyond the routine ones.

In 1985 Lucille, after becoming increasingly ill, was diagnosed as HIV-positive herself, after likely contracting the illness from one of her operations. Lucille continued to work until her death in 1996, and in the interim the hospital's old tuberculosis wing was converted into an HIV/AIDS ward (Cowley, 2005:135). In 1993, The Comboni Samaritans of Gulu[24], a Catholic community-group, was founded to work with Lacor Hospital's HIV/AIDS programme. The personal connection to HIV was certainly one factor in Lacor Hospital's role in driving the HIV/AIDS response, but it was also a result of their connections with the rural missions in the region, as well as church donors in Italy and Canada.

By 1996 Lacor Hospital was one of the biggest hospitals in the country with a nursing school, 446 beds and four wards (Accorsi *et al.*, 1998:11). It became a major centre for HIV/AIDS research, treatment and education. It was the primary site for the project 'Global Support to the National Plan for HIV/AIDS Control in Uganda'– a shared project between the Italian and Ugandan governments and co-founded by the Italian Ministry of Foreign Affairs and the Italian National Institute of Health (Accorsi *et al.*, 1998:12). The Italian relationship with Northern Uganda is strong, in particular given its link to the Verona Fathers, among the most prominent missionary groups in the region. With the virtual collapse of state health services, the hospital played a pivotal role in both responses to HIV and research in Northern Uganda. As the HIV sentinel surveillance site for Northern Uganda it is also the data of the hospital that is used in analysing the impact of HIV and AIDS in the Northern region. The hospital is based on a Catholic ethos that does not provide or promote contraceptives. Given its pivotal role in responding to HIV/AIDS in the region, this moral position had a distinct effect on the types of response in the region and the reproductive health services available. Lacor Hospital's outposts in the Gulu district and the links between the hospital and Catholic

[24] Henceforth referred to as 'the Comboni Samaritans' or 'Comboni'

missions created channels for the limited education and information that was reaching rural areas. It was through direct links between these missions and Dr Lucille that knowledge about the disease was taken to rural areas, and Catholic HIV education programmes were started in some schools.[25]

HIV responses were therefore powerfully shaped by the local histories and networks of missionary activity and medication in the region. Missionary interventions, and associated medical interventions, have formed part of contestations over power, consciousness, beliefs in healing and affliction, and morality in Africa (Comaroff and Comaroff, 1991, Vaughan, 2007). Uganda was no exception: there was a conscious attempt by missionaries, and later by Teasdale and Corti (Cowley, 2005), to marginalise local healers and indigenous spiritual beliefs. In Northern Uganda, the ARV interventions should be seen as a continuation of the long history of missionary involvement in the region. For instance, large community-based leprosy responses in the 1970s and 1980s were run through Catholic hospitals and missions, and were the forerunners of the AIDS responses.[26] In addition, while USAID and other major international financers of AIDS programmes such as the DFID focused their programmes in the south, Italian donors focused their programmes in the north. By the late 1990s, however, the hospital's reputation had grown and it attracted the attention of USAID, with US Secretary of State, Madeleine Albright, visiting in 1998 (Albright 1998).

The impact of faith-based responses in Northern Uganda was not limited to the Catholic hospitals. For instance, World Vision – the major HIV/AIDS partner in the district government's Area Development Programme – was openly evangelical and did not distribute condoms. The faith-based influence on knowledge and behaviour in Northern Uganda was

[25]Interview with Father Alex Pizzi, Priest, St Joseph's Mission, Opit, 18 June 2009.
[26]Interview with Father Alex Pizzi, Priest, St Joseph's Mission, Opit, 18 June 2009.

shown in a 2002 national survey. Northern Uganda had by far the lowest number of women responding that condoms were a way of avoiding HIV infection, with only 20,6 percent of women compared with 30 percent in Western Uganda, 37.7 percent in Eastern Uganda, and 57.2 percent in Central Uganda. The North also had by far the highest numbers of women responding that faithfulness was a way of avoiding infection, with 77.5 percent. The next highest, in Central Uganda, was only 65.4 percent (UNICEF & GoU, 2002:60).[27]

Two things are clear from the above narrative: first is that Northern Uganda was not a recipient of the mass drive towards education and communication about HIV/AIDS in rural areas which was a trend in other high-prevalence rural areas of the country; second, the responses that did take place were deeply rooted in faith-based rather then governmental responses. The section below will explore these experiences from a community-based perspective and, in particular, how changing understandings of HIV/AIDS were coupled with the social transitions of conflict and displacement.

Community-based accounts

In this section I look at the experiences of people on the ground, drawing on interviews with HIV-positive people as well as with people whose status was unknown. I will start with a detailed discussion of how HIV/AIDS was interpreted prior to the displacements beginning in 1996 and accelerating in the early 2000s and then argue that forced displacement of the population into camps provided a major turning point in understandings around HIV/AIDS.

[27] The survey analysis itself does not actually attribute these results to faith-based responses.

The dominant Luo translation of HIV/AIDS during my fieldwork was *twoo jonyo*, literally meaning 'the disease that makes you thin'. However, the development of understandings around HIV in Northern Uganda has a complex history bound up with the changing social spaces of conflict. HIV/AIDS in Northern Uganda has long been associated with forms of witchcraft and sorcery, as it was elsewhere in the country (Hooper, 1990:148). Behrend (1999:26) describes the predominant form of this as poisoning, known locally as *awola* or *yat.* She also refers to *kiroga* as a form of witchcraft associated with revenge. *Kiroga* is associated with *ajwaka,* who are local healers and spirit mediums. Behrend explains that someone who seeks revenge may approach an *ajwaka* who then uses a vengeful sprit or *cen* to 'inflict on the victim insanity, infertility, any of many kinds of disease – including AIDS – or death' (Behrend, 1999:26). She argues that many in Northern Uganda understood AIDS as a form of *kiroga*:

> Since not only death in war, but also death from AIDS, which has spread to a terrifying degree throughout Acholi, was interpreted in the idiom of kiroga, Acholi was transformed into a land where everyone suspected and tried to harm everyone else (Behrend, 1999:27).

Furthermore, Behrend (1999:34) argues that

> Although the government has launched several Western-style information campaigns, this has hardly diminished the suspicions and charges of witchcraft because the two explanations are not mutually exclusive, but compatible. Few in Uganda today would deny that one contracts AIDS through sexual contact. But the idiom of witchcraft addresses the question 'Why me and not another?'

This point is also made by Allen (2000) with reference to medical care among the Madi in Northern Uganda. He argues that 'frequently biomedical and local herbal cures are combined

and may be embraced by overlapping, sometimes competing, interpersonal explanations' (Allen, 2000:170). Behrend's study was not focused on HIV/AIDS but she makes several important claims that I develop here. She argues that the increase in witchcraft allegations in the area was clearly associated with the increase in deaths from war and AIDS up until around 1988 (Behrend, 1999:28). After this, Behrend claims, a 'mechanism of self-limitation' formed, and 'AIDS became increasingly interpreted as either a natural disease or a divine punishment'; she adds that 'since by now there is hardly a family in Gulu that does not mourn for one or more members killed by AIDS or in war, accusations of witchcraft seem absurd'(Behrend, 1999:28).

My own evidence both correlates and contrasts with elements of Behrend's claim. First, I agree that biomedical understandings of HIV/AIDS existed alongside understandings based on witchcraft. However, while Behrend implies in the quote above that interpretations of HIV/AIDS in terms of witchcraft had disappeared by the time of her fieldwork in the early 1990s, my interviews showed that pluralistic interpretations existed throughout the 1990s and into the 2000s. In addition, according to the oral histories I conducted, the shifts in interpretation had little to do with a mechanism of self-limitation based on high mortality but due to greater access to education as well as the direct observation of AIDS sufferers that arose from the time of forced encampment onwards.

There were several other names for the symptoms associated with AIDS that were used throughout the 1980s and 1990s, and particularly prior to the period of encampment. Understandings of HIV were linked to various forms of poison/witchcraft, spirit possession and transmission by air and water. HIV/AIDS in Northern Uganda and particularly in rural areas was throughout the 1980s and 1990s known under a variety of names; most notably

twoo acwii, literally meaning 'the disease that sucks your blood'. *Twoo* means illness. *Acwii* can refer to 'a type of beetle which sucks juice out of beans or cowpeas' and is also linked to the verb *cwiiyo*, meaning 'sucking' (Odonga, 2005:5, 49). The usage of *twoo acwii* as a description of the symptoms of AIDS was common, particularly in Gulu and Amuru. However, the meaning and understandings of *twoo acwii* were diverse. Take this account from a 68-year-old woman in Amuru district:

> They would say that *twoo acwii* is some sickness which drains people's blood. People used not to know where the sickness came from, but when you got this sickness they would separate your home from the rest. They gave you natural herbs, and separated all your things. You don't stay among the people. There were people [with the disease], but not many. There wasn't any teaching about HIV/AIDS, and people lacked an understanding of the disease. They would say at times that they have bewitched you (*aroga roga*), or that it was an airborne disease. They used to go to the *ajwaka*, and would even give you the local herbs. They would boil it in water, and even bathe the patient. They used not to stigmatise, but people would worry a lot that the person is getting thin.[28]

In my interviews, there were numerous other accounts along these lines. *Twoo acwii* also began to be associated with soldiers in the area as well as with monkeys – a possible invocation of origin theories about HIV/AIDS coming from monkeys:

> People used to know of it as *twoo acwii*. And this *twoo acwii* was believed to come from the monkeys. I would say that the HIV virus was rather common among Museveni's soldiers. It's not a bias, but that is the truth. Before the war we never experienced this.[29]

[28] Interview with Ajulina Akot, 68-year-old HIV-positive woman, Otong Satellite Camp, 23 February 2008.
[29] Interview with Martina Auma, 70-year-old woman, Lacor, 31 March 2008.

Seeking treatment from *ajwaka* for HIV/AIDS still persisted in the camps during the time of my fieldwork between 2006 and 2009, though to a limited extent. For example, a woman in Lalogi explained the conflict around her HIV test in 2002. She went and tested blood at Lacor, but before testing, she was very weak and would fall sick frequently. Her parents thought she was bewitched, so they took her to an *ajwaka*. When they got to her to the *ajwaka*, he told the father that the spirit of the mother, who died when she was young, was haunting her. The *ajwaka* performed a ritual called *jok awiyeya* in which two goats were slaughtered, one indoors and the other outdoors. The goat slaughtered in the home was intended for the spirit of the mother to eat, the one in the bush for members of the family participating in the ritual. The ritual shows how different perceptions of HIV co-existed into the 2000s and sometimes caused contestations within families and communities. These themes are explored in more depth in Chapter Six with reference to antiretroviral therapy.

With increased access to HIV education during the time of encampment, some *ajwaka* started changing their treatments. As an *ajwaka* explained,

> *Twoo acwii* was the name of *twoo jonyo* before they realised it was that. In the 1980s people called it *twoo acwii* because it would drain all your blood and then it came to be known as *twoo jonyo* because it would make you thin. Nowadays they call it *twoo* slim. In the past this sickness was not known to many and people assumed it was a kind of *aroga* caused by hatred or love. I also used to believe that this sickness was as a result of a curse put on someone. I received many clients who had this problem but little did I know that there was a disease called *twoo jonyo*. I thought this disease was caused by *aywaya* – when someone who is infected washes away the sickness by the roadside and puts either a rope or money on that spot so whosoever picks it up or steps on that would also get infected. When these clients visited I would treat the symptoms and signs on them like rashes, cough, diarrhoea, swelling of the stomach, and limbs and hope they

> would recover. In some cases they feel better for some time but then later they die because AIDS has no cure. With our stay in the camp, we got a lot of knowledge from the different organisations through their sensitisations[30] and posters. I was in Alero camp and the NGOs who visited were TASO, Comboni Samaritan, and Red Cross. These sensitisations were useful because I got to know the causes, places to find help, dealing with HIV patients, precautions and HIV testing.[31]

The *ajwaka* explained that he would still try to treat the symptoms of HIV but knew now it was transmitted and that there was no cure. He also explained how he always used clean razor blades to avoid transmission. His account indicates that forms of medical pluralism persisted and that the activities of traditional healers have also changed. Unlike elsewhere in the country, where programmes such as the Traditional and Modern Health Practitioners Together Against AIDS and other Diseases (THETA), pioneered by TASO, were created to engage traditional healers, in Northern Uganda these healers have been largely marginalised from formal programmes. The *ajwaka* cited above also considered himself a Christian, indicating that medical pluralism can co-exist with religious pluralism and that the shifting understandings of HIV were embedded in shifting spiritual and moral understandings in which biomedicine played a role.[32]

An indication of the persistence of alternate forms of causal explanations of HIV into the 1990s is the account of a 21-year-old woman who was displaced to Opit camp in 2002. She explained that, 'In the villages before the camp, HIV was called *twoo maddongo*. It was believed that if someone who had that sickness washes him or herself on the road and you step on that water the sickness would get you.'[33]

[30] 'Sensitisation' is common Uganda parlance for education on a particular issue.
[31] Interview with anonymous *ajwaka*, Layibi, June 29 2010.
[32] These issues will be explored further in Chapter Six.
[33] Interview with anonymous 21-year-old woman, HIV status unknown, Opit, 12 August 2008.

Most likely, the semantic origin of this is linked to the word *maddo*, meaning swabbing a wound with hot water (Odonga, 2005:149). Several different names for HIV/AIDS circulated, most prominently *twoo acwii*. The understandings of illness in terms of forms of sorcery and witchcraft not only required an *ajwaka* to intervene, but placed complex obligations of care on families that began to breakdown once biomedical and sexual understandings of the illness became prominent. These obligations help explain the shifts in care and stigmatisation that came about through AIDS interventions. These themes surfaced in the accounts of two sisters, Susan and Jacinta, both living with HIV in Opit. They recounted to me their experience of their brother's death from AIDS in 1993 and their associated changes in understandings around the illness. Susan explained,

> We were in Lango district in a place called Loro. There were people who were coming from the upper side of Lira, who were witches (*lujok*). They would put medicine for you, and your legs would become swollen. There were times when other things would grow from your legs, like mushrooms could grow from your legs. The poison would grow from your leg in the form of a mushroom, until you die. So, when this disease started coming, then people believed that, because the witches were there, and so it meant that this disease was caused by the witches. I first heard about AIDS when the sister to my husband who used to work in Kampala came. She was sick, and so thin, until she died. So people used to say she might have died of HIV/AIDS. But back in the village, people used not to have a deep understanding of HIV/AIDS. When someone came who is suffering from HIV/AIDS, they would think it was a kind of *yat* that was put for that person. It would involve a lot of things, like calling for the *ajwaka* to see what was wrong. The *ajwaka* remained in the house until she died. [After this] my own brother died of AIDS. So I got to realise it was sexually transmitted. My brother became so thin. He had diarrhoea, he had wounds on his body, and rashes. By then everyone used to fear him. No one used to touch him. We children were never allowed to come near him. It was my grandmother who was taking care of

> him. So, with that experience, it wasn't only in our home. There were many other people who were dying of the same disease. So, if you had the same signs, people would suspect that that was the very disease that was killing people. But what we knew was that this disease has no cure, and there was no medicine for it. If you had to buy the medication for it, it was more expensive than you could afford.[34]

Susan understood how HIV was transmitted earlier than her sister Jacinta. Jacinta explained that, while she had seen many people with the symptoms of AIDS that had killed her brother,

> These people would not accept that it was AIDS. At that time there was very little knowledge of HIV/AIDS, until the year 2000. That was when people started getting education, and then blood testing came in. But in the 1990s, there was nothing that people knew. All they knew was that it was a kind of medicine/poison (*yat*[35]), that they would put for people, and they would fall ill. They would call it *Twoo pien*. It was believed that if you die, and you were thin, it was that *twoo pien*, and it was believed that if you are dying, and you are thin and have diarrhoea. *Twoo pien* meant the kind of the disease which makes you thin, and makes you lie down until you die. With *twoo pien*, you will have to kill a goat, and take the soup. It always happened that when someone is sick of HIV, they tend to ask for only meaty things, like maybe a chicken, or meat, so they would fear that if they don't give this to you, then your *cen* will return to haunt (*acena*) people. So they would kill a goat for you, so that you eat that goat, and that will make your *cen*, not to come to haunt.[36]

Cen are described by Finnström (2008:159) as a form of 'ghostly vengeance.' It is significant here that, while HIV was understood as a form of sorcery, the threat of *cen* from those who died of AIDS was invoked to ensure that those with HIV were cared for. However, it seems

[34] Interview with Jacinta Adong and Susan Auma, HIV-positive sisters, Opit, 20 July 2008.
[35] *Yat* may refer to either medicine or poison
[36] Interview Jacinta Adong and Susan Auma, HIV-positive sisters, Opit, 20 July 2008.

that with the bio-medicalisation of explanations of HIV transmission, established forms of moral and spiritual obligations towards the ill begin to disappear.

The accounts also show that in rural, conflict-affected areas of Northern Uganda changes in perceptions and understandings of HIV/AIDS resulted from a slow process of information filtering through informal channels and interpreted within local understandings of affliction and disease causality (Allen, 2000), rather than from mass media campaigns and community-based responses. While being in common circulation, knowledge of the sexual transmission of illness co-existed with other forms of causal interpretations throughout 1990s and into the 2000s.

Encampment

The period of intensive encampment from 1996 onwards, and accelerating in the early 2000s, ushered in a radical shift in the lives of those living in conflict-affected areas. As discussed, it led to the decline of agricultural production, the congestion of homesteads and extreme existential and moral uncertainty; the spread of HIV/AIDS also became widely associated with displacement and militarisation (Dolan, 2009, Finnström, 2008). However, numerous respondents in my research also claimed that information around HIV/AIDS was greater in the camps than in the villages. In spite of the dire health conditions of encampment, it was during the phase of encampment in Northern Uganda that the knowledge of the symptoms and causation of HIV became widely known. Numerous respondents reported increased levels of information about HIV in the camps when compared to the villages. A typical

response was: 'In the village there wasn't information about HIV, but there is in the camp.'[37] Or one respondent expressed it,

> There is a lot of information about HIV in the camp. There is a lot of change toward HIV in the camp. There is a lot of counselling, there is a lot of understanding, there is a lot of guidance about HIV and the medication. In the village no-one used to know about the existence of such information and people used not to mind about using condoms. There weren't condoms in the village. It is only because we are in the camp that we got such information. They would send counsellors, especially when it was time for distribution. These people would come and encourage people to come out and go for tests if they were sick. They would come and counsel you and guide you about where the services are available, and that is why there is a lot of change here in the camp toward HIV.[38]

From 1996 access to services and testing in the camps gradually increased through mobile provision from World Vision and the Red Cross, among others.[39] However, with encampment came not only increased access to information but also the increased visibility of symptoms of HIV/AIDS. As members of a focus group from Pabo explained,

> There was nothing like HIV/AIDS in the village. It's when people came to the camps that this disease came. When we were back in the village, people used to know only about syphilis. We had not heard of HIV/AIDS. It's just from the camp here that we started hearing about HIV/AIDS. I started hearing about it in 2000.
>
> When I came to the camp is when I started hearing about HIV/AIDS and seeing people with it. And they would talk about it on the radio.[40]

[37] Interview with Mary Lanyero, 35-year old HIV-positive woman, Atiak, 8 March 2008.
[38] Interview with Martina Auma, 70-year-old woman, Lacor, 31 March 2008.
[39] Focus group with home-based caregivers, Pabo, 23rd February 2008..
[40] Focus group with anonymous mixed-gender HIV-positive respondents, Pabo, 22 February 2008.

Radio programming on HIV increased intensively in the early 2000s and camps provided an environment in which many people could share radios. As one woman from Opit explained,

> My education on HIV/AIDS was through the radio. The radio is good, because it passes important information to people. Though I never had a radio, my neighbour had, and whenever it came to time for announcements I would listen from my neighbour. I would get sick often, but I used to care about going to the hospital. But I hear them say on the radio, that there was HIV testing.[41]

The camps, particularly those close to the town, were easier for HIV prevention organisations to reach and, in the late 1990s, World Vision as well as the Red Cross and the Comboni Samaritans provided limited education in the camps. These 'sensitisations' increased significantly in the 2000s. The camps not only brought about greater access to information and services, but also social and moral re-evaluations of HIV/AIDS. In particular, the camps became associated for many inhabitants with sexual immorality, idleness, disease and the loss of productivity. HIV/AIDS became a symbol of the displacement, representing a broader condition of uncertainty and moral breakdown (Mergelsberg, 2009, Dolan, 2009).

The gradual ways in which experiences of the war and encampment shaped changing understandings of HIV/AIDS is revealed in the story of Charles Kilama, a former LRA abductee. Charles was a fighter with the LRA for several years before he escaped. He is now HIV-positive and living in a village near Pabo. He explained some of the changes brought about by encampment:

[41]Focus group with Santa Akello and Jessica Ajok, HIV-positive co-wives, Opit, 2 March 2008.

> At that time [in the village prior to encampment] we used not to think about *twoo jonyo* so much, but we would often think of soldiers who were coming from the cities who were thin, and then they used to say that it was poisoned charms (*aroga*). [42]

Charles's explanations of *aroga* and *kipwaro,* a form of spirit possession, reveal the ways in which HIV was understood at first as a threat from the southern areas of the country. It also reveals that, in the early stages of the epidemic, AIDS was often associated with the wealthy– a common theme in my interviews:

> According to my understanding, *aroga* is when this person who becomes sick may have done something wrong, perhaps to a rich man where he was, then the rich man used a spirit (*jok*). There were some kind of spirits especially in the cities known as *kipwaro* that I believe that if you do something wrong like if you steal, the *jok* is sent to you to punish you. I think the *kipwaro* may be sent by *ajwaka* because it's only the *ajwaka* who know how to deal with *kipwaro*. People used not to have the knowledge about *twoo jonyo*. All people knew was that *twoo jonyo* was a kind of *aroga*. People just used to believe that those who came from the cities could have been bewitched. There wasn't any education on HIV so it was hard for people to really know. It's only when they came to the camp that the information about HIV came to many. That was roughly after five years in the camp.[43]

With the greater impoverishment of the region during the time of the war, the illness began to be associated with those who had money to migrate as well as soldiers. The spread of HIV

[42] Interview with Charles Kilama, 30-year-old HIV-positive man & former LRA abductee Parobang Parish, 14 August 2008.
[43] Interview with Charles Kilama, 30-year-old HIV-positive man & former LRA abductee Parobang Parish, 14 August 2008.

came to represent a combination of social anxieties around the loss of livelihoods as well as the military threat.

Charles went on to explain that during his time in the LRA he received no education about HIV. 'In the bush,' he said, 'we never had any information about HIV. All the education that was given to us was if you fight hard, you will topple the government. So the issue of HIV was not known to us.'[44]

Information about HIV went along with the increasing visibility of AIDS symptoms in the congested conditions of the camp to produce wide scale changes in understandings of the disease. As Beatrice Akello of Pabo explained:

> It is true that people started recognising most of the signs and symptoms of AIDS while living in the camp, because in the camp people are staying together, there are lots of sensitisations and teachings, compared to the village. In the village even if someone had the disease it was hard to tell because people weren't informed about the symptoms of the disease unlike in the camp when there were a lot of sensitisations and people could see [the symptoms]. It's just because in the villages, the homes are far apart, and it's hard always to notice the signs and symptoms from a different home. But when it came to the real disease, or the signs of a disease, they would take it as a different disease or take it for witchcraft. But when they came to the camp, they used to tell them to take blood. And when they took the blood, they told them they were HIV-positive. And that is how the signs and symptoms became known to people, and now they know if you have this and this sign, you have HIV/AIDS.[45]

[44] Interview with Charles Kilama, 30-year-old HIV-positive man & former LRA abductee Parobang Parish, 14 August 2008..
[45] Interview with Beatrice Akello, 40-year-old HIV-positive woman & TASO CASA, 21 February 2008.

The increase in information that accompanied encampment was important in changing perceptions about HIV/AIDS, but these changes were also a function of the increased visibility of the congested environment of the camp. It became easier in these settings to identify – or misidentify – the symptoms of HIV/AIDS. In this sense, the spatial structuring of the camps interacted with the information about disease. In turn, this interacted with the social interpretations of illness, embedded in widespread fears of witchcraft and existential uncertainty. The effects of this produced shifts in understandings from those based on fears of sorcery to new understandings based on fears of social breakdown, rupture and militarism.

As discussed above, another source of changing views about the disease was the radio broadcasting of HIV/AIDS education, which intensified in the early 2000s, along with greater access to radios in the camps. Many people could now listen to a single radio. Numerous respondents affirmed that they had first heard about HIV through radio broadcasts and that radio was more accessible in the camps than in villages. This is a typical view expressed in a focus group: 'Back then [in the village] we didn't have radios and there weren't radio stations in Gulu, there were only Kenyan radio stations. So we did not hear about it, we only started hearing about it from the camp.'[46]

While the process of encampment was a defining moment in the shift of knowledge around HIV/AIDS in Northern Uganda, this process only gained momentum with the funding that followed the increased humanitarian interest in Northern Uganda in the 2000s.

[46]Focus-group with David Kilara, Lamunou Cecelia & Obal John, mixed-gender HIV-positive respondents, Pabo, 22 February 2008.

The humanitarian shift in the 2000s

As discussed above, the changing responses to HIV/AIDS in the 1990s were closely bound up with the shifting social geography of conflict. The North was largely neglected by the state, NGOs and donors during the 1990s. However, in the early 2000s, the situation began to change, particularly under the influence of increased humanitarian interest in the region. In 2003, Jan Egeland, then UN Under Secretary General for Humanitarian Affairs and Emergency Relief Coordinator, labelled the conflict in Northern Uganda 'the biggest forgotten, neglected humanitarian emergency in the world today' (France-Presse, 2003). This statement represented a major shift of humanitarian aid efforts toward Northern Uganda, and HIV responses increased as part of this move. HIV/AIDS programmes in Northern Uganda were to become among the most well-funded in the country. This shift coincided with the move of organisations like TASO and AIC to Northern Uganda. By 2004 Northern Uganda was the largest recipient of HIV/AIDS funding in the country (UAC, 2005) – a shift in funding laying the basis for the rapid expansion of HIV programming and ARV provision in the North.

Dr Alex Coutino was the director of TASO when they opened their Gulu branch. He explained the reasoning for the late move to Northern Uganda:

> If you have insufficient funding when you have to make your choices, and there's a place that has this terrible conflict, there's no way your staff are going to go up there. So I would say we were under no political pressure not to go there, so to

> speak. Maybe – and I'm just recalling – there was the perception that conflict was the main issue, not HIV. Unfortunately, of course, conflict causes HIV to thrive.[47]

A combination of the security challenges of the conflict, and a more general developmental neglect of Northern Uganda limited HIV/AIDS programming and social responses in North. HIV/AIDS programmes and social responses came to reflect broader shifts in the history of the conflict – from shifts in policies of forced displacement to shifts in humanitarian responses in the region. The ways these shaped the onset of ARV provision will be explored in the next chapter.

Conclusion

This chapter has argued that the characteristic features of the Ugandan 'success story', which involved extensive community mobilisation, widespread information, and a general openness about the disease, were largely absent in Northern Uganda during the 1980s and 1990s, particularly outside of municipal areas. This poor response was largely a result of the conflict, which made it difficult to reach rural areas and led to the mass departure of health staff from the region. The geographic inequalities of the HIV/AIDS programming reflected the broader developmental neglect arising from the conflict. While the north was generally excluded from the national response, there was nonetheless some response to HIV/AIDS. Faith-based and particularly Catholic responses played a major role in responding to HIV/AIDS in both town and rural areas, through networks of missions. These interventions can be viewed as a continuation of a long history of mission medicine in the area and significantly shaped preventative messages in the region by promoting abstinence instead of

[47]Interview with Dr Alex Coutino, former National Director of TASO, Kampala, 2 July 2009.

condom use. In addition, pluralistic explanations of HIV/AIDS, involving both biomedical understandings of disease causation and those premised on forms of witchcraft persisted well into the 2000s. My findings challenge the existing literature, which claims that biomedical explanations became dominant earlier. This is another sign that changes in perception taking place elsewhere in the country took place in a far slower, more diffuse and fragmented way in Northern Uganda.

The transitions in understandings and interpretations of HIV/AIDS and the social transitions that followed were mapped onto the social transitions of conflict and displacement. There was a distinctive socio-spatial logic to this arising from the ways in which population movements and residency were restricted by conflict and regulated by displacement. In this sense, responses to HIV/AIDS were shaped by the spatial production of conflict and displacement – the ways in which mobility and the spatial layout of everyday life were reproduced (Lefebvre, 1991, Harvey, 2006). The insecurity in Northern Uganda produced the exclusion of large sections of the population from mobilisations and HIV responses taking place elsewhere in Uganda, particularly in the South. In addition, it produced a stark divide between urban and rural responses *within* Northern Uganda. It was in this environment of relative exclusion and social uncertainty along with increasing humanitarian interest in the region that ARV provision arrived.

Chapter Two: Treatment and Triage in a Conflict-Affected Setting

Along with the tide of humanitarian interest in Northern Uganda, and following years of exclusion from wide-scale HIV interventions, ARV programmes began in the region from 2002 onwards, expanding rapidly from 2005. This chapter introduces the ARV programmes surveyed in this study and the ways they navigated the terrain of conflict and the post-conflict transition. I locate these approaches within the array of strategies used in other resource-poor settings. I ask the question, in what ways have the challenges of displacement and conflict shaped strategies of ARV provision? I argue here that ART programmes in Northern Uganda have incorporated both primary and emergency healthcare measures; as such, they do not fit easily into the common distinction between relief and development initiatives. Further, treatment organisations were reliant on and constricted by the security, infrastructural and political constraints of the complex emergency in Northern Uganda. I demonstrate that treatment access was shaped by both the institutions of humanitarianism and the stark spatial inequalities of conflict. However, the reliance of treatment organisations on community workers as well as the long-term commitments necessary for treatment required these organisations to operate in a manner quite distinct from that of other humanitarian actors in the district. Developing the themes of the previous chapter, I elucidate how ARV provision in Northern Uganda was shaped by the histories of missionary medication in the region and by the constellation of governmental and non-governmental actors operating in this complex emergency.

The chapter opens with a literature review of ARV provision strategies to resource-limited settings. I will then introduce the three programmes under study: The AIDS Support

Organisation (TASO), St Mary's Hospital Lacor[48], and the Uganda Ministry of Health (MOH) programmes, as well as supporting programmes including *Médicins sans Frontières* (MSF) and the Northern Uganda Malaria, Tuberculosis and HIV/AIDS Programme (NUMAT). In this chapter I take a birds-eye view on how the conflict shaped ARV therapy rollout; the following chapters will inquire into the social relations around this endeavour.

ARV provision in resource-limited settings

I begin here with a review some of the technical aspects of ARV provision and discuss how ARVs have been provided in resource-limited settings. I then move on to discuss existing experiences in conflict-affected settings as well as the guidelines for treatment provision to conflict-affected settings being developed by UNHCR among other organisations. The treatment programmes in Northern Uganda will be assessed in their continuities and breaks with existing practice elsewhere.

Combination Antiretroviral Therapy (cART), otherwise known as highly active antiretroviral therapy (HAART), is the most effective treatment for HIV and AIDS, though it cannot cure the illness. It is generally given in the latter stages of illness, when the level of white blood cells, or the CD4 count,[49] drops low. If there is a lack of diagnostic machinery, clinical observation is used to place patients on treatment according to WHO guidelines, which provide four stages of HIV progression defined symptomatically (Calmy *et al.*, 2004b).

[48] Henceforth referred to as 'Lacor Hospital'.

[49] CD4 cells are white blood cells. These cells coordinate the immune response against viral, fungal and protozoal infections, and signal other cells to perform special functions' (Institute for Medicine: 310). A CD4 level of below 200 cells per mm 3 was the WHO recommended guideline for placing patients on ART, but this changed to 350 cells per mm 3 in 2009 (Hayward 2010).

Treatment is usually a combination of three drugs.[50]If a patient is failing on first-line treatment they may be placed on second-line treatment. However, second-line treatment in resource-limited settings hasn't been widely available (Gupta and Pillay, 2007:512). In 2006, only 4 percent of those on ART in resource-limited settings were receiving second-line treatment (Bennet *et al.*, 2008b). There are new classes of treatment, but these are virtually unavailable in developing countries due to high costs and patents (Gupta and Pillay, 2007:513). ART also has highly variable nutritional requirements depending on the drugs used. ART and food interactions can affect medication efficacy, side effects, nutrient utilisations as well as experiences of hunger (Castleman *et al.*, 2004). The antibiotic co-trimoxazole (In Uganda this is widely referred to by the brand name Septrin, which this thesis will follow) may have significant benefits prior to and during ART, particularly in areas affected by malaria and bacterial infections, and for those with WHO stages 2 to 4[51] of the disease (UNHCR, 2007a:12).

Combination ART requires rigid and life-long adherence criteria. A standardised measure of good adherence is over 95 percent, as well as an undetectable viral load (Simoni *et al.*, 2008:516, Attaran, 2007: e83). Rigid adherence to treatment is associated with viral suppression and treatment success, while non-adherence can lead to treatment failure, rapid disease progression, the development of drug resistance and the hastened death of the patient (Rabkin M *et al.*, 2002, Weiser *et al.*, 2003:282, Gupta and Pillay, 2007:511). The factors influencing the progression of drug resistance include: ART coverage, length of use, and the numbers failing on treatment. Related factors include the patient's time on failing regimens,

[50]The two most commonly used classes of ARVS are reverse transcriptease inhibitors and protease inhibitors (PI). Reverse transcriptease inhibitors include both non-nucleoside (NNRTIs) and nucleoside/nucleotide varieties (NRTIs). Most first line combinations include a combination of three of these (Castelman *et al.*, 2004).

[51]WHO (2005) has developed a clinical staging protocol for use in the absence of diagnostic CD4 tests to asses eligibility for ART. The staging involves a sequence from Stage 1 (asymptomatic or with lymphadenopathy) to Stage 4 in which there is immune breakdown and extreme symptoms like wasting. It is recommended that ART be commenced when a patient is either in stage 3 or 4, depending on symptoms.

the magnitude of viral rebound, and the fitness of resistant strains (Bennet *et al.*, 2008a:25). Remaining on a failing regimen can also worsen drug resistance.

In spite of the initial alarmism over the prospect of poor adherence and the development of resistance in the developing world, these fears have not materialised. Early results from a worldwide WHO drug resistance surveillance study showed that drug resistance has not been a major concern: 'Initial fears of widespread ART failure, leading to a high potential for transmission of drug-resistant HIV have not been borne out'(Bennet et al., 2008a:25). Even in resource-limited settings, treatment outcomes have been similar to cohorts in high income countries. The successful provision of ART in resource-limited communities with high rates of adherence has been evidenced in poor countries such as South Africa, Botswana, Haiti, and Malawi, (Ferradini *et al.*, 2006, Kasper *et al.*, 2003, Farmer, 2005a, Bogards and Goudsmit, 2003, Calmy *et al.*, 2004a, Wouters *et al.*, 2009).

There are, however, still significant difficulties facing ART scale-up in resource-limited settings. From the perspective of treatment providers, these have included lack of health staff, infrastructure and basic resources, irregular supply lines, lack of diagnostics, and geographically dispersed clinics (Simoni et al., 2008:518, Bogaards and Goudsmit, 2003). From a patient-perspective, there may be difficulties with transportation, financial constraints, and fears over stigmatisation (Mills *et al.*, 2006: 2055-2056, Tuller *et al.*, 2009, Kiguba *et al.*, 2007: 220-222, Amnesty, 2008). It is also important to distinguish between barriers to the adherence of treatment and access to treatment, though these can be interconnected (Tuller et al., 2009, Crane *et al.*, 2006). A systematic literature review of patient-reported barriers to adherence found that significant barriers to adherence remain, including 'fear of disclosure, substance abuse, forgetfulness, suspicions of treatment,

regimens that are too complicated, number of pills required, decreased quality of life, falling asleep, and access to medication'(Mills *et al.*, 2006:2039). Adherence also may be affected by a number of social and economic factors including cost, transport and missing work, the difficulties of labour or household tasks, or sharing medicines (Castro, 2005:1219, Leclerc-Madlala, 2006).

Retention in ART programmes is also critical. A 2007 literature review concluded: 'Since the inception of large-scale ART access early in this decade, ART programs in Africa have retained about 60 percent of their patients at the end of two years. Loss to follow-up is the major cause of attrition, followed by death' (Rosen *et al.*, 2007:1691). There are four main reasons for attrition from ART programs: 1) death; 2) 'loss to follow-up' (patients missing visits or not collecting medications for a specified period); 3) transfers to other facilities; and 4) patients stopping medication for a variety of reasons such as drug side-effects (Rosen *et al.*, 2007:1692). Treatment discontinuation may create the same concerns over drug resistance as poor adherence. Unplanned treatment interruptions are associated with 'increased short-term risk of progression of HIV disease and death compared to continuous ART' (El-Sadr and Neaton, 2006), though this is dependent on the nature of discontinuation, as discussed below in the section on viral resistance. However, it also has devastating effects on the patient, and may lead to death in the short term (Rosen *et al.*, 2007:1692).

Resistant mutations to one drug can also create resistance to other drugs within the same class. This is a particular concern with NNRTIs, including Nevirapine and Efavirenz, which are important for treatment in the developing world due to low-cost generic production.[52] However, they are problematic for two reasons: first, they have a low genetic barrier to

[52]These were commonly used medications in Northern Uganda.

resistance and, second, they have a long half-life, worsening the effects of erratic adherence or treatment interruption (Gupta and Pillay, 2007:512). Resistance to NNRTIs can even develop within 48 hours if drugs run out. Furthermore, it has been shown that resistance to NNRTIs is associated with a greater risk of mortality than resistance to protease inhibitors (Hogg *et al.*, 2006, UNHCR, 2007a:10)

Furthermore, access to treatment is not simply a question of material concerns: social concerns over stigmatisation, as well as issues of identity and risk, may also prove a barrier to those with HIV seeking treatment. Allison and Seeley (2005) have conducted ethnographic work on ART delivery in fishing communities in Uganda. They argue that constant exposure to risk, mobility and gendered identities affect ART provision negatively. The constant exposure of fishermen to risk and danger is an integral part of their masculine identity and may deter men from seeking ART (Allison and Seeley, 2005). Beck (2004) also explores how fears around damage to masculine identities impact access to ART in Khayelitsha, South Africa, by discouraging men from seeking treatment. A study of perceptions of ART in Nigeria stressed the importance of both affordability and education through mass media and other sources in shaping access to treatment (Ogunro *et al.*, 2006). Whyte *et al* (2004) have focused on the 'dilemmas of unequal access' in Uganda in the early stages of ARV provision. They found that unequal access to ART was shaped by finances, distance, organisational hierarchy and membership (for instance, within TASO, counsellors received treatment first), as well as networks of patronage. With scarce resources and limited access to free ART, families sometimes had to choose which of their members would access ART and which would go without. Treatment access may also be affected by suspicions towards biomedicine based on social and historical experience, such as the experience of apartheid (Posel *et al.*, 2007, Fassin, 2007a, Steinberg, 2008).

Access to treatment is a highly gendered process. Recent studies have shown that in many developing countries there are a higher proportion of women in treatment programmes than men. This evidence challenges a common perception that women are necessarily more vulnerable or discriminated against in HIV treatment, and calls for an understanding of treatment access that 'considers that perceptions and practices are shaped by broader gendered and non-gendered social dynamics' (Desclaux *et al.*, 2009:804).

The development of ART provision to resource-limited settings involved a paradigmatic shift away from the highly individualistic approaches common in wealthy countries –which involve intensive diagnostic observation and a range of possible treatment combinations– towards a public-health approach to providing treatment. The public-health approach developed by the WHO entails 'standardized treatment protocols, standardized management approaches, and decentralized service delivery'(Bennet et al., 2008b). This approach has fared well in comparison with the individualistic approaches (Keiser *et al.*, 2008:1109). Promoting adherence in resource-limited settings has involved developing new strategies, particularly community-based monitoring. Shortages of human resources at both local and national levels is perhaps the most significant obstacle to the scale-up of ART (Wouters et al., 2009:1177-1178, Kober and Van Damme, 2004). This constraint has led to the focus on using non-medically trained community workers, as well community-based strategies to support the scale-up. Based on experiences in Malawi, Mozambique and South Africa, where ART rollout was very labour-intensive, Kober and Van Damme (2004:106-107) argue for the 'task-shifting' of treatment distribution and monitoring to health workers like nurses and clinical officers, as well as community members. 'Task shifting' is defined by the WHO as 'a process whereby specific tasks are moved, where appropriate, to health workers with shorter

training and fewer qualifications'(WHO 2008 cf Jaffe, 2008: 574). Community support can take diverse forms, including mobilising both paid community workers and volunteer community health workers, as well as support groups and social networks (Wouters *et al.*, 2009:1178). Social support, including adherence monitoring and counselling, has been shown to be more effective than simple information provision (Simoni *et al.*, 2008:516).

An important strategy to monitor adherence, adapted from TB programmes, is directly observed therapy (DOT), which involves clinic staff or trained patients observing patients taking their pills (Mukherjee *et al.*, 2006, Farmer, 2002). However, these programmes are also resource-intensive and difficult to sustain over the long term, particularly in resource-limited settings (Simoni *et al.*, 2008:517). DOT may take a variety of forms, including community- or clinic-based strategies. A common strategy to ensure adherence includes the use of a 'treatment-buddy' – someone, usually within the household, to remind patients about adherence. Peer support groups can also be used to discuss issues surrounding difficulties with access and adherence (Wouters *et al.*, 2009:1178). Strategies of task-shifting do not only apply to adherence monitoring, but can also be used for distribution, as in the case of TASO in Uganda, where health workers with few qualifications provided home-based treatment and monitoring, with good results (Jaffe, 2008:574).

A longitudinal study in the Free State, South Africa, showed that 'community support initiatives, in this case the availability of treatment buddies, community health workers, and support groups, significantly and consistently improved the patient's chance of success', measured in terms of CD4 count and viral load (Wouters *et al.*, 2009:1183). The study found that community support was a more significant factor than either educational level or knowledge about HIV/AIDS. A qualitative study in Gaborone, Botswana, also argued that

active participation in social networks, avoiding internalised stigma, and the acceptance of HIV status contributed to good adherence (Nam *et al.*, 2008).

Concerns around both adherence and patient-retention have not, however, adequately taken into account the problems that mobility creates. As the reviewed literature shows, ARV provision strategies have assumed a sedentary, rather than mobile, population. Mobile populations may include migrant workers, nomadic communities and forcibly displaced communities. While patterns of movement may differ substantially between and within these population groups, making generalisations difficult, there is a need for both research and practical initiatives to better consider the unique challenges associated with mobility. , As Kenny *et al*. (2010: 3) note, 'among those who have traditionally not been reached by HIV (as well as other health) interventions, mobile populations rank especially high,' and they highlight the neglect of conflict-displaced populations. Below, I will review the limited research that has been conducted on ARVs and mobility, including forced displacement.

Recently, various actors have started to raise and grapple with the challenges of mobility. Among these, an NGO in Nigeria was using a mobile van to reach nomadic populations like the Fulani and provide ART. The study recommends providing ART to nomadic communities through monitoring migratory patterns, and using a mobile team, radio and community participation to provide communication and serve as a referral network (Habib and Jumare, 2008:184). There is no clear evidence that migration consistently affects adherence negatively and results are variable in different settings (Lima *et al.*, 2009, McCarthy *et al.*, 2009, Vearey, 2008). However, a recent MSF study in Lesotho has shown that rates of loss to follow-up among migrant workers in Lesotho was, after a year of treatment, over six times that of non-migrant patients (Bygrave *et al.*, 2010). Along with this

MSF study, there are several sets of guidelines and studies targeted at treatment to displaced communities. Nonetheless, few strategies have been developed to specifically target forced mobile or conflict-affected populations.

HIV/AIDS treatment has for many years been ignored in complex emergencies (Salama *et al.*, 2004:1809), and there is still great caution about it. As Waldman (2008:377) writes, 'before initiating programs for the management of tuberculosis and HIV/AIDS, for which interruption of treatment, once begun, can have disastrous long-term consequences, relief agencies should proceed with due deliberation.' Reasons for the exclusion of displaced communities from ART scale-up include 'a long-standing and largely unchallenged view that the provision of medical assistance for chronic illnesses is not feasible in such settings' (Mills *et al.*, 2009:201,204). Research on ART provision to displaced communities is a new field in practice, policy and research. Paul Spiegel (2004) of UNHCR was among the first to call for the expansion of ARV to displaced communities, while warning that strategies required adaptation to these settings. In particular, he noted that 'treatment is life-long and numerous problems may arise, including the possibility of increased drug resistance if refugees repatriate to areas where ART is not available' and suggests that 'a community-based infrastructure adapted to the specific situation should be employed when providing ART' (Spiegel, 2004:332).

Two important sets of guidelines, which overlap significantly, have been released by UNHCR, one in collaboration with the Southern African Clinicians Society (SACS), relating to ART provision to displaced communities (UNHCR, 2007a, UNHCR & SACS, 2007) . Both sets of guidelines frame the entitlement to ART as a human right from which the displaced should not be excluded. Importantly, access to ART and medical assistance is

linked to the protection goals of the UNHCR. The reports address the importance of weighing up the right to treatment against the potentially harmful effects of treatment disruptions. The guidelines recommend: that ARV provision should be started 'in the earliest possible stages of an emergency response to forced displacement'; that continuity of treatment should be ensured; that minimum criteria, such as the availability of resources and adequate supervision, are in place prior to implementation; that sustainability is emphasised; and minimum of one year's approved funding is recommended (UNHCR 2007a: 6-7). The UNHCR raises concerns about possible treatment interruptions that may arise with mobility and conflict. To deal with these possibilities, the organisation recommends: contingency planning in case of interruption (for instance providing additional stocks of treatment, and in particular of NNRTI regimens which have a long half-life); and providing a stock for 'covering the tail' of disrupted regimens (including providing dual nucleosides for a week after stopping NNRTIs) (UNHCR, 2007a:10). The guidelines play down the possibility that treatment interruption could create major problems for drug resistance:

> The increase of ARV resistance by stopping and then re-starting the therapy in a controlled fashion is not considered to be more of a risk for populations that have been displaced by conflict than other populations. The largest threat to developing ARV resistance remains persons taking ARVs in an incorrect manner; this threat is no larger for forcibly displaced populations than other populations (UNHCR, 2007a:6).

Specifically, for the long-term provision of ART, it is recommended that refugees should be allowed to move to areas where ART is available, or be provided with the same services as the local population. Imminent repatriation should not hinder the provision of ARVs, though efforts to ensure treatment continuity should be put in place. Significantly, if a refugee does not wish to return on the basis of access to medication,

> The UNHCR...cannot actively be engaged in returning the individual and must take the utmost efforts to advocate for this person to be permitted to stay in the country of asylum on humanitarian grounds until sufficient medical services will be established in the country of origin (UNHCR, 2007a:8-9).

In the case of return movements, the guidelines advocate that patients with advanced clinical AIDS should delay departure and commence treatment. If the patient is healthy and has a good CD4 count, options may include: planning for transfer to a new site, or remaining for at least three months to monitor the early stages of treatment, and then being provided with a three to six month stock. If a patient insists on leaving immediately or in the near future, the guidelines say that three to six months treatment may be provided, along with referral letters. Patients are, however, discouraged from doing so because adherence is likely to be poor without proper monitoring, and this in turn may lead to the development of drug resistance. Drug combinations should also be adjusted to those most likely to be available in the area of movement. In particular, the guidelines stress the explanation of all the options to the patient (UNHCR & SACS, 2007:6-7).

The UNHCR & SACS address the importance of understanding the particular social situation of displaced persons and state that 'a displaced person may not have the traditional support of family or friends, although there may be strong cohesion among displaced communities' (UNHCR & SACS, 2007:5). This analysis is potentially misleading in its assumption of 'traditional support', in particular given the widespread stigmatisation of those living with HIV. Furthermore, levels of cohesion among displaced communities require empirical analysis identifying inequalities within displaced communities.

However, in spite of the push by UNHCR, the move towards providing ART to conflict-affected communities has not been universal. For instance, the Sphere project, signed by a coalition of over 400 NGOs, which provides a set of minimum guidelines for disaster responses, has not promoted the provision of ARVs either in the original guidelines (Mills *et al.*, 2009:204) or in their 2010 revision. While Mills et al (2009:204) argue that the original guidelines reflected the public-health and scientific thinking of the day, which was 'overly concerned with drug resistance and the expectation that adherence would be poor', the 2010 revisions do not change this:

> The provision of antiretroviral medications to treat People living with HIV/AIDS (PLWHA) is not currently feasible in most post-disaster humanitarian settings, although this may change in the future as financial and other barriers to their use fall (Sphere Project, 2010 : 284).

This intransigence could potentially reflect both the lack of data on existing treatment programmes, as well as concerns over financing. Spiegel (2010:9) has also highlighted the difficulties in making the transition from emergency funding to long-term funding in ensuring the continuity of ART programmes in conflict-affected settings.

In practice, MSF have been pioneering in providing antiretroviral therapy in conflict-affected settings. Ellman *et al*., (2005) provide findings based on MSF's ART programme in Bukavu, Eastern Democratic Republic of Congo. The authors report that good levels of adherence to ART and stable supply lines have been maintained. In spite of the threat that conflict may pose to drug supply, the article also argues that provision of ART to refugees and internally displaced people may be simpler as 'people in a closed camp are easier to access than they would be in their rural communities' (Ellman et al., 2005: 278). MSF has had two ART

successes in the DRC – East Bukavu and Kinshasa. Together they supported almost 2300 patients. The patient survival rate was over 80 percent (90 percent in Bukavu) and, despite destabilisation and displacement from the conflict, there were low dropout rates (4.7 percent in Bukavu and 1.9 percent in Kinshasa). During conflict in Bukavu only 5 of the 66 patients at the time had a treatment interruption, and they returned later. MSF argue that successful ART programmes during conflict require a contingency plan for disruption, including providing adequate education to patients over risks of disruption, a skeleton staff to keep programmes running during conflict, 'communication networks to be able to contact patients', emergency drug stocks to provide patients with, drug storage that is secure from conflict, decentralised health facilities, and treatment information cards (UNICEF and UNHCR, 2006). MSF's results in terms of adherence and mortality compared well to results from non-conflict settings (UNICEF and UNHCR, 2006: 39-40).

Other than the Bukavu programme, there are few other major treatment programmes servicing displaced communities studied in the existing literature. The paucity of research, both social science and public-health oriented, on the topic, was stressed by a review of ARV programmes in conflict-affected settings (Mills *et al.*, 2009). The paper discusses a case study on Nepal, in which provision to remote, conflict-affected settings has been extremely limited, particularly in geographically difficult to reach areas. In spite of a national ART plan, displaced communities have largely been excluded from treatment provision. Similarly, in Burma (Myanmar) conflict-affected groups have had little access to provision of ART, other than along the Thai-Burma border (Mills et al., 2009: 2005-2006). The paper reviews two papers on Northern Uganda that I will address below (Olupot-Olupot *et al.*, 2008, Kiboneka *et al.*, 2009). Aside from outlining the difficulties of accessing ART as a result of conflict and geography, the review says little about the social dimensions shaping access. The review

provides some broad recommendations: communications between providers and patients in times of conflict are essential; emergency or 'runaway' treatment packages to prepare for treatment interruptions should be provided; links with neighbouring regions and providers are necessary to prepare for movement; patient-held clinic cards should be provided; radio should be used for communication and awareness, and patient-related concerns should be addressed (Mills *et al.*, 2009:207).

A quandary posed for ARV programmes in conflict-affected settings, which is largely unaddressed in the existing literature and which I will explore below, is that it does not fit easily into existing emergency healthcare, humanitarian assistance or development paradigms of intervention. Public-health interventions in conflict-affected and displaced communities have been primarily framed within an emergency medical assistance, rather than a primary healthcare, paradigm (Van Damme, 1998:139). As a result, interventions are often short-term and targeted towards the immediate problems of complex emergencies, including outbreaks of infectious illness like diarrhoeal diseases, measles and meningitis, acute respiratory infections, and food supplements for malnutrition (Connolly *et al.*, 2004, Levy and Sidel, 2008). In practice, many long-term refugee situations require healthcare to operate 'between development and emergency' (Van Damme, 1998) and between primary health and emergency medical assistance paradigms.[53] The provision of long-term treatment for HIV and TB does not fit easily into this emergency medical assistance paradigm, and requires a longer term approach. Along these lines, the goals of ART

[53]Van Damme (1998) distinguishes these two paradigms. Primary healthcare relies on long-term strategies, including building infrastructure and capacity; has a focus on care and not only cure; and relies on stable alliances between state and non-state actors. Emergency medical assistance is focused on short-term curative strategies; is often implemented by external actors; and has little emphasis on sustainability or capacity building.

programmes to displaced communities sit uneasily between the concerns of humanitarian relief and development. Explaining this distinction, Duffield (2008:33) writes,

> Humanitarian relief is usually described as denoting impartial, externally directed, short-term emergency measures geared to saving life. Development, however ... is regarded as longer-term help to improve social resilience through strengthening community organisation and self-reliance.

There is no clear transition between humanitarian relief and development, but these approaches to external intervention may clash (Duffield 2007: 33). ART interventions to conflict-affected settings require rigorous and long-term adherence monitoring and continuity and yet have to adapt to the humanitarian and political constraints of conflict. The success of ART programmes in conflict-affected settings relies on, it will be argued here, long-term planning with a sensitivity to the constraints and uncertainties of conflict and post-conflict transitions. The ways in which these challenges have been navigated in Northern Uganda is examined below.

