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**Stigmatization, Disclosure and the  
Social Space of the Camp:  
Reflections on ARV Provision to the  
Displaced in Northern Uganda**

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# Stigmatization, Disclosure and the Social Space of the Camp: Reflections on ARV Provision to the Displaced in Northern Uganda

## Abstract

*This paper is part of a study of the social effects of antiretroviral provision to displaced communities in northern Uganda. It focuses on the effects of antiretroviral provision, and associated care and support on stigmatization. It argues that while antiretrovirals have helped reduce forms of stigmatization, particularly linked with visible signs of illness, new forms of stigmatization have emerged, linked to the invisibility of illness. These changes should be understood as linked to the changes in the disease trajectory, and the social context in which they emerge. In the context of the displacement camp, where secrecy is low, there are high levels of non-verbal disclosure, which I term socio-spatial disclosure. In addition, the language of stigmatization is embedded in the experiences of social suffering in the camps, and particularly linked to lack of productivity, perceived immorality, and militarization. This paper aims to contribute to the theory of stigmatization by linking an analysis of the disease trajectory to that of 'social space'.*

## Introduction

Northern Uganda has suffered from two decades of civil war, between the Government of Uganda and the Lord's Resistance Army. Over one and a half million people have been forcibly displaced into large, congested displacement camps. Since 2003, the provision of combination antiretroviral treatment (ARVs /ART) has been scaled-up in the region, and by the end of 2008 over 15 000 people have been provided with ART in war affected districts of Northern Uganda<sup>1</sup>, in towns, camps and rural areas. This paper focuses on the social space

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<sup>1</sup> Government of Uganda, Ministry of Health ART Data, December 2008. This figure includes government and NGO provision in Amuru, Gulu, Kitgum, Pader, Lira and Apac – districts in which there was active conflict prior to the cessation of hostilities in August 2006.

of the displacement camp and the ways the camps have shaped the social effects of antiretroviral provision in particular its impacts on stigmatization. Social space refers to the inter-relationships between material spaces, the activities and agency of embodied subjects, the exchange networks of information and objects, as well as the meanings and representations certain spaces give rise to (Harvey, 2006, Lefebvre, 1991). I understand stigmatization as “the devalued status that society attaches to a condition or attribute” (Steward et al., 2008:1226), though conceive this a social processes. This paper argues that understanding the changing trajectories of stigmatization requires an analysis of the visibility of the body, and disease course, in its social environment. An analysis of spatiality, neglected in the existing literature on stigmatization, helps illuminate these dynamics.

In this paper, I discuss the following key findings from my fieldwork and analysis in Uganda. Antiretrovirals, and associated treatments for opportunistic infections, have brought about substantial improvements in the lives of those with HIV. In addition to the biomedical benefits, the frequency and intensity of stigmatization, especially linked to fears of transmission, have declined. New support networks have formed rapidly around treatment sites and programmes. However, new forms of stigmatization have arisen as a result of antiretroviral treatment, particularly linked to the perceived invisibility of illness and the threats of onward transmission. The language of stigmatization is embedded in the social and moral world of the displacement camps of Northern Uganda. In particular this is closely linked to themes of perceived immorality, militarization, and lack of productivity. Changes in stigmatization are also linked to patterns high levels of serostatus disclosure, though not only voluntary verbal disclosure. Treatment programmes in the camps, as well as associated food support, have been highly visible and have precluded secrecy for many seeking care and treatment. I term this ‘socio-spatial disclosure’. Changes in stigmatization are also closely linked to changes in the observable symptoms of disease, and the ways these are observed in the context of the camp.

First, this paper outlines the social and historical context of the displacement camps in Northern Uganda, and provides a historical backdrop in which to analyze the changes brought by ARV provision. Thereafter, I describe the research methodology and the theoretical framework, drawing on existing theories of stigmatization. The core of the paper will expands on, and provides evidence for the findings outlined briefly above. The paper will explore the case study of Opit displacement camp in Northern Uganda. Finally, I will outline some theoretical propositions, hoping to contribute to the existing literature on stigmatization.

# The social space of the 'camp' in Northern Uganda

The war in northern Uganda has been a continuation of the war in which Yoweri Museveni's National Resistance Movement (NRM) took power in 1986. Following NRM's takeover, there was the emergence of several rebel groups in the north<sup>2</sup>, 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 has also a political agenda 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 delegitimize them as a political force (Branch, 2005, Finnström, 2008).

The 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 camps". Initially, there were a few hundred thousand people in these camps, which grew to over 1.5 million people by 2004 (Branch, 2005:19). Virtually the entire rural populations of districts like 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. Actual protection in the camps was lax, and the population often suffered violence under ill-disciplined and 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 way for the Ugandan government, with the support of international NGO's, to exercise control of 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, and the breakdown of agricultural production leading to malnutrition and widespread dependence on food aid. These factors were viewed as a "a vector for social breakdown and moral disintegration" (Dolan, 2009:169), and created a strong sense of political and development neglect among the populace (Finnström, 2008). In particular, the camps became

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<sup>2</sup> Northern Uganda was not a support base for the NRM.

associated with the spread of HIV and sexual immorality (Mergelsberg, 2009, author's interviews). The linkage of material conditions with a social and moral discourse is particularly important for understanding the social space of the camp, and its representation in the language of stigmatization, which will be discussed.

A World Health Organization (2005) mortality survey found crude mortality rates in the Acholi region to be “well above the emergency threshold” of 1 per 10 000 per day with “staggering” excess mortality rates. The situation in the camps was far worse than in the municipal areas. The report found that HIV/AIDS is the second highest cause of death (after malaria); at the time ARV provision was extremely limited. An estimated 13.5% of deaths were caused by HIV/AIDS. The actual sero-prevalence figures in rural areas of northern Uganda are far from clear, as data is scarce. A 2005 Sero-Behavioural Study (MOH, 2006) based put the figure for the north Central region at 8.2%, compared with a national average of 6.4%, although the report does not disaggregate figures by either region or urban rural differentiation, so it is unclear to what extent this applies to the camp context. Similarly, it is unclear whether the camps actually contributed to the increased spread of the disease.

Risk factors, such as increase poverty and vulnerability may have increased the spread of HIV. However, restraints on mobility could have served as a counteracting effect (Allen, 2006, Westerhaus, 2007). Soldiers are widely considered by camp residents to be associated with the spread of the disease (Finnström, 2008:186, author's interviews). There is no epidemiological evidence of this at a population level. However, the association of the camps with the spread of HIV and militarism came to shape the experiences and language of stigmatization, which is discussed below.

Uganda is widely considered to be a success story with regards to responses to HIV, in terms of reducing HIV sero-prevalence. The response in parts of the country included the extensive reach of information into rural areas, local communities embracing and adopting strategies against HIV, the widespread formation of community based groups with HIV, and increased community discussion about the disease during the late 1980s and 1990s (Epstein, 2008:161-162, Low-Beer et al., 2004). However, based on extensive oral histories as well as archival research<sup>3</sup>, I argue the widespread social and political

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<sup>3</sup> In the archives of the Ministry of Health Programme, Kampala; The AIDS Control Programme, Kampala; ACORD Gulu; St Mary's Hospital Lacor, Gulu; World Health Programme, Gulu.

response to HIV/AIDS was largely absent in the north until the mid 2000s<sup>4</sup>. Support groups for those with HIV in rural areas were scarce, as was information and knowledge of transmission. In this sense, experiences of those with HIV came to reflect a broader marginalization of the northern region. In particular insecurity meant that camps were hard to reach with HIV support programmes. Intensive Acholi radio programming on HIV only began in the early 2000s. In the camps, Catholic missions were to provide an important site for responses to HIV, lending a strongly moralized response to the disease, which is discussed below.

The exclusion of the camps from programmes elsewhere in the country is represented by the case of Pabbo, one of the largest camps in the north with a population of over 50 000 at its peak. Pabbo, vast and around 40km from Gulu town, typifies the marginalization of the north from the responses elsewhere in the country. The first group for those living with HIV in the camp was in 2000, and it was only a few years later that they received some support from NGO's and the local Catholic mission. In 2000, 23 women with HIV formed the first group of those with HIV in Pabbo. The group was called *Yabbo Wang Wu* AIDS Group, which means 'open your eyes.' Ideas of seeing and visibility permeate the discourses around HIV/AIDS in the camps, which will be discussed. The early life of the group was characterized by struggle and intense stigmatization. Evelyn Aber is one of the few still alive of those who founded the group. She describes their early experiences:

We were the first group in Pabbo. Most of them died. We are left now with seven. Ah. People suffered. Then, people could stigmatize. 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...If you were moving somewhere, if you are very thin, if you are passing away, they just point at. They say 'you look at this person with AIDS. This one dying of AIDS, don't move closer to him'. They blamed you...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 go and interact or eat with them, because if they despised me, why should I go next to them and eat with them?

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<sup>4</sup> There is not space here for a more in-depth analysis of this evidence, which is the topic of another paper I am writing.

This account reveals the contours of stigmatization in the camp prior to the introduction of ARVs, and is resonant of numerous other accounts in Pabbo and other camps. Given the lack of HIV information at the time, the stigmatization reflects concerns over transmission – so-called instrumental stigma – but also resonates with the broader social condition of life in the camp, and thus has a symbolic dimension. Those with HIV were associated with immorality, death as well as worthlessness. Certainly, the association of HIV with death and immorality is present in forms of stigmatization elsewhere (Deacon et al., 2005:46, Sontag, 2002). However, within the camp, these attributes come to reflect the broader condition and social suffering of the camp population themselves.

The marginalization of those with HIV from support reflects the marginalization of the community as a whole, a marginalization not only from the responses to HIV, but also from economic and political development Finnström (2008: 64). The perception of the spread of HIV is associated with life in the camp. As Mergelsberg (2009:45) who conducted ethnographic research contemporaneous to my own, writes regarding the camps, “HIV/AIDS is evoked in a discourse on morality: it is a metaphor for an uprooted and immoral life in the camps.” However, the experience of HIV is not only metaphorical – it is an experience affecting many households, and those with HIV and their symptoms of illness have become very visible within the congested conditions of the camp. The interpretations of these signs of illness, it is argued here, resonate with broader social and historical factors shaping daily life in the camp; they reveal the ways in which the body becomes “embedded in a history that is both individual and collective: the trajectory of a life and the experience of a group” (Fassin, 2007a:175). Those with HIV are doubly marginalized, as displaced persons and as HIV positive. Their physical and social vulnerability are connected with the suffering of the population in general; in this, those with HIV occupy, in the social and moral world of the camp, both a marginal but also a symbolically powerful position. This ambiguous position is significant in understanding the changes that take place with the expansion of antiretrovirals to the camps. To understand the changes that antiretroviral have on stigmatization requires understanding the changes in the disease trajectory, the symptoms of illness, as well how these changes are observed and interpreted in the social domain.

## **Methodology**

This paper is based on nine months doctoral field work, conducted in four separate visits to Northern Uganda between July 2006 and June 2009. The



object of this study was to understand how the conditions of displacement shape the social efficacy of HIV/AIDS treatment. During the first field visit, a cessation of hostilities was signed in August 2006 between the Lord's Resistance Army and the Government of Uganda. The period researched here is thus based on displacement camps during a time in which there was not active conflict, and in which the return process was getting underway.<sup>5</sup> However, through oral histories I seek to describe the conditions during the period of active conflict.