ARV provision in Northern Uganda

Notwithstanding the profusion of impediments caused by conflict, antiretroviral provision commenced in Northern Uganda in 2002 and was expanded swiftly to rural areas from 2005 on. The constraints on these endeavours included the continual threat of violence, roads ravaged by weather and neglect, health-centres abandoned by their staff, and a dispossessed population that had been sidelined from the mass HIV education campaigns of the previous decade. The challenges of the region were extreme, and there were few precedents to guide treatment provision in such a setting. Antiretroviral interventions required a long-term

approach that did not gel easily with the short-term aims of most humanitarian actors. However, treatment providers had to negotiate an exceptional and uncertain environment. In this section I wish to explore the ways in which this context was apprehended and the successes and missteps of what was, in essence, an experimental project.

As raised in the previous chapter, the arrival of antiretrovirals came with a tide of humanitarian interest in the region. When the major programmes got underway between 2002 and 2006, there were few precedents or guidelines treatment to conflict-affected settings. The approaches were developed through adapting, sometimes in an *ad hoc* fashion, to the difficulties of an uncertain situation. Strategies were adjusted from national guidelines as well as experiences in other resource-limited areas of Uganda and elsewhere. Below I outline the three major programmes in this study, which were the three major ARV programmes in the Gulu, Amuru and Lira Districts. Two are well-resourced NGO programmes, one secular in approach, the other faith-based, and the third is the Ugandan Ministry of Health (MOH) programme which had to rely on several supporting NGOs. The discussion below will recount how these programmes developed, while demonstrating how their strategies were shaped by conflict and displacement.

Ugandan Ministry of Health

Northern Uganda, after a decade of relative neglect, was not far behind other regions of Uganda as a recipient of state antiretroviral programmes. A combination of high HIV sero-prevalence rates and pressure from humanitarian groups compelled these endeavours northward. However, the state health services in the region, decimated by years of conflict, were in a weak position to adequately support these therapeutic interventions. Nonetheless,

they were advanced with little attention to the awaiting challenges of conflict, or strategies to respond to these. The lacunae in these programmes were manifold: few staff trained in HIV-medication, no reliable monitoring for adherence or continuity, poor data collection, and inadequate ordering and procurement systems, among others. There were no special considerations made for either outbreaks of conflict or mass population movements. Given the extreme lack of health infrastructure in the region, state health services had to rely on many different non-state actors, often without much co-ordination between them. These supporting agents often supported state health sites on a relatively ad-hoc basis and without stable long-term strategies. Nonetheless state health services in Northern Uganda, along with external support, managed to get thousands onto treatment over several years. This was a significant step in overcoming the previous exclusion of the region from HIV/AIDS responses.

Antiretroviral therapy provision had started in Uganda nationally in 1997 as part of a UNAIDS Drug Access Initiative, though treatment was only provided in Kampala, and was taken over by the Ugandan Ministry of Health and continued from 2000. The programme garnered major funding from the Global Fund to fight HIV/AIDS, tuberculosis, and malaria (Global Fund) which helped support the expansion of treatment and by 2003 six regional hospitals were providing subsidised treatment including Gulu. (Okero *et al.*, 2003: 5). The model used for ART scale-up in Uganda nationally was a 'primary care and community home-based care model' based on providing treatment through hospitals or health centres (level four) and giving ongoing counselling and check-ups, family education and directly observed therapy (Okero et al., 2003: 9). A critical point for this study is that the primary

care and community home-based model was applied to Northern Uganda with no specific adaptation to the conditions of conflict.[54]

Whereas Northern Uganda has been sidelined in the prevention efforts of the previous decade, Gulu Town was among the first places outside Kampala to receive treatment. The introduction of ART interventions in Northern Uganda was described Dr Elizabeth Namagala, the National ART Co-ordinator, who was part of the initial scale-up:

> One of our principles was equitable distribution of services and to make sure every region had an ART site.... There was an outcry for more help in the North. A lot of lobbying was done. There was a lot of international pressure to provide services. ... Humanitarian organisations were lobbying. The sero-surveys showed there was a lot of HIV. WHO was leading the effort to roll out treatment in the North.[55]

In 2004 the MOH began to provide free ART (WHO, 2006). By September 2006, Gulu Hospital had 478 active patients[56] and by December 2008 this had risen to 1270 patients (MOH, 2008). Gulu Hospital offered no home-based care or directly observed therapy. For adherence reporting they relied on pill boxes and patient reports.

In 2005 a decision was taken by the MOH along with the WHO to expand ART to rural health centres. By 2006 all sub-counties in Gulu district (including Amuru at the time) had ART services[57]. While these rural facilities had trained ART teams, they were under severe constraints. A WHO and MOH consultancy report outlined these constraints: there was a lack

[54]Interview with Dr Elizabeth Namagala, National ART Co-ordinator, Ministry of Health, Kampala. 10 July 2009.
[55]Interview with Dr Elizabeth Namagala, National ART Co-ordinator, Ministry of Health, Kampala. 10 July 2009.
[56] Interview with Sister Josephine Abur, Nurse at HIV/AIDS Clinic, Gulu Regional Referral Hospital, Gulu Town, 11 August 2006.
[57] Treatment sites included Awach, Anaka Hospital, Atiak, and the Fourth Military Division.

of a medical officer at either Lalogi or Atiak, continual stock-outs of medications for opportunistic infections, limited staff trained in HIV/AIDS management, limited follow-up registries, few staff trained in the comprehensive management of HIV/AIDS, the 'lack of district / regional ART teams to supervise ART teams at health facility level' and 'no organizations supporting clients in ART care, especially nutritional and adherence support outside of Gulu municipality' (Kayita, July 2006). It was clear that state ART provision was under severe strain. In 2006 numbers on treatment at rural health centres were extremely low (Kayita, July 2006). [58]

Given the lack of capacity to respond to the challenges in Northern Uganda, the MOH had to rely on an array of both emergency medical actors, particularly MSF, as well as HIV NGOs with a longer-term approach.[59] The WHO was providing the lead in support state ARV provision and yet didn't manage to set-up evaluation and monitoring processes. As the head of WHO noted in 2008,

> One of the serious gaps is the compliance. We don't have a strong system to look after the compliance ... the thinking we have at this stage is to train the village health teams (VHTs) and use them as agents in the community to monitor all these issues – AIDS, TB-DOTs, and supporting people on treatment. But it's still in the planning phase. So, it's a really serious concern.[60]

Furthermore, non-governmental support to MOH clinics set up parallel supply lines, operated on disease-specific funding, and established limited time frames. In late 2006, Northern Uganda Malaria AIDS/HIV and Tuberculosis Program (NUMAT) was formed and started

[58] The report recorded 51 patients at Awach, 93 patients at Lalogi, 118 patients at Atiak, and 181 at Anaka.
[59] Notably the Joint Clinical Research Council which provided both its own treatment supply-lines through state health facilities but also diagnostic support to MOH programmes, in particular CD4 testing.
[60] Interview with Solomon Fisseha Woldetsadik, head of WHO Gulu sub- office, Gulu Town, 23 August 2008.

providing supply-line and community-based support to state health clinics. However, this programme too did not pre-empt many of the challenges for treatment continuity that were created by mobile populations, as will be discussed in later chapters. The problems facing state health services were exacerbated by a national funding crisis, caused by the temporary withdrawal of funds from the Global Fund. All Global Fund grants were withdrawn in 2005 (Global Fund 2006) after allegations of mismanagement of funds, though were reinstated after a commission of inquiry in 2006. The funding shortfall created drug shortages and supply-line problems that exacerbated the situation in Northern Uganda, along with other areas of the country.

The difficulties of the post-conflict situation were typified by Anaka Hospital. At the outset of the ART programme the hospital did not have an NGO working with them on treatment monitoring, but had some support from the village health team. Anaka had started to receive supply-line support from NUMAT by 2008. The hospital was affected badly by the conflict, including being directly attacked and looted by the LRA. Many health staff left as a result. The acting director of the hospital explained that,

> the conflict has had a great impact on the management. It has been very difficult to attract health workers in this area. Specifically medical officers or doctors. It has been difficult for them to come and work here. The place seems remote and there are so many missing social amenities. So they may not stay here long enough. And then, where we are seated, was renovated. But there are other parts of the hospital [including accommodation] that were vandalised by the insurgency.[61]

[61]Interview with Ngek Ojwang, Acting Medical Superintendant, Anaka Hospital, Anaka, 11 March 2008.

ART was introduced to the hospital in 2005 and led to an increase in those seeking HIV testing. However, as a result of staff shortages and national supply line problems, the hospital experienced frequent stock-outs:

> We could report to the national medical stores, but we were told, we don't have drugs in stock, so they're not able to help you much. Then occasionally, it's also probably late reporting. They rely on our reports to send us drugs. If you don't report, you don't expect. [62]

The case of Anaka reveals how the damage of the conflict, particularly in terms of infrastructure and lack of health-staff, intersects with broader challenges concerning management and supply-lines at a national level.

Several government health-clinics received support from different branches of MSF. MSF supported health centres in Atiak, Lalogi and Aromo. Various branches of MSF (Spain and Holland) operated in these areas, indicating a lack of co-ordination between MSF programmes. While I did not conduct extensive research on MSF programmes, it was clear that the short-term emergency approach had significant shortfalls when providing ART in this context. MSF set up its own supply lines and paid for community-based staff who were left unemployed when MSF left. For instance, once MSF (Holland) left Atiak there was no vehicle and no support for community-based adherence monitors. NUMAT had trained three community workers in April 2007,[63] but these were inadequate to monitor all the patients in the HIV clinic.[64] The Atiak programme had patients from all over the region, including Sudan, which created difficulties for monitoring.

[62]Interview with Ngek Ojwang, Acting Medical Superintendant, Anaka Hospital, Anaka, 11 March 2008.
[63]Interview with Alana Kanrac, village health team focal person, Atiak, 23 June 2008.
[64]Interview with Tony Okello, health worker at Atiak HC 4, Atiak, 23 June 2009.

The MSF Aromo Programme in Lira collapsed with its withdrawal and patients were referred to the Ogur Health Centre. The health centre was 28 kilometres away, which caused significant problems for patients even though there were only around 20 patients on treatment at the time of withdrawal.[65]

In September 2006 I visited Lalogi Health Centre. There was only one nurse working at the HIV clinic. There was some additional support for mothers and children from Health Alert, and a few volunteers trained to do adherence support by UNICEF, but it was clear the centre was extremely understaffed.[66] Later MSF (Spain) was to take over the health centre. Visiting again in 2009, the transition was remarkable. There was a new ward, a new laboratory, and new staff quarters. From the 96 patients on treatment in 2005, there were now around 450 on ARVs.[67] The ARV programme was running extremely successfully. However, MSF was in the process of withdrawing in 2009, leaving the centre once more with few staff. Approximately 90 percent of the staff at the health centre had been employed by MSF.[68] They had employed 30 community-based adherence monitors, and while NUMAT were going to provide support, it was doubtful they could support all of these. While MSF (Spain) made a significant attempt at phased withdrawal –taking place over several month in mid-2009 and with a large buffer stock of medication –it too encountered problems with withdrawal, and stocks ran out after only two months.

Overall, the primary health and community-based model for ARV treatment could not be easily implemented in Northern Uganda. It required significant support from NGOs operating in both an emergency and primary health care approach, and the result was a

[65]Focus-group with Martin Ayar and Cipriano Akweno, health workers, Aromo HC3, 15 March 2008.
[66]Interview with Everlyn Anyango, Enrolled Nurse, Lalogi Health Centre 4 15 September 2006.
[67]Interview with Dr Basil Lemma, MSF field-doctor, Lalogi Health Centre 4, 25 June 2009.
[68]Interview with Dr Basil Lemma, MSF field-doctor, Lalogi Health Centre 4, 25 June 2009.

patchwork of often ad-hoc responses rather than a co-ordinated and clear strategy to adapt to the challenges of the conflict and the post-conflict transition. Nonetheless the programmes were successful in getting many patients onto treatment. It is difficult to assess the extent of the problems or successes of MOH antiretroviral programmes in Northern Uganda as data on continuity and adherence - in contrast to the extensive data sets of the NGOs discussed below - is woefully lacking.[69] Most published studies, discussed below, rely on the data sets of NGOs and so are potentially misleading when generalised to more poorly-resourced state health services. The difficulties facing state ARV rollout in Northern Uganda have not been unique to Northern Uganda: difficulties with health-staff shortages and stock-outs have occurred elsewhere in Uganda[70] and are common problems in resource-limited settings. However, the challenges of a poorly resourced state health system are exacerbated by conflict. The experiences of Northern Uganda do, however, clearly show the problems in adapting primary healthcare models of ARV provision to conflict-affected settings.

The AIDS Support Organisation.

TASO entered unfamiliar terrain in Northern Uganda when they established a Gulu branch in 2004. However, they came with extensive experience in community organisation throughout Uganda. Furthermore, TASO has provided subsidised ARV treatment in Uganda since 2002 (Whyte et al., 2004). TASO's entry into the region was also made possible by a huge boost in funding available through the newly formed PEPFAR. TASO's entry into the region relied strongly on existing humanitarian actors and infrastructure, as well as political support. Dr Alex Coutino, who was the chairperson of TASO at the time, explained:

[69] I was given approval to view MOH data-sets on Northern Uganda, but the data was so incomplete no analysis could be conducted.

[70] Interview with Dr Elizabeth Namagala, National ART Co-ordinator, Ministry of Health, Kampala. 10 July 2009.

> The decision for TASO to go to the North was met with a lot of resistance, both within and outside...People felt that expansion in the North was too risky – period. A couple of donors were happy. They had the North in their horizon, and were understanding that conflict and IDPs are a breeding ground for HIV.[71]

TASO chose to work in Gulu as they viewed it as the area of greatest need. The new TASO centre was built on land belonging to the local state hospital, Gulu Regional Referral Hospital. The entry into Northern Uganda required the facilitation and support of both local politicians[72] and the humanitarian institutions and resources. Coutino explained:

> We always intended to go to the IDPs. We just piggy-backed on the UN food deliveries and the security, because we would sit in all these security meetings and so on, and co-ordinate our trips to the IDPs. But then remember that at that time the conflict had peaked and, although there were episodes, was starting to decline. [73]

It is therefore clear that, from the outset, treatment intervention relied upon different branches of the state as well as the humanitarian actors in the region. The most clear institutional link between TASO and humanitarian actors was through emergency food assistance. TASO formed an alliance with World Vision, an evangelical organisation, to distribute specialised food supplies sourced from the World Food Programme (WFP) to those with HIV and TB, an intervention called the Food for Health Programme (FHP). Later they also formed a relationship with ACDI Voca, another food assistance agency. TASO was to keep the registry lists for the FHP even when recipients were on other treatment programmes. In this

[71]Interview with Dr Alex Coutino, former National Director of TASO, Kampala, 2 July 2009.
[72]Including Walter Ochora, the National Resistance Movement, Local Council 5 Chairperson at the time.
[73]Interview with Dr Alex Coutino, former National Director of TASO, Kampala, 2 July 2009.

way they entered into direct relations with emergency humanitarian agencies, although their approach was a long-term and not an emergency strategy.

The start in Gulu was extremely difficult. Dr Mulongo Muhamed, TASO's national medical officer, recounted the challenges:

> When we started ART, we were first of all overloaded with numbers to screen for ART. We found that there were many people in the late stages of the disease, compared to other centres. There was more malnutrition at the time of screening than in any other centre. Actually, when we started ART, this was the centre that reported the highest deaths due to ART related anaemia. So starting we had more numbers, but clients also had more problems on ART. So, in terms of continuity of care, we had high deaths, but some of the factors were because people were coming late, and many people were malnourished, so ART depressed some people.[74]

I analysed the patient mortality data for TASO, which confirms this account. Mortality of this cohort (representing patients on ART within the first six months) starts steeply at over 9 percent in the first quarter and then rapidly reduces.[75] ART thus entered a context substantively different to other rural settings in terms of need and response. Patients were in worse physical condition, primarily as a result of malnutrition and disease progression, and so prone to higher rates of mortality. The difficulties were also linked to the social and spatial effects of conflict.

From 2005 to 2007, field officers, on motorcycles, delivered ARVs to households within the Gulu municipality and the camps near to the town. These field officers conducted follow-up

[74]Interview with Dr Mulongo Muhamed, Medical Officer TASO Headquarters, Gulu Town, 22 July 2008
[75]CDC/TASO quarterly reports 2006 to 2009.

on clients a few times a week in the early stages of treatment and then fortnightly. Household members were trained to remind clients on ART to take their medication. TASO also provided HIV 'sensitisations'[76] in camps as well as supporting drama groups and radio programmes. Clinicians provided clinical care either at outreaches or the TASO centre in Gulu Town. Special contingency planning for the outbreak of conflict involved giving patients a telephone hotline number, or arranging a military escort for them to the nearest TASO centre (Kiboneka *et al.*, 2009:2), although these methods were rarely used. The only major interruption to treatment provision as result of conflict occurred in December 2005, when field officers could not deliver medicine to patients in Bobi or Minakulu or anywhere beyond a radius of nine kilometres.[77] Patients were required to collect their medications in the town, but there were no major disruptions to treatment continuity during this period.

In spite of the initial challenges a prospective cohort study of TASO patients in Northern Uganda showed extremely good results. There was only a total mortality of 4.2 percent and over 92 percent of patients had an adherence of 95 percent or above, considered a gold standard for adherence (Kiboneka et al., 2009). The study used a composite adherence measure involving 'drug possession ration' (i.e., pill count), 'pharmacy refill records' and 'three day recall report by patients or caregivers'.78 The study found that adherence was comparable to both other rural settings and developed settings. Surprisingly, it also showed that mortality was even lower than in other areas of Uganda such as Rakai. The study further showed no major differences in adherence or mortality in camp and urban settings (Kiboneka

[76] 'Sensitisations' is a reference to community education in common Ugandan parlance.
[77] Interview with Christopher Osege Eretu, TASO field officer, Gulu Town, 16 September 2006.
[78] There is some question about the validity of this method reported adherence. Kiboneka *et al.*'s (2009) study on adherence above uses a composite adherence measure, involving both self-reporting and pill counts However, my own analysis of CDC data shows wide variability between self-reporting measures and pill counts. At times there were differences between reported adherence and pill counts of over 30 percent. This indicates systematic over-reporting of adherence. While in the field, I observed that field officers sometimes completed reports hastily and with little patient consultation. Another potential explanation is that patients were afraid of reporting poor adherence.

et al., 2009: 3-4). Based on these findings, it concluded that 'provision of such treatment in contexts with armed conflict is both feasible and potentially highly successful' (Kiboneka et al., 2009:5).

While this conclusion is broadly convincing, there are key issues that the study does not address, particularly the problems with patient retention faced during the return period. [79]Even in 2006, health workers in TASO were concerned about movement arising from the 'decongestion' programme – the breakup of camps into smaller satellite camps. As a field officer told me in 2006,

> We hope to introduce a community system if clients go back to their villages. Camps have made it relatively easy to reach people's homes. There are many clients around. It would be more difficult with the villages spread out – that's why they're coming with the new plan. To me, I feel like the new slots are too little. There are many clients registering. [80]

Or as Charles Odoi explained in 2006,

> The challenges are many – now the government has come up with decongestion which might make us lose track of some of the people we are serving. We have the challenge of insecurity… in some situations, people are going in a direction, and you can't go there. Sometimes the rebels have attacked a particular place. [81]

However, it was only in late 2007 that they shifted to an approach of using decentralised community distribution points as well as community-based adherence monitors (CASA),

[79]This is given extensive discussion in Chapter Six.
[80]Interview with Christopher Osege Eretu, TASO field officer, Gulu Town, 16 September 2006.
[81]Interview with Charles Odoi, TASO Counselling Co-ordinator, Gulu Town, 7 August 2006.

who received training and support in the areas that TASO serviced. This lag was due to donor financing constraints and caused significant problems, as will be discussed in later chapters.

Though I found most patients committed to adherence and few said they had missed medication, adherence monitors reported there were adherence problems with some patients due to alcohol abuse, lack of food, and transportation issues.[82] These issues were similar to findings of a qualitative study on barriers to ART adherence in North-eastern Uganda's conflict-affected Teso region (Olupot-Olupot et al., 2008). The authors found that patient-reported barriers to ART adherence included transportation, human security, food insecurity, and weather conditions.

Overall, TASO's adaptation of mobile community-based strategies used in other areas of Uganda proved extremely successful in the early years of treatment provision. Mobile field-officers could negotiate both the town and camp areas well and efficiently. TASO adapted to the needs of its patients, particularly with regard to food support, by forming alliances with food assistance agencies. Furthermore, using the institutions and resources of humanitarian agencies allowed the organisation to adapt quickly to a new context. The strength of its community networks allowed TASO to communicate well with patients and provide intensive monitoring of adherence in both towns and camps. However, its strategies came under strain with the population movements during the return period, as populations scattered and distances to patients increased. There was contingency planning for the more immediate

[82] Interview with Beatrice Akello, 40-year-old HIV-positive woman on ART & TASO Adherence Monitor, Pabo Camp, 21 February 2008; interview with Esther Aciro, St Joseph's Mission and Comboni adherence supporter, Opit, 17 June 2009, among others.

outbreaks of conflict, but not a clear strategy for longer term sustainability, as will be discussed in later chapters.

St Mary's Hospital Lacor

In contrast to TASO, St Mary's Hospital Lacor [83]– the missionary hospital introduced in the previous chapter – had a long history of involvement in Northern Uganda and had been involved in the HIV/AIDS response from the days of Lucille Teasdale in the 1980s. In addition its relationship with rural areas was extensive through its network of Catholic missions. This history was to fundamentally shape its response to treatment provision during the conflict.

Lacor Hospital began to provide ART in 2002. In this programme, clients had to pay for ART at a 'cash and carry' window of a hospital-based pharmacy. Allen (2006b:24) raises concerns about the unmonitored treatment provided through this window creating problems for adherence and drug resistance. At one point over 200 patients were buying treatment in the pharmacy, but this had dropped to under 30 patients by 2009 [84] as a result of the expansion of free programmes; the concerns raised by Allen about the window are unlikely to have eventuated given the small numbers of patients receiving treatment through it.85 In September 2004, The AIDS-Relief Consortium started funding the Lacor Hospital's ART programme. PEPFAR was the primary funder, and Catholic Relief Services (CRS) was the major local partner.[86] CRS directly administered the programme on a local level. CRS-

[83]Henceforth referred to as Lacor Hospital.
[84]Notes taken from Lacor Hospital pharmacy registry, June 2009.
[85]Notes taken from Lacor Hospital pharmacy registry, June 2009.
[86] The programme was also given technical and financial support by the as well as the Institute for Human Virology, University of Maryland, and the Futures Group.

administered funding was faith-based and could not be used for programmes that distribute or promote the use of condoms.

A Catholic community organisation, The Comboni Samaritans of Gulu,[87] provided monitoring and support to clients on the CRS programme. They also provided clients with water purifier and mosquito nets, and offered support with school fees. They had a number of full-time employees, including social workers and counsellors, as well as community-based volunteers to monitor treatment. Patients were observed taking therapy by community-based adherence monitors every day for three months at their homes, and then weekly after that for six months. The CRS/Comboni strategy endeavoured to promote behavioural change based on Catholic values, although it did not exclude anybody on religious grounds. Comboni Samaritans also ran public awareness, or 'sensitisation', workshops in communities and camps in Gulu and provided counselling for their clients. Before going onto ART, clients were required to have CD4 tests as well as liver and renal function tests. These tests were subsidised.

Lacor Hospital and Comboni shifted to a community-based strategy at the inception of their programme, which proved very effective in ensuring treatment continuity. Doctors at Lacor Hospital were also concerned about return movements from the outset and encouraged Comboni to start planning for return by selecting community treatment monitors from diverse geographical regions.[88] Lacor Hospital operated on-site with only one ART outreach at Opit, established in late 2008. Extensive networks of community-based treatment monitors, paid a small stipend, were chosen by the Comboni Samaritans from different geographic

[87] Henceforth referred to as the 'Comboni Samaritans' or simply 'Comboni'.
[88] Telephone interview with Masimo Opiyo, Chairperson of the Comboni Samaritans, , 29 March 2010.

areas. Masimo Opiyo, chairperson of the Comboni Samaritans, explained how the community-based strategy used community-based volunteers,

> We had a family member trained to monitor, and that person trained together with the patient. The volunteers [i.e., adherence monitors] stayed together with the patients and the family members and were there to monitor and check [adherence]. Sometimes the volunteer cannot see the all the patients in one day. At that time, our people were still in the camps. If you have outpatients in the camp, we would take the volunteers in the same camp. If you were to look at where these patients would be going back, we realised that these patients were coming from so many places. We look at a number of patients coming from a specific place, if there are many, we can choose beneficiaries. [89]

Lacor Hospital also experienced high rates of mortality in the early period of their programme. In the last quarter of 2005, mortality rates among patients who had been in the programme for under six months was over 18 percent, and this rate gradually declined to around 5 percent by mid-2007. As in the case of TASO, high early mortality reflects patients coming out very late in their disease stage. Lacor Hospital also showed consistently good adherence. A cross-cohort study conducted by Christopher Lafond (2005b), with clients of Lacor Hospital, showed high rates of adherence among clients on ART in displacement camps. Lafond (2005a: 25) found that 'all but one of the subjects reported adherence rates greater than 90 percent'.[90] Less-than-perfect adherence was almost twice as common among males (22.58 percent) as it was among females (12.16 percent). The adherence rates of clients on ART in the camps did not differ significantly from those living in the Gulu Municipality or Kampala. Similarly, Zabulon *et al.*, (2006) conducted an adherence study

[89] Telephone interview with Masimo Opiyo Chairperson of the Comboni Samaritans, 29 March 2010.
[90] However, the measure of 90 percent adherence that Lafond reports falls below the standard measure of 95 percent.

of 105 patients at Lacor Hospital and found high rates of adherence and low dropout as well as good responses to treatment. They concluded that 'the results show a good immunological and viralogical response and a strict adherence to ART, thus suggesting ART can be successfully implemented in a region affected by civil strife and all related logistical problems.' As with TASO, my own qualitative research on adherence found that adherence levels appeared high, with few respondents citing problems.[91]

In the previous chapter, I discussed how church hospitals and missionaries played a significant role in the response to HIV in the region. This history was to shape the provision of ART. Comboni formed close ties with the missions in Opit in the early phases of treatment. The introduction of ART thus deepened the integration between church and healthcare in conflict-affected rural areas. The response was therefore not based on an emergency healthcare model, but rather continued the institutional history of mission involvement in the region. This history allowed the programme to be less reliant on humanitarian organisations in the region and to embark on community-based strategies from the outset, even in conflict-affected areas. Faith-based PEPFAR funding gave new force to the mission-based responses to HIV. Also, given the long-history of Lacor Hospital in the region, their programme was less reliant on the involvement of politicians. As Opiyo noted, 'The level of politicians' involvement is very minimal. We don't involve politicians so much, but they're sometimes involved in projects to encourage the people to view the projects as belonging to the people.'[92]

[91]The adherence data for Lacor was incomplete and so I was unavailable to conduct the same analysis that I have done with TASO above.

[92] Interview with Masimo Opiyo, Chairperson of Comboni Samaritan, Lacor, 27 August 2008.

Thus, the strategies and experiences of the three programmes in this study differed substantially. They were all negotiating the terrain between a primary healthcare and an emergency medical care approach, as necessitated by the long-term requirements for sustainable ARV provision. However, the complex emergency in Northern Uganda shaped the programmes in distinctive ways. Models used in non-conflict-affected settings were applied to Northern Uganda, but required adaptation to both the conditions of displacement and the institutional and political networks of the complex emergency. Lacor Hospitals ART programme built on a long history of missionary medical intervention in the region, as well as early responses to HIV/AIDS. The TASO programme, new to the region, became closely aligned to humanitarian organisations for infrastructural as well as political reasons. The MOH programmes suffered most severely from shortages of resources and staff and showed little planning for the specificities of the complex emergency. As a result, many of its tasks were taken over by non-governmental actors, thus creating problems of sustainability. For all three programmes the adaptation of ARV models was shaped on an ad-hoc basis rather than through clear strategies. Contingency plans for the conflict tended to be developed in response to an uncertain and dynamic situation.

Treatment access and spatial triage in Northern Uganda

An important consideration, in light of the above, is the degree of access to treatment that was afforded the population of Northern Uganda. Conflict and displacement have shaped access to treatment in specific ways. Treatment organisations imposed extremely limited 'catchment areas' – geographic areas in which they would provide treatment to patients - in the early period of treatment provision. In addition, access to treatment was shaped by the social ecology of conflict – the threat of violence, as well as environmental factors (distances, rains,

disease) which were exacerbated by bad roads and insecurity. The ability to get to treatment sites, as well as information about treatment, shaped treatment access.

An analysis of spatiality here enables us to grasp how forms of triage operate well beyond the health centre itself and are shaped through socio-political forces. Nguyen writes of 'urban form as triage' in reference to housing policy in Abidjan shaping access to health services (Nguyen, 2010:143). This insight is important, as it brings together the perspective of biopower and ideas of spatial divisions of inequality, which Harvey refers to as 'uneven geographical development' (Harvey, 2006:71). Spatial divisions shape access to lifesaving treatments and these spatial divisions themselves are the outcomes of socio-political processes. The complex emergency in Northern Uganda has produced a distinctive form of socio-spatial triage.

Spatial triage is shaped by catchment areas that exist throughout Uganda and in many parts of the developing world. Akhtar and Izhar (1994: 230) and Whyte et al. (2004:17), draw attention to the centrality of catchment areas – the physical distance between population clusters and health facilities –in shaping access to medical services. In the early stages of treatment in Northern Uganda, catchment areas were extremely limited. TASO had a catchment area of 35 km in the early phases of their work, but in 2006 this changed to 70km as a result of the improved security. St Mary's started with a catchment area of 40km which changed to 80km in mid-2006. Gulu Hospital by contrast had no criteria of residence for patients seeking treatment.[93] However, even while treatment slots were available, few outside the municipal areas had the resources or information to travel long distances.

[93]Interview with Dr Elizabeth Namagala, National ART Co-ordinator, Ministry of Health, Kampala. 10 July 2009.

Prior to 2006, there were few treatment sites in conflict-affected rural areas. Many health centres in the camps were understaffed and had no HIV services such as testing or prevention of mother to child transmission.[94] Access routes to the camps for services based in the town were blocked by the threat of violence. For instance, in December 2005 TASO field officers had to stop travelling outside of the municipal areas because of the threat of conflict.95 Thus, the conflict made spatial inequality between towns and rural encampments extreme. The poverty of encampment meant that few could afford to travel long distances, making distance a major issue for both treatment providers and those with HIV. Charles Odoi of TASO highlighted these issues in 2006: 'Distance is a big challenge for both the service provider and service recipient. We are not yet operating in all these places. Some places are still inaccessible.'[96]

However, access to treatment was not only institutionally defined through catchment areas, but fundamentally shaped by other factors – particularly transportation and distances, as well as information and knowledge about treatment. MOH programmes were decentralised to rural areas from 2005 on, but these were poorly resourced, and were not accompanied by the social support and education programmes of the larger NGOs. As discussed above, they had extremely low take-up in the early phases. The low levels of people seeking treatment in these areas indicated that lack of HIV education, stigma and limited resources also constituted a form of triage: the factors likely shaped knowledge around treatment and willingness to seek treatment. This is a likely reason for low levels of treatment uptake in the early years of MOH treatment provision at rural health centres. These programmes were not

[94]Interview with Grace Angom, Midwife, Cwero camp health centre, Cwero, , 12 September 2008.
[95]Interview with Osege Christopher Eretu, TASO Field Officer, Gulu Town, 16 September 2006.
[96]Interview with Charles Odoi, TASO Counselling Co-ordinator, Gulu Town, 7 August 2006.

accompanied by the type of community education programmes that the NGOs could provide. For instance, treatment uptake expanded dramatically at Lalogi after MSF took over the health centre[97]. In spite of the availability of the pills themselves, the majority of patients remained in the municipal areas. This would change in the years between 2006 and 2009 as programmes expanded intensively into rural areas and there was freer mobility following the cessation of hostilities.

The issue of transportation was the major recurring complaint cited by patients in the camps as well as caregivers as a barrier to treatment access. Even if treatment slots were not full, as was the case at Lacor and Gulu Hospital in August and September 2006, many could not get to the treatment centre or even to testing sites. For TASO, distance and insecurity played a central role in their strategies. According to Motebe Kimera, chairperson of TASO Gulu in 2006:

> The majority of clients are coming from the municipality and a few from a distance of 25to 30 kilometres around. The problem that we have been challenged with is that we have wanted to expand services. Our coverage area should be 75km, but some areas have not been easily accessible due to the insecurity. [98]

While the majority of patients on ARVs were clustered around the Gulu municipality, there were also a significant number of patients who commuted into Gulu from distant conflict-affected areas such as Kitgum, Lira, Awach, Pader and Apac to get ART from the Gulu Hospital.[99] The spatial shaping of treatment access also led many patients to change their

[97] Interview with Dr Basil Lemma, MSF field-doctor, Lalogi Health Centre 4, 25 June 2009.
[98] Interview with Motebe Kimera, Chairperson TASO Gulu, Gulu Town, 18 September 2006.
[99] Interview with Sister Josephine Abur, Nurse at HIV/AIDS Clinic, Gulu Regional Referral Hospital, Gulu Town, 11 August 2006.

residential areas. Lakop Christine, the nurse and counsellor in-charge at Lacor Hospital's HIV/AIDS Clinic explained:

> People have moved. Those days [prior to changing catchment areas] if you are far away outside of the catchment area, we would not support you. Many people shifted to rent within the municipal. Some came from Atiak, some from Pader and Awer. [100]

Although none of the treatment providers collected data concerning mobility, I came across numerous reported cases of patients changing their residency in order to access treatment. [101] This was to create significant problems when patients started moving back to their home areas during the return process.

Another way in which the spatiality of the conflict shaped treatment provision was the layout of camps themselves. The proximity of households to one another made it easier for field officers to visit a number of clients in a short space of time, in contrast to more scattered rural homesteads. For instance, when I visited the area of St Thomas with the field officer Osege Christopher Eretu, we could walk between several households with clients of TASO. As Osege said: 'Camps have made it relatively easy to reach people's homes. There are many clients around'.[102] In spite of the dire conditions in the camps, they made the distribution and monitoring of treatment relatively easy by comparison with later years when the return movements were underway. The implications of the spatial dimensions of displacement and conflict will be a recurrent theme throughout this thesis.

[100] Interview with Christine Lakop, Nurse and Counselor in Charge, Comboni Samaritan Lacor 18 September 2006.
[101] I provide an in-depth case study of this movement from Ngai sub-county in Oyam in Chapter Three.
[102] Interview with Osege Christopher Eretu, TASO Field Officer, Gulu Town, 16 September 2006.

A final point when discussing the ARV and associated support programmes, is to consider their extent and reach. By December 2009, over 14 000 people were collectively receiving ART in Gulu, Lira and Amuru.[103] Furthermore, it is important that ARV programmes do not only affect individuals but entire households and families affected by ARV. Numbers on the Food for Health Programme[104] reveal the extent of this. In April 2006, a total of 2,893 households were receiving food support, amounting to a total of 17,358 recipients. By July 2008, this had risen to 3,331 households in the Gulu and Amuru districts, reaching 26,847 people. Not all of the recipients were HIV-positive since provision was done on a household basis; yet these figures do indicate the large numbers of households affected by HIV. Since there was another food programme provided by ACDI/VOCA for those living with HIV, numbers could be significantly higher.[105] Moreover, many HIV-positive people were unregistered if they lived outside distribution area or were not registered. The extent of the relationship between HIV treatment organisations and those providing food assistance indicates a key way in which ART became aligned with humanitarian assistance.

Conclusion

I have argued in this chapter that ART programmes in Northern Uganda do not fit easily into present paradigms of medical care. While they develop strategies used in other resource-limited settings, they have had to adjust these to the challenges of the complex emergency: the threat of conflict, lack of staff, damaged infrastructure and extreme uneven geographical

[103] Uganda Ministry of Health Data, 'Number of active ART clients in each facility at the end of December 2009' [Given personally to the author]

[104] The Food for Health programme provided specialised food support for those living with HIV as well as TB outpatients. This was facilitated through a consortium involving the MOH, TASO, Lacor Hospital with World Vision as major implementing partner, though TASO kept the registry lists. The intention initially had been to provide each patient with food support for nine months, before being phased out. However, the difficulties of the conflict meant that many were on specialised food support for several years.

[105] I could not obtain data from ACDI/VOCA, as my requests were not approved.

development. Furthermore, the long-term requirements of treatment provision necessitated that providers form deep community connections. In essence, from the outset, they were developing longer term developmental strategies but, at times, failed to plan for future transitions and population movements. The provision of ARVs therefore did not fit into a temporal transition between relief and development; as such, it could be assimilated into neither a primary health care nor an emergency health care paradigm (Van Damme, 1998). The ways in which major NGOs provided treatment differed substantively in accordance with the availability of resources, relationships with donors, state and humanitarian actors, and relationships with conflict-affected communities. TASO formed close alliances with humanitarian organisations. St Mary's drew on its long history in the region and on networks of missions and churches. The MOH suffered from severe staff and resource shortages (exacerbated by financial mismanagement at a national level) and had to rely on a patchwork of external actors.

The programmes discussed here were essentially experimental, adapting to the changing circumstances of conflict and mobility rather than running according to clear strategies. Access to treatment was shaped by institutional catchment areas but also the spatial production of conflict, particularly relating to the difficulties of transportation and distance. There were certain benefits to encampment, in spite of the dire health conditions of the camps. The close proximity of homesteads in camps meant that treatment monitoring was relatively easy. This situation was, however, to change radically with the return movements of populations, as will be discussed in later chapters.

Chapter Three: The Social Lives of ARVs in Northern Uganda

Antiretroviral therapy provision has engendered new forms of sociality in Northern Uganda. These have been enveloped in social experiences of illness, conflict and displacement. Sites of treatment distribution were places where those with HIV could meet one another, overcome isolation, and form new networks of care and solidarity. In this manner, ARV interventions have induced radical changes in the social lives of those with HIV. These new forms of sociality have been nested within kinship relations dislocated by displacement. These social transitions have emerged from a history of neglect, both of the Northern population and, in particular, of those living with HIV.

This chapter explores how the social transitions of illness and displacement have traversed each other, exacerbating the vulnerability to each, but also creating new possibilities for sociality. To survive with HIV (particularly in the context of the camps, where there was little privacy) was to be exposed to illness, to exclusion, to the perpetual gaze and pin-pointing of others. In this sense, the vulnerabilities of HIV-status were integral to the formation of new communities and identities under conditions of extreme adversity – a theme explored over this and the following chapter. Furthermore, new social networks formed around HIV-status were mainly constituted by women. In this manner, new forms of sociality arose from the gendered transitions of displacement. I outline these new forms of sociality in terms of several practices: the rituals of treatment and support; discourses of counselling and kinship; mobility; and new sexual relationships and gender relations. I argue that an analysis of biosociality, conceived broadly, illuminates these practices, but they are part of broader transitions of displacement and broader webs of attachment.

The social lives of ARVs surfaced from the entanglements of many intersecting paths –each with their own complexities and vulnerabilities, their histories of violence and trauma. Here, I trace the contours of these paths, the ways that the rituals of treatment – waiting, testing, taking pills, and talking – gave life to new hopes and desires, but also to disillusionment. I explore the sites of treatment – the clinics, homes, the shades of trees – as loci in which life-paths meet and are altered. In tracing these paths, I will also map the terrain of displacement by drawing on contrasting field-sites. I begin this chapter with a general overview of the literature on the ART and biosocial transitions. I will argue that the social transitions in Northern Uganda have a specificity to them arising from the intersectional experiences of disease and displacement. This chapter will focus on three sites – Pabo, Opit and Layibi – while also considering research from other areas. The chapter closes with a case-study of former LRA abductees who are HIV-positive and come to exemplify how HIV status can be an avenue of inclusion in situations of social abandonment.

ARVs and biosocial transitions

I outlined in the introduction the concepts of the 'social lives of medicines' and of 'biosociality', which are guiding concepts in this chapter. Here, I develop how these concerns have been explored in research on ARV provision. ART creates new hopes, as well as new struggles. Biosocial transitions involve changes at multiple levels: transitions in individual hopes and expectations as well as in social and political relationships and identities.

A key theme in emerging studies of ART is the transition of HIV from a fatal to a chronic disease (Ndlovu, 2009). Russel *et al.* (2007) and Russel and Seeley (2010) examine this transition in rural Eastern Uganda. Along with the provision of ART, people with HIV have

experienced various phases of disruption and adaptation in re-establishing 'a livelihood, relationship and hope' damaged by illness and social marginalisation (Russel *et al.*, 2007:344). They developed adaptive strategies to 'regain control, create order, reduce dependence on others and feel "normal" again', while dealing with new uncertainties over medicine supply, as well as social and environmental conditions (Russel and Seeley, 2010:376, Russel et al., 2007). While ART gives patients 'hope, [and] a new lease of life' (Ndlovu, 2009:66) and may decrease 'the fear of imminent death and serious illness' (Abadia-Berrero and Castro, 2006), new uncertainties arise. For instance, fears concerning the toxicity of treatment led women on ART in South Africa to vacillate between the 'fear of death, and hope' (MacGregor, 2009:93). The shift to chronicity may also create conflicted identities – a study of HIV-positive manual workers in Milan showed that biomedical notions of being a strong patient conflicted with ideas of being a strong worker (Alcano, 2009). In Serbia – a transitional setting characterised by social uncertainty and a fragile health system– patients on ART have had to negotiate an unreliable health system where drugs are often unavailable (Rhodes *et al.*, 2009). Alongside new hopes, renewed anxiety and uncertainty over treatment provision may arise. This' fragile hope' involves the negotiation of different levels of expectation. Rhodes *et al.*(2009:1057-1058 my emphases) write:

> Treatment insecurity and the revision of patient expectation is managed in relation to horizons of transition rather than technological advance. A metanarrative of transition connects accounts of expectation at the level of the individual with those at the level of the nation-state to moderate the disjuncture between global promise and local experiences.

The transitions brought about by ART are not simply ones of personal or social identity, but are closely linked to new forms of political identity, citizenship, and power relations. The

linkage between local and transnational identities has been explored by João Biehl, who conducted ethnographic work in a community-based AIDS hospice in Salvador, Brazil, which catered primarily to the homeless, former prostitutes, transvestites and drug users. This transitional space of treatment is not simply one of healing but also of continued marginalisation and social struggle. State ART provision constituted a new form of governmentality and biopolitics that changed patients' personal and political identities: 'the deployment of AIDS therapies thus instantiates new capacities, refigures value systems and alters people's sense of their bodies and of the future' (Biehl, 2007:326).

Recent studies on ARV interventions have focused on emergent forms of 'therapeutic citizenship' and 'clientship.' Nguyen (2005: 126) coined the term 'therapeutic citizenship', referring to new 'claims made on a global social order on the basis of a therapeutic predicament.' Nguyen (2005:126) writes: 'therapeutic citizenship is a biopolitical citizenship, a system of claims and ethical projects that arise out of the conjugation of techniques used to govern populations and manage individual bodies.'

This new form of identity and citizenship is closely linked to new forms of power relations. Nguyen, writing on Ouagadougou, focuses on how the treatment endeavour is part of a broader set of 'confessional technologies,' including support groups and counselling, through which social formations oriented around disease at local levels are shaped through relations with transnational donors. Along with new forms of citizenship, new forms of sovereignty and triage emerge, with new networks of local and global actors deciding who lives and who

dies (Nguyen, 2010).106 De Waal (2006: 113-115) makes a similar argument, writing that the provision of ART sets up

> a form of reconstituted statehood in which citizens have a range of different entities to which they can appeal, none of which commands all of the sovereign space, and which between them only provide for a minority of people living in a particular territory ... We are on the brink of an unparalleled life-controlling intrusion into African society, and we just don't know what it will look like.

These transformations are profound, involving not only physical transformation but also new social relations and new political identities. Recent studies have both developed as well as questioned Nguyen's idea of therapeutic citizenship and the importance of new global identities. Meinart et al. (2009) argue, with reference to Kampala and South Eastern Uganda, that new forms biosociality or therapeutic citizenship are less significant than the reorientation of friendship, kinship and clientship. 'Clientship' involves a 'hierarchical relation between the individual (client) and the programme (patron)' (Meinert et al., 2009:205). ARV interventions require the renegotiation rather than supplanting of existing social relations and hierarchies. Differentiations between programmes in terms of services and diagnostic capacity also introduce new forms of inequality. Whyte et al. (2009:242), writing on the same study in Eastern Uganda, refer to 'therapeutic clientship', and focus on broader networks of reciprocity rather than the rights and obligations associated with citizenship. Similarly, Gibbon and Whyte (2009: 97-98) warn against viewing health identities and socialities in isolation from relations of kin, work and family, which may be of greater importance to the patient. Cassidy and Leach (2009) have found that in Gambia there

[106]Nguyen's study was, however, conducted in the 1990s and early 2000s, before the emergence of the GHIs and large-scale treatment programmes. It therefore represents an empirical reality that has changed substantially over the past decade.

is often disillusionment with the expectations of therapeutic citizenship. Rather than expressing a set of entitlements, patients may feel disempowered and voiceless in relation to global funding agencies, or compelled to play certain roles in order to access resources. Patient priorities may remain focused on local relations, including 'membership of family, neighbourhood or community and the informal economic and social rights that come with this, as well as notions of what it means to be a Gambian or a foreigner' (Cassidy and Leach, 2009:29). Similarly, many in Zambia have resisted going onto ART as it is considered a concession to international agencies which impose their agendas, reinforce dependency, and separate people from local kinship ties. The identity of the 'AIDS patient' was a locus for contestations around local and international agendas, as well as around views of science and medicine (Frank, 2009:518-519). Desclaux (2004: 127) argues that ART provision in West Africa has caused household disputes and has reinforced forms of hardship and social exclusion Provision of ART leads to social changes, such as the strengthening of communities living with HIV, but may also 'reinforce internal distributions of power' through the inclusion and exclusion criteria of programmes (Desclaux 2004: 127).

This literature reveals that, inasmuch as ART may introduce new forms of global and local identities and entitlements, its social efficacy often involves primarily the renegotiation of existing relationships. In developing this literature, I ask: what forms of social change does ART engender in the exceptional context of conflict and displacement? I will argue here that social transitions are framed primarily in terms of local relationships, but these relationships have been disrupted and reconstituted by displacement. I begin this discussion by introducing some of the sites of treatment provision and exploring how these have become loci for new socialities.

Treatment Sites

Ingold (2009:33) writes that 'where inhabitants meet, trails are entwined, as the life of each becomes bound up with the other. Every entwining is a knot and the more that life-lines are entwined, the greater the density of the knot'. Treatment sites are knots of meeting, places where those who have often had to come to terms with their HIV status alone meet others who share the same condition, the same experiences of shame or stigmatisation. They are places of dense entanglement. Treatment sites in Northern Uganda were often at clinics or health centres, but also homes (where TASO delivered their treatment), under trees, in old churches. It is this gathering together that constitutes a central dimension of the 'social efficacy' of medicine – the effects of medicines on social relations (Whyte *et al.*, 2002:170). Through this gathering together, new friendships, new sexual partnerships and new families are formed. New ways of talking about illness and social relationships develop. They are places where stigmatised identities can become 'project identities' – identities that aim to transform social understandings and perceptions of illness (Parker and Aggleton, 2003). But these sites can also be places of distrust and blame, where certain groups are marked out as causing disease.

It is important, as Whyte (2009:241) notes, not to isolate the treatment site or clinic and view it apart from household, family and other social relationships. Nonetheless, treatment sites, beyond their medical role in dealing with afflictions, may be loci through which new networks and inter-household relationships are formed. These relations extend beyond the treatment site into the community, and so the paths between the clinic and the household should be traced in order to grasp emergent socialities. I will begin the empirical discussion in this chapter by introducing some of the key sites of HIV-related sociality in this thesis. In

line with the above discussion, I will not only focus on a clinic, but also on a home and church. From these I will trace out various life-stories and practices of sociality, demonstrating the ways HIV-related and displacement-induced vulnerabilities intersect in the creation of new social relationships.

Opit

Opit at its peak was a camp of over 20 000 people, with the bulk of migration arriving in the early 2000s. By 2008, following the return period, the camp population had dropped to approximately 4000 permanent residents.[107] Opit is around 35 kilometres from Gulu Town. The surrounding area is lush and forested. There was a lake nearby and forest reserves. The camp was one of the most dangerous in the region: the LRA would often pass nearby or hide in the forests, and kidnappings and killings were common. The area surrounding the lake was land-mined. A main road ran through the camp lined with small stores and lodges (such as the 'pit maber', or 'good eating') set up in dilapidated concrete buildings. Half the main road was electrified in 2006, giving rise to a series of bars, a disco, and video halls where the youth, and some older residents, drank and danced at night. From the main road, a side road led past the health centre and a soccer field to St Joseph's Catholic Mission.[108] The mission, located on the periphery of the camp, contained a church and compound adorned by a dusty star and was surrounded by paw-paw trees. Within the compound were gardens with turkeys, pigs and gazelles. Expansive fields of rice and sweet potatoes unfurled to hills beyond the encampment.

[107] Interview with Louisa Seferis, AVSI camp management coordinator, Gulu Town, 18th August 2008.
[108] Henceforth referred to as 'St Joseph's.'



Opit Mission

I stayed at St Joseph's in 2006 and 2007, and visited often in 2008, when I stayed in a lodge along the main road. From the 1990s the mission had become a space of meeting and sanctuary for those living with HIV. The HIV support group meetings took place at the Mission, in the shade of its trees, or in a small hall. Residents of Opit were among the first in conflict-affected Northern Uganda to have access to ARVs, due to financial support from the Mission and the work of a Catholic priest called Father Alex Pizzi. Alex was a key figure in the provision of ARVs to those in Opit. He arrived in Northern Uganda since 1973. Fluent in Luo, he has lived in the region throughout the time of Amin and, later, the war with the LRA. He has been kidnapped twice by the LRA. As a young man, aged 19, Alex was a professional football player with AC Milan. However, he left his football career to study in a seminary, eventually moving to Africa. He was at various mission stations in Northern Uganda and has been at Opit from the 1990s. In 1997, Alex started buying ARV treatment for

six people in Kampala[109]. In 1998 ARVs became available for sale in a pharmacy in St Mary's Hospital Lacor. With donations from Europe, he started buying ARVs for a few patients. Alex's initial endeavours were later formalised through funding by CRS and AVSI, an Italian NGO, in 2005.[110] Patients were given transport money to go to Lacor to receive treatment. Community-based workers were trained by Comboni and provided ARV adherence monitoring. By 2006 over 500 people were members of the HIV support group at the Mission. In December 2007 the Opit Health Centre began providing ARVs. This meant that patients no longer had to travel from Opit to Lacor to receive treatment. By 2008, there were over 800 members of the HIV support group, though a number of these were now in outlying villages.[111] There was also significant migration from other areas into Opit in order to access HIV services (discussed below). Reductions in stigmatisation have been significant over the years, and the mission became a place of sanctuary for many living with HIV in Opit and the surrounding region.

When I first visited in 2006 I was guided around the camp, and particularly the area of the mission, by Charles Olal. Charles was a former soldier in the Ugandan army, was one of the first to begin receiving ARVs in the area, and was also a Comboni community volunteer. I spent the morning with him, watching him and his wife taking their pills before their morning bathing, boiling a pot of water on a wood stove. We sat outside on stools and drank tea. In the area, there seems to be an acceptance of HIV as part of life. Charles and his family lived near the mission. Indicating the area around him, he explained, 'most of the people around here are also clients.' Many living with HIV had chosen to live near one another, close to St

[109] This was, to my knowledge, the first provision of ARVs to a camp in Northern Uganda.
[110] This account is based on interviews with Father Alex Pizzi, St Joseph's Mission, Opit, 4 December 2007, 12 December 2008 & 18 June 2009.
[111] These figures were obtained from the keepers of the clients' registry books, Cipriano Odong, in 2006, and Esther Odong in 2008.

Joseph's from which they received support with health, accommodation and food. They gave one another support with the daily struggles of dealing with disease. 'When somebody goes for the medication, you can help her by looking after her children,' said Charles.[112]

The taking of ARVs becomes part of the daily rituals of those on treatment. Jessica Ajok, a woman living with HIV in Opit, explained:

> For me, even my neighbours will come and remind me it's time for medicine. Even the person who gave us the house will remind us, go and take your medicine. It's part of our life now. When it's time for the ARVs, it's like a bell in your head. When you're going to visit somebody, you put it in your pocket and you go with it. [113]

These accounts point to show that treatment adherence became a social relationship, a new engagement between those with HIV and their social worlds. Significantly, the social bonds formed around ART included, not only HIV patients, but also their families and neighbours. As Nibbe (2010) notes, the spatial re-orientations of camp life created new relations resembling those of family and kin.

It is significant that treatment was only provided in Opit's health centre, an outpost of Lacor Hospital, in late 2008. However, as a result of transport support to access Lacor Hospital and the Mission's support for those with HIV, a dense fabric of relations was created around HIV status and treatment. Adherence monitoring was an activity carried out by the Comboni Samaritans, by family members, and also by neighbours. The mission itself became a space

[112] Interview with Olal Charles. HIV-positive man & Comboni Adherence Monitor, Opit, 26 August 2006.
[113] Focus group with Santa Akello and Jessica Ajok, HIV-positive co-wives, Opit, 2 March 2008.

of gathering for those with HIV. The social lives of ARVs became part of the rhythms and difficulties of camp life.

Knowledge of the mission and available treatment spread to surrounding areas, resulting in migration into Opit in order to access treatment and support. In particular, there was a significant migration from the Ngai sub-county, in the neighbouring district of Oyam, where no treatment was available. Many people from Ngai reported moving to Opit specifically to access medication, even after the conflict had ended. The registry book of the Comboni adherence monitor in Ngai showed that over 70 patients from Ngai were receiving HIV treatment, either Septrin or ARVs, through Lacor Hospital, and the majority of these would have to have lived in Opit in order to receive treatment as Lacor Hospital would not provide treatment to those living in Oyam district. For those in Ngai, Opit was not the nearest camp, so people moved to the camp specifically to get access to treatment. Many who came to Opit split with their families in order to do so. As one man from Ngai, who moved to Opit specifically to get HIV treatment, explained:

> We [the displaced population in Ngai] were divided into four. Some people went to Awoo camp. Some people went to this set-up camp, Onekwok, and then other people went to Ngai centre. The number of people who went to Opit were mostly the sick people. So when I was already in Opit, when I heard that somebody was sick, I would tell them to come so that lives were saved where I came from. [114]

Another man, Simon Omara, who became a Comboni adherence monitor, said: 'I moved to Opit camp in 2006 because I was sick, not because of the conflict. People in Ngai weren't

[114] Interview, with anonymous HIV-positive man, Ngai sub-county, July 2009.

forced to go, it was out of their own choice.'[115] Or as a woman from Ngai recalled: 'I lived in the camp when I was weak and when I was better I came back to Ngai. I only went to the camp for medication and stayed for some time.'[116]

Charles Olal, who we met above, would also tell those with HIV in his home area to move to Opit. As he explained, 'In this area we are in the land of the missions, we are free to put our houses. Here we have people from Ngai, Ongako, Palenga, Lalogi, even some from Dino. Most of them are clients coming for the medication.'[117] However, the spatial boundaries of treatment and catchment areas were monitored by treatment providers. In 2007 Olal was dismissed as a Comboni community worker for actively encouraging patients to move from outside the catchment area.[118] This reveals how forms of spatial inequality of services, and spatial triage, produced as a result of conflict and displacement, have social effects at a local level. ARV treatment produced both mobility and contestations over who is to live and who is to die.

Pabo

Far north of Opit, towards the border with Sudan lies Pabo. Forty five kilometres from Gulu Town,[119] it was one of the largest camps in Northern Uganda, reaching 50 000 people at its peak, though this population had fallen to 30 000 by August 2008.[120] It was a dense sprawl of homesteads on the route between Gulu and Juba. The area was known for its rice production, and on the main road were rice mills, women with roadside mosaics of beans

[115] Interview with Simon Omara, HIV-positive Comboni adherence monitor, Ngai, Oyam District, 14 August 2008.
[116] Interview with Evelyn Ajok, 34-year-old HIV-positive woman on ART, Ngai sub-county, 14 August 2008.
[117] Interviews with Charles Olal, Opit, 26 August 2006 & 6 December 2007.
[118] This was confirmed by both Olal and by the Comboni Samaritans.
[119] Interview with George Okello, UNOCHA data officer, Gulu Town, 15 June 2009.
[120] Focus-group with Isaac Odiya and Lucy Aber, Norwegian Refugee Council camp management, Pabo, 25 August 2008.

beside restaurants housed in shacks. In 2008, my research assistants and I stayed in a new tiled lodge called the White House. In the evenings, locals and soldiers came to drink there. Three cell-phone towers stood over the camp.



Children outside the TASO Outreach, Pabo

When I first visited Pabo in August 2006, TASO had few clients in the camp. During this time they served only those who could afford to travel for medication in Gulu Town. At the time, TASO estimated that only 10 clients in Pabo were receiving ARVs from them[121] and there were no other treatment sites in Pabo. By February 2008, when I returned, the situation had changed rapidly and there were close to 500 HIV-positive TASO clients in Pabo.[122] During this 2008 visit I witnessed a remarkable example of 'the social lives of medicines'

[121] Interview with Dr Judith Aloyo, head of ART unit, TASO Gulu, Gulu Town, 18 September2006.
[122] Interview with Beatrice Akello, 40-year-old HIV-positive woman & TASO adherence monitor, 21 February 2008.

(Whyte *et al.*, 2002) – that is, the forms of social relationship that form around the provision of medication – at the TASO treatment site. TASO used a state health centre which opened out onto a large stretch of sand. Children played in this area, workers dug sand for bricks, and there was a constant stream of people walking through it. The health centre had an outside platform with a low wall, and anyone entering the health centre was visible to those in the empty stretch of sand. On treatment days TASO also used their labelled car for registrations and medical check-ups. Piles of files lay outside the centre. The queues of those waiting for treatment – Septrin or ART – were visible to anyone walking past. To come and seek treatment was to be exposed to the gaze of the community. At the treatment site there was an extraordinary array of people seeking treatment. Lined up together were men, women and children, uniformed soldiers, and former LRA rebels and abductees. The stories recounted below will show how the treatment site provided a place of intersection for multiple life-paths, creating new forms of sociality, but also of contestation.

In addition, the local Catholic mission, the Church of Mary Magdalene, supported a number of community support groups. Several income-generating projects for those with HIV had been provided by AVSI. A number of home-based caregivers supported by AVSI and the church provided support to the ill before the arrival of ARV provision, though treatment provision catalysed a major shift in treatment throughout the camp.

In Pabo we spent many evenings eating in the home of our friend Beatrice Akello, the local TASO adherence monitor, along with her two daughters and her cat called ‘Peace’. Beatrice lived in a concrete room beneath one of the cellphone towers, next to the army barracks. Sitting outside her house in the evenings eating beans or *malakwan*, a sour herb, we witnessed the way her home had become a centre of social gathering for many of the

'clients'. In the evenings they would often come by to speak to her, to share news or troubles. As I got to know the different 'clients' in the camps, I would often find them in each other's houses, visiting and socialising. Beatrice also had close relations with her neighbours, often speaking to them or using their tools, such as their grinding stone.



Beatrice Akello and her daughter.

Beatrice was forty years old in 2008 and had two daughters. Her parents' land was in Pabo, and she had lived there for much of her life, observing the changes in the area as the camp was built around their home. Beatrice was married in 1989 and thinks she contracted HIV from her husband. When Beatrice found out she was HIV-positive her family rejected her and refused to help her with her children's school fees and other requirements. Her husband, a local businessman, died in a car accident. After this, her HIV status and recruitment as a community worker and adherence monitor became a way of re-establishing some social

standing and creating a new social identity. Though Beatrice continued to face stigmatisation in the community, her life and social standing became focused around her HIV status. HIV status became a new form of social bond. As Beatrice expressed it, 'If some is living positively and they meet someone who is also HIV-positive, you become friends.'[123]

The new social relationships in Pabo were not as strong as those in Opit, having had less time to develop. However, the introduction of ART catalysed a major transition in the social lives of those with HIV, as will be explored in this chapter below and the following. Those with HIV identified with one another and established themselves as a distinct group – this was in part forced upon them, as without privacy in the camp, they had little choice but to disclose their HIV status if they sought treatment. Notwithstanding this, the practices of treatment observation and social support, gave rise to HIV status as a distinctive identity. An indication of this was on World AIDS Day in 2007, not long after the introduction of ARV provision to the camp, almost 300 HIV-positive residents of Pabo marched across the camp to the mission. As one man explained, 'The march as organized by us. We were informed us that it was World AIDS Day and people who are sick, should go and march, so we went in large numbers.' [124] Those with HIV began to use their status as a sign of strength and to re-establish their social standing and identity.

The home of Florence Atoo in Layibi

Layibi is a semi-urban area on the peripheries of Gulu Town, a frontier between the bustle of the town and the bush. On the main road to Kampala there was the perpetual tremor of

[123] Focus-group with Evelyn Aber and Beatrice Akello, HIV-positive women, Pabo, 24 June 2009.
[124] Quote from David from focus-group with David Kilara, Lamunou Cecelia & Obal John, Mixed-gender HIV-positive respondents, Pabo, Amuru District, 22 February 2008.

traffic. Nearby was a half-built lodge covered with piles of sand, called The Beach, in which the intention was, as rumour had it, to create a fake beach – another surreal example of Northern Uganda's transitional moment. From the markets of Layibi an unused train-track passed through the area, overgrown with grass, a reminder of the how the North had become disconnected from the other regions of the country. Life in Layibi was neither urban nor rural: many had fields, and there were rivers and palm trees around. Along the railroad from the market, several hundred metres from the main road, past palm tree and fields, was the home of Florence Atoo. It became a place of meeting for many of those living with HIV in Layibi. The story of the building reflects of much of the region's suffering.



Florence and her Children

Florence was forced to move from her home village into the town in 1987 after being attacked and raped by a soldier from the National Resistance Army (NRA) when she was a

schoolchild in primary seven. Some of the girls with her were killed and burned. She was put in a shelter in the town run by the Red Cross. She did not know about HIV and received no education. She had heard about a disease called *twoo acwii* that she thought was contracted from animals, but she only learnt HIV was transmitted sexually in the mid-1990s. In Gulu Town Florence met and married a man who later died. She recalled:

> In that time I was living in the place that they put us when we ran from the village. This man came and started admiring me, courted me and then rented for me a house. We moved in together with him and started staying as husband and wife. But then afterwards he became ill until he died. When he passed away I persisted in that house and then I had my brothers dying so all the children were brought to my mother. So a combination of me in the house and the rest of children was a lot burden. So when I realised I was falling sick and I went for a test to World Vision. They took me to Lacor [Hospital], carried out the test and when they brought for me the result it was HIV-positive. Then they started helping me, providing a home until they built the house you see here because the children are so many to care. [125]

In 2006, she was looking after fourteen children. She explained: 'Here in Layibi I'm taking care of orphans. There are other children here whose parents have been killed by the rebels and then there are other children who are orphans because of HIV.'[126]

The house, built in concrete, stood out in an area where many still lived in huts. It gave Florence a sense of social standing. Florence was to become the chairperson of a local support group for those living with HIV in Layibi – *Twoo Jonyo pe Koyo*. The space outside her home was a place for weekly meetings. Many members of the group had been displaced

[125] Interview with Florence Atoo, 37-year-old HIV-positive woman & chairperson of Twoo Jonyo Pe Koyo' HIV/AIDS support group, Layibi, 27 July 2008.
[126] Interview with Florence Atoo, 37-year-old HIV-positive woman & chairperson of Twoo Jonyo Pe Koyo' HIV/AIDS support group, Layibi, 27 July 2008.

into the town. The group consisted of an array of people – Florence's brother, a motorcycle driver, a local teacher, market women and farmers.

Some group members had moved from the camps to the town specifically to access treatment. Among these, Margaret Ogiri[127] had move moved to Layibi from Palaro, where no treatment was available. In Palaro her husband had been kidnapped and murdered by the LRA. Margaret found out she was HIV-positive in 2002, after testing at Lacor Hospital. Fearing she would die soon, Margaret moved to Layibi in the hope of getting healthcare, and started treatment in December 2004. In 2006, Margaret rented two huts in Layibi for 10 000 shillings each a month. One is for her and one for her children. She made a living buying produce from others with land and selling it at Layibi market. She also cultivated other people's gardens for a small wage. Without this money she could not pay school fees. If ART were available in the village in Palaro, she told us, and there were peace, she would consider returning. However, she said that she would remain in the town until her children's education was completed because there were no schools in her home village. Margaret had no money for transport to Palaro, and could not even attend her father's funeral. She said there were many people in Palaro who wanted ART but could not afford the rent in Layibi. Margaret had many friends in Layibi who were HIV-positive – Florence and the support group among them. They helped each other in whatever ways they could. For instance, when a person was without food, they gave food to that person. If a person was very sick, they would report it to the caregiver or go to Comboni to call the ambulance. They shared ideas and advice, and supported each other if there was death in the family. The comradeship became an important way of dealing with struggles and losses of disease. As Florence said,

[127] This account is based on an interview Margaret Ogiri, 41-year old HIV-positive woman, Layibi, 17 September 2006.

'We can help each other emotionally. If you counsel your friend, if you have some pain, then the pain can cool.'[128]

Twoo Jonyo pe Koyo was constantly trying to get support for livelihood projects, even submitting a proposal to the Global Fund but never receiving a reply. The group's attempts revealed the limitations on self-organisation – unless attached to or created by a large NGO, groups have little chance of accessing finance. Over the course of this research, the projects planned by the group never materialised. Nonetheless, the friendships they formed proved resilient and endured despite increasing movement back to the villages, as will be discussed in later chapters.

The sites discussed above formed places of meeting and gathering for those with HIV. They reveal that the social lives of ARVs have extended beyond the treatment site into different social domains. These social lives have become embedded in the social spaces of spaces of displacement – a theme that will run throughout this thesis.

Biosocialities

The case-studies of sites of meeting and gathering above are far from exhaustive, but aim to show how the socialities of therapeutic practice traverse different domains – the treatment site, public spaces, the household – and shape relations there in different ways. The social lives of ARVs also traverse both institutional and social relations. I use the term biosociality to indicate these new relations. The key dimensions of what I term biosociality, include

[128] Interview with Florence Atoo, 37-year-old HIV-positive woman & chairperson of Twoo Jonyo Pe Koyo' HIV/AIDS support group, Layibi, 27 July 2008.

practical support, emotional support or counselling, therapeutic rituals, neighbourliness and kin-like relationships, as well as gender and sexual relations.[129]

Practical support refers to support primarily given in times of illness (for instance, taking people to the hospital, or looking after the children when they have to go to hospital). *Emotional support* or *counselling* designates forms of talk about HIV status and therapeutic practices that extend beyond the formal patient-counsellor relationship; thus understood, these discourses are integral to a broader mode of engagement geared toward providing care, encouragement and solace to those struggling with HIV. *Therapeutic rituals* encompass practices revolving around treatment itself, including reminding patients about adherence, travelling to treatment centres together, and waiting for treatment or food support. *Neighbourliness* or *kin-like relationships* arise from spatial congestion of the camps, and to some extent the towns, and involve the partial substitution of kinship networks for those oriented around disease status; this process at times involves the evocation of family and blood ties to refer to HIV status. In addition, biosociality involves the reorientations of *gender* and *sexual relations* among those who were HIV positive. Conflict and forms of blame may also form between those who are HIV-positive; for instance, between civilians and soldiers, and between those who are considered good clients or bad clients.

To be clear, my usage of the term 'biosociality' extends beyond Rabinow's (1996) concept of biosociality conceived as a mode of sociality based on shared diagnostic practices and biological/genetic conditions. The applicability of biosociality applied to ARVs in this sense has been rightly questioned by Meinert *et al*.(2009), Whyte(2009), Gibbon and Whyte (2009)

[129] A further dimension, which is discussed in the following chapter, is the idea of a 'resistance identity' (Parker, R & Aggleton, P, 2003) – a group identity formed in response to treatment and aiming to transform the idea of what HIV is.

and Cassidy and Leach (2009), who stress that it is important to understand the social transitions elicited by ARVs in terms of how they affect family, kinship and patron-client relations. I have no dispute with this. However, I believe the concept remains useful in illuminating new forms of social interactions formed around disease-status and treatment as well as diagnostic practice, as long as these are understood to be embedded in broader networks of social relations and social transitions. In inquiring into these forms of sociality below, I aim to demonstrate how they become nested in processes of displacement-induced transition. Given that the categories of biosociality outlined above are closely intertwined, I will not discuss them discretely but as connected strands of social transition.

To start, I will briefly consider how devastating the cumulative effects of both HIV/AIDS and conflict can be for households in rural, agricultural-based societies. In any rural society, 'vicious interactions between malnutrition and HIV' may be set in motion: HIV/AIDS may lead to household labour shortages through morbidity and death, the loss of assets and skills, the increased burden of care, and (Barnett and Whiteside, 2006:241). Conflict exacerbates these effects: in Northern Uganda reduced access to agricultural land and weakened households through violence and high rates of morbidity and mortality (WHO 2005). These vulnerabilities were deeply felt. In addition, many in Northern Uganda suffered intense social marginalisation, particularly prior to the introduction of ART. Many of the patients I spoke to told me how, prior to treatment, they had been severely ill, unable to walk or garden, and also found their social support in the camp environment eroded. As one woman in Ogur, Lira, explained:

> When I went to the camp in 2003 I had already lost my husband. He left for me children, and one of my children was in senior four and was supposed to go to senior five, but because I had no way to make him stay on, I had to make him stay

> home. In the villages as a single mother, and being weak – I can't dig – it becomes difficult to feed the children that I have. Then at one time I also fell ill, so I had to get an operation, but I never had the money. And I had no means of leaving behind the children, because there was no one to look after them. [130]

Such accounts were common. ART helped many I spoke to re-establish a small amount of agricultural production, often on rented land and on the peripheries of the camps. Once on treatment, the slow return to health allowed a return to cultivating land. For those who could not access communal or family land, some rented land, while others sold their labour. The provision of specialised food assistance facilitated this return to health. ART allowed a return to productive work but also a return to communal life. A thirty-six-year-old woman at Opit told me how she never used to dig when she was ill. Having since gone onto ART, she said, 'Now I can go to the garden, and eat and live in the community.'[131]

However, even with ART, many still complained of food-shortages and lack of energy. HIV-related socialities arose from the biophysical effects of HIV, and subsequently ART; still, they deeply connected social interpretations of the disease. As discussed in the introduction to this thesis, I conceive vulnerability as the ways in which physical weakness is socially recognised (Butler 2005). The cumulative effects of physical incapacity and displacement were not unique to those with HIV/AIDS. For instance, regarding the disabled in the camps of Northern Uganda, Muyinda (2008:71-72) writes:

> Although the consequences of conflict affect all people (including those without disabilities), what makes the disabled people different is that physical disability requires, in general, a much more active and collaborative relationship between

[130] Focus group with Uwan Ogal, Uventino Ongola, Ida Akita, Rose Atim, Secondina Olero and Sam Ojera, mixed gender HIV-positive respondents, Ogur health-centre, 1 August 2008.
[131] Interview with anonymous 36-year old HIV-positive woman, Opit, 25 August 2006.

> the affected person and the rest of the people; the lives of the disabled people were largely shaped by the attention they received from others, making social response and the relationships involved central to their lives – and this is all more so in an emergency situation.

Muyinda explains the relation between physical incapacity and social relations through the concept of 'embodied sociality', which is 'the idea that the body is the basis for sociality, and sociality shapes the body' (Muyinda, 2008:20). Similarly, HIV-related socialities emerge from the exposure of ill and healing bodies to webs of social relation and interpretations. HIV-related vulnerabilities and socialities have a distinctiveness arising from the symbolic power of HIV-status in the camps and its associations of social and moral breakdown. This, in turn, has shaped the relationships between HIV-positive people, their families, and their communities.

As discussed in the introduction to this thesis, the conflict in Northern Uganda created a crisis, the severity of which was compounded by its complexity: the disruption but not the complete breakdown of village-based lineages; the emergence of new authorities, both in the camp leaders and the military and humanitarian actors; and the near substitution of family with humanitarian actors in regulating access to resource entitlements. With regard to the last point, treatment organisations noted how, for many of their clients, family support had been corroded as a result of both HIV and displacement. As Charles Odoi, the head counsellor at TASO, explained: 'support in family is very minimal. It is a poor environment. When you make a comparison, the level of poverty here is quite biting. They may want to support, but it is minimal.'[132] I found that vulnerabilities and new forms of sociality were highly gendered, as discussed below. It is under such conditions that biosocial relations formed.

[132]Interview with Charles Odoi, TASO Counselling Co-ordinator, Gulu Town, 7 August 2006.

Biosociality linked to therapeutic practice is firstly a pragmatic response to survive and adhere to treatment under conditions of adversity. In addition to monitoring adherence, networks of the HIV-positive as well as community health workers would provide support and care, such as cooking, cleaning, and childcare, in the case of medical crisis. For instance, in Opit a woman recounted being close to death and in a state of madness, and was cared for by another woman with HIV, as there was no family support.[133] In this sense a primary mode of sociality is providing a safety net in times of crisis. Under the conditions of extremity that characterised the camps in Northern Uganda families were often unable, or unwilling, to provide necessary support to HIV-positive members. As Jacinta Adong, an HIV-positive woman in Opit, explained,

> My treatment provider gives me what my family can't provide. For example, when I fell ill and became mad my family did all they could like feeding, taking me to hospital, washing me, but they couldn't heal me. My only healer was Comboni Samaritan who gave me medication, counselled and transported me to and from hospital. The priest also helped my family with money to help in feeding me while in the hospital because my family couldn't afford at that time.[134]

Even for supportive families, like Jacinta's, the extremity of the camp environment limited the basic support they could provide: treatment organisations and networks, including the church, played an important role in providing healthcare beyond ART itself. Hence, it was in terms of immediate relations, rather than through conceptions of 'therapeutic citizenship' that

[133] Focus-group with Mary Abalo, Akulu Rose Akoo, Susan Auma, Jacinta Adong, Anonymous, HIV-positive woman, Opit, 17 February 2008.
[134] Interview with Jacinta Adong, HIV-positive woman, Opit, Gulu District, 3 July 2010.

most respondents explained the social transitions induced by ART to me. As one woman in Layibi expressed it:

> I don't think my HIV status affects in any way my citizenship or my feelings of citizenship ... but it did change my relationship with the rest of the community who are of the same HIV status as me. We do visit each other and offer help when one is sick. We clean the compound, clean the house, and take each other to the health centre.[135]

It was, however, both the proximity of those with HIV in the camps, as well as semi-urban areas, which fostered these networks of care.

As Nibbe (2010) notes, the spatial dislocations of displacement produced new forms of daily practice and kin-like relationships. Though Nibbe does not write about HIV/AIDS, HIV status became an emergent kin-like relationship. This was discussed above with reference to both Opit and Pabo, where the spatial proximity of many of those with HIV in the camps allowed for the rapid formation of new community groups and networks after the arrival of ARVs. Therapeutic practices like adherence monitoring and counselling became catalysts of social interaction – primarily among those with HIV, but also for their family members and even supportive neighbours. Community-based adherence monitors, like Beatrice Akello from Pabo (introduced above), played a greater role than simply the monitoring of treatment. They played an essential part in bringing those with HIV together, and their homes became places where HIV-positive people would often gather, outside of formal therapeutic schedules.

[135]Interview with anonymous HIV-positive woman, Layibi, 5 July 2010.

As Dennis Okello in Opit explained -'the camp has brought people together, and the sick people are close to each other. When you hear that your friend is sick, it is easier to move and go and visit.'[136] The operations of the local Comboni and mission community workers were important in fostering this support:

> The caregiver brings us together, because the caregiver sets up a date in each month for us to meet, and if we meet we talk about different issues. We are educated on sanitation, and we are educated on how to live our lives, and we are educated on visiting others. In case they are sick then you will have to visit, and if your friend has a problem, for instance with death [in the household], then you will have to contribute something to help your friend out. [137] (Silberia Amony)

In such social interactions the idea of 'counselling' extended beyond the patient-provider relations. The common Luo translation of counselling is *nwako tam*, which literally means 'sharing ideas or thoughts.' In this sense, the idea of 'counselling' as a relationship of counsellor and patient was much less dominant than the idea of counselling as sharing stories, thoughts, and encouragement. The following quotes reveal this form of talk,

> We give help such as sharing with one another. We share our ideas, such as comforting each other, saying don't mind about this disease, or for instance when she has a sickness, to tell her to go the hospital. (Agnes Adoch)[138]

> When I go to the health centre I make friends and we do talk a lot. We exchange stories and we give each other support. We talk about our condition and we ask each other how the person is faring with the disease. (Grace Akello)[139]

[136] Focus-group with Florence Awio, Dennis Okello, Lucy Angee, Silberia Amony, Charles Ojok, mixed-gender HIV-positive respondents, Opit, 12 August 2008.
[137] Focus-group with Florence Awio, Dennis Okello, Lucy Angee, Silberia Amony, Charles Ojok, mixed-gender HIV-positive respondents, Opit, 12 August 2008.
[138] Interview with Agnes Adoch, 42-year-old HIV-positive woman ,Opit, 1 March 2008, 20 April 2008.
[139] Interview with Grace Akello, 38-year-old HIV-positive woman, Opit, 19 April 2008.

Hence, speaking about HIV and treatment became a form of social interaction. Furthermore, the actual counsellor-patient relationship became far more than simply a means of coping with disease; it was also about coming to terms with the experiences and traumas of conflict. As TASO's head counsellor of explained,

> We try our level best to see how we can support traumatised people. Everybody, we serve here, besides being HIV or traumatised. The trauma is rooted in being HIV, or having lost a parent, or being raped, or having to kill someone. Our process is simple and friendly. All counsellors have a basic knowledge of trauma. All counsellors have HIV knowledge, but also some trauma counselling. [140]

Emerging from the silences and abandoned spaces of encampment, HIV status was transformed into a discourse framing social interactions. Patients would often visit each other to discuss the logistics of taking medication, but also the emotional distresses of HIV and displacement. Often evoked by respondents in our interviews was the idea of *cwiny*. *Cwiny* is a notion of interiority evoking mind, emotion, 'the beating of the heart' or 'life-force' (Behrend, 1999) and is central to Acholi conceptions of selfhood. *Cwiny* is also associated with temperatures: heat representing distress, and cooling, healing. The cooling of *cwiny* was an often-evoked metaphor for the benefits of counselling and sociality. As Beatrice Arach, a woman living with HIV in Pabo, expressed it,

> They [her friends living with HIV] support me emotionally, because they come and advise and counsel you, and tell you how to go about the sickness. They tell

[140] Interview with Charles Odoi, TASO Counselling Co-ordinator, Gulu Town, 7 August 2006.

> you this is the life in the world, so that even though you have so much pain in your heart (*cwiny*) at the time, then it cools down. [141]

The notion of a shared disease expressing a new form of kinship and family affinity is also commonly invoked. For instance, a man in Pabo stated 'Here we stay as brothers. If you meet your colleague somewhere, there is something you share in common, that is the disease.'[142] Or as a woman in Layibi framed this idea,

> I know a group of people living with HIV and we are all friends. When we get our medication we behave like children who belong to one mother, and we always talk about the disease. If you are not HIV-positive and you are with us, you might get bored, but we never tire of talking about it.[143]

Furthermore, relationships among those with HIV were not always harmonious. There was, at times, resentment towards local adherence monitors for not fulfilling their duties. In addition, blame for disease transmission also circulated HIV-positive networks, and these were enhanced by their encounters at treatment sites. For instance, in Pabo, where camp residents share a treatment site with a number of soldiers, many of whom don't even speak Luo, this form of sociality reinforced feelings of suspicion and resentment. These sentiments were expressed in a focus group among those living with HIV:

> All those soldiers are sick, and if you heard your daughter was caught sleeping with those soldiers, you know that your daughter is sick. [We know this] because

[141] Interview with Beatrice Arach, 32-year-old HIV-positive woman, Pabo Camp, 15 July 2008.
[142] Interview with Charles Kilama, 30-year-old HIV-positive man & former LRA abductee, Parobang Parish, 14 August 2008.
[143] Interview with Evelyn Alanyo, 33-year-old HIV-positive woman, Layibi, 19 June 2008.

> we get the medicine with the soldiers in the same place at TASO. (David Kilara) [144]

> We blame it all on the soldiers. They are the one's who started bringing this disease to us, especially these soldiers coming from the other ends of Bundibugo. (Ceclia Lamunou) [145]

Despite such feelings of hostility, I met an HIV-positive soldier who was originally from Pabo and had family in the camp, and he was very integrated into the relationships of the residents with HIV. Broader social divisions thus also shaped HIV-related socialities. There was also suspicion towards those who were relatively wealthy in the camp: 'Most of the rich people in the camp don't come out that they're sick. So their work is to court our young girls with money.'[146]Also, most of those who were openly HIV-positive tended to be in their late 20s and older, so there was suspicion towards youth hiding their HIV-status. In addition, these new networks were dominated by women, and highly gendered patterns of sociality developed.

Gendered socialities

The new networks of care being formed as a result of ARVs were mainly between women. Higher levels of stigma and resistance to HIV testing made men more vulnerable to HIV-related disease and death. Interviews and focus groups revealed that higher levels of shame

[144]Focus-group with David Kilara, Lamunou Cecelia & Obal John, mixed-gender HIV-positive respondents, Pabo, 22 February 2008.
[145]Focus-group with David Kilara, Lamunou Cecelia & Obal John, mixed-gender HIV-positive respondents, Pabo, 22 February 2008.
[146]Focus-group with David Kilara, Lamunou Cecelia & Obal John, mixed-gender HIV-positive respondents, Pabo, 22 February 2008.

among those with HIV, as well as a perceived loss of authority, prevented many men from seeking treatment. As a man in one of the focus groups on gender explained,

> Some men are not informed, they don't value treatment. Even though they are living, they see themselves as dead. Should they survive a life of medication? At times, they stop the wife from coming out openly, because they think it's useless. [147]

Many women had lost husbands and children to AIDS, violence, or separation and this gave rise to forms of solidarity that extended beyond biomedical management to shared ways of negotiating hardship resulting from these losses. The effects of stigmatisation and exclusion intersected with the social dislocations of displacement. As Acholi and Lango society is virilocal, women in Northern Uganda would often be displaced with their husband's extended family and therefore were often spatially separated from their own parental families (or with few entitlements to access their limited resources). Thus, HIV-related exclusion from these families – as a result of stigma and blame – often meant exclusion from family networks of support. In Northern Uganda, many women were blamed by their husband's family for bringing the disease into their households. This in itself is not specific to displacement, but the result was that many women, in particular, ended up in camps alienated not only from land but family support, as their parental families were in different camps. As one woman who lived without family support in Ngai explained, 'My husband's family said I am the one that killed their son, so I should move out of their home.'[148] Such accounts were common.

[147] Focus-group with Almy Jessica Akena Phillip Akello Betty Akello; Odong Patrick, mixed gender HIV-positive respondents, Pabo, 24 February 2008.
[148] Interview with Evelyn Ajok. 34-year-old HIV-positive woman, Ngai sub-county, 14 August 2008.

In cases of extreme exclusion and stigmatisation and the collapse of support channels, resources channelled through the church, treatment programmes, those with HIV and adherence monitors can become primary modes of support as well as sociality. As one woman from Opit explained,

> I don't have any source of food, I used to depend on the good given to me by Father Alex, but now father is not there.[149] Esther [her caregiver and adherence monitor] gives me a little food to cook, not much. I'm not a registered member of World Food Programme. My family, friends and neighbours know about my HIV status. Some others know about my status, because they see me falling sick, and my lost body weight. But I do not have to hide even from them. I tell them I am HIV positive, because it is something that is seen. My family members [who live in Ngai sub-county, not within the camp] despise me. They don't want to stay with me near. My family members don't want to eat with me from the same plate. They don't want to drink from the same cup I've taken from. They don't want to use the same basin I've used, because they believe that I will spread my sickness to people. They don't want to come near me, because they think HIV spreads. But basing on the sensitisation they told me, they say that HIV doesn't infect from sharing basins, cups or food. But my family members are scared of me... I have very many friends at the health centre. We give each other supportive advice, like they tell me to lead a good life, and follow time for taking the medication. There's no one from my family, but it's Esther who gives me the treatment. She brings it from her home everyday, because if it stays with me, I can't follow the right time, and easily forget. I take my ARVs at eight. [150]

However, it was not only disease-related stigma that led to the dislocation of kinship networks. For a number of woman and men, the process of household HIV disclosure required by treatment organisations for the onset of ART caused divisions and separations

[149]Father Alex Pizzi left for Opit for medical care for most of 2008.
[150]Interview with Elaine Ayuma, 35-year-old HIV-positive woman, Opit,. 20 April 2008.

among couples, often leaving women without a broader social support network. As Betty Akello, who had separated from her husband after disclosing her HIV status and was looking after six children in Pabo, said:

> When you separate a woman carries a greater weight. Most of the children tend to go with the woman, and when a woman goes to her home there are times when you have no relatives to help you through, and if you get sick and slip down, there is no-one to help the children. For my case I am alone. So, if I am to fall sick who will help my children? ... I really got angry when I tested positive. How could it happen when I was struggling so hard for my children's future? I thought I wouldn't live up to this long, because it came into my mind that I should kill myself and I never wanted to look at the man who infected me again. I felt like killing him. But my strength stands in medicine. [151]

She explained the situation regarding land:

> If there were equal rights over land between men and women it would be good. But in Acholiland, there are no equal rights over land. I give an example of myself. The land which my mother cultivated is available, but I'm suffering as if my mother never had land. My husband owns land but they don't allow me to cultivate there either.[152]

This was a recurrent theme among many of those I interviewed: experiences of women who were, as a result of displacement, conflict or stigma, shifted to the peripheries of family and kinship networks of support.

[151] Focus-group with Almy Jessica Akena Phillip Akello Betty; Odong Patrick Pabo, mixed gender HIV-positive, 24 February 2008.
[152] Focus-group with Almy Jessica Akena Phillip Akello Betty; Odong Patrick Pabo, Mixed gender HIV-positive, 24 February 2008.

Household death can also exacerbate the dislocations of encampment. For instance, Judith,[153] a young HIV-positive woman from Kitgum, was married to a man and moved to Lacor camp, after which her husband died and she was left with no family support in Lacor. She has a small livelihood in the camp, selling knitted table cloths. With three children to support, she had to rely on WFP assistance, though this did not adequately cover their food needs. Moreover, she had to sell some of the food to pay for school fees. Her mother still lives in Kitgum, where there is family land left barren because of the conflict. She told me that she would return to Kitgum but was worried she would not receive her ARVs there. 'My main hope in life', she explained ,'is to live for a while in order to take care of my children. They are the most valuable thing in my life.' [154] At the time, she had few other friends who were HIV-positive but received support from the counsellors. 'Counselling encourages me, even if I feel worried,' Judith explained. She told me that, 'when I am dying I want to go back to Kitgum as I don't think anyone will take care of me here.' This story, among others, reveals how new expectations made possible by ART could also go along with new struggles and cutting people from their kinship ties.

In this sense, the 'sensitisations' of the treatment programmes, encouraging people to test, could also have a corrosive effect on households and kinship networks. As a Comboni social worker explained to me: 'Families are separating. Women are leaving. Marriages are breaking up. Women are leaving husbands in order to get treatment.'[155] I also came across several cases of women leaving men after the man has disclosed his HIV status.[156] The separation of couples as a result of HIV disclosure, of both men and women, was a widely reported phenomenon.

[153]Interview with Judith (pseudonym) 29-year-old HIV-positive woman, Bobi health centre, 8 August 2006.
[154]Interview with Judith (pseudonym) 29-year-old HIV-positive woman, Bobi health centre, 8 August 2006.
[155]Interview with Openy Dennis, Comboni Social Worker Layibi, 1 September 2006.
[156] For instance, interview with Patrick Akana, 27-year-old HIV-positive man, Layibi, 27 August 2006

While the process of HIV education aimed to promote trust between spouses and sexual partners, HIV testing and disclosure could exacerbate distrust. The erosion of trust was also a commonly reported effect of displacement. As a young woman, whose HIV-status is unknown, explained it,

> To me I would say that the war has changed the lives of people. Because nowadays there is no trust between a man and a woman. The war has caused a situation of insecurity. You always feel insecure that when your man leaves you, and goes to another place. Your man can get a disease and give it back to you, so it's always better to stay together with your man. It doesn't mean that all the time you hold hands with your man, but you should stay where you are always in touch with your man, not very far.[157]

Distrust between partners was widely reported by both men and women. HIV testing, treatment and disclosure could actually play on these feelings of insecurity and distrust produced by displacement.

As discussed, there were highly gendered patterns of treatment access. Across programmes, the majority of those accessing treatment were women. For instance, in September 2006 Lacor Hospital had 1006 females on ART and only 434 males.[158] TASO, in April 2007, had 806 female adults on ART compared to only 278 adult males.[159] Wide gender disparities remained relatively constant over the years covered by my fieldwork (2006 to 2009) and were widely reported. This pattern has been observed across Africa, (Desclaux *et al.*, 2009: 84). Possible reasons include greater biological susceptibility of women to HIV infection, but also

[157] Interview with anonymous 21-year old (status unknown), Opit, 19 April 2008.
[158] Interview with Betty Esoko, Data Officer, Lacor Hospital HIV/AIDS Unit, 18 September 2006.
[159] Personal email communication with Charles Odoi, Head Counsellor TASO Gulu, 17 March 2007.

social factors including the increased use of health services by women, the role women are expected to play as caregivers, or the important role women have played in HIV/AIDS activism. As Desclaux *et al*. (2009) point out, this trend questions existing conceptions of vulnerability or assumptions that women with HIV are more vulnerable than men. They write:

> Gender hierarchies are better described with reference to a common scale of cultural values, inverting the gender balance towards female pre-eminence in some aspects of social life. HIV may render apparent and enhance this dynamic, notably by strengthening women's networks through support groups ... and other socialising effects of AIDS care (Desclaux et al., 2009: 805).

To an extent, this was the case in Northern Uganda, though I demonstrate in the discussion below that HIV groups can also reinforce gender hierarchies even if women outnumber men.

The primary reason cited in Northern Uganda for more women accessing ART than men was that men feared social exclusion and stigmatisation more than women, and so feared both testing and going on to ART. The emotional obstacles to seeking treatment were that many men feel *lewic,* an Acholi word meaning shyness and shame, as well as *lworo*, meaning fear. They also feared 'pinpointing', being laughed at by others, verbal abuse and losing sexual partners. The experience of *lewic*, implying shyness and guilt, seems to arise from a sense of moral wrongdoing if a man is found positive. As respondents in a focus group on gender relations explained,

> Some men fear that if they go to test and they are found positive, their women will be rude to them and blame them for bringing the sickness home, and there are many relationships that have gone down because of that (Betty Akello).

> This sickness is bringing separation between very many couples, because of this sickness, because if one partner tests and finds they are HIV positive it will cause a lot of quarrels in the family (Phillip Akena).[160]

However, seeking testing and treatment could also result in the renegotiating of household and gender roles. Auma Filda, an HIV positive woman who became a Comboni community worker, recounted the story of her own test:

> When I went for a test later on I tested positive. I became so angry I wanted to kill him. I even had a thought of killing all the children and everything. Day and night I would think. Day and night I would cry. I would say 'Why me?' I wouldn't care about eating, I wouldn't care about breast feeding the baby I had. All the time I became weak and weak and weak because I never ate, I never breastfed my child, I never cooked anything. The whole night I was thinking of being positive and dying the next day. But when caregivers started visiting me and encouraging me I became a little stronger. Until one day I convinced my husband to also come with me and test. When we tested we started on ARVs. That's why I am stronger now and I can talk to you now. I'm now approaching two years on the ARVs and I'm glad my husband is on ARVs too.[161]

Treatment organisations, particularly TASO and Comboni, worked on counselling the partners of their clients to encourage disclosure and TASO offered household testing for family members of clients.

[160] Focus-group with Jessica Almy, Phillip Akena, Betty Akello & Odong Patrick Pabo, mixed-gender HIV-positive respondents, 24 February 2008.
[161] Interview with Filda Aumah, HIV-positive woman & Comboni Samaritans adherence monitor, Opit camp, 20 April 2008.

Treatment sites themselves became places where new sexual relations and partnerships were formed. The story of Albino Ojok, a miller in Minakulu, and his partner Katy Opio is illustrative. Katy tested positive for HIV, but her former husband refused to test, leading to the breakup of their marriage. She explained:

> That is the reason why we separated. I would keep on getting pregnant and having miscarriages. My 'home-people' came to collect me from my home when I was sick, and he even refused to come to the hospital. He would not to accept [going for a test]. Even the elder brother sat him down and said 'it's better to know your status than die' but he still refused.[162]

Ojok's former wife died of AIDS. After her death, he tested for HIV and started seeking treatment. At the treatment centre, he met Katy:

> My first wife passed away in 2004, so when she passed away, I as a man couldn't stay without a wife. In 2006 I started getting medication from TASO. From there I met Katy and we started courting. We would speak like good friends at the health centre. After that we started staying like husband and wife in the same house. [163]

This story shows how forms of social conflict but also forms of friendship and partnership emerged from the sites of treatment. Sexual relationships, marriage and partnerships between those with HIV became very common, and were actively encouraged by treatment organisations in order not to spread the disease.

[162]Interview with Ojok Albino and Katy Opio, couple living with HIV, Minakulu, 11 July 2008.
[163]Interview with Ojok Albino and Katy Opio, couple living with HIV, Minakulu, 11 July 2008.

Hence, negotiating HIV and treatment has also involved negotiating the disrupted gender relations of displacement. Dolan (2002) has argued that, within the context of displacement, Acholi men have not been able to fulfil their social roles as providers for their families and children – their relational forms of masculinity. This may have led to increased levels of domestic violence as men attempted to reassert their conventional authority. Under such conditions, a militarised vision of ideal masculinity emerged, as soldiers were among the few men with money and social power (Dolan, 2002). Furthermore, Simoni (2007: 28) argues that in Northern Uganda coming to terms with HIV status involves a re-evaluation of masculinity. My evidence shows that this is partially true – many men who have been tested have had to be encouraged by treatment organisations and commit to treatment in order to provide care for their children. Therefore the challenges and expectations of treatment move beyond the individual to the survival of the family and of children in particular.

Many men, like women, said that their primary reason for seeking treatment was to be better able to care for their children. Thus, the care of children became a source of a transformative masculinity. As Phillip Akena explained, trying to account for the difference between him and other men who feared coming out to test:

> The difference came when I lost a child to AIDS. My child was sick often. And when they took her to Lacor, she tested positive. My wife had to test too and tested positive. After this, our child died. And since my wife had come out openly I also had to come out and test and get medication, because if I didn't, then it meant my children would have no one to look after them. I have five other children and I still have a long way to look after them.[164]

[164] Focus-group with Jessica Almy, Phillip Akena, Betty Akello & Odong Patrick Pabo, mixed-gender HIV-positive respondents, 24 February 2008.

In addition, a number of men with HIV took it upon themselves to 'counsel' other men and to encourage them to test. Care and counselling thus became an important part of masculine identity associated with HIV. This may not be directly tied to experiences of displacement but it is significant that, with the loss of forms of masculine authority and symbolic power arising from displacement, care and counselling allowed men and women to re-establish forms of social value and recognition, and thus to survive.

However, HIV support groups could also be used to reinforce gendered hierarchies. HIV support groups also provided avenues for the re-establishment of gendered hierarchies. Positions of influence, for instance those employed to facilitate food support, tended to be held by men. Furthermore, some men used HIV support groups to recreate a vision of masculinity based on many sexual partners. One man, who was the World Vision community representative for food support, as well as the leader of the local HIV support group, met more wives through the group. He stated:

> They [the Comboni Samaritans] had gathered us together, and sensitised us. The number of women were greater than the number of men. And what they told us is that we shouldn't go out and start staying with an HIV-negative person; you can marry someone who is HIV positive too. That is why I took from the HIV-positive women, because I thought that if at all these women were left, they would go out to other men who would be HIV-negative, and the virus would be spreading.[165]

The resources available to new HIV-support groups allowed certain members to utilise these to reinstate new forms of patriarchy with different justifications linked to HIV prevention. The formation of new HIV socialities was therefore shaped by social hierarchies disrupted,

[165] Interview with Christopher Mwaka (Psuedonym), HIV-positive man, Ngai sub-county, 18th August 2008.

but not effaced, by displacement. In addition among those with HIV there were varying levels of acceptance by families. The importance of biosocial relations in an individual's life was strongly dependent on these levels of support. Among the most marginalised individuals I encountered, and who reveal the powerful intersections of HIV/AIDS and conflict, are former LRA abductees, who are HIV positive. The final section of this chapter explores their experiences.

LRA returnees and HIV/AIDS.

Populations in the camps and conflict-affected zones of Northern Uganda have had to deal with the constant threat and trauma of violence as well as negotiate the return of former abductees. As noted by Allen (2006a: ch 6), few of those returning from life with the LRA have been through 'traditional' reconciliation ceremonies, and those returning bring with them the threat of *cen* and the moral contamination of violence. These members of the community are often treated with ambivalence and stigmatised due to their participation in the LRA's violence. As discussed below, these forms of fear and exclusion may intersect with AIDS-related stigma. Take this example of a woman abducted by the LRA, who married a soldier in Pabo camp who abandoned her, and was left in Pabo without any support. She explained her decision to go and test after a long period of illness:

> This lady was staying the other side of the mission, and afterwards she was chased from there, so she had nowhere to stay, so she came to live with me. And every time she would take medication, and one time I asked her what medicine is she taking, and she told me she was taking medicine for HIV/AIDS.[166]

[166]Interview with anonymous 36-year-old HIV-positive woman and former LRA abductee, Pabo, 25 February 2008

At the treatment site she was to meet many living with HIV/AIDS: 'Yes, I've met very many, and that's why I'm strong. They give me emotional support. The counselling does help me. I have relatives here, but they do not know that I'm their relative, so I live my own life. '[167]

At Opit there were a number of former LRA abductees who were HIV-positive. Among those I spoke to, these were perhaps the most vulnerable and isolated from other networks of social support. For those who have suffered extreme exclusion, in particular returning LRA combatants with HIV, HIV-related socialities became central channels for social engagement.

Ruth was a young woman in Opit, who was the former 'wife' of an LRA commander. She was abducted as a teenager and believes she contracted HIV while with the LRA. Later she was taken by government soldiers in a battle and then returned home. She explained the difficulty of returning to the camp:

> When I reached home, my relatives started running away from me. They would say I was going to give my sickness to the younger ones. Until someone came and told Father Alex, that there was someone who has just come back from the bush and needs help. I was brought here, and taken to Lacor for a blood test. I went back and stayed with my parents. But when I was there, they didn't show any interest in me. I went and stayed in the hospital for three months. No one came to visit me. The only person who cares is Father. That's why he got angry with my people and bought a house for me here.[168]

She had a child while in the bush with the LRA, whom she brought back. Both she and the child were stigmatised for having been with the LRA. She explained the response by members of the community, 'They insult my child, that the bad spirits (*cen*) in your mother's

[167]Interview with anonymous 36-year-old HIV-positive woman and former LRA abductee, Pabo, 25 February 2008

[168]Interview with Ruth (pseudonym), former abductee living with HIV, 17 February 2008.

eyes, of those your mother killed in the bush, have made you come and disturb our children.'[169]

For Ruth and others like her, who are extremely marginalised, HIV status provides a form of community and identity. She said that most of her friends are HIV-positive and explained that 'there are so many with HIV, who are my friends. I can't even count.' [170] However, later we were to hear that she had got involved with a soldier and become pregnant, moving to a different area and treatment programme.

Another example was Okuto, an eighteen-year-old man I met in Opit. He had returned from the bush without going through any reconciliation ceremony to find both his parents dead. His mother had died of AIDS. He stayed with his uncle, but his family exploited him: 'there were lots of abuses. Because they wanted me to do everything, including carrying water. So I found there was nothing good I could do.'[171] When he tested HIV-positive his uncle told him 'that is how the world is' and he was later chased out of the house. He found an empty hut where he lived. 'I was just begging from the neighbours for something to cook, and I would prepare it for myself', he explained.

He eventually went onto ARVs after getting support from St Joseph's, the local mission. He explains, 'my life changed, because I feel better now, and I have been struggling to work by myself, because there is no one who can take me back to school.' [172] He wanted to study tailoring at a local training centre. Through receiving treatment at St Joseph's he had met

[169]Interview with Ruth (pseudonym), former abductee living with HIV, 17 February 2008.
[170]Interview with Ruth (pseudonym), former abductee living with HIV, 17 February 2008.
[171]Interview with Okuto (pseudonym), 18 year old HIV positive man, former LRA abductee Opit, 7th December 2007.
[172]Interview with Okuto (pseudonym), 18 year old HIV positive man, former LRA abductee Opit, 7th December 2007.

new friends, mostly older than himself, and also a new girlfriend – they share a Comboni caregiver. The two live and cultivate together, and plan to have a child once she is on ARVs. This story reveals how, for those suffering extreme marginalisation, HIV support groups and treatment can open up new avenues of sociality and new horizons of hope. Still, Odong and his partner struggled to find training and work in the camp and their positions were fragile and uncertain. This story illustrates how the new horizons of hope that ARVs opened up were also constrained by the continuing struggles of encampment and poverty.

A final story is that of David Odong worked in a mill near the market in Pabo, living in a hut nearby. He was 27 years old when we met him in 2008. At 15 he had been abducted by the LRA and spent four years in the bush in the unit of Odhiambo, one of the LRA commanders who was mainly based in Sudan. He explained that those who were weak or showed signs of illness were murdered. After escaping from the LRA he joined the Ugandan army.

According to Odong, sexual relations were not allowed among the lower ranks in the LRA,[173] though sometimes the young men would 'just steal' (implying rape). David claims to have had no sexual relations with the LRA. In the bush, AIDS had been a distant reality for David: 'I did not know about AIDS, I only knew about fighting...I saw many people getting thin, and they would even die. And if you become energy-less, so that you can't move, they kill you.' [174] Each unit had a medical professional that had been abducted, and they would loot medical stores for medicine and provisions. There was attention to hygiene and needles were always boiled. The image Odong gives of life with the LRA was ruthless, but also disciplined.

[173] This is also a finding of Allen (2006)

[174] Interview with David Odong, 27-year-old HIV-positive man & Former LRA abductee, Pabo camp, 23 February 2008.

During a battle between the LRA and the Ugandan army (UPDF) near Atiak, he escaped and reached Pabo. Without passing through any of the reception centres, he joined a local defence unit and was moved to Odek. There he met a woman, with whom he had five children. After some time he started falling ill and in 2007 tested HIV-positive and decided to leave the unit.

Back in Pabo he found himself stigmatised for being a former rebel and for being HIV-positive: 'They would say, "look at this one, he's returned from the bush."' David explained that 'every time you go chat to your friends they would point at you, that you're a rebel. When they used to stigmatise us, we thought of living only with us returnees.' [175]



David Odong

[175] Interview with David Odong, 27-year-old HIV-positive man & Former LRA abductee, Pabo camp, 23 February 2008.

He and his wife starting to receive Septrin from TASO in 2007, creating new hopes for the future. David said: 'They educate us that by getting the medicine, you can live a longer life, and even the younger children you have, you can take care of them until they are at least an older age, so that gives me happiness'. [176]He earned a little money from the mill and was still struggling with illness. The soldiers' barracks had been built over his family land and so he had little hope of reclaiming productive agricultural land after the conflict. This story shows how the intersecting effects of conflict and HIV produce extreme forms of vulnerability. ART can open up new horizons of hope and possibilities for support, but many still remain exposed to the extreme adversity of life in displacement camps. In such cases accessing treatment can provide a form of stability and orientation through uncertain times.

Conclusion

This chapter has shown how the biosocial transitions engendered by ARV provision in Northern Uganda have been interwoven with displacement-induced transitions. These have produced intersectional vulnerabilities arising from both displacement and the physical and social effects of HIV/AIDS. Displacement was characterised by both continuity and rupture with pre-displacement relations and obligations. Displacement strained and re-oriented existing communal and family relations. HIV-related vulnerabilities intersected with these: high levels of stigmatisation, particularly prior to ARVs, led to the erosion of household relationships, as well as relationships with extended families. HIV-disclosure, including treatment-seeking behaviour, often further eroded strained relations (though of course there was substantive variability in this). Even when there was support from family, the adversity of encampment and displacement often made it difficult for families to support those who

[176] Interview with David Odong, 27-year-old HIV-positive man & Former LRA abductee, Pabo camp, 23 February 2008.

were ill (for instance in helping them access medical care). Furthermore, new HIV-related socialities oriented around therapeutic practice were extremely gendered, with mainly women coming out for testing and treatment. This allowed new networks of solidarity to form, but also created new vulnerabilities. These vulnerabilities were particularly pronounced during the return period, when many women were left without access to land – a theme that will be discussed further in the latter chapters of the thesis. Negotiating treatment involved the renegotiating of gendered relations; however, treatment support groups could also be spaces where gendered hierarchies were re-established.

In this context of uncertainty, HIV treatment not only brought renewed health but was a catalyst for new social bonds. As treatment organisations penetrated the social spaces of displacement – through an array of fieldworkers, counsellors and community volunteers – HIV treatments became part of the broader transitions of displacement. New forms of sociality and clientship were developed in the context of uncertain and disrupted social relations. Treatment provision formed new networks among those with HIV, both through the agency of treatment providers and caregivers and through the spontaneous self-organisation of patients at the treatment sites. However, divisions and forms of exploitation within these communities also existed. Biosocial relations did not supplant kinship or family relations, but interacted with these. Nonetheless, in situations where family relations were extremely strained by displacement, and separated from the spatial order of village life, new biosocial relations could play an extremely important role in the survival of those with HIV. In addition, for those who were most marginalised by their family and kin, like former rebels, HIV-related identity and community became a primary source of social life and care.

The processes described above may not be unique to displaced settings, but they were given a specific form by the extreme conditions and spatial production of conflict and displacement. The proximity of households in the camps meant that new networks of care and solidarity among those with HIV could form rapidly. These processes were also apparent in semi-urban areas around the towns, where dwellings were also very concentrated, but were more apparent in the camps. The spatial form of biosocial relations, and its role in disclosure, changing levels of stigmatisation, and shaping new identities is discussed in the next chapter.