The methodological was qualitative, inter-disciplinary and informed by a set of theoretical approaches. The methodology of this study takes inspiration from the approach of the "social lives of medicines", outlined by Whyte, Van der Geest and Harden (2002). The approach focuses on the social efficacy of medicines, entailing "what giving and taking medicines does for the social relations of those involved" (Whyte et al., 2002:170) and the ways in which they "co-produce effects in particular situations" (Whyte et al., 2002:14). To explore these dimensions I adopted the approach of the multi-sited ethnography. 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 at both an institutional and community level, and using methods such as interviews, case histories, observation of clinical practice, and village level ethnography (Whyte, 2005:1). A comparative approach between sites, while problematic in non-variable controlling qualitative research, can still help outline strands of multiple causality of a complex phenomena (Ragin, 1987: 14) .

For the broader doctoral research, of which this paper is a part, I conducted research in NGO, health centre, and community settings. Treatment organizations included The AIDS Support Organization (TASO), St Mary's Hospital Lacor and their community support Comboni Samaritan, 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 material for this paper is primarily based on research from Opit in Gulu district, and Pabbo in Amuru.

The research relies on both observation and extensive interview analysis. At the time of writing, interviews conducted and analyzed include: 128 people living with HIV were interviewed, 72 medical workers, 41 other key informants (NGOs, political leadership, community informants). Semi-structured interviews

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<sup>5</sup> The implications of the return process are the focus of another paper I am writing.

in multiple sites were used which gave a broad regional context, and allowed for a broad comparative perspective, across different sites and programmes. In-depth life histories we also conducted with several informants, with whom I met a number of times over the three years of research. These provide both historical and ethnographic depth, as revealing “juxtapositions of social contexts” (Marcus, 1995:110). In analyzing interviews I sought “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 this research, I have used real names where consent was given to do so. The aims, outcomes and uses of data were fully explained to each participant. 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. Luo-English translation by Ajok Flavia Susan and Orace David Tom was used. While my Luo was not adequate for interviews, significant time was spent discussing terminology and meanings.

Finally, there is need to move beyond merely analyzing interviews to exploring the social and spatial conditions of their emergence, the ways in which certain views, forms of knowledge, and common sense are formed. Observation as a methodology is central to this: observing the sites of treatment, the spatiality of the camps, the ways in which bodies become visible provides an interpretative position in which statements can be contextualized, and the social conditions of their formation inferred. In particular here, I focus on how spatial conditions shape the formation of identities and knowledge. As Foucault (1977) outlines knowledge-power relations are formed through spatial practices, and in relation to bodies and the observation of bodies. This has both methodological and theoretical implications. In the first, methodological observation can help situate the formation of discourses in the material and spatial settings in which they arise. Furthermore, in a socio-spatial approach the “site” itself becomes an object of study - it cannot simply be seen as a geographic or institutional locus. Here, along with Massey (Massey, 2005:5) I conceive space in terms of a “multiplicity of trajectories”. Social spaces can be valid objects of study, not simply because of their geographic boundedness, but as a locus of intersection (of mobility, social gathering, services, and representation, for instance). This methodological approach reveals dimensions of stigmatization shaped by the disease trajectory, as well as the changing socio-spatial context.

# Cimmotok: Theories of Stigmatization and Social Space.

The Acholi word for stigmatization is ‘cimmotok’, which literally means ‘pointing at the back of someone’s head’<sup>6</sup>. The word, as a reference to stigmatization, was introduced into the region through NGO’s in the late 1990s and 2000s, though has come to shape understandings of stigmatization. Ideas of disclosure and stigmatization were closely related; the idea of being marked out in public as HIV positive was considered a form of stigmatization, even if not accompanied by verbal abuse. The word was also used in a broader sense to refer to a range of forms of both verbal abuse, as well as exclusion from resources, and direct violence, such as beatings. However, more than simply a semantic conflation of notions of stigma and disclosure, I will argue that, in the social space of the camp, changing forms of disclosure and visibility have been closely linked with changes in stigmatization. Here, I will briefly outline how I situate my analysis in terms of existing theories of stigmatization, and social space. In the closing section of this paper, I will propose certain theoretical outcomes of the study, which may deepen these theories, in particular with an attention to spatiality.

Goffman (1973: 14) conceptualizes stigma as a socially identified deviation from a perceived norm: ‘the term stigma, then, will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed. Furthermore, I conceive stigmatization as series of processes linked to the labelling of social difference, and the marginalization of those labelled (Link et al., 2001:363). This process of stigmatization involves an interaction between belief, perception, and enactment (Steward *et al.*, 2008).’ In my own analysis, I view stigmatization as an outcome of social relations integral to the lived environment in which it occurs.

There is a division in the literature between instrumental and symbolic stigma. 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, Herek, 2002:41). Here, I treat instrumental and symbolic as part of interconnected processes, as this reflects the experiential perspective of those living with HIV. Stigmatization, it is argued here, is a result of encounters in a lived environment and not simply of

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<sup>6</sup> My assistant Ajok Susan, as well as other informants, explained the genealogy of the word to me. See also Odonga, Alexander (2005) *Lwo-English Dictionary*. Kampala, Fountain Press. for separate explanations of ‘cimmo’ and ‘tok’

a set of beliefs or instrumental intentions. Parker and Aggleton (2003:21) argue that stigmatization 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) – this involves both material and symbolic strategies. However, as demonstrated below, these strategies are resisted, and result in the deployment of new ‘resistance identities’ (Ibid: 19).

Goffman places emphasis on 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 and argue that ‘the shape of the stigma trajectory is intrinsically tied with the disease course’ (Alonzo et al., 1995:305). Furthermore, the relationship between disease course and stigmatization is bound up with social interpretations of bodily signs. However, these authors give little attention to the ways and contexts in which the disease trajectory is observed and interpreted: spatiality is central to this, as it shapes the ways in which embodied information is conveyed. Gayatri Reddy is one of few theorists who focus on spatiality and visibility in her analysis of stigmatization. Reddy (2005) argues that visibility of bodies, and the associations with places, is central to how individuals become incorporated within certain knowledge and power relationships. Furthermore, the interpretation of the body by both the individual and society is integral to how the body is inscribed with historical process, both physically, and symbolically (Fassin, 2007a).