Chapter Four: Stigmatisation, Disclosure and the Social Space of the Camp

Introduction

This chapter examines how the displacement camp's social space has shaped patterns of HIV disclosure and stigmatisation in Northern Uganda. ART and education interventions have reduced levels of stigmatisation. However, new forms have arisen. These changes are linked to high levels of HIV disclosure in camps due, in significant part, to increased visibility and lack of privacy. This chapter also critiques existing theories of HIV stigmatisation by drawing attention to the interlinked dimensions of spatiality and observation. Conceptually, the chapter links a theory of social space to that of stigmatisation as a social process. This approach helps outline the specificity of the camp environment in comparison with town and rural settings. I introduce the concept of 'socio-spatial disclosure': the process through which individual and collective HIV status becomes known to a broader community as a result of socio-spatial conditions. The implications of this for stigmatisation are outlined: these involve the increased awareness and tolerance of those with HIV over time, though with heightened stigma in the early stages, as well as new forms of suspicion towards those on ARVs. Stigmatisation, disclosure and blame in Northern Uganda are also shaped by social stratification along the divides of gender and class, as well the divide between local communities and soldiers. In addition, the forms of legal exception in the camp environment have allowed the local camp leadership to enforce, sometimes coercively, limitations on stigmatising behaviour. Here, I situate the biophysical transitions produced by ART within the socio-spatial transitions of encampment. In addition, I explore how the dominant themes in stigmatising language reflect the lived world of the camp.

Cimmotok: Stigmatisation and social transition

The Acholi word for stigmatisation is *cimmotok.* Literally, it means 'pointing at the back of someone's head'.[177] The word, as a reference to stigmatisation, was introduced into the region by NGOs in the late 1990s and 2000s and has come to shape understandings of stigmatisation among local communities. More broadly, ideas of disclosure and stigmatisation were closely related; the idea of being marked out in public as HIV-positive was considered a form of stigmatisation, even if it was not accompanied by verbal abuse. The word was also used in a broader sense to refer to various forms of verbal abuse, as well as exclusion from resources and direct violence, such as beatings. I argue here that, in the social space of the camp, changing forms of disclosure and visibility have been closely linked with changes in stigmatisation. Here, I will briefly outline how I situate my perspective in relation to existing theories of stigmatisation (focusing on disease-based stigma) and social space.

Goffman's (1973) work is the foundation for most contemporary theories of stigma. He conceptualises stigma as a socially identified deviation from a perceived norm; the term refers to 'an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed' (Goffman, 1973:14). Stigmatisation can also be viewed as series of processes linked to the labelling of social difference and the marginalisation of those labelled (Link and Phelan, 2001: 363). This process of stigmatisation involves an interaction between belief, perception, and enactment (Steward *et al.*, 2008). The literature on stigmatisation makes a division between instrumental and symbolic stigma.

[177] My assistant Ajok Susan, as well as other informants, explained the history of the word to me. See also Odonga, Alexander (2005)

Instrumental stigma results from unfounded fears of infection or conflicts over resources. Symbolic stigma is based on the perceived relation between HIV and morally deviant groups or activities (Deacon *et al.*, 2005: 41, Herek, 2002). Here, I treat instrumental and symbolic stigma as part of interconnected processes, as this reflects the experiential perspective of those living with HIV. Stigmatisation, it is argued here, is a result of encounters in a lived environment and not simply an outcome of a set of beliefs or instrumental intentions. As Steward *et al*.(2008) suggest, stigmatisation can be viewed as a set of overlapping representations and practices, often contradictory, that form part of a lived experience of fear and uncertainty. In these processes instrumental and symbolic forms of stigma are deeply intertwined.

Parker and Aggleton (2003:21) argue that stigmatisation involves the 'reproduction of social difference' and is embedded in unequal power relations. It is 'deployed by concrete and identifiable actors seeking to legitimize their own dominant status within existing structures of social inequality' (Parker and Aggleton, 2003: 18) and this involves both material and symbolic strategies. However, as demonstrated below, these strategies are resisted by stigmatised groups, and result in the deployment of new 'resistance identities' (Parker and Aggleton, 2003: 18). While Parker and Aggleton use Goffman and Foucault (discussed below) as their foundational theorists, they ignore the importance of observation, spatiality, and biopower in their work. This leads them to understate the role that observations of ill individuals in concrete settings plays in changing forms of stigmatisation.

Goffman emphasises observation of bodies in his analysis of stigma (Goffman, 1973:124). The visibility and invisibility of the stigma, as a discrediting attribute, affects knowledge around it. Alonzo and Reynolds introduce a temporal aspect to this, with reference to HIV-

related stigma, and argue that 'the shape of the stigma trajectory is intrinsically tied with the disease course' (Alonzo and Reynolds, 1995:305). Furthermore, the relationship between disease course and stigmatisation is bound up with social interpretations of bodily signs. However, these authors give little attention to the material environs in which the disease trajectory is observed and interpreted: spatiality is central to this, as it shapes the manner in which embodied information is conveyed. Gayatri Reddy is one of the few theorists who focus on spatiality and visibility when analysing stigmatisation. Reddy (2005) in a study of 'eunuch-transvestites' in India, argues that the visibility of bodies, and the associations with places, are central to how individuals become incorporated in certain knowledge and power relationships. Reddy (2005) discusses 'scopic pathways of stigma'. She understands visibility as central to stigmatised identity. She writes: 'acts of seeing and being seen are deeply invested with moral value, emphasizing not merely the individual body/self, but his/her link to the collective or outside world' (Reddy, 2005:259). Describing how the visibility of *hijras* at clinics on certain days creates associations between the clinic and the perceived shame of the *hijras*, Reddy contends that both bodies and spaces are invested with representations of shame, and these shape forms of stigmatisation.

The discussion above leads to the question of how to conceptualise the relation between observation, spatiality and social discourse. Foucault's analysis of space and visibility is useful here. For Foucault, visibility and space are components of the formation of knowledge-power relations. Foucault (1977) uses the phrase 'network of gazes' to indicate the webs of observation in which individuals are observed and categorised. Observation itself is part of a normalising process through which individuals are marked and marginalised. The marking out of individuals sustains power relations: 'all mechanisms of power…are disposed around the abnormal individual, to brand him and to alter him' (Foucault,

1977:199). This insight is relevant to understanding stigmatisation as social process. The identification and naming of the diseased takes place in concrete settings, and is formulated in terms of labels, statements and understandings. The intersection between visibility and knowledge is central to practices of exclusion: 'by saying what one sees, one integrates it spontaneously into knowledge; it is also to learn to see, because it means giving the key of a language that masters the visible' (Foucault, 2007a: 140). Furthermore, the formation of medical knowledge in social settings is oriented around categories of exclusions which are analogous to stigma (Foucault, 2007a: 17). This chapter pays attention to how the observation and labelling of individuals with HIV shapes their social position. It is also important to understand that forms of labelling and interpretation are historically shaped. The interpretation of the body by both the individual and society is integral to how the body is inscribed with historical processes, both physically and symbolically (Fassin, 2007a).

Experiences of stigmatisation are bound up with both direct experiences of marginalisation and labelling, but also with perceptions of social norms. Steward *et al*., (2008:1226), define stigma as 'the devalued status that society attaches to a condition or attribute' and outline four ways in which stigma is experiences by those living with HIV. First, there are experiences of 'enacted stigma' which refers to 'overt acts of discrimination and hostility directed at a person because of his or her perceived stigmatised status'. Second, 'felt normative stigma' describes the 'subjective awareness of stigma'. Third, 'internalized stigma' describes the condition where stigmatising beliefs are believed by those stigmatised. Fourth is 'vicarious stigma', in which forms of stigma are learned by the stigmatised through others, either through observation or stories. These facets are often interwoven and are all relevant to the discussion here.

Socio-spatial disclosure

While the literature commonly describes stigmatisation as a social process, disclosure is often conceived more narrowly through a lens of voluntary or involuntary practices. Disclosure is generally viewed by treatment providers as important for the provision of ARVs, as failure to disclose can lead to poor ART adherence (Doherty *et al.*, 2006). Disclosure of HIV status can also lead directly to experiences of stigmatisation. Given both the positive and negative effects of disclosure, its relative neglect in the literature on stigmatisation is concerning. Moreover, when it is discussed in the academic literature, there is a common assumption that disclosure occurs, if at all, both verbally and voluntarily (Medley *et al.*, 2004). While voluntary verbal disclosure may be an ideal, HIV status may, in practiced, be disclosed non-verbally and involuntarily, through such actions as an individual's presence at a testing or treatment site (Steinberg, 2008, Whyte *et al.*, 2010), visibly taking medication, the possession of commodities related to HIV support, such as breast-milk (Doherty *et al.*, 2006), or as a result of receiving material support (Whyte *et al.*, 2010:82). Recognisable signs of illness may also signify HIV status, although these may also lead to misrecognition when opportunistic infections, such as TB, are associated with HIV.[178] In this section I wish to explore how disclosure is intimately linked to stigmatisation as well as to the spatial conditions of the camp. I propose and will explore the concept of 'socio-spatial disclosure' as the process through which HIV status is disclosed to others through visual or other non-verbal markers, which are not necessarily voluntarily communicated.

All the field-sites I visited in the course of the research were marked high by levels of HIV disclosure. Among the reasons for this is that disclosure was imposed both by treatment

[178] Personal communication, Bruno Dujardin, Free University of Brussels, May 2009.

organisations at a household level and the socio-spatial conditions of the camp. TASO and Lacor Hospital required disclosure to household members in order to go onto ARVs. TASO labelled this 'supported disclosure' and provided counselling helping patients and their families to deal with being HIV-positive. This was to ensure treatment adherence.[179] However, *de facto* the camp environment in particular made secrecy around receiving HIV treatment nearly impossible, unless one had money to seek treatment elsewhere or purchase it oneself.

The introduction of ARVs by TASO to Pabo in late 2006 catalysed a major change in the experiences of HIV in the camp. As discussed in the previous chapter, the treatment site at the local health centre was highly visible. The visibility of those seeking treatment meant that confidentiality was not possible. As an HIV-positive woman in Pabo explained: There are more older people getting the medicine. At the beginning we were very few. Whenever we would go get the medicine from TASO, people would get full to see us as if we were acting (Betty Akello).[180]

This was true for several other camps too. Mere physical presence at a treatment centre or distribution point was a form of disclosure, but one in which the categories of voluntary and involuntary did not easily apply. When TASO arrived to begin their treatment programme in 2006, many gathered around thinking it was some form of humanitarian support and so those seeking treatment were observed by many others. Both the spatial conditions of the camp, in which the HIV treatment programme was entirely visible to the community at large, as well

[180] Focus-group with Almy Jessica Akena Phillip Akello Betty; Odong Patrick, Mixed gender HIV-positive respondents, Pabo, 24 February 2008.

as the conditions of adversity, dependency and marginalisation, would come to shape the social effects of treatment in the social space of the camp.

There were also specialised food distributions for those with HIV in the camps. These took place outside the health centre and in full view of the community in Pabo. The visibility of the treatment site and HIV testing services, as well as the specialised food support for those with HIV, run by World Vision, created discomfort for many. This may have been more pronounced for some, particularly men, as it was primarily women who sought testing and treatment. As a man in Pabo pointed out: **'**Whenever they would see you come for voluntary counselling and testing (VCT) people would pinpoint, so many people did not come for testing.'[181]

Visibility at treatment centres also led to stigma, particularly in the early period of treatment provision. Joseph Oliel, a TASO client in Pabo, explained:

> When we started the ARVs that's when people started abusing us, and insulting us, but before they did not know of our status, so there were no insults... when you go to collect your food, people always collect around, and keep looking at you. They always say that this is the food for the weak people, the sick people. When people are many, insults are not there. But if you are alone, that's when people can start insulting you.[182]

Charles Kilama, an HIV-positive man and former LRA abductee, expressed similar discomfort. He had disclosed his status to his uncle, with whom he lived in Pabo. However,

[181] Focus-group with Caroline Akello, Geoffrey Olwa and Anonymous woman, Mixed-gender HIV-positive respondents, Ogur health-centre, 1 August 2008. Focus group with Caroline Akello, Geoffrey Olwa and Anonymous 28-year-old HIV positive woman. , Ogur HC 4, 1 August 2008.
[182] Focus-group with Joseph Oliel and Cristin Acan, HIV-positive couple, Pabo, 24 August 2008.

he said: 'I never told anyone else my HIV status, but they got to know about it, because I always moved to the health centre.'[183] When asked how he felt about this, he explained:

> There are times when I felt bad because if I am passing they tend to laugh, and they tend to tell very provocative stories in the name of someone else, and yet they are talking about me. It's a form of stigmatisation. But I try not to think about it.[184]

Others, while experiencing discomfort and stigmatisation as a result of their visibility, have also noted positive effects. Beatrice Arach said that, while she suffered stigmatisation for being HIV-positive, 'it is good that we are seen because someone will notice the effects of ARVs'.[185] This comment resonates with the views of many clients who believed widespread disclosure was for the better and had led to a reduction in stigmatisation. The physical presence of the healing body thus became a means of exhibiting the effects of ARVs to the broader community.

At the TASO site in Pabo discussed above, caregivers and treatment monitors were publicly known and associated with the HIV programmes. Receiving home-based care was a very visible process in the camps. Some camps were served by TASO field officers on motorcycles who moved to patients' homes to monitor and deliver treatment. Their arrival was a very visible event, with other camp dwellers gathering to see who had arrived at the camp. There were also more subtle forms of disclosure. Comboni provides their patients with recognisable commodities, in particular a white jerry can for water purification. Jerry cans for

[183] Interview with Charles Kilama, HIV-positive man & former LRA abductee, Parobang Parish, 14 August 2008., Pabo, 14 August 2008
[184] Interview with Charles Kilama, 30-year-old HIV-positive man & former LRA abductee Parobang Parish, 14 August 2008.
[185] Interview with Beatrice Arach, 32-year-old HIV-positive woman, Pabo, 15 July 2008.

water collection in the area are almost universally yellow, and so white jerry cans became associated with HIV status. There were also special food provisions delivered to those who were HIV-positive. They received a yellow corn soya blend, rather than white maize meal, as this was the starch component in most food support programmes.[186]In other camps other than Pabo that I visited there were similar dynamics, though rural and town areas differed. For instance, in Bobi, a camp close to Gulu Town, it was relatively easy to see who was receiving treatment at the health centre in spite of a fence around its periphery. In Awach, the health centre and HIV treatment site was also in an open space in the centre of the camp.

The visibility of those seeking treatment meant that confidentiality was not possible in most camps. Mere physical presence at a treatment site led to disclosure of HIV status. In the towns, however, it was possible to take treatment without letting neighbours or employers know. For instance, a soldier at TASO Gulu told me that several soldiers received treatment at the TASO branch in Gulu Town to avoid disclosing their status.[187]The architecture of the TASO building closed visibility off from the street. The treatment site at Gulu Hospital is at the back of the hospital and visible to those within the hospital, but not those outside. The HIV clinic at Lacor Hospital was also closed off from the rest of the hospital, as well as the community. Also, while the towns were congested, the population was still more dispersed than in the camps. Many patients who could afford transport costs and were healthy enough to move about travelled to these sites from elsewhere. However, for many in the camps, with little income and energy, travel was prohibitive: this was the reason transport support helped so many in Opit to get treatment in Lacor.

[186]Thanks to Ayesha Nibbe for bringing this to my attention.
[187]Interview with Opok (pseudonym), HIV-positive soldiert on ART (TASO), Guly Town, 22 July 2008.

For those in rural areas like Lira, where displaced populations had returned, it was possible to travel to larger centres to get treatment without disclosing one's status, as the government health services did not enforce household disclosure, and the distances meant one could receive treatment without observation. Sammy Okello, an HIV-positive man in Lira who had started treatment in Ogur health centre while still in the camp, but had subsequently returned to the village, explained this:

> It is easier to keep your HIV status secret in the village than in the camp where people were so close each other, and you can't easily hide your secret of being positive. In the village, you can get out, test your blood and you start getting medicine, even without someone knowing that you come and do this.[188]

Sammy also thought that stigmatisation based on physical symptoms could force people into testing in the camp:

> Living in the camp forces someone to declare their status. It's when people see you very thin, that people will start giving you advice that you should go take your blood, and when you take your blood you are declared HIV-positive or negative. I find this has a positive effect, because when people laugh at you it forces you to go and test. [189]

These dynamics are what I refer to as socio-spatial disclosure. Disclosure is linked to the visibility of people at treatment sites, and their connections with HIV support programmes. This form of disclosure defies the binary of voluntary or involuntary disclosure, as patients cannot choose to whom they disclose. The only way to keep privacy is not to seek treatment.

[188] Interview with Sammy Okello, HIV-positive man, Ogur sub-county, 25 April 2008.
[189] Interview with Sammy Okello, HIV-positive man, Ogur sub-county, 25 April 2008.

The implications of this are complex, and linked to the visibility of the effects of treatment on the body. This is the topic for the next section.

Stigmatisation and the disease course

In my interviews, there was an overwhelming sense that those who were on ARVs had physically improved – though some had suffered from minor side-effects in the early stages of treatment – and that these improvements were viewed by many around them in the camps. The lessening of physical signs of illness had reduced the intensity of the experience of stigmatisation. This supports Alonzo and Reynolds' (1995) claim that changes in stigmatisation follow changes in the disease-course. Given the radical physical changes that ARVs induce, shifts in stigmatisation could also be pronounced after the onset of treatment. Interviewees whose HIV status is unknown confirmed this process:

> ARVs have changed people's attitudes towards HIV. Because when they introduced ARVs people started looking as normal as any other human being. You can't easily identify a person who is sick from the person who is not sick. The one who is sick looks the same as the one who is not sick. So how will you start criticising and abusing that this person has HIV when the person looks the same as you.[190]

> The sensitisation only changed the levels of stigmatisation a little, but the ARVs helped a lot, because if you see those who are taking ARVs, someone begins when they are so weak and gains when the time goes on. People will wonder if

[190] Interview with 21-year old woman, HIV-status unknown, Opit, 19 April 2008.

> it's still right to stigmatise, because the person you stigmatise will lead a normal life like you, so it will become useless to stigmatise someone who won't die. Most people have a tendency of predicting to the clients [HIV patients] days when they are going to die, they can say only one week, but after one week ... if they see this person is not dead, they will say these ARVs are really good.[191]

Many with HIV reported decreased stigmatisation as their health improved. Education concerning the transmission of the disease helped, but this knowledge was given a visceral meaning in the social spaces in which those on ARVs were observed. Patients with HIV often experience most intense stigmatisation during the periods of visible illness: As Beatrice Arach, a woman with HIV in Pabo, said: 'the stigmatisation gets worse when they see rashes all over my body. They suspect that I am going to die soon.'[192]

Such accounts are common, illustrating the close link between stigmatisation and the body. In addition, those who were better could now partake in limited agricultural activity. Access to resources through the support offered to those with HIV also lessened the marginalisation by families. However, while the health improvements of those on ARVs led to reductions in stigmatisation, particularly around fear of transmission, and helped reduce the burden of illness on families, new forms of stigmatisation emerged.

The new health of those living with HIV– their 'fatness' and their perceived normal appearance – created new fears that they were spreading the disease to the population intentionally. The life-giving potential of ARVs and their social meanings are paradoxical: they give life, but the bodies of those with HIV remain infused with associations of threat and death. The language of HIV also produces paradoxes that shape perceptions. To recall: the

[191] Interview with Juliano Anyoo, 37 year old man with HIV & Comboni community worker, Parak camp, 23rd June 2008.
[192] Interview with Beatrice Arach, 32-year-old HIV-positive woman, Pabo, 15 July 2008.

most common word for HIV/AIDS is *twoo jonyoo,* roughly meaning, 'the disease that makes you thin'. In Luo, there is no distinguishing between HIV as the causal mechanism, and AIDS as a syndrome. ARVs produce a situation where those who have 'the disease that makes you thin' are no longer thin. Though not voiced in the idiom of sorcery and witchcraft, new forms of stigmatisation emerge with a similar logic: there is a fear of secret killing and of living corpses. As much as ARVs introduce a new discourse of 'living positively', the associations between HIV and death persist. As Nighty Aber, a woman living with HIV in Pabo, explained:

> In the market when you are passing, they will point at you and say – 'look at this one, they are the people on ARVs, they are now fat and now they are killing people. You should tell anyone who is trying to court them, to stop. These are all useless people, they are moving corpses. You see her moving there, she is a corpse, she is a ghost'. It becomes so hard for us. It's hard for us to move.[193]

The themes of uselessness, as well as the threat of death, here coalesce with the observed physical changes brought about by ARVs–particularly the gaining of weight, which makes HIV itself invisible. Numerous interviews with HIV-positive people raised similar concerns: accusations that 'fatness' allowed them to kill, as well as the idea of a 'living corpse'.

The observation of those living with HIV forms part of the social lives of medicines themselves. It is linked to both the formation of social interpretations of illness and the ways in which the ill are placed within a social order. Observation itself is part of a normalising process through which individuals are marked, marginalised and inserted into a moral order.

[193] Focus-group with Nighty Aber, Anna Akello, Hellen Lanyero, Filder Achola & Nighty Aceng, HIV-positive women, Pabo, 24 February 2008.

However, rather than bodies simply being placed in pre-existing categories, the changes in bodies form part of changing social relations. The disease-course intersects with the trajectory of social transition and the uncertainty this creates. Bodies and their interpretations become sites of contestation. Their healing becomes not only a biophysical matter but one deeply embedded in social experience. Understanding the social positions of those with HIV and their place in the social and symbolic hierarchies of camp life is critical to understanding changes in stigmatisation as well as the shifts in power relations that take place through HIV treatment and social responses to the disease. These dimensions are explored in the life history of Evelyn Aber below.

Evelyn Aber

Evelyn Aber lived in a small concrete room near the market place in Pabo. In 2008 she was in her late thirties and had known she was HIV-positive for a decade. She was one of the earliest people to test and openly disclose her HIV status in the camp. She is therefore a witness to the changes in the lives of those with HIV over the years.

Prior to Evelyn's displacement in 1996 she had not heard of HIV/AIDS or understood how it was transmitted. However, in retrospect, she thinks her husband, who was a soldier, may have died of AIDS. Evelyn tested HIV-positive in 1998 at a World Vision mobile testing unit, one of the few organisations providing infrequent HIV testing to Pabo. It would be two years before she told anyone about her HIV status: 'When I found out I was positive, I didn't

disclose my status to anyone. I just stayed like that, without even telling my family members.' [194]

Evelyn chose to disclose her HIV status after she shifted from the Catholic Church to a local Pentecostal Church. While her new church provided no HIV education and support, she said it gave her a new spiritual strength. In 2000, she and 23 others living with HIV formed the first group of those with HIV in Pabo. The group was called *Yabbo Wang Wu* AIDS Group, which means 'open our eyes.' Ideas of seeing and visibility permeate the discourses around HIV/AIDS in the camps. The early life of the group was characterised by struggle and intense stigmatisation:

> We were the first group in Pabo. Most of them died. We are left now with seven. Ah. People suffered. Then, people could stigmatise. If you are ill, if you know that you are HIV-positive, they just leave you alone in the house. They don't even move close to you. People were dying just lonely at their house. We visited them. We would wash them ourselves. [195]

According to Evelyn , the word *cimmotok,* meaning stigmatisation, was introduced into the area by NGOs providing HIV education and support in the 2000s. Evelyn explains her understanding of the word:

> In fact *cimmotok* is used in several ways. One way is if you are passing, and someone is talking against you. Or someone who has tested positive comes and starts boozing – self-stigma – until they die. Or others, once they know their

[194] Interview with Evelyn Aber, 38-year-old HIV-positive woman & founding member of the 'Yabbo Wang Wu' HIV/AIDS support group, 25 May 2008.
[195] Interview with Evelyn Aber, 38-year-old HIV-positive woman & founding member of the 'Yabbo Wang Wu' HIV/AIDS support group, 25 May 2008.

> status they buy some drugs and take it all, and then they die. Instead of going for services, you just think of dying. [196]

She also considered neglect and violence as stigmatisation, and has known others living with HIV in the camp to have experienced it. She recounted the period prior to the introduction of ARVs:

> Some neglected their family members. They didn't take care of you. They beat you, they chased you away from the family. They didn't let you use their latrine or bathroom. Once they know you are positive, they didn't want to share with you, because they said you might pass the virus. [197]

In the days prior to ARV provisions, those living with HIV suffered from severe abuse and neglect. This was closely related to the visibility of the signs of HIV on the body, as Evelyn explained:

> If you were moving somewhere, if you are very thin, if you are passing away, they just point at you. They say 'you look at this person with AIDS. This one dying of AIDS, don't move closer to him.' They blamed you. They said that you are the one looking for the disease. What can I say? I might be a woman. I'm married, and if I'm inside a house, from where did I get it? Which means my man, my boss, is the one who brought it. But they still said I'm the one looking for it.[198]

The practice of blaming those with HIV for their condition had a strongly gendered element, with many women being blamed by families and communities for the deaths of their

[196] Interview with Evelyn Aber, 38-year-old HIV-positive woman & founding member of the 'Yabbo Wang Wu' HIV/AIDS support group, 25 May 2008.
[197] Interview with Evelyn Aber, 38-year-old HIV-positive woman & founding member of the 'Yabbo Wang Wu' HIV/AIDS support group, 25 August 2008.
[198] Interview with Evelyn Aber, 38-year-old HIV-positive woman & founding member of the 'Yabbo Wang Wu' HIV/AIDS support group, 25 August 2008.

husbands. Evelyn 's reference to her husband as 'my boss' indicated the unequal relationship of power in their relationship. Her account shows how stigmatisation is broadly conceived and covers pointing-out, as well as violence and neglect. It also shows that fear of transmission (instrumental stigma), as well moral accusation (symbolic stigma) were intertwined. In addition to blame for contracting HIV, a strong theme in Evelyn's account, as well as those of others, was the association of HIV with worthlessness and death. This is clear in the arduous work of educating, or 'sensitising', the community about HIV in the early phase of the HIV support group. As Evelyn recounted:

> When I would move with the community-based organisations, women within the camp, whenever they went to weed, would talk about me. And whenever someone comes and tells me about that I would get so annoyed, because they would call me a 'moving coffin' and they would call me a worthless person now. But then I made sure I told people my status everywhere I moved, so that stigma became something which they wouldn't talk about. It wasn't easy for me to go and interact or eat with them, because if they despised me, why should I go next to them and eat with them? [199]

The group of those living with HIV received no formal support until 2003. In this year AVSI, a Catholic NGO, started providing formal support and training home-based caregivers in a group called Women and Children First Organisation (WACFO), based at the local Catholic mission. However, it was the introduction of ARV provision by TASO in 2006 that caused the most radical change in attitudes. Once the services started there were higher numbers of people, though mostly women, coming out for testing. This led to high rates of disclosure. This form of disclosure was not necessarily verbal and was more often linked to the physical presence of patients at treatment sites. Evelyn explained:

[199] Interview with Evelyn Aber, 38-year-old HIV-positive woman & founding member of the 'Yabbo Wang Wu' HIV/AIDS support group, 25 August 2008.

> Yes, more people are coming out. Even now, most of them who are hiding, they are coming out, because they saw us, we are no different. We are staying safe. There is no sign [of the illness], we are staying very well. They are coming out. [200]

According to Evelyn, the treatment provision and the effects of ARVs were visible to the broader community:

> TASO, they are distributing the drugs, just openly in this health centre there, just open, not in a hidden place. Most of the people come see how TASO looks like. They come and see people are very healthy. People are coming. When TASO started their services, people came. Most of them wanted to know what services these people are doing.[201]

Evelyn claimed that this had positive effects on the stigmatisation. She said: 'These days stigmatisation is missing, because they don't even think about it so much, like that time. We are now staying free.'[202] However, other stories sat uneasily alongside these claims. While verbal stigmatisation had been reduced, there was still the threat of violence against those who did not disclose, particularly in sexual relationships. Evelyn recalled:

> We lost even three or four women, who didn't disclose their status to their fellow friend [i.e. sexual partners]. They killed those women. In 2006 we lost two, in 2007 we also lost two…they were beaten to death, because they said 'you don't

[200] Interview with Evelyn Aber, 38-year-old HIV-positive woman & founding member of the 'Yabbo Wang Wu' HIV/AIDS support group, 25 August 2008.
[201] Interview with Evelyn Aber, 38-year-old HIV-positive woman & founding member of the 'Yabbo Wang Wu' HIV/AIDS support group, 25 August 2008.

> tell them the truth about whether you are living positive, and then you infect people.'[203]

These women were friends of Evelyn's, and she based her account on the accounts of the family of the murdered women, as well as witnesses. The murderers, although known by the families and the public, were never punished. Evelyn explained:

> The parents of the woman took the woman and buried her. The man is still around, and he's still in a school. He beat the woman and when the parents went to pick up the woman and go with her to the hospital, and while entering the hospital she died. The woman was pregnant. The woman was called Agnes. The lady was beaten by the man, and her husband said the woman refused to tell her status, and let him kill her. The other case is Pauline. She was a good lady. She was getting the services from WACFO. WACFO was giving her assistance. They gave her money and she went and boozed, taking alcohol. Then from there she was misbehaving with a man, and the man decided to beat her until she died. It was in 2006. We heard that she died, because in the daytime she was OK. And we heard she was beaten in a bar, where they were selling alcohol. Then they beat her until she died. Nobody did anything. The parents took the body and buried her…you know with bars, there are so many people. They didn't do anything.[204]

Evelyn explained the lack of action taken against the murderers by the local police or army as follows:

> They don't bother, they say you are a killer. We think that's what they might be thinking, because they don't react. A human being died, without even reacting.

[203] Interview with Evelyn Aber, 38-year-old HIV-positive woman & founding member of the 'Yabbo Wang Wu' HIV/AIDS support group, 25 August 2008.
[204] Interview with Evelyn Aber, 38-year-old HIV-positive woman & founding member of the 'Yabbo Wang Wu' HIV/AIDS support group, 25 August 2008.

> Someone is beaten to death, and they don't even take action. What does it mean? Hm?[205]

Evelyn's story revealed that while it had become easier to be open about HIV status, there were dangers for those, particularly women, who try to keep their status secret under conditions where secrecy was extremely difficult. The visibility of those with HIV was changing perceptions of the disease, but created new fears about those seeking treatment.

The stigma laws

A primary concern for those living with HIV was protection from the violence that results from stigmatisation. Evelyn's account revealed that there was little protection from direct violence arising from HIV disclosure. Camp leaders did, however, provide limited protection from stigmatisation to those with HIV. A widely held perception across different camps was that there was a law (*cik*) against stigmatising. This is in part due to the ambiguous concept of *cik*, which can refer to both a social norm and a state law. This 'law' against stigma, although never written down, was enforced to an extent by local leaders. I found accounts of these stigma laws in diverse areas including Pabo, Lacor and Ogur sub-county in Lira, though not in Opit. Below are some views referring to this 'law':

> The rate of stigma has reduced. Because the office of the LC3 (local councillor) has put a rule against stigmatisation, and whoever stigmatises you as a way of

[205] Interview with Evelyn Aber, 38-year-old HIV-positive woman & founding member of the 'Yabbo Wang Wu' HIV/AIDS support group, 25 August 2008.

> stopping you using the latrine, you go there to the office and they will punish him.[206]

A member of the LC's office in Pabo confirmed that there was no formal by-law against stigmatisation although they were considering introducing one[207]. However, the LC's office in Pabo did provide some protection against stigmatisation. For instance, Betty Akello recounted a story of taking a complaint about a neighbour who was stigmatising her to the LCs office (we actually bumped into Betty at the office after she had laid the complaint). The woman was called in front of the LC3 and threatened with imprisonment, after which she stopped troubling Betty. 'She respects me now' Betty told us.[208] I encountered the idea of there being a law against stigma in several different sites, as the comments below show:

> They have made a law here in the camp against stigmatisation. If you are caught stigmatising someone or saying that this person is safe and this person is sick then they arrest you and they apply the law. I can't say properly which people enforce this law of not stigmatising, but they always ring a bell and when the whole community comes together then they pass on a rule. They tell you that such and such a person is no longer welcome in the camp. I don't know the people or organisation who enforce this, but they call all the zone leaders and the camp leaders and tell them what is on the ground. Then the whole camp would be warned against it. There is no stigmatisation in the camp, even for those who were formerly abducted. They have put them into groups and they are training even the formerly abducted so there is no stigma attached to anyone, be they an HIV-positive person or a former abductee (HIV-positive woman, Lacor).[209]

[206]Focus-group with David Kilara, Lamunou Cecelia & Obal John, mixed-gender HIV-positive respondents, Pabo, 22 February 2008.
[207] Interview with Kenneth Nyeko, Councillor LC3 Office and member of sub-county AIDS task force, Goya Parish, Pabo, , 27 August..
[208] Focus-group with Joseph Oliel, Betty Akello, Beatrice Akello, Olga Scayo& anonymous soldier. Mixed-gender HIV-positive.Pabo, 24 June 2009.
[209]Interview with Dawn Ano,76-year-old woman, traditional birth attendant, Lacor, 1 April 2008.

Ideas of the stigma law have also circulated in town areas, though they seem to derive from the rural areas and camps. As one woman, displaced to the town, explained:

> Nowadays there is a law (*cik*) here; nobody stigmatises. The law educates us that if you are stigmatising it's the same as stigmatising yourself. People have been warned. They put you in front of a crowd and warn you. I have even heard of someone going to prison...I've never seen it happening, but in Oneng where I used to live people would not even eat with people with HIV and some of these people were put in front of a crowd, educated and warned because these people are humans like us.[210]

> In the camp people used to fear the law. The camp leader used to say if you abuse those with HIV, you must report to him, that's why people feared abusing (HIV-positive woman, Walela Parish, Lira).211

The latter quote was from Walela parish, Lira. There we also came across a camp leader who claimed to have instituted a law against stigma during his time as camp leader. He explained its genesis:

> I went to a workshop in Lira, and from there they educated us that we should tell the community that we should stop stigmatisation of people who are living with HIV and people who have returned from the bush. And so when I came back from the camp I told my community that whosoever will be caught stigmatising or abusing the sick or the returnees will be dealt with accordingly, because this could be a reason why people don't want to come out and test.[212]

[210] Focus-group with Margaret Akidi, Jennifer Alaro, Acan Lily, HIV-status unknown, Layibi, Gulu District, 22 June 2009.
[211] Interview with Rose Akello, 36-year-old HIV-positive woma, Walela Parish, 15 March 2008.
[212] Interview with Cipriano Okello, former Walela camp leader, Walela Parish, Lira, 15 March 2008.

This reveals how, in the exceptional spaces of encampment and conflict, coercion was used to protect those with HIV. The application of these measures was not consistent across camps. More broadly, the idea of a law against stigma was part of an emerging discourse around HIV in Northern Uganda, in which stigmatising those with HIV was becoming socially unacceptable. Local leaders who supported those with HIV helped accelerate this trend, but it was also driven by the slower processes of education and disclosure that I have outlined in this chapter, in which the provision of ARVs provided a major role. Changes in stigma were a result of a complex interaction of biophysical changes from ARVs, emergent forms of biosociality, as well as the social and legal spaces of the camps. If we revisit the idea of 'therapeutic citizenship' as explained in the previous chapter, it becomes apparent that, while there were few who framed the social transitions of HIV in terms of citizenship, the above evidence does show greater support by local leaders and more confidence by those with HIV in seeking protection at a local level. This protection was limited, as discussed above due to reluctance by the police or the army to protect victims of violence emerging as a result of stigma. Moreover, the language of stigmatisation itself became infused with militarism. This is discussed below with reference to the case of Opit.

The soldiers of the priest: The social and moral space of displacement

We have discussed how spatiality, observation and the disease-course are important for understanding the changes in stigmatisation catalysed by ARVs, but have yet to establish how these changes came to figure in the social world of the camp. I will explore two dimensions of this problematic: first, I consider how the language of stigmatisation reflected the lived experience of the camp; and second, I explore how the changes in stigmatisation reflected the ambiguous position of those with HIV in social and symbolic power relations – perceived as both killers and victims. I will explore

these issues through a case study of the camp Opit, introduced in the previous chapter. This case study also illustrates many of the themes discussed above.

Father Alex of St Joseph's Mission, Opit, described the situation prior to the provision of ARVs:

> It would seem through my experience in the beginning, the people with HIV/AIDS were treated like dogs. People feared or despised them: 'Why did you get this disease?' and so on. Also, in the same family, you could find that they were chased away also from the group, especially when they came in the camps in 2004, 2005. The people were afraid to get the disease, so they were pushing them away, not to go to the same toilets. They were despised people.[213]

The situation changed with the introduction of ARVs. Alex said,

> They saw the benefit of the drugs. We prepared the families [of those with HIV] to welcome them, and we taught them how they could get and how they could not get this disease, but not to chase them away. So you find that the community and the families started to welcome them. [214]

In my visits to Opit, and in interviews, I found that stigmatisation towards those with HIV was generally low in intensity, aside from some extreme cases, and that HIV/AIDS seemed an accepted part of life in the camp. However, a very common form of insult, arising from the provision of support by the mission, was *mony pa padi* (or simply *mony padi*) meaning 'soldiers of the priest' or 'soldiers of the Father', referring to Father Alex. This label was something often experienced by those living with HIV in Opit – sometimes in an insulting

[213] Interview with Father Alex Pizzi, Priest, St Joseph's Mission, Opit, 12 December 2007.
214 Interview with Father Alex Pizzi, Priest, St Joseph's Mission, Opit, , 12 December 2007.

manner, at other times more in jest. However, the label 'the soldiers of the priest' as a form of stigmatisation revealed how stigmatisation was embedded in the language and experience of conflict in the camps. It drew attention to the associations between those with HIV and soldiers or rebels (both can be described as 'mony'[215]), as well as the association between those with HIV and the mission. The label was universally experienced by those with HIV in the camp, but also widely known by others.

I spoke to a group of young men between 16 and 19 years old who lived in Adak, a transit camp near Opit. They had all grown up in Opit and their HIV status was unknown. Their knowledge of HIV and its transmission was good, and several of the young men had had family members with the disease. They claimed not to stigmatise those with HIV, though when asked about the *mony pa padi* they all knew the label. I asked them to explain what it meant. These are some of their replies:

> *Mony pa padi* are those who go to the priest's home for help, food, or drugs.
>
> *Mony* are people who kill. *Mony,* if they're for the government they keep you, or, if not, they kill you. It's because those people are with the father, so they still kill people.
>
> It's because whenever I go to a dance hall, these people are those who pick up young girls and infect them. It's because they are on ARVs, so they look healthy.
>
> Sometimes, these females from *mony pa padi* look for young boys without relatives and keep them.

215Also described by Odonga (2005) as a 'war, campaign, or raid.'

> It's very easy to see and know them at the mission, because whenever I go there for casual labour at the mission I see them.[216]

These statements revealed much about the forms of stigmatisation arising in the camp, the language linked to both the visibility of those with ARVs and their potential threat. Although these boys and young men expressed sympathy for those who were positive, they also felt threatened by them. These contradictory sentiments are revealed in their statements about friends who were HIV-positive:

> Those who are HIV-positive should not over-think. So we go to comfort them, so they go to get medication and live longer.
>
> Sometimes we talk to them, and say 'don't worry about death, maybe me who is not infected will die faster than you.'[217]

These statements revealed that HIV is felt both as threat – associated with conflict and displacement – and as a shared social condition.

The label *mony pa padi* was embedded in a complex set of associations: soldiers and rebels were associated with violence and death, as well as with the spread of HIV, and there was a widespread fear among local communities that those with HIV would deliberately kill people. Furthermore, those with HIV were associated with the local priest, Father Alex, and the church. The label was thus not metaphorical, but metonymical: those labelled and marked as HIV-positive came to be associated with a web of meanings deriving directly from the experience of life in the camp. The ill and healing bodies of those with HIV, which were

[216] Focus-group with male youth, HIV-status unknown, Adak transit camp, 15th June 2009.
[217] Focus-group with male youth, HIV-status unknown, Adak transit camp, 15th June 2009.

visible in the camp setting, came to signify the fears and uncertainty of the camp. Yet precisely because of these associations, responses of care and of stigmatisation co-existed. Stigmatisation, rather than being an ideology or set of beliefs (Deacon *et al.*, 2005), can be viewed as a social and linguistic response to the uncertainty of life and fear of death.

The experiences of those labelled *mony pa padi* were telling. A strong support network developed in the camp, and the mission became a place of meeting and gathering. In 2008 Santa Akello was a thirty-two-year-old woman living openly with HIV in the Opit camp. Her most intense experience of stigmatisation was when she was very sick, suffering from a rash, diarrhoea and a cough. A neighbour in the camp insulted her everyday, telling her not to use the latrine. 'When I was sick, they used to tell me that I was useless, and I will die soon.' [218] As we have seen, the theme of uselessness was a recurring insult levelled at those with HIV, in Opit and elsewhere in Northern Uganda. However, there were major reductions in stigmatisation targeted at Santa and others. Santa used to sell pancakes in the local market. She said:

> Even now, there is not much stigmatisation. When I had just tested, I used to make pancakes. When I would take these pancakes to the market, people would refuse to buy them. But nowadays, when I take my pancakes to the market, people will buy them. People know the real cause of the disease now. Formerly they used to call us 'soldiers of the priest', but now it is going down.[219]

218 Interview with Santa Akello, 32-year-old HIV-positive woman, Opit, 3 March 2008.
219 Interview with Santa Akello, 32-year-old HIV-positive woman, Opit, 3 March 2008.



Santa Akello and child

The stigmatisation that Santa had experienced had been fundamentally related to physical illness rendering her useless, as well as fear of contamination, and had little to do with accusations of sexual or moral deviance. 'No one has said that I have done something bad/immoral (*rac*). The nature of this disease is that even your relatives can neglect you'[220], she said. Santa's primary experience of stigmatisation had been related to so-called 'instrumental' stigmatisation – the fear of contamination and her lack of productivity, her 'uselessness'. With her health improving on ART, the stigmatisation had lessened because the bodily signs of illness had retreated.

Resistance Identities

From the socialities developing around ART and as a response to stigmatisation a 'resistance identity' (Parker and Aggleton, 2003:19) began to form among those with HIV – an identity formed in response to social exclusion. In particular, those with HIV often stressed that HIV/AIDS is a general condition, thereby inverting the stigmatising gaze. As Beatrice Arach[221] of Pabo said:

> As a group we always have meetings every Sunday. When we are returning to our homes they start stigmatising us saying 'look at these HIV patients. They are now coming back from their meeting.' [However] I don't have the fear in my heart to move in any place. Because the finger which points at me is one, and the rest are pointing back at him. So I don't have any fear.[222]

[220] Interview with Santa Akello, 32-year-old HIV-positive woman, Opit, 3 March 2008.
221 Pictured on the front cover
222Interview with Beatrice Arach, woman living with HIV, Pabo, 15 July 2008.

As we have seen in the previous chapter, HIV-related identities sometimes were framed in idioms of family and kinship. On occasion, the very notion of HIV-infected blood was constitutive of an identity defined by contrast with those who had 'clean blood'. This is illustrated by the story of Esther Abura, a woman in Ogur. Esther explained that she had a brother-in-law. Once she wanted to borrow an ox to use for ploughing, but when she went to ask her brother-in-law's wife, his wife became angry and started abusing Esther. The wife accused Esther of begging for the oxen as a pretext for seducing her (Esther's) brother-in-law – an allegation which the wife considered particularly damning given that Esther was HIV-positive. Esther said: 'That is why I am so bitter now. I don't want to involve myself with those who have 'clean blood', with those who are not infected. I stand alone and identify myself with being HIV-positive.'

An identity formed in response to marginalisation – a resistance identity – can also become a project identity – an identity which seeks to reshape social forms (Parker and Aggleton, 2003:19). This task is not simply a project of those with HIV. It is also a project by the members of the community, who have come to see HIV as a broader social problem, linked to conflict and displacement. The examples discussed above demonstrate that this response was often ambiguous and contradictory across different sites in Northern Uganda. Those with HIV became the bearers of a series of social ills: for this they were both excluded and cared for. They were excluded because they represented the fears and anxieties of a community suffering from displacement, marginalisation, and militarisation, and they were cared for because they were also viewed as the victims of these processes. The rollout of ARVs took place in this social and moral world, and responses to their effects were shaped by it.

Conclusion

My objective here has been to outline how the specific spatiality of the camp environment shaped the social efficacy of HIV/AIDS treatment, and influenced the identification of those with HIV and the changing forms of stigmatisation as a social process. I have argued that socio-spatial disclosure, along with forms of voluntary disclosure, led to reduced stigmatisation of those living with HIV. The positive effects of ARVs were very visible to the community at large, encouraging many to come out for testing and seek treatment. However, the initial introduction of ARVs could involve an intensification of stigma, as those living with HIV became visible and were thereby vulnerable to labelling and marginalisation. Moreover, while previously entrenched forms of stigmatisation may have lessened, new forms of stigmatisation related to the provision of ARVs arose. Furthermore, the way in which HIV was given social meanings was linked to the visibility of those who were HIV positive and the discourses around HIV, morality and conflict that circulated in the social space of the camp.

The spatial dynamics of disclosure, in which disclosure is imposed through visibility at health centres or through seeking material and social support, may arise in settings other than displacement camps. For instance, a study by Whyte *et al.* (2010) in rural Eastern Uganda observed similar dynamics and complexities of disclosure. However, the extreme spatial congestion of the displacement camps, as well as widespread reliance on food and other material support due to the conflict, makes the camps an exceptional social space and made these dynamics more pronounced. In my own comparative analysis, these dynamics were more extreme in the camps than in towns or other rural settings. The theory of socio-spatial disclosure proposed here could, however, be applied to non-conflict-affected settings.

This chapter has argued that the analysis of stigmatisation must also involve an analysis of complex socio-spatial dynamics. There is no simple linear relationship between the provision of ARVs and the lessening of stigmatisation. The relations between observation and the bodies of those living with HIV, the spatial formations which shape patterns of observation, and the social spaces in which treatment interventions take place are central to understanding the effects of ARVs on stigmatisation. However, these changes evolve in terms of shifting social norms. The idea of the 'stigma laws', I have argued, showed this. While few by-laws were actually enforced, the concept reflects a shifting normative environment in which stigmatisation of those with HIV was becoming unacceptable within local communities. This was partly as a result of the support of local leaders, but also strongly linked to the transformations in bodies and social organisation engendered by the introduction of ARVs into conflict-affected areas of Northern Uganda.

Chapter Five: 'God's Hands are in Our Drugs': Religion, Clientship and the Power over Life.

Introduction

This chapter develops the themes of clientship and power. I argue that ARV interventions have been deeply embedded in value-based and ideological approaches to ART in Northern Uganda. To support this argument, four claims are developed: first, ARV interventions in Northern Uganda were shaped by the agendas and resources of global donors channelled primarily through NGOs; second they were shaped by faith-based concerns and moral judgements; third, these moral evaluations shaped clientship relations; and fourth, ARV interventions elicited contestations over medical pluralism at a local level. In developing these claims, I illustrate how ART interventions operated in a multi-scalar fashion, linking international donors and local treatment providers with the life-worlds of patients. These linkages may not be exclusive to conditions of displacement, but they have been shaped by local histories of conflict and displacement. Here I argue that with the disruption of relations of kinship, obligation and authority that accompany displacement, biomedical interventions have greater flexibility to re-establish relations of authority. Also, continuing the discussion in Chapter One, I will explore how forms of medical pluralism persist in Northern Uganda, while demonstrating that Acholi rituals of healing have been increasingly excluded from the treatment of HIV/AIDS.

This chapter focuses on the faith-based programme of Lacor Hospital and the Comboni Samaritans, but argues that relations of moral authority are not exclusive to faith-based

programmes. It situates this analysis within the conceptual frame of biopower and continues the argument of Chapter Two by demonstrating that ARV interventions are part of a weak form of biopower rather than part of the large-scale surveillance and management of life. In particular, therapeutic practices are situated within what Vaughan (2007:132) terms a 'medico-moral' discourse in which biomedical and moral concerns are interwoven.

Clientship, morality and biopower

First, I will outline a theoretical perspective on clientship, authority and biopower in order to situate the evidence of this chapter and develop the approach outlined in the introduction. Biopower is conceived as the 'power to foster life or disallow it to the point of death' (Foucault, 1998:138). It involves the ways in which certain individuals and populations are allowed to live, while others are abandoned. Furthermore, the life and well-being of the population, including its health and sexual life, became the direct object of forms of government. Biopower operates through two modes: the 'biopolitics' of governing populations and the 'anatamo-politics' of regulating individual bodies, although in practice these form a continuum (Nguyen, 2010:112, Lock and Nguyen, 2010:24-25). Sexual relations are a target of biopower as, through them, the intimate lives of individuals and the reproduction of population are bound. As Foucault writes: 'at the juncture of the "body" and the "population" sex became a crucial target of a power organized around the management of life rather than the menace of death' (Foucault, 1998:148). This insight is critical to the analysis of antiretroviral treatment: antiretroviral interventions aim both to sustain the life of the population and to regulate the sexual lives of individuals.

As Lock and Nguyen (2010:5) argue, value judgements implicit in health interventions are often veiled; they write that 'biomedical technologies are embedded in the social relations and moral landscapes in which they are applied.' In this vein, biomedical interventions should not be considered simply the imposition of an institutional or technical agenda. They involve the contestation of biopower in terms of both practice and knowledge (Rose, 2007:54) The relation of biopower to morality is central in this analysis. Morality is not simply about promoting the good, but also about regulating social relations and harm (Heald, 1999:4-5). Morality intersects with biopower in constituting social regulations and the governance of life at the levels of both discourse and practice. In particular, sexual morality and power is tied up with gender relations and strategies of social reproduction (Kabeer, 1994:227). The construction of subordinated, gendered identities can legitimate physical violence against women as well as reproduce relations of gendered domination (Momsen, 2004:98). Morality plays a dual social role: it can form the basis of social regulation and coercion, and also serve as social memory through which societies can cope with upheaval and uncertainty (James, 1999:145-146).

Biopower– conceived as the regulation over life and sexuality– may intersect with, and also disrupt, existing gender relations and modes of social reproduction. Biopower in medical interventions may generate medico-moral discourses. Megan Vaughan (2007), in her book *Curing their Ills: Colonial Power and African Illness*, analyses the forms of contested power relations in British colonial and medical interventions. Her analysis of both state and missionary interventions still has relevance for study of contemporary biomedical interventions. In particular, it illuminates the ways in which the biomedical and moral infused one another, and became contested. The 'medico-moral' discourses were never singular, but disease became the focus of moral contestation and part of local power dynamics (between

colonialists, missionaries and local elites, as well as between men and women) (Vaughan, 2007:Ch 6). The infusion of the medical and moral is not simply a colonial artefact, but a social reality that is a major part of contemporary responses to HIV/AIDS. For instance, Behrend, writing on Western Uganda, claims that 'although officially promoting a medicalised concept of AIDS, many of the Christian churches in practice use concepts of sickness and healing that are based on supernatural powers, the powers of the Christian God and his adversary Satan' (Behrend, 2007:46). These insights will be discussed below with reference to Northern Uganda.

These relations of power and morality may permeate ART interventions at an institutional, provider-client, and community level. Public health literature on the 'patient-centred approach' aims to prioritise the perspectives of patients in the clinical encounter, through involving patients in decisions, improving communication between patients and treatment providers, and being open about adverse events (Coulter, 2002:648). This body of literature and practice, developed in the United Kingdom and applied mainly to first world health systems, aims to shift medical care away from the paternalistic attitudes of physicians as authority figures towards patient concerns (Ganz, 1997:1169, Coulter, 2002:650). The approach is useful insofar as it acknowledges the relationships of authority that exist in the clinical encounter. It is limited, though, in that it places the locus of authority primarily in the encounter between physician and patient. It neglects how the provision of medical treatment itself, particularly in community-based strategies, is embedded in local social worlds and webs of authority. Furthermore, community-based strategies involve an array of provider-patient encounters outside of the physician-patient relationship, including those with counsellors, field officers, and community adherence monitors.

Emergent perspectives on clientship with reference to HIV treatment, introduced in Chapter Three, are illuminating in this regard. Understanding the social effects of biomedical interventions on relations of authority requires analysing more than the doctor-patient relationship and also taking into account the broader networks of social relations in which medical interventions are embedded. The patron-client relationship of the treatment provider and patient is likely situated within other patron-client relationships, as Meinert *et al*., (2009: 205) argue with reference to HIV treatment programmes in Uganda. With regard to these clientship relations in Eastern Uganda, Whyte (2009:239) emphasises the ways in which treatment programmes become part of the home-life of patients and are based on relations of reciprocity between providers and 'clients', rather than stressing a focus on biopower. She furthers this analysis, making the distinction between 'therapeutic clientship' - as a set of relations based on reciprocity - and the 'the rights and obligations' of 'therapeutic citizenship' (Whyte, 2009:242). As Whyte observed in eastern Uganda, ART programmes have expectations of their clients, including taking their medication, 'living positively', eating well, avoiding alcohol, engaging in safe sex and not worrying too much (Whyte, 2009:239).

While I agree that reciprocity and expectation are part of the therapeutic relationship, I do not consider these exclusive to relationships of authority. Rather, relations of reciprocity may exist alongside those of authority. In this sense 'clientship' is implicated in relations of biopower, though this may be a weak form of biopower: that is, the management and regulation of life and sexuality is far from totalising or dominant, but is part of a network of relationships of authority including family, gender relations, and political or military authority, for instance. Furthermore, the morality in medical interventions may form part of medico-moral discourses circulating more generally within a community. Nonetheless, the

form of power exerted is significant not only in terms of the regulation of life, but also in limiting choices. For the word 'client' itself does not only indicate a patron-client relationship, but also may have the connotation of a consumer or agent who can choose a particular service. However, 'clients' in resource-limited settings healthcare choices may be limited: 'clients' may not be able to choose health-services that open up a spectrum of options. Aside from the limitations of resources, this has a moral aspect, particularly with contraceptives and reproductive health. The ways in which faith-based morality limited these choices in Northern Uganda is explored below. I will start the discussion with an account of PEPFAR, the largest funder of ARV programmes in Northern Uganda, and then move on to consider provider-patient relationships before discussing how treatment interventions are embedded in relations of authority and value at a community level.

Biopolitics and Humanitarianism

ART interventions were not simply technocratic fixes to an adverse situation; they were tied to the sets of influence and power operating in the region. While they were not dependent on individual politicians, their activities were shaped and constrained by the wide array of humanitarian, military and political actors in the region – and operated between state and nongovernmental agendas. Furthermore, the expansion of ART in the region came with the power to foster, survey and regulate the life of large numbers of people. Further questions therefore arise: to what extent are ART providers implicated in the biopolitics of humanitarianism? How has access to life-saving treatment been shaped?

The linkage between biopower and humanitarian intervention has been explored by writers such as Duffield (2008) and Fassin (2007). Duffield (2008:28) argues that in the absence of

state services, particularly in conditions of conflict, development agencies manage the lives of the population in a form of 'contingent sovereignty' which is a 'zone of donor and NGO experimentation in the biopolitics of state reconstruction, basic needs and self-reliance'. Humanitarian interventions involve the management of populations, for instance through the management of camps, and humanitarian organisations make decisions about which lives 'it is possible or legitimate to save' and this may involve 'selecting AIDS patients to be given antiretroviral drugs for lack of resources'(Fassin, 2007b:501). Decisions around whom to treat constitutes a power over life. Furthermore, the divergent programming of state and non-state actors, discussed above, shapes who has this power.

The strength of NGO organisations *vis á vis* state health services, discussed in Chapter Two, illustrates the degree to which this power was given over to non-state actors. This was a result of both local pressures on health-services, but also of global trends in health-financing. The arrival of ARVs in Northern Uganda coincided with the rise of the new Global Health Initiatives (GHIs) – particularly US President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, TB and Malaria – which led to increased funding for ART worldwide (Shiffman, 2007). The availability of both GHI funding and humanitarian support helped kick-start ARV expansion, but the multitude of different models operating also strained services and co-ordination. The rapidity of the expansion meant that NGOs, rather than state services, garnered the bulk of resources and major global funders like PEPFAR expressed reticence to work with the state and preferred to channel resources through NGOS (the exception being the Global Fund). [223] This was part of a worldwide trend

[223]Interview with Dr Alex Coutino, former National Director of TASO, Kampala, 2 July 2009.

in AIDS financing,[224] but did little to address the deleterious condition of state health services in Northern Uganda[225].

Non-governmental provision of ARVs constitutes a form of biopower related to what Nguyen (2010: 113) - with reference to HIV/AIDS programmes in West Africa - terms a ' 'nongovernmental' biopower that disseminates through a patchwork of international organizations and community groups.' This took a specific form in Northern Uganda as a result of the complex emergency, which was shaped by the following factors: the strong presence of humanitarian organisations and their associated co-ordinating mechanisms; the security orientation of the state along with the associated weakness of its administrative structures and its lack of infrastructural and staff capacities; and finally, the forms of social organisation arising as a result of displacement. The latter was particularly shaped by the widespread dependence of population on external actors.

The spatiality of health surveillance in Gulu Town is illustrative of the ways in which the HIV response fits into power relations in the region. Across from the main district headquarters, there is a small building housing a reception area and two offices with cracked windows. This is the office where government census and population data is kept. It is hidden behind a large mango tree. In this building is the office of the District HIV/AIDS Co-ordinator. On several occasions I wandered into the office with nobody in it. In one office, on a virus-riddled computer, the district population data are kept. The setting was markedly different from the air conditioned offices of the United Nations Office for the Coordination of

[224] PEPFAR has come under intense global criticism for implementing top-down disease-specific programmes through NGOs while bypassing state actors (Sridhar and Batniji, 2008: 119).
[225] For instance, in 2008, Gulu had only 25% of required human resources in health (Interview with Solomon Fisseha Woldetsadik, Head of WHO, Gulu Office, Gulu Town, 23 August 2008.)

Humanitarian Affairs (UNOCHA), which was doing population monitoring, of UNHCR with their on-site Irish pub, the leisurely buildings of WHO or even of the TASO buildings, where two offices were dedicated to data collection and research management. The buildings reveal something deeper about the structure of governance in this post-conflict area: the management and surveillance of the population was primarily a function of external agents, with the district government playing a secondary role. This was particularly visible in the health care sector. WHO was essentially responsible for all data collection and surveillance regarding the various epidemics of hepatitis E, cholera, malaria, and measles. There was no centralised co-ordinating mechanism for data on HIV/AIDS. From 2006 onward the cluster system was introduced on the recommendation of the Humanitarian Response Review commissioned by Jan Egeland, the UN Emergency Relief Co-ordinator (Morris, 2006). While the UNHCR takes responsibility for leadership on emergency shelter, camp co-ordination and management, and protection, the WHO took leadership of the health cluster in Northern Uganda. The Health, Nutrition and HIV/AIDS Cluster Group was established in 2006. The cluster was oriented towards the health emergencies of the post-conflict period, yet had no mechanism for the planning and monitoring of chronic illness and patient retention

Even the TASO and St Mary's programmes, both funded primarily by PEPFAR and reporting to the Centre for Disease Control (CDC), did not share data. NUMAT, which provided support to state services, complained that other organisations were not sharing data.[226] The state health surveillance system was in disarray, with wide-scale non-reporting of clinic data in spite of WHO guidance with the system. Data collection on population and health was primarily conducted in WHO, UNOCHA, UNHCR, St Mary's and TASO offices, as well as the more distant offices of donors in Kampala and further afield in Atlanta, where the CDC

[226] Field notes from workshop with representatives of TASO, St Mary's, and NUMAT, July 2009.

headquarters are, rather in the offices of either the district or national state. The management of data is an indicator of the distribution of resources in the region. It also indicates where power lies in producing knowledge about the region, with NGO resources far exceeding those available to governmental actors. There is a cyclical relationship between NGO programmes and knowledge that these ARV programmes illustrate. The ARV programmes that were best financed (St Mary's, TASO and NUMAT) also had the capacity for rigorous data collection and analysis, as well as the financial resources required to publish the results. Similarly, all food assistance evaluations, including the Food for Health Programme, were conducted by non-governmental actors.

The point here is not simply that the state was under-resourced in relation to non-state actors but also that it became marginal both in the production of knowledge about the region as well as in the day-to-day surveillance and monitoring of those with HIV. Furthermore, what distinguished the non-governmental ART interventions from many large-scale humanitarian interventions was the reliance on extensive community involvement and education. Within the nexus of humanitarian organisations their position was relatively unique: they were part of humanitarian surveillance and co-ordinating structures, but were also involved in developing intimate relationships with the population through counselling services, community groups and so on. For these reasons, ART organisations were one channel through which the connections between the intimate lives of the displaced and their biological sustenance were connected to a broader complex of state, non-state and humanitarian actors.[227]

[227]Another channel is, for instance, the widespread and potentially problematic use of trauma counsellors at the rehabilitation centres for former rebels (Allen, 2006a: Chapter Three)

Foucault, in his analysis of biopower and 'governmentality', drew the connection between statistical and epidemiological surveillance and the governance and management of populations (Foucault, 2007b:104). These forms of knowledge constitute the population as an object to be managed and regulated. However, given the fragmented and incomplete nature of population surveillance in Northern Uganda, it must be concluded that health surveillance constitutes a very weak form of biopower. The collection of data and production of knowledge reveals where the resources and forms of surveillance lie, and the ways in which local state actors have become peripheral. ARV interventions are embedded in the biopower of humanitarianism in that they are involved in the management of the life of the population through a matrix of co-ordinating agencies, while at the same time are intimately involved in the anatomo-politics of nurturing the lives of individual bodies through treatment and nutrition, as well as the provision of moral and psychological guidance. The moral agendas of global funders intersected with local interests and institutions, as is discussed below.

Donor agendas in local context

US President George W Bush's introduction of PEPFAR in 2003 produced a major boost to the provision of ARVs in Northern Uganda, but also encouraged a highly moralised approach towards prevention and treatment. Bush's announcement of $15 billion for HIV/AIDS came one week before the invasion of Iraq, and so played into a global public relations campaign, promoting an idea of US foreign policy as 'compassionate as well as tough' (Epstein, 2008:220). PEPFAR managed to garner the support of Conservative Congress representatives (Pisani, 2009:191-192). The PEPFAR programme would come to form part of what Alex De Waal calls the 'salvation agenda' of American foreign policy, rooted in

Christian charity, whereby 'humanitarians act according to a script in which they bring some kind of salvation to unfortunate victims' (De Waal, 2006:63). Money was limited to providers that supported family planning and promoted condom use; one third of prevention money had to go to abstinence programmes. In this endeavour faith-based groups were defined as 'priority local partners' (PEPFAR, 2005).

Uganda was no exception. The moralised intent of PEPFAR money played into the conservatism and religious agenda of local politicians and helped provoke a shift in government policy away from providing condoms to promoting abstinence. Pressure was placed on PEPFAR implementing agencies to invest money in faith-based and abstinence-based ARV provision. Although government services continued to provide condoms, the funding catalysed the expansion of evangelical and faith-based groups (Boler and Archer, 2008:102). According to an official with in-depth knowledge of the funding process, St Mary's Hospital Lacor was 'low-hanging fruit'.228 It was to become the largest non-governmental provider of ARVs in Northern Uganda. Such funding strategies did not simply involve the top-down enforcement of religious 'dogma' as some critics have argued (Pisani, 2009:187). Rather, the moral imperatives of global funders intersected with the moral agendas of local health-institutions.

At St Mary's Hospital Lacor, the medico-moral discourse was to shape institutional practice and policy, even among those who did not agree with it. Doctors adopted a referral system whereby they would give information around contraceptive options, though they could not provide these directly. These dilemmas were particularly acute when dealing with HIV-positive patients in discordant relationships (one partner positive, the other negative). In such

[228]Interview with anonymous advisor to the Centre of Disease Control, Uganda, 2009.

cases, it seems some doctors provided condoms even where this meant breaking with formal policy. For the most part, however, policy was to shape practice. Dr Barbara Nattabi, a doctor who worked with the Lacor AIDS clinic from 1997 to 2006, and who is a Roman Catholic herself, explained:

> What was very clear when I worked in Northern Uganda was we had a dilemma of reproductive health for all patients, particularly for HIV-positive patients. The ideological background for the biggest hospitals in Northern Uganda is that they are Catholic-based and Catholic-run and in that sense we know the Catholics don't condone forms of family planning. They have natural family planning methods, and they don't believe in abortion, and all sorts of other things. So you have a situation where you have an HIV-positive patient, at most you can discuss, but you cannot provide the full reproductive health care to which they are entitled. And this is a moral dilemma for the whole country because if you have some of the biggest health providers in the country who provide good and adequate health care in one sense, but at the same time cannot provide other healthcare because of their ideological beliefs, you may have a situation where patients lose out, and may not be able to access certain care. So this I think was both a problem for the hospitals in Northern Uganda which are Catholic based, but also the PEPFAR programme which also has a Christian ideology behind it. Most of the people they're providing drugs to, they're not providing reproductive health options. This is a dilemma for us who are Roman Catholics. Because even during our training and interaction with patients we always have this issue of what is the best we can provide to our patients. We were taught as doctors if a patient needs reproductive health options as a doctor you can tell them where to get them from, but it's particularly difficult if you're the one giving basic health care to the patient, and have to refer them somewhere else. We did not have many debates about it, because we knew the ideology of the hospital. Maybe now people are thinking more about it in the light of prevention of mother-to-child transmission (PMTCT) and ARV resistance transmission, people are now beginning to think about it more, because they also think that HIV patients not only need to protect other people, but protect themselves from super infection

> [i.e. drug resistant viral strains] . This debate is coming out more in the country, but the Catholics are holding out.[229]

What is clear from this account, and from conversations I had with other doctors working with Lacor, was that there was not simply an unthinking application of religious 'dogma.' Rather, doctors had negotiated an uncomfortable line between public health issues (particularly drug resistance and the onwards transmission of the virus), the needs of patients, and the faith-based constraints of the hospital. The medico-moral discourse still exerted power over patients by limiting reproductive health choices, as well as over doctors by limiting the options they could offer patients. This had a spatial logic in rural areas where, in the absence of functioning state services, faith-based services were the only ones available (as was the case in Opit). These factors were enhanced by the effects of conflict, in which other health services declined, and in some cases, like Opit, only Catholic-run health services are available. As one doctor put it, 'missionary hospitals were meant to fill a gap in health services. The problem with Northern Uganda is that everything is a gap.'[230]

Lacor Hospital was not a religiously or socially homogenous institution; health workers from many faiths worked and negotiated practices within it. Many dealt with these contradictions through systems of referral to other organisations as we have seen. However, these were not consistent; nor were alternative possibilities always available. For instance, in Opit, when ARVs became available in late 2007, there were no free condoms available, and this was still the case in 2009. Free condoms were only available at the health centre in Lalogi, 10 kilometres away. Certain patients, however, said that some doctors had given them condoms, clearly against the formal policy. Among the community caregivers, some distributed

[229] Interview with Barbara Nattabi, Former Doctor at St Mary's Lacor, Kampala, 12 November 2007.
[230] Conversation with anonymous doctor at Lacor Hospital, June 2009.

condoms, while others did not. In Pabo, home-based caregivers, who were trained by AVSI, a Catholic organisation, and who had their offices in the Catholic mission, acknowledged that they distributed condoms to those with HIV. In fact, some never even knew that the Catholic Church barred the use of condoms.[231] While the local sisters at the Catholic mission at Pabo, who helped coordinate the caregivers, did not actively promote or distribute condoms,[232] they did not seem to actively prohibit or speak against their distribution, and this may account for the caregivers' ignorance.

Many patients, even those who were Catholic, questioned the bar on the use of condoms. Ongom Alice, a Catholic TASO volunteer, explained: 'this thing is very complicated. I have the Catholic faith, but I see the need of condoms for HIV.'233 Furthermore, there is some difference among priests about condom policy. Over dinner with a local bishop, I heard the bishop referring to condoms as 'killing'. However, for other priests, as well as nuns, there is some confusion and clear exasperation over the issue. When I asked Father Alex Pizzi about the issue, he replied: 'I went to the archbishop who said the Church doesn't allow the use of condoms. Some other fathers asked about infection, re-infection, and so on. So, this I cannot answer properly. But the bishop says the church is still saying no. So, we don't know.'[234]

In spite of differences in practice, faith-based approaches exerted a strong institutional influence and constrained action, limiting the choices of those who sought healthcare. In the context of a complex emergency or post-conflict situation, where health care options are limited, the spatial organisation of access to treatment and reproductive health care also

[231] Focus Group with Home-Based Caregivers, Pabo, 23rd February 2008.
[232] Interview with Sister Mary Costello, Nun at Church of Mary Magdalen and founder of WACFO, Pabo, 23 August 2008.
[233] Interview with Alice Ongom, Taso Client and Drama Group Member, Gulu, 13 June 2009.
[234] Interview with Father Alex Pizzi, Opit, 14th December 2007.

shapes the options available to patients. However, biopower operates not only through institutional limitations but also through the production of forms of knowledge.

Clientship and Authority

Patients often feel indebted to their treatment providers and under their authority. As one client told us, 'the treatment providers own your life.'[235] From the perspective of recipients of life-saving medical treatment, their obligations are not necessarily those of reciprocity but also of debt.

I will begin by discussing the activities of the Comboni Samaritans, the community support organisation for St Mary's Hospital Lacor. The attitude of the Comboni Samaritans towards its clients was not limited to providing adherence monitoring, but extended to promoting behavioural change based on abstinence. The power over life given to those who provided access to life-saving treatment can be used in a very direct way to control perceived immorality. As a social worker for the Comboni Samaritans said in 2006:

> We talk to some people. We even use some threats. If a client continues to misbehave, we discontinue the drugs and enrol more responsible people, rather than someone who is there to infect the community. This is how some people can change; they know if they don't have the drugs they will die. Those drugs are very expensive.[236]

[235] Interview with anonymous HIV-positive woman, Layibi, 15 July 2010.
[236] Interview with Social Worker, Comboni Samaritan, Lacor, 1st September 2006.

The view of this social worker shows the relation between authority, morality and economy in treatment provision. While few patients were actually taken off drugs, the implicit threat that they might be underpinned the form of authority that treatment providers held. Beyond the implicit threat of discontinuation, this form of authority also involved the regulation of health, sexual and even marital relations. Masimo Opiyo, the chairperson of the Comboni Samaritans, explained the organisation's attitude towards their 'clients':

> they should go to see a doctor or a counsellor so that they get advice on how to handle their desire to get married while having HIV or AIDS. They should know that they are sick. They should not forget that they are sick, and their sickness should be well-managed, because if they start to enter into a sexual relationship then even the good health that they think they have gained can be destroyed and they can become sick again. Yes, because of cross-infection, and because continued sexual relationship can also lead to some weakness in the body. So we talk to them a lot about their sexual behaviour, but we normally encourage them to abstain, and if they cannot then they can use a condom, which is not one hundred per cent effective – we cannot talk fully about it because it cannot fully protect somebody.[237]

Opiyo expressed approval of a relation of authority in which the doctor, counsellor (and priest) gave advice on how to manage sexual relations. In a similar vein, Esther Aciro, a Comboni volunteer at Opit, explained:

> We cannot stop the clients from having sex, but if they have sex, they should seek guidance from the doctors. The issues of condoms the Catholics don't stress, and we don't educate people to use them...if the people who are ahead of me, like the Pope, don't stress condoms, who am I, his worker, to advocate them?[238]

[237] Interview withMasimoOpio, Chairperson of Comboni Samaritan Lacor, 27 August 2008.
[238] Interview with Aciro, Esther,Comboni Caregiver, Opit, 17th June 2009.

As mentioned above, there was significant variation in how the norm over condoms was applied, particularly among community workers. Patients were given contradictory messages. At a Comboni workshop in Awoo that I observed in 2006, there were significant differences between the two counsellors present regarding a question about condoms from one of the clients. One man suggested seeking advice regarding family planning; the other was adamant that condoms should not be used. The second counsellor told the group, though addressing women in particular:

> The Catholic Church does not allow contraception pills. Condoms not allowed. It's not human … we have to respect God. Those who want to use condoms should go to the priest for permission, other than that they should remain as they are. The demand of sex is not bad. But if you know you're going to get pregnant, why do you allow people to have sex? If you do the child will die. People should be sensitised to know when to play sex and why. The money paid for your dowry is not for your life. When you find a man who is forcing you to have sex, it's better you leave him. Women should be sensitised about this. [239]

This advice, delivered with some fervour, revealed much about the forms of discourse circulating around sexuality. It is of course standard that the church promotes abstinence outside of marriage; the difference with HIV is that marriage without sex was being promoted. The context is also significant as this was specifically a meeting for HIV-positive people by a group providing services. This 'sensitisation' became, not only a forum for education about treatment and the risks of onward HIV transmission, but also an attempt to control 'when to play sex and why'. This discourse asserts women's rights over their sexual lives; however, it does not address the social determinants limiting choice. One of the women's discussion groups at the same meeting raised the problem that women were being

[239] Notes from Comboni clients meeting, Awoo, 14th September 2006.

forced by their husbands to have sex. While some women do leave their husbands, social and structural conditions make this difficult, as they may be denied access to agricultural land, and even to their own children. The second discursive assumption is a negation of female desire: the act of sex itself becomes linked with moral transgression, and the threat of transmitting the virus to children. The formation of this medico-moral discourse as part of the experience of 'clients' became clear in a discussion group for female clients (men and women were separated at these sensitisations): the group suggested that women be given medication to stop them desiring sex. The injunction to refrain from sexual activity, even if ignored, can cause confusion and guilt among clients especially in the context of ARV treatment. As a 31-year-old HIV-positive woman and client of Comboni Samaritan explained:

> Comboni tell us that when you are sick with HIV, you shouldn't give birth. They don't agree on the issue of condoms, and they will tell people to stay apart. It becomes hard. As human beings when you are weak, you may not have sexual desire, but when you gain and have strength, the sexual desire returns, and you will find yourself having sex. This is with both men and women.[240]

Of course, many 'clients' continued to have sex and sexual relations as well as children, in spite of the advice of the Comboni Samaritans. This was clearly visible as a number of Comboni clients we spoke to had young children or were pregnant and Comboni were concerned about high rates of pregnancy.[241]

The authority of treatment organisations is strong, for they are providing medical, nutritional and psychological support to patients. This is a distinct form of biopower in which the care of

[240]Interview with Joyce Akidi, 31-year-old HIV-positive woman on ARVS (St Mary's), Opit. 1 March 2008.
[241] Interview with Masimo Opiyo, Chairperson of the Comboni Samaritans, Lacor, 1 September 2006.

life is given over to an external agency. It is also a relationship that may substitute for other relations of social control such as the clan (*kaka*) and the family in regulating both sexual behaviour and labour. The situation of the counsellor mirrors, in some sense, the confessional structure that Foucault (1998) and Nguyen (2010) write about. The relationship between counsellors and clients is one in which sexual, spiritual and biological lives are managed: it is part of a re-orienting of social authority and control over sexual relations. These counselling sessions invoke a 'confessional technology'; a technology through which the relationship of talking and listening produces a new form of ethical subject that can be worked upon (Nguyen, 2010).

Counselling is not simply about adherence; it involves guiding patients in their diet, sexual relations and even spiritual affairs. A common idiom used by TASO counsellors for the return to health of patients on ART was a 'paradigm shift from death bed to sex bed.'[242] Importantly, while TASO officially adopts a secular medical approach to treatment, religious motifs re-emerged in the counselling sessions. As Charles Odoi, head TASO counsellor in 2006, explained,

> Prayers are very important. There are three aspects. The mind, physical body and the soul. Counselling focuses on these three. If you treat the mind without treating the soul, it is dangerous. We treat the physical body, the mind, and you must treat the soul. We have a component of spiritual counselling, but which is not that big. We refer clients to spiritual leaders – priests, reverends, bishops – it is very paramount. But we also have various religions that also endanger the life of individuals.[243]

[242] Interview with Charles Odoi, TASO Gulu Counselling Co-ordinator, Gulu Town, 7; 8 July 2008.
[243] Interview with Charles Odoi, TASO Gulu Counselling Co-ordinator, Gulu Town, 8 July 2008.

Given the strong role of Christianity in Ugandan society, the focus on religion is unsurprising. TASO meetings always began with a prayer. However, it is significant that treatment interventions and counselling did not constitute a secular alternative to religious approaches to healing, but were intimately connected to them. Religion shaped treatment interventions even if this was not the formal policy of institutions. Odoi was one of many personnel working for ostensibly secular institutions but harbouring strong personal religious convictions. He said:

> I am a Catholic myself. They don't want to push anything in relation to condoms. Here at TASO we don't promote condom use, a condom is the last thing we always speak about. In a situation where all else has failed, then let the condom be the last weapon to protect yourself. [244]

In these ways religious and biomedical discourses co-existed even within secular institutions. Furthermore, the counselling sessions produced a space in which biological health, labour, nutrition, sex and spiritual healing were intertwined. A new language of 'living positively' developed that instituted new forms of social relations and relations of control. Under conditions of displacement, this had particular social and material implications. Many HIV-positive respondents explained that they did not cultivate and didn't have regular sex because the doctors and counsellors told them not to expend too much energy. The following quote is typical: 'The doctor warned my husband not to have much sex, because it takes away his energy. There are times we share a bed, but do not have sex.'[245] Beyond constraining sexual relations, the regulation of treatment adherence intersected with regulation of the consumption and production of food and alcohol. This is not unique to Northern Uganda and

[244] Odoi makes reference here to practices of wife-inheritance as well as the use of razor blades by traditional healers. Interview with Charles Odoi, TASO Gulu Counselling Co-ordinator, Gulu Town, 8 July 2008.
[245] Interview with Cristin Akec, 43-year old woman, TASO adherence monitor (HIV status unknown), Pabo, 24 February 2008.

is part of treatment programmes elsewhere (Whyte, 2009:239, Steinberg, 2008:143-144). In Northern Uganda, however, clients are extremely dependent on their treatment providers for both medical and food support and hence pressured to conform to their codes.

There are, however, important differences between ART programmes in the ways in which their authority is used. In TASO's programme, there is an attempt to enhance the power of patients in their own sexual negotiations. The Comboni Samaritans promote a more conservative approach by, for instance, running workshops in which patients discuss how they can better fulfil their conventional gendered roles in the household.[246] There was little attention given to the problems women may face in remaining abstinent. In some MOH programmes, the medicalisation of sexual relations in ARV programmes limited the agency of their HIV-positive patients. A dominant theme across different providers was that sexual decision-making should be left to doctors. As one HIV-positive woman from a focus group in Ogur said regarding condoms:

> If the disease is already with us, why should we ask about it, we will just remain with what is with us, rather than ask for the condoms. If at all the doctor or the health personnel find it necessary for the condoms to be distributed to us, they are the ones to decide, it's not on us to decide.[247]

It was not only doctors who were given a certain power in relation to decision-making, but also local adherence monitors, who, in Pabo, were referred to as 'boss' by their clients. These relations of authority did not mean that patients followed advice. Strategies of deception became part of the 'clientship' relation. One woman in Pabo told me how her

[246]Feedback and discussion workshop attended byby Juliet Arica (NUMAT), Beatrice Akello (TASO CASA), Richard Mwaka (Comboni Samiritan), Margaret Anek (TASO Counsellor), Lillian Onega (TASO data officer), Gulu Town, 26 June 2009.

[247] Focus group with anonymous mixed-gender HIV-positive respondents, Ogur, Lira, 25th April 2008.

husband would refuse to use condoms, but insisted that she told their counsellor that they were using condoms.[248] The authority and implicit threat of treatment discontinuation in treatment provision may oblige patients to claim they were following advice, even if they were not. It also may veil power relations at a household level where, in a case like this, women may not be able to report honestly the challenges they were facing.

The authority of treatment organisations was contested and limited, and alongside the weakness of surveillance, constituted a weak form of biopower. The reciprocity of 'clientship' was nonetheless embedded in relations of obligation and indebtedness, as well the regulation of many areas of life. The specificity of this is captured in the analysis of 'biopower.' However, this biopower is not hegemonic in relation to other forms of social authority and obligation, but refigures them and is implicated in the social transitions of displacement.

Local social and moral space

As we have seen, a highly moralised approach to HIV characterised responses to HIV in Northern Uganda, even prior to the introduction of ARVs. I have outlined how forms of medico-moral discourse and biopower permeated HIV treatment programmes at an institutional level. Encampment itself triggered forms of moral contestation and uncertainty. HIV was associated with displacement and social breakdown. However, it was also associated with certain sites in the camps, in particular the disco. Little blue signs were posted at schools around Northern Uganda displayed messages such as 'stay abstinent,' 'don't drink' and 'don't go to discos'. The camp discos emerged after the period of

[248] Interview with anonymous 34-year old HIV-positive woman on ART (TASO), Pabo, 24 August..

curfews[249] subsided, and were places for dance, drink and reverie. However, drink and discos came to typify an immoral life in the view of many camp residents. There is also a perception by some that HIV is linked to the death of the Acholi as a people. Take this account by a 60 year old woman, not living with HIV:

> There is no solution to AIDS; there is no solution to drunkenness; there is no solution to discos, because if and people are willing to set up discos then there is no solution. And if the alcohol still exists then there is no way to stop it. What we are praying for is that god given us a medicine. Just like in the past when our parents used to have a sickness like syphilis and gonorrhoea and it was curable, in that even though you get sick you can go and get the traditional herbs and you get healed, or you can go to the hospital and you get healed again. That's what we are praying for, but if nothing is done then the whole Acholi population will get wiped out. The door to each and every home will be locked and that will be the end of the Acholi nation.[250]

For this woman, ARVs were only a temporary solution, and a cure for AIDS was needed. However, the account also illustrates that a medical intervention was also considered a necessary response to social ills; it also resonates with the perception that AIDS is a risk that threatens the Acholi as a people, and not simply individuals.

The manner in which drinking, smoking, dancing, and sexual intercourse, viewed as being bad for adherence and health, become bound up in a discourse in which there were 'good clients' and 'bad clients'[251] illustrates how the biomedical dimensions of ARVs were linked up with morality and power. The medical and the moral became bound up in classifying

[249] The period of curfews on movements during the night was variable across sub-counties but most had ended by early 2006.
[250] Interview with NikolinaAgeo,62-year-old woman, Lacor, 1st April 2008.
[251] While these terms were not used in interviews the recurred frequently with health workers and adherence monitors in informal conversation.

behaviour and patients. Esther Aciro, a community worker in Opit, explained: 'there are immoral (*malik*) acts such as dancing, and smoking.'[252] Those living with HIV who went to bars and discos were, in her view, responsible for spreading the disease. She said some of these people were arrested for 'defilement' – having sex with girls under sixteen. 'The ones who are arrested are those who go to bars and discos,' Esther explained. Another TASO community worker in Pabo said to me that, in her opinion, the clients who drank and went to discos were responsible for spreading the disease. Among health workers, those with HIV, and the community at large, those on treatment were placed into moral categories according to their perceived behaviour.

Condemnation of alcohol abuse as a cause of poor adherence is commonplace and expresses a genuine concern over poor adherence – it is not specific in to Northern Uganda, and not simply a moralised judgement. However, in Northern Uganda, the medico-moral has permeated the HIV response and become embedded in the social spaces of displacement. The attempt to morally regulate activities such as drinking, dancing, smoking and sex– whose excesses are widely considered the effects of displacement – through a biomedical intervention exemplifies both the ways in which biomedicine was embedded in forms of social control and the ways in which individuals and institutions attempted to re-establish order and meaning under conditions of extreme uncertainty.

While certain behaviours (such as drinking alcohol, smoking, visiting discos and having illicit sex) were considered immoral and were associated with 'bad clients' in Northern Uganda, the disclosure of status can also be associated with virtue. The linkage of disclosure to virtue, or religious conversion, has been discussed in several contexts relating to HIV/AIDS. Comaroff

[252]Interview with Esther Aciro, Comboni adherence monitor, Opit, 17 June 2009.

writes on South Africa that 'claiming positive identity can be tantamount to a conversion experience: quite literally, a path to salvation, since identification can bring access to medical care and support' (Comaroff, 2007:204). Fassin (2007a:256-257) also writes that, in South Africa, acknowledging one's HIV status can entail a moral conversion, and an adoption of new values: 'truth, faithfulness, dignity and respect', and can also be deeply bound up with religious experience. Allen (2007:359), in his study of the Azande of Southern Sudan, writes how some living with HIV 'demonstrate that they are moral persons' by being open about their status, and through their association with the prevention efforts of churches. There were similar themes of virtue and rebirth emerging in Northern Uganda. As Betty Akello phrased it, 'The drugs TASO are giving us are good. [With them] someone is born again.'[253]

In Northern Uganda, due to the strong role of the churches in responding to HIV, disclosure has also been linked by some in the camps and towns to a form of virtue. This virtue is expressed best by the Acholi word *maleng,* which connotes something good in the moral and biblical sense, but also means to be 'clean' or 'pure'[254]. Esther Aciro, one of the volunteers at Opit mission, explained: '*maleng* means something good before God'. Esther said that it was a moral act for those with HIV to disclose their status. 'It's good (*leng*) for a client to open up and say it, because by that God will bless you, for talking the truth.'[255] In Opit, the Catholic Church was an early space in which those with HIV could disclose their status. Esther described how, in 2004 and 2005, it was a weekly occurrence for those with HIV to stand up and disclose their status in the church during mass. The act of disclosure in front of the church congregation was not only a way of providing information about HIV, but also

[253]Focus-group with Joseph Oliel, Betty Akello, Beatrice Akello, Scayo Olga, anonymous soldier, Mixed-gender HIV-positive respondents, Pabo, 24 June 2009.
[254] I heard it being used in a literal sense, as in to clean the dishes. According to Ononga (2005:135), it means 'clean' or 'pure'.
[255]Interview with Esther Aciro,Comboni Caregiver, Opit, 17 June 2009.

considered by some to be part of the healing process itself. As one woman who disclosed her HIV status in front of the Catholic Church at Opit, and also spoke in front of her village congregation, explained: 'We went to the church one day, we stood in the church and said we are positive. God will bless me, so that I will live because I came out in front of people. It is good (*leng*) to tell everyone, so you won't infect others.'[256]

This account shows how religion and medicine were intertwined in the healing process. The concern for living longer and preventing onward transmission was infused with notions of purity and God's blessing. In a sense, through the act of disclosure, the impure and contaminating associations of HIV were effaced. While the spatial conditions of the camp imposed disclosure on many seeking treatment, for some HIV disclosure became associated with moral and spiritual purity. The interconnectedness of God and biomedicine at an experiential level need not be viewed as contradictory: biomedicine can be understood as a means through which God works. In Gulu Town, I was told, local Catholics living with HIV took their pills to their parish priest to be blessed in a clear invocation of the ritual of Eucharist. One of these women, Alice, declared, 'God's hands are in our drugs.'[257] The phrase expresses clearly the ways in which religious beliefs and biomedicine had become interwoven: accepting the biological efficacy of treatment does not preclude a view that other forces are at play.

Medical pluralism and contestations

I outlined in Chapter One how pluralistic understandings of the causality of HIV/AIDS persisted well into the 2000s. Rather than ART provision providing a clean break with

[256]Interview with Silberia Akot, HIV-positive woman, Gulu District, 17 June 2009.
[257]Interview with Alice Angom, HIV-positive woman & TASO Drama Group Member, Gulu Town, 13 June 2009.

medical pluralism, it provoked new forms of contestation and uncertainty. The relation between medicine and religion became a source of disputes over social understandings of illness and cure. During the phase of conflict and displacement, HIV treatment interventions in Northern Uganda have, alongside the churches, increasingly marginalised indigenous conceptions of healing and local practitioners. In particular, the services of local healers, *ajwaka*, and herbalists were viewed as dangerous and pernicious by many medical professionals and community health workers. Comboni Samaritan were direct in condemning the use of *ajwaka*. As Masimo Opiyo, the chairperson of Comboni explained,

> Our position on the *ajwaka* is that like any other community health workers, we encourage our beneficiaries not to go to the traditional healers. From the traditional healers, they are not medically examined. We advocate for our community to seek medical services from the hospital, and not to go to these categories of people. We have seen risks. Many of our people who didn't know much were going to traditional healers, and they were losing their lives. They were also using their razor blades, on two, three, four people. We do not encourage this.[258]

TASO had invited some *ajwaka* to participate along with religious leaders in HIV education and training workshops[259] but in general there was no sustained effort to incorporate traditional healers and, in practice, they were often treated with suspicion. Beatrice Akello, the TASO community worker, said, 'TASO has been telling people not to go to *ajwaka*, if you have malaria or TB, go to the health centre. Get tested and get medication there.'[260]

[258]Interview with Masimo Opiyo, Chairperson of Comboni Samaritan, Layibi, 29 March 2008.
[259]Personal email communication with Michael Ochwo, TASO head of counselling, 8 November 2010.
[260] Focus group with mixed-gender HIV-positive respondents, Pabo 4^{t} June 2009.

We frequently asked respondents whether they visited *ajwaka*, and none replied that they did. However, there are indications that this was a methodological limitation, as there were secondary reports of those on treatment visiting *ajwaka* and the two *ajwaka* that we spoke to ourselves reported receiving patients on ART, as is discussed below. Respondents may have associated us with treatment programmes and felt that they were transgressing requirements if they admitted to seeking alternative treatment sources. A focus-group of TASO clients did report they knew of others on HIV treatment visiting *ajwaka* but noted that this was discouraged by TASO.[261] In addition, many patients said that their families had wanted to take them to see traditional healers, often resulting in family disputes.

It was within the family that many disputes over therapeutic practice took place. The account of a 30-year-old woman living with HIV in Lira, who had returned to her village, is worth quoting at length:

> I have a story of a girl. The girl was in her home. She became very thin, and used to have diarrhoea. If she was sleeping, you would not think a human being was sleeping, she would sleep flat on the ground. Her home was near Alero. When the brothers to this girl told me that she was very sick, I told them to bring the girl to me, so that I could see what was wrong with the girl. The girl was brought to my home and she was very weak. So, I told the brothers that the girl is suffering from HIV. The brothers told me that this girl is not sick with HIV, there is no need to waste time on someone who is going to die so soon. We had a lot of arguments that resulted in my asking the brothers if they would allow me to take the girl to the hospital. When they accepted, I begged for a bicycle. I carried the girl on the bicycle to [Ogur health centre], where her blood was tested. She was found HIV-positive. The doctor prescribed a drug that she could take ... After two months, the girl had some change, she would stagger, she would move, she had something

[261]Focus-group with Joseph Oliel, Betty Akello, Beatrice Akello, Scayo Olga, anonymous soldier, Mixed-gender HIV-positive respondents, Pabo, 24 June 2009.

> she would move a little bit with. After two months I brought her back home under the medication. Then God told me something – he said this patient of yours needs prayers, so I called some of my pastors and some of the people from the Pentecostal Assemblies of God (PAG) church to come and lead the prayer. The *cen* in her ran away, and then when the brothers got to know that she was a little better, the brothers came to tell me how this girl was just bewitched. The husband came to ask that I give him the girl, so that he could take her to a herbalist. But I said this person is not going anywhere. This person is under the protection of God and is covered by the blood of God, so let me keep this girl and take care of her. She stayed and after four days, the growth in the anus broke. But then I realised she had problems. She had sores in her private parts. So I had to run back to the health centre to tell the doctor the whole story. The doctor gave me some other pills and directed me on how to provide the treatment, so I started providing the treatment for the girl, until she became better. And now as I talk, the girl is so fat and healthy. She's looking so good. And now everyone in the village has come to trust her and everyone has turned to believe. Even the husband has come back to fetch her. I gave that testimony in front of all the HIV-positive people, and it was a great thing that no one could believe. [262]

This story shows how the idea of God as healer and ARVs as effective medication, as well as HIV as having both a medical and spiritual cause, were compatible. Christianity (in this case Pentecostal), spiritual and biomedical healing were not of necessity opposed: rather biomedicine became a form of spiritual purification. Testing and disclosure helped purify individuals from both sin and *cen.*

The exclusion of indigenous healing practices from treatment programmes also reflected the negative attitudes of the churches towards *ajwaka* and other local practitioners. *Ajwaka* were often associated with the devil. Akot Silberia, an HIV-positive woman who lived in Opit but had returned home, said: 'there used to be *ajwaka* [prior to displacement], but these days

[262] Focus group with mixed-gender HIV-positive respondents, Ogur, Lira, 1 August 2008.

nobody likes the *ajwaka*. There is no work of the devil; people only pray. It is Satan, he eats your things, and your body will not cure.'[263] Traditional healers were viewed as opposed both to God and to physical healing.

In spite of the discursive exclusion of *ajwaka* in these cases, it seems that in practice *ajwaka* were used alongside treatment organisations. As one *ajwaka* we spoke to explained: 'I have never heard of organisations working with the *ajwaka* but the *ajwaka* also get the ARVs from these AIDS organisation [to administer treatment themselves].'[264] This indicates that there may have been more openness among the *ajwaka* to biomedical interventions than acknowledged by treatment organisations. Within communities, as well as among traditional healers, there appears to have been a diversity of pluralistic practices and not a stark divide between biomedical and other forms of healing. The concerns that local forms of healing, particularly practices involving razor blades, may have been implicated in the transmission of HIV seem to have been founded in on fears of practices that may no longer be common.[265] For instance, a former local healer who believed she had contracted HIV from razor blades, recalled:

> I would work with both the children and the adults. My work was almost the same as the *ajwaka*, but also of a doctor. I used to use the traditional medicine to heal. Whenever I made the cuts I put the traditional herbs and after this you get healed. I used to work on different diseases, like removing the false teeth from children, or removing something from the throat. It's such a long time ago that I can't remember all the herbs but what I remember is that there were a type of berries called *ocuga*. You can't find them here, they were back in the village. We

[263] Interview with Silberia Akot, HIV-positive woman, Gulu District, 17 June 2009.
[264] Interview with anonymous Ajwaka, Layibi, 29 June 2010.
[265] This is an area requiring further research.

> used to use the razor blades just like that. No-one used to sterilise them. Not even boiling them.[266]

However, she explained that these practices had largely disappeared out of fear of HIV: 'No, these practices are no longer there. People fear that if you use the razor blades, or even the safety pins on another person, that person could be infected and infect you. Even a mere pin, no one would touch it. These things were mostly back in the villages.' [267]

Another *ajwaka* we spoke to said that she worked with people on ARVs but did not consider traditional healing and biomedicine incompatible. She explained:

> HIV has no cure. Even the brightest scientist has failed in getting its cure. It is wrong for an *ajwaka* to confuse the public that he or she has the cure to this disease. Just like a medical doctor, we cure opportunistic infections but not the virus. I do treat running stomach, rashes, headaches and swellings on the body. It is very clear the cause of HIV – no one believes it's caused by witchcraft. In the past people thought it was some kind of witchcraft because they had not been sensitised about the causes of HIV...The church is very negative toward the operation of our spiritual healing. They believe we are confusing people to worship the devil but in actual sense the people cannot do without our operation. There are certain sicknesses which cannot be cured by the *yat munu* ['medicine of the strangers or whites'] so they are referred to us for any type of spiritual healing. There are many Christians who visit for spiritual consultation and healing of different sicknesses ... I have not heard on radio or paper written that there are traditional healers working with NGOs. There are many people on ARVs who visit us, they either visit because some of our medicines work better

[266] Interview with Florence Alobo,51-year-old HIV-positive woman and former herbalist, Pabo. 9 March 2008.
[267] Interview with Florence Alobo, .51-year-old HIV-positive woman and former herbalist, Pabo. 9 March 2008.

> or to bring their sick relatives. I would have liked so much to work with the different NGOs but none of them has confronted me.[268]

Though we only interviewed two practicing *ajwaka* and there is need for further research in this area, these interviews suggest that there was among them a greater openness to engaging with HIV education and biomedical practices than was acknowledged by treatment organisations. Nonetheless, the divide between treatment organisations and *ajwaka* did reveal that the biomedical discourse in HIV/AIDS treatment was viewed by treatment providers as compatible with Christianity, but not with local practices of healing. This indicates both a strong, though often implicit, moral dimension to HIV/AIDS treatment, but also the power to exclude discursively, if not entirely in practice, certain indigenous forms of healing.

Conclusion

This chapter has argued that ARV interventions in Northern Uganda were strongly value-laden. Interventions were shaped by the anti-statist thrust of large donors, as well as the presence of humanitarian agencies, giving NGOs greater resources and control over the production of knowledge. Furthermore, the strength of Christian values was the outcome of the strong influence of faith-based organisations in treatment programmes, discussed in Chapters One and Two. However, it was also the outcome of the intersection between local missionary histories and global donor agendas. This chapter has argued that power relations and medico-moral discourses infused multiple levels of the AIDS treatment endeavour. These levels included donor and treatment-provider relations, the relations of providers to patients,

[268]Interview with anonymous *ajwaka*, Onang Village, 12 & 20 December 2010.

as well as contestations within local moral and social worlds. Furthermore, local healing practices were marginalised, both institutionally and discursively. Despite this, forms of medical pluralism clearly persisted but reliance upon local healers was widely denied by patients on HIV treatment.

The power relations discussed above are far from a top-down assertion of authority – they involve multiple and diffuse channels. The conceptual lens of biopower provides a means of analysing these relations, though it requires significant adaptation. I have argued here that the authority imposed by treatment providers in Northern Uganda may be considered a weak form of biopower. The regulation of life, nutrition and sex along with the biomedical surveillance of treatment reorient relations of authority. Under conditions of displacement and social dislocation, treatment organisations became new forms of authority in the spaces of disrupted kinship and family relations, yet did not entirely supersede these. This weak form of biopower in that it is neither totalising nor omnipresent in the lives of patients. However, it is still significant in permeating multiple areas of individual and social life including sexuality, agriculture, diet and religion. The powers of these organisations may have been enhanced by the fragile circumstances in which their 'clients' found themselves as a result of conflict and displacement and, at times, patients suffered guilt and anxiety over these codes. The biopower of ART interventions lies in the ways external interventions traverse local hierarchies, practices and knowledge.

Chapter Six: The Risks of Treatment and Return

Introduction

This chapter is the first of two exploring the intersecting challenges of HIV/AIDS and of return. It lays the theoretical foundation to be applied over the next two chapters while developing the themes of previous chapters. I focus here on the immediate negotiation of the return process among those living with HIV, as well as treatment providers. The next chapter focuses on the longer-term implications of the return process. Here, the perceptions of risk relating to return, as well as forms of vulnerability and survival during the return process, are explored from both a patient and treatment provider perspective. The challenges of the return process involve the interaction between livelihood, biomedical and social concerns: in addition to family relationships, the sociality and clientship of HIV treatments shape decision-making processes around return. For a number of those living with HIV, return is not the chosen option: finding sustainable solutions to remain in camps, or towns, may be preferable. Challenges facing those with HIV and treatment providers are connected. The period of return has been the most challenging phase of the treatment programmes so far in terms of treatment continuity. Treatment providers have faced increased problems of mobility, monitoring and resource constraints. These challenges arise from the spatial transformation of the transitional period.

Understanding these processes requires a theoretical approach that brings together social analyses of repatriation with public health approaches to ARV provision. The impact of health-care on decisions to return is insufficiently explored in the literature on repatriation. Similarly, there is little discussion of repatriation in the existing literature on ARV rollout in

conflict-affected settings. This chapter addresses these concerns. I continue the discussions of stigmatisation, vulnerability and sociality discussed in previous chapters, arguing that these have a significant impact on the return process. In addition, the phase of return can be analysed as a process of socio-spatial transition. The social dimensions of displacement and repatriation are important to address in public health planning around HIV/AIDS, in order to ensure sustainability of ARV programmes, as well as durable solutions to the challenges of disease and displacement. Similarly, health concerns impact upon protection issues among the displaced.

Conceptualising return and transition

Studies of forced migration have shown that repatriation involves a complex of both material and social constraints, which often place significant burdens on returnees (Rogge, 1994:3, Rogge and Lippman, 2004). Rather than a clean break from displacement, the return process is an evolution from the conditions of displacement which can continue to have implications for years (Black and Koser, 1999, Holtzman and Nezam, 2004). Return also often involves cross-migration, the splitting of families, and mobility as a coping strategy. It is often not a linear process but a cyclical and staggered process (Sorensen 2004, cf. Black and Gent, 2006:21), and this has been the case in northern Uganda (Green, 2008:78-79). All these factors lead to the question: 'when does internal displacement end?'[269]Given that internal displacement, unlike refugee status, is not a legal status, there is no clear end-point and the effects of displacement may persist even when the causes of displacement have disappeared (Mooney, 2003). Furthermore, social integration and social relations are of great importance in the post-displacement phase. Holtzman and Nezam's (2004) study of displacement in Balkan and former Soviet states finds that the long-term effects of displacement affect

[269] This was the title question of Forced Migration Review, May 2003

multiple facets of life including health-care, education, psychology, employment, and assets. They put it pithily: 'displacements of a decade or longer represent more than simply a transient reality for those affected' (Holtzman and Nezam, 2004:xv).

Return may help alleviate the material difficulties of displacement; however, the physical and material difficulties of the return process can be extreme. In agrarian communities these may involve the difficulties of transportation, clearing bush, restarting agriculture, and rebuilding homesteads (Rogge, 1994). Displaced communities may leave areas where there is access to basic services such as water, sanitation, education, and health-care and return to areas with worse access to services, poor governance, and property disputes (Rogge and Lippman, 2004:5). Economic opportunities in the places of displacement may be better than opportunities in sites of return, providing reasons to stay (Kibreab, 1996: 54). The physical difficulties that may face those living with HIV/AIDS may not be unique, but the additional burdens of illness, even with treatment, may severely limit physical capacity to undertake these tasks. Furthermore, families weakened by loss and illness may suffer labour constraints at the level of the household and not only the individual.

Physical and material concerns are closely wound up with socio-political factors. The challenges and long-term implications of return are often framed in terms of 'durable solutions' or 'sustainable return'. The notion of 'durable solutions' remains cloudy. It is primarily used in policy-based documents, rather than academic writing. However, given its sway in the implementation of policy and programmes, it is important to discuss its validity and usefulness. The Inter-Agency Standing Committee (IASC 2010) including the UNHCR, the UNDP, IOM and UNICEF has recently attempted to standardise the term with reference to internally displaced populations and to outline a set of indicators for measurement. It

defines a 'durable solution' as a state when 'internally displaced persons no longer have any specific assistance needs that are linked to their displacement and can enjoy their human rights without discrimination on account of their displacement' and return is understood as 'sustainable reintegration at the place of origin' (IASC, 2010:A1). The IASC report outlines a broad array of indicators that need to be accounted for in analysing return. It argues that finding durable solutions is a 'long-term process of gradually diminishing displacement-specific needs and involves protection, human rights, justice, peace-building, shelter and livelihoods concerns (IASC 2010:7).

The IASC report does stress the importance of ensuring the rights of the displaced and that solutions should be developed in cooperation with IDPs. However, a significant problem with the report is that it places the agency for achieving durable solutions primarily on state and humanitarian actors. It argues that 'the primary responsibility to provide durable solutions for IDPs and ensure protection and assistance needs to be assumed by the national authorities' who should coordinate a response along with humanitarian and development actors (IASC, 2010:11). This is an outcome of the practice-oriented uses of 'durable solutions,' and reveals a bias towards institutionalised and managed solutions, rather than acknowledging the importance of responses within displaced communities. What is neglected in this approach is the importance of *intra-communal* relations in facilitating sustainable return. This is a critical issue when looking at the role of the vulnerable and marginalised within communities.

An associated concept to durable solutions, used more commonly in academic writing, is that of 'sustainable return.' Black and Gent (2006) review the literature on sustainable return, exploring it both from the perspective of 'reintegration of individual returnees into their home

societies' as well as from the point of view of broader macroeconomic and political indicators (Black and Gent, 2006:15). They acknowledge that the impacts of displacement may continue for years and that the process of measurement is fraught with difficulties (Black and Gent, 2006:32). However, they suggest a working definition: 'return migration is sustainable for individuals if returnees' socio-economic status and fear of violence or persecution is no worse, relative to the population in the place of origin, one year after return' (Black et al 2004, cf. Black and Gent, 2006:26). This approach is clearly problematic when an entire rural population has been displaced, as is the case in vast areas of Northern Uganda. An alternate baseline may be pre-displacement criteria.

Rogge and Lippman (2004:5) argue that sustainable return requires participatory processes which are tied to 'rebuilding the social fabric and social capital of communities' and which give attention to the special needs of members of the community like women-headed households, ex-combatants, and orphans, but stress that this needs to be done within a holistic and integrated approach so as not to reinforce community division. Similarly, Bradley (2006), reviewing the literature of return, argues that return may heighten the vulnerability of groups such as women, children, the elderly and disabled –groups who may be marginalised in decision-making processes. Decision-making may be tied to a complex of social factors, and can take place at different levels of society from coercive top-down decisions (Kleine-Ahlbrandt, 2004:23) to community-based, household or individual decisions (Green, 2008). Decision-making will not necessarily run along the lines of pre-displacement community structures, but can be influenced by new identities and roles formed under conditions of displacement (Bradley, 2006). This is a critical point when applied to those with HIV – should those living with HIV be targeted with specific interventions in the return phase, or simply be helped along with members of the broader community?

A subsidiary concept frequently associated with sustainable return is that of *reintegration*. Though the concept overlaps with sustainable return, the literature on this takes a less temporal and more qualitative perspective, viewing the situation of returnees in terms of their levels of well-being and security. Kaun (2008:2) defines reintegration as 'a process that displacement-affected persons undergo which is characterised by human security and individual perceptions of inclusion and belonging to a place.' It is a definition that can apply to refugees, the internally displaced and even those who stayed in war-affected areas. Kaun argues that the idea of reintegration includes the process of social transformation implicit in the experience of displacement. Factors to take into account in reintegration include security of food, education, community and person, political environment and local ecology (Kaun, 2008:3). In particular, health security includes access to clinics, medication and medical personnel, as well as information about health and rights. In addition to institutional factors (access to markets, availability of services, and so on) that are required to guarantee these entitlements, individual relations to place and community and confidence in human security are needed (Kaun, 2008:4). The dual emphasis on both institutional factors and individual relations is important for my analysis, though Kaun overemphasises individual perception and pays little attention to the importance of different forms of social relations that may shape reintegration.