A key theoretical concept in this paper is spatiality, or ‘social space’. 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). The mobility of people, information and objects forms 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 class inequalities (Lefebvre, 1991). 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). This analytic frame, it is argued, elucidates the contours of conflict and displacement, and the ways these shape daily life. War and displacement produces 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, and so on. It is argued here that these dimensions not only shape the transmission of HIV, but also the provision of treatment, and its social outcomes.

Finally, while stigmatization has been conceived of as a social process, disclosure is often conceived narrowly through a lens of voluntary and involuntary disclosure. Disclosure is seen as important for the provision of ARVs, as a lack of disclosure can lead to poor adherence to antiretroviral treatment (Doherty et al., 2006). Disclosure of HIV status of HIV can also lead directly to experiences of stigmatization, however many articles on stigmatization have no discussion of disclosure. Disclosure is mostly discussed in terms of verbal and voluntary disclosure (eg Medley et al., 2004). However, HIV status may be disclosed non-verbally through other ways, such as an individual's presence at a testing or treatment site (Steinberg, 2008, Whyte et al., 2010), their visibility taking medication, or possession of commodities related to HIV support, such as breast-milk (Doherty *et al.*, 2006), or receiving material support (Whyte *et al.*, 2010). Recognisable signs of illness may also signify HIV status, although these may also lead to misrecognition when opportunistic infections, such as tuberculosis, are associated with HIV<sup>7</sup>. In this section I wish to explore how disclosure, intimately linked to stigmatization, is also a complex process linked to the spatial conditions of the camp. I propose and will explore the concept of 'socio-spatial disclosure', as the process through HIV status is disclosed to others through visual or other non-verbal markers.

## **ARV Provision and Disclosure**

In 2003 free antiretroviral (ARV) provision for those living with HIV/AIDS began to be scaled up in the region, in both towns and rural areas, to thousands of people living with HIV/AIDS (PHAs). Combination antiretroviral therapy can significantly prolong the lives of those with HIV, though it has intensive monitoring and adherence requirements. Antiretroviral treatment to displaced

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<sup>7</sup> Personal communication, Bruno Dujardin, Free University of Brussels, May 2009.

and conflict affected communities on such a large scale is a pioneering and experimental project. Treatment providers included the Ministry of Health, The AIDS Support Organization, and St Mary's Hospital Lacor, among others. Antiretroviral provision has been centred around the towns, but treatment has also been available to residents of the camps through health centres, treatment outreaches, as well as transport support to towns, as was the case of Opit. The provision of antiretrovirals was also accompanied by the expansion of education efforts, radio programming, and support with groups for those with HIV. The NGO programmes, including TASO and St Mary's Lacor, involved community based education and treatment monitoring. The programmes have catalyzed major social changes for those with HIV: new support networks have formed, and knowledge around the disease and treatment has been greatly increased. Furthermore, in some areas, like Opit, there has been mobility from distant areas into areas where treatment is available. The social effects are not simply linked to ARVs, but also associated treatment, in particular the antibiotic co-trimoxazole (known by the brand-name Septrin) given to those not yet on ARVs. The overall impacts of these programmes have been a substantive reduction in both the frequency and intensity of stigmatization in areas of treatment provision. Everlyn Aber from Pabbo camp, whom we have met, has been openly positive for close to a decade. She says: "These days stigmatization is missing. We are now staying free." This is perhaps an exaggeration, but it reveals a strong sense among those with HIV of the improvements since the introduction of ARVs. However, I will argue here that this is a non-linear process, and as forms of stigmatization lessen, new forms emerge.

This paper is concerned in particular with outlining the specificity of the context of the displacement camps, and how changes in the social experiences of HIV are linked with the physical changes in the body, and how these become meaningful in the social world. In emphasizing the structural factors of observation and spatiality, I do not mean to neglect the impact of education, only to argue that knowledge in itself catalyzes changes only in relation to the lived world and social space in which disease is experienced, observed and interpreted. I thus begin the core of this analysis, looking at the social lives of ARVS and their links to disclosure, the forms of social spaces produced by treatment interventions, and the impact of these on stigmatization. I will then move on to a closer analysis of the dimensions of socio-spatial disclosure, observation, and the disease trajectory.

## Socio-Spatial Disclosure

In the field-sites I visited from 2006 to 2008, there were high levels of HIV disclosure. The reasons for this is that disclosure was imposed both by treatment organizations at a household level, and due to the socio-spatial conditions of the camp. The camp environment made secrecy around receiving HIV treatment nearly impossible, unless one had money to seek treatment elsewhere or purchase it oneself. This process was interlinked with criteria of disclosure imposed by treatment programmes like that of TASO, and St Mary's Lacor: disclosure to household members in order to go onto ARVs. This was to ensure treatment adherence.<sup>8</sup> TASO labelled this 'supported disclosure' and provides counselling helping patients and their families to deal with being HIV positive. However, in the camps there was little choice not to unless one could afford to travel to other sites, for instance in the towns, an option unavailable for most camp residents.

At the TASO treatment site in Pabbo in 2008, I witnessed a remarkable example of what is termed "the social lives of medicines" (Whyte *et al.*, 2002), the forms of social relationship that form around the provision of medication. The health centre opens out onto a large stretch of sand. In it, children play, workers dig sand for bricks, and there is a constant stream of people walking through it. The health centre has an outside platform with a low wall, and anyone entering the health centre is visible to those in the empty stretch of sand. On treatment days TASO also use their labelled car for registrations and medical check-ups. Piles of files lie outside of the centre. The queues of those waiting for treatment – Septrin (co-trimoxazole) or antiretroviral treatment - are visible to anyone walking past. At the treatment site there is an extraordinary array of people seeking treatment, as my interviews there showed. There are men, women and children. Among these are uniformed soldiers, many of whom can't speak the local language Luo, as they come from other areas of the country. There are also former LRA rebels and abductees. The visibility of those seeking treatment means that confidentiality is not possible in this context, and this is true for several other camps. Mere physical presence at a treatment is a form of disclosure, but one in which the categories of voluntary and involuntary do not easily apply.