While Kaun pays some attention to vulnerable or marginalised groups and the dilemma that social participation can exclude marginal groups (Kaun,2008:14,30), little theoretical attention is given to this question. This absence is pervasive in the literature on return. For instance, in a discussion of returning Malawian youth in Zambia whose families were sent into exile under Banda, mainly for being Jehovah Witnesses, Cornish *et al*. (1999) argue that

the process of return involves difficulties over a lack of resources as well as identity and a sense of belonging. They argue that experiences differ between age groups among returnees but do not give substantive attention to other differences. In addition to differences *within communities*, differences *within families* are often ignored. For instance Hardgrove's (2009) study of Liberian refugees in Ghana explores the role of the family in the return process. Families are conceived as bound by 'affection, obligation, dependence or cooperation' (Hardgrove, 2009:484-485) and are treated as coherent. Analysing the family, rather than only the individual is critical. However, Hardgrove's view neglects the fact that families may also be characterised by forms of exclusion and contestation over resources. The challenges facing those living with HIV in the return process include marginalisation within families, kinship groups and communities. This is not exclusive to those with HIV: for instance, returning rebels and child soldiers face intense obstacles to social inclusion (Robertson and McCauley, 2004), but the combination of the biological and social vulnerabilities of those with HIV give HIV-related vulnerability a specificity.

A final and key notion in the conceptual repertoire on return is that of 'voluntary return', which has become a standard axiom of refugee and internal displacement policy. The UN General Assembly has repeatedly affirmed commitment to the voluntary repatriation of refugees and the UNHCR affirms that refugees and IDPs should be able to return 'in safety and with dignity'(UNHCR, 2004:3). Safety implies legal and physical safety, as well as material security. Dignity is an ambiguous concept, implying that returnees are not 'manhandled' or split from their families, are treated with respect and are accorded their rights by national authorities (UNHCR, 1996). The idea of voluntary return has been assimilated into a broader approach towards sustainable solutions to displacement, in which return is one option among others. For instance, the UNHCR promotes the so-called "4Rs"

approach: repatriation, reintegration, rehabilitation and reconstruction (Lippman and Malik 2004). While international refugee law and protocols have no legal sway over internally displaced communities, the notion of voluntary return with safety and dignity is widely promoted by the UNHCR and other agencies. In Uganda, it has been adopted as part of the national policy for internally displaced persons that states: the Government commits itself to promote the right of the IDPs to return voluntarily, in safety and dignity, to their homes or places of habitual residence or to resettle voluntarily in another part of the country (GoU 2004:23). The implementation of this policy in Northern Uganda is discussed below. The UNHCR policy on ART (UNHCR, 2007a) raises for the first time the important role that ARVs may play in voluntary return. The policy states that the UNHCR cannot facilitate the return of a refugee against her will if the continuation of life-saving treatment is at risk. As yet, however, there is no empirical work on understanding how ART informs perceptions of return among displaced people living with HIV.

Above I have framed the dominant conceptual vocabulary used to understand return. However, an important and largely unexamined domain is spatiality. Like the phase of displacement itself, the return phase represents a profound transformation of social and spatial relations. This does not simply involve a return to a pre-displacement spatiality. First, the long-term impacts of the war affect infrastructure; for example, health services, government administrations, and community buildings may have been damaged or destroyed. War also creates new patterns of uneven geographic development which affect social relations in the post-conflict phase. The camps are certain to remain in some form, and the larger ones were, in late 2008, in the process of being reclassified as towns.[270] The return of the displaced involves changing residency patterns and the geographic dispersion of the

[270] Author's Notes, Camp Coordination Camp Management Cluster Meeting, Gulu Town 7 August 2008

community. In the process, new patterns of mobility are created. In Northern Uganda the return phase has been marked by significant mobility between return areas and the camp (Green, 2008). Similarly, large-scale return movements to rural areas were preceded by the creation of smaller 'satellite' displacement camps. The opening up of trade routes and centres also creates new paths of movement, or reopens old ones. [271] In Northern Uganda there have also been new technological relations, particularly with widespread cell-phone coverage in Northern Uganda: new relationships across distances are possible as a result. Taking these developments into account, it becomes apparent that the social and material impact of conflict and displacement shapes the socio-spatial conditions of the repatriation phase.

This chapter and the next will focus on how the health concerns and particularly HIV/AIDS intersects with the socio-spatial transitions of return. Surprisingly little attention in forced migration studies has been to given to how health-care informs decisions around return, especially for the chronically ill. Health-care has generally been treated as part of a basket of basic services which may impact on decisions around return, and which may worsen in the return process (for instance Rogge and Lippman, 2004, Dolan, 1999, Kibreab, 1996). Allen, in a study of Sudanese refugees returning to the West Nile region of Uganda, shows how the return movement exacerbated health risks among refugees as they repatriated to areas where there were severely constrained health services. Illnesses such as diarrhoeal diseases and sleeping sickness pose serious problems to returnees (Allen, 1996:242-245). However, Allen does not explore how health issues affected the process of decision-making around return. Similarly, the public health literature on complex emergencies rarely addresses or mentions the return process (see for instance Waldman, 2006, Salama *et al.*, 2004, Toole, 2008, Perrin,

[271] In particular the comprehensive peace agreement in Southern Sudan has made Juba a centre of regional trade.

1996). Sirkin *et al*. (2008) – a rare exception to this trend – write that protection needs in the return phase also require the re-establishment of health services in return areas, a focus on livelihoods, and the establishment of socio-economic rights.

Similarly, the literature on ARV provision in conflict settings (Culbert *et al.*, 2007:797, Bennet et al., 2008b), discussed in Chapter Two, does not address the return process, and the challenges it may pose for long-term sustainability of ART. Neither does it give significant attention to the importance of social relationships in ensuring long term sustainability in these settings. The UNHCR guidelines on ARV provision to displaced communities state that 'measures to secure the continuity of treatment of returnees under ART must form an integral component of the planning of the repatriation' (UNHCR, 2007a). However, no operational recommendations are outlined. This chapter examines how the dynamics of repatriation influence those living with HIV, and how treatment access shapes the return process or decisions to integrate or resettle in sites of displacement.

Return in Northern Uganda

In Gulu and Amuru, freedom of movement was officially declared in all sub-counties in June 2007, formally allowing all the displaced to return home.[272] This was preceded by the 'decongestion' process – the creation of satellite camps – in 2006. In Lira, the repatriation process began in 2006, and almost the entire camp population had returned by 2008. In Gulu and Amuru, by April 2008, 45% of the 453, 359 population in displacement camps had left – either to transit sites (24%) or villages (21%) (UNOCHA, July 2008). As discussed in Chapter Two, in Gulu and Amuru a cluster-based approach was being used from 2006 on to

[272] Interview with Latissa Sanchez, UNHCR Associate Field Officer, Gulu, 18 August, 2008.

facilitate camp closure and return. Clusters consist of planning groups involving non-governmental and governmental representatives, who meet to coordinate actions. There are health and nutrition, camp management, education, and early recovery clusters, among others. The UNHCR promotes 'durable solutions' based on voluntary decisions that may involve staying within the camp, returning home, or resettling elsewhere. When camps are more than 50% empty (based on a 2005 baseline) they are eligible for phase-out. Volunteer phase-out committees were tasked with assisting to break down houses and fill latrines.[273] As discussed in Chapter Two, the cluster-based 'management' of the return process is an exemplar of how population control was largely delegated to non-governmental actors.

The government's commitment to the notion of voluntary return has been variable. In the early phases of the return period there was a strong emphasis on return as an immediate and enforceable outcome, though this gradually softened and government began to place greater emphasis on voluntary return and freedom of movement (Green, 2008:76). However, in late 2008 district leaders were still strongly emphasising return as the desired option. For instance, on Radio Mega I heard an announcement that Mackmot Kitara, the LC5 Vice Chairman, thanked NGOs for their help during the conflict but argued NGOs should support those who have returned to the villages and should suspend support for those living in the camps as it would make them lazy and discourage them from returning to the villages.[274] Also, in August 2008 the precise meaning of 'voluntary return' remained undefined in any formal policy documents. Furthermore, there was no clear resolution of the tension between the property rights of the landowners on whose land the camps were constructed and the rights of IDPs to voluntary return.[275]

[273] Interview with Latissa Sanchez, UNHCR Associate Field Officer, Gulu, 18 August, 2008.
[274] Author's fieldnotes, 23 Aug 2008.
[275] Author's Notes, Camp Coordination Camp Management Cluster Meeting 7 August 2008

My interviews show that a number of landowners started charging rentals for living on their land, and threatening eviction. However, residents of the camps I visited were afforded protection from eviction. A focus group from Opit revealed some of these dynamics:

> Now, for my case, our land was somewhere down here. But the land during the insecurity was not very safe, so we decided to move in the middle of the camp in the centre where it was relatively safe. Where we are staying now the landlord is demanding 10, 000 shillings while we are waiting for the new grass to be ready to begin construction (Lilly Adoch).[276]

> The camp commandment was trying to explain that the landowners should leave the people to go back at their own will. They should go back voluntarily, because if you force someone to return and the person goes back and gets problems there, then you are to blame. A person should be free either to go back home, or to stay in the camp here, and it doesn't mean that the person has gone back home they should destroy the building. The building should be there so if the person goes back home, if they have a problem there, they can come back and sleep. If it's insecure home (Sophia Aroka). [277]

Uncertainty among IDPs, local government officials, lawyers, and district officials seemed widespread. To my knowledge, however, there was only one reported forced eviction by a landowner in the Gulu district by August 2008, near to Gulu Town,[278] though threats by landowners were widespread, causing significant anxiety among those with HIV.

[276] Focus-group with Simon Odong, Judith Okeng, Lilly Adoch, SecondinaAkia, Sophia Aroka Mixed gender HIV-positive respondents, Opit, 12 August.
[277] Focus-group with Simon Odong, Judith Okeng, Lilly Adoch, Secondina Akia, Sophia Aroka, Mixed gender HIV-positive respondents, Opit, 12 August.
[278] Author's Notes, Camp Coordination Camp Management Cluster Meeting 7 August 2008

In Lira, however, return movements began earlier in 2006 and 2007. The district government claimed that return was voluntarily.[279] However several respondents in Ogur sub-county claimed that landowners eventually forced the remaining camp residents off their land and destroyed their houses. This posed significant problems for those with HIV as the respondents cited below reveal:

> They were in the camp for five years. The owner of the land forced people off. All of the houses were demolished and they had to go live under trees. It happened to many in the camp and they were given no protection by the Parish chief.[280]

> Many of the people with HIV died when they were forced out of the camps, because when people went back to the villages, there was no support with food, medicine and so on.[281]

Forced evictions can pose major problems for those on HIV/AIDS, severing their treatment and forcing them into areas where they cannot cultivate or find food. Protection against eviction and ensuring voluntary return is thus critical for ensuring the sustainability and continuity of ART. However, even without eviction the stresses and uncertainties of the return period can place significant strain on those with HIV, among others in their community. The next section will explore the perceptions of risk and vulnerability arising from the return phase, as well as the strategies that were being used to negotiate this uncertainty.

[279] Interview with Dan Othiono, Disaster Preparedness and Recovery Coordinator, Lira District, Lira Town, 20 August 2008.
[280] Focus-group with Caroline Akello, Geoffrey Olwa and Anonymous 28-year old HIV-positive woman, Mixed-gender HIV-positive respondents, Ogur HC, 1 August 2008.
[281] Focus-group with Caroline Akello, Geoffrey Olwa and Anonymous 28-year old HIV-positive woman, Mixed-gender HIV-positive respondents, Ogur HC, 1 August 2008.

The perceived risks of return

In this section I will explore the perceived risks of return among those with HIV who had remained in the camps or were moving between camps and villages. The potential risks of return facing those living with HIV can be categorised into three broad categories. First are the physical difficulties of return after long-term displacement, alongside the effects of illness on both individuals and households. These difficulties can obstruct rebuilding homesteads, digging latrines, restarting agricultural activity and ensuring food security. Second, there are social risks to return, such as the dispersal of support networks formed during displacement, and renewed exposure to stigmatisation or marginalisation. Social marginalisation can also threaten food security and health under conditions of severe resource constraints. Third are the medical risks associated with access to health services and HIV treatment. A longer-term public health risk is that if ART is not properly monitored, and there are breaks in treatment, this could lead to the spread of drug-resistant strains of HIV, as discussed in the second half of this chapter.

Interviews and focus groups among those still in the camps showed an interweaving of physical, medical and social concerns. These comments from women in Pabo in February 2008 are illustrative:

> The problem that we shall get if we go back, there will be stigmatisation and hatred (Helen Lanyero).[282]

[282]Focus-group with Nighty Aber, Anna Akello, Hellen Lanyero, FilderAcola & Nighty Aceng, HIV-positive women. Pabo, 24 February 2008.

> We shall face problems when it comes to our medication, because we shall be far away, and some of us don't have people to bring us so far. You find that in our situation, even in the camps, the landowners are chasing us away (Filda Acola).[283]

> We shall face a problem in that when we go back to the village, you don't have the strength to dig anymore. And there are cases where some of us have been neglected by our families. Now, we have no reason to go back home, because even if we go, we won't be able to support ourselves. So, the only way they can show us kindness is by giving us some area where we can stay near to the hospital (Nighty Acheng).[284]

These comments express concerns relating to the increased distances of return areas from health centres, including losing access to medication; fears over the threat of eviction by landowners; and fears of stigmatisation and neglect by families. For those who are acutely ill, or have lost household members, perceived risks of return are high, as these accounts of some women from Opit, whose husbands have died, demonstrate:

> I tried making bricks, but I couldn't because I am alone. So I'm waiting for the end of this year, when the grasses are ready, then I can try again, but it depends on the energy I have (Silberia Amony).[285]

> I have a serious problem when it comes to construction. I don't have a husband. I'm alone. You don't have the strength to go build a house back in the village. You don't have money to hire people to make a house for you. You don't even have something to feed the children. So most of the time, I will have talk to the

[283]Focus-group with Nighty Aber, Anna Akello, Hellen Lanyero, FilderAcola & Nighty Aceng, HIV-positive women, Pabo, 24 February 2008.
[284]Focus-group with Nighty Aber, Anna Akello, Hellen Lanyero, FilderAcola & Nighty Aceng, HIV-positive women, Pabo, 24 February 2008.
[285]Focus-group with Florence Awio, Dennis Okello, Lucy Angee, Silberia Amony, Charles Ojok, Mixed-gender HIV-positive respondents, Opit, 12 August 2008.

> Father [Alex, from St Joseph's Mission, Opit] to give me money to help look after the children. [286]

For many in Opit, there was at least some material support available in the camp through the mission, giving an incentive to remain in the camp. In contrast, the prospect of returning to their home area alone with children was prohibitive for many women. The views above express the constraints of women who are particularly concerned about the physical difficulties of construction. However, these concerns did not only occupy HIV-positive women as a number of HIV-positive men also expressed concerns over construction. In addition, for those with acute illnesses alongside HIV, the difficulties of return seem insurmountable. As a young man suffering from both HIV and cancer in his leg explained: 'My fear is mostly because I am weak now, and I can't do much to support my family, so there is a probability that if I go back home, then I can't dig, my family will stay hungry.'[287] These interlinked issues around access to food and health-care, including ARV medication, were dominant issues in shaping perceptions of risk around return and proved to be substantive concerns, as will be discussed in the section below.

Furthermore, fears about return were not limited to material concerns and extended also to social anxieties, particularly around perceived stigmatisation in return areas. Fears around stigmatisation in the return phase varied across different sites.[288] Furthermore, perceptions of stigmatisation were a concern at both community and at a family level. Interviews showed that those whose family members stigmatised them were less likely to want to return than those who had supportive family members, as they would be living with their family

[286] Focus-group with Simon Odong, Judith Okeng, Lilly Adoc, Sekondina Akia, Mixed gender HIV-positive respondents, Opit, 12 August 2008.
[287] Interview with Bosco Ocire, 26 Year Old Man with HIV Pabo camp, 14 July 2008.
[288] For instance, many claimed the area of Ngai in Oyam to be an area with high levels of stigmatisation due to the lack of HIV services and education in the region during the conflict.

members in the return areas. I met several people living with HIV who did not want to return to their family land for fear of stigmatisation from members of their family and village. As one woman in Opit explained:

> There is stigma in the families. My family wants to take away my children, fearing that I will give them the disease. I don't want to go back to my village where my family won't take care of me. I would rather remain here, where there is care. I have dedicated my life to staying in Opit.[289]

By contrast, for individuals like Evelyn Aber in Pabo, who had experienced positive support from her family, decisions around whether to return were linked to clan-based, rather than household, decision-making criteria. She said, 'nowadays the grass is not ready. All of my fathers [referring to the clan-elders] are thinking that after this season, we should go back home...They told me I can't go back alone, because they wanted us to go together. So, if I'm sick, they should take care of me.'[290]Internal relationships within families and households thus affected decision-making around return.

These issues illustrate the role of biosociality in shaping displacement. Decision-making about return involved a complex negotiation over social relations and networks of kin and family. For those with little family support, biosocial relations with others living with HIV as well as with local adherence monitors and caregivers were critical. Because the transitional period threatened the social ties formed between those with HIV, family and clan relations became important in decisions around return, in ways they had not been during the time of encampment. The support networks among those with HIV in the camps were an incentive to

[289] Focus-group with Mary Abalo, Akulu Rose Akoo, Susan Auma, Jacinta Adong, Anonymous woman, HIV-positive women, Opit, 17 February 2008.
[290]Interview with Evelyn Aber, TASO client and founding member of Yabbo Wang Wu AIDS Group, Pabo, 25 August 2008.

remain in the camps, but many were also aware that these were under strain during the period of return.

There was a spatial logic to this: many living with HIV knew those with whom they would live in proximity in return areas, as village areas were structured geographically according to family and clan (*kaka*). The levels of acceptance experienced by those with HIV from their family, clan and village members in the camps shaped their willingness to return. In addition, the vulnerabilities of family members also shaped decision-making. If family members themselves were vulnerable for reasons other than HIV, this also affected decisions about return. The case study below explores these interwoven material and social concerns about return, through the thoughts and experiences of an HIV-positive woman in Pabo.

Beatrice Arach

Beatrice Arach, whom we met in Chapter Four, was a 32-two-year-old HIV-positive woman in Pabo. She had suffered severely from stigmatisation, linked to a recurrent rash, but she was positive overall about the gains made in fighting HIV. In 2008, when I first met her, she wished to remain in the camp, and she was still there in mid-2009. Her decision-making was wound up with concerns about her health, access to healthcare, the care of her mother and children. She explained:

> If everyone is going back, then I'll have to go back. There's no need staying here if everyone has already gone back, but if people are still here then I will stay, because with my weakness I can't go back. My mother is weak too, so no one will bring me quickly to the clinic if I fall sick, back in the village. My mother

> hasn't gone back to the village. My mother is still here. There is no one to build a house for her back in the village, so we are living together with my mother. [291]

The risks for Beatrice were compounded by other fears of insecurity, as well as concern for her children:

> Now, the rebels are not there and we are uncertain whether they will stay away forever. If they come back and get me in the village, I can't run; I will be too weak to run. Another thing is that my children are still in school, and if I go back my children may not be in the position to study again.[292]

She considered the loss of the social networks and support in Pabo something that would compound the difficulty of the return process: 'Definitely life will be hard. When I go back to the village they [friends living with HIV] won't be in a position to visit me, because they are far away'. However, her associations of the camp with moral and social decline, and with the spread of HIV were strong. Ultimately, in spite of the concerns outlined above, she said:

> To me, I say that I would rather go back to the village, because if I stay with my children it means that my children are prone to getting HIV too. In the camp, if not all, then very many are infected. I don't say that my children won't get HIV back in the village, but there's a chance that if I go back they may not. [293]

Despite her desire to return, her ability to do so remained contingent on her return to health: 'If I return and I'm in good health, not like I am now, then I think I can dig. [cultivate]'

[291]Interview with Beatrice Arach, 32-year-old HIV-positive woman, Pabo camp, 15 July 2008.
[292]Interview with Beatrice Arach, 32-year-old HIV-positive woman, Pabo camp, 15 July 2008..
[293]Interview with Beatrice Arach, 32-year-old HIV-positive woman, Pabo camp, 15 July 2008.

This account revealed the interacting social, physical and medical concerns that shape the return process. Access to treatment was not the primary determinant of the choice about whether to return, but it shaped other concerns. In addition, the physical weakness caused by HIV did not constitute the sole barrier to return –vulnerabilities were dependent on networks of social relations. In particular, in Beatrice's case, the strength and continuity of social relations with others living with HIV was of concern, as was the weakness of her mother. HIV status thus permeated both the material and social dimensions of decision-making.

Decision-making around return

There are several options available to the displaced: move permanently to rural areas or town, stay in the camps or towns if possible, or try to maintain a mobile existence between sites. In 2008 there were still many HIV-positive people in camps with no wish to return in the near future. The same was true of the towns. None of the treatment providers discussed above had been keeping adequate mobility data. In light of this I conducted mapping exercises with four out of a total of eight community-based treatment monitors in Opit to get an indication of how many living with HIV were still in the camp. This exercise suggested that around 5 percent of those still living in Opit in mid-2008were openly HIV-positive.[294] My research assistants and I also facilitated a mapping exercise with all three TASO community workers in Pabo, as well as one working for the JCRC, amounting to a total of 237 people with HIV, which showed 208 still present in the camp. A community-based organisation for people with HIV/AIDS (PHAs) in Pabo, WACFO, kept a database of members. In August 2008 it showed 271 still in Pabo, 49 in transit sites, and 24 who had returned to villages (WACFO, August 2008). The above data are only partial, but serve to indicate that a significant

[294]The exercise mapped 318 people with HIV/AIDS in Opit who were receiving treatment (ARVs or Septrin). 139 were still in the camp and 5 had houses both in the camp and village. This is not the total number of those with HIV still in Opit, yet still represents around 3.4% of the 4000 still in the camp.

proportion of those living knowingly with HIV remained in Opit and Pabo in 2008. In the towns, perceptions by TASO workers were that many displaced to the towns remained, though there was a significant return movement from the towns to rural areas too. Among those we spoke to in Layibi (on the outskirts of Gulu Town) from 2006 onwards, many still remained in the town by 2008 and 2009, although some were starting to go back to the villages to cultivate, rather than moving back permanently.

Perceptions around return in both camps and towns were often conflicted. As I have shown, socio-spatial themes inform decisions about return. Distances, transportation, proximity to health centres, and proximity to friends are all issues of concern. Many I spoke to emphasised the benefits of biosociality over those of kinship. The most extreme examples were those who suggested that the government should create camps, especially for those with HIV, around the health-centres. This notion was raised in focus groups with those living with HIV in Pabo and Atiak.[295]As Betty Akello put it:

> To me I feel like moving with medicine is quite hard and transporting some of these drugs is hard because our roads are not all that good. So, if possible what the government could do is build a camp where they put all the sick people and where healthy people don't come to visit so that among the sick people we help each other and it's always easy to bring medicine for us (Betty Akello).[296]

Others wished to establish permanent livelihood in the camps, through small businesses and trade. In Pabo, for instance, there was support for livelihood programmes through WACFO, which provided money to start up small business. Many failed, though a minority of those

[295]Focus-group with Almy Jessica Akena Phillip Akello Betty Akello; Odong Patrick mixed gender HIV-positive respondents,Pabo,24 February 2008.; Focus-group with anonymous HIV-positive respondents, Atiak, 28th August 2008.

[296]Focus-group with Almy Jessica Akena Phillip Akello Betty Akello; Odong Patrick mixed gender HIV-positive respondent,Pabo,24 February 2008.

living with HIV have managed to set up businesses and stalls, allowing them to remain in the camps. The camps located around sub-county headquarters will remain centres of trade, as they were prior to displacement.

Mobility between villages and camps was also common, particularly among those who were displaced only a few kilometres from their home areas, and so could move to family land during the day in order to cultivate or collect wood. There was also some evidence of people having houses in both camps and villages – though this was a more general strategy, and not unique to those living with HIV (Green, 2008). Mobility between camps and villages was also a strategy for negotiating the increased distances from health services.

Charles Ojok was a 31-year-old HIV-positive man living in Opit. His home village was in Odek sub-county, a two-hour bicycle ride from Opit. Charles had a house in the village and a house in the camp. He said: 'I alternate; if I stay there for two weeks, I might come back here and stay for the same duration.' [297] His decisions regarding where to stay were closely linked to his health:

> My village is quite far, and when I go back to the village, I might get defeated in going back to fetch the medication. I might not have the transport money to continually bring me to the hospital. This medication you should not miss; you should take it every day. And if I miss it, then it means I've broken a strong rule for the medication. I would like to stay here in the camp where I am near to the medication. When I'm going back to the village, I go back to check on my children. When I decide to stay in the village, it's hard to come back to the hospital when I get malaria because I might not have anyone to bring me immediately to the hospital. So I might move between the village and the camp,

[297] Focus-group with Florence Awio, Dennis Okello, Lucy Angee, Silberia Amony, Charles Ojok, mixed-gender HIV-positive respondents, Opit, 12 August 2008.

> because when I go to the village I know I am healthy, and I can move back if I'm not feeling so fine. [298]

This strategy reveals how both bodily health and spatial relations are considerations in negotiating return. Mobility became a strategy to mitigate the increased distances to health centres, as well as to cope with the fragility of ill-health.

Joseph Oliel, from Pabo, used a similar strategy. Joseph said, 'because of my sickness I always go to the village, so I have to stay both in the village and the camp. At any moment, the sickness might put me down, and there's no one to bring me to the health centre.'[299] It was a common practice among those living far from the camps to stay with others with HIV in the camps when coming to the camps for medicine, or to share houses. This is an example of the interactions between changing spatial relationships and social networks. We met several HIV-positive patients who stayed with other patients when returning to get medication.

For some of those who came from remote areas, return was not possible at all. Akulu Rose Awony was a 37-year-old woman living in Opit. She was married to a soldier who later died from AIDS. His family blamed her for infecting him, barring her return to his land. Her parents' household was in a distant village, Omoro, in Lira district, where ARVs were not available. She had moved near Opit with her husband and now felt unable to leave. 'I can't go back to Oromo, because I can't leave my medication' she said. 'If my husband hadn't left

[298]Focus-group with Florence Awio, Dennis Okello, Lucy Angee, Silberia Amony, Charles Ojok, mixed-gender HIV-positive respondents, Opit, 12 August 2008.

[299]Focus-group with Joseph Oliel and Cristin Acan, HIV-positive couple, Pabo, 24 August 2008.

me with this sickness, I wouldn't be here in Opit now; I would be far in our place.' [300]It was common for HIV-positive women to be denied access to their husband's land, as they were blamed for their husbands' deaths. They would therefore have to return to their parents' land, where as married women they were often not entitled to land in the villages of their birth, and they were thus reliant on the generosity of parents or brothers.

Charles Okot and Grace Aroma, a couple living in Opit (originally from Ngai), experienced similar problems. Charles explained: 'We came to the camp in 2006. Last year, I went back to Ngai, but I couldn't stay in Ngai, that's why I came to stay here again, because I'm sick.' [301] He was one of those who was not registered for food support, and relied on support from the mission in Opit. Charles explained the difficulties of return:

> To me, going back to the village is still a myth. I can't go back to the village, because it's going to be hard to transport me back to the camp to access medical attention. I know now that we are taking ARVs, and we are healthy people. But we are not so healthy because we get fever often. And if you are deep in the village, who is going to carry you back into the camp to access medical attention? So, it's still hard. [302]

Grace supported this view:

> To me, I would choose to remain in the camp, because if we go back to the village, the village is so far. And you can't come back easily to access medical attention. If in the villages we had the health centres and hospitals, then we would go back. But if there are no health centres there, then we can't go back. [303]

[300] Interview with Rose Akulu, 37-year-old HIV-positive woman, Opit, 1st March 2008.
[301] Focus-group with Charles Okot and Grace Aroma, HIV-positive couple, Opit, 25 June, 2008.
[302] Focus-group with Charles Okot and Grace Aroma, HIV-positive couple, Opit, 25 June, 2008..
[303] Focus-group with Charles Okot and Grace Aroma, HIV-positive couple, Opit, 25 June, 2008..

The couple do, however, return to their home land to cultivate, but always sleep in the camp. This indicates that, when determining their place of residency, they prioritised relation to medical care over access to their agricultural land.

Still, residents of the towns experienced similar concerns to those in the camps. In Chapter Three, I introduced Florence Atoo in Layibi. I visited Florence in both 2008 and 2009. In 2008, she explained how many members of their HIV support group had chosen to remain in the town:

> Many have not gone back because there is no medication back in the villages and there might be problems with transport. People [with HIV] are still in the town because of medication. They are saying that they are staying for medication. And they don't have any way to reach home. They don't have any transport and if you are sick who is going to construct for you a house? And there are others who are widowed. They don't have husbands and they don't have anyone who can help them when they are in the village. The reason why I'm saying that is because here in Layibi I'm taking care of orphans. There are other children here whose parents have been killed by the rebels and then there are other children who are orphans because of HIV. I can't go back because the house was already built here so I'll have to stay back and get the ARVs for these kids and mine too. If I go back I don't even have strength to dig so I just have to remain here and get my ARVs and the ones for the children.[304]

When we met Florence again in July 2009 her circumstances had altered and she had started returning to her village to cultivate. She said that many in her group had started returning to the villages, though they kept houses in Layibi so that their children could continue going to

[304]Interview Florence Atoo, 37-year-old HIV-positive woman & chairperson of 'Twoo Jonyo Pe Koyo', Layibi, 27 July 2008.

school. The treatment sites in the town had nonetheless remained a place of meeting. Florence said: 'I still see them when they come to town. I am always happy to see them. They must come. They are tied to this place because of the medicine.'[305]

ARVs were not the sole reason why those with medical care would remain in the town. Other health concerns, including access to good prenatal care, also shaped decisions about return. Monica Ageno, in Layibi, explained the changes over the past year in 2009:

> Yes, there's a lot of change. People are going back to the village. Even me, as I speak, my mother is in the village, and most of my family members are still in the village. And if all goes well, even me, I might go back in the village. Then we will just come back to collect our medication. Now that I'm pregnant I need to stay near the hospital, I can't go all that far, because here I'm near to the hospital, and any time the labour begins, I can just rush, but from the village it is really far, and any time the labour pains begins I can't rush. So, I can't go back because I need to save the life of my child. And then there is the promise that they're [Comboni Samaritans] going to give me help with milk, so I need to stay near where I can pick up milk for my child. I can't move from the village to here to get the milk, because it might be on a weekly basis.

During the return period, therefore, concerns about medication had become entangled with other concerns – school fees, pregnancy, family support – in shaping decisions. Furthermore, decisions about return could divide households, with individuals within households having different priorities. The case study of a family living in Opit illustrates well this.

A case study of a family

[305] Conversation with Florence Atoo,HIV-positive woman & chairperson of 'Twoo Jonyo Pe Koyo', Layibi, 15 June 2009.

I first met Grace Alanyo and Mary Ajing, two of four co-wives, in March 2008. In August 2008, I met Grace again, as well as her husband Christopher Mwaka. Christopher's home was in Ngai, and he had moved to Opit specifically to access medication. In Opit, he joined the HIV support group, and became temporarily the World Vision community worker in the camp, where he met Grace and Mary. He had met his two previous wives prior to displacement in Ngai, in Oyam district, the border of which is about 15km from Opit. He had sixteen children, several of them after he knew he was HIV-positive.

In February 2008, both Grace and Mary affirmed that they did not want to go to live in Ngai, an area in which they had never lived before. Grace expounded at the time:

> Life is very important. It's because of the medication that we are looking like this. That is why we decide to stay next to the hospital. But if it's a forced [relocation], if we are defeated and have nowhere to stay, then we will go back to the village, but it's not to our liking that we should do that.[306]

They said that they had discussed the return as a family, and decided to remain. At this point Christopher was very ill, and could not return. When I returned in August 2008, Grace expressed similar sentiments. At this stage her primary concern was how to start up a small business that would enable her to remain in the camp, though medical concerns were also a priority. She said:

> I still want to stay here. I'm thinking of the hospital, because if I go back and am attacked with malaria, it becomes hard for me to travel here. So, I'm waiting for this year. If I see any change this year, then I will go back.[307]

[306]Interview with Grace Alanyo & Mary Ajing (Pseudonyms), HIV-positive co-wives, Opit, 12 March 2008.
[307]Interview with Grace Alanyo & Mary Ajing (Pseudonyms), HIV-positive co-wives, Opit, 12 March 2008.

At this point, Christopher's health had improved, and he was moving between the camp and village. In Opit he ran a local bar selling cassava beer and 'wine' (a blend of sugar, yeast, water and food colouring) while in the village area he was restarting cultivation. Christopher explained this strategy of moving between the camp and the village:

> I stay for the same number of days in the camp and village, I just move between the two places...The reason why I'm still in the camp, is because of my business. There is more business in the camp, but I will divide some in this area, and if I see it is doing well, then I will bring the rest of my family here. I have many children and I can't just come and sit and do nothing that earns me money. [308]

While Grace prioritised her health as a reason for staying in the camp, Christopher focused on business. However, clearly having wives in the camp suited him, as they provided support when he was ill and needed to return to Opit. Christopher said he wanted to take care of the family and have all his wives return to the village. However, it seemed that Grace had little support and preferred to rely on her own means in order to survive and take care of her children. She expressed significant concern that she did not have enough food to take her child off breast-feeding and onto solid foods so as to help avoid the transmission of HIV to the child. 'Life is hard because we have little food. And then even the flour for porridge, which I would use for this child is not there' [309], she said.

As mentioned above, in August 2008 World Vision food support had not arrived for two months. Since the food support had not arrived, Grace said that the household daily food provisions had halved. Grace had been selling some of the food support in order to save money to start a small business in the camp. She had also been selling fried dough in the

[308] Interview with Christopher Mwaka (Psuedonym), Ngai sub-county, 18th August 2008.
[309] Interview with Grace Alanyo & Mary Ajing (Pseudonyms), HIV-positive co-wives, Opit, 12 March 2008.

local market, but this business collapsed after a period of illness. However, because of her weakness, she felt that running a small business in the camp was better suited to her physical condition than returning to agriculture. She explained:

> We look for something to eat within the camp with the little money that we have. I don't have any business at present, but I'm planning to borrow some money to begin a small-scale business, even if it means making little chapattis or small doughnuts, and selling them on the roadside. I can't dig now, I'm following the instructions from the doctors, because if I begin digging I have the fear that I may fall so sick.[310]

Grace's parent's home and village was a few hours walk from the camp, and she still returned to the family land in order to gather wood, though she did not cultivate. Her mother had died, and her father also migrated between the village and Opit. This indicates that, in order to cope, women like Grace had to draw on a diverse range of resources that were often geographically dispersed.

Christopher also expressed concern over food. His two wives who had returned to Ngai and started cultivation, but he had doubts concerning his ability to feed his family so that all his wives and his children could return to the village. Christopher wished that his wives would live with him in Ngai. However, Grace said she hoped to remain in Opit:

> I have now two options. One is to go back home [referring to Ngai], if I don't get any money to sustain me back in the camp here. But if I get enough money to sustain me in the camp here, then I won't go back. The reason I want to remain in

[310] Interview with Grace Alanyo & Mary Ajing (Pseudonyms), HIV-positive co-wives, Opit, 12 March 2008.

> the camp is because I'm sick, and in case I am attacked by any sickness than I'm near the hospital. [311]

We see from this case study that the interactions between social and spatial dynamics were important in shaping decisions in the return phase. Splitting the family between the return site and Opit was a way of protecting against the onset of illness. Christopher could always return to Opit, and did, when he fell ill. It also allowed a careful management of resources. The camp provided a source through the income of the bar and Christopher's home village provided food through agriculture. Grace also had access to her parents' land as a source of wood-fuel, though not of food. Her reasons for staying in the camp were focused on the camp as a source of income, as well as treatment (for HIV and opportunistic infections) and health security. The different concerns within the household revealed different priorities, though also perhaps a degree of unstated conflict. Grace's account indicated her uncertainty about Christopher's ability to take care of the family and an unwillingness to move to his land. There may also have been tensions between the wives and disputes with Christopher. Splitting families could be a coping strategy for both medical and livelihood reasons in the return period, but could also be a response to conflicts of interest along communal, family and gender lines.

When we returned in June 2009, we found the family had split up completely. One wife, Mary, had refused to return to Ngai with Christopher, who had physically beaten her. Grace had returned to a different area to live with her aunt, and we could not find her. These family dynamics illustrated the more sinister side of HIV-related biosociality, and the ways these biosocial relations could be exploited by men with some economic power and influence, as was discussed in Chapter Three. These family dynamics also revealed how, as the return

[311] Interview with Grace Alanyo & Mary Ajing (Pseudonyms), HIV-positive co-wives, Opit, 12 March 2008.

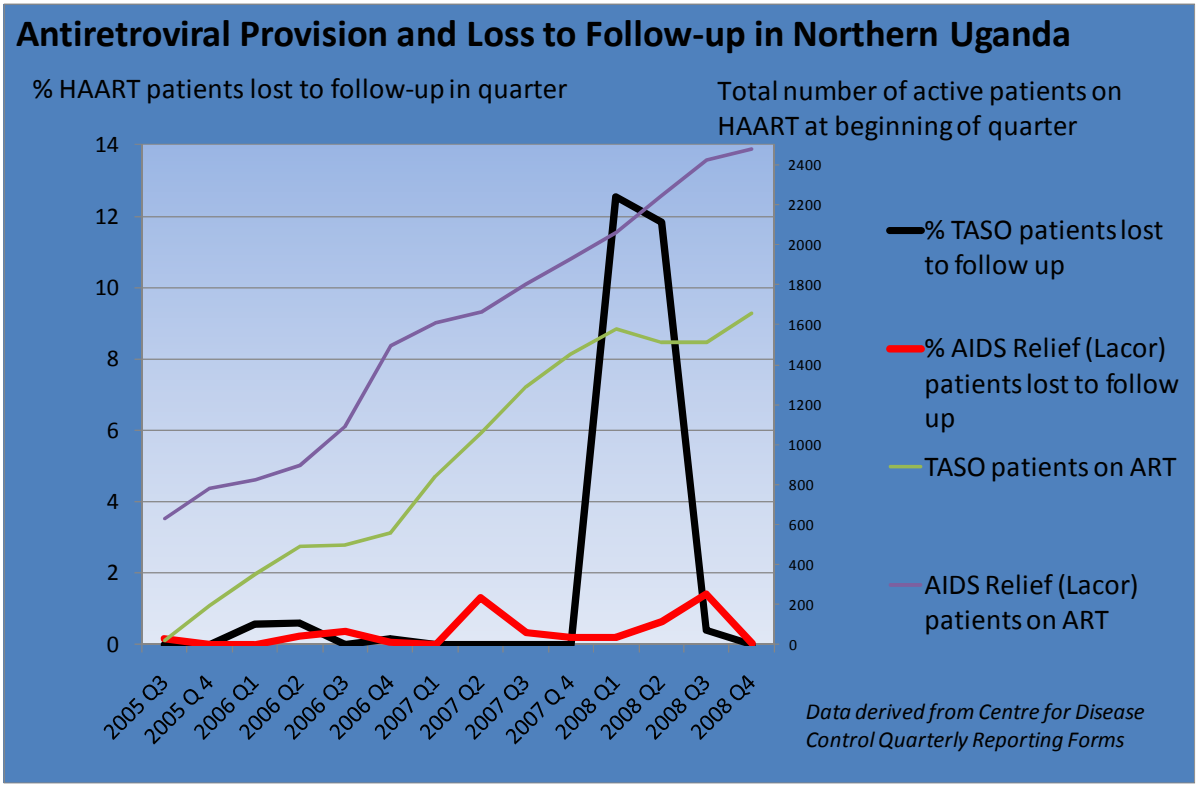
process progressed, Grace and others like her chose to return to the villages despite their initial desire to remain. The processes surrounding migration and return are thus dynamic and uncertain.

The public health risks of return

The return period not only created difficulties for those living with HIV, but also for treatment organisations trying to monitor patients. As discussed in Chapter Two, in the environment of the camp, monitoring and follow-up of those on ART was made relatively easy due to the congestion of homesteads. However, return movements, and the opening of trade routes, have made continuity of treatment much more complicated. The scattering of the population and increased distances between patients and their nearest health centre created difficulties for patients and providers. Some patients are so sick that they cannot come to collect their medication and those who have lost all their relatives have nobody to collect their medication for them. All programmes have had to contend with patients who miss appointments or who give up on treatment.

TASO's strategy of home-based provision and monitoring using motorcycles was very effective when populations were static, but came under strain when patients moved further away. In the first two quarters of 2008, over 10 percent of patients were lost in each quarter (see Figure 1). However, a strategic shift to using community members to monitor and track patients, as well as decentralised treatment distribution points in rural areas, allowed TASO to radically reduce lost patients to under 1% in the second half of 2008.

Figure 1: Loss to follow-up



Source: CDC Quarterly Reports (My analysis)

These results accord to the feedback received from fieldworkers. Tommy Otoo, a field officer for TASO, explained in August 2008:

> In this period of decongestion [i.e. return] one of the biggest challenges is following up these clients. Secondly, the distance has also increased. Thirdly, we are losing track of some of the clients, and for those who have gone back, there's that aspect of stigma, stigma is on the increase. There is also lack of the basic needs like food, housing, shelter – these are inadequate. In some cases, children have dropped out of school. Water and sanitation is a big challenge. And there's still fear. Survival has become difficult, so the clients have begun to engage in hard labour, some are burning charcoal, they're farming under these conditions. And those whom we cannot reach are finding difficulty in transport costs to come and collect their drugs. In addition to that, there are no proper medical services. In

> some places the buildings are there, but the drugs are not there, for treatment of opportunistic infections and the like. [312]

This account showed clearly that the difficulties for those living with HIV in negotiating the return phase interact with the difficulties facing organisations during this phase. In late 2007 TASO began setting up community distribution points in rural areas, to provide to patients near their homes, which were supported strongly by patients I spoke to. Records of lost patients (see Figure 1) and interviews with health workers both indicate that these approaches were at first slow in keeping pace with movements, but later managed to reduce missing patients radically (below 1 per cent in the second and third quarters of 2008). Monitoring of mobility patterns had been done – but on an *ad hoc* basis with field officers attempting to keep track. Additionally, with strained resources, the task was hampered from its inception. Attempting to track patients in return areas was thus a strain on time and resources.

Many TASO field workers had anticipated the challenges that would be created by the return process – in both my interviews and institutional meetings – and had pushed for a decentralised approach from as early as 2006. However, they were not granted the funding necessary to implement this until late 2007. It was in late 2007 and early 2008 that most of the loss to follow-up occurred.[313] This raises a critical point: financing for treatment strategies to displaced communities needs to be flexible enough to allow organisations to adopt new strategies in changing circumstances. If financing and authorisation was available when the local TASO workers wanted to implement the new strategy, the large loss to follow-up arising from increased mobility might have been avoided.

[312] Interview with Tommy Otoo, Taso Field Officer, Gulu Town, 25 July 2008.

[313] As loss to follow-up is measured as missing appointments for three months, the figures in the first and second quarters of 2008 reflect patients who initially went missing in the latter quarters of 2007, i.e. precisely the period when freedom of movement was allowed in Gulu and Amuru.

St Mary's Hospital Lacor had shifted to a community-based monitoring strategy from the outset of their programme, with the help of the community organisation Comboni Samaritan –a strategy which proved very effective in ensuring continuity of treatment. Extensive networks of community-based treatment monitors were chosen from different geographic areas and few patients were lost during the return period, never exceeding two per cent in a quarter. The success of Lacor Hospital shows that extensive community networks can be as effective as decentralising treatment provision in ensuring ART continuity. The experience of Opit illustrated how choosing community-based monitors from different geographic regions could be successful. In Opit, the community workers moved to a diverse array of rural areas around Opit, ensuring that there was significant coverage when return movements began. Low loss to follow-up illustrated that foresight as well as dialogue with communities could help reduce the numbers of lost patients, while also allaying some of the fears about the return process among those with HIV. However, the programme still experienced significant challenges during the return process with regard to missed appointments. Masimo Opiyo, chairperson of Comboni Samaritan, said:

> The problem with our clients, they're trying to go back home, but now accessibility to the hospital and to the health centres is becoming a problem to them, and also to us the health workers, because we cannot meet them as frequently as we want to, and they can also not reach us as frequently as they want … [This is] affecting our clients on ARVs, sometimes, they miss appointments because they can walk three days to reach Lacor for instance, because they are sick and they walk slowly. It's a terrible problem.[314]

[314] Interview with Masimo Opiyo, Chairperson of the Comboni Samaritans, Lacor, 27 August 2008.

According to Opiyo, over 100 out of approximately 2000 patients missed appointments in July 2008, mostly due to lack of transport, and had to be tracked down.[315]

An additional challenge cross-cutting all programmes (including Comboni, TASO and NUMAT) was that community-based adherence monitors were themselves often HIV-positive and were also battling with the difficulties of transition. The small stipends[316] provided were often inadequate to cover even their time, and community monitors across programmes said they were unable to follow patients as rigorously as in the camps. For instance, in Ngai, Simon Omara of the Comboni Samaritans, who is also living with HIV, reported increased difficulties monitoring and meeting those with HIV. He said:

> The major difficulties I face is the distances are far, and most people take their medication at eight o'clock, and it is already dark, and you may find it has started to rain, you may encounter drunkards on the way who disturb you, and another problem, is if you have to cover a long distance that makes you weak. [317]

It is difficult to assess the impact of the return process on MOH programmes. Government health services did not keep or process adequate data to address the extent of loss to follow-up, but field interviews suggest that it may be significant. In general, state health services faced a crisis in the transitional phase. The conflict had led to severe shortages of human resources in healthcare. The WHO estimated that, by August 2008, Gulu District had only 25% of the health staff it required.[318] Thirteen health centres in the district were dysfunctional.[319] There were serious problems with drug supply chains, with frequent

[315] Interview with Masimo Opiyo, Chairperson of the Comboni Samaritans, Lacor, 27 August 2008.
[316] The stipends ranged between 20 000 and 30 000 Ug Shillings (around £10) per month.
[317] Interview with Simon Omara, HIV-positive Comboni Samaritans adherence monitor, Ngai, 14 August 2008.

318 Interview with Solomon Fisseha Woldetsadik, Head of WHO, Gulu Office, Gulu Town, 23 August 2008.
319 Interview, Dr Solomon Woldetsadik, head of WHO Gulu sub-office, 23 August 2008.

stockouts of medication including ARVs -causing patients to miss treatment, as discussed in Chapter Two. These stockouts were compounded by the shortage of medical staff and mobility.[320]

The potential challenges of the return period for HIV treatment were generally under-estimated during the conflict. For instance, as discussed in Chapter Two, ART supplied by the MOH was expanded to some rural health centres in 2005 with no contingency plan for the return period and often little capacity for treatment monitoring. Coordination between programmes and sharing of experience were also problematic. The Health, Nutrition and HIV/AIDS cluster meetings chaired by the WHO focused on the more immediate challenges of transition, such as the hepatitis E and malaria outbreaks[321], and were not appropriate forums to develop longer-term approaches or monitoring capacity for patient retention in HIV as well as TB programmes. In addition, my own review of the 2008 minutes of the health cluster meetings[322] revealed there is little general discussion about the long-term impacts of illness for the return process and minimal attentiveness to vulnerable groups, though there was a consciousness of the need for longer-term planning.

The head of the Gulu sub-office of the WHO, and co-chair of the cluster group on Health and Nutrition in Gulu and Amuru, expressed grave concern over supply-line problems and poor monitoring in the region, leading potentially to resistance to HIV and TB drugs. 'One of the serious gaps is the compliance. We don't have a strong system to look after the compliance,' he said.[323] The WHO and District Health Services were exploring using volunteer village health teams to monitor compliance, but this was still in the planning stage during the period

320 Interview, Dr Solomon Woldetsadik, head of WHO Gulu sub-office, 23 August 2008.
321 Hepatitis E broke out in Northern Uganda in early 2008, and there was a malaria outbreak in June 2009.
322 Health, Nutrition and HIV/AIDs Cluster meeting minutes, 2008, [emailed to the researcher by WHO]
323 Interview, Dr Solomon Woldetsadik, head of WHO Gulu sub-office, 23 August 2008

of my field-work. This is, in part, a problem of distribution by the national medical stores, but is also a result of poor reporting systems exacerbated by a lack of health staff. In addition, the government facilities apply no upper limit on those they place on ARVs or Septrin. This leads to stockouts as there are inadequate drug supplies.

As discussed in Chapter Two, selected rural health centres with ART provision were supported by different branches of MSF, which included community support, although these faced staff and supply-line challenges once MSF withdrew. In late 2006, the five-year NUMAT programme was established to assist state health services with supply lines, community support and the decentralisation of treatment. This was a welcome development though in places, like Lira, community support started after the return movements were underway. Treatment was still unavailable in a number of rural health centres by 2010, though coverage had improved significantly since the cessation of hostilities.

In Chapter Two, I discussed the challenges facing MOH treatment provision as result of the deleterious effect of the conflict on health services. However, the return process exacerbated concerns over adherence and continuity. For instance, according to the acting medical superintendent of Anaka: '[Patients] are moving far away and it's becoming problematic for them having to come and pick up the pills.'[324] In Atiak, as discussed in Chapter Two, the withdrawal of MSF left the HIV-clinic with few staff. NUMAT started to provide community monitoring for the ARV programme after MSF's withdrawal, but NUMAT community workers were struggling with increased distances arising from the return process. In Lalogi, where MSF Spain had supported the state health clinic, including the ARV services, drug shortages were reported only a month after withdrawal, in spite of MSF leaving behind a 9-

[324] Interview with Alfred Onen Acting Medical Superintendant, Anaka Hospital, 11th March 2008.

month buffer supply.[325] These issues reveal some of the difficulties of the transition from emergency-based approach to ART provision to longer-term strategies.

When I visited Ogur health centre in Lira in July 2007, I came across HIV/AIDS patients waiting in vain for their treatment, lingering beneath the large mango trees around the centre. The three health staff trained to distribute ARVs were away on training and leave, and there were stockouts of key ARVs such as Triomune, as well as Septrin. One man I spoke to had not received treatment for three months. ARVs had been introduced to the health centre a year earlier, in June 2006. Since then, stock-outs of key medications, including ARVs and Septrin, had been common. Accommodation at the health centre was still lacking, and staff came in from Lira each day. Often health staff could not make it to work if vehicles were unavailable or the roads poor.

The ART programme at Ogur began shortly prior to the return process. This was the account given by Dr Margaret Elang, the doctor in charge at Ogur hospital, about the programme during the resettlement phase:

> When it came to refilling drugs you would find that patients didn't come. They were cultivating. Patients would miss drugs. This is because of food security. WFP stocks were finished or sold, so people had to cultivate. On days they had to come to refill, very few would come. The other issue was distance. Previously when there was a camp, people were coming for drugs easily. Village Health Teams would remind people. Now people have gone back, distances are bigger. Distance is creating more people missing. In the rainy season people are farming.

[325] Telephone Interview with Ambrose Acede, Lalogi Data Officer, August 2009.

> Some are also so sick they cannot come collect. For those who have lost all relatives, when they fall sick, there is no one to come and collect for them.[326]

Starting an ARV programme under these conditions – without adequate community monitoring or management systems – has been problematic as frequent drug shortages posed risks to patients' health. Risks of sub-optimal adherence were also far higher given the lack of community-based adherence monitors. Furthermore, if drug resistance was to develop, the increased mobility in the return period might spread to a broader geographical area than immediately around the treatment site.

Concerns about poor adherence were also exacerbated by the poorly coordinated phasing-out of food support. Nutrition and drug efficacy are linked. As Castleman *et al*. (2004:14) write,' food insecurity limits the capacity of PLWHA to comply with special food requirements for ART, which can result in reduced drug efficacy, compromised drug regimen adherence, aggravated side effects, or a negative nutritional impact.' Numerous informants, even those on ARVs, told me how lack of energy was a symptom of HIV, and reduced their ability to cultivate. Several community-based treatment monitors also cited lack of food as an obstacle to good adherence.

In July and August 2008, there was significant confusion among recipients about the future of food support. The major food support providers, World Vision and ACDI-Voca were not undertaking a policy of blanket phase-out at the time. Food support was intended to be phased out at a household level after evaluations had been conducted.[327]However, rumours and misinformation abounded in the camps about food support ending. These were

[326] Interview with Dr Margaret Elang, in-Charge Ogur Health Centre 4, Ogur Health Centre 18th August 2008.
[327]Interview with WFP Food for Health Coordinator, Komakec, Gloria,World Food Programme, Gulu 24th August 2008

significantly exacerbated in late 2008 by a two-month delay in the arrival of food support, causing many to believe it had ended. According to the coordinator of the Food for Health Programme (FHP), in Gulu, this was a result of supply-line shortages linked to the global food crisis in 2008.[328] This caused significant anxiety among those living in the camps; there was a general perception that staying in the camps was not possible unless food support was provided.