The introduction of antiretrovirals by TASO to Pabbo in late 2006 catalyzed a major change in the experiences of HIV in the camp. When TASO arrived to begin their treatment programme in 2006, many gathered around thinking it was

some form of humanitarian support. Everlyn Aber, who we have previously met, explained:

TASO are distributing the drugs, just openly in this health centre three, 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.

Both the spatial conditions of the camp, in which the HIV treatment programme was entirely visible to the community at large, as well as the conditions of adversity, dependency and marginalization, would come to shape the social effects of treatment in the social space of the camp.

There were also specialized food distributions for those with HIV: these took place outside the health centre in full view of the community in Pabbo. The visibility of the treatment site, as well as the specialized food support for those with HIV, run by World Vision created discomfort for many. This may have been a barrier for some, particularly men, in seeking treatment as it was primarily women coming out and seeking testing and treatment. Joseph Oliel, a TASO client in Pabbo explains,

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.<sup>9</sup>

Another HIV positive man in Pabbo, Kilama Charles, a former LRA abductee expressed similar discomfort. He had disclosed his status to his uncle with whom he lived in the camp. However, he says, 'I never told anyone else my HIV status, but they got to know about it, because I always moved to the health centre.' I asked him how he felt about this. He said:

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

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<sup>9</sup>Interview Oliel, Joseph & Acan, Cristin. Pabo, 14-08-08



someone else, and yet they are talking about me. It's a form of stigmatization. But I try not to think about it.<sup>10</sup>

However, others, while experiencing discomfort and stigmatization through their visibility also noted positive effects. Beatrice Arach held that while she suffered stigmatization for being HIV positive, 'I think it good that we are seen because someone will notice the effects of ARVs'.<sup>11</sup> These comments are resonant of the views of many clients who have believed the disclosure of many is for the better, and has led to a reduction in forms of stigmatization. The physical presence of the healing body thus becomes a form of exhibiting the effects of ARVs to the broader community. In this sense, disclosure can be a form of challenge to marginalization, even an act of virtue in taking upon the self the broader sufferings of the community.

In the camps, those who are HIV positive were visible in their homes, receiving care, but particularly treatment sites, and food collection points. The TASO site in Pabbo been discussed above. Caregivers and treatment monitors become publicly known and associated with the HIV programmes. Receiving home-based care is a very visible process in the camps. In some camps served by TASO field officers on motorcycles move to patients' homes to monitor and deliver treatment. Their arrival was a very visible event with people coming to see who had arrived. There are also more subtle ways of disclosure. Comboni Samaritan provides their patients with certain recognisable commodities, in particular a white jerry can given for water purification. Jerry cans for 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 provided to those who were HIV positive. They received a yellow corn soya blend, rather than white maize meal which was the starch in most food support<sup>12</sup>. Interview clearly showed that the dynamics of the displacement differed clearly from both the towns and rural areas. The town treatment sites were generally blocked off from public visibility. For instance some soldiers sought treatment at these sites, rather than army hospitals in order to ensure confidentiality. Similarly, in rural villages, it was easier for villagers to seek medication away from the eye of community and family members if they chose not to disclose their status.

The above 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

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<sup>10</sup>Interview Kilama, Charles. Pabbo, 14-07-2008

<sup>11</sup>Interview Arach, Beatrice Pabo, 15-07-2008

<sup>12</sup>Thanks to Ayesha Nibbe for bringing this to my attention

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. 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.

## Stigmatization and the Disease Trajectory

In my interviews, there was an overwhelming sense that those who were on ARVs had visibly improved, 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 stigmatization. This links with the argument of Alonzo and Reynolds (1995) that changes in stigmatization follow changes in the disease trajectory. This argument has particular application to antiretrovirals, due the physical changes they have on the body. This process was confirmed by interviewees whose HIV status is unknown and by those with HIV. The quotes below illustrate this:

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 criticizing and abusing that this person has HIV when the person looks the same as you? (21 year old women, status unknown, Opit camp)

The sensitization [education] only changed the levels of stigmatization 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 it's still right to stigmatize, because the person you stigmatize will lead a normal life like you, so it will become useless to stigmatize someone who won't die. Most people have a tendency of putting to the clients [HIV patients] days when they are 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.<sup>13</sup> (HIV treatment monitor, living with HIV, Opit)

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<sup>13</sup> Interview Anyoo, Juliano. Awoo, 23-06-2008

Many with HIV experienced decreased stigmatization as their health improved. This was clearly helped by the education over the transmission of the disease, but this education was given meaning in the social spaces in which those on ARVs were observed. Patients with HIV often experience most intense stigmatization during the periods of visible illness: As Beatrice Arach, a woman living HIV in Pabbo says,

Yes, the stigmatization gets worse, because when they see rashes all over my body, they suspect that I am going to die soon, that I'm badly off so I will die soon.<sup>14</sup>

Such accounts are common, illustrating the close link between stigmatization and the body. In addition, those who were better could now partake in limited agricultural activity, as well as access resources through the support offered to those with HIV lessened the marginalization by families. However, while the health improvements of those on ARVs lead to lessening forms of stigmatization, particularly around fear of transmission, and linked to the burden of the ill on families, new forms of stigmatization emerge. The new health of those living with HIV, their "fatness", and their perceived normal appearance has created new fears, that they are spreading the disease to the population intentionally. The life-giving potential of ARVs and its social meanings is paradoxical: it both gives life, but the healthy body of those living with HIV remains infused with associations of threat and death. As the return to physical health is visible, it also creates fears about the invisibility of the disease itself. As one women living with HIV, Aber Nighty, of Pabbo said:

In the market when you are passing, they will point at you and say – 'look at this one, they are the people on ARV's, 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.<sup>15</sup>

The themes of uselessness, and the threat of death, here coalesce with the observed physical changes brought by ARVs, particularly the gaining of weight, which make HIV itself invisible.

The observation of those living with HIV is not only an observation of an

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<sup>14</sup> Interview Arach, Beatrice Pabo, 15-07-2008

<sup>15</sup> Focus Group with Nighty, Aber; Anna, Akello; Hellen, Lanyero; Filder, Achola & Nighty, Aceng. Pabbo 24-02-2008

enclosed collective, but forms part of the social lives of medicines themselves. It is linked to both the formation of social interpretations of illness, but also the ways in which the ill are placed with a social order. Foucault (1977) uses the phrase ‘network of gazes’ to indicate the webs of observation in which individuals are observed and categorized. Observation itself is part a normalizing process through which individuals are marked and marginalized. However, rather than bodies simply being placed in pre-existing categories, the changes in bodies form part of changing social relations. The disease trajectory intersects with the trajectory of social transformation. Bodies and their interpretations become the sites of contestation. Their healing becomes not only a biophysical matter, but one deeply embedded in social experience. The social position of those with HIV, their place in the social and symbolic hierarchies of camp life is critical to understanding changes in stigmatization, but also the shifts in power relations that take place through HIV treatment and social responses. These dimensions are explored in the following section.

## **The Soldiers of the Priest: The Social and Moral Space of Displacement.**

We have discussed how the implications of spatiality, observation and the disease trajectory are important for understanding the changes in stigmatization catalyzed by ARVs. Finally, it is important to understand how these changes come to figure in the social world of the camp. I will explore two dimensions of this. Firstly, how the language of stigmatization reflects the lived experience of the camp. Secondly, how the changes in stigmatization reflect the ambiguous position of those with HIV in social and symbolic power relations. I will explore these issues with the case study of the camp Opit, in the Gulu district. This case study also illustrates many of the themes discussed above.

Opit, at its peak was a camp of over 20 000 people. The bulk of the migration to Opit was in the early 2000s. At present it has dropped to around 4000 permanent residents<sup>16</sup>. The major return migration to villages took place in 2008; however, a number of those with HIV were still in the camp by 2008 and 2009. A case study of Opit illustrates many of the dimensions of spatiality discussed in the theory section above. Opit is around 35km from Gulu Town. The surrounding area is beautiful – lush and forested. There is a lake nearby and forest reserves. The camp was also one of the most dangerous in the region: the LRA would often pass nearby or hide in the forests and kidnappings and killings were

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<sup>16</sup> Interview with AVSI camp management coordinator Seferis, Louisa. Gulu, 18-08-2008

common. The area around the lake was land-mined. A main road runs through the camp. It is lined with small stores, lodges (such as the 'Pit Maber', or 'good eating') set up in dilapidated concrete buildings. Half the main road has been electrified since 2006 and there are a series of bars, a disco, and video halls along this main road, where the youth, and some older residents, drink and dance at night. From the main road, a side road leads past the health centre on the left, and a soccer field on the right. St Joseph's Catholic Mission is a church and compound adorned by a dusty star, and surrounded by paw-paw trees. Within the compound are gardens with turkeys and gazelles. Many of those living with HIV gather to meet in the mission beside the trees. I stayed at the mission in 2006, and 2007, and visited often in 2008, while I stayed in a lodge along the main road. The mission has become a space of meeting and solace for those living with HIV. They have group meetings at the mission, often gathering in the shade of its trees. Over the past few years, many HIV positive people have moved to be near the mission, sometimes even from different districts where support for those with HIV was not available. 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 key figure in the provision of ARVs to those in Opit. Alex has been in Northern Uganda since 1973, is fluent in Luo, and has lived in the region throughout the time of Amin and throughout 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. After seeing an article about Africa in a magazine, he was thrown into a moral crisis and left his career to study in a seminary, eventually moving to Africa. He was at various mission stations in Northern Uganda and has been at Opit since the 1990s. In 1997, Alex started buying ARV treatment for six people from Kampala. 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 became formalized through funding by Catholic Relief Services and AVSI in 2005. Patients were given transport money to go to Lacor to receive treatment. In December 2007 ARVs started being provided in Opit health centre. Community based workers are trained by Comboni Samaritan provide monitoring of ARV adherence. The situation is different to Pabbo, as there has been support for those living with HIV for longer, as well as access to ARVs for longer as a result of the transport support provided to the mission. The numbers of those living openly with HIV are also larger: in 2006 over 500 people were members of the HIV support group at the mission. By 2008, there were over

800, though a number of these were now in outlying villages<sup>17</sup>. There was also significant migration from other areas into Opit to access HIV services. Improvements in stigmatization have been significant over the years. Alex describes 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.<sup>18</sup>

The situation changed with the introduction of ARVs. Says Alex:

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.

In my visits to Opit, and in interviews, I found that stigmatization 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.

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 manner, at other times more in jest. However, the label “the soldiers of the priest” as a form of stigmatization reveals how stigmatization is embedded in the language and experience of conflict in the camps. It reveals the associations between those with HIV and soldiers or rebels (both can be described as ‘mony’<sup>19</sup>), 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.

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<sup>17</sup> These figures were obtained from the keepers of the clients registry books, Cipriano Odong in 2006, and Esther Odong in 2008.

<sup>18</sup> Interview Father, Alex. Opit, 04-06-2007 and 09-06-2007

<sup>19</sup> Also described by Odonga (2005) as a ‘war, campaign, or raid’

I spoke to a group of young men, between 16 and 19 years old, living in Adak, a transit camp near Opit. Their HIV status was unknown. They had all grown up in Opit. Their knowledge of HIV and its transmission was good, and several of the young man had had members of the family with the disease. They claimed not to stigmatize 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 the 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.

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.