At a meeting for those with HIV in Pabo in February 2008, people expressed extreme concern about the ending of food support and a TASO counsellor encouraged people to shift programmes from World Vision to ACDI Voca, believing that World Vision support was ending during 2008. This is an indication of the forms of inequality that developed between different programmes and among those with HIV, with some being able access continuing food support and others not. In addition, ACDI Voca support was only available to TASO patients. At the same meeting, some were insistent that they would not move to the village, with one man saying, 'If they move us to the village, they will kill us.'[329] Other primary concerns at the meeting were over stigmatisation and housing in return areas. At another focus group in Pabo, those with HIV said that they thought that they would die if food support was withdrawn.[330]

The WFP and FHP along with the treatment organisations, also contributed to the confusion over food assistance. For instance, while I was told in late 2008 that there was no intention for an immediate blanket phase-out, by June 2009 the programme had been effectively

[328] Interview with WFP Food for Health Coordinator, Komakec, Gloria,World Food Programme, Gulu 24th August 2008

329 Notes from HIV-positive clients meeting, Pabo, 24 February 2008.

[330] Focus-group with Beatrice Arach, Romana Akoko, Rodolfo Ongum. Mixed gender, HIV-positive respondents, Pabo, Amuru District.

phased out and was only providing food to Extremely Vulnerably Individuals (EVIs), with HIV-positive people being excluded from this category.[331] The exercise of labelling EVIs will be discussed in the next chapter; here it is significant to note that the withdrawal of food support placed significant burdens on those with HIV and, for some, led to poor adherence. The discussion below is from June 2009 in Pabo, where FHP assistance was withdrawn in 2008:

> The implication [of the withdrawal of food assistance] is that it has reduced my CD4 count. When I was on food aid my CD4 count was 700, now its 270 and I might soon be put on ARVs (Betty Akello).
>
> Whenever you take [ARVs] the drugs weaken you. This is because they've stopped giving food (Anonymous soldier).
>
> Life is hard; before life was a bit easier [with food assistance]. What I've cultivated, I've not yet harvested. Fields have been spoiled. (Joseph Oliel)[332]

So severe were the food shortages that even a local TASO adherence monitor reported missing her pills. The evidence above demonstrates that the constraints and uncertainties of the withdrawal of humanitarian food assistance intersected with fears around the return process to create a sustained sense of anxiety and uncertainty among those living with HIV in displacement camps. The potential effects of the withdrawal of food assistance, along with effects of missed appointments, ARV stock-outs and increased loss to follow-up across both

[331] Interview with, JacklynBira, WFP field ,monitor,Gulu Town, 15 June 2009.
[332] Focus-group with Joseph Oliel, Betty Akello, Beatrice Akello, Scayo Olga, Anonymous Soldier, Mixed-gender HIV-positive respondents, Pabo, 24 June 2009.

state and NGO programmes remains to be seen, though clearly the possible spread of drug-resistant strains of HIV in the long-term have exacerbated.[333]



Joseph Oliel and son.

Conclusions

This chapter has sought to outline the challenges facing those living with HIV in displaced communities in Northern Uganda as they negotiated the return process. It has linked this

[333] It is not possible to assess the extent of this due to a wide range of variables. These include: the regimens that missing patients were on (NNRTIs being more prone to the development of drug resistance); how patients themselves who went missing handled treatment breaks (sudden stops being less likely to cause resistance than continued poor adherence) and whether patients who went missing died or transferred to other treatment sites without notifying their programmes. Furthermore, during the time of the research there was no drug resistance surveillance in Northern Uganda, which requires specialised diagnostic capacity Addressing these issues is beyond the scope of this research and would require a large-scale social and epidemiological study.

analysis with the broader difficulties facing treatment programmes throughout the region. Just as the social effects of these ART interventions are shaped by the unique socio-spatial environment of displacement, they are shaped by the spatial changes of the return process. In Northern Uganda HIV posed both physical and social obstacles to successful return. The vulnerabilities of those with HIV were related to both material and physical constraints, but also recurrent concerns regarding stigma and social marginalisation. The material challenges included difficulties of housing construction and of restarting agricultural production. In particular, these involved negotiating increased distances to health centres and treatment sites.

Decision-making about return among those living with HIV involved complex choices about livelihoods, health care and access to medication, as well as social concerns. Forms of biosociality and clientship shaped perceptions and choices regarding the risks of return and these were, at times, weighed against the support from family and kinships networks. Perceptions about levels of social and medical support in areas of return were key to shaping decision-making for both residents of camps and towns. The processes of decision-making around return also revealed the tenuous nature of biosocial relations: they were a source of social meaning as well as a safety-net in times of illness, but could not substitute for the access to land resources available (or not) through kinship relations and necessary to undertake return.

Furthermore, conditions of return made adherence monitoring significantly more difficult, and led to treatment ruptures for a number of patients. Withdrawal of food assistance created intense anxiety for those with HIV, but also affected treatment adherence in some cases. In addition risks of the spread of drug resistant strains of HIV have been enhanced. Having

shown in this chapter how population mobility in the transitional period created major challenges and uncertainties for both patients and treatment providers, the following chapter explores the challenges and vulnerabilities of return itself.

Chapter Seven: *Kwo Tek*: Living with Return

Introduction

The displaced do not return to the world they left. The familiar landscape that is mapped by wild palm, banana trees, rivers and hills is also marked with loss and change. Previously productive fields may be covered by wildgrass and acacia in which bush-rats and mosquitoes have proliferated. Few families who left return intact. For those whose path of illness has crossed conflict and displacement the persistent reality of the past weighs on the most quotidian concerns. The effects of disease and displacement persist and 'life is hard' (*kwo tek)*. Returning home after years of encampment is a fraught process; it holds the possibility of renewal, of a restoration of what was lost, but it is also a slow process of restarting life and livelihood. However, I will suggest in this chapter that while the negatives of illness and displacement persist, so do the potentially positive effects of new forms of knowledge, resilience and sociality produced in the spaces of encampment.

In this final narrative-based chapter I explore the persistence of the effects of illness and displacement in the social and material reconstitution of daily life in return areas. The themes of the durability and sustainability of return shape my analysis – in this I continue exploring the theoretical questions of the previous chapter, rather than outlining a new perspective. However, in this chapter I aim to explore in more depth how issues of social and biosocial relations shape experiences of return. I probe the rhetoric of 'durable solutions' and 'sustainable return' in cases where the sustenance of life remains inherently fragile and uncertain. A key question I ask is: are the concepts of 'durable solutions' or 'sustainable return' meaningful for those living in continuing biological and social vulnerability? If so,

what are its conditions? Instead of focusing on return as a temporal or material horizon that is crossed, I conceive the process as a further social transition in which the effects of displacement persist.

Furthermore, I interrogate the uses and labelling of vulnerability in Northern Uganda and whether these adequately capture the intersecting forms of disease-and displacement-induced vulnerabilities. Here, as in previous chapters, I understand vulnerability not in terms of pre-given categories (such as gender, age or disease status) but as the way in which the physical body is exposed to others and to its environment, and forms part of a web of social relations and norms (Butler, 2004: chapter two). Survival is not conceived passively, as merely remaining alive, but as the active and continuing process of ensuring biological health while seeking a socially meaningful existence (Fassin, 2007a:261-263). In line with the theme of social space, return is conceived as the social reconstitution and renegotiation of the lived environment. I focus on two areas of return: Ngai sub-county in Oyam district and Ogur sub-county in Lira district. Both of these areas have a distinct trajectory of displacement and return and, in line with the multi-sited analysis offered here, they reveal the ways in which sites shape experiences of displacement and return. I supplement the focus on these regions with interviews and focus groups from several other areas. I also introduce a comparison, drawn from fifteen focus groups and several interviews, between the experiences of those with HIV and those whose HIV sero-status is unknown. The chapter is oriented around several individual stories which reveal the contours and complexities of the themes under discussion.

The singing people: Silberia and Beatrice



Silberia Akot, 2008

In mid-2009, my research assistant Tom, and I travelled the village path to the homesteads of Silberia Akot and Beatrice Aciro, two woman living with HIV. The tobacco leaves were heavy and withered. The fields had been planted but the groundnuts were dying from the heat and there was no harvest. The rains, being late for the second year, had not come and food assistance had been withdrawn. When describing her predicament, Silberia employed the colloquialism *kwo tek*, meaning 'life is hard', or 'life is heavy'. This phrase captures some of the difficulty of return as an experience, not only of homecoming, but of inertia and physical strain. It was one shared by many we had visited. Almost a year earlier, in August 2008, we had visited Silberia and it was evident that she was still struggling with many of the same

problems. Silberia lived with her husband, two adolescent twins and an adult son who is also HIV-positive.

Silberia was receiving ARVs from the Lacor outreach at Opit, several kilometres away. Her children had dropped out of school due to lack of money and food was scarce. Her husband was ill with TB and refused to test for HIV – one of the many men in the region refusing to test out of pride or shame. He was taken off his TB treatment because of alcohol abuse. An emaciated dog scratched around the dry sand in the homestead. The dogs were used both for hunting and protection.

Some of the hopes of the return period were dissipating. When we met Silberia for the first time in 2008, a few months after she had returned home, the harvests were poor, but she was happy to be back –'Living in the camp was very hard. I feel good to be back at home. I like the food at home. I feel good the wind is always blowing. The air is cool.' Still, returning was a hard process: 'The first night I returned I prayed that nothing bad should happen. When I first came back I used to fear, but not anymore. I thought people might come in the night and rob me.' [334] The first season had been bad– drought had killed the groundnuts and Silberia had only harvested a basin as opposed to the bag that was the norm prior to displacement. The first bean crop had suffered from a worm infestation.

Several hundred metres down the path from Silberia, another woman with HIV lived. They had been friends for over a decade before their displacement. However, it was HIV that had brought them together in the camp and now in their home area. Their friendship reveals some of the fragility and tenacity required for life in areas of return. Beatrice had returned to

[334] Interview with Silberia Akot, HIV-positive woman, Tegot Parish, 13 August, 2008.

her home with only her children. During the conflict she had fled with her husband to Gulu Town. He had committed suicide and, unable to afford to remain in the town, she left for Opit camp, where she stayed for a month before returning home.

She had told us: 'I decided to come back because I didn't have any money to keep myself well in the camp. I thought if I came back I could cultivate some crops I could use for sustaining life.'[335] On the family land there were only widows and an old man, her husband's father. Beatrice received no help with cultivation or food support and survived through her own labour.



Beatrice Aciro and child.

Beatrice and Silberia met again in Opit. Beatrice tested HIV-positive in the camp and began visiting Lacor Hospital with the help of Father Alex. Beatrice had a son who was HIV-

[335]Interview with Beatrice Aciro, 32-year-old HIV-positive woman, Tegot Parish, 13 August, 2008.

positive and on ARVs, although Beatrice was only on Septrin. On a distant hill were radio and cell-phone towers. The lights from these towers, flickering on at the same time each evening, signalled the time for Beatrice to give her son his pills. The distant tower lights had become part of her daily cycle of life and treatment. She gave her son his pills when the sun rose in the mornings. Treatment shapes the relation between individuals and the spaces they dwell in. It forms part of the transition from displacement to return.

When food was short both of the women were forced to participate in casual labour (*leja leja*), for which they were paid in beans or 1000 shillings a day. The women were sometimes subjected to stigmatisation while labouring. 'We also get stigmatisation, and they call us the singing people or the soldiers of the priest,'[336] Silberia explained. The term the 'singing people' is a reference to the association of those with HIV with the church.

The two visited one another daily and if either was ill they offered the other help. Beatrice said: 'It's hard because sometimes if you fall sick from malaria there's nobody to come see me. But if my friend can come to see me she will take me to the clinic.' [337] Both of these women laboured in the fields, though pain and illness limited the amount they could cultivate. Silberia told me, 'If I over-dig I feel the pain, but if I cultivate something small there is not much pain.' [338] The women received little support from those around them and Silberia said of the clan leaders, 'They don't say anything. They don't help.'[339]

The story of this friendship captures the heaviness of return, and the fragile forms of biosociality created in rural areas. These women were made to negotiate the difficulties of

[336] Interview with Silberia Akot,HIV-positive woman on ART (St Mary's), Tegot Parish, 17 June2008.
[337] Interview with Beatrice Aciro, 32-year-old HIV-positive woman,Tegot Parish, 13 August, 2008.
[338] Interview with Silberia Akot,HIV-positive woman on ART (St Mary's), Tegot Parish, 17 June2008.
[339] Interview with Silberia Akot,HIV-positive woman on ART (St Mary's), Tegot Parish, 17 June2008.

troubled relationships and family loss, of looking after children with little support and of trying to sustain their own health. They could provide little material support to one another, but their friendship was central to survival in rural areas. In times of crisis and illness, particularly for Beatrice, Silberia was a final safety net. In the camps, illness was a shaping feature of social identity; here it was less so. Those who had returned relied on their family and clan (*kaka*) and were given little support. Silberia was still with her husband but he was chronically ill, and provided little productive support. Silberia had an adult son, also HIV-positive, who lived in the same compound but was also struggling to re-establish himself in the return area.

In this context of social and material fragility, taking medication overlaid the landscape with new paths and new rhythms – the monthly walks to the clinic, the daily taking of pills, the paths between the homes of those with HIV, the Sunday church meetings in which the women would disclose their illness and pray for others to seek treatment. The vulnerability of bodies of those with HIV shaped their relation with the landscape. Illness was visible on the land: the lines where the maize, sorghum, beans and millet met the wild grasses showed the physical limits of the cultivators. Illness could limit the ability for those who are displaced to find security or sustainability in rural areas for years, as the study below of Ogur sub-county in Lira shows.

Ogur sub-county, Lira District

Ogur is a small trading site in Lira District, around 20 kilometres from Lira Town, though roads are poor. The drive passes through fields of rice, sunflowers and wetlands filled with bulrushes. There is a sunflower oil factory in the town which provides an outlet for

sunflowers as a cash crop. The proliferation of these bright flowers, rare in Gulu, was a sign of the emergent economies in the region. The conflict in Lira was not as long as in Gulu and Amuru and the return movements began significantly earlier, in 2006, though with less preparation and support for those returning. The UNHCR cluster programme was not implemented in Lira and the return process was 'managed' by the local District Disaster Management office.

When I visited in 2008, some residents had been home for over two years. Ogur was one of the few rural outposts in Lira in which ART was available during the time of my fieldwork. It was a former camp, although little sign of the camp remained. During the return movements there were forced evictions by landowners, though government officials deny this. Several informants attested to being forced out of their homes and having their homes destroyed while being inadequately prepared for return. Some had to go to their villages and sleep under trees, as discussed in the previous chapter.

I rented two rooms with my research assistants Tom and Susan in the trading centre for a week. The bare walls of the rooms were decorated with newspaper articles about Joseph Kony and the war. We slept on mats on the floor, cooked on a coal fire, and at night listened to the scuffling of rats in the coal. Each day an old Acholi woman who was our neighbour brought us maize, telling Susan that, as fellow Acholi in a Lango area, they were family. There was a gravestone beside our house that the woman told us we had to stand on in order to get cell-phone reception.

In the room beside us lived a young woman, Stella Akello, the old woman's granddaughter. She was looking after two boys– a young boy called Jasper, who was HIV-positive, and an

older boy, both orphans. Stella's aunt, the children's mother, had died of HIV/AIDS. We were told by the local health worker that the aunt had been tested for HIV but treatment stocks had run-out when she visited the clinic. In exasperation she had returned home, where she died. Stella was left looking after the boys with only the help of her elderly grandmother. Stella had never been displaced, but had moved into the trading centre after the war to stay with her grandmother.

At night, through the gap between the tin walls and the roof, we would hear the three singing hymns together, as well as popular songs from the radio, including Bosmic Otim's Acholi hit, *Kopango,* meaning 'is everything OK?' We stayed there during a regional hepatitis E outbreak but were assured by locals that the local well was safe. In the evenings there was a constant stream of children carrying heavy jerry cans full of water. Each evening, cooking over our coal fire, we would ask Stella to join us for a meal. Though she clearly had little food she declined to eat with us at first, though. After a few days she joined us. Later her reasons for refusal became clearer. She told Susan that the area was full of witches (*lujok*) and we should be careful. She warned that we shouldn't take food from anyone or trust anybody that smiled at us, and that in one of the areas that we visited there was a witch who had been leaving poison on the path for children.

Stella's story is a counterpoint to those who have struggled with encampment, and now return, but also a reminder of the fragility of life in rural areas affected by HIV. She lived in a trading centre, on land damaged by war, in a family devastated by illness – a reminder that rural poverty and illness also displace. She was not a returnee, nor living with HIV, and yet her vulnerability was deeply bound up with social and family experiences of displacement and HIV. She told us:

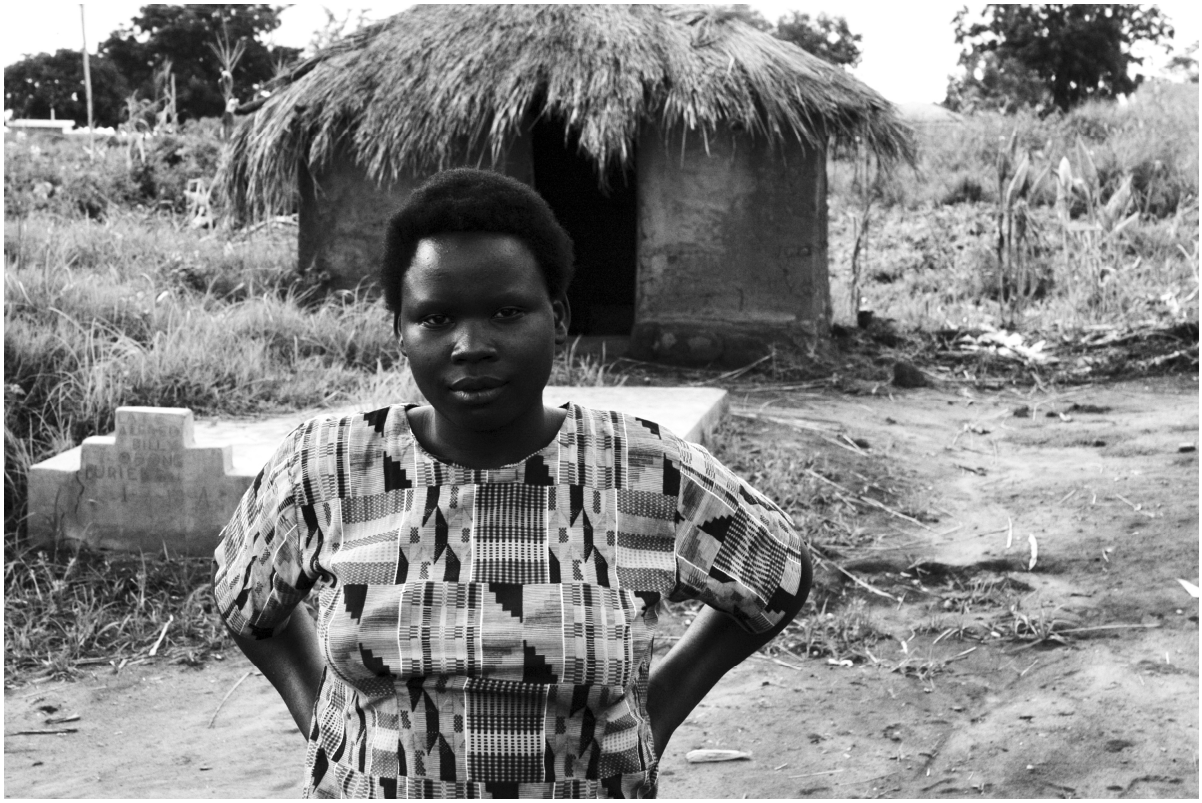
> In our home we had an aunt who died of HIV/AIDS and left behind this child who is Ayoo Jasper. This boy calls me mummy, as he doesn't know who his real mother is. My grandmother always monitors his medication but if she is not there then I take over. He takes his medicine twice a day, at 8am and 8pm. I can't insult anyone with HIV/AIDs because I know it can attack anyone.[340]



Jasper and his grandmother

Though not HIV-positive herself, Stella is one of those whose life became shaped by the daily cycles of ART. Providing treatment and care for Jasper became part of the experience of life in a post-conflict setting.

[340]Interview with Stella Akello, 18 year old woman, Ogur trading centre, 5th August 2008.



Stella Akello

We visited several rural households and conducted several focus groups with HIV-positive returnees in Lira. There was widespread difficulty with the return process among those with HIV in the region. Below are some views from a mixed-gender focus group:

> The problems we are facing in the villages as HIV-positive people, are that in the villages we need to eat, we need to feed when you're taking the medication, but it's quite hard to do such a thing because we don't have the sources.
>
> Some of the building materials are very heavy, and you need someone with a lot of energy, but with our HIV status, we can't.
>
> There's no benefit in going back to the village. My husband died two years back. I have children who go to school. If at all the sickness puts me down, I can't dig; I can't plan for everything.

> Now, those who are healthy are digging, but the ones who are sick can't dig anymore. We have been laid down because of the sickness. [341]

These concerns overlap with the perceptions of risk explored in the previous chapter: they reveal that these perceptions of risk are substantive fears and correlate to the experiences of those who have returned for over a year. Similar sentiments were common throughout Ogur as well as other return areas.

To restate the argument: the difficulties of return are not just about individual capabilities, but also about those of the family. Women without husbands struggled most of all with the process of constructing houses and agriculture, but this vulnerability affected men too. The longer-term effects of displacement interweave with the effects of HIV in the return process. HIV may prevent those who were displaced from ever reaching pre-displacement levels of prosperity.

Rose Iyoko's family shows this clearly. Rose Iyoko, a 32-two-year-old woman living with HIV in Lira, returned in 2006 with her husband. Because of the conflict, they had lost their livestock and farming equipment. Shortly after their return, they suffered extreme food shortages after food support ended. They struggled to reconstruct their houses and it often rained through the roof. Despite being on ARVs, the effects of illness made it difficult to return to working the land. Rose said: 'We can't compare before we went to the camp to now. We had cattle to plough and we had the energy. We would cultivate three acres with revolving crops. Now, we plough only one acre.' [342] The loss of assets as a result of conflict and displacement was irrecoverable due to the limitations of disease. Lack of medical

[341] Focus-group with anonymous mixed-gender HIV-positive respondents, Ogur sub-county, 24 April 2008.

[342] Interview with Rose Iyoko, 32 year old woman with HIV, Ogur Sub-County, Lira, 4th August 2008.

services also created problems, as Rose explained: 'We have problems with transport. I have problems when the children fall sick with malaria. It is difficult to get them to the hospital.' [343] This exemplifies the cumulative effects of displacement and illness. ARV provision may mitigate the effects of HIV, but does not eliminate them. Recently, though, the family had started getting some food support again through ACDI Voca. Their story shows how the vulnerability here was not only about a loss of assets, but also about the loss of strength and labour power. In general, the experiences of those we interviewed in Ogur sub-county showed that few had achieved any stability and most remained vulnerable and unable to return to pre-displacement levels of well-being and production. Most households had not regained food security and limited food support was being reintroduced.

Displacement causes a loss of assets and production while HIV, even with treatment, poses a severe limitation on the ability to re-establish pre-displacement levels of productivity due to both the energy limitations on individuals and the reductions of household size and labour capacity as a result of death. A return to an agrarian livelihood with HIV is extremely difficult. Those who prospered tended to have some form of small business. The struggles faced by returnees in Ogur revealed that the perceived risks of return, discussed in the chapter had validity. The return process in Lira, however, did differ from that of the Gulu, Amuru and Oyam districts where the return process was slower, and accompanied by greater external intervention.

Gulu and Amuru districts.

The return home brings a complex of feelings of hope and disillusionment for many. There was a strong sense among returnees of escaping encampment after many years, but also fear

[343] Interview with Rose Iyoko, 32 year old woman with HIV, Ogur Sub-County, Lira, 4th August 2008.

and disillusionment. These complexities are captured in a focus group conducted in Bobi with TASO patients who had returned home:

> In the village now I'm free, and I do everything out of my own freedom. In the camp they used to rule me like a prisoner. In the camp if they said you can't go to the garden until ten it meant that you'll have to stay back and go after ten. Now, in the village I do whatever I wish at the time that I want. In the camp the soldiers used to rule over me (Tom Okello).[344]

> It should be better in the village, but it is not any different. Now, with me I'm on my own, I don't have anyone to help me out. All my children died, and now I have orphans I am taking care of. Instead of going back to the village and enjoying the village, I go back and have a lot of problems with feeding and nothing to eat. In the village if you are HIV-positive, you have to stay alone. No one visits you, no one comes to talk to you to counsel you. You will have to stay in your home alone (Pilmena Akello).[345]

The individual who struggled most with the return process, in this mixed age and gender group, was an elderly woman without family support. Tom, one of the other focus group participants, lived near Pilmena and would often visit her and see if she was doing alright. The vulnerability caused by HIV may exacerbate other forms of social exclusion, including those based on age and gender. There are, however, mixed benefits of return. According to one woman,

> The village is better. In the camps we were like prisoners, but now we are freed of the problems. We have problems back in the village because we are being

[344]Focus-group with Tom Okello, Josephine Ajok, Florence Auma, PilmenaAkello, mixed-gender-HIV positive respondents, Minakulu, 11 July 2008.
[345]Focus-group with Tom Okello, Josephine Ajok, Florence Auma, Pilmena Akello, mixed-gender-HIV positive respondents, Minakulu, 11 July 2008.

> laughed at, we are being stigmatised, and we are being abused. Everywhere you pass, you just have to bend your head and pass out of shame. If at all there's any help that the NGOs or government can come up with to help us overcome that then we shall be glad, because then at that time we can move upright and face the people who stigmatise us (Florence Auma).[346]

Even for those whose lives had improved with the return process, struggles against stigmatisation were re-emerging. The return process led to the loss of the networks of care among those with HIV. This was felt particularly severely by those without strong social and family support. As a woman who had returned home from Pabo explained,

> I miss the community of people that live together now that I've returned. It is hard to live back in the village. It is hard to stay there alone. At home, we are only three. If my husband is away, if my husband moves to the centre, I'm alone. Life is hard without that [a community living with HIV together].[347]

As in Lira, many of those with HIV struggled with the return process. Several focus groups in Opit and interviews showed that there were difficulties with food, construction and the weather similar to those experienced in Lira. The primary difference was that the community of those with HIV in Opit was much stronger than it was in Lira and the network of community workers much more extensive. This allowed those who had experienced the sociality and sense of community in Opit to take their experiences back to their home areas. The story of two sisters living with HIV in the Ngai area illustrates this well.

[346]Focus-group with Tom Okello, Josephine Ajok, Florence Auma, Pilmena Akello, mixed-gender-HIV positive respondents Minakulu, 11 July 2008.

[347]Focus-group with anonymous mixed-gender HIV-positive respondents, Pabo, 19 May 2008.

Agnes Adoch and family

In June 2009, Tom and I met Agnes in her home village in Ngai and spent the afternoon with the family. I had met Agnes several times since 2006 in Opit. When we met her again she was sitting in the family compound with her mother, aunt, and two siblings. There were four in the family that were HIV-positive. One of these, her sister Beatrice Awei, was also home. In the compound was a small cross beneath a palm tree marking the place where a child had been buried.

The family showed us their land. The area was dry and the crops were not doing well– a result of the late rains in 2009. We walked through spiky bulrushes. Millet, maize, sorghum and weeds clustered together above the dry earth; the fingers of millet curled into one another like small fists. Burnt stumps of grass lay in areas where the ground was being prepared. Some trees had been chopped down, though the mango trees and some local herbs were left in the fields. Groundnuts grew from the earth with tiny purple flowers beside the thick leaves of the *otigo* herb. The family told me that there are no longer bad spirits (*jok*) here; they have been chased away to the swamps with prayer. Return involved not only a material but spiritual regeneration of the land.



Agnes Adoch

Agnes Adoch was from the area of Ngai in Oyam. Her history and paths across the region are ones shaped by both conflict and illness. She had married and moved to Minakulu, close to Gulu Town. However, due to violence and rebel attacks in the area she and her husband moved back to her family land in Ngai, Oyam, where they both began falling ill. In Ngai they heard that healthcare and medication were available in Opit and decided to move to Opit to get treatment in 2005 after they tested positive for HIV. She was on Septrin and had not started ARVs by the time we met her, but the future prospect of going onto ARVs was central to Agnes' considerations about the future. The decision to move to Opit involved separating from family. In the camp, her husband's abuse of alcohol and smoking worsened. He had already married a second wife. Though he had tested for HIV, he refused to start ARVs and

died in the camp. Agnes was left in the camp without family and the community of those with HIV around Opit formed a nucleus of social life for her in the camp. Agnes always intended to return home to her parents' land. She explained the reasons to us in April 2008, after she had returned:

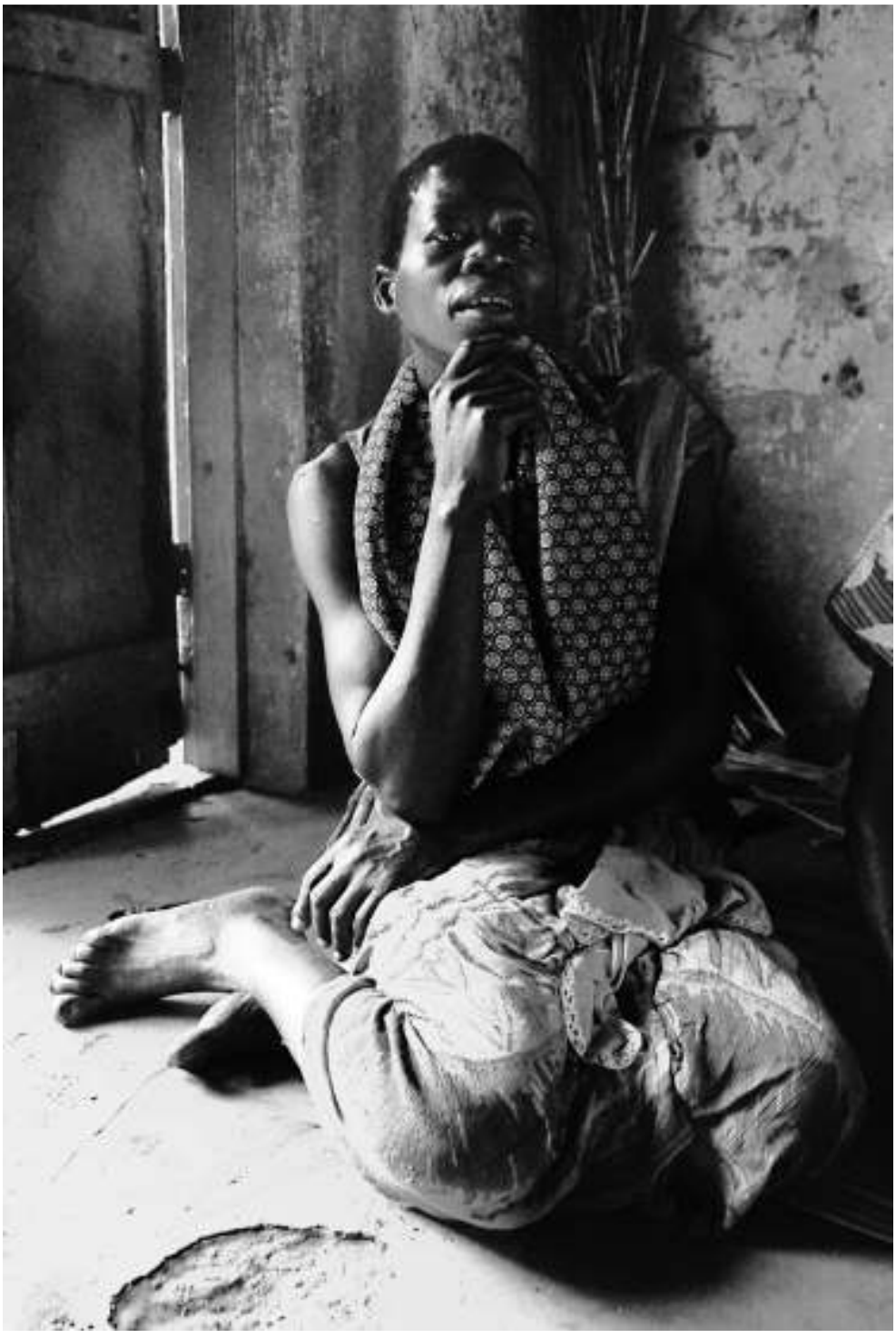
> The reason why I'm staying at my father's land up to now is because I was excluded from my husband's place. From my husband's place, they wouldn't allow me to use land, or allow me to use anything. They never wanted me to stay there. My mother in law hates me and doesn't want to see me; that's when my father took me away and brought me to stay with him. Even he told me that he couldn't see his daughter die, he had to do something before I die. He brought me to the hospital, and up to now he says that when I'm feeling weak, I can borrow his bicycle and he can bring me to the hospital, so that I'm not very badly off.[348]

However, when we met her again in August 2008 she had returned to the camp after having fallen ill. This was the second time she had returned home and then come back to the camp following the onset of illness. Her parents were unable to take care of her adequately in the village. Her house in the camp had been destroyed, and she was living in the house of another 'client' with HIV. Agnes subsequently returned again to the camp before settling at home in 2009.

In 2007, her sister Beatrice Awei was falling ill and she came to live with Agnes in Opit camp, even though the conflict had ended. Like Agnes, Beatrice's paths were shaped by HIV. She was married and moved to Aboke, but after falling ill her family fetched her and took her home. Beatrice and her husband lived for a short period in the Ngai camp. However, after

[348] Interview with Agnes Adoch, 42-year-old HIV-positive woman, Opit, 20 April 2008.

hearing from Agnes about the treatment accessible from Opit, Beatrice moved to Opit to stay with Agnes.



Beatrice Awei

This narrative reveals some of the paradoxical mobility of illness – while some were moving away to return areas, others were moving into the camp to get medical care. However, both Agnes and Beatrice had moved home by 2009. In the return areas they were trying to educate those in the villages around them about HIV and AIDS, as well as speaking at their local church. Both sisters preferred life at home to the camp, though they felt that stigmatisation was worse in the rural areas than it had been in the camp – a perception widely reported by other respondents. This was a result of returning to an area in which treatment was only recently available and there had been few HIV education interventions.

When we were driving home we gave Beatrice a lift on our motorcycle. We stopped along the way to drop her off and took shelter from the rain. There we discovered that a number of people with HIV had gathered in a small room. It was the first meeting of a new village HIV support group that Beatrice and others had arranged. The group had been initiated by people with HIV without the help of an external organisation, though they had been encouraged to form groups through radio broadcasts, probably by TASO. The group aimed to provide a meeting point for those with HIV in the sub-county and to mobilise for support with income generating projects. Nothing like this had existed in their area of Ngai before, despite it being over two decades after the major campaigns had begun elsewhere in the country. Beatrice and others who had been part of the HIV support group in Opit camp had brought their knowledge back home and were part of an inchoate movement to educate those in the area about treatment and HIV. Without immediate prospects of financing or the support of an NGO they had still gathered and started forming new networks. During the meeting an old man wandered in on the group. They explained to him that this was a group for those living with HIV. He was not HIV-positive himself but decided to join the group anyway, causing some hilarity among the members. It seemed to indicate to me that the experience of HIV is

changing from one of exclusion to one of shared experience of a social condition. The relations of biosociality were being extended into broader networks of social support. However, without strong family support, life remains uncertain and fragile for many, as the story of Mary Lanyero below shows.



A new HIV support group in Ngai sub-county at their first meeting

Mary Lanyero

We first met Mary, a woman in her mid-thirties, in early 2008, in Atiak, a camp and trading centre near the border of Sudan. Her parents had died, and after separating from her husband she had little support in the camp. She had recently returned from prison, where she had spent three months, after a skirmish with her husband's second wife. The co-wife had been insulting her about her illness, and had been treating her young children poorly, making them

carry jerry cans. Mary had hit her on the head with a hoe. In prison, her regimens had become confused, and she stopped treatment, suffering from terrible side-effects as a result.

Her youngest child was also HIV-positive. Due to staff constraints at the local clinic, she was not given the option of preventative ART for her child. As she explained:

> I don't know whether it was bad luck, or what. I went to the hospital often, but the nurses were not there. I went to a clinic, to some woman who would give me antenatal service so when it came time for delivery, I had the fear that I hadn't been going to antenatal, so I had the fear that the nurses would quarrel, so I just delivered from home here. By then I never knew that I was HIV-positive. So it was bad luck. So I have never gone for antenatal, so I don't know what happens now. Then, we never had a very good antenatal clinic here.[349]

Struggling to survive in the camp, she had been selling alcoholic brew on the roadside, where she met soldiers, and had relationships with two of them. It was by one of these men that she believes she was infected with HIV:

> I entered these two relationships with soldiers because I was desperate. I needed money, and the money that I got from these relationships, I used it for constructing these houses. If I had continued struggling like that, I wouldn't have landed into problems. There was a neighbour here who was deceiving me frequently, to start falling in love with soldiers in order to get money, but if it hadn't been for that, I wouldn't have gotten sick. [350]

During the conflict, the soldiers would send local motorcycle taxis (*boda bodas)* to collect women from the camp, and take them to the barracks in the bush. When she found out she

[349] Interview with Mary Lanyero, 35-year old HIV-positive woman Atiak, 22 May 2008.
[350] Interview with Mary Lanyero, 35-year old HIV-positive woman, Atiak, 22 May 2008.

was HIV-positive, she did not believe the test results, so she travelled to retest at St Mary's Hospital Lacor, where she began her medication. She later changed to Atiak, because of the costs of transport. She joined a group of people with HIV that MSF helped to form, as well as joining a local choir:

> We sing in the community here. When visitors are here, we sing for them. Me, I'm not interested in spreading the disease. Those who are hiding are the ones who are interested in doing that... Because of the group people do not stigmatise a lot. There are times when other people in the community say that we are not sick, that we are pretending because we want help...This medicine has reduced stigmatisation in such a way in that it has made us look the same as the rest. We are not any different from the rest. So, you can't point out who is sick, and who is normal... people are seeing the good part of the ARVs, because it makes your thinness disappear.[351]

When we first met Mary, her position was very precarious. She did not think it would be possible to return home; staying in the camp seemed the better option:

> I won't go back, because if I go back to the village there is no one to build for me. Even these houses in which I am living. I worked hard and made them with money. My body can't support me in building. So, if they say that there is a grader which is coming to destroy all the houses here, then I will not stay. But if not, then I will stay.[352]

We asked what assistance could be given to those with HIV in the return period. She said:

> According to me, if there was any kind of assistance to be given, they should make houses in a separate place so that the HIV patients stay alone, and so it would be better, because like that the disease would not spread, because people

[351] Interview with Mary Lanyero, 35-year old HIV-positive woman Atiak, 8 March 2008.
[352] Interview with Mary Lanyero, 35-year old HIV-positive woman, Atiak, 22 May 2008.

> would fear them[she laughs]. That would be better, because they won't stigmatise us. Because they will already know that these are sick people, and if possible they will give us a uniform. That will be better. If we are together like this, they won't stop the spread of HIV. [353]

In mid-2008 she changed her mind and decided to return to her husband's village, Rai, around 10 kilometres from Atiak. She was being threatened with eviction, and wanted to return in order to restart agricultural production and look after her children. Her husband had let her stay on the land, but had given her no help and so she had built a house for herself. However, with the lack of rain, there was little food and she was forced to return to Atiak in search of work. In June 2009 Tom and I met her working at a local restaurant, or 'hotel'.[354] The owner, a woman, did not pay her anything and did not treat her well – she worked only for food. She had constructed another hut nearby, but the landowners were once again threatening eviction. When we last saw her, she was being heckled by a drunken man in her restaurant.

Mary's story reveals the fragility of a young woman buffeted by disease, loss, weather and a neglectful family. The disease itself was a result of the poverty caused by displacement. In the transitional period it was not just the disease that hindered her from finding a place of rest and security but also neglect and stigma by her husband and his wife. Left to cultivate by herself, she drifted between her husband's land and the camp, where she survived by working in an environment that made her vulnerable to exploitation. As her parents were dead, she had nowhere else to go. Within this dire situation she still found meaning and hope in song and in educating those around her. This was, in a sense, the essence of her survival. She sustained her biological existence, and her hope, though there seems little chance that

[353] Interview with Mary Lanyero, 35-year old HIV-positive woman, Atiak, 22 May 2008.
[354] Conversation with Mary Lanyero, 35-year old HIV-positive woman, Atiak, 24 June 2009.

anything like a 'durable solution' will be possible for her. Susan, my research assistant, bumped into Mary in May 2010 and reported once again that Mary had returned to the village and was again hopeful, as the rains had been good. The cycle of return had started once again but it was unclear where or when it would end. For others – and more particularly men – a relative stability was possible with some access to material and family support.

Charles Kilama



Charles Kilama

-Charles Kilama, whom we met in Chapter One, was abducted as a young man and spent several years with the LRA before he escaped. He spent much time in Sudan fighting the Sudanese People's Liberation Army (SPLA). In 2003 he escaped after a battle near Atiak. After spending a year at a World Vision rehabilitation centre, he returned to Pabo to stay with

his uncle and resettle with his wife. He tested HIV-positive with his wife in 2006 and decided to return to the village of his birth in early 2008 with his uncle. Charles recalled:

> The reason why I decided to go back home was the information given to us by the government that there was nothing wrong, so people could go back. So, in the dry season we decided to build our huts and try our luck out there in the village. If at all there is something wrong out there in the village, we would come back to the camp. But our trial was good, that's why we are still there until now.[355]

He used some money he had received as part of the rehabilitation programme for returning rebels to pay for an ox plough to plough the land. When we visited in 2008 the gardens were lush and doing well, as rains had been better around Pabo than Opit. Charles did not have any problems making the huts on his compound but still has some trouble with digging:

> As HIV patients we have trouble. For food you will need something for the sauce and something for the starch. So you need four to five gardens, which is not possible, because only in one garden you take a lot of time to finish. So you can't dig much. That is the problem I've found. [356]

He travelled by foot back to the treatment centre. 'When it is my appointment date,' he said, 'I get up early and walk to the health centre. After getting my medication I return home late, when the sun has gone down a little.' [357] Life was far better in the village than in the camp:

> In the village here, you don't need to move everyday to and from the garden. In the camp we used to wake up as early as six, in the good days when they would

[355] Interview with Charles Kilama, 30-year-old HIV-positive man & former LRA abductee Parobang Parish, 14 August 2008.
[356] Interview with Charles Kilama, 30-year-old HIV-positive man & former LRA abductee Parobang Parish, 14 August 2008.
[357] Interview with Charles Kilama, 30-year-old HIV-positive man & former LRA abductee Parobang Parish, 14 August 2008.

> allow us to get out, and you would begin moving to the garden, and then you would have to move back. Here you can get up at seven thirty, you do your work, and after finishing your work you don't have to move back. You just sit and you rest. And if you feel you want to do more work, you do a little and then you come back and rest. I am very happy to be here. Here I can teach my children the way that I want. In the camp our children were getting spoilt. If they hear some abusive languages among people in the camp, then they think that it is life. Then a young kid knows how to abuse people in dirty language. [358]

For Charles, returning with his wife, uncle and four children has allowed him to reconstitute a family life that seemed lost when he was abducted. Returning home was a reconstitution of both material and moral worlds. It involved a re-establishment of a social order with hierarchy and regulation, in particular with regard to children.

Though the return process had been hard, Charles had fared comparatively well. An expanse of green surrounded his home and it seemed his fields were thriving. Being able to pay for an ox plough in the transition home certainly helped. Charles also did not live far from the medical centre as it is only half an hour's walk from Pabo. His story showed that even those who may have been worst affected by war – those who were abducted by the LRA – could find hope and comfort in the return process. The sustainability of his return was not only a matter of personal survival but also of finding a space to raise children and re-establish a connection with the past. However, for some, these possibilities were severely limited.

[358]Interview with Charles Kilama, 30-year-old HIV-positive man & former LRA abductee Parobang Parish, 14 August 2008.



Ajulina Akot at her home in Otong sub-county

Ajulina Akot

We met Ajulina Okot in February 2008 in Otong, a satellite camp several kilometres beyond Pabo. She was a 67-year-old woman living alone, though two of her six children lived in the surroundings. Unlike in Pabo, there were few that were openly HIV-positive in Otong, and Ajulina did not know any. Her husband had died several years previously. She explained why she moved to Otong: 'The reason why I decided to shift here was because of a problem of water and firewood. I thought that it would be better that if I was near home, I could go and collect firewood.' She relied on food support and struggled to get back to Pabo for her ARVs from TASO. Laughing, she told us, 'It's a problem moving to go and get medicine in

Pabo. If I come back from there, I can't cook even. I move on foot for three to four hours to get to Pabo.'[359]

She wanted to return to her husband's land but had no one to construct a house for her. Her family blamed her for giving her husband HIV. By her own wry admission she believed that she contracted the illness from a Buganda lover she had in the 1980s in Kampala. She said of her husband's family: 'They treat me badly. They tell me that I went wandering around to look for AIDS. They allowed me to dig, but they don't allow my children to dig for me. So I should dig myself, if I have any energy.' She wanted to move back to her home but was worried about construction. 'As for my case, I don't have anyone to help construct a house for me. If I have to go back to the village, there is no one even to dig for me. So, it's my request, that they can put a house for us. Even a uniport [a hut made of iron sheets].' [360]

Over a year later, in June 2009, Tom and I went to find Ajulina. A young man in Otong said he knew where she lived, and pointing to a primary school in the distance said she was nearby. We ended up driving 20 minutes through the fields of upland rice that this area of Amuru is famous for. Eventually we found her home but she was not there. A neighbour stood on a termite mound looking for her. While we waited we chatted to a boy in late adolescence. He complained to us that to meet girls now he had to go all the way to Pabo as in the village there were only relatives around. Eventually Ajulina came trudging along the road and seemed happy to see us. She said it was good to be back in the village but it was far from the medical centre. She would have to walk for five hours and wait in the queue. Afterward, she would sleep at the mission. I asked her if she had memories of the area before

[359] Interview with Ajulina Akot, 68-year-old HIV-positive woman, Otong Satellite Camp, 23 February 2008.
[360] Interview with Ajulina Akot, 68-year-old HIV-positive woman, Otong Satellite Camp, 23 February 2008.

displacement and she said: 'only memories of war, and running from the rebels'.[361] However, she recalled that before the war there was always enough food.

She claimed she was not cultivating (though there were some small fields around her house) and she relied for food ACDI Voca, who were stopping her support in July. I asked what would happen when it was stopped, and she said, 'We will die.' The statement may seem an exaggeration but, as a TASO caregiver had told us, another elderly patient had recently died in a return area without support in her home. Ajulina's story shows how the vulnerability of disease and age may intersect. Without strong family support, she was dependent on food support that was ending soon and the future seemed uncertain. Yet Ajulina seemed to treat her condition with a sombre humour.

There was much more I wanted to ask, but it was getting dark and we had to return to Gulu. As we were driving from Ajulina's home we heard drumming and dancing among the fields of wild rice. We drove to find what it was and found a group of young men performing the *larakaraka,* one of the old dances of courtship. With the war the local dances had disappeared, and with them old spaces of courtship. The young men and teenagers were practicing the dance to form a village-based HIV and AIDS education group. The group was supported and given some funding by a local CBO. It had a poignant circularity that in the home areas where they did not grow up, youth are reclaiming an old convention to teach about HIV. It is an old practice from times remembered or imagined only by the older adults, a time viewed as untainted by the immorality of conflict and the scourge of AIDS. This brings me to a final reflection on the challenges remaining in the struggle against the spread of HIV and other challenges still facing the broader community.

[361] Interview with Ajulina Akot, 68-year-old HIV-positive woman, Otong Sub-county, 26 June 2009.

HIV-related vulnerabilities

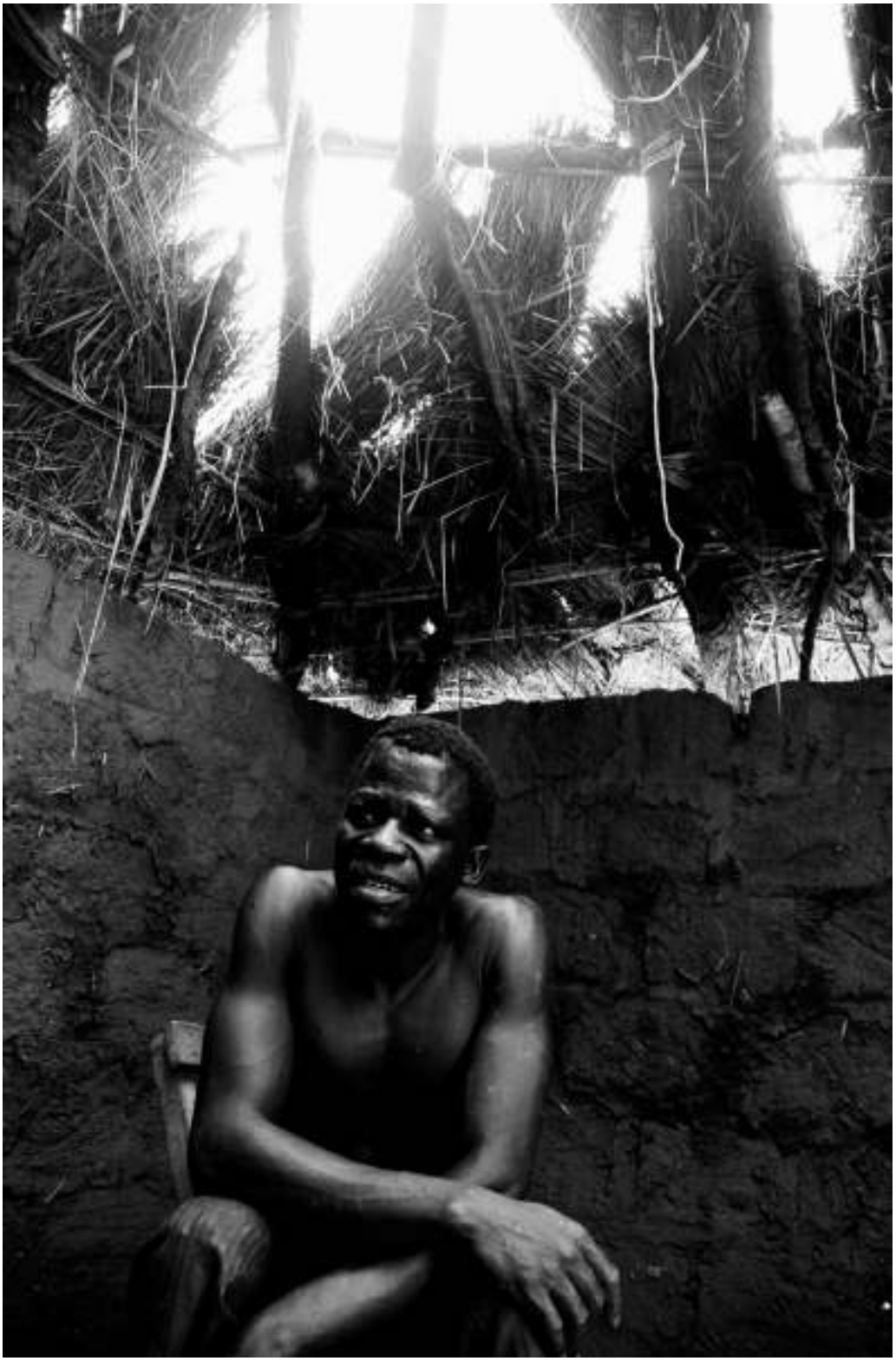
When analysing the negotiation of encampment and return, it is important to focus not only on those with HIV but also those in the broader community. Even the able-bodied experienced significant struggles during the return process. I close this chapter with some cases of those whose HIV status is unknown, in order to situate the experiences of those with HIV in their social context. Vulnerability is a biophysical condition (vulnerability to illness, malnutrition, physical suffering, and so on), but it is also a condition that traverses social relations. It is through understanding the broader context of struggle, survival and vulnerability that the ways in which HIV interacts with the struggles of return can be understood.

In August 2008, we visited the home of Dennis Okello and his wife Lily Ajo, a couple in their thirties, in an area on the border of Gulu and Oyam districts. They had returned to their land from a trading centre near Karuma in February 2008. In Karuma they had earned a living through fishing. Their HIV status was unknown but they were mostly in good health despite having suffered from malaria and diarrhoea since returning. However, the roof of their house was not complete and the rain came through it at night. They could not complete the roof because the grasses nearby had been burnt and then recent rain had dampened the remaining grass. Dennis explained: 'The benefits of coming back are that there is now peace and we are not renting any land.'[362] However, 'The major problems are a lack of food and accommodation. As you can see, we have not even finished this house.' They had not yet

[362] Focus-group with Dennis Okello and Lilly Ajok, Couple in return area, HIV-status unknown, Ngai sub-county, 17 August 2008.

had their first harvest but had only managed to cultivate around one acre of the four available to them. 'We are cultivating one instead of four because instead of cultivating our own land we have to get money from cultivating in another man's garden.'[363] Their beans, like those at Silberia and Beatrice's fields nearby, were damaged by drought. They did not have problems clearing the land; the main problem was a lack of food while waiting for the harvest, forcing them to do casual labour *(leja leja).* We see here that the vulnerabilities of transition existed but were not primarily linked to labour limitations or health. Rather, they concerned issues of food, money, capital and environmental factors. Even for the able-bodied, return can be a fraught process. However, unlike those with HIV, there was less threat that the problems could lead to a rapid decline and death. This couple were less constrained by labour and energy than by the material conditions in which they found themselves. They shared the struggles of many who were HIV-positive, but were less exposed either to stigma or to disease.

[363] Focus-group with Dennis Okello and Lilly Ajok, Couple in return area, HIV-status unknown, Ngai sub-county, 17 August 2008.