These statements reveal much about the forms of stigmatization arising in the camp, the language linked to both the visibility of those with ARVs, but also their perceived threat. The statements also reveal the vulnerability of these young men, left in their transit camp, without money for secondary school or work.

Free condoms are rarely distributed in the area, and the nearest health centre distributing condoms is over 20km away. The boys claimed that it is easier for them to walk to Opit around 10km away<sup>20</sup> – a Catholic site not distributing condoms – to get an HIV test than to get condoms. This also reveals how Catholic based programmes can also limit access to contraceptives and reproductive health choices. To buy a box of condoms is 500 shillings, equivalent to the wage for half a day’s casual labour. And so, although they

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<sup>20</sup> Distances taken from UNOCHA Gulu (July 2008) *Gulu and Amuru Districts Briefing Pack* UNOCHA, Gulu

express sympathy to those who are positive, they also feel threatened. They also say about friends who are 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’.

These statements reveal that HIV is felt both as threat – associated with conflict and displacement – but is also felt to be a shared social condition. The label *mony pa padi* is embedded in a complex set of associations: soldiers and rebels are associated with violence and death, as well as the spread of HIV; there is fear of those with HIV deliberately killing people; and those with HIV are associated with the local priest, Father Alex, and the church. The structure of the label is thus not metaphorical, but metonymical: those labelled and marked as HIV positive come 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 are visible in the camp setting, come to signify through association the fears and uncertainty of the social world of the camp. Yet precisely because of these associations, responses of care and of stigmatization can co-exist, at a communal level, but also among individuals. Stigmatization, rather than ideology or set of beliefs (Deacon *et al.*, 2005) can be viewed as a social and linguistic response to the fear and uncertainty of life.

The experiences of those labelled *mony pa padi* are telling. A strong support network developed in the camp, and the mission became a place of meeting and gathering. Margaret<sup>21</sup> is a thirty two year old woman living openly with HIV in the Opit camp. Her most intense experience of stigmatization was when she was very sick, suffering from a rash, diarrhoea and a cough. A neighbour in the camp would insult 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’. As we have seen, theme of uselessness is a recurring insult levelled at those with HIV, both in Opit and elsewhere in Northern Uganda. However, there have been improvements. She used to sell pancakes in the local market. She says:

Even now, there is not much stigmatization. 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

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<sup>21</sup> Not her real name



real cause of the disease now. Formerly they used to call us ‘soldiers of the priest’, but now it is going down.<sup>22</sup>

The stigmatization that Margaret has experienced has been fundamentally related to fear of contamination, as well as physical illness rendering her useless, and less 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,’ she says. Margaret’s primary experience of stigmatization has been related to the so-called ‘instrumental’ stigmatization – the fear of contamination, but also insults around her lack of productivity, her ‘uselessness’. With her health improving on antiretroviral therapy, the stigmatization has lessened because of the bodily signs of illness have lessened.

Furthermore, for some, while the physical signs of illness disappear, and external stigmatization reduces, internal stigmatization remains powerful. Ruth<sup>23</sup> is young woman in Opit, who was the former wife of an LRA commander, after being abducted as a teenager. She has experienced, what can be termed ‘intersectional stigma’ (Berger, 2004): stigmatization based on more than one causal factor. She is stigmatized both as a former rebel. She believes she contracted HIV while with the LRA, after being taken by government soldiers in a battle and then returning home. She explains the difficulty of returning to the camp<sup>24</sup>:

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, 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.

She had a child in the bush, whom she brought back. Both she and the child were stigmatized for having been in the bush.

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<sup>22</sup> Interview 03-03-08, Opit

<sup>23</sup> Not her real name

<sup>24</sup> Interview RUTH, Opit, 17-02-2008,

They insult my child, that the bad spirits (*cen*) in your mother's eyes, of those your mother killed in the bush, have made you come and disturb our children.

She has also been abused with the label, 'soldiers of the father', and told she useless. When I ask her if she would like to get married, she replied, "No, I don't have hopes for getting married, because I'm useless I'm the same as dead. Many people say that is someone is already sick, there is no use marrying her." Later we were to hear that she had got involved with a soldier and become pregnant, moving to a different area and treatment programme.

Here, we see how the damage of stigma and marginalization can run deep, even while external conditions may improve. For Ruth, among others who are most marginalized, HIV status provides a form of community and identity. She says that most of her friends are HIV positive and, "there are so many with HIV, who are my friends. I can't even count."

We have seen, from the above accounts, that HIV is closely linked to the formation of new social formations and identities, oriented around HIV status. New forms of biosociality emerge, by which I mean, relations of identity, shared care, communication and obligation focused around the HIV positive status (see Meinert et al., 2009, Rabinow, 1996). These identities arise out of the experience of stigmatization, but also in terms of a shared experience of illness. Often evoked is the metaphor of being siblings:

Here we stay as brothers. If you meet your colleague somewhere, there is something you share in common, that is the disease<sup>25</sup>

The bodies of those with HIV, disclosed to the community around them, do become a form of "resistance identity" (Parker and Aggleton, 2003), a way to reduce stigma. A particular form of resistance, is stressing that HIV/AIDS is a general condition, by inverting the stigmatizing gaze. As Beatrice Arach says,

Even as a group, because as a group we always have meetings every Sunday. When we are returning to our homes they start stigmatizing 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.'<sup>26</sup>

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<sup>25</sup> Interview Kilama, Charles. Pabbo, 14-07-2008

<sup>26</sup> Interview Arach, Beatrice Pabbo, 15-07-2008

The identities are both imposed, such as the label ‘soldiers of the priest’, but also through shared experiences, are chosen. In a context of loss, violence and displacement, HIV paradoxically becomes a form of attachment and rootedness. The majority of those seeking treatment are women, and the new relationships formed around treatment involve new and gendered networks of care among those living with HIV.<sup>27</sup>

Finally, another side of experiences of stigmatization is that many with HIV have also received care, support and comfort from members of the community. This is likely a result of increased knowledge about disease transmission in recent years, but also a response to the association of HIV and conflict. As one mother of an HIV positive women in Opit told me, “we did not blame her, it was because of the war that she got HIV”.

Therefore an identity formed in response to marginalization – 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 by those with HIV, but also a project by the broader community, who have come to see HIV as a broader social problem, linked to conflict and displacement. This response is often ambiguous and contradictory, as discussed above. Those with HIV become the bearers of a series of social ills; for this they are both excluded and cared for. They are excluded because they represent the fears and anxieties of a community suffering from displacement, marginalization, and militarization; and cared for because they too are perceived as the victims of these processes. The rollout of ARVs takes place in this social and moral world, and responses to their effects are shaped by it.

## Theoretical Propositions

From the above account, I wish to extract certain theoretical propositions. In this study I argued that socio-spatial factors are significant in leading to HIV disclosure of individuals and collectives *en masse*. Spatial factors explain how HIV becomes known in a community, and how its trajectory and the effects of treatment on the body are observed, and impact on stigmatization. This form of disclosure is connected with voluntary self-disclosure, but does not fit neatly into simple conceptions of voluntary or involuntary disclosure. I propose the concept of ‘socio-spatial disclosure’ as: *the processes through which information regarding an individual’s or a collective’s HIV status is signified –*

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<sup>27</sup> I will explore issues of gender and biosociality in more depth in another paper I am writing.

*through visual or other markers - to others as a result of the spatial circumstances in which those living with HIV/AIDS seek medical care and support.* 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.

Second, stigmatization should be conceived as a socio-spatial process. There are several dimensions of social space that are relevant to understanding processes of disclosure and stigmatization. First, there is *the observation of individuals in particular sites*. The HIV status of an individual or group may be disclosed through being observed at a particular site, such as a treatment site or service collection point. Signs of illness may also be observed and interpreted, as indicating HIV status. The ways in which individuals are observed by others are shaped by the spatiality of living conditions, as well as the architecture or position of treatment sites. Certain special commodities (such as food support) may also signify HIV status. Second, is the *naming of individual or collectives as HIV positive*. This involves how certain observations are incorporated into knowledge through the naming of individuals as HIV positive. This is not a neutral process, but involves morality and power relations, in that naming may place individuals in a marginalized position. In addition, stigmatization is not a static process: processes of naming and interpretation may be linked to changes in the disease trajectory, as well as forms of information available in communities. Observation and information are shaped by life-world and moral frameworks of a community. In this sense, both observations and information dissemination are given meaning in a social and historical context. Stigmatizing language and beliefs may not be coherent, but their very paradoxes may reveal the concerns and anxieties of a community. Furthermore, those named as marginal can challenge these imposed identities. As Parker and Aggleton (2003) write, stigmatization may involve the formation of new “resistance identities”. It may also cause new forms of social networks oriented around certain locales. However, the lines of stigmatization and responses to need not follow existing power relations, and may subvert existing forms of hierarchy (Deacon et al., 2005). Furthermore, the ways in which identity and change become part of broader processes of social transformation is linked to the ways in which discourses around HIV are formed in relation to lived social space.

## Conclusion

My objective here has been to outline how the specific spatiality of the camp has shaped the social efficacy of HIV/AIDS treatment, and is significant in

understanding the marking of those with HIV, and changing forms of stigmatization as a social process. I have argued that socio-spatial disclosure, along with forms of voluntary disclosure, have resulted in the improvements in stigmatization of those living with HIV. The positive effects of ARVS have been very visible to the community at large, leading to high numbers coming out for testing and seeking treatment. However, the initial introduction of ARVs can involve an intensification of stigma, as those living with HIV become visible and open to being marked. Moreover, while forms of stigmatization may lessen, new forms of stigmatization arise related to the provision of ARVs. Furthermore, the ways in which HIV has been given social meaning are linked to the visibility of those who are positive, but also the ways in which discourses around HIV, morality and conflict circulate in the social space of the camp.

The spatial dynamics of disclosure, discussed here, 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 observes similar dynamics and complexities of disclosure there. However, the extreme spatial congestion of the displacement camps, as well widespread reliance on food and other material support due to the conflict makes the camps an exceptional social space and these dynamics very acute. In my own comparative analysis, these dynamics were more extreme in the camps than in town or other rural settings, although they occurred to a more limited extent in these. The theory of socio-spatial disclosure proposed here could, however, be applied to non-conflict affected settings.

Theoretically, this paper has argued that the analysis of stigmatization must involve an analysis of complex socio-spatial dynamics. There is not simply a linear relationship between the provision of ARVs and the lessening of stigmatization. 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 takes place is central to understanding the effects of ARVs on stigmatization.

While I have argued that socio-spatially imposed disclosure has had a generally positive effect in Northern Uganda, this does not entail that it will in any circumstance – the social and political circumstances of settings are variable. However, in general these dimensions should be taken into account in the planning of interventions and not merely left implicit. In particular, this should be applied when providing ARVs to displaced and conflict-affected settings, due to the exceptional spatiality of displacement camps. This could involve discussion among treatment providers – but in particular discussion with the

potential recipients of treatment themselves (for instance those who have tested, but aren't yet on treatment). This was rarely the case in Northern Uganda. The views of those living with HIV should be understood and taken into account. Saying this, the over-emphasis on secrecy and privacy may serve to reinforce stigmatization around HIV and the lack of knowledge around ARVs. Lack of confidentiality should not be an excuse for not providing life saving treatment.

The social disclosure of HIV status by a significant group, even if not fully voluntary, may have positive impacts in the long term, if there is support for those disclosing their status - both medical and material support, but also spaces to meet, and form new relationships. This has taken place in Northern Uganda in some areas, and led to remarkable experiences of social transformation and improvements in stigmatization. However, the experiences of Northern Uganda are also closely linked to experiences of war and displacement, and the forms of social change deeply embedded in local realities.

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