Dennis Okello

During the course of 2009 and in early 2010 my research assistants and I conducted around fifteen focus groups with those whose HIV status[364] was unknown in order to provide a broader community perspective on the struggles facing those with HIV. Common problems facing the broader community were lack of water sources in home areas and associated parasitic infections, problems with food during the time of transition, and distances from schools and health centres. In general, issues surrounding health were less prominent in these interviews than among those with HIV, although problems with malaria and parasites in children were common. Aside from the initial transitional period and the times of bad rain, the food situation had improved for most. We asked the groups to identify those who they thought were struggling the most with the return period and the most common responses were the elderly, widows, single mothers, child-headed households and those with HIV. Many expressed sympathy for those with HIV, though there were some fears that they were spreading the disease in return areas. As one man commented:

> I remember sitting by the fireside in the olden times listening to stories and Acholi traditions from my grandfather. Today my children are able to practice the same tradition in an effort to renew our cultural heritage that was almost squashed during camp life. HIV-infected people have returned to villages together with us. Some of those people are not graceful and are continuing to spread new infections amongst the population. I am afraid our entire generation might be wiped by this killer disease.[365]

The theme of the re-establishment of a moral order in the areas of return was constant. By this I mean the re-establishment of discourses of social regulation and hierarchies, relating to

[365] Focus-groups with male respondents, HIV status unknown, Parak camp, 26 Jan 2010.

an array of practices, including sexuality (Heald, 1999, Zigon, 2008). Most thought that this would slow the spread of HIV as people returned to productivity, alcoholism was reduced and the youth were more disciplined. As an elderly women said with great conviction:

> I can tell you that in the village we are going back with ghosts. We are not going back with children. We are going back with very destroyed children. We are going back with children who don't listen. We are going back with children who are mad. We are going back with children who are sick.[366]

HIV thus remained not simply an experience of physical illness but a symbol of social and moral uncertainty. Its status within the community remained symbolically contested, exposing those with HIV to both care and contempt. The challenges of return involved not simply the physical challenges, but the challenges of establishing a position in an uncertain social order.

Driving to Opit in June 2009 we stopped to speak to a group of young men and boys ranging from their mid-teens to early twenties, who were playing cards outside a small store in Adak transit camp.[367] We sat with them and played cards for awhile and then did an impromptu focus group. The discussion revealed much about the nature of vulnerability in the return areas. Having grown up in the camp, the boys were struggling to find a way in which to lead productive and adult lives in the return areas. They were particularly anxious about productivity and marriage. As an 18-year-old explained, 'The youth, they don't have the strength or money to get engaged. It would be good to get a technical skill and forget about these things.'[368]

[366] Interview with Martina Auma, 70-year-old woman, Lacor, 31 March 2008.
[367] Introduced in Chapter Four.
[368] Focus group with male youth, Adak, 15th June 2009

All the boys agreed that it was much more difficult to meet girls in the return area than the camp as there were mainly members of the same clan living in the immediate proximity. Also, the laws around 'defilement' or sex with girls under sixteen were strongly enforced. All claimed to have been sexually active from early adolescence in the camp. As one member of the group explained about the return areas: 'Dating is hard. Even if you find someone they [i.e. local police or authorities] may come and arrest you.' Another explained, 'When we were in the big camp people would go for another tribe, you would go for Congolese or Lango girls. In this place we are the same clan so it becomes difficult.' [369] While the camp was viewed as a form of prison for many, for these young men, the return areas were imprisoning.

All members of the group possessed a good working knowledge of HIV transmission. However, free condoms were rarely distributed in the area, and the nearest health centre distributing condoms was over 10 kilometres away. The youth struggled with the practical difficulties of return. They were still living in the transit camp though they laboured in the fields of their home areas, which were nearby. Most had dropped out of secondary school because they could not afford the fees. Furthermore, they recounted obstacles to re-establishing lives in the villages. One explained: 'The problem barring us from going to villages is we are trying to build houses. We also don't have working equipment such as hoes, axes and slashers.' [370]

The experiences of those not living openly with HIV are important for the discussion of HIV-related vulnerability. This is because even the able-bodied confronted severe social and

[369] Focus group with male youth, Adak, 15th June 2009
[370] Focus group with male youth, Adak, 15th June 2009

material deprivations in the return process. For these youth there were also difficulties with starting life in rural areas that they had left when they were very young. They were without money or capital and thus denied the ability to take up a socially meaningful existence as adult men through productivity and marriage. Their vulnerability did not arise from biological susceptibility to illness (although HIV and other diseases were a constant threat), but rather from the inability to translate physical vitality into a form that was socially valued. This observation demonstrates Butler's (2004) conception of vulnerability – vulnerability does not arise simply from a biophysical state, but rather the exposure of that biophysical state to social recognition. As I have argued, vulnerability should be viewed relationally; it is a condition arising from biological exposure to illness and other hardships, as well as integral to social relationships. The ways in which societies and institutions categorise forms of vulnerability is part of that vulnerability itself. Vulnerability does not equate to poverty, or simply a lack of income. Vulnerability is also linked to physical capabilities, as well as to forms of sociality and social recognition. HIV-related sociality is thus integral to understanding vulnerability. The young men discussed above could not find social recognition, as they lacked both capital and the prosperity to translate physical health into a socially valued existence. In contrast, those with HIV, in some cases, had managed to translate their illness into a socially meaningful existence through new forms of sociality and by revaluing their HIV status, though they faced problems of continued stigmatisation. These comparisons reveal the ways in which vulnerabilities intersected with a biophysical condition, but were also embedded in social relations.

Adequately understanding and contextualising HIV-related vulnerabilities requires attentiveness to both the physical and symbolic status of the disease. ARVs certainly helped those with HIV cope with the material and physical challenges of return, yet many still

suffered weaknesses and shortages of food. During the period of my fieldwork, there were few programmes providing support to those with HIV during the return process and none in my chosen field-sites, though TASO and other organisations like the WFP had started developing livelihood programmes. These fell outside the scope of this research, but it is significant that all of those with whom I spoke in my areas of research were not recipients of these programmes and had not received additional support with the return phase. As we saw above, the withdrawal of food assistance was mostly confused and abrupt.[371]

In general, humanitarian agencies, like the cluster groups and the food assistance programmes, were unable to address adequately the internal differentiations within displaced communities. These difficulties were particularly apparent when considering the pragmatics of ARV provision. A UNHCR rapid qualitative assessment of HIV-related needs was conducted in 2008 (UNHCR and UNAIDS, 2008). The report foregrounded problems similar to those that I had encountered when conducting my research. Among these was the lack of services and facilities in return areas, including water-points, schools and health facilities. Challenges peculiar to those with HIV included: increased distances to health centres, lack of HIV services in rural areas and a potential increase in stigmatisation in home areas. The report argued that, like orphans, the elderly and single mothers, those with HIV were a vulnerable group requiring special attention (UNHCR and UNAIDS, 2008:26). It does not, however, address the question of what is meant by vulnerability.

The UNHCR report raises some important challenges confronting those living with HIV in return areas, but both its content and institutional life are revealing of the limitations of classifying those with HIV as a vulnerable group. The outcome of such a categorisation is

[371]ACDI Voca continued providing food assistance, but only to TASO clients. This in itself created much confusion.

that vulnerability is viewed as something that can be alleviated *primarily by external actors*. Among the report's valuable recommendations (including health-system strengthening, the expansion of prevention activities through community groups, and the decentralisation of treatment), there are practically no recommendations regarding the vulnerability of those with HIV themselves, other than noting that they require special assistance. The sole recommendation is to: 'develop protection programs for groups especially vulnerable in a situation of transition, such as people living with HIV/AIDS, orphans and vulnerable children widows, and specific programs for sex workers' (2008:34). It does not clarify what this would entail in practice. As has been discussed, there is a clear need for protection from eviction for those who are very ill and need to remain near a health centre. However, the idea of 'protection' seems premised on the idea of vulnerability as relative resilience to an external shock, and not integral to social relations. It will be argued here that the forms of vulnerability among those with HIV are linked to the biological effects of HIV, and particularly lack of energy; but, just as significantly, vulnerability must be assessed in relation to whether forms of sociality and networks of care persist and are created in the return process. External actors may facilitate and support social networks of care, but this requires a long-term approach and not simply short-term interventions supporting the return process (although these can help overcome the physical and material obstacles to return).

In addition, the implementation of the recommendations in the report is telling: its distribution and take-up was poor. In spite of the UNHCR's supposed consultation with organisations, few of the managers of key HIV/AIDS service providers, including TASO, were even aware of the existence of the report. While it was distributed to the HIV/AIDS, Health and Nutrition Cluster Group, chaired by the WHO, it was not discussed in the group,

as two members of the group (including the chair) confirmed.[372] This indicates not only a failure of follow up, but also a structural problem of managing the transition from emergency to development even with the cluster system.

Difficulties over defining vulnerability were widespread. The UNHCR found that the original guidelines for defining EVIs included practically the entire community and so had to revise these.[373]The identification of vulnerable groups within camps was relatively haphazard. This partly arose because the implementing agencies involved in camp management could not use the criteria provided by the WFP and UNHCR adequately. As the data officer for AVSI, who were charged with 'camp management' (coordinating the operations of district leaders and NGOs) of Opit explained: **'**It has been a challenge to define EVIs from UNHCR criteria. If we took the first definition, 50 per cent of the camp are EVIs. Now we are trying hard to identify EVIs. There are many single parents, child-headed households, those with epilepsy and chronic illness.'[374] Similarly, the Norwegian Refugee Council – who were 'managing' Pabo – first used EVI criteria using WFP criteria, then switched to using those provided by the UNCHR, but the latter were 'too broad'[375] and EVI registration was finally done on a household basis.

The National Protection Cluster chaired by UNHCR in Northern Uganda developed a framework to identify EVIs (UNHCR, 2008). Priority was to be given to those that 'are actually vulnerable rather than potentially vulnerable' and the general categories for assessment included unaccompanied children, disabled persons, older persons (persons over 60), single parents or widows, as well as those with serious medical conditions. Chronic

[372]Interview with Ilona Varallayay, ARC HIV/AIDS project coordinator, Gulu Town, 20 June 2009.
[373]Interview Carmen Monclus,, UNHCR Gulu Protection Officer, Gulu Town, 11 August 2008.
[374]Interview with Peter Ocen, AVSI Data and Field Logistics Manager,Gulu Town, 11 August 2008.
[375]Interview with Charles Ojok, *NRC Data Entry Officer,* Gulu Town, 17 August 2008.

medical conditions constituted extreme vulnerability when 'a person would qualify if she/he is unable to support one self [sic] due to the direct consequence of her/his medical conditions.' (UNHCR, 2008). This would potentially include those with HIV and those on other chronic medication. However, in 2008 there was little targeted support for EVIs in the process of return and little support for those with HIV aside from food support, which was being phased out. In essence, vulnerability became part of a process of 'bureaucratic labelling'[376] framing who may have access to additional resources, with little attentiveness to the social relations shaping vulnerability. This resulted in some relatively facile responses for dealing with vulnerability. For instance, the UNHCR proposed radio programming to encourage clans to look after vulnerable groups.[377] Furthermore, the EVI guide says that there should be engagement with community members about who is most vulnerable. However, during the time of my fieldwork there was little discussion with communities.

The observations above are not advanced with the intent of exposing administrative or bureaucratic incompetence; rather, they aim to reveal the difficulties of labelling vulnerability and implementing appropriate support programmes in the short timeframe between relief and development. Vulnerabilities are tied closely to social relations, and those recognised as vulnerable within communities – and thus cared for – are likely to be better off than those who are marginalised and excluded. However, as I have attempted to demonstrate throughout this thesis, the social transitions through which excluded groups are re-incorporated into social relationships take time. Those with HIV were not necessarily the most physically incapacitated in the camps; the disabled, for instance, struggled greatly in the

[376]Zetter (2007) uses the notion of 'bureaucratic labelling' with reference to how categories such as 'refugee' are incorporated into global bureaucratic structures and serve to channel access to resources. This concept though, could also be used to understand the ways in which certain groups within displaced communities are prioritised and institutionally segregated in channelling resources.

[377] Interview with Carmen Monclus, UNHCR Gulu Protection Officer, Gulu Town, 11 August 2008.

camps (Muyinda, 2008). ARVs were absolutely critical to providing health and slowing the decline to AIDS, yet important too was the social role of networks of care. Biosocial networks were important during the time of encampment, but reintegration into return areas required acceptance by broader networks of family or kin.

Conclusions

The return process cannot be separated from the social transitions of displacement. The vulnerabilities of HIV-positive individuals are intimately tied to their relationships with one another but also with family and community. The mass migration of the return process can disrupt social relationships of support formed during displacement: the critical challenge of return is ensuring *continuity with displacement*, rather than a break from it. It lies in ensuring that the gains, and not merely the adversities of displacement, persist. The intersecting vulnerabilities of displacement and disease cannot be left behind: survival depends on the social identity and sense of community that can be drawn from these vulnerabilities. However, the return process also reveals the fragility of biosociality - of networks of support oriented around disease status - as these may easily be stretched in the return process, even if they are partially reconstituted in return areas. Integration into family and communal networks of support is essential for sustaining health and stability in return areas.

The stories above have demonstrated that retaining continuity between displacement and return is critical to return's challenges. The investment in community-based treatment monitoring and support during the time of displacement has been critical for ensuring security for HIV-positive people in return process. Certainly there may be a space for livelihood interventions and targeted help with the return process, which have been significantly lacking in Northern Uganda. Those with HIV could benefit greatly from

increased support with construction, transport, bush clearing and initial ploughing among other immediate concerns. However, negotiating the challenges or returns requires longer-term social transitions prior to the return process. The reintegration of those with HIV into return areas required a process of overcoming stigmatisation and re-establishing networks of care. In this sense, the conceptual repertoire of forced migration studies and humanitarian interventions, including ideas such as 'durable solutions' or 'sustainable return' are difficult to apply to those whose health remains continually uncertain, and for whom the re-establishment of pre-displacement prosperity may be impossible. In general the literature has neglected the importance of relations and divisions *within displaced communities* as well as the importance of social transitions that take place during displacement.

Similarly the bureaucratic vocabulary of 'vulnerability' in its application in Northern Uganda has not touched on the key concerns of those living with HIV. My intention here has not been to argue that those with HIV are the most vulnerable, nor necessarily deserving of privileged support in regard to other groups. Rather, I have aimed to show how the course of HIV amplifies vulnerabilities facing many among returning populations. Vulnerability and survival are linked to the negotiating of both the physical and symbolic challenges of return: re-establishing livelihoods, as well as establishing socially valued lives in a time of uncertainty. In facing these challenges, return represents a continuation rather than a rupture with the experiences of encampment. ART provision can help a great deal with the return process, yet patients mostly do not return to their earlier levels of strength and productivity. For those with HIV, the process of re-establishing a relationship to the land, family and community are shaped physically and symbolically by their disease status. It is a process that, at least in the years of this study, was highly uncertain.

Final Conclusions

In the introduction I posed three broad questions which this thesis aims to answer: first, how have HIV treatment interventions been shaped by conflict and displacement; second, what have been the effects of these ART interventions on the social relationships of their recipients; and finally, what are the social relationships necessary to ensure the sustainability of treatment under conditions of displacement and return? In this conclusion, I will draw findings from the various chapters to address these questions in turn. I will close this thesis with some personal reflections on my experiences.

How have HIV treatment interventions been shaped by conflict and displacement?

The answer to this question cannot be made without situating ART interventions within a longer time-frame, in order to understand the types of responses that preceded them. During the 1980s and 1990s, Northern Uganda was largely excluded from the wide-spread social responses to HIV characteristic of the Uganda HIV 'success story'. In deeper rural areas, responses were fragmented and infrequent. Encampment allowed many people to be reached more easily, but still interventions were late in comparison to elsewhere in Uganda. The strong role of church hospitals and catholic missions in the early years lent the responses a strongly faith-based timbre. After a decade of neglect and marginalisation from Uganda's HIV 'success story', which involved a large-scale government and community-based response to the disease, ARV interventions came upon a wave of intensified donor and humanitarian interest in the region. Treatment providers entered a transitional and

exceptional situation. From 2005 ART provision expanded rapidly, helped by the diminishment of active conflict. ARV provision in the North was not significantly behind elsewhere in the country; yet it faced distinct challenges related to the conflict. Treatment organisations entered an environment in which much of the groundwork laid over a decade of community organisation and education elsewhere in the country was absent. They were working with populations experiencing high rates of morbidity, malnutrition and mortality. Insecurity, poor transport infrastructure and the deleterious condition of state health services exacerbated difficulties. The programmes in this study negotiated these challenges in different ways. TASO, new in the region, formed close links with humanitarian organisations and adapted strategies – like home-based distribution – developed elsewhere in the country to new conditions. Lacor Hospital and the Comboni Samaritans relied extensively on their long-history in the region and connections to rural areas through Catholic Missions. The Uganda Ministry of Health tried to integrate Northern Uganda into the national strategy using a primary healthcare and community-based model but faced enormous challenges as a result of the deleterious state of health services in the North. They had to rely on support from an array of organisations operating with mixed emergency and development approaches. What is clear from these experiences is that neither a standard primary health-care and community based model of ART, nor a short-term emergency health model of treatment provision would be adequate for this context. Treatment providers had to navigate - with varying degrees of success - a mid-path, attending to the extremities of the context while keeping in mind longer-term perspectives. It was also necessary to form relationships with humanitarian agencies, particularly those providing food assistance, in order to ensure good adherence to treatment. In spite of these initial challenges, treatment providers (at least the NGOs) managed to achieve results comparative to, and in some cases better than, treatment

programmes in other areas of Uganda. The clinical outcomes of MOH programmes remain unclear as data is largely missing, and no published studies are available.

In addition, the channels of access to treatment were shaped by the spatial production of conflict: the extreme geographical unevenness of conflict, the unique spatialities of displacement camps, and the constraints on movement as a result of the war. This constituted, particularly in the early stages of treatment, a form of spatial triage, with the bulk of services focused around town areas. Few in further rural areas had access to treatment and where MOH treatment became available, there was often little education or community support leading to a low take-up of treatment. However, when ART interventions were extended to camps, the congestion of the camps also made the monitoring of treatment relatively easy due to the proximity of many patients to each other. Community and home-based models of treatment delivery and adherence monitoring operated extremely well in these settings, though the long-term sustainability of these models was strained with the mass mobility of the return movements. In addition, ARV interventions also became, at a micro-level, part of the spatial production of conflict and displacement: they created new forms of mobility to treatment sites, shifting patterns of residence, and new social channels through which medicines and knowledge were circulated. At both a structural and intimate level, the provision of ART was deeply intertwined with the social spaces of conflict and displacement. A further fundamental aspect that requires consideration with treatment provision to displaced communities is the necessity to prepare for the post-conflict phase and its populations moments. This is addressed in the third question.

What have been the effects of ART interventions on the social relationships of their recipients?

Antiretroviral therapy interventions in conflict-affected areas of Northern Uganda, including towns and rural areas, have engendered remarkable transitions. Thousands have experienced renewed health, allowing them to return to productivity and social life, even under conditions of adversity. However, these social transitions have emerged in a context of adversity and have involved struggles to overcome exclusion and stigmatisation. Furthermore, ART interventions themselves have also exerted authority over the lives of their clients and thus shaped their social relationships. The answer to this question – which has concerned the core of this section – is answered in three parts dealing with sociality, stigmatisation and power relations respectively. I also frame how ART interventions come to affect the decision-making around the return period.

Biosociality

The intersections of illness and displacement-induced vulnerabilities have shaped the experiences of transition for those living with HIV, as well as their experiences of therapy and healing. Displacement-induced transitions included the radical decline of agricultural productivity, rises in morbidity and mortality, the radical reorganisation of spatial life, social and moral disruption, as well as the wide-scale dependency of the population on external assistance. HIV has exacerbated many of these effects – reducing household productive capacity through death and illness, as well as increasing biophysical susceptibility to illness and malnutrition. Many of those with HIV have been doubly displaced: by conflict and by disease-based stigma. In this context, ARV interventions have created new opportunities for

gaining access to resources and social networks. The social lives of ARVs in Northern Uganda have been striking. In towns, camps and rural areas, treatment has brought together diverse classes of people – men and women of all ages, children, former rebels, soldiers, professionals and agriculturalists. The social support along with treatment provision has fostered new forms of sociality around disease status, and around the very sites of treatment. For some of the most marginalised, including former LRA abductees with HIV and widows, disease status has offered a new form of belonging and community. In particular new social networks around HIV status were dominated by women. For many women, these networks allowed them reduced dependence on men and regain social standing, but this also made some vulnerable in the long-run when access to land and resources were at stake. Furthermore, for some men, seeking treatment involved a re-evaluation of masculinity and a focus on the care of children, while others tried to re-establish their authority within biosocial networks.

I have framed these new forms of sociality in terms of 'biosociality'. The key dimensions of what I term biosociality include practical support, emotional support or counselling, therapeutic rituals, neighbourliness and kin-like relationships, as well as gender and sexual relations. These relations arise from both therapeutic practices and the discourses they produce. Biosociality goes beyond identification based on therapeutic management and involves new identities and networks formed around experiences of HIV *as a social* condition. In Northern Uganda the experiences of HIV are intertwined with experiences of conflict and displacement: HIV has become associated, by those with the disease as well as in broader social discourse, with experiences of loss, violence, moral breakdown, and militarism. I do not view biosociality as a discrete set of social relations, but as nested in broader networks of family and kin, involving, for instance, new forms of solidarity and care

among family members. However, HIV-related identities and relations may play a significant role where experiences of social exclusion are strong. In particular, in a context of social disruption arising from conflict and displacement, biosocial relations and HIV-related identities may offer a particularly strong form of identification. The socio-spatial conditions of the camps bore similarities to peripheral town areas where many internally displaced ended up. Town areas also experienced social transformations among those with HIV with the arrival of ART. However, the settings of the camps were more adverse, privacy was less, and there was less opportunity for income generation. Though difficult to quantify, my field experience suggests that social re-orientations were more powerful in the camps than in towns or return areas. In the camps, the extreme lack of privacy along with severely constrained productivity allowed for the rapid formation of new forms of sociality.

Stigma and social space

The strength of biosociality has also been a result of the socio-spatial conditions of encampment where those with HIV are very visible and become socially constituted as a defined group. This visibility is particularly apparent when treatment provision and specialised food support were distributed in full view of their surroundings. Hence, I have argued that socio-spatial factors are significant in leading to HIV disclosure of individuals and collectives *en masse.* This pattern disclosure has been central to social transitions in forcing people to disclose their HIV status, but also creating a strong sense of identity and community as a result of stigmatisation. Spatial factors explain how HIV becomes known in a community, how its trajectory and the effects of treatment on the body are observed, and how it impacts on stigmatisation. This form of disclosure is connected with voluntary self-disclosure, but does not fit neatly into simple conceptions of voluntary or involuntary

disclosure. I proposed the concept of 'socio-spatial disclosure', understood as the processes through which information regarding an individual's or a collective's HIV status is revealed to others as a result of the spatial circumstances in which those living with HIV/AIDS seek medical care and support. This may be through visual or other markers. While there is a degree of voluntariness to the decision, the individual cannot control to whom the information is conveyed, and may be disclosing unwillingly as a result of severe conditions.

However, while these factors worsened stigma towards recipients in the early stages, over time the visibility of ARV provision began to have a positive effect, reducing levels of stigma. Furthermore, stigmatising language and beliefs may not be coherent, but their very paradoxes may reveal the concerns and anxieties of a community. In Northern Uganda the biophysical changes in bodies were interpreted through the symbolic landscape of displacement, involving fears over unproductiveness, idleness, and militarism. In the transitional spaces of displacement and return, the symbolic place of those with HIV vacillates between one of care (they epitomise the sufferings of the population) and one of uncertainty and fear (they are the new witches and soldiers – secretive, fat, and killing others). The language of stigmatising, particularly with labels like the 'soldiers of the priest' – referring to HIV-positive people in Opit – reveals how interpretations of HIV/AIDS are embedded in the social and moral worlds of displacement.

Power

Strategies of exclusion and power are not only present within communities, but are part of the practices and institutions of ART provision – in this sense, they are central to reshaping patterns of behaviour and relations of authority. Antiretroviral interventions are not simply biomedical interventions: they engender new forms of power relations. The aim of sustaining

life becomes aligned with other aims which create and reinforce, but also subvert, relations of inequality. These operate on multiple spatial scales. First, the global dimension through which international donors impose certain conditionalities and surveillance on local treatment providers. Second, the ways in which treatment providers have power over their patients, and promote certain values through their programmes. These forms of medico-moral control link to sexuality, food and social relations. Patients may resist these but they imbue a strong consciousness of debt and control among patients. In particular, in the context of displacement and complex emergency, the linkage of HIV treatment with food programmes means that the foundations of biological existence become linked to external actors, as discussed in Chapter Three. Third is the social and moral world in which treatment programmes are received, and in which norms are contested. Contestation over gender relations is important as is the role of biomedicine in relation to other practices of physical and spiritual healing. In the context of displacement, these factors become linked both to social and moral interpretations of HIV/AIDS and its relations to conflict, but also the broader humanitarian complex operating in Northern Uganda. Moreover, programmes can be avenues for local contestations over resources.

Along with new social networks emerge new forms of clientship, authority and political relationships. ARV interventions reorient relations of authority and social hierarchy. They institute new regimes of bodily regulation relating to sexuality, diet and productivity. In Northern Uganda treatment organisations not only provide medication but also channel the provision of specialised food support. As a result of these connections the biological continuation of life is invested in external actors. In the contexts of displacement where social and kinship relations have been weakened and agricultural productivity has diminished, this induces a particular dependence on external actors. However, I have argued

that this constitutes a weak form of biopower – rather than the large-scale biopolitics of population management and surveillance, it involves the penetration of forms of social and sexual regulation into the social body. These are not new discourses, and they have their origins in church and missionary teaching, but they take on a new form when closely tied to long term chronic biomedicine. Decisions around sexuality, diet and movement are referred, to an extent, to external actors – doctors, priests and counsellors. In the exceptional environment of the camp, where forms of moral regulation are contested and uncertain, treatment organisations and their networks of community workers form networks of social actors providing both guidance and authority in the intimate lives of those with HIV. Counselling becomes a trope for wider sets of social relations and is not simply viewed as a relationship between client and caregiver.

Return

The social relations engendered by ARVs have come to shape the longer-term life paths of those on treatment, particularly in the period of return. Both the biosociality of ARV treatment as well as the forms of regulation, guidance and authority they instil have long-term effects. They reshape patterns of daily life but also channels to support and resources. Disease-based socialities can provide people with friendship and support, but they come with their dangers. These new forms of sociality have remained fragile in the context of the social transitions of displacement and return. During the return phases, where humanitarian assistance is being withdrawn, displaced populations are forced to rely again on family and kinship networks in order to have access to resources. Pre-displacement relations of authority were being re-established. In particular, in spite of its illegality, women were widely excluded from the land of their deceased husbands. Relations of family and kin were critical in the

return process, - the challenges of return could not be easily substituted by short-term interventions by external actors (however, these could have helped, but were largely absent). However, the longer term process of social change and acceptance were of great importance; in this HIV treatment organisations contributed significantly. This is a key point: social changes engendered *during* encampment, in creating a broader acceptance of those with HIV, were critical to in ensuring the well-being of those with HIV during the return period.

Medical treatment and ARV provision in particular is a significant factor in shaping return decisions among those with HIV, as are forms of biosociality. Important considerations shaping decision-making regarding return include distances to health centres and treatment sites, concerns over lack of energy for housing construction and restarting agriculture, as well as social concerns of stigmatisation and exclusion. Comparative focus groups have shown that, while considerations of health-care are important for other returnees, they play a particularly important role for those with HIV. The return process is shaped by interlinked social and material considerations. While there is an important space for helping those with HIV, among other *potentially* vulnerable groups with some of the physical burdens of return, social relations are more significant for the long term well-being of those living with HIV, as well as the continuation of treatment. Without extensive networks of social support, those with HIV can easily fall into cycles of poor adherence. At its most extreme this could lead rapid decline and even death. Long-strategies taking into account the return period are thus critical for sustainable treatment provision. However, in this process biosociality must be transformed into broader social change in which those with HIV are accepted and included in the larger networks of community. Without this they remain extremely exposed to emotional and physical suffering and decline.

Furthermore, I have argued in the thesis that existing conceptualisations on 'durable solutions' and 'sustainable return' are inadequate to grasp the specific vulnerabilities relating to HIV/AIDS, as they fail to account for the longer-term social transitions necessary for well-being during the return period, as well as the importance of attending to divisions *within* displaced communities. In addition, these vulnerabilities elude easy bureaucratic categorisation precisely because they are so embedded in social relationships. Nonetheless, the lessons from these experiences and challenges do still have a practical application, particularly in conceptualising and planning the long-term sustainability of ART provision through times and conflict and post-conflict transitions. This is the topic of my final question.

What are the social relationships necessary to ensure the sustainability of treatment under conditions of displacement and return?

Sustainability of treatment relied on the transition from biosociality to more extensive social support and acceptance among those with HIV. This has, to a significant extent, taken place in Northern Uganda, though not in all cases. The findings in this thesis lead to a strong conclusion that community-based HIV treatment strategies are not only possible but beneficial for sustainable treatment to displaced communities: they are important for biomedical concerns around adherence and treatment continuity, as well for the long term well-being, - medical and social – , of those living with HIV and who are negotiating the difficulties of transition. Extensive networks of community treatment monitors have been shown to be effective in helping support treatment continuity during periods of mass population movement, particularly in the case of Lacor Hospital which managed the transition from displacement to return with low rates of lost patients, primarily as a result of the early shift to using community members as adherence monitors as well as preparing these

workers for the return period. The strategies of TASO using home-delivery faltered due to the extreme strain of resources during the return period resulting in high rates of lost patients, but a shift in policy to using community adherence monitors and a decentralised distribution points helped reduce this radically. The MOH programmes clearly struggled with the transitions – as interviews revealed. This was a result of population movements, shortages of staff and the withdrawal of emergency medical providers, like MSF. However, the extent of this is difficult to gauge given the paucity of data on reporting on these services.

There are key lessons that can be learned from the experiences in Northern Uganda that could be adapted to ART provision in other displaced settings. First, the return period poses significant challenges to HIV treatment programmes as a result of increased distances between service providers and often mobile HIV positive populations. Second, decentralised treatment provision and geographically dispersed community-based support can help to ensure the continuity of treatment, as well as allay patient fears and anxieties about return. Third, the return process can place extreme burdens on those living with HIV, as well as community-based ART adherence monitors, especially those who are themselves HIV-positive. There is a role for targeted support under these conditions, for instance with food and transportation. Fourth, the HIV-positive patients may struggle with adherence during transition as a result of increased distances, as well as renewed food insecurity with the withdrawal of food assistance. HIV-positive people on ART should also be supported with treatment adherence during the time of transition and return in a manner that accounts for the challenges of the period. Finally, data collection in post-conflict situations focuses not just on adherence but also on patient attrition. Data from well-resourced non-governmental programmes cannot be viewed as representative of all programmes; there is a need in Northern Uganda, and elsewhere, for an assessment of more poorly resourced state

antiretroviral programmes. While treatment provision can be successful in assisting conflict-affected communities, the transitional phase poses a new set of challenges and can increase the chances of drug resistance developing as a result of lost patients and poor adherence. It is important for treatment interventions, as well as public health models of treatment provision, to account for both the social dimensions of displacement and the significant challenges that the return process creates.

Final Reflections

There is, of course, in the course of research and writing so much that eludes one and that imprints itself in ways that are almost unintelligible. In the research, one puts oneself at stake: the stories and images recur in surprising ways, surfacing when one least expects it, in dreams and in day-to-day moments. The landscape of Northern Uganda has imprinted itself on me, its wetlands and hills, its extremity and sadness. Yet, the privilege of watching a place emerge from violence, of hearing so many stories – with its all their pain and difficulties – has been powerful. For all the problems and challenges that this thesis has outlined with ART, one fact should not be forgotten: thousands with HIV in Northern Uganda are alive today, when a mere decade ago they would be dead from a treatable disease. This is perhaps the primary reason I chose this project: to witness how HIV/AIDS – the cause of mass death and social devastation – can transformed into a disease that can be lived with.

The transitions that ARV provision have engendered have, with all their difficulties, been remarkable. This sense is expressed by Ilama Charles, one of Comboni Samaritan's founding members, who has watched the changes since ART was introduced:

> There were tremendous changes. People were dying, but now there is hope. You saw people who were brought on wheelchair, starting riding bicycles, lifting jerry cans of water on their head. The quality of life of the clients improved a great deal. They became productive. There were others who were policemen that were almost being laid off. Now I see them doing their duty. Even nurses, farmers, peasants. Another thing also, it has decreased the burden on the hospital. If you went to the medical ward you would find the hospital filled with patients, even some are sleeping on the floors. Sometimes you have twenty, twenty five patients with opportunistic infection in ten bed wards. Medical personnel were really stressed. These have disappeared; they now go once a month for their ARVs. It has also lessened the burden of orphans. People were dying and leaving their children. But now people are living and taking care of their children. In those days, guardians were looking after relative's children and their own, so some people were having up to fifteen children, which is too much. Sometimes these caretakers were very old, in their sixties or seventies, and living in poverty. Sometimes you find children alone, a child of thirteen taking care of other children. So ARVs have really helped a great deal. People have come out very much and it has put a lot of demand for the services for HIV testing. [378]

The emergence of Northern Uganda from two decades of devastating war has thus been a profound transition. ARVs have made it possible, even with all the attendant difficulties, for many with HIV to participate in this peace.

Father Alex Pizzi has been a central figure in this thesis, as one of the first people to help provide ARVs to a camp in Northern Uganda. His name, throughout the district, came to be associated with HIV/AIDS in both positive and negative ways, as the 'The soldiers of the priest' for those with HIV in Opit has shown. After a long period of illness in both 2008 and 2009, Father Alex returned to Opit. I was fortunate to meet with him again in June 2009, for

[378] Interview with Charles Ilama, Founding member of The Comboni Samaritans, Lacor, 1 September 2006.

only two months later he was killed in a surreal accident. After living in Northern Uganda for four decades, through the times of Amin, Obote and the Lord's Resistance Army, and being abducted by the LRA twice, he died after being knocked over and speared by one of his pet gazelles on the mission. There was, however, something poignant in the timing of his death. After two decades of war he finally got to see the people he loved return to their homes. He had the trust and goodwill of those living with HIV and many others and he had travelled around the region speaking to people in the return areas. His words capture some of the spirit of the return period:

> What I've found that is good is more or less all the people have left the camps and gone back to the villages. This is really like a miracle, because the people can be free in their homes and villages, to work and do what they like. You can say, 'they were freed from their slavery' and they are feeling independent. You can see the people feel better, and they are happy, and they start again to work. The people with HIV, the people that were here in the past are still here, but all the others they went. This you can say can be a really good medicine for them, going home. This is very important. We hope it will last, in their villages.[379]

Alex was buried in Opit.

And yet for all the hope that ART has brought to the region, the spectre of inequality and death associated with AIDS has not disappeared. In this thesis I have recounted numerous stories of survival, of hope and struggle. However, there are others who never lived to enjoy this peace. I will close this thesis with the story that affected me most deeply.

[379] Interview with Father Alex Pizzi, St Joseph's Mission, Opit, 24th June 2009.

I met Lilly Adong in December 2007 in the grounds of St Joseph's mission, in Opit camp. As this narrative has shown, the mission was a place of gathering for those with HIV in the camp. Lilly, was a twenty six year old HIV- positive woman, formerly abducted by the Lord's Resistance Army as a teenage girl, though had later escaped. She was forced to be the sixth 'wife' of a senior commander in the same unit as Joseph Kony. She escaped from the bush, and discovered her parents were dead, and later that she was HIV positive. She was rejected by her remaining family, who told her 'you're just a wasted, useless thing, why didn't you die in the bush?'".[380] She was caught in a limbo, living in a camp with nowhere to return to. "I don't have proper hopes about where to go. I don't even have my mother's place to go, not even our home. I don't even have a husband,' Lilly said.

She sought solace in the community living with HIV in Opit: a strong community of over 800 people, whose congregation has been fostered by the provision of ARVs to those in the camp. Here, Lilly met many others living with HIV which gave her strength. I visited Opit again in March 2009. My research assistant, Susan, and I went to speak to Lilly with her treatment monitor. She was very ill, and so we didn't continue the interview. She lay on the bed clutching her head in pain. She said her neck was stiff and she couldn't move. She was dressed only in a cloth. She seemed to be in agony, covering her eyes. Her mouth cried out, but her voice was silent. She could not touch her chin to her chest, a sign of meningitis. Cryptococcal meningitis is a common opportunistic infection among those with HIV.

She told us her relatives had neglected her, not cooking in the mornings when she was hungry. If they cooked later, after she had been sleeping all day, she would just vomit up the

[380] Interview with Lilly Adong (pseudonym), 26-year old HIV-positive woman (deceased), Opit, 7 December 2007.

food. The only thing she had managed to ingest in the last few days was juice. Her mother's sister was a drunkard and didn't take care of her properly. She had been to the local health centre, but they had not diagnosed anything, and wished to go to hospital. Her caregiver told us that they would not take her into hospital without a family member to look after her. This shocked me: it was the first time I realized fully the gravity of social exclusion. For those on the periphery of social relations, neglected by their families, this can also be a barrier to hospitalization. However, she needed someone to come with her to be admitted to hospital. Her aunt agreed and the St Joseph's Mission vehicle took her to Lacor. This was the irony of the situation: in order to be taken to hospital, she was dependent on her aunt who had been insulting and neglecting her.

We returned to visit Lilly twice, and were told she was improving, and would be out of hospital soon. There was a local sister at the hospital whose role it was to take care of patients from Opit, to ensure that they had food and were taking their medication. We were away for a week and then returned to Opit, assuming she had returned home. In Opit we went to find her, but her room was still locked. A neighbour also with HIV, came to us, furious, telling us how she had visited Lilly in hospital, that she was in a terrible state, that her drugs were sitting under her bed, and nobody had been giving them to her and her treatment monitor had not been visiting her. For some reason the sister in charge of the Comboni patients had not been informed that she was there. We returned immediately to Lacor, and her description was true. Lilly was thin, shivering, her medication beneath her bed untaken. Lilly had not been eating, and the aunt had refused to let her be fed through a drip. We alerted the sister, and after consulting the doctor, she restarted Lilly on her medication and fed her.

The next day I wrote an email to a friend. It went as follows: 'I have had a dismal day. Last night we went to visit a woman in hospital who I had been interviewing - she had been neglected completely by the caregiver in hospital, not received her medication or food. It was really sad and horrifying to see, this woman who had been healthy in December, reduced to a waif, twitching and gasping. She died last night.'

The pain of that day lingers, for both Susan and I. We can come to understand through our own experiences, what it means to be abandoned to death, and it is a bitter lesson. Social relations in any resource poor setting are critical to health systems. Health systems are social systems. They comprise sets of relations between people, resources, and information and are part of the reproduction of daily life. The basic tasks of healthcare: transportation, washing, cleaning, feeding are undertaken for the most part by relatives of patients, or require other social support. Without these tasks, already fragile systems cannot function. More than ever with the provision of ARVs non medical workers must play a critical part in health interventions. It is through strands of community, family, and friendship that personal and physical sustenance remains possible, that life is reproduced, though the breaking of these can be devastating. Sometimes the social support among those with HIV and their caregivers can fill the gap of a lack of family support, but at other times these relations fail.

When we had spoken to Lilly the December, I asked Lilly whether finding others with HIV at the mission has been good. She replied, 'Yes, it has been good, because it has helped me learn to find consolation in my heart.' I asked her if she would like to stay with them if she could, and she replied, 'I would always love to stay with them, if I find them.' The community of those with HIV/AIDS were Lilly's last community.

I close this thesis with this story, not to diminish the achievements that have been made or the struggles of those with HIV and those who have struggled to provide treatment under conditions of extreme adversity. I close with it as a counter-point to these stories of life, as a reminder both of how much has been achieved, but also of the continual fragility of social relations, of bodies that remain vulnerable even with the help of biomedicine. It also reveals how important community among those with HIV can be for the most marginalised individuals.

As I have argued, the effects of HIV/AIDS and displacements reinforce one another. Their effects are not only dislocations in space, but involve the reconsidering of the self and of social identity under extreme conditions. Ingold (2006:15) writes, 'the movement of life is specifically of becoming rather than of being, of renewal along a path rather than a displacement in space.' As much as displacement is about movement in space, the ways in which it is overcome are not simply about the reversal of this movement. They are also about the ways in which new paths open, new possibilities and horizons of hope. The sufferings of displacement and of disease do not preclude the possibilities for both individual and social renewal. ART interventions do not create these paths, but they do open them: the paths traced between homesteads in the bush, between women checking on one another, reminding each other to take their pills and not to think too hard, the paths people cross through wild grasses to gather with one another and to give one another solace: these are the movements of life that help transcend the dislocations of displacement. As ARVs allow for renewed health, but not the cure of HIV, the condition of those on ARVs is one of uncertainty - a prolonged and life-long transitional state. The challenge for treatment organisations, communities and those living with HIV is to find some peace, security and sanctuary within these transitions.

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Other Anonymous Interviews

8 August 2006. 29-year-old HIV-positive woman on ART (TASO), Bobi, Gulu District.

8 August 2006. 25-year-old HIV-positive man on ART (TASO), Bobi, Gulu District.

8 August 2006. 41-year old HIV-positive woman, Bobi, Gulu District

10 August 2006. 66-year-old HIV-positive woman on ART (Gulu Independent), Pabo, Amuru District.

10 August 2006. 37-year-old HIV-positive woman, Pabo, Amuru District.

14 August 2006. 31-year-old HIV-positive woman on ART (TASO), Minakulu, Gulu District.

15 August 2006. 39-year-old HIV-positive woman on ART (TASO), St Thomas, Gulu District.

16 August 2006. 23-year-old HIV-positive woman on ART (Gulu Regional), Gulu Town, Gulu District.

16 August 2006. 51-year-old HIV-positive man on ART (Gulu Regional), Gulu Town, Gulu District.

22 August 2006. 45-year-old HIV-positive man on ART (TASO), Bobi, Gulu District.

23 August 2006. 37-year old HIV-positive woman on ART (TASO), Gulu Town, Gulu District

25 August 2006. 27-year-old HIV-positive woman on ART (Lacor Hospital), Opit, Gulu District.

26 August 2006. 27-year-old HIV-positive woman on ART (Lacor Hospital), Opit, Gulu District.

26 August 2006. 35-year-old HIV-positive woman on ART (Lacor Hospital), Opit, Gulu District.

26 August 2006. 25-year-old HIV-positive man on ART (Lacor Hospital), Opit, Gulu District.

26 August 2006. 30-year-old HIV-positive woman on ART (Lacor Hospital), Opit, Gulu District.

29 August 2006. 50-year-old HIV-positive man, Bobi, Gulu District.

29 August 2006. 42-year-old HIV-positive woman on ART (TASO), Bobi, Gulu District.

29 August 2006. 35-year-old HIV-positive woman on ART (TASO), Bobi, Gulu District.

31 August 2006. 32-year-old HIV-positive woman on ART (Gulu Regional), Gulu Town, Gulu District.

31 August 2006. 18-year-old HIV-positive woman on ART (Gulu Regional), Gulu Town,

Gulu District.

31 August 2006. 41-year-old HIV-positive woman on ART (Gulu Regional), Gulu Town, Gulu District.

31 August 2006. 32-year-old HIV-positive man on ART (Gulu Regional), Gulu Town, Gulu District.

11 September 2006. 42-year-old HIV-positive man on ART, Lalogi, Gulu District.

11 September 2006. 36-year-old HIV-positive woman , Lalogi, Gulu District.

11 September 2006. 50-year-old HIV-positive woman , Lalogi, Gulu District.

11 September 2006. 30-year-old HIV-positive woman , Lalogi, Gulu District.

15 September 2006. 31-year-old HIV-positive woman on ART (Lacor Hospital), Lalogi, Gulu District.

15 September 2006. 29-year-old HIV-positive woman, Lalogi, Gulu District.

15 September 2006. 65-year-old HIV-positive man, Lalogi, Gulu District.

15 September 2006. 37-year-old HIV-positive woman, Lalogi, Gulu District.

16 September 2006. 27-year old HIV-positive woman on ART (TASO), Lamogi, Gulu District.

14 February 2008. 32-year-old HIV-positive woman, Gulu Town, Gulu District.

25 February 2008. 36-year old HIV-positive woman and former LRA abductee,Pabo,

2 March 2008. 39-year-old HIV-positive soldier on ART (Gulu Independent), Opit, Gulu District.

10 March 2008. HIV-positive 40-year-old HIV-positive woman on ART (TASO),Pabo. Amuru District

14 March 2008. HIV-positive woman, Lira Town.

12 April 2008. 46-year-old HIV-positive teacher, Gulu Town.

25 August 2006**.** 36-year-old HIV-positive woman, Opit Camp.

21 February 2008. 26-year-old HIV-positive Soldier, Pabo Camp

1 March 2008. 42-year-old HIV-positive woman, Opit, Gulu District

19 April 2008. 21-year old woman (HIV-status unknown),Opit, Gulu District.

20 April 2008. 47-year old woman (HIV status unknown),Opit.

25 April 2006. 49-year-old HIV-positiveman ,Agweng Camp, Lira District.

1 May 2008. 31-year-old HIV-positive woman, Ogur sub-county. Lira District.

19 May 2008. 24-year-old man (HIV-status unknown),Pabo, Amuru District.

18 June 2008. HIV-positive woman on ART (Lacor Hospital), Layibi, Gulu Town.

15 July 2008. 26-year-old HIV-positive man, Pabo.

16 July 2008. 37-year-old HIV-positive woman, Gulu-Lira border.

21 July 2008, 22 July 2008. HIV-positive soldier on ART (TASO)

1 August 2008. 42-year-old HIV-positive woman on ART (Ogur Health Centre3), Walela Parish, Lira District, 1 August 2008.

1 August 2008. 28-year-old HIV-positive woman on ART (Ogur Health Centre 4), Ogur, Lira District.

2 August 2008. 30-year-old HIV-positive man, Ogur, Lira District.

24 August 2008. 34-year old HIV-positive woman on ART (TASO), Pabo, Amuru District.

June 2009. Advisor to Centre for Disease Control.

21 June 2009. Pentecostal Preacher, Gulu Town.

23 June 2009. 17-year-old mother, HIV-status unknown. Atiak, Amuru District.

August 2009, Interview, anonymous HIV-positive man, Opit,

29 June 2010. Ajwaka, Layibi.

15 July 2010. HIV-positive woman on ART (TASO), Layibi.

12 & 20 December 2010. Ajwaka, Onang Village.

Focus-groups

11 September 2006. HIV-positive women, Lalogi, Gulu District.

14 September 2006. Mixed-gender HIV-positive respondents, Awoo, Gulu District.

16 September 2006. Family focus-group, Unyama, Gulu District.

4 February 2008. HIV/Aids Support Group, Pabo, Amuru District.

22 February 2008. David Kilara, Lamunou Cecelia &Obal John, mixed-gender HIV-positive, Pabo, Amuru District.

17 February 2008. Mary Abalo, Akulu Rose Akoo, SusanAuma, Anonymous, Jacinta Adong. HIV-positive women on ART, Opit, Gulu District.

23 February 2008. Home-based caregivers, Pabo, Amuru District.

23 February 2008. Focus-group with Achaa Alice and Owac Yi, TASO adherence monitors, Otong.

24 February 2008. Cristine Lolem, Sansy Fanee, Pawhar Anong, Anonymous man, mixed-gender HIV-positive, Pabo, Amuru District.

24 February 2008 Nighty Aber; Anna Akello; Hellen Lanyero; Filder Achola& Nighty Aceng, HIV-positive women. Pabo, Amuru District

24 February 2008. Almy Jessica Akena Phillip Akello Betty, Odong Patrick, mixed gender HIV-positive respondents, Pabo, Amuru District.

2 March. Santa Akello and Jessica Ajok, HIV-positive co-wives, Opit, Gulu District. ,

9 March 2008. Beatrice Arac, Romana Akoko, Rodolfo Ongum, mixed gender, HIV-positive, Pabo, Amur District.

12 March 2008. Grace Alanyo & Mary Ajing (Pseudonyms), HIV-positive women, Opit, Gulu District

15 March 2008. Martin Ayar and CiprianoAkweno, Health workers, Aromo Health Centre 3, Lira District.

19 May 2008. Mixed-gender HIV-positive, Pabo, Amuru District,

24th April 2008. Mixed-gender HIV-positive, Ogur sub-county.

25 April 2008. Esther Abura, Roselva Akello,; Margaret Aciro, &CiprianoOyen, mixed-gender HIV-positive, Ogur, Lira District.

25 June, 2008. Charles Okot and Grace Aroma, HIV-positive couple, Opit, Gulu District.

11 July 2008. Ojok Albino and Katy Opio, Couple Living with HIV, Minakulu,

11 July 2008. Tom Okello, Josephine Ajok, Florence Auma, PilmenaAkello. mixed-gender-HIV positive (returned to home areas), Minakulu.

17 July 2008. Peter Opio and Ojok Albino. HIV-positive men. Akuki Village, Minakulu, Gulu District.

20 July 2008. Jacinta Adong& Susan Auma, HIV-positive sisters, Opit, Gulu District, Gulu District,

1 August 2008. Uwan Ogal, Uventino Ongola, Ida Akita, Rose Atim, SecondinaOlero and Sam Ojera, (HIV-positive), Ogur health-centre.

1 August 2008. Caroline Akello, Geoffrey Olwa and Anonymous woman, HIV-positive. Ogur health-centre.

1 August 2008. Severino Odong and Paul Oyoo,HIV-positive men, Ogur, Lira.

11 August 2008. Agnes Tino, Silberia Akot, Scovia Apio, HIV-positive women, Opit, Gulu District.

12 August 2008. Florence Awio, Dennis Okellos, Lucy Angee, Silberia Amony, Charles Ojok, mixed-gender HIV-positive respondents, Opit, Gulu District.

12 August 2008. Simon Odong, Judith Okeng, Lilly Adoch, Sekondina Akia. mixed

gender HIV-positive respondents, Opit.

13 August 2008. Female youth, HIV-status unknown, Opit, Gulu District.

24 August 2008. Joseph Oliel and Cristin Acan, HIV-positive couple, Pabo, Amuru District.

17 August 2008. Dennis Okello and Lilly Ajok. Couple in return area, HIV-status unknown, Ngai sub-county, Oyam District.

24 August. Susan Amomo, Florence Akello, Grace Abur. HIV-positive women. Pabo, Amuru District.

25 August 2008. Isaac Odiya and Lucy Aber. Norwegian Refugee Council camp management, Pabo, Amuru District.

28 August 2008. Mixed-gender HIV-positive, Atiak

12 September 2008. Mary-Abalo; Akutlu-Rose; Auma-Susan; Adong-Jacinta &Aciro-Monica, HIV-positive (living in return areas), Opit, Gulu District.

21 August 2008. Nighty Abonyo and Julius Amony. AVSI Resident Field Officers, Opit, Gulu Camp.

13 June 2009. Male youth, HIV-status unknown, Gulu Town.

13 June 2009. Male focus group, HIV-status unknown. Gulu Town

15th June 2009. Male youth, HIV-status unknown, Adak transit camp, Gulu District.

21 June 2009. Margaret Akidi, Jennifer Alaro Acan Lily, HIV-status unknown, Layibi, Gulu District.

23 June 2009. Women living in return area, HIV-status unknown. Pacilo-Juba transit site, Amuru District.

23 June 2009, Men living in return area, HIV-status unknown. AbaloKodi transit site, Amuru District

23 June 2009. Florence Lamwaka and Vincent Ocien, NUMAT network supper agents. Atiak, Amuru District.

24 June 2009. Joseph Oliel, Betty Akello, Beatrice Akello, Scayo Olga, Anonymous Soldier. Mixed-gender HIV-positive. Pabo, Amuru District.

24 June 2009. Evelyn Aber and Beatrice Akello. HIV-positive women. Pabo, Amuru District.

29 June 2009. Women in return area, HIV-status unknown. Barlimo, Gulu District.

22 January 2010. Male respondents, HIV status unknown, Alokulem, Gulu District.

26 January 2010. Male respondents, HIV status unknown, Parak, Gulu District.

28 January 2010. Female respondents, HIV status unknown, Awach, Amuru District.
29 January 2010. Male respondents, HIV status unknown, Opit, Gulu District.
29 January 2010. Female respondents, HIV status unknown, Tegot, Gulu District.
1 February 2010. Male respondents, HIV status unknown, Pabo, Amuru District.
1 February 2010. Female respondents, HIV status unknown, Pabo, Amuru District.
10 May 2010. Mixed-gender HIV-status unknown, Parak camp.

Meetings and Workshops

24 February 2008. HIV-positive clients meeting, Pabo. Amuru District.
7 August 2008. Camp Coordination Camp Management Cluster Meeting, Gulu Town
26 June 2009. Feedback and discussion workshop facilitated by Matthew Wilhelm-Solomon. With attendance by Juliet Arica (NUMAT), Beatrice Akello (TASO CASA), Richard Mwaka (Comboni Samiritan), Margaret Anek (TASO Counsellor), Lillian Onega (TASO data officer)

Other Data Sets

Centre for Disease Control/Lacor Hospital. *ART Quarterly reporting forms 2005 to December 2008* [provided personally via email]
Centre for Disease Control/Lacor Hospital. *ART Quarterly reporting forms 2005 to December 2008*
Uganda Ministry of Health Data, *Number of active ART clients in each facility at the end of December 2009* [provided personally via email]
WHO, *Health, Nutrition and HIV/AIDs Cluster meeting minutes*, 2008, [provided personally via email]
Women and Children First Organisation (WACFO). August 2008. *Summary Data,* Pabo